

LABORATORIO DEI DIRITTI FONDAMENTALI

**Health as a fundamental right:  
experiences of migrants in Torino**

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*La salute come diritto fondamentale: esperienze di migranti a Torino*, Bologna, Il Mulino, 2015  
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*The Laboratorio dei Diritti Fondamentali (LDF) began operating in Torino in 2011. The Laboratorio carries out research into fundamental rights, with particular attention to the practical nature of safeguards in place during the various moments, places and occasions in the life of the population. The Laboratorio, in accordance with the teachings of the European Court of Human Rights, deals with “concrete and effective rights, not theoretical and illusory ones”. Through its research, the Laboratorio intends to offer suitable and feasible solutions on the basis of experience or suggested by interdisciplinary studies of human rights.*

*The activities of the Laboratorio dei Diritti Fondamentali are supported by*



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## Acknowledgements

Warm thanks go to Giuseppe Costa, who allowed the Laboratorio dei Diritti Fondamentali to access the data of the *Servizio Sovrazonale di Epidemiologia* [suprazonal epidemiology service] of the local health authority TO3 and to Luisa Mondo for her help, indications and advice during this project.

Thanks to all the participants in the network *Gruppi Immigrazione e Salute* (GrIS) Piemonte [immigration and health groups], who were a constant reference point and a precious source of information.

Our thanks also go to Lorenzo Brunelli, Chairman of *Associazione Camminare Insieme* and their group of voluntary doctors and cultural mediators. Thanks also to Roberto Beneduce, Simona Taliani and the work group at the *Centro Franz Fanon*.

Warm thanks to the coordinators and the staff of the outpatient services and the hospital departments in which our research was carried out. Although it is impossible to mention everyone who, in various ways, contributed to this work, we would like to thank Mariella Baucia of the social services of the *Unità Spinale* [spinal unit] at the CTO Hospital; Dario Boni of *Cgil/Fillea Edili* [trade unions]; Margherita Busso at the Amedeo di Savoia Hospital and the cultural mediators who work there: Mercedes Caceres, Edelmira Reyes and Jessica Ferrero of *Associazione Alma Mater*; Laretta Capponi of the public relations office at the CTO Hospital; Rossana Cerri and Marco Grosso of the public relations office AOU Città della Salute e della Scienza; Vittorio De Micheli and Chiara Pasqualini of *Seremi* in Alessandria; Riccardo Falchetta at the Forensic Medicine Department of Sant'Anna Hospital; Pietro Ferrero, Giulia Randazzo and Daria Iacoboni at the *Comitato Collaborazione Medica* (CCM) [committee for medical cooperation]; Paolo Franzese at the Accident and Emergency Clinic, San Giovanni Bosco Hospital; Wilma Gabutti at the job centre of *ASAI*; Patrizia Ghiani, head of the project Mamma+ at *Gruppo Abele*, Helena Igiescu and Barbara Mamone of *Mamre*; Cheng Ming of *Associazione Angi*; Dorothy Quilici of the Cgil Filt Haulage Contractors [trade union]; Miranda Ralli of the *Centro Marco Cavallo*; Estela Robledo of the *Prisma* project; Blentj Shejab and Kassida Kairallah of the multi-ethnic association of cultural mediators – *Ammi*; Teresa Spadea and Raffaella Rusciani of *Scadu* in Grugliasco.

A particular thankyou goes to the administrators and volunteers at the associations AMECE – *Association maison d'enfant pour la culture et l'éducation*; ANGI – *Associazione Nuova Generazione Italo-Cinese*; Acist – *Associazione Culturale Islamica San Salvario Torino*; *San Lorenzo dei Romeni* and *Zhi Song* – *Associazione Socio-Culturale Italo-Cinese*.

Thanks from the heart to our colleagues and assistants Aurora Lo Bue and Federica Viello, who have made a valid contribution to our work, and to Elsa Ghironi and Luisa Greco who worked in synergy with our research.

Finally, the most heartfelt thanks go to our interlocutors, migrants and operators, who gave us their time and shared their experiences and their stories with us, allowing us to produce this volume.

This volume is the fruit of shared work and a process of constant interdisciplinary comparison. The introduction and the conclusion are a collective product and the result of the work of the entire research group.

- The first chapter was written by Anthony Olmo.
- The second chapter was written by Pietro Cingolani and Ana Cristina Vargas. In particular, Ana Cristina Vargas wrote paragraphs from 2.1 to 2.5 and Pietro Cingolani paragraphs 2.6 to 2.10.
- The third chapter was written by Ana Cristina Vargas.
- The fourth chapter was written by Eleonora Castagnone.
- The fifth chapter was written by Pietro Cingolani.
- The sixth chapter was written by Anna Cristina Vargas.
- The seventh chapter was written by Laura Ferrero.
- The eighth chapter was written by Pietro Cingolani and Laura Ferrero. Specifically, Laura Ferrero wrote the paragraphs from 8.1 to 8.3 and Pietro Cingolani paragraphs 8.4 to 8.6.
- The boxes 1, 2 and 5 were prepared by Anthony Olmo, while boxes 3 and 4 were prepared by Eleonora Castagnone.

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## Foreword

The report published here is the result of the second phase of a project begun at the *Laboratorio dei Diritti Fondamentali* (LDF) in 2011. Research carried out by Irene Biglino and Anthony Olmo produced the volume entitled *Health as a Fundamental Right: A study on migration and healthcare in Turin* published in 2014 in this series. This second volume picks up the conceptual framework offered by the legislative content of the right to health, thus emphasising the unitary meaning that we intended to give to the research. In the first phase, the work carried out by the jurist researchers, supported by specialists in other disciplines, was concentrated on the offer of health services and treatments available to migrants. In this second phase, entrusted mainly to anthropologists and sociologists, a complementary perspective was adopted, based on the reconstruction of the experiences of the migrants in their relationship with the health services.

Their voices and their narrations have been given ample space. The intention that drives this second research project, in its relation to the first, was to overcome the usual dimension of description of the normative and the institutional reality, examining their efficacy and adequacy by reconstructing the effective experience of the migrants.

The research phase, of which this document is the result, was conducted using ethnographic methods; it brought to light significant convergences with the previous study, but it also offers a considerable enrichment of the understanding that LDF offers to the public health authorities, the social services and those responsible for drawing up and enacting public policy. The results attained and made public through the two research reports can also be useful for those who work in the vast world of private social welfare, traditionally a rich and compelling element situation in Torino.

The link between social research and the more specifically legal area of human rights is the distinguishing mark of the activities of the *Laboratorio dei Diritti Fondamentali* which, following the indications of the European Court for Human Rights, deals with “concrete and effective rights and not theoretical and illusory ones”. The latter are those set out in the legislation, while the former are those that people live with, or which they lack. The markedly complex context of the social, cultural and economic profiles that make the migrant vulnerable (but also those who are not migrants) was a particularly suitable area for interdisciplinary research. To all the young and expert researchers who, starting from their various scientific experiences, contributed to this research, go the thanks of LDF.

Vladimiro Zagrebelsky

## Introduction

According to the definition of the World Health Organization, health is *a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity*.<sup>1</sup> This perspective implies the interdependence between the body, the mind and society, and to safeguard it an approach aware of the person in all their complexity and the context in which that person is immersed is needed. When we deal with matters of health, or rather *the right to the enjoyment of the highest attainable standard of physical and mental health*, it is therefore necessary to transcend the strictly medical-health level and consider the set of social, political, historical, economic and cultural factors that deeply affect the subjective experience. This is also in line with the positions of the United Nations Organization, which defines the right to health as *health services, goods and facilities provided to all without any discrimination. Services, goods and facilities that are available, accessible, acceptable and of good quality*.<sup>2</sup>

This research project carried out between 2012 and 2014 by a group of researchers from *Laboratorio per i Diritti Fondamentali* (LDF) deals with the health of foreigners in Torino. The migrants represent a social group characterized by what James Quesada, Laurie Hart and Philippe Bourgois called a condition of “structural vulnerability”<sup>3</sup> in which there is an identifiable interdependence between the personal biography, the social marginality and the medical pathology. Seen thus, vulnerability is the product of the position that the migrant occupies within a given social order, of the rights that are granted or denied to him, of the spaces for participation to which he has access.

The concept of “structural vulnerability” has to do with the economic and material aspects that affect well-being and which can generate forms of “social suffering”<sup>4</sup>. This notion, however, is wider and also refers to the way the migrant is seen and represented and the impact that this representation has on his identity and his subjectivity. During this research numerous negative images of foreigners emerged, which speak of a historical moment in which xenophobia, discrimination and prejudices are anything but overcome.

As we will have the opportunity to emphasize in the following chapters, there is a link between all these forms of everyday discrimination – from micro-traumas to effective situations of social exclusion – and the mental and physical health of foreigners. To fully understand the needs and the expectations of migrants in the health and welfare sectors, and to identify the obstacles to the realization of a comprehensive right to health, it is essential to consider simultaneously, the health profile of the migrant, the social, cultural and

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<sup>1</sup> 22 July 1946, Official Records of the World Health Organization, N. 2, 1948, page 100, introduction. Enacted in Italy by legislative decree of the Head of State *pro tempore* N. 1068, March 4<sup>th</sup> 1947, *Gazzetta ufficiale* N. 236, October 1<sup>st</sup> 1947, ordinary supplement N. 2360.

<sup>2</sup> The United Nations Special Rapporteur on *The Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health*, 2006, Joint Fact Sheet WHO/OHCHR/323, August 2007 (revised and integrated November 2013).

<sup>3</sup> J. Quesada, L. K. Hart and P. Bourgois, *Structural Vulnerability and Health: Latino Migrant Laborers in the United States*, in *Medical Anthropology*, 30, 2011, N. 4, pages 339-362.

<sup>4</sup> For an introduction to this concept, see A. Kleinman, V. Das and M. Lock (ed.) *Social Suffering*, Berkeley, University of California Press, 1979.

economic aspects and the individual subjective dimension, which are expressed in the process of signification of the experience.

This research is based on the use of qualitative methods, in particular field research and direct observation of the contexts studied, which allowed contact with patients being treated at hospitals and outpatient clinics of the national health service, such as the Spinal Unit at the Città della Salute teaching hospital<sup>5</sup>, the CTO Hospital<sup>6</sup>, the gynaecology and obstetrics department of the Maria Vittoria Hospital and the migrant health clinic (MISA) at the Amedeo di Savoia Hospital<sup>7</sup>. A second fundamental context in which our research developed was the local network of advice centres, *Centri ISI* (health information for migrants) and other spaces dedicated to the care of the immigrant population. The collaboration with private associations was particularly important, since they offer information, guidance and basic or specialized health services. Amongst these are the medical clinic ‘Giovanni Paolo II’ at the Sermig (*Servizio Missionario Giovane* – missionary youth service), a place that offers health assistance to people in difficulties, thanks to the voluntary services of specialists and the *Association Camminare Insieme*. Here it was possible to interview the users and to carry out field research which allowed us to observe and understand the daily activities of the clinic and specific projects such as the “Mother’s Room”. These two realities are now well established and can count on a network of specialists who offer help free of charge. They also form, thanks to their position in the popular district of Porta Palazzo, a point of contact for the population at risk that serves the immigrants who, by choice or often by necessity, do not use the National Health Service. In the field of ethnopsychiatry, the cooperation with the *Centro Franz Fanon* who allowed us to consult the records in their files and take part in the coordination meetings with the team and in the scientific and cultural activities organized by the association. Interviews were held at the *Centro Mamre*, an association specialized in ethnopsychiatric treatment.

On the question of health and work, the meeting with the users of the ASAI (voluntary association) and the CGIL (trade union) services was fundamental. The majority of the interviews with workers were carried out here.

Another important source of information was the participation in the follow up of a wide range of public and private training, prevention and health education projects dealing with immigration and health and led by migrants or operators. In some of these projects, the researchers were involved as organizers or as trainers. This active participation gave rise to dynamics that we consider an integral part of the research: on the one hand, it represented a moment for restitution and reciprocity and on the other, it made possible a process of discussion, which opened the doors to the co-construction of an interpretation of the phenomena investigated. In these contexts the presence of the researcher directly influenced the processes observed, leading to a type of pondered observation, which approached the research-action method, that is to say, a

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<sup>5</sup> Unità Spinale Unipolare dell’Azienda Ospedaliera Universitaria Città della Salute, Torino.

<sup>6</sup> Centro Traumatologico Ortopedico, Torino.

<sup>7</sup> The MISA clinic deals with prevention and treatment of infectious diseases amongst the migrant population, with a specially trained team of infectologists and cultural mediators.

type of social research in which the researcher observes the context while acting on it. A research context that it is worth mentioning is the prayer room *Omar Ibn El Khattab*, in the San Salvario district. The association that manages the mosque and a group of doctors and mediators from the MISA clinic came together in 2014 to organize at this and other prayer rooms in the city, meetings on health topics. We took part as observers and were also actively involved in the organization of the events.

The interest in the activities for promoting health at the prayer rooms is part of our wider interest in the processes of organization and promotion of health within the community, above all through the networks of formal and informal associations of the migrants themselves. In these contexts, we generally encountered a good tendency to collaboration, perhaps due to the shared objectives of the research. The people who work in these situations, in fact, are probably aware of the importance of their presence in the community of reference and the fact that a group of researchers was interested in this phenomenon was probably seen as an attempt to valorize their work.

The research started in the northern districts of Torino, and in particular, in *Barriera di Milano*, one of the urban areas with the highest concentration of foreign residents, which is home to an immigrant population heterogeneous in age, origins, date of migration and generation<sup>8</sup>. In this district, in addition to the resources necessary for basic services (including GPs, paediatricians, paediatric clinic and family planning clinic) there are also National Health Service hospitals and clinics. In the area there are also associations providing social-welfare services or support in access to medical treatment. As the research proceeded, however, we found that, while some reference points are clearly linked to the place of residence, others are not connected to the closeness to home, but are chosen for other reasons. The initial boundaries were therefore insufficient and were gradually extended to include the major teaching hospitals and other structures and spaces utilized by the users. For this reason, it was essential to maintain a flexible approach to the research, adopting where possible, the same elasticity and capacity for adaptation present in the services and in the stories of our interlocutors.

During the research project, seventy-five in-depth interviews were held with migrants, twenty-four with cultural mediators and volunteers at the associations of foreigners and twenty-four semi-structured interviews with privileged witnesses.

In an anthropological-social research project, the interviews often represent the culmination of an extensive process of meeting and reciprocal acquaintance. The initial approach and the construction of a relationship of trust were facilitated by the linguistic skills of the researchers (Romanian, Spanish, English and French), which allowed them to conduct the interviews in the mother tongue of those interviewed, creating greater intimacy. Many meetings were held at the homes or workplaces of the interviewees, contributing to the creation of a climate of trust and allowing us to observe with discretion some aspects of their daily lives. Direct observation of the reality characterized by considerable social difficulties, as in the

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<sup>8</sup> For a description of the characteristics of the district and the social relations within it, see the chapters relating to *Barriera di Milano* in the volume by F. Pastore and I. Ponzio (ed.) *Concordia discors*, Rome, Carocci, 2013. Refer also to the material available online: [www.concordiadiscors.eu](http://www.concordiadiscors.eu).

case of the Rom camp in Lungo Stura Lazio, contributed to highlighting the way the stories of health are preview gathered; the aspect of illness and access to treatment is intrinsically linked to topics of social marginality, to the precariousness of accommodation and the lack of income.

The interviews with the migrants, although numerous for a qualitative research project, are not a representative sample from a statistical point of view. They are rather intended to be an in-depth preview of the most significant cases, allowing us to focus on the heterogeneous nature of the situations and at the same time, the common problems that many immigrants are forced to deal with. The framework of the semi-structured interviews opens with an exploration of the personal history, with particular attention to the migratory process and the present living conditions, finally identifying the factors that have had an impact on adequate access to treatment. Particular attention was paid to variables such as legal status, education, social class, employment, linguistic competence, information about and awareness of rights.

Through the narration, it was possible to understand the various experiences of access to the health services, analysing the positive and negative aspects of the meetings with the operators, episodes of discrimination and the coherence of expectations and the health services effectively received.

The voices and the experiences of the migrants allowed us to understand the viewpoints of the operators, investigated during the first phase of the project<sup>9</sup>, from a new perspective. The various readings of a similar welfare service are at times convergent, but often, in addition to the common points, there are elements of disaccord that indicate divergent interpretations and latent misunderstandings.

The interviews with the privileged witnesses, in particular the health workers and the professionals involved in the activities of the clinic, although they were not the focus of our inquiry, allowed us to better understand the policies and the methods by which the services are provided, and the representation of the foreign user which is the basis of the services. To this, we can add those conducted with the cultural mediators, the representatives and members of the associations of migrants and other key figures who, although not always directly involved in the services, represent a bridge between the citizens and the network of health-welfare services.

Finally, a precious source was the presence at the meetings at the GRIS (Gruppi Immigrazione e Salute – immigrant health groups), which are the local units of SIMM (Società Italiana Medicina delle Migrazioni – Italian group for migrants' healthcare). These units were founded to “stimulate networking and encourage the knowledge and cooperation between those who – in the institutional and voluntary fields – are involved in various ways in guaranteeing rights, access and availability of health services for immigrants.”<sup>10</sup>

The qualitative data is flanked by epidemiological data supplied by the Epidemiological Service of the local health authority ASL TO3, and is based on thirty-six indicators for the construction and monitoring of the health profile of the immigrant population developed within the project *La salute della popolazione*

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<sup>9</sup> I. Biglino and A. Olmo, *La salute come diritto fondamentale: una ricerca sui migranti a Torino*, Bologna, Il Mulino, 2014.

<sup>10</sup> S. Geraci, M. Bonciani and B. Martinelli, *La tutela della salute degli immigrati nelle politiche locali*, Roma, Caritas Diocesana, 2010.

*immigrata: metodologia di analisi*<sup>11</sup> and *La salute della popolazione immigrata: il monitoraggio da parte dei Sistemi sanitari regionali*<sup>12</sup> coordinated by the Observatory on the inequalities in healthcare in the Marche region.

One of our objectives was to integrate qualitative and quantitative approaches. These methods, at times considered unethical or incompatible, may in fact be complementary. The qualitative research has allowed us not only to access the information necessary for interpreting the epidemiological data, but also to remodel the research questions, acting as a corrective to basic assumptions that, in some cases, were found to be erroneous. The link between qualitative and quantitative approaches also allowed us a better understanding of the individual experiences in the field of the right to health, without losing sight of the overall picture, social and epidemiological that forms the background.

One of our priorities was to attain information that could not be explored through an epidemiological analysis, or, in other words, to confront those cases in which the demand for health did not meet the institutions that provide it, or, for various reasons, could not receive an answer from them. In this type of situation, the alternative routes to health and the recourse to pluridirectional forms of medical transnationalism, which therefore fall within the scope of the research thanks to the importance of the experiences of the migrants, are of particular importance.

During the project, the importance of the agencies emerged: they are persons who are not passive subjects of the treatment, but active subjects who interact with the system, building (with more or less valid results) their own routes to health. The search for solutions and strategies is mainly individual, however in some cases, still sporadic but increasingly significant, the communities have begun to act collectively to find an answer to the health needs that are still not met. Bearing in mind these forms of self-organization and participation represents, in our opinion, an essential foundation for building a more inclusive health system, closer to the needs of the users.

The first chapter presents the legislation on the right to health and the main rulings on health and immigration. They represent the conceptual framework for categorising and analysing the data gathered.

The second chapter deals with the question of social suffering and marginality, with particular attention for the link between physical health and mental health and the impact of the economic crisis on the safeguards for the health of migrants in the most vulnerable groups. It also looks into the case of the Rom minority, which represents specificities from a juridical and the social-welfare point of view.

The third chapter looks at the mother-child area, a priority area of intervention in which, within the general framework of a mainly positive situation, there are still criticalities linked to economic and social

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<sup>11</sup> Agreement between the Italian Ministry of Health and Agenas: *La salute della popolazione immigrata: metodologia di analisi*, 2009, project *Promozione della salute della popolazione immigrata in Italia*, Accordo Ministero della Salute/Ccm-Regione Marche.

<sup>12</sup> Agreement between the Italian Ministry of Health and Agenas: *La salute della popolazione immigrate, il monitoraggio da parte dei sistemi sanitari regionali*. National project, October 2013, <http://www.agenas.it/lea/la-salute-della-popolazione-immigrata-il-monitoraggio-da-parte-dei-sistemi-sanitari-regionali-ccm>.

factors, the lack of information about rights and existing services and a lack of availability of family networks and social safety nets.

The fourth chapter is dedicated to the correlation between health and work, and is based on structural elements of disadvantage that characterize the integration of foreigners in the Italian economy. The employment and working conditions of foreigners are analysed as social determinants of health, with particular attention for accidents in the workplace and professional disease, the forms of safeguard guaranteed by INAIL<sup>13</sup> and the methods of access to worker's health. Finally, in this section we look at work as an obstacle to access to health and to appropriate treatment, highlighting an area of potential conflict between the right to health and the right to work.

The fifth chapter concerns infectious diseases, an area of great concern that has attracted the attention of the media for what we could call the "syndrome of the incubus", that is the stigmatization of the foreigner as a carrier of disease.

The sixth chapter centres on two of the most important instruments of integration and the management of interculturality: cultural mediation and training. These instruments contribute to generating a more symmetric and knowledgeable approach to treatment, encouraging accessibility and acceptability of the services.

In consideration of the strong link between the public and the private sectors that characterizes the situation in Torino, the seventh chapter looks into the role that the migrant associations can play in the area of health and well-being. The associations of foreigners are a new subject in the associative panorama of the city and by placing the analysis of associationism within the wider question of social capital; the chapter introduces the topic of community welfare, describing the associations of migrants as agents of accessibility, acceptability and health literacy.

The eighth chapter concentrates on medical transnationalism, a useful concept for highlighting the plurality and pluridirectionality of health services. The decision to conclude with this topic reflects the desire to reposition the information that emerged from the previous chapters in a wider cultural and spatial framework: the one in which the people interviewed move.

In the conclusions, we consider the links between marginality and vulnerability and summarize both the criticalities that emerged and the examples of good practice observed in the field.

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<sup>13</sup> INAIL – Istituto nazionale per l'assicurazione contro gli infortuni sul lavoro – National institute for insurance against accidents at work.

## Chapter One

### The right to health and legislation on access to health services

This chapter is dedicated on the one hand to presenting the essential framework of the right to health – and in particular the legislative sources and the essential elements of the normative content – and on the other hand, to giving a summary of the relevant measures on health and immigration.

As far as the first point is concerned, this overview is necessary in order to reaffirm the conceptual framework within which the research is collocated, while bearing in mind that this volume is the second published by the Laboratorio dei Diritti Fondamentali as part of the research project dedicated to the right to health of the migrant population in the city of Torino.

The first phase of the research aimed to define the overall situation at an institutional level, making considerable use of interviews with operators in the public sector and in the private social sector in contact with the migrant population. The aim of the second phase was to gather the testimonies of the migrants themselves, in order to further investigate the most important topics.

Within this framework, the definition of the right to health and the normative content were adopted to categorize, problematize and analyse the questions that emerged from the field research. A similar analysis allowed us to interpret the results of the research, highlighting the main problems from the standpoint of human rights in general and the right to health in particular. This exercise, apart from its intrinsic interest and value, also allowed us to draw attention to any shortcomings of the Italian authorities with regard to the obligation to respect, protect and fulfil the right to health deriving from the ratification of numerous international treaties that sanction it, and our country's Constitution. Finally, we must stress that, considering the unitary nature of the conceptual framework adopted during the two phases of research, here it will be sufficient to confirm the essential aspects of the right to health, referring to the first volume<sup>14</sup>

With regard to the summary of the principal legislation in Italy on matters concerning health and immigration, a similar overview is necessary in order to clarify which opportunities for access to the health services are available to migrants, also according to their legal status with respect to the rules that govern entry to the country and residence in the national territory. This legislation is, in fact, the first and perhaps the most important discriminant that determines the effective possibility of access to health services for a migrant and, consequently, the possibility of realising his or her right to health.

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<sup>14</sup> I. Biglino and A. Olmo, *Health as a fundamental right: a study on migration and healthcare in Turin*, Bologna, Il Mulino 2014

1. *The right to health: definitions and sources*

First, it is necessary to clarify that the expression “right to health” refers, in synthesis, to the more complete expression “right to the best attainable conditions of physical and mental health”<sup>15</sup>. As is evident, the right to health must not be seen as a right to be healthy, but is shaped by a much more complex perspective. From the very start, we must consider this right to be composed of two macro components, that is to say ‘freedoms’ and ‘entitlements’. The freedoms include the freedom to control one’s own health and body, and freedom from external interference (such as torture, inhuman and degrading treatment, non-consensual medical treatment and experiments). The rights include the right to utilize a system for the safeguarding of health that guarantees equal possibilities for all to enjoy the best conditions of health available. Moreover, it must be stressed that the right to health does not only deal with the measures and initiatives undertaken in order to guarantee the attainment of the highest standards of health, but also the way in which these are adopted and supplied. Particular emphasis is in fact, dedicated to the transparency of the decision-making processes and the principle of non-discrimination, which must inspire every initiative.<sup>16</sup>

The complexity of the content of the right to health is evident from this reconstruction. To some extent, this complexity refers also to the particularly significant role that this right occupies within the wide-ranging spectrum of human rights. In fact, this, in a hypothetical hierarchy of rights, occupies a crucial position in guaranteeing many other rights, and more generally, in guaranteeing a dignified life.<sup>17</sup>

Finally, it is necessary to state that the right to health is almost universally recognized. Every state has in fact ratified at least one of the international human rights treaties, which sanction the right to health.<sup>18</sup>

The first declaration on the right to health at international level is to be found in the introduction to the 1946 Constitution of the World Health Organization (WHO). This defines health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”.<sup>19</sup> It also states that, “The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition.” Although over the years many attempts have been made to find an alternative and more restrictive definition of health, the one in the WHO constitution has so far remained the universally accepted starting point. This definition is centred on integration, rather than on the opposition of two concepts: one negative (the absence of disease or infirmity) and the other positive (promotion of human well-being).

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<sup>15</sup> Committee on Economic, Social and Cultural Rights (CESCR) *General Comment 14. The Right to the Highest Attainable Standard of Health*, UN Doc. E/C. 12/2000/4, August 11<sup>th</sup> 2000.

<sup>16</sup> P. Hunt and G. Blackman, *Health Systems and the Right to the Highest Attainable Standard of Health*, in *Realising the Right to Health. Swiss Human Rights Book*, ed. A. Clapham and M. Robinson, Vol. III, 2009, page 43.

<sup>17</sup> E. Riedel, *The Human Right to Health: Conceptual Foundations*, in A. Clapham and M. Robinson (ed.) *Realizing the Right to Health*, op. cit., page 36.

<sup>18</sup> Office of the High Commissioner for Human Rights at the United Nations and the World Health Organization, *Fact Sheet 31: The Right to Health*, Geneva, OCHR/WHO, 2008. Italy has ratified all the major treaties we discuss in this paragraph, except for the International Convention for the Protection of Migrant Workers and Their Families (1990).

<sup>19</sup> World Health Organization, Constitution, July 22<sup>nd</sup> 1946. Official Records of the World Health Organization, N. 2, 1948, page 100. Enacted in Italy by the Head of State *pro tempore*, March 4<sup>th</sup> 1947, N. 1068, *Gazzetta Ufficiale* N. 236, October 1<sup>st</sup> 1947, ordinary supplement N. 2360.

The right to health found its first formal recognition in the Universal Declaration of Human Rights in 1948.<sup>20</sup> This includes health within the wider right to an adequate standard of living (Article 25)<sup>21</sup>

The Declaration states:

1. Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.
2. Motherhood and childhood are entitled to special care and assistance. All children, whether born in or out of wedlock, shall enjoy the same social protection.

Although the Universal Declaration of Human Rights is not legally binding, the doctrine recognizes, almost unanimously, that many of its regulations have now attained the status of *customary international law*<sup>22</sup>.

The right to health finds another important source in the International Covenant on Economic, Social and Cultural Rights, 1966<sup>23</sup>, the most important international instrument in the field of economic, social and cultural rights.

Article 12 of the Covenant states that:

1. The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.
2. The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for:
  - a) The provision for the reduction of the stillbirth-rate and of infant mortality and for the healthy development of the child;
  - b) The improvement of all aspects of environmental and industrial hygiene;
  - c) The prevention, treatment and control of epidemic, endemic, occupational and other diseases;
  - d) The creation of conditions that would assure to all medical service and medical attention in the event of sickness.

The definition given by Article 12 of the Covenant was further specified by the Committee on Economic, Social and Cultural Rights of the United Nations in the General Comment N. 14 on the right to

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<sup>20</sup> General Assembly of the United Nations, *Resolution 217 A (III) Universal Declaration of Human Rights*, UN Doc. A/810, adopted December 10<sup>th</sup> 1948, page 71.

<sup>21</sup> See: N. Pillay, *Right to Health and the Universal Declaration of Human Rights*, in *The Lancet*, 372, December 13<sup>th</sup> 2008.

<sup>22</sup> See *inter alia*, H. Hannum, *The Status of the Universal Declaration of Human Rights in National and International Law*, in *Georgia Journal of International and Comparative Law*, 25, 1995-1996, pages 287-314.

<sup>23</sup> General Assembly of the United Nations, *International Covenant on Economic, Social and Cultural Rights*, United Nations Treaty Series, Vol. 993, adopted December 16<sup>th</sup> 1966, page 3. Ratified in Italy Law N. 881, October 25<sup>th</sup> 1977, *Gazzetta Ufficiale* N. 333, December 7<sup>th</sup> 1977.

the highest attainable standard of health<sup>24</sup>. These two tools give the most comprehensive and widespread definition of the right to health, a definition that has also inspired the conceptual framework of this research project.

The right to health is also recognized in a number of international agreements on matters regarding human rights. Amongst these is the International Convention on the Elimination of All Forms of Racial Discrimination, dated 1965<sup>25</sup>, the Convention on the Elimination of All Forms of Discrimination Against Women, dated 1979<sup>26</sup>, the Convention on the Rights of the Child<sup>27</sup>, the Convention on the Rights of Persons with Disabilities, dated 2006<sup>28</sup>, the International Convention on the Protection of the Rights of All Migrant Workers and Members of their Families, dated 1990.<sup>29</sup> The profiles relating to health in the working world were studied by the International Labour Organization (ILO), respectively in the Convention N. 155 on Occupational Safety and Health (1981)<sup>30</sup> and the Convention N. 161 on Occupational Health Services (1985)<sup>31</sup>.

Other fields, all within the United Nations system, are also particularly interesting from our perspective. In particular, the activity of the conventional bodies that safeguard the system of the treaties – the *Treaty Bodies*<sup>32</sup> – and the figure of the Special Rapporteur on the right to the best attainable conditions of physical and mental health (from here on “the Special Rapporteur on the right to health”).<sup>33</sup> From the start of the mandate, this figure has presented annual thematic reports and reports on the missions carried out in various countries. Amongst the specific topics analysed by the Special Rapporteur are: the indicators of

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<sup>24</sup> Committee on Economic, Social and Cultural Rights (CESCR) *General Comment 14* op. cit. gives “authoritative interpretations” of various articles of the international agreements on economic, social and cultural rights, with the aim of helping countries to fulfil their obligations.

<sup>25</sup> General Assembly of the United Nations, *International Convention on the Elimination of All Forms of Racial Discrimination*, United Nations Treaty Series, Vol. 660, adopted December 21<sup>st</sup> 1965, page 195, Article 5(e)(iv). Ratified in Italy, Law N. 654, October 13<sup>th</sup> 1975, *Gazzetta Ufficiale* N. 337, December 23<sup>rd</sup> 1975.

<sup>26</sup> General Assembly of the United Nations, *Convention on the Elimination of All Forms of Discrimination Against Women*, United Nations Treaty Series, Vol. 1249, adopted December 18<sup>th</sup> 1979, page 13, Article 12. Ratified in Italy, Law N. 132, March 14<sup>th</sup> 1985, *Gazzetta Ufficiale* N. 89, April 15<sup>th</sup> 1985.

<sup>27</sup> General Assembly of the United Nations, *Convention on the Rights of the Child*, United Nations Treaty Series, Vol. 1577, adopted November 20<sup>th</sup> 1989, page 3, Articles 6, 24, 25. Ratified in Italy, Law N. 176, May 27<sup>th</sup> 1991, *Gazzetta Ufficiale* N. 135, June 11<sup>th</sup> 1991, ordinary supplement N. 35.

<sup>28</sup> General Assembly of the United Nations, *Convention on the Rights of Persons with Disabilities*, United Nations Document A/RES/61/106, adopted December 13<sup>th</sup> 2006, Annex I, Article 25. Ratified in Italy, Law N. 18, March 3<sup>rd</sup> 2009, *Gazzetta Ufficiale* N. 61, March 14<sup>th</sup> 2009.

<sup>29</sup> General Assembly of the United Nations, *International Convention on the Protection of the Rights of All Migrant Workers and Members of their Families*. UN Document A/RES/45/158, adopted December 18<sup>th</sup> 1990, Article 43. As mentioned in the text, Italy has not ratified this convention.

<sup>30</sup> International Labour Organization, (N. 155), *Convention concerning Occupational Safety and Health and the Working Environment*. International Labour Office, June 22<sup>nd</sup> 1985, Geneva, June 25<sup>th</sup> 1985. This convention has not been ratified by Italy.

<sup>31</sup> Id. International Labour Organization, (N. 161), *Occupational Health Services Convention*. International Labour Office, June 22<sup>nd</sup> 1981, Geneva, June 25<sup>th</sup> 1985. This convention has not been ratified by Italy.

<sup>32</sup> The *Treaty Bodies* are committees of independent experts that monitor implementation of the core international human rights treaties. Each State party to a treaty has an obligation to take steps to ensure that everyone in the State can enjoy the rights set out in the treaty. These committees look for effective or potential violations, examine the information supplied by the governments and other interested parties, such as, for example NGOs, and formulate recommendations. See *inter alia*, Committee for the United Nations on Economic, Social and Cultural Rights, *General Comment*; op. cit., *United Nations Committee for the Elimination of All Forms of Discrimination Against Women*, General Recommendation N. 24; Article 12 of the Convention (*Women and Health*) UN Doc, A/54/38/Rev. 1, January 19<sup>th</sup> – February 5<sup>th</sup> 1999, Chapter 1; Committee on the Rights of the Child, *General Comment 3, HIV/AIDS and the Rights of the Child*, UN Document CRC/GC/2003/1, March 17<sup>th</sup> 2003 United Nations Committee Elimination of All Forms of Racial Discrimination, *General Recommendation 30, Discrimination against Non-Citizens*, UN Document CERD/C/64/Misc. 11/rev. 3, January 10<sup>th</sup> 2004.

<sup>33</sup> United Nations High Commissioner’s Office, Fact Sheet 27: Seventeen Frequently Asked Questions about United Nations Special Rapporteurs, Geneva, OHCHR, 2001.

health and an approach based on human rights; the right to sexual and reproductive health; the right to the best attainable health standards and to water and hygienic services; the right to health, access to pharmaceutical products and the right to intellectual property; mental disability and the right to health; the right to health and the criminalization of the behaviours and sexual orientation; sex work and the transmission of HIV; the right to health in relation to development; the right to health and informed consent; the right to health and the reduction of maternal mortality.

The right to health has also found widespread recognition from the principle Community organizations, that is to say the European Council and the European Union. With regard to the system of the European Council, the main source of right to health is to be found in the European Health Insurance Card<sup>34</sup>, which contains various rulings that guarantee, implicitly or explicitly, the right to health. The principle rule is Article 11, which states:

With a view to ensuring the effective exercise of the right to protection of health, the Contracting Parties undertake, either directly or in cooperation with public or private organizations, to take appropriate measures designed inter alia:

1. To remove as far as possible the causes of ill health;
2. To provide advisory and educational facilities for the promotion of health and the encouragement of individual responsibility in matters of health;
3. To prevent as far as possible epidemic, endemic and other diseases.

The health and well-being of children and adolescents are protected by articles 7 and 17. The health of pregnant women is protected by articles 8 and 17, while the health of old people is governed by article 23<sup>35</sup>.

In addition to the European Health Insurance Card, we must also mention the Convention on Human Rights and Biomedicine of the Council of Europe, dated April 4<sup>th</sup> 1997<sup>36</sup>, which is intended to guarantee equal access to health services of adequate quality, according to the medical needs of the individual, and it imposes on the countries the duty to attain suitable standards. Article 3 of the Convention states that “Parties, taking into account health needs and available resources, shall take appropriate measures with a view to providing, within their jurisdiction, equitable access to healthcare of appropriate quality.”

Finally, we will mention that the right to health is also recognized in the European Convention on Human Rights<sup>37</sup>. In fact, although this convention does not explicitly foresee the aforementioned right, it is

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<sup>34</sup> European Health Insurance Card, CETS N. 163 Strasbourg, May 3<sup>rd</sup> 1996. Ratified in Italy, Law N. 30, February 9<sup>th</sup> 1999, *Gazzetta Ufficiale* N. 44, February 23<sup>rd</sup> 1999, ordinary supplement N. 38.

<sup>35</sup> For further information see, Council of Europe, *The Right to Health and the European Social Charter*. Information document prepared by the secretariat of the ESC, Strasbourg, ESC, 2009.

<sup>36</sup> Council of Europe, Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine, (CETS N. 164, Oviedo, April 4<sup>th</sup> 1997. This Convention has not been ratified in Italy.

<sup>37</sup> *Convention for the Protection of Human Rights and Fundamental Freedoms*, CETS N. 5 Rome, November 4<sup>th</sup> 1950. Ratified in Italy, Law N. 848, August 4<sup>th</sup> 1955, *Gazzetta Ufficiale* N. 221, September 24<sup>th</sup> 1955.

indirectly guaranteed thanks to an expansive interpretation of other correlated rights<sup>38</sup>. Amongst these are the right to life (Article 2)<sup>39</sup>, the prohibition of torture, inhuman or degrading treatment (Article 3)<sup>40</sup> and the right to a private and family life (Article 8)<sup>41</sup>.

The right to health is also recognized by the legislation of the European Union. This right is, in fact, explicitly protected by Article 35 of the EU Charter of Fundamental Rights<sup>42</sup>. It must be remembered that the European Union, in the light of its development and competencies, does not have exclusive competence in matters of health, it can only intervene to complete and encourage cooperation between the member states and the possibility of defining health policies at Community level is to be excluded. The safeguarding of health, at Community level, is however mainly a matter of coordination of national systems, with particular attention for the three areas of reference: the safeguarding of workers in the workplace, cross border access to health services and safeguards for users.

Lastly, the right to health is recognized in the Italian national legislation, and in particular in Article 32 of the Constitution<sup>43</sup>. It is the only right expressly defined as “fundamental”, and a “collective interest” that “guarantees free medical care to the indigent”<sup>44</sup>.

The concrete safeguards for the right to health, in the Italian legislation, found their first and most important confirmation in the creation of the National Health Service (*Servizio Sanitario Nazionale* – SSN), through the Law 833/1978<sup>45</sup>. Operating through the local health authorities (*Aziende Sanitarie Locali* – ASL), the institution and the aims of the SSN was to enact the constitutional decree, guaranteeing access to the health services and the right to health for all citizens. It is also important to mention that following the reform of Title V of the Constitution<sup>46</sup>, the “determination of the basic level of benefits relating to civil and social entitlements to be guaranteed throughout the national territory” has remained the exclusive prerogative of the state<sup>47</sup>, seen as the levels necessary to guarantee a free and dignified existence for those needing treatment and their family<sup>48</sup>.

## 2. The legislative content of the right to health

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<sup>38</sup> See: R. Chenal, *Il diritto alla salute e la convenzione europea dei diritti dell'uomo*, in *I diritti sociali come diritti della personalità*, ed. R. Cavallo Perin et al, Naples, Edizioni Scientifiche Italiane, 2010, pages 75-96.

<sup>39</sup> See, for example, European Commission on Human Rights, *Association X vs United Kingdom*, appeal N. 7154/75, decision on admissibility, July 12<sup>th</sup> 1978; European Court of Human Rights, *L. C. B. vs United Kingdom*, appeal N. 23413/94, sentence June 9<sup>th</sup> 1998; *Karchen et al vs France*, appeal N. 5722/04; *Keenan vs United Kingdom*, decision on admissibility March 4<sup>th</sup> 2008; *G. N. et al vs Italy*, appeal N. 43134/05, sentence December 1<sup>st</sup> 2009.

<sup>40</sup> See, for example, European Commission on Human Rights, *D. vs United Kingdom*, appeal N. 30240/96, sentence May 2<sup>nd</sup> 1997; *Keenan vs United Kingdom*, appeal N. 27229/95, sentence April 3<sup>rd</sup> 2001; *Moussel vs France*, appeal N. 67263/01, sentence November 14<sup>th</sup> 2002.

<sup>41</sup> See, for example, European Commission on Human Rights, *Lopez Ostra vs Spain*, appeal N. 16798/90, sentence December 9<sup>th</sup> 1994; *Storck vs Germany*, appeal N. 61603/00, sentence June 16<sup>th</sup> 2005; *Taskin et al vs Turkey*, appeal N. 46117/99, sentence November 10<sup>th</sup> 2004; *Tatar vs Romania*, appeal N. 67021/01, sentence January 27<sup>th</sup> 2009. See also European Commission on Human Rights, *X vs Austria*, appeal N. 8278/78, ruling December 13<sup>th</sup> 1979.

<sup>42</sup> EU Charter of Fundamental Rights, proclaimed in 2000, it became legally binding on the EU with the entry into force of the Treaty of Lisbon in December 2009.

<sup>43</sup> Constitution of the Italian Republic, *Gazzetta Ufficiale* N. 298, December 27<sup>th</sup> 1947.

<sup>44</sup> Italian Constitutional Court, ruling N. 423, December 2<sup>nd</sup> 2005.

<sup>45</sup> *Gazzetta Ufficiale* N. 360, December 28<sup>th</sup> 1978.

<sup>46</sup> Constitutional Law N. 3, October 18<sup>th</sup> 2001, *Gazzetta Ufficiale* N. 248, October 24<sup>th</sup> 2001.

<sup>47</sup> Constitution of the Italian Republic, Article 117, paragraph 2, letter m), December 27<sup>th</sup> 1947.

<sup>48</sup> S. Bartole and R. Bin (ed.) *Commentario breve alla Costituzione*, Padova, Cedam, 2008, pages 302-332.

In this section, we will briefly present the legislative content of the right to health, that is to say, the substantial elements that compose this right. For this purpose, we will pay particular attention to the nature of the right drawn up within the United Nations, in particular by the Committee for Economic, Social and Cultural Rights.

The basic tenets of the right to health can be divided into two main categories: the right to medical treatment or to health services (generally meant as the supply of preventive services, treatment and rehabilitation) and the right to preconditions underlying health or the determinants of health. It is necessary to emphasise the importance of both categories, since the right to health is often identified only with medical treatment. The right to the best attainable standards of health must, in fact, be seen as an inclusive right that extends not only to prompt and adequate medical treatment, but also the determinants for health. Amongst these determinants of health, of most interest for the field of human rights is access to clean drinking water and to adequate sewage disposal, the availability of food and sufficient nutrition, the safety and quality of the home, the healthiness of the living and working environments, access to information on health and the prohibition of discrimination<sup>49</sup>.

In our attempt to fully understand the implications of the adoption of an approach that combines health and human rights, the Committee on Economic, Social and Cultural Rights has declared that there are four fundamental standards or criteria that the countries must respect, if the right to health is to be met. They are the criteria of *availability*, *accessibility*, *acceptability* and *quality*<sup>50</sup>.

(a) *Availability*. Functioning public health and health-care facilities, goods and services, as well as programmes, must be available in sufficient quantity within the State party. The precise nature of the facilities, goods and services will vary depending on numerous factors, including the State party's developmental level. They will include, however, the underlying determinants of health, such as safe and potable water and adequate sanitation facilities, hospitals, clinics and other health-related buildings, trained medical and professional personnel receiving domestically competitive salaries, and essential drugs, as defined by the WHO Action Programme on Essential Drugs.

(b) *Accessibility*. Health facilities, goods and services have to be accessible to everyone without discrimination [...]. Accessibility has four overlapping dimensions:

\* *Non-discrimination*: health facilities, goods and services must be accessible to all, especially the most vulnerable or marginalized sections of the population, in law and in fact, without discrimination on any of the prohibited grounds.

\* *Physical accessibility*: health facilities, goods and services must be within safe physical reach for all sections of the population, especially vulnerable or marginalized groups, such as ethnic minorities and indigenous populations, women, children, adolescents, older persons, persons with disabilities

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<sup>49</sup> General Assembly of the United Nations, Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, UN Document A/62/2014, August 8<sup>th</sup> 2007.

<sup>50</sup> The definitions in this paragraph are taken from the General Comment N. 14.

and persons with HIV/AIDS. Accessibility also implies that medical services and underlying determinants of health, such as safe and potable water and adequate sanitation facilities, are within safe physical reach, including in rural areas. Accessibility further includes adequate access to buildings for persons with disabilities.

\* Economic accessibility (affordability): health facilities, goods and services must be affordable for all. Payment for health-care services, as well as services related to the underlying determinants of health, must be based on the principle of equity, ensuring that these services, whether privately or publicly provided, are affordable for all, including socially disadvantaged groups. Equity demands that poorer households should not be disproportionately burdened with health expenses as compared to richer households.

\* Information accessibility: accessibility includes the right to seek, receive and impart information and ideas concerning health issues. However, accessibility of information should not impair the right to have personal health data treated confidentially.

(c) Acceptability. All health facilities, goods and services must be respectful of medical ethics and culturally appropriate, i.e. respectful of the culture of individuals, minorities, peoples and communities, sensitive to gender and life-cycle requirements, as well as being designed to respect confidentiality and improve the health status of those concerned.

(d) Quality. As well as being culturally acceptable, health facilities, goods and services must also be scientifically and medically appropriate and of good quality. This requires, *inter alia*, skilled medical personnel, scientifically approved and unexpired drugs and hospital equipment, safe and potable water, and adequate sanitation.

In addition to identifying the criteria with which the countries must comply, the Committee on Economic, Social and Cultural Rights provides indications and principles that we consider it useful to mention here:

#### *The principle of non-discrimination*

In the General Comment N. 14, the Committee highlights the fact that the countries are forbidden to enact any form of discrimination in access to the health services on the basis of race, gender, language, religion, opinion, physical or mental disability, health, sexual orientation, political orientation, and so on, with the intention or the effect of destroying or compromising equal rights to the enjoyment or exercise of the right to health<sup>51</sup>. The obligation to guarantee non-discrimination is closely linked to the principle of equality, which implies that the countries must pay attention to the entire population. This does not mean that they should be dealt with in exactly the same way, but rather that the health service must recognize, and

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<sup>51</sup> Committee on Economic, Social and Cultural Rights, *General Comment 14*, op. cit.

foresee, the specific differences and needs of the groups within the population, in particular those, like the migrants, who show a disproportionate level of mortality, illness and disability<sup>52</sup>.

### *The right to participation*

The Committee emphasises that an approach to health based on human rights makes it possible to demonstrate that the aim of creating efficient and sustainable health services is only possible if the persons take a direct role in the planning of the policies, the programmes and the strategies designed to safeguard them. The participation of the communities in the definition of the policies and of the other activities governing the right to health increases the probability that the needs of the community will be dealt with efficiently. In fact, only thanks to the action and the involvement of the community is it possible to attain true emancipation, and only through emancipation is it possible to reach the necessary level of empowerment for the understanding and full vindication of human rights, including the right to health.

### *The obligations for the state governments*

The incorporation of human rights in the legislation of the various countries brings certain precise obligations. In fact, these have been identified in the international law of human rights, as the obligation to *respect, protect, and fulfil* the human rights. Therefore, the governments are legally bound to meet this series of obligations for each of the rights mentioned in each human rights treaty that they have ratified<sup>53</sup>. The definitions are once again based on the General Comment 14.

- States are under the obligation to *respect* the right to health by refraining from (directly or indirectly) denying or limiting equal access for all persons to preventive, curative and palliative health services; abstaining from enforcing discriminatory practices that could cause personal harm, illness or deaths as a State policy.
- Obligations to *protect* include the duties of States to adopt legislation or to take other measures ensuring equal access to healthcare and health-related services provided by third parties. It is opportune to point out that the States are not responsible for the actions or omissions of non-government bodies (such as multinational companies – including pharmaceutical companies, health insurance companies, biomedical research institutes and private health services), however they are responsible for ensuring that third parties do not limit people's access to health-related information and services.
- The obligation to *fulfil* requires States parties to give sufficient recognition to the right to health in the national political and legal systems, preferably by way of legislative implementation, and to

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<sup>52</sup> J. Asher, *The Right to Health: A Resource Manual for NGOs*, London, Commonwealth Medical Trust, 2004.

<sup>53</sup> T. Van Boven, C. Flinterman e I. Westendorp (ed.), *Maastricht Guidelines on Violations of Economic, Social and Cultural Rights*, Utrecht, Netherlands Institute of Human Rights, 1998. Se also: A. Eide, *Economic, Social and Cultural Rights as Human Rights*, in *Economic, Social and Cultural Rights. A Textbook*, ed. A. Eide, C. Krause e A. Rosas, Dordrecht-London, Martinus Nijhoff, 1995, pages 9-28.

adopt a national health policy with a detailed plan for realizing the right to health. States must also give priority to the health needs of the disadvantaged or vulnerable members of society.

- The obligation to *fulfil* the right to health also includes the obligation to *facilitate*, to *provide* and *promote* actions that create, maintain and restore the health of the population.
- *Facilitating* the right to health requires the States to take positive measures that enable and assist individuals and communities to enjoy the right to health.
- *Providing the right to health* requires the States to intervene when individuals or a group are unable, for reasons beyond their control, to realize that right themselves by the means at their disposal.
- The obligation to *fulfil (promote)* the right to health requires States to undertake actions that create, maintain and restore the health of the population. The promotion of health is an important component in the measures necessary to enact the right to health. It emphasises the close link between good health, information and instruction. In order to enjoy the right to health, the persons and the community must have access to adequate and appropriate information regarding health.

#### *Progressive Realization*

The right to the best attainable health conditions is subject to the principles of progressive realization and the maximum available resources. This can be traced to the awareness that the objective of creating a comprehensive and integrated health system, that guarantees access for all citizens, cannot be reached immediately. What the countries are asked to do is to adopt efficacious measures with the aim of attaining this objective. Paul Hunt and Gunilla Backman have identified three main consequences of this principle<sup>54</sup>. The first consequence is that the States must adopt a national plan for the development of their healthcare system, which covers both the public and the private sectors. A further implication of progressive realization is the principle that to be effective, a healthcare system must include suitable indicators and parameters of reference, in order to evaluate whether the country is improving its health service and progressively realising the right to health<sup>55</sup>. The last implication deriving from progressive realization is the principle commonly known as non-retrogression. This means that a State must maintain at least the level of right to health that existed in the first place and it is not admissible to adopt measures that lower this level<sup>56</sup>.

#### *Core obligations*

Although, as previously stated, the realization of the right to health is subject to the principle of “progressive realization”, this does not emancipate the States from meeting certain obligations considered essential. Meeting these levels cannot be waived, even in situations of economic crisis. Amongst the core obligations are:

- \* To ensure the right of access to health facilities, goods and services on a non-discriminatory basis; especially for vulnerable or marginalized groups;

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<sup>54</sup> P. Hunt and G. Backman, *Health Systems and the Right to the Highest Attainable Standard of Health*, op. cit.

<sup>55</sup> See E. Riedel, *The Human Right to Health*, op. cit., page 36.

<sup>56</sup> P. Hunt and G. Backman, *Health Systems and the Right to the Highest Attainable Standard of Health*, op. cit.

- \* To ensure access to the minimum essential food which is nutritionally adequate and safe, to ensure freedom from hunger to everyone;
- \* To ensure access to basic shelter, housing and sanitation, and an adequate supply of safe and potable water;
- \* To provide essential drugs, as from time to time defined under the WHO Action Programme on Essential Drugs;
- \* To ensure equitable distribution of all health facilities, goods and services;
- \* To adopt and implement a national public health strategy and plan of action, on the basis of epidemiological evidence, addressing the health concerns of the whole population; the strategy and plan of action shall be devised, and periodically reviewed, on the basis of a participatory and transparent process; they shall include methods, such as right to health indicators and benchmarks, by which progress can be closely monitored; the process by which the strategy and plan of action are devised, as well as their content, shall give particular attention to all vulnerable or marginalized groups.

The Committee also confirms that the following are obligations of comparable priority:

- \* to ensure reproductive, maternal (pre-natal as well as post-natal) and child health care;
- \* to provide immunization against the major infectious diseases occurring in the community;
- \* to take measures to prevent, treat and control epidemic and endemic diseases;
- \* to provide education and access to information concerning the main health problems in the community, including methods of preventing and controlling them;
- \* to provide appropriate training for health personnel, including education on health and human rights.

### 3. Legislation on matters regarding health and immigration

As explained at the beginning of this chapter, the possibilities for the immigrant population to see their right to health realized depends, mainly, on the degree of access to the health services guaranteed to them, on the basis of their legal status and national law<sup>57</sup>. For this reason, the following section will be dedicated to presenting an overview of this legislation<sup>58</sup>. First, it is necessary to state that the possibility of access to the health services varies mainly according to the country of origin of the migrant and to the

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<sup>57</sup> It must be remembered, for the purpose of comprehensiveness, that the legislative framework is not merely national. In fact, following the reform of Title V of the Constitution, the subject “health and immigration” has been divided between “exclusive” legislation (immigration is one of the questions over which the Italian State maintain full legislative powers) and “concurrent” legislation (the safeguarding of health is one of the subjects in which the regional authorities have legislative power). Therefore, although the policies on immigration ruled at national level – and given the State obligation to guarantee equity in fulfilling the right to health – the measures for integration and promotion, also in the health sector, must be enacted and realized locally. See also in this sense the agreement stipulated on December 20<sup>th</sup> 2012 during the permanent conference for the relations between the State, the regions and the independent provinces of Trento and Bolzano (*Conferenza Stato-Regioni e PA*) which largely absorbed the document *Indicazioni per la corretta applicazione della normative per l’assistenza sanitaria alla popolazione straniera da parte delle regioni e province autonome italiane* already approved by the Health Committee of the *Conferenza Stato-Regioni e PA* on September 21<sup>st</sup> 2011. The purpose of this agreement was to standardise the practices and the level of assistance guaranteed to foreign citizens in the various regions.

<sup>58</sup> This overview is a mere summary of the most important legislation. For greater detail see the Appendix I of the first research report (I. Biglino and A. Olmo) *Health as a fundamental right: a study on migration and healthcare in Turin* op. cit.) and the information given in the various chapters of this volume.

presence and the type of residence permit they hold. The principle discrimination made in this sense is between the migrants from EU countries and those from non-EU countries.

#### *Citizens of a state member of the European Union*

With regard to healthcare guaranteed to citizens of one of the European member states, the main distinction to be made is between those who make a brief stay (less than three months) and those who stay for a longer period (more than three months)<sup>59</sup>.

For periods of less than three months, it is possible to enrol with the SSN, if the person is not a seasonal worker and for holders of form E106 with validity of three months<sup>60</sup>. Access to health services is available when presenting the European Health Insurance Card issued by the country of origin. When the European citizen presents the Card to the foreign institute, they may be asked to prove that they are enrolled, or they will be charged the entire fee for the service or treatment and at a later date the foreign citizen can apply for full reimbursement from the appropriate institution in their own country. Holders of the European Health Insurance Card or an equivalent document have the right to urgent and necessary treatment and to all the services necessary for their state of health, in order to continue their stay.

For periods in excess of three months, the EU citizen will, in various cases<sup>61</sup> be compulsorily enrolled with the SSN, with equality of treatment to Italian citizens resident in Italy and at the expense of the SSN. Other categories of subject have the right to voluntary enrolment, on payment of an annual contribution<sup>62</sup>.

Those who are domiciled in Italy or who intend to stay for a period of more than three months and who do not have the right to enrol with the SSN, and who have no healthcare rights in their country of origin or other suitable document that covers all the risks in the national territory<sup>63</sup>.

EU citizens in a state of indigence, who are in Italian territory without being assisted by their country of origin and are without private insurance coverage, have the right to imperative and urgent treatment<sup>64</sup>. The local health authorities (ASL) are required to keep a separate record of these treatments and services, in order to attempt the recovery and/or negotiation of the costs from the competent States. These records are kept on the basis of what is called, in the Piemonte Region<sup>65</sup>, *codice Eni* (non-enrolled Europeans code) and is

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<sup>59</sup> The main normative text on the matter in Italy is D. Lgs. 30/2007 which ratifies the Directive 38/2004. D. Lgs. N. 30, February 6<sup>th</sup> 2007, *Gazzetta Ufficiale* N. 72, March 27<sup>th</sup> 2007.

<sup>60</sup> Italian Ministry of Health, Informative Note, August 3<sup>rd</sup> 2007.

<sup>61</sup> *Ibidem*. Amongst these are, *inter alia*, subordinate or independent workers; holders of “permanent resident permits” matured after five years residence in Italy and holders of the form E106/SI, E109/SI, E120/SI, E121SI.

<sup>62</sup> Amongst these see, *inter alia*, Community citizens who enjoy immunity or privileges foreseen by the immunity and privileges foreseen by the Vienna Convention on Consular Relations; citizens who do not have the requisites to enrol with the SSN; students and au-pairs; Community citizens who work in Italy and are subject to the welfare legislation of their country of origin (except in cases of compulsory enrolment when they are holders of Community forms).

<sup>63</sup> D. Lgs. 30/2007, Article 7, paragraph 1, letters *b*) and *c*).

<sup>64</sup> Italian Ministry of Health, Informative Note, August 3<sup>rd</sup> 2007. Amongst the urgent and essential treatment and services foreseen are healthcare relating to the health of minors and maternity and to voluntary abortion, under the same conditions as those foreseen for women enrolled with the SSN. Finally, vaccination campaigns, international disease prevention, diagnosis and treatment of infectious diseases are also foreseen.

<sup>65</sup> Regione Piemonte, Circolare Assessorato Tutela della Salute e Sanità (regional department of health) Prot. N. 822/DA2009, January 9<sup>th</sup> 2008.

attributed on the occasion of the first dispensation or on request by the interested party. The treatments and services are dispensed on the same basis as Italian citizens with regard to any sharing of the cost.

### *Non-EU citizens*

The reference legislation on this matter<sup>66</sup> distinguishes between those who hold a residence permit and are compulsorily enrolled with the SSN; those who hold a residence permit and can be voluntarily enrolled with the SSN; those who are legally resident in the country but cannot be enrolled with the SSN; those who are not legally resident in the country and cannot be enrolled with the SSN.

- *Non-EU citizens with residence permits and compulsorily enrolled with the SSN*: the right to compulsory enrolment with the SSN derives from the reason that authorises the issue of a residence permit and that consequently allows the person to reside in Italy<sup>67</sup>. Compulsory enrolment guarantees the same treatment as that foreseen by law for Italian citizens, with regard to the choice of the GP and/or paediatrician and for sharing of costs.
- *Non-EU citizens with residence permits and voluntarily enrolment with the SSN*: foreigners who hold a residence permit for more than three months and who do not fall within the categories compulsorily enrolled with the SSN<sup>68</sup>.
- *Non-EU citizens residing illegally in Italy and without the right to enrol with the SSN*: non-EU citizens who reside in Italy illegally (temporarily resident foreigners) do not have the right to enrol with the SSN. The consolidated legislation (TUI) foresees that these people must be guaranteed treatment at outpatient clinics and urgent hospital treatment<sup>69</sup>, or essential treatment<sup>70</sup>, and ongoing treatment for illness and accident<sup>71</sup>. In particular, social safeguards are guaranteed for pregnancy and maternity, with treatment equal to that offered to Italian citizens, the safeguarding of the health of minors, vaccinations according to current legislation and as part of the collective prevention campaigns authorized by the regional authorities, interventions for

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<sup>66</sup> See the *Testo Unico Disposizioni concernanti la disciplina dell'immigrazione, norme sulle condizioni dello straniero* (consolidating legislation on immigration and conditions of foreigners), D. Lgs 286, July 25th 1998, *Gazzetta Ufficiale* N. 191, August 18th, ordinary supplement N. 139, in particular Articles 34, 35 and 36. See also D.P.R. N. 394, August 31st 1999, *Gazzetta Ufficiale* N. 258, November 3<sup>rd</sup> 1999, Ordinary Supplement N. 190, Articles 42, 43 and 44. See, finally, Italian Ministry of Health, Circular N. 5, March 24<sup>th</sup> 2000, *Gazzetta Ufficiale*, General Series N. 126, June 1<sup>st</sup> 2000.

<sup>67</sup> On the basis of Article 34 of the aforementioned Testo Unico and Article 42 of the *Regolamento di attuazione del Ministero della Sanità* (enactment by the Italian Ministry of Health), Circular N. 5, cit., and subsequent legislation, foreigners with a residence permit have the right to compulsory enrolment for, *inter alia*, subordinate work; independent work; family reasons; political asylum/political refuge; humanitarian asylum/humanitarian reasons/subsidiary protection; requests for international protection; requests for asylum in accordance with the Dublin Convention; holders of the residence permit and long-term residents; non-EU family members of EU citizens enrolled with the SSN; foreign minors present in the territory, whether holders of a residence permit or not; stateless persons; reasons of health/humanitarian reasons (except for those resident under Article 36 TUI); foreign citizens – and their cohabiting spouse in a state of pregnancy and/or for the six months following the birth of the child, who have applied for a (non-renewable) residence permit for medical reasons.

<sup>68</sup> Voluntary enrolment is granted to non-EU citizens who are legally living and/or present in Italy for, *inter alia*, study; religious reasons (which do not fall within the categories for compulsory enrolment); au-pairs; family members aged over sixty-five who entered Italy to join their families after November 5<sup>th</sup> 2008.

<sup>69</sup> “Urgent treatment” includes treatment that cannot be delayed without danger to life or the person’s health.

<sup>70</sup> “Essential treatment” includes healthcare, diagnostics and therapies relating to pathologies that are not dangerous in an immediate timeframe, or short-term, but which in time could cause greater threats to health or risks for the life of the person (complications, chronicity or degeneration).

<sup>71</sup> TUI Article 35, paragraph 3. The programme of preventive medicine must also be extended to illegal foreign residents to safeguard individual and collective health. For the purpose of essential treatment, including bone marrow transplant, the illegal foreign resident is equal to the Italian citizen.

international disease prevention, prophylaxis, diagnosis and treatment of infectious diseases and any necessary sanitation of the relative centre of infection<sup>72</sup>, and treatment, prevention and rehabilitation in the case of drug abuse<sup>73</sup>.

With regard to the methods for providing basic healthcare for this latter type of user, the D.P.R. 394/199, Article 43, delegates to the Italian regions the organization of the health services, that is to say, the definition of who must provide basic healthcare<sup>74</sup>. As we will see in the next chapters, for this purpose, in 1996, the Regione Piemonte set up the Centri di Informazione Salute Immigrati (Centri ISI – immigrant health information centres)<sup>75</sup>, and since 2004 these centres have been responsible for providing healthcare for illegal foreign residents. This healthcare is guaranteed by the issue of a card with an individual STP (straniero temporaneamente residente – temporary foreign resident) code. Finally, it must be mentioned that the essential healthcare is assured at an equal level to the conditions of an Italian citizen with regard to the sharing of the costs. However, as we will see, the illegal foreign resident, if they have declared themselves indigent, may be exonerated from the cost of the treatment or service (ticket), in a similar manner to an Italian citizen, with exemption code X01, which is valid exclusively for the specific treatment or service provided. Furthermore, interventions of preventive and collective healthcare are guaranteed free of charge when they relate to the safeguarding of individual and collective health, in particular: welfare during pregnancy and maternity, safeguards for the health of minors, vaccinations according to current legislation and as part of the collective preventive campaigns organized by the regional authorities, interventions for international disease prevention, prophylaxis, diagnosis and treatment of infectious diseases and any necessary sanitation of the relative centre of infection with the aim of prevention, care and rehabilitation in cases of drug abuse, treatment relating to exempted pathologies.

Lastly, the question of the crime of *clandestinità* (illegal residence in Italy) although it does not directly concern the legislation on healthcare, has in any case – as noted during the first phase of the research – a considerable impact on the way the migrants access the health services. At the time the first volume was written, we noted that the existence of this crime still hampered many migrants, due to their fear (in any case unfounded) that they would be reported to the police by the doctors and other health workers<sup>76</sup>. On May 17<sup>th</sup> 2004, the delegated law N. 67/2014<sup>77</sup> was enacted, which foresaw, *inter alia*, the abrogation of the crime of illegal residence on the first entry to the country, foreseen in Article 10-bis of the TUI. In fact, this must be transformed into an administrative offence. The effective abrogation must be ordered, by legislative decree, within eighteen months from the enactment of the law.

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<sup>72</sup> TUI, Article 35, paragraph 3.

<sup>73</sup> D.P.R., October 9<sup>th</sup> 1990, n. 309, *Gazzetta Ufficiale* N. 255, October 31<sup>st</sup> 1990, ordinary supplement N. 67.

<sup>74</sup> D.P.R. 349/99, Article 43, paragraph 8.

<sup>75</sup> Regione Piemonte, Delibera Regionale N. 56-10571, July 15<sup>th</sup> 1996.

<sup>76</sup> I. Biglino and A. Olmo, *Health as a fundamental right: a study on migration and healthcare in Turin* op. cit. Chapter 5.

<sup>77</sup> Law N. 67, *Gazzetta Ufficiale* N. 100, May 2nd 2014.

Chapter Two  
Social suffering and marginalisation

## 1. *Migration and social suffering*

At present, in the world, there are about 232 million people who have abandoned their place of origin and undertaken a migratory journey<sup>78</sup>. While in some cases the migration may represent an opportunity for personal growth and a constructive experience, in many other cases the migrants must face systematic violation of their human rights and are subject to numerous forms of violence, discrimination and exploitation during the journey and at their destinations<sup>79</sup>.

The migratory experience is often associated with poverty, unfavourable residential conditions, poor social recognition and the placement in inferior, illegal and temporary work, lacking safeguards from a contractual standpoint. These conditions are worsened by the existential fatigue of having to fit in with a new and often hostile reality, the need to learn a new language, to rebuild a network of relationships and affections, to deal with a different culture and become familiar with new customs that sometimes contrast with the semantic and operative<sup>80</sup> background thanks to which each individual interacts smoothly with their daily life.

The situation in Piemonte is a clear example of the link between immigration and economic and social insecurity. According to the *Dossier statistico immigrazione 2014* (immigration statistics dossier) in the year 2013 the foreign population felt the effects of the economic crisis particularly intensely, registering a rate of unemployment around 22.8%, while for Italians it was 8.9%<sup>81</sup>. Moreover, as shown by the report *Il mercato del lavoro in Piemonte nel 2013* (the labour market in Piemonte in 2013), the number of jobs available for foreign workers was not capable of absorbing the demographic flows, which, though lower than in the past, but are in any case present and significant. This problem, already clear in the year 2012, has worsened due to the reduction in the number of jobs available in the industrial sector and was a reason for concern by 2013, becoming a “genuine social emergency”<sup>82</sup>.

The considerable asymmetries that characterize the migratory phenomenon place the foreigner in a position of “structural vulnerability”<sup>83</sup>, which is evident in the area of the right to health. The concept of vulnerability has to do with the degree of exposure to risk and the capacity to respond to a crisis. We can speak of “structural vulnerability” when we are in the presence of a condition of vulnerability that is not linked to individual choices or actions, but which is based on structural social conditions, which limit the capacity for action and affect the decision-making processes of the individual.

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<sup>78</sup> General Assembly of the United Nations, *International Migration and Development, Report of the Secretary-General*, UN Doc. A/69/207, June 30<sup>th</sup> 2014.

<sup>79</sup> General Assembly of the United Nations, *Report of the Special Rapporteur on the Human Rights of Migrants*, UN Doc. A/69/302, August 11<sup>th</sup> 2014.

<sup>80</sup> I. Quaranta and M. Ricca, *Malati fuori luogo. Medicina interculturale*, Milano, Raffaello Cortina, 2012.

<sup>81</sup> UNAR and Centro Studi e Ricerche Idos (Ed.) *Dossier statistico immigrazione 2014. Dalle discriminazioni ai diritti*.

<sup>82</sup> Regione Piemonte, *Il mercato del lavoro in Piemonte nel 2013*, Torino, 2014, page 55.

<sup>83</sup> J. Quesada, L.K. Hart e P. Bourgois, *Structural Vulnerability and Health: Latino Migrant Laborers in the United States*, in «Medical Anthropology», 30, 2011, n. 4, pages 339-362.

As stated in a recent report by the World Health Organization *Governance for Health Equity*, “These inequalities can accumulate over the life course and are often perpetuated across generations, leading to persistent shortfalls in health and development potential in families, in communities and in our societies”<sup>84</sup>. In fact, health and well-being are moulded by the distribution of economic means, by the balance of power and resources, both material and symbolic, available to a given social group<sup>85</sup>.

As we saw in the first chapter, essential aspects of the right to health are both the right to medical treatment, and the right to live in social conditions that allow people to attain their health potential. Although the foreign population in Torino is, on average, young, and in general healthier than the Italian component<sup>86</sup>, the weight of disadvantageous social-economic conditions has a considerable effect with regard to healthcare<sup>87</sup>.

In the first volume, we emphasised the way in which the distribution of healthcare in the city of Torino shows considerable inequalities and the general conditions of health are more precarious in the disadvantaged areas of the city, which generally include a large number of migrant residents. “The socio-economic dimension” in fact “represents the main determinant in the differences in health within the city of Torino”<sup>88</sup>. In particular, it is clear that with respect to the principal structural determinants (income, instruction, employment) and the principal intermediate determinants (material living standards – such as the home, the working environment – psychosocial factors, such as isolation and discrimination – and behavioural factors) the migrant population generally stands in a more precarious and vulnerable position.

In this chapter, we will return to the role of social determinants in the safeguarding of the right to health of the migrants in Torino. However, here, the approach will differ with regard to that previously adopted, inasmuch as it will present the life stories they narrate, in addition to the numbers and the statistics, the mechanisms and the processes that converge to generate various forms of “social suffering”<sup>89</sup>. A first example of the close link between the social sphere and the health sphere is offered by the interview with Najib, for whom the lack of work is a problem that, with a domino effect, affects all the other aspects of her life in Italy.

At one time, there was clandestine employment in Italy, but now not even that is available. You ask me what my health problems are, and I tell you that the problem is that there is no work. There is a lack of work. If you work well, the other things go well. It is sufficient to find work. If I find work, I live well: health is good; things go well with my friends, with my family. (Najib, 30 years old, Egypt).

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<sup>84</sup> C. Brown *et al.*, *Governance for Health Equity. Taking forward the Equity Values and Goals of Health 2020 in the WHO European Region*, World Health Organization, Regional Office for Europe, 2013.

<sup>85</sup> I. Biglino and A. Olmo, *Health as a fundamental right: a study on migration and healthcare in Turin*, Bologna, Il Mulino, 2014, pages 141-166.

<sup>86</sup> E. Coffano, M. Del Savio and L. Mondo (ed.), *Rapporto: Stranieri e salute*, Regione Piemonte, Assessorato alla tutela della salute e sanità, politiche sociali e politiche per la famiglia, 2012, (report on the health of foreigners for the Department of Healthcare, Social Policies and Family Policies, Regione Piemonte), <http://www.comune.torino.it/statistica/osservatorio/stranieri/2012/pdf/24-stranieri-e-salute.pdf>.

<sup>87</sup> In the first volume, we discussed in depth the question of inequality of healthcare and social conditions. Cfr. I. Biglino e A. Olmo, *Health as a fundamental right: a study on migration and healthcare in Turin*, Bologna, Il Mulino, 2014., op. cit., pages 135 onwards.

<sup>88</sup> *Ibidem*, page 142.

<sup>89</sup> For an overall framework of this concept, see A. Kleinman, V. Das and M. Lock (Ed.), *Social Suffering*, Berkeley, University of California Press, 1997.

In the life stories it is possible to note a multiplicity of definitions of the concept of marginalisation, which do not only refer to extreme poverty, but also to the lack of relational networks or social capital, to political exclusion and the more limited access to information and spaces for participation. The marginality, moreover, affects the perception of self and limits the capacity to interact with the institutional spaces, which may even generate a feeling of anguish and impotence. This is what one of the women interviewed emphasised.

I am often afraid when I have to go to the doctor's or when I have had to go to the hospital. There is no real reason... I have all the necessary documents, so perhaps more than fear I should say that it is anxiety. An anxiety that relates to being an immigrant: the language, the fact of being in a different country, the fact of not quite knowing how things work. All this makes you very unsure [...] Once I had a very severe pain in my side; I have heart problems, so I was afraid that it was linked to that... I went to the A&E department, but in the waiting room I was worried because the nurse told me, quite bluntly, that if she gave me a 'white code' (non-urgent treatment) I would have to pay a fee, so I said to my husband, "if they give me a white code, we will leave, I won't have them examine me". However, it was a serious matter, I am always afraid of not knowing how to evaluate the situation, of exaggerating, of doing the wrong thing... also, at times in the A&E department they are prejudiced, they think, and they say to you, that foreigners use the A&E wrongly. That time they gave me a 'green code' (urgent treatment required), it was a muscle strain, caused by the type of work I do, because I often have to lift the women I care for and in the kitchen, every day, I lift very heavy pots and pans. And this, in any case, I mean the anxiety... not the fear of being reported to the police, but the feeling of impotence, this, well... The hospital is an unusual place, it is an institution, a healthcare institution, a structured body that makes you feel powerless. It is as if, when you enter, someone else takes the situation in hand and leaves you on the edge of all the decision-making. We are always, so to say, in a situation of inferiority, but while in my country I felt that I had the tools for evaluating the situation and demanding a service, here this inferiority is massive and it is very strong, because I am another, I am a foreigner. I don't feel that I have the tools necessary for demanding my rights. (Gabriela, 52 years old, Colombia).

This testimony clearly highlights the many obstacles that make the realization of the right to health difficult for the migrant population. Some of the problems relating to the accessibility of the social services already identified in the first volume emerge clearly, such as the way the immigrants access and utilize the services, the linguistic barriers, the difficulties of dealing with an unfamiliar environment and the problems relating to economic accessibility. At the same time, it is possible to see other obstacles, not identified in the first phase of the research, relating to the subjective approach, to the feeling of impotence and inferiority when forced to interact with a complex and distant institution.

The foreigners, in both their informal interactions and within institutional spaces, are often represented as "others" for whom it is difficult to identify the characteristics, with respect to "we Italians". Prejudices and the stereotypes, although often not admitted, are the order of the day. During the research project numerous negative images of the foreigner emerged, which testify to the importance of the explicit (or more frequently the veiled) forms of xenophobia and discrimination. In some cases, these images were reported by the interviewees, in other cases they were observed directly in the healthcare institutions, but the clearest examples of stereotypes of the migrant appear above all in the informal settings and the media. An inconvenient figure, the foreigner is sometimes represented as an invader, a carrier of disease, as a potential terrorist, a delinquent, as someone who endangers the autochthonous identity and values. However, above all, the prevailing image of the migrant is as an undesirable and illegitimate competitor, who takes precious resources from the Italians in a moment of economic crisis.

The way one is perceived by others affects self-perception in a decisive manner and can affect the capacity to act to attain one's rights or to behave in a constructive manner. It is interesting to note how in many interviews the interlocutor expresses a strongly felt need to be treated as "a person" and not as "an immigrant": it is not by chance that the sociologist Alessandro Dal Lago used the expression "non-persons" to highlight the mechanisms of exclusion, both implicit and explicit, aimed at foreigners, especially when they are illegal residents<sup>90</sup>.

The word "person" is linked to both the need for social recognition and to the need for equality on the plane of fundamental rights. As shown by the national committee for bioethics in 1998<sup>91</sup>, an intercultural approach to treatment should arise from common values in a politically democratic community, such as safeguards for human rights and the principles of solidarity and subsidiarity: these are the essential foundations for the construction of "equal and intercultural healthcare"<sup>92</sup>.

The question of discrimination emerged repeatedly during the first phase of the research. In particular, it was noticed, as confirmed by the reports, that discrimination influences the realization of the right to health in the migrant population in a markedly negative manner<sup>93</sup>. It was emphasised that discrimination often overlays "the inequalities already present for vulnerable and marginalised groups" and how this "increases the vulnerability with respect to problems of health and limits the efficacy of health treatments"<sup>94</sup>.

## 2. *Welfare in times of crisis*

The protection of the health of migrants and the more vulnerable groups clashes with a situation of general lack of resources and cuts in public spending for healthcare. Every consideration on the right to health today must therefore take into account the present economic crisis, considered by many analysts the most serious in history, since the Great Depression of 1929. For the Office of the High Commissioner for Human Rights of the United Nations Organization:

[...] Consequently, the ability of individuals to exercise their human rights, and that of States to fulfil their obligations to protect those rights, has been diminished. This is particularly true for the most vulnerable and marginalized groups in society, including women, children, minorities, migrants and the poor, who suffer from decreasing access to work and social welfare programmes, and reduced affordability of food, housing, water, medical care and other basic necessities. The negative impacts of the financial crisis and subsequent austerity measures are also seen to exacerbate existing structural inequalities<sup>95</sup>.

In Italy, as in other European countries, the public spending for welfare has been reduced considerably in recent years, affecting the healthcare system and magnifying the existing inequalities. In this

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<sup>90</sup> A. Dal Lago, *Non-persone. L'esclusione dei migranti in una società globale*, Milano, Feltrinelli, 2004.

<sup>91</sup> Comitato nazionale per la bioetica, *Parere del Comitato nazionale per la bioetica sui problemi bioetici in una società multi-etnica*, 16 gennaio 1998. Full text at: [http://www.governo.it/bioetica/pdf/Problemi\\_bioetici\\_in\\_una\\_societa\\_multi-etnica\\_ok.pdf](http://www.governo.it/bioetica/pdf/Problemi_bioetici_in_una_societa_multi-etnica_ok.pdf).

<sup>92</sup> M. Ricca, *Medicina equa e interculturale. Per una cittadinanza sanitaria cosmopolita*, in *Malati fuori luogo*, op. cit., pages. 57-95.

<sup>93</sup> I. Biglino and A. Olmo, *Health as a fundamental right: a study on migration and healthcare in Turin*, Bologna, Il Mulino, 2014., op. cit., page 162.

<sup>94</sup> *Ibidem*, pages 162-163.

<sup>95</sup> Office of the High Commissioner of the United Nations for Human Rights, *Report on Austerity Measures and Economic and Social Rights*, UN Doc. E/2013/82, May 7<sup>th</sup> 2013, page 3.

context, it is fundamental to monitor the safeguards for the right to health of migrants, with particular attention for the more vulnerable groups, such as women, children and illegal residents.

As we saw in the first chapter, from a legislative standpoint, Italy offers many opportunities for access to healthcare for migrants<sup>96</sup>. The reference legislation in this case is the *Testo Unico sull'immigrazione* (TUI, – consolidated law on immigration – D. Lgs. N. 286, July 25<sup>th</sup> 1998 and subsequent amendments and integrations). Briefly, it guarantees the possibility of registration with the Regional Health Services (SSR), with equal rights in relation to Italian citizens, resident European citizens, non-EU citizens in the following categories: with residence permits, for those who have applied for the renewal of their residence permit, due to subordinate work, independent work, for family reasons, political asylum, humanitarian asylum, while awaiting adoption, fostering or for acquisition of citizenship. Healthcare is also guaranteed for dependant family members who hold a residence permit.

Foreigners with a residence permit who do not fall into the above categories, students and au-pair workers must take out private insurance and can also voluntarily register with the national health service, paying the fees foreseen.

Illegal foreign residents are guaranteed “outpatient clinic treatment and urgent or essential hospital treatment, even if continuative, for illness and injury and are included in programmes for preventive medicine protecting individual and collective health”<sup>97</sup>. This right is extended to the non-EU citizens illegally resident in the country, who are known in Italy as STP (*stranieri temporaneamente presenti* – temporarily resident citizens) and to EU citizens without a residence permit and without the requisites for registration with the national health system, known as ENI (*europesi non iscritti* – unregistered European citizens). The legislative framework at national level, although necessary, is not sufficient to complete the analysis of the regulations that govern the possibility of access to the health services by the migrant population. As already mentioned, following the reform of Title V of the Constitution<sup>98</sup>, the matter in question has remained suspended between “exclusive” legislation and “concurrent” legislation. On the one hand, immigration is one of the questions on which full legislative powers have been maintained by the State, while on the other, health falls within the legislative powers of the regional authorities. This means that, although the State has the power to define policies on immigration and the obligation to guarantee equal access to healthcare<sup>99</sup>, the regional authorities are responsible for the legislative and administrative functions of healthcare and hospital treatment, the identification of the principles on which the services and the health safeguards are organized, the financing of the local health authorities and the hospitals, technical activities, promotion and support of the local health authorities and hospitals, and the monitoring and evaluation of the services provided. To simplify, the effective access and fruition of the health services by migrants is defined at regional and local level. The progressive administrative and political decentralization has led to a

<sup>96</sup> See also, I. Biglino and A. Olmo, *Health as a fundamental right: a study on migration and healthcare in Turin*, Bologna, Il Mulino, 2014., op. cit., appendix 2.

<sup>97</sup> Testo unico delle disposizioni concernenti la disciplina dell'immigrazione, norme sulla condizione dello straniero (Testo unico sull'immigrazione, TUI), D. Lgs N. 286. July 25th 1998, *Gazzetta Ufficiale* N. 191, August 18th 1998, ordinary supplement N. 139, Article 351 N. 1.

<sup>98</sup> Constitutional Law, October 18th 2001, N. 3, *Gazzetta Ufficiale* N. 248, October 24<sup>th</sup> 2001.

<sup>99</sup> In particular, it is responsible for defining the essential levels of assistance (LEA - livelli essenziali di assistenza).

considerable lack of uniformity throughout the country with regard to the effective enactment of the national legislation on this matter and the actual means of access to and use of the services.

An important step in safeguarding the migrants' right to health is represented by the agreement between the government, the regional authorities and the independent provinces on the document *Indicazioni per la corretta applicazione della normativa per l'assistenza sanitaria alla popolazione straniera da parte delle regioni e province autonome*, signed in December 2012<sup>100</sup>. The document responds to the need, widely felt, to standardize the methods of providing healthcare for foreigners, resolving the interpretative difficulties generated by the quantity of regulations and laws issued over the years and the considerable variation in the situations that the operators must deal with. In addition to these are the new laws arising from the extension of the European Union and the right to freedom of movement for European citizens.

To monitor the enactment of the agreement, the *Società Italiana di Medicina delle Migrazioni* (SIMM) established ten indicators that correspond to the most widespread criticalities with regard to the methods of application of the legislation on protection of the right to health. Amongst these we would mention: the guarantee of registration with the SSR (regional health service) for minors whose parents hold a residence permit and those who are awaiting a residence permit; the provision to temporarily resident foreigners (STP) of essential treatment, in order to ensure that the therapeutic and rehabilitation cycle is completed up to the possible resolution of the pathology, including (if necessary) transplants; the definition of the exemption code X01 for the STP and the equality of healthcare and organizational levels of the STP code and the ENI code<sup>101</sup>.

In the Regione Piemonte – which ratified all the above indicators – the hub of public assistance for illegal migrants are the ISI Centres. These centres, which have been operating since 1992, were officially recognized in December 2014. On the same date, the guidelines for the various ISI Centres under the local health authorities that had not taken part in the experimental phase were approved. As from the PSSR 2007-2010 (PSSR: *Piano Soco-Sanitario Regionale* – regional health and welfare plan) the ISI Centres became a reference point for the hospitals. According to these guidelines, the Centres must:

- a) Map and monitor the health conditions of the foreigners present who do not have the right to register with the SSN;
- b) Intervene in the field of prevention;

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<sup>100</sup> *Indicazioni per la corretta applicazione della normativa per l'assistenza sanitaria alla popolazione straniera da parte delle regioni e province autonome* – Indications for the correct application of the legislation on healthcare for the foreign population by the regions and the independent provinces. The document was first discussed in 2009, when a technical board of representatives from the regional authorities and the independent provinces, promoted by the Regione Marche met. In May 2011, the board produced a first document, which was approved on September 21<sup>st</sup> 2011 by the joint regional health commission (*Commissione Salute della Conferenza delle Regioni*) and, subsequently sent to the Italian ministry of health for transmission to the state-regional conference (*Conferenza Stato-Regioni*) on May 8<sup>th</sup> 2012. The Minister approved the document on December 20<sup>th</sup> 2012. The agreement was published in the *Gazzetta ufficiale* N. 32, February 7<sup>th</sup> 2013.

<sup>101</sup> A full list of the indicators, summarised here, can be found at [www.simmweb.it](http://www.simmweb.it). a) Registration with the SSR for minors whose parents do not hold a residence permit; b) compulsory registration with the SSR for those awaiting a residence permit; c) compulsory registration with the SSN also during the waiting period for a first residence permit, for one of the reasons that give the right to compulsory registration with the SSN; d) voluntary registration with the SSR for the over-65; e) STP guaranteed essential treatment to ensure the therapeutic and rehabilitation cycle is completed until the pathology is resolved, including transplants, if necessary; f) preventive issue of the STP code to facilitate access to treatment; g) definition of the exemption code X01 for the STP; h) compulsory registration of Community parents of Italian minors; i) voluntary registration of Community residents; l) equity of treatment and organizational levels between STP code and ENI code.

c) Answer the requests for health expressed by this section of the population.

The ISI Centres are therefore an important resource for both the hospitals and for the users, to whom they guarantee outpatient services (specialist and basic) and an activity of reception, information, assistance and facilitation of access to the public service. In the first volume, we explained the fundamental role played by these centres in guaranteeing access to the health services for the migrant population that does not comply with legislation on residence.

However, nowadays, the cuts in the health budget have caused difficulties for the system. The lack of funds, already dealt with at length in the first volume<sup>102</sup>, together with the poor professional and personal standing of the operators who work there, have made the job difficult and generated a high level of burn out. In the informal conversations, the operators often refer to the feeling that they were “catapulted into the front lines” without having suitable training to deal with the numerous critical situations that arise every day.

The case of Lungo Dora Savona is significant: at the clinic, there are only a few GPs, who must examine a huge number of patients (a maximum of fifteen minutes is foreseen for each patient). The cultural mediators, whose presence is essential also during these few minutes of the examination, are instead forced to carry out mainly organizational activities, the issue of codes, sorting and filtering the users. There are long queues, complex bureaucratic procedures and the users are often very unsatisfied. These operative tasks, which go beyond their role, sometimes create confusion in both the users and the mediators themselves and it is not surprising that, in these conditions, some of them retreat into excessively rigid attitudes.

These problems clearly affect the relationship with the users, who do not give a positive evaluation of the ISI. From the interviews there emerges the perception of “operators that it is impossible to talk to”, who “shout”, who are “annoyed”, who are too tired and inattentive to the needs of the users. Moreover, the ISI Centres are not seen by the users as a place to find information, facilitation and assistance, but as a hostile place to which they go “to fight for a pass”.

A space that originally had a wide-ranging and pioneering function, now risks transforming into a hostile bureaucratic centre in which the contradictions of the system are concentrated. Operators and patients are trapped in the structural dynamics that completely transcend their power of action. The feeling of impotence is, on both sides, very high. All this undermines the trust in the public services and leads to the search, at times chaotic and expensive, for alternatives.

The situation we have described clearly shows how the lack of resources – a problem that can, initially, be categorized under the umbrella of the availability of services – can only have negative, knock-on effects, with regard to both the services offered and the accessibility to the same.

Despite these criticalities, it must be said that the problems seem to be concentrated in the reception phase, while the medical examinations are spoken of in positive terms. The doctors at the surgeries and the clinics are very willing to help and efficient from a clinical standpoint. Also, at the ISI, there is a stable and structured mediation service and once the first stage has been overcome, a relationship of trust is established

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<sup>102</sup> I. Biglino and A. Olmo, *Health as a fundamental right: a study on migration and healthcare in Turin*, Bologna, Il Mulino, 2014., op. cit., pages 47-55 and 81-90.

between the mediators and the users, and people often return to speak to them, or simply to have a prescription read and explained, even when they could turn to their GP. This confirms, once again, the importance of the cultural accessibility of the services and, as we will explain in detail in the sixth chapter, the essential role of the cultural mediator<sup>103</sup> in creating a bridge between the two groups which would otherwise never meet, the foreign patient and the health services.

The field research showed the important role played by the private social sector in guaranteeing the availability of health services. Although there are no structured forms of cooperation, in fact there are informal networks between the doctors at the clinics and the private social centres operating in the area. These networks are particularly efficient and necessary in the face of critical situations on the social plane. It is, however, important to define the role of the various players and the differences between the various institutions more clearly, since they are not always understood by the patients.

It must be mentioned that those who work in the field are reluctant to criticize the ISI Centres, because they are afraid of encouraging those who would prefer to close them. In a period of cost-cutting and progressive restrictions of public welfare, structures such as the ISI, which assist the marginalized and vulnerable members of the population, are in many cases considered a burden that drains resources from other areas and other patients. The dissatisfaction of the users is therefore to be read in a constructive sense, as a spur to improve and develop the potential of places such as the ISI. In fact, the ISI Centres are a pioneering innovation that the Regione Piemonte brought to bear in order to give a prompt response to the health needs of the migrants, and so far, they have given generally positive results, showing that it is worth continuing to invest in them.

### 3. *Extreme social marginalisation*

One of the problems with which many of the research projects dealing with the question of health for migrants have been forced to deal with is that of the difficulty in contacting the more marginalised and vulnerable sections of the population. In our case, a privileged vantage point was the outpatients' clinic of the association *Camminare Insieme*, founded in 1993 with the aim of offering qualified and free medical care to persons who could not make use of the national health service. This initial objective was later reorganized to take into account normative, social and demographic changes that had occurred during the last twenty years: although at the start of the nineties, the main problem was to overcome a legislative vacuum that prevented illegal immigrants from receiving healthcare, today the focus is on poverty and extreme social marginalisation, which, as we will try to show in this paragraph, represents a serious obstacle for the protection of the right to health. Every year the association accepts more than 1,600 new patients, almost all of whom are foreigners<sup>104</sup>, the association offers general and specialist medical services<sup>105</sup> and organizes

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<sup>103</sup> See in this volume, chapter 6 I. Biglino and A. Olmo, *Health as a fundamental right: a study on migration and healthcare in Turin*, Bologna, Il Mulino, 2014., op. cit. pages 103-110.

<sup>104</sup> The economic crisis, however, has led to the registration – for the first time – of some indigent Italian patients. Further information can be found in a detailed report on the activities of *Camminare Insieme* in the year 2012 at <http://www.camminareinsieme.it/>.

<sup>105</sup> In particular: cardiology, surgery, dermatology, ultrasound scans, endocrinology, gynaecology, neurology, ophthalmology, orthodontics, orthopaedics, ear, nose and throat treatments, paediatric care, pneumology.

specific projects dedicated to health and welfare and economic assistance for Roma women, foreign women with children, disabled foreign minors, and in support of educational and scholastic projects. Many of the interviews in the next pages were gathered during a period of ethnographic research carried out at this organization, in which the authors of the chapter were observers of the outpatients' clinic and the projects underway.

The case of Rachid, a homeless foreigner, is a clear and exemplary illustration of the way in which health and treatment are essential elements of social and economic conditions. Rachid, who comes from Casablanca, arrived in Italy in 2001 and he soon found work as a cook, was able to obtain the necessary documents and rent an apartment in the district of Barriera di Milano, with his fellow countrymen. In 2009, however, his situation changed suddenly and drastically.

At first my life was not like this, now everything has changed, the wind has turned and I have lost my job, I have lost my home, do you understand? I began to smoke and to drink [...]. I can't go back to Morocco, it would be worse... then, last June, I became ill. I went to the hospital and they gave me some medicine. When I wake up, I come here to the clinic, or I go to the ISI... I have problems with my stomach, because of the drink. I swear to you, I really need to go to hospital. When I am in hospital, I don't smoke. And when I am not in hospital, there is the problem of where to live, and I smoke and drink. I am homeless, do you see? I have a load of problems and I can't stop smoking... and then, it is cold. Now, I sleep at the Red Cross "winter emergency service" at the Pellerina Park. There are eight people in every room, and it is so cold, too cold. If anyone is ill, everyone gets ill. It is not possible to wash the blankets, you can't get washed. You see? No, no, no... I swear to you, it is humiliating. A little while ago, I went to the Amedeo di Savoia Hospital and I was there for five days... I felt better, but it was only five days, perhaps four days. You go there... you see?... and they treat you well, but they don't solve the problem, because once you leave there are so many people who are ill. I realize that it is our problem. Anyway, here in Italy, when it comes to health, it is better for us foreigners than almost anywhere in Europe. When you are in hospital you don't have to worry about anything else [...] the important thing is that you should go to the doctor, then the doctor knows what to do. The problem is out there. (Rachid, 45 years old, Morocco).

As can be seen from this testimony, the loss of employment is often, for the foreigner, the start of a process of overall disruption of the lifestyle. Loss of employment is soon followed by the impossibility of renewing a residence permit, the loss of the home and a gradual disintegration of self, which in the case of Rachid, is clearly manifested in addiction.

Rachid, although he considers himself very fortunate in the healthcare he receives from the clinics and through the ISI Centre, the private social services, and the hospital, is well aware that these interventions are merely palliatives with regard to an overall situation that represents a serious obstacle to healing.

The right to adequate living conditions has repeatedly been directly related to the right to health. Life on the streets brings extreme difficulties: the cold; the lack of suitable bedding and clothing; insufficient food; frequent recourse to alcohol, cigarettes or drugs; close contact with other people, who are often ill; the impossibility of washing; inadequate hygiene and other problems that the homeless encounter every day make attempts to deal with illness vain from a strictly clinical standpoint and destroy the good that was done during the hospital stay.

Situations like that of Rachid call for the activation of complex health and welfare interventions that, at present, it is rarely possible to foresee.

Amongst the numerous problems faced by those who live in conditions of extreme marginality, is the impossibility of accessing adequate food, in particular in the case of chronic pathologies, which require specific dietary standards. This is the case of Ibrahim, an Iraqi refugee, who has lived legally in Italy for about fifteen years, and who, although he has a home, has such a low income that he is forced to live on the waste food he finds at the markets and at the soup kitchens.

If you go to Porta Palazzo (the largest open-air market in Europe, NdT) you will see another world, other people. A world that makes you suffer. There are lots of people wandering around looking for stuff... whatever is left over. I do it, too. If I didn't do this, I wouldn't be able to survive. I am a man, I am old... but there are young people, children. It really hurts me. I have seen Germany, I have seen France, it's not like that there, but here it is. Anyway, I am not hungry. I find plenty of things at Porta Palazzo and then I go to the soup kitchens. Sometimes I come here and they give me something from the food bank. The problem is my health. I have problems with my heart. I was operated on in Belgium, not here in Italy, and now I have a lot more problems and I have diabetes. I know that there are a lot of things that I shouldn't eat, the doctor at the clinic always tells me so, but I have to eat what I find. (Ibrahim, 60 years old, Iraq).

The impact of poverty on health protection is clearly shown by scabies, which has recently become an emergency in Torino. Scabies is a contagious dermatological disease caused by a mite, it is difficult to contain and causes severe itching. The treatment foresees the use of a lotion that must be applied in the evening for five days, after a hot bath and after carefully cleaning the affected areas with a brush. It is also essential to change underwear, bedding and clothing every day. These must be sterilised, closed hermetically for two weeks in special containers and then washed at 90°C. Similar precautions are necessary for disinfecting the showers and living areas used by an infected person. It is therefore obvious that when suitable living conditions are lacking, it is impossible to carry out the treatment adequately. Here, the case of Malik, a Pakistani worker with little knowledge of Italian, is typical. Not having found any other place to live, he has been staying for a few months with a group of his countrymen in a non-residential building, without adequate sanitary conditions and without access to a shower, or a place to wash his clothes and his bedding.

They told me that it is... what is it called? Scabies. I came to be examined and they have treated me. I had to buy some medicine. It took all the money I had. I don't have a job, I sometimes manage to find a day's work, but not always. I put the lotion on, but it was no use. No use at all. After a week, it was just as bad, perhaps worse. Now I have come back and they say that I didn't do it properly, that I have to do it again. I have to take a shower every day and I have to wash everything... bedding, clothes, everything. How can I do that? We don't have anywhere to wash! I told the doctor, but she said "look, if you don't do that, we can't solve the problem". (Malik, 26 years old, Pakistan).

The cases cited here are typical of the impact of the social determinants in safeguarding the right to health. As Paul Farmer states, "social inequalities based on race or ethnicity, gender or religious creed, and – above all – social class are the motive force behind most human rights violations<sup>106</sup>." In order to intervene in favour of protection of health, it is necessary to recognize the pathogenic effects of social inequality and to construct pluri-dimensional healthcare services that take into account the social sphere. The cases described

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<sup>106</sup> P. Farmer, *Public Health Matters*, in *American Journal of Public Health*, 89, 1999, N. 1, page 1048.

also represent precisely what is meant by the concept of “interdependence” of human rights. The full realization of a right, such as the right to health, is in direct correlation with the contextual realisation of many other rights: in the cases cited, in fact, there is a clear example of the interrelation of the right to health, the right to an abode and the right to food.

#### 4. *The concept of “medical indigence”*

From almost all the interviews, there emerges a problem linked to paid treatment, in particular with regard to specialist treatment, rehabilitation therapies, diagnostic tests and the purchase of medicines not covered by the SSR.

I had a problem at the market, you know that, I picked up some boxes that were too heavy and I had problems with my spine, yes. I went to the doctor, at the ISI Centre in Lungo Dora Savona. She was a very good doctor. She gave me some tests to have done... an ultrasound scan and she sent me to the hospital. I don't have a residence permit; I work two or three days a week at the market. I arrive every day at four or five o'clock in the morning, but I don't always find someone who needs help. It's a terrible job, I swear to you: loading and unloading, setting up the stalls, doing everything... they give you 20 euro a day, sometimes 25. If it is a good week, you make 100 euro, but some weeks it is only 50 euro. There is one good thing, we Moroccans help each other. If someone has a house, then three, four, even five of us live together, we share everything, the shopping, everything, the rent, the electricity, the gas... and that is how we manage, how we can get by. When you have no money, someone else gives you some, then, when you work... maybe the next month... you contribute a little more. That is how we live, really [...]. When I went to book the tests, I knew that I would have to pay the ticket... they said to me “when you come the next time, you will have to pay 75 euro”. Then I had to do physiotherapy for my back, twice a week. I swear to you, really, 70 or maybe 75 euros are a lot of money for me. I thought of Bossi and Maroni (Italian politicians of the far right Lega Nord Party, NdT), because they bring in these laws that don't let us apply for a residence permit and register for unemployment. (Isiah, 35 years old, Morocco).

The case of Isiah is particularly interesting, because it concerns a very frequent situation, in which, although he is not strictly indigent, the sick person is in an economic situation that makes it extremely difficult to pay the ticket (the fee for medical services). Also, since he cannot register for unemployment, he does not have access to the exemptions foreseen<sup>107</sup>.

This case directly refers to the concept of “medical indigence” elaborated by the Italian Constitutional Court to indicate an economic situation that prevents access to specific medical treatment. Article 32 of the Italian Constitution identifies health as a fundamental right, guaranteeing free treatment to the indigent, however, the costs of the healthcare are very variable, and the share of the fee to be paid can sometimes represent an obstacle for the patient. The condition of indigence consequently requires a flexible, dynamic and contextual formulation that takes into account the economic capacity of the sick person in relation to the costs of the treatment needed<sup>108</sup>.

The practical tool for guaranteeing exemption for payment of the fee in the case of medical indigence is the code X01, which relates to “urgent or essential outpatient treatment of non-EU citizens who

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<sup>107</sup> The right to exemption for unemployment is guaranteed to citizens who have ceased employment (due to dismissal, resignation or expiry of a contract) and are registered with a Job Centre. A person who has never officially been employed, cannot be considered unemployed.

<sup>108</sup> For a detailed discussion of the content of the ruling of the Constitutional Court see the final report of the first phase of the research. Cfr. I. Biglino and A. Olmo, *Health as a fundamental right: a study on migration and healthcare in Turin*, Bologna, Il Mulino, 2014., op. cit., in particular paragraph 2.1.5.

are not legally resident in the country and lack sufficient economic resources”<sup>109</sup>. The code X01 is issued exclusively for the single treatment that the subject is not able to pay for and, in Torino, it can only be issued by the ISI Centres<sup>110</sup>. The patients we interviewed, however, knew nothing of these exemption codes, or if they had any information, were often unable to obtain them. Therefore, once again, we find the situation that emerged during the first phase of the research and previously in this volume. There is a serious lack of information about one’s rights – exemplified in this case by the lack of information about the possibility of an X01 exemption – which inevitably becomes an unsurmountable obstacle to access to health services and the realization of the right to health. The next testimony elaborates on this point.

The ISI Centre, forgive my language, is crap. At the counter, you meet people who shout at you, they don’t give you any information, you have to pay for your prescription... What’s it called? Yes, the prescription. You have to pay; they don’t give you the exemption. But, I can’t use this hand, I can’t work... so I have no money. The only time they helped me was when I saw a doctor. He was helpful, he told me about these clinics, where you can get free treatment or where you can do physiotherapy and they give you medicines. (Omar, 34 years old, Egypt).

The method for applying for the X01 code is often confusing for the migrant users. For the patients, it is not always clear who has the right to exemptions and which treatments are considered “essential”<sup>111</sup> and which although seen as important by the patients, cannot be considered so, and are therefore not subject to exemptions.

The importance of information, also in this field, appears very significant. What is evident, above all when comparing the results of the second phase of the research with those of the first phase, is the importance of the economic obstacle in accessing the services.

Finally, a question already known and which we will simply mention in passing, is dental care, which represents one of the most frequent health problems and one of the most difficult to manage for migrants who cannot afford private assistance. This problem, present also in many Italian families who live in difficult social conditions or have been affected by the crisis, should lead to a review of the criteria that currently govern the healthcare in this field.

##### 5. *Communication, information and authoritative knowledge*

Social marginalisation has numerous implications with regard to communication and, at the same time, as we will see in the seventh chapter, the lack of information is a contributory cause of marginality. It is, therefore, a vicious circle in which marginality makes it difficult to access information and the lack of information contributes to worsening the condition of marginalisation of the person in question.

The difficulty of access to correct and prompt information is particularly felt by those who do not have adequate linguistic skills, or who have just arrived in Italy. In fact, although the linguistic barrier cannot

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<sup>109</sup> TUI Article 35, paragraph 3; D.P.R. N. 394, August 31st 1999, *Gazzetta Ufficiale* N. 258, November 3rd 1999, ordinary supplement N. 190, Article 43, paragraph 4.

<sup>110</sup> Better known, but impossible to obtain if not legally resident, are the exemption codes of the E series (01 for children under six and those aged over sixty-five with low income; 02 for the unemployed registered with a Job Centre and their dependants; 03 and 04 for pensioners on welfare benefits or with a minimum pension).

<sup>111</sup> For a definition of “urgent treatment” and “essential treatment” provided by the Italian Ministry of Health in Circular N. 5/200, see the first chapter of this volume, paragraph 3.

always be sufficiently overcome by posters and leaflets distributed in a number of languages, they are certainly a step in the right direction, but they do not take into account the rate of illiteracy in the language of origin, nor do they substitute verbal transmission, which is the preferred channel for transmitting information.

Almost all the interviews show a clear preference for the networks of friends and family. Alongside these networks, that centre on the subject (in fact they are personal networks) there are networks that we could call 'of the community' and which centre on the associations, the meeting places, the religious centres, the work place and places of daily life<sup>112</sup>. These networks may be more or less formalized, but in some cases, they are widely recognized.

If I need information or to resolve a problem, I go to Porta Palazzo. There I find the Moroccans, they know everything. They are very shrewd. Perhaps because they have been illegal residents for a long time, they have had to learn how to get by. They know how things work. I learned about this clinic from them three years ago and now I always come here. They said, "go there, they will help you". They explain everything to you and they tell you what to do. If you need to know something about documents, about health, you go to them and they say [...] 'don't go to the GP. He doesn't speak English, he hasn't got time, he is tired, he hasn't got the patience to listen. Italian doctors have too many patients. They can't look after difficult patients like me. Then, they are old. It is not like in other countries, like in Belgium, where the doctors are young and smart. (Ibrahim, 60 years old, Iraq).

Here we find confirmation of the situation that emerged from the first phase of the research, the importance of word of mouth, peer education. This is undoubtedly the main channel through which information is transmitted and sought within the migrant community.

The role of information is fundamental for access to medical care at the time of registration with the SSN. The legislation on healthcare is complex and from this complexity derives the objective difficulty encountered by the immigrants in understanding their rights. Moreover, the fluctuations in the legislation on residence permits and the exasperating slowness of bureaucracy (for example in the case of amnesty) makes it difficult to use the existing welfare services and complicates the periodic renewal of the ENI and STP codes, which must be done every six months. Often, the situation changes so rapidly that it is either no longer possible to renew a permit issued only a few months earlier. These difficulties are more serious in the case of persons with a low level of education or with learning disabilities. This is the case of Corina, a young woman from Romania, who finds it difficult to cope with the contradictory instructions and seems confused by procedures that are beyond her control.

I went to the ISI Centre early this morning, but they wouldn't give me a card. But I say, "sorry, I have come here many times to get my card..." this time they said no! I don't understand... why did they give me a card the other times, and this time no? I haven't got a contract. I have nothing, I am unemployed... I have nothing. I did it lots of times before, but today they won't give me a card. I said, look, all they did was ask for a document, that's all. Now, it seems that you need other things. I don't know. I don't understand. I said 'I have nothing... not even an Italian identity card... I don't even have that.' The woman at the counter was a blonde, who shouted, she was Italian, I think, and she shouted. I said 'why are you shouting?' and she said 'I am not shouting'. But she kept on shouting. And I thought, 'she is shouting, well, let her shout'. (Corina, 24 years old, Romania).

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<sup>112</sup> On this question and for a discussion of "community welfare" and the role of the associations, see chapter seven of this volume.

Difficulties in communication are the order of the day when doctor and patient meet<sup>113</sup>. Lacking a common language and in the absence of the cultural mediators, it is necessary to use non-verbal communication, gestures and physical contact (touching, pointing, signing, scratching).

Although we recognize the importance of non-verbal communication, it is essential to dispel the widespread idea that, if one is patient and willing, the objective examination, the clinical tests or (in the best cases) drawings will be sufficient to guarantee quality healthcare and to understand each other.

Amongst the most typical cases is that of Fatima, a Moroccan widow who, although she says she is “in good health”, tells us that for some time she has suffered from pain in the lower abdomen, which required a lengthy series of tests, from which it was evident that there was a serious problem, however, this was obviously not clear to the woman.

They took a photograph of me here (she points to the place where she has pain)... then they took another one... then I came here to the clinic and back to the Cottolengo Hospital, for the tests. There, they took another photograph...

*An x-ray? An ultrasound scan?* Yes, yes... a photograph.

*Why did they do these tests?* I don't understand...

*Why did they take the photograph?* For the pain, for the pain 'here' (she points, once again, this is the place where she has pain, but she does not know its name.)

*Did they explain what the tests were for?* No, I don't understand...

*Did they give you the results?* Yes... after they took another one, another photograph. Perhaps they will have to operate, that's what they said.

*But did you understand what the problem is? Why they need to operate?* It's because of the pain... for the pain I told you about. (Fatima, 42 years old, Morocco).

This fragment of an interview clearly shows the way communication works during the meetings at the clinic: the interrupted sentences, the extremely limited vocabulary makes it impossible for the patient to explain clearly the discomfort they feel, to speak of the symptoms, to ask questions and to ask for explanations. The understanding of the clinical condition by the foreign patient is, in these cases, extremely limited, which reduces the independence of the sick person and their decision-making powers.

A problem closely linked to the linguistic and communicative difficulties is, in fact, that of informed consent. In cases such as that of Fatima, it is quite evident that, even if she signs a formal document, there is no adequate understanding either of the tests carried out, or of the reasons for which they were necessary.

For the doctor, at the same time, it is extremely difficult to reconstruct the patient's clinical history, to give clear and comprehensive information on complex pathologies, to explain the reasons for the diagnostic tests and to give indications about the therapy. Social marginality also makes it difficult to set up programmes of prevention and health education.

The main resource in the face of these communication difficulties, as we said, is the cultural mediator, although Fatima, like many of the migrants interviewed, has never asked for one. In fact, not everyone knows that this resource exists, often they do not know the word “mediator”, nor are they familiar with the role of this professional figure: we will deal in-depth with this topic in chapter seven.

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<sup>113</sup> Cfr. I. Biglino and A. Olmo, *Health as a fundamental right: a study on migration and healthcare in Turin*, Bologna, Il Mulino, 2014., op. cit., pages 117-130.

Also in a situation of sufficient understanding from a merely linguistic standpoint, serious misunderstandings are still frequent, which definitely hinders the doctor-patient relationship. Often, there is a tendency to take for granted the cultural and social context of reference, forgetting to what extent it determines the semantic background of the words.

The difficulties in communication combine with a more generalized difficulty in listening, which, in turn, is linked to the migrant's lack of knowledge about their bodies. From this point of view, the story of Jorge, a Peruvian who has resided in Italy for five years, who went through a long and difficult ordeal, assisted by his wife, before finding the cause of a problem that was increasingly intense, but which was always trivialized by the various operators, so that no further diagnostic tests were carried out.

For two years I put up with a pain, a very strong pain for which I did not know the reason. An unbearable pain, here at the mouth of my stomach. I threw myself on the ground, then sometimes it got better. I put up with it for two years, but they never did any tests. Everywhere I went they said "it's gastritis, you must take the medicine". I told them "look, it is an unbearable pain, I already take the medicines, but they do nothing." Then, after two years, one night, I couldn't take any more and I went to the A&E department – by this time two or three years had gone by. When I got there, they told me the same thing. So, I said "look, I can't take it any more, this pain is unbearable, I've had it for two years and no-one listens to me." I was really angry! So then, for the first time, they did some tests and they found some really big liver cysts. They had to operate immediately, urgently. It was not the first time I had been to the hospital, or to the doctor, but no-one listened to me, no-one believed I really had pain, they thought it was nothing. (Jorge, 38 years old, Peru).

A similar situation is represented by the case of Cécile, who has to explain repeatedly to her family doctor that she has "a health problem", which was evident long before she came to Italy and which presents the main symptoms of high blood pressure and chronic pain in the abdominal area.

My doctor does not want to listen to me, he has no patience... I don't know if you understand me. I told him that I have high blood pressure and that it hurts here. But the doctor said, "No! This is not important." He said, "Your blood pressure is not so high." I asked 'why?', but he wouldn't explain. He just said that. (Cécile, 36 years old, Cameroon).

The difficulties in communicating and, perhaps, a certain diffidence with regard to the patient's capacity for evaluating the symptoms, lead the doctors to consider further tests unnecessary and to resolve the situation with a bland analgesic. Certain that she was not well, Cécile insisted on returning to the doctor's asking for referral to a specialist and the opportunity to have blood tests carried out, but it was useless and the relationship between the pair became increasingly tense. Finally, on the advice of her sister-in-law, she went to a private social clinic.

I came here and I saw the lady doctor. How do you say it? The cardiologist? She took my blood pressure and it was high. I asked her to write it down, so that I could go to my doctor and show him, so that I could get a prescription for the blood tests, but he only said, "Yes, in effect your blood pressure is high... but you just need to rest a bit: it is stress." Oh no, no, no! I am not going there any more. (Cecile, 36 years old Cameroon).

After many difficulties, Cécile managed to get a prescription for tests, but, despite the recurrent symptoms, no problems were found and the slightly high blood pressure is not sufficient to explain the woman's discomfort. The operators say that this situation is frequent: in many patients, they find a diffuse and imprecise discomfort, which finds expression in the body, but which it difficult to ascribe to a specific

diagnosis. In these cases, it is not easy to distinguish between psychosomatic disturbances and other pathologies not revealed by the tests.

The problem of the therapeutic choices and the diagnosis greatly transcend the competence of the writer and it is not one of the objectives of this study to open a discussion on the subject. It is however, important to show how the meeting with the foreign patient often makes it necessary to pay particular attention to the communicative sphere and adopt an approach to health that is aware of the link between the body, the mind and society. An efficacious intervention must therefore combine the more specifically medical aspects with careful listening and with interventions aimed at the social-welfare aspect and the psychological sphere.

In fact, the interviews confirm the problems of mental health associated with the migratory experience, and the difficulty in finding an answer to mental health problems through the SSN<sup>114</sup>. In the first volume of the research it was emphasised that the department and centres for mental health are amongst the services worst hit by the cuts in funding and by the crisis.

Particularly interesting from this point of view are three centres: the Centro Marco Cavallo, Mamre and Centro Frantz Fanon. These centres, although from diverse theoretical perspectives, adopt an approach based on ethnopsychiatry, a discipline based on the recognition of the profound role of social, historical and experience in moulding the individual subjectivity. They all, to a greater or lesser extent, stand in a critical position with respect to an environment such as biomedical and medical psychiatrics, which tend to start from the assumption of the universal validity of its formulation. Often the consultancies of the operators, a service offered by all three centres, open the doors to a different representation of the body, of health and of illness.

In the case of Mamadou, discussed during the cycle of meetings “The world in a room” organized by CCM<sup>115</sup> in cooperation with the Piemontese School of General Medicine, may be useful to clarify this concept. Mamadou, aged 32 and born in Senegal, was registered with the SSN and when he standard blood tests ordered by his GP they showed that he had diabetes. He began a period of treatment that led him to slim considerably and reach his ideal weight. The doctor was very pleased with his patient’s clinical progress and so he was very surprised when some months later, after a summer holiday in Senegal, his patient returned to the surgery, convinced that he was at death’s door.

The problem, as the doctor was able to discover during a number of meetings, began when Mamadou returned home. His wife, seeing him so thin, found it difficult to recognize him and she suspected that he had been seeing other women and had contracted HIV. The test was negative, but the situation did not improve at all, also due to a series of episodes of impotence, which prevented the couple from having sexual relations. Taken to a traditional healer, the man was told that he was seriously ill and that since he had not listened to the “call” and had “lost himself in the place of emigration”, there was now “nothing to be done”:

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<sup>114</sup> *Ibidem*, page 82.

<sup>115</sup> The Comitato di Collaborazione Medica (CCM) is an NGO founded in 1968 by a group of doctors from Torino with the aim of allowing access to basic healthcare in low-income countries. Their activities were carried out through missions in Burundi, Ethiopia, Kenya, Somalia, Southern Sudan and Uganda. More recently, in Italy, the CCM has been working to promote the right to health of migrants and refugees, organizing awareness campaigns for citizens and promoting training courses for doctors and nurses.

When he returned to Italy, Mamadou, terrorised by the healer's words, insisted that his doctor discover what his real illness was and that he "should give him something" to save him from the illness that afflicted him. In effect, the clinical tests showed a high level of prolactin, but they were not conclusive and the doctor was increasingly disconcerted by the patient's anguish and his pressing and desperate requests for help.

This episode highlights the need to take into account the reference context and to explore in depth the implications of the relational and identity disruptions that can be perceived in the episode of non-recognition of the migrant when he returned to Senegal. The words of the patient, in fact, seem to evoke the *wootal*, the traditional call, described amongst the Wolof, which "represents a procedure practiced in traditional medicine, designed to attract the migrant and make him return to his own country"<sup>116</sup>. If it is ignored, this call can trigger fatal consequences, even the – clinical or social – death of the patient.

Rather than discarding these beliefs as mere superstition, we can see in the words of Mamadou, a symbolic language that speaks of the physical and psychological suffering, which originates in the effort of migration and in the threats to the integrity of self that follow. In these cases, it is fundamental to organize interdisciplinary diagnostic and welfare procedures that take into account both the clinical aspects and the ethnopsychological and relational aspects. It is necessary to adopt a non-judgemental approach, open to dialogue in order to guarantee quality assistance and to give a prompt response to a cry for help presented in terms that are radically different from biomedical language.

#### 6. *The Roma. An exemplary case of the link between social marginalization and health*

The Roma are the social group for which the inequalities of health with respect to the rest of the population are most evident; these inequalities can largely be traced to the conditions of social exclusion in which they live. The voices of the health operators and the Roma citizens we gathered in Torino confirm a worrying situation already highlighted at national<sup>117</sup> and European<sup>118</sup> level. The Roma have worse health conditions, are less aware of their rights and daily face a series of difficulties with regard to access to and enjoyment of health services. The report of the European Commission published in 2014, identified seven indicators that show that Roma health is inferior to that of the rest of the European population: mortality rate and life expectation, the presence of infectious diseases, hazardous behaviour, poor access to and use of the health structures and the prevention programmes, the prevalence of chronic diseases<sup>119</sup>.

Before presenting the stories of health gathered, it is important to define more precisely which subjects we are speaking of, and to do this we must problematize the categories "Roma" and "gypsies", which are used with such approximation by the common citizens, by journalists, policy makers, representatives of the institutions and the health workers themselves. The anthropologist Piasere emphasises

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<sup>116</sup> R. Beneduce, *Frontiere dell'identità e della memoria. Etnopsichiatria e migrazioni in un mondo creolo*, Milano, Franco Angeli, 2004, page 52.

<sup>117</sup> A. Ricordy, F. Motta e S. Geraci, *SaluteRom. Itinerari possibili*, Bologna, Pendragon, 2014.

<sup>118</sup> ERRC, *Ambulance not on the Way. The Disgrace of Health Care for Roma in Europe*, Budapest, 2006; European Commission, *Roma Health Report. Health Status of the Roma Population. Data Collection in the Member States of the European Union*, Bruxelles, 2014.

<sup>119</sup> European Commission, *Roma Health Report*, op. cit, page 31.

that “gypsies” is a term historically used by the *gaje*, that is the “non-gypsies”, to indicate “a fairly varied group of people, with cultural diversity at times considerable, whose only common characteristic is that of, perhaps, a negative connotation for those who do not consider themselves gypsies<sup>120</sup>”. This is a question of primary importance because, it is starting from precise ideologies, that we have constructed in Italy a public and scientific discourse on the “gypsy” other, which has influenced the policies in various settings, from the residential, to the scholastic and the working world, even reaching the healthcare sector. The situation that we have photographed in Torino can only be understood in the light of this recent past.

Subjects with a considerably variegated characteristics are lumped into the generalized category of “Roma”, starting from their national origins, their legal status, the duration of their permanence in Italy, the residential solutions adopted<sup>121</sup>. With regard to the health of this population, it has been shown that it generally depends on the precarious nature of the living conditions which (above all in the spontaneous camps) involve very worrying hygiene and sanitary conditions. As of today, no systematic, in-depth study of the health conditions of the Roma in Italy has been carried out, except for some localized works, which examined small samples of the population in specific contexts<sup>122</sup>.

In Italy, the life expectation for the Roma is the lowest in Europe, with twenty years less than the average population<sup>123</sup>. A study carried out in 2009 set life expectation at 45 years and, with regard to infant mortality, it indicated 6.5%, a very high rate if compared with the 3.5% of the non-Roma population<sup>124</sup>. There is however no specific quantitative data on the use of the services, nor on the forms of preventive health amongst the women. From the studies cited it is clear that the most common pathologies are cardiovascular diseases, such as arterial hypertension, metabolic syndromes, respiratory diseases, gastrointestinal diseases, migraines and osteoarticular pain. Many of these problems depend on the incorrect lifestyles, such as smoking and poor diet, in addition to exposure to precarious environmental and residential conditions and the weather<sup>125</sup>. Moreover, the diseases are aggravated by late diagnosis and lack of continuity

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<sup>120</sup> Piesere also reminds us that “Modern Europe has created tens of stigmatized groups, formed of families and individuals who were expelled by production processes and pauperized and who were literally thrown onto the streets or the margins of the villages [...]. To propose *a priori* that all gypsies are of Indian origin, is to censor this capacity of “creating gypsies” that Europe has had and continues to have.”

(L. Piasere, *I Rom d'Europa. Una storia moderna*, Roma-Bari, Laterza, 2004, page 18).

<sup>121</sup> From the data supplied by the *Ufficio Nomadi* of the City of Torino it appears that in 2013 there were 3,037 Roma living in Torino, 0.33% of the resident population. Amongst them were people of Romanian origin (1,500 people, about 50%), of Slavic, Montenegrin, Kosovan, Serbian, Bosnian and Croatia origin (about 1,242 people, 41%) and of Piemontese Sinti origin (295 people, about 9%). These are numbers that underestimate the effective presence, since, above all the Romanian Roma can legally enter the country without having to report their presence. The legal situation also varies: the Piemontese Sinti have Italian citizenship, amongst the Slavic Roma many do not have a residence permit, or any other type of identity document, while some have attained the status of political refugee or stateless person, the Romanian Roma are EU citizens and therefore do not require any form of residence permit when they come to Italy. The residential solutions also vary: 1,500 people live in spontaneous settlements (59%), 847 in camps equipped for mobile lodging (32%), 440 in council housing (6%) and 250 in private accommodation (3%).

<sup>122</sup> See, for example, L. Monasta *et al.*, *Review of the Scientific Literature on the Health of the Roma and Sinti in Italy*, in «Ethnicity and Disease», vol. 22, 2012, N. 3, pages 367-371. It is however, necessary to avoid generalising the results, extending them to the entire Roma population, since in these studies the Roma who live in precarious conditions are over-represented because the studies were carried out in ghetto districts or slums. Moreover, there are still very few studies on chronic pathologies and non-contagious diseases.

<sup>123</sup> H. Frazer and E. Marlier, *Promoting the Social Inclusion of Roma*, Ceps and Instead, series European Network of Independent Experts on Social Inclusion, 2011, N. 3.

<sup>124</sup> Observation, *EU Values: The Roma Migration Challenge. Italy Report*, Roma, 2009.

<sup>125</sup> With regard to the social-residential conditions, a survey conducted at European level by UNDP and FRA showed that in Italy the Roma have double the probability (compared with the autochthonous population of living in family groups at risk of poverty and that a third of the homes were overcrowded, lacking a kitchen, an indoor bathroom and electricity. UNDP and FRA, *The Situation of Roma in 11 EU Member States. Survey Results at a Glance*, 2011.

in the therapies. Amongst the subjects most affected by complications for their health are the children: the study by Ricordy and colleagues highlights the fact that problems such as acute bronchitis, pharyngotonsillitis, middle ear infections, intestinal infections are all related to the difficulties of their living conditions. The situation in the camps is, in itself, a risk factor for the health of the children<sup>126</sup>.

In Torino, no specific work has been produced on the health of the Roma population, except for the analysis of data gathered during welfare-health inspections at the spontaneous camps<sup>127</sup>. In these analyses, we find confirmation of the data on the pathologies that emerged from the European research previously cited. The information we give in the next paragraphs is the fruit of meetings and interviews with the health sector operators and with Roma subjects in their homes (apartments or huts in the spontaneous camps), and at the health structures such as the ISI Centres and the clinic of the association Camminare Insieme. The majority of the Roma we interviewed were of Romanian origin and had lived, or were living, in the area of Lungo Stura Lazio, a large slum that has developed since the nineteen-nineties in the northern suburbs of Torino, along the banks of the river, on ground previously occupied by illegal allotments. Since 2002, the number of residents has increased, following the removal of the visa requirement for Romanian citizens, and the presence estimated at the end of 2013 was about 1,400 people<sup>128</sup>. The camp is in an isolated position with respect to all the services, including the sewers, the only source of running water is a drinking fountain on the main road, there is no connection to the electrical supply, no toilets and the rubbish is piled behind the huts. Moreover, the camp is at considerable risk from flooding and this has forced the civil protection unit to organize temporary evacuation on more than one occasion.

The analysis of this context, with its many problems, clearly shows that it is not possible to consider healthcare a separate factor from all the other structural conditions that influence the life of the persons involved. This population lives in exceptional conditions that are continually exacerbated. The demands for normalization of the behaviour of the Roma citizens, by other citizens and the institutions, are inappropriate and short-sighted, since many interventions are based on an 'emergency situation' approach, which has promoted and confirmed the regime of exception and marginality that it was meant to contrast<sup>129</sup>.

#### 7. *From the camp to the A&E department. The difficulties faced by the Roma in gaining access to the health services*

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<sup>126</sup> A. Ricordy, F. Motta and S. Geraci, *SaluteRom*, op. cit. A study dating from 2004 indicates the presence of respiratory difficulties as 23% of the Roma children aged between 0 and 5 years old. According to a report by the FSG, other problems concern the low rate of vaccination (more than 25% of the children has never been vaccinated, or has not respected the calendar of vaccinations) and forms of malnutrition and dental problems due to poor preventive treatment. Cfr. FSG Health Area, *Health and the Roma Community, Analysis of the Situation in Europe*, Madrid, Fundación Secretariado Gitano, 2009.

<sup>127</sup> Terra del Fuoco, *Analisi socio-sanitario dei campi rom abusive di Lungo Stura Lazio e Via Germagnato*, Rapporto di attività, Torino, 2009.

<sup>128</sup> In January 2014 the city of Torino began an important process to dismantle the camp and place the families in other residential solutions. This process is the subject of a research project entitled *Le case dei Rom* (the Roma's houses), which the author of this paragraph is carrying out on behalf of Fieri (Forum Internazionale e Europeo di Ricerche sull'Immigrazione).

<sup>129</sup> Alunni observes that in various Italian situations, the local authorities have chosen to take mobile clinics to the registered camps, with SSN doctors on board. Why, asks the researcher, are the doctors surprised by the undisciplined and suspicious attitude of the patients, when they are seen as an expression of the system that tends to exclude and marginalise them? L. Alunni, *La morale delle avvertenze. Circolazione, uso e manipolazione dei farmaci nei campi rom di Roma*, in «AM. Rivista della Società Italiana di Antropologia Medica», n. 35-36, 2012, pp. 41-63.

From the various testimonies gathered, it was clear that information about the Italian health system is fragmented and contradictory. Many people told us that they did not know what services they had a right to, at least not until they were in a situation of extreme necessity, which forced them to seek an emergency solution. This confirms a general trend already found in the migrant population, which seriously limits access to the health services. For anyone who lives in conditions of considerable precariousness, health is not seen as a priority, because they are forced, daily, to resolve much more urgent problems.

These persons, in approaching the Italian health system, often rely on their experience in relation to the health service in their country of origin and believe that similar characteristics will be present in Italy, a question already examined in the first volume of the research<sup>130</sup>. For example, they do not know that basic healthcare in Italy is completely free of charge, and therefore, to save money, they often postpone a medical examination until the symptoms make it impossible to avoid.

Maria, who comes from Bucharest, has resided in Italy since 2011, at the Lungo Stura Lazio camp. She has no children and in the camp, she shares a hut with a niece and contributes to the family finances by begging. She has a congenital pathology of the kidneys and in the winter of 2012, she contracted an infection of the urinary tract, caused by the cold. In 2013, she caught tuberculosis, for which she was taken to the Amedeo di Savoia Hospital. It was a great comfort to her to discover that the medical treatment was free of charge.

In Bucharest, I had a GP but I wasn't insured because I never had an employment contract and at that time we paid for healthcare. In Bucharest, the medicine for my kidneys cost five million RON, about €100, and I had to take a packet every month and I didn't have the money to pay for it... When I came to Torino, to stay with my niece I didn't go to the doctor's because I thought it would cost the same as in Romania. But then, one day, I was so ill that I went to the A&E and then to the hospital. And I found out that it doesn't cost anything, it is a gift. Otherwise I wouldn't have gone there I and I wouldn't have stayed there. (Maria, 55 years old, Roma from Romania).

What strikes us in this testimony is the term that Maria uses, "a gift", which suggests a vision of healthcare as exclusively a paid service. This incorrect information concerns the rules and the conditions of access and it is translated into behaviour that is also emphasised by the healthcare workers. One doctor, for example, told us that he was amazed by the fact that a Romanian Roma, after being examined at a public clinic, asked how much the fee was and was surprised when he said that treatment was free of charge. The woman was imitating a widespread custom in Romanian healthcare services, where theoretically free services are in fact paid for 'under the counter' to the workers.

The lack of information is also evident because very few people in the Lungo Stura Lazio camp hold an ENI code, which would allow them to go to the ISI clinics and therefore have access to all the services made available by the national health service. This serious deficiency led the District 6 of the local health service ASL TO2 to support a proactive health project, during which, for more than a year, a female doctor, accompanied by a group of mediators, made twice-weekly visits to Lungo Stura Lazio and other irregular camps in the area to introduce the residents to the services available at her clinic. Thanks to the issue of a tax code (*codice fiscale*) and later an ENI code, it was possible to promote access to the guaranteed public health

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<sup>130</sup> I. Biglino and A. Olmo, *Health as a fundamental right: a study on migration and healthcare in Turin*, Bologna, Il Mulino, 2014, pages

services<sup>131</sup>. This initiative was not always positively received by the potential users, since for those who have always lived in a situation of suspension and exceptionality, the bureaucratic procedures necessary for attaining the services are considered too complex.

The information gap means that, in circumstances of particular social exclusion, there is a space for action by informal mediators who take advantage of their strategic position, transmitting the knowledge and the resources that the weaker subjects need. One of our interviewees told us that some people at the camp were selling painkillers and antibiotics provided free of charge by the clinics at a high price<sup>132</sup>. These reports also show that the strong intracommunity solidarity that many non-Roma, including the healthcare workers imagine to exist within the camps is a mirage.

Access to the healthcare services and, in a subsequent phase, continuity of treatment is made more difficult by the circumstances of considerable precariousness of the slums. Many inhabitants are obliged, due to internal or external situations, to abandon their homes and move elsewhere<sup>133</sup>. Ion is a Romanian Roma who lived from 2008 to 2011 in the abandoned Continassa farmstead in, in the west of Torino. His first daughter was born in Romania in 2006, before he arrived in Italy; the second was born in 2010 in a hospital in the city. Despite the total precariousness of his lifestyle, thanks to the intervention of volunteers from a religious association, his wife and daughters have regularly attended the local clinic and the children have a paediatrician. In December 2011, following an arson attack on the farmstead, Ion and his family had to leave, moving first to the city of Genova and later returning to occupy a hut in the south of Torino. The contacts with the paediatrician were lost and so was the possibility of monitoring the health of the children, a fundamental means of prevention and control.

This type of mobility is not chosen, but forced by circumstances and it threatens the right to health. The effect is that of an incredible fragmentation of treatment, fragmentation that occurs not only on a local scale, but also on a transnational scale, as we will see in the chapter seven. This fragmentation is often read by the institutions not as a response to an inadequate offer, but as a confirmation of a presumed desire not to 'put down roots' and of 'nomadism'.

#### 8. *The meeting between the Roma and the operators and the meaning of care in situations of extreme marginality*

For people who live daily in situations of great precariousness the refusal to seek medical treatment, or the scepticism in trusting the doctor's instructions are also linked, in some cases, to a more psychosocial

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<sup>131</sup> In addition to this project, which ended in December 2014, the City of Torino has, since 1995, promoted "AutoRoma" a project to increase awareness and use of the health services in the two authorised camps in Strada dell'Arrivore and Via Germagnano. The service was located near the camps and close to the family and paediatric clinics of the district. Once a month, the paediatric nurse from the clinic went to the camps, met the mothers and children and, according to their needs, gave them appointments at the clinic. The project involved an integrated, multi-profession team composed, apart from nurses, of operators from the local authorities, a social worker and an educator, and educators from a social cooperative. In recent years funding has been reduced, so the space for the Roma within the clinic has been closed. According to the paediatric nurse who described the experience, "the interest in this population has unfortunately decreased", although the Roma mothers from the camps now make more assiduous use of the local services.

<sup>132</sup> A similar situation was documented in Rome, where a group of people were providing 'day after pills' from France to the women resident in the camps, at a fee. Cfr. *La morale delle avvertenze*, op. cit.

<sup>133</sup> For more information see Box 1.

component. Going to the doctor's means recognizing one's status as a sick person. Once the illness has been given a name, it takes on a form and a substance that becomes permanent. This is the account of a patient met at a clinic.

In Romania a doctor diagnosed a stomach tumour, but I was so frightened that I did not go to the doctor's. I thought that if I didn't pay attention to it, it would go away. That is why I left, so that I could think about something else, for the joy of being with my family here in Torino. Then I arrived in Italy and I was very ill, I had to have a biopsy and now I am on a waiting list. (Esmeralda, 48 years old, Romania Roma).

Many people, for this reason, try to limit their contacts with the healthcare structures, in particular with the hospitals, and they try to rely on those services that, in their opinion, will reduce the waiting times and the invasiveness of the treatment. One young Roma woman said,

I don't like hospitals, I can't stand them. Hospitals are places for sick people, if you stay there it means you are really sick [...] When my child was born he had some minor problems and I wanted to leave the hospital and go home immediately, the first day, but I couldn't because they said I had to breastfeed. Otherwise, I would have left him with the nurse until he was well. (Ioana, 20 years old, Romanian Roma).

In this story we are struck by the way the total delegation of care to the hospital personnel is linked in part to the perception of incapacity to solve the child's problems on the one hand, and on the other, as the hospital as a contaminating space, a place for sick people. The lack of information on the illness itself and on the therapies combine.

It is precisely from this point of view that we must read the excessive use of the A&E department, to which many of the Roma turn, also in non-emergency situations. One interviewee observed ironically,

For us it is always an emergency. For example, there is the nomad emergency, then the emergency legislation<sup>134</sup>. This is why we prefer to go to the A&E, that way we solve the problem more quickly." (Ion, 35 years old, Romanian Roma).

Some scholars have also tried to explain the fear of illness and the access to healthcare structures by referring to non-biomedical visions, but rather to moral and spiritual concepts<sup>135</sup>. For example, while we were speaking to a pregnant girl about smoking in pregnancy, the belief that illness can be contagious through a glance became evident.

I can't stop smoking, I don't like electronic cigarettes. Anyway, my father smokes at home, when I am there... This is not a problem for the baby, because I have always smoked and nothing happened to the other baby. I have never hated anyone. Deformities happen when someone hates you, or when you wish someone ill. (Ramona, 20 years old, Romanian Rom).

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<sup>134</sup> For more information see Box 1.

<sup>135</sup> A. Sandu, *Rules from above, Views from below: Accessing and Using Child Health Services in Post-Communist Rural Romania*, in *Poverty, Urbanity and Social Policy: Central and Eastern Europe Compared*, Ed. J. Aidukaite, New York, Nova Science Publishers, 2009, pages 59-79; P. Mladovsky, *Research Note: To what extent are Roma disadvantaged in terms of health and access to health care? What policies have been introduced to foster health and social inclusion?*, LSE and European Commission 2007.

During the interviews, none of the Roma patients reported forms of open discrimination by the healthcare workers, an aspect that emerges from numerous reports concerning the condition of the Roma in Italy<sup>136</sup> and in other European countries<sup>137</sup>. Many healthcare structures are not welcoming and inclusive for patients that belong to social groups such as the Roma, and the interviews that follow confirm, at least implicitly, this impression. Some health workers emphasised that their colleagues show annoyance and discomfort when dealing with patients considered problematic and lacking in respect for the rules.

The doctors also have their limits. Many do not want to dirty their hands; they would never go to a Roma camp. They prefer to meet the patients at their surgeries, which are nice and clean. It is a question of status, working with the gypsies is not “cool”. Just think that there were three permanent contracts available at the ISI Centre and only twenty candidates. It is incredible when they tell you there are no job opportunities in the public sector... And, when the director of District 6 sent out a circular asking who wanted to take part in the Roma camp project, none of the doctors, apart from myself, was available. (Italian female doctor, ISI Centre).

This diffidence on the part of the healthcare workers is sensed by the patients, who in turn feel towards the doctors and the institution they represent a sense of discomfort and an unbridgeable distance. This is what a cultural mediator told us.

The doctor is viewed with awe, if not with fear. Not only because he or she is not Roma, but also because they are poor people and they come from the countryside. The doctor is rich, he has a different culture from theirs, and then he has to touch their sick body. Only rarely in their lives they have had direct contact, on an equal basis, with a doctor. I will tell you this story to help you understand better. A woman came here to the clinic with her children and another Roma woman, who never came in, although she had her child with her. When we asked the first woman, she said that she didn't want to come in because she was too dirty and she thought the doctors would not even want to touch her child. I went to her and I encouraged her to come inside, I gave her some moist towelettes, because they didn't have running water in their hut. The (female) doctor examined the child and told her that her little boy was beautiful, and she answered, smiling, that the doctor certainly had beautiful children, too. From that moment onwards, the woman has come almost every month. I am sure that it was the first time she had been treated with dignity by a doctor. (Romanian cultural mediator, association Camminare Insieme).

While on the one hand there is a distance that is perceived as unbridgeable, there are healthcare practices that have resulted in a positive meeting between doctors and patients. Banu is a man of thirty-two years old; he comes from Bacau in Romania and is the father of four children aged between twelve and three years. In the summer of 2010, he had a bad fall from the staircase of the ruined house in which he was living. After a coma of some weeks, he had to stay in hospital for more than two years and he was discharged with a total paralysis of the legs. Thanks to the intervention of the community of Sant'Egidio he has obtained a rented house near the hospital, where he lives with his wife and children. This accident has revolutionized his life. In a society where the gender roles are still very clear, the illness and the disability are experienced very dramatically, above all when it is the man who is affected, the head of the house. An illness is a disaster that

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<sup>136</sup> For more information see Box 1.

<sup>137</sup> ErRC, *Ambulance not on the Way*, cit. In this study, carried out in Spain, Hungary and Bulgaria, many Roma said that they did not receive appropriate treatment or that they were treated in a manner considered inferior to other non-Roma patients, during the medical visits and stays in hospital. They reported episodes in which the sheets were not changed, in which physical contact was denied, there were no professional figures during specialist visits, they were entrusted to the care of untrained medical students, there was verbal abuse and racial language.

brings misfortune to the entire family. That is why it is hidden and, if it is evident, it leads to profound isolation.

The rent is paid by Sant'Egidio, our food is paid for by Sant'Egidio and Caritas. They bring us everything we need. My wife takes the children to nursery school and to school, then she returns home to look after me. She doesn't have time to go begging. I chose to stay in Italy because if we were in Romania, I would have to pay four million RON a month to her, about 100 euro, but I haven't got all that money. In Romania everything costs money, if you go to a doctor you have to pay, even just to be examined. Here, it is not like that. I didn't go back to Romania after the accident and I don't even want to go back. It is very difficult for me. There is no future in Romania. My disability is seen as a very bad thing in our family. Some ignore us, above all our relatives; when they see a case like mine, they run away, they are frightened... But what I did not find from my family, I found in Italy. The doctor at the Molinette Hospital was very kind; he was so good, I have never seen anyone like that in all my life. When he had an extra catheter, he brought it to me, because the catheters are very important. I don't think a relative could respect me more than he does. In Italy I did not feel discriminated, I felt good and lucky, in spite of my terrible misfortune. (Banu, 32 years old, Romanian Roma).

From this story, once again, we can see the fundamental role of the private social services in guaranteeing the availability of treatment and services that the public service now finds it increasingly difficult to guarantee. In this sense, the City of Torino, thanks to the incredible vitality of the private social services, is probably unique in Italy, because there is a (frequently very beneficial) integration between public and private social services.

#### 9. *"It is part of their culture". Misunderstandings and prejudices*

Misunderstandings are frequent and they complicate the meeting between the healthcare professionals and the patients. The misunderstandings are of varied nature and intensity, but when it is a question of Roma patients, they occur with greater frequency because a mental image of this group has grown up that it is difficult to undermine. Often, the operators show a cultural reading of the patients' behaviour that it is difficult to deconstruct. Attitudes that derive from the need to answer material problems are read as cultural behaviours, incompatible with models of care and assistance of the majority society. Saletti Salza highlighted the fact that over the years, in various parts of Italy, social workers have reported that Roma mothers have left their newborn children in the hospital maternity wards<sup>138</sup>. What was seen by the hospital management as abandonment of a minor, a practice that was traced to unacceptable cultural models, for the Roma mothers was a protective choice, since these women believed that they were safeguarding the newborn children by entrusting them to the nurses during the most severe weather. These reports have often led to the juvenile courts taking proceedings against the parents and in some cases have led to the children being declared available for adoption. In the above research, conducted at seven courts in Italy, it emerged that a Roma minor was seventeen times more likely to be declared adoptable than a non-Roma minor. According to the author, the social services and the judges sometimes expressed opinions biased by cultural

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<sup>138</sup> C. Saletti Salza, *Dalla tutela al genocidio? Le adozioni dei minori rom e sinti in Italia (1985-2005)*, Firenze, Cisu, 2010.

prejudice; in the face of situations and attitudes dictated exclusively by material hardship, the origin of the situation of risk for the minor was attributed to an indistinct “Roma culture”<sup>139</sup>.

To return to the results of our research, often a refusal of the offer of healthcare by the Roma users is not interpreted by the operators as a response to the inadequacy of the service offered, but as the product of their cultural limits. NACU, in a study carried out amongst the doctors who operate in the Roma camps in France, highlighted the fact that these misunderstandings create considerable frustration amongst the operators.

In some interactions between doctors and patients the perception of the ethnic difference does not seem to take into account other reasons, becoming a source of incomprehension... For example, the fact that a Roma woman has five or six children is seen by the doctors as “cultural” and not as an “individual choice”. “It is part of their culture to want a lot of children”. The behaviour of the Roma woman is interpreted as respect for the tradition, while the use of contraceptives and the fact that a patient of French origin chooses to have only one or two children is seen by the same doctor as “an individual choice”<sup>140</sup>.

The behaviour of the Roma interviewed must be seen not so much as elements of a presumed traditional culture, as situations of material hardship in which they have found themselves and in which they continue to live. The majority of these Roma come, in fact, from contexts in which the traditional way of life was uprooted during the years of socialism, with phenomena of urbanization and strong cultural assimilation. In their country of origin these Roma people rarely turned to the healthcare structures because they were very expensive, or because they were the object of genuine discrimination within these structures, and this habit continues in Italy. What emerges is, therefore, a strong polarization perceived and described, between those who dispense treatment and those who receive it<sup>141</sup>.

The most interesting and recurrent of these misunderstandings concerns the use of medicines. This is what one doctor told us.

There are a lot of antibiotics circulating in the camps, they can be obtained without a prescription, with the connivance of irresponsible, I would also say criminal, pharmacists. The Roma have a passion for medicines, if they can't get them in Italy, they are prepared to pay a lot more in Romania or in Bosnia, because they really need to have them. At times, it seems to me that they don't trust Italian medicines, or generic ones. In some cases, they are hypochondriacs. It is a question of their culture that we have not been able to overcome. (Female Italian doctor, ISI Centre).

To explain this “passion” it is not sufficient to appeal to an undefined culture. It is necessary to consider the relationship that the medicine creates between the people. When a doctor prescribes medicines,

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<sup>139</sup> The courts analysed in Saletti Salza's research were Torino, Firenze, Napoli, Bologna, Venezia, Trento and Bari. Between 1985 and 2005 these courts declared 258 Roma children adoptable, 2.6% of the total number of minors declared adoptable by these courts. Since the Roma population represents 0.2% of the national population, the Roma minors should not have been more than 13. Starting with this data further research was carried out at the juvenile court in Rome, from which it emerged that, between 2006 and 2012, adoption proceedings were begun for 1 Roma minor out of 20, compared with 1 non-Roma minor out of 1,000. With respect to a non-Roma minor, a Roma is sixty times more likely to be reported to the police, fifty times more likely to see adoption proceedings taken and 40 times more likely to be declared effectively adoptable. See Associazione 21 Luglio, *Mia madre era rom. Le adozioni dei minori rom in emergenza abitativa nella regione Lazio (2006-2012)*, Roma, 2013.

<sup>140</sup> Nacu, *The Politics of Roma Migration: Framing Identity Struggles among Romanian and Bulgarian Roma in the Paris Region*, in «Journal of Ethnic and Migration Studies», vol. 37, 2011, N. 1, page 145.

<sup>141</sup> D. Singh, *Attitudes and Praxis of Traditional Forms of Health Care in a Post-Communist Romanian Romani Community*, in «Anthropology of East Europe Review», vol. 29, 2011, N. 1, pages 127-140.

it is an official recognition of the illness<sup>142</sup>, this recognition of the illness is also proof of the interest by the health worker, a very important element for subjects who live on the margins of society. The medicines are not always taken according to the doses and therapies prescribed. These transgressions represent an adaptation and a response to the instrumental incompleteness of the offer that comes from outside. The patients are willing to spend more for the medicines, providing they are the original ones, the ones that are most advertised. Also, precariousness and mobility produce discontinuity and confusion in the therapies.

Many of these immigrants go back and forth. They go to Romania and get medicines; they come here and get more... This is a risk for their health, even when they must follow a specific therapy. Then there are major problems with cultural differences: for many immigrants health is a question of here and now. It makes no sense to speak of prevention; they only come here when they have a serious or very serious problem. (Female Italian doctor, ISI Centre).

They come and ask for lots of antibiotics when their children are ill. At times if we do not give them antibiotics, they get very angry with us. We insist on giving paracetamol, partly to avoid liver damage, and because when antibiotics are really needed, they will no longer have any effect... For the Romanian Roma it is difficult to go to the doctor's surgery, because when they go they have to take presents, and so it is considered better to get a stock of products when you *do* go. This happens with the diabetics, too. For example, they have insulin sent over from Romania, rather than going to get it here. It is a question of not understanding the system. Often they say that they take a little insulin and then they ask for more so that they can eat sweets, but it is not possible to increase the dosage and in any case, they eat sugar. This can cause serious problems. (Romanian cultural mediator, association Camminare Insieme).

Taking a medicine can be seen as a micro-political act. The body becomes the instrument for affirming one's otherness, since being recognized as ill means being recognized as subjects. The freedom to use medicines (to take them when and where one wants, to mix them, to use them for purposes other than that prescribed) continues to be an affirmation of one's subjectivity. Not the fruit of ignorance, nor a cultural limit. This is what one mother told us.

When I arrived in Torino in November 2012, I lived in a hut in Lungo Stura Lazio. My daughter, when she was little, had convulsions. It was winter and... she got the very big ears, (the woman is referring to the colloquial Italian term for mumps '*orecchioni*' or big ears, NdT) I couldn't take her to the hospital because there was too much snow... Then the doctor at the hospital finally gave her some medicines, but I didn't always give them to her, then I went to Greece and I let it go. The doctors told me there was a problem of mental deficiency, God help me! Then, a few years ago, when she was fifteen, she began to lose her hearing. So we went to the hospital and the doctor gave her a hearing aid, but not because I didn't give her the medicines! (Tatiana, 41 years old, Romanian Roma).

The choices that respond to a subjective evaluation and not to biomedical rationality can cause irritation or despair amongst the healthcare workers. For those who live in a situation of total marginality, as in the case of the Roma, exercising the full right to health should be pursued beyond a framework of emergency and extreme necessity. For some subjects, although it may seem paradoxical, a dramatic event such as a seriously invalidating accident becomes the only opportunity for passing from total invisibility to acceptance within the majority society. This was, for example, what happened to the Roma citizen Banu.

One risk always lying in wait in these situations is that of passing from the plane of recognition of the right to assistance and to the treatment of forms of dependence amongst patients and healthcare workers,

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<sup>142</sup> P. Trevisan, *La «salute» dei rom: una questione piuttosto ingarbugliata. Riflessioni an-tropologiche sulla letteratura medica riguardante gli zingari*, in «La Ricerca Folklorica», n. 50, 2004, pages 53-63.

forms that are reproduced in a perverse manner. On the one hand these relationships lock the persons into the roles of needy patients and saviours, on the other they risk confirming the stereotypes and prejudices of public opinion that unjustly labels the Roma as social parasites.

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**Box 1.** *The Roma question in Italy: the standpoint of the institutions for the protection of human rights,* Anthony Olmo

The condition of the Roma population in Europe is one of the most hotly debated questions in the international field of human rights. The specific situation in Italy is particularly worrying, in fact, our country has been severely criticised by the European and international institutions for the protection and promotion of human rights.

This paragraph will present the principal problems identified by these international organizations. This panorama is opportune since it allows us first to integrate with further material the characterization and the analysis of the conditions of the Roma community in general in Italy and in the area of interest for our study. Moreover, the information that emerged from the studies by these institutions appears particularly fitting for our analysis since the problems identified play a crucial role because they are decisive for the health of the community in question, which, in the face of living conditions of particular hardship and marginality, see their opportunities for the right to health effectively annihilated.

Before presenting in detail the problems identified, it is opportune to briefly identify the principal international organizations that have investigated the situation of the Roma population in Italy<sup>143</sup>. A predominant role is played by the Council of Europe, which, as is known, dedicates a significant portion of its work to the Roma question. Amongst the bodies of the European Council that have been closely involved in this question there is, above all, the European Commission against Racism and Intolerance (ECRI). As is known, part of its mandate foresees the periodic monitoring of the situation in each member state on racism and intolerance. In this framework, the four reports on Italy are of particular interest – they were drawn up respectively in 1998<sup>144</sup>, in 2002<sup>145</sup>, in 2006<sup>146</sup> and in 2012<sup>147</sup> - in which ample space was dedicated to the problems that distinguish the Roma population.

The question was also examined by the Commission for Human Rights of the Council of Europe. In particular, they emphasised the two visits carried out in 2008, by the former Commissioner Thomas Hammarberg and in 2012 by the present Commissioner Nils Muižnieks<sup>148</sup> during which serious problems emerged regarding the Roma communities in the national territory.

The condition of the Roma in our country has also been reported to the Committee of the European Social Charter, the body charged with supervising respect by the member states of the European Social Charter<sup>149</sup>. In particular, the case of the *Centre on Housing Rights and Evictions (COHRE)* against Italy<sup>150</sup>, the Committee denounced the behaviour of the Italian authorities during the phase of what was known as the 'nomad emergency'<sup>151</sup>. The case in question saw Italy severely condemned by the Committee, which found violations of the right to a home<sup>152</sup>, the right to protection against poverty and social marginalisation<sup>153</sup>, the right to social, legal and economic safeguards for the family<sup>154</sup>, the rights of migrant workers and their families to protection and assistance<sup>155</sup>. Moreover, every violation was accompanied by the parallel violation of the prohibition of discrimination, thus further aggravating the sanction imposed.

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<sup>143</sup> In this paragraph we will, nonetheless, also refer to contributions from other international and national bodies.

<sup>144</sup> European Commission Against Racism and Intolerance (ECRI) *Approccio paese per paese dell'Ecri. Rapporto sull'Italia*, CRI (1998) 48, June 15<sup>th</sup> 1998.

<sup>145</sup> *Ibidem.*, *Second report on Italy* CRI (2002) 4, April 23<sup>rd</sup> 2002.

<sup>146</sup> *Ibidem.*, *Third report on Italy* CRI (2006) 19, May 16<sup>th</sup> 2006.

<sup>147</sup> *Ibidem.*, *Fourth ECRI report on Italy*, (fourth cycle of monitoring), CRI (2012) 2, February 21<sup>st</sup> 2012.

<sup>148</sup> Council of Europe, *Report by Thomas Hammarberg, Commissioner for Human Rights of the Council of Europe, Following his visit to Italy 13-15 January 2009*, CommDH(2009)16, 16 aprile 2009. See also *Id.*, *Memorandum by Thom as Hammarberg Commissioner for Human Rights of the Council of Europe, Following his visit to Italy on 19-20 June 2008*, CommDH(2008)18, 28 July 2008. See also *Id.*, *Report by Nils Muižnieks Commissioner for Human Rights of the Council of Europe, Following his visit to Italy 3-6 July 2012*, CommDH(2012)26, 18 September 2012.

<sup>149</sup> Council of Europe, *European Social Charter* (revised), STCE, N. 163, Strasbourg, May 3<sup>rd</sup> 1996. Ratified in Italy with law N. 30, February 9<sup>th</sup> 1999, *Gazzetta Ufficiale* N. 44, February 23<sup>rd</sup> 1999, ordinary supplement N. 38.

<sup>150</sup> *Centre on Housing Rights and Evictions (Cohre) c. Italia*, appeal 58/2009, Decision, June 25<sup>th</sup> 2010.

<sup>151</sup> See *infra*.

<sup>152</sup> Council of Europe, *European Social Charter*, op. cit., Article 31, paragraphs 1, 2, 3.

<sup>153</sup> *Ibidem*, Article 30.

<sup>154</sup> *Ibidem*, Article 16.

<sup>155</sup> *Ibidem*, Article 19, paragraph 1, 4 letter c) 8.

As already announced, on the basis of the conclusions drawn by the above bodies, it is possible to identify the main problems that characterize the condition of the Roma in Italy. Below we will present some of the questions that emerged.

### *The nomad emergency and the clearance of the nomad camps*

Great attention has been paid by the international bodies to the problems linked to what are known as “security pacts” and the “nomad emergency”. As readers will recall, starting from around 2005, in order to respond to a presumed threat to public order and security posed by the Roma community<sup>156</sup>, the Italian authorities began to adopt measures for identifying persons belonging to this community and defining suitable sites for camps where they were authorised to stay. The first step in this sense was the signing of the so-called “pacts” between the national authorities and various local authorities, including the cities of Napoli, Roma, Milano, Firenze, Torino, Genova and Bologna. Basically, these pacts foresaw the delegation of powers to the Prefects in order to enact a plan designed to solve the nomad emergency. In May 2008, the government officially declared this emergency in the regions of Campania, Lombardia and Lazio<sup>157</sup>. One year later, in May 2009, the same emergency was extended to the regions Piemonte and Veneto.

The adoption of these measures and the declaration of emergency was in fact based on Law N. 225 dated February 24<sup>th</sup> 1992 – amended by D.Lgs N. 59 dated May 15<sup>th</sup> 2012<sup>158</sup> – on the institution of the national service for civil protection, and made it possible to declare a state of emergency in the case of natural calamity, catastrophe or other events that, due to their extent and intensity, could not be dealt with using ordinary means<sup>159</sup>. On the basis of the declaration of emergency, the prefects of the areas involved – nominated “Special Commissioners” – were given special powers in order to facilitate the adoption of initiatives regarding the Roma population. The breadth of the powers granted to them was considerable and, although on the one hand they could also be used to adopt initiatives in favour of this community, in many occasions they were used to introduce measures that had a discriminatory effect. Examples of such measures are the census of the Roma living in the camps, the gathering of fingerprints, the dismantling and enforced clearance of illegal settlements – often without foreseeing alternative residential solutions – the creation of new camps, often in distant, fenced areas, with surveillance and controlled access, which it was only possible to enter by present an identity document<sup>160</sup>.

The policies for the clearance of existing settlements and the creation of new camps in which to transfer many groups attracted considerable attention at international level. As already mentioned, Italy was condemned by the Committee for the Social Charter for the enforced clearances and the violation of the rights of the communities involved. Moreover, ECRI repeatedly criticised the policies adopted by Italy in this sense<sup>161</sup>, as did the Commissioner for Human Rights<sup>162</sup>. Furthermore, the High Commissioner for the National Minorities of the Organization for Security and Co-operation in Europe (OSCE)<sup>163</sup> which highlighted the fact that the Roma communities in camps that were often isolated and distant from the residential centres, only served to marginalize these communities even further, moving exactly in the opposite direction from greater integration<sup>164</sup>. In general, as the Extraordinary Commission of the Senate for the Safeguarding and Promotion of Human Rights also recognizes, the policy of nomad camps is something that has very few counterparts in other European countries. It is easy to understand, even only intuitively, how such measures

<sup>156</sup> In those years there were a series of serious episodes that involved persons of Roma origin.

<sup>157</sup> See D.P.C.M., May 21<sup>st</sup> 2008, *Gazzetta Ufficiale* N. 122, May 26<sup>th</sup> 2008. See also the Ordinances of the President of the Council of Ministers, numbers 3676, 3677 and 3678, May 30<sup>th</sup> 2008 which introduced urgent civil protection regulations designed to meet the state of emergency in relation to the settlement of nomadic communities in the regions of Lazio, Lombardia and Campania. See also the Guidelines dated July 17<sup>th</sup> 2008 for the enactment of the Ordinance of the President of the Council of Ministers numbers 3676, 3677 and 3678, May 30<sup>th</sup> 2008 concerning the settlement of nomadic communities in the regions of Lazio, Lombardia and Campania.

<sup>158</sup> Legislative decree N. 59, May 15<sup>th</sup> 2012, *Gazzetta Ufficiale* N. 113, May 16<sup>th</sup> 2012.

<sup>159</sup> Law N. 225, February 24<sup>th</sup> 1992, *Gazzetta Ufficiale* N. 64, March 17<sup>th</sup> 1992, ordinary supplement N. 54, Article 21, letter c): “For the purpose of activities of civil protection the events that are identified as [...] (c) natural calamity or linked to the actions of man, which due to their intensity or extent must, with immediate intervention, be dealt with using extraordinary means and powers to be used for a limited and previously defined period of time.”

<sup>160</sup> *Fourth ECRI report on Italy*, (fourth cycle of monitoring), CRI (2012) 2, February 21<sup>st</sup> 2012.

<sup>161</sup> *Ibidem*.

<sup>162</sup> See European Council, *Memorandum by Thomas Hammarberg, Commissioner for Human Rights*, op. cit.

<sup>163</sup> Organization for Security and Co-operation in Europe (OSCE) and the High Commissioner for National Minorities, *Assessment of the Human Rights Situation of Roma and Sinti in Italy, Report of a Fact Finding Mission to Milan, Naples and Rome on 20-26 July 2008*, Warsaw, The Hague, March 2009.

<sup>164</sup> The question was also analysed by other international organizations. See United Nations Committee for the Elimination of Racial Discrimination (CERD). *Consideration of Reports Submitted by States Parties under Article 9 of the Convention, Concluding Observations of the Committee on the Elimination of Racial Discrimination, Italy*, UN Doc. CERD/C/ITA/CO/15, May 16<sup>th</sup> 2008; See also Consultative Committee on the Framework Convention for the Protection of National Minorities, *Second Opinion on Italy*, ACFC/INF/OP/I(2002)007, adopted February 24<sup>th</sup> 2005.

constitute a reality “incompatible with any project for inclusion and integration where they reproduce [...] conditions of cruel marginalization”<sup>165</sup>.

It must be emphasised that in November 2011, the Council of State declared illegitimate the decree of the President of the Council of Ministers dated May 21<sup>st</sup> 2008 with which it declared the state of emergency and the subsequent ordinances<sup>166</sup>. The highest body of administrative justice judged that the decree had not sufficiently justified the existence of an emergency, having referred only to certain news events involving persons of Roma origin.

#### *The anti-gypsy lobby and the political and media debate*

A further problem regarding the condition of the Roma community in our country, widely reported by the international organizations for the safeguarding of human rights, is that of the anti-gypsy lobby and the debate, present in political environments and in the media with regard to the Roma.

The Commissioner for Human Rights, in his report on the visit to Italy in May 2011, said that he was quite concerned by the existence in the Italian political debate of racist and xenophobic statements with regard to the Roma and the Sinti. As an example, the Commissioner reported the use of the term “*Zingaropoli*” (gypsy metropolis) used in electoral material during the municipal elections in Milano in 2012<sup>167</sup>. The question was also discussed by ECRI<sup>168</sup> and CERD<sup>169</sup>. Both organizations harshly criticized the presence of and the increase in racist and xenophobic discourses between politicians at various levels, and the lack of reaction by the legal authorities in consideration of the extent of the problem.

The anti-gypsy lobby, as already mentioned, does not only concern the political environment, the media are also involved. The OCSE report of 2008 emphasised that the media often contribute to amplifying news episodes that involve persons of Roma origin, often with negative tones that have contributed to increasing the feeling of hostility in public opinion<sup>170</sup>.

#### *Violence towards Roma*

A further question widely debated in international quarters is the widespread violence towards the Roma community and the inadequate reaction of the Italian legal system<sup>171</sup>. The Commissioner for Human Rights strongly emphasized the need for the authorities to make more effort in monitoring “crimes of hatred” and ensuring that the racist connotation of these crimes was effectively punished<sup>172</sup>. This in many cases does not occur and the Commissioner emphasized that the legal authorities, on the contrary, seem to minimize the racist motivations of such crimes. The same impression was confirmed by CERD<sup>173</sup> and by ECRI<sup>174</sup>, who stated that the number of inquiries carried out was low, despite the high number of crimes against the Roma.

#### *Other problems*

Numerous other questions interest the Roma community in our country. First of all, we must emphasize that even now, a large number of persons belonging to the Roma community are still uncertain about their legal status. In fact, many result as stateless. It is estimated that the number of Roma in this condition is approximately 15,000<sup>175</sup>; the majority come from the territory of the ex-Yugoslavia, having fled from the conflicts that unsettled the area in the nineties. For this reason, many came to Italy as refugees, without documents and unable to prove their identity, an impossibility that in many cases continues today.

This condition, for these people, is almost Kafkaian. On the one hand, due to the lack of an identity document, they risk expulsion, although they cannot ever be deported to any country, because they are stateless<sup>176</sup>. At the same time, although they are *effectively* stateless, they are unlikely to be declared *legally* stateless, since they lack a certificate

<sup>165</sup> Italian Senate, Extraordinary Commission of the Senate for the Safeguarding and Promotion of Human Rights, *Final Report on the Inquiry into the Conditions of the Roma, Sinti and Nomads in Italy*, approved by the Commission on February 9<sup>th</sup> 2011, *Legislatura*, page 5.

<sup>166</sup> Italian Senate N. 6050, November 16h 2011. The Court of Cassation (joint civil units), sentence N. 9687/13 registered April 22<sup>nd</sup> 2013, rejected the appeal against this sentence and confirmed the illegitimate nature of the decree of the President of the Council of Ministers dated May 21<sup>st</sup> 2008.

<sup>167</sup> Council of Europe, Commissioner for Human Rights, *Report by Nils Muižnieks*, op. cit., page 3.

<sup>168</sup> *Fourth ECRI report on Italy*, (fourth cycle of monitoring), CRI (2012) 2, February 21<sup>st</sup> 2012.

<sup>169</sup> CERD, *Final conclusions of CERD on Italy*, op. cit., paragraph 22.

<sup>170</sup> OCSE and the High Commissioner for National Minorities, *Assessment of the Human Rights Situation of Roma and Sinti in Italy*, op. cit., page 25.

<sup>171</sup> Council of Europe, Commissioner for Human Rights, *Report by Nils Muižnieks*, op. cit., paragraphs 107-112.

<sup>172</sup> *Ibidem*, paragraph 114.

<sup>173</sup> CERD, *Final conclusions of CERD on Italy*, op. cit., paragraph 19.

<sup>174</sup> *Fourth ECRI report on Italy*, (fourth cycle of monitoring), CRI (2012) 2, February 21<sup>st</sup> 2012.

<sup>175</sup> *Ibidem*.

<sup>176</sup> *Ibidem*, page 33.

of residence or a visa, documents necessary to apply for recognition as a stateless person<sup>177</sup>. Clearly, the condition of irregularity makes it impossible for them to integrate into Italian society, since they cannot find regular work, access public services and so on.

ECRI emphasises the dramatic condition of children born to stateless persons. In order to register these children with the public records office – a right that is recognized – they must present an identity document, or a residence permit, which they do not possess<sup>178</sup>. The immediate consequence is that the majority of these children are not registered. At the same time, this situation will create further problems when they are eighteen years old, the moment in which they could theoretically claim Italian citizenship. Since, in the majority of cases, they cannot prove continuous residence in the country an application for citizenship must be refused<sup>179</sup>.

A further problem reported by the international bodies, regards the exclusion of the Roma from the list of historical-linguistic minorities safeguarded by Law 482/1999, which foresees the possibility of introducing legislation to protect and develop the language and culture of the minorities in question<sup>180</sup>. The Rom, and their language Romani, do not enjoy this protection<sup>181</sup>. Equally, on a symbolic level, the genocide of the Roma during the Second World War the *Porajmos*<sup>182</sup>, is not mentioned by the Law N. 211, July 20<sup>th</sup> 2000, which instituted the day of memory on January 27<sup>th</sup> every year<sup>183</sup>.

Finally, considerable space is dedicated in the international studies to the problem of the Roma population in accessing education and work. With regard to education, the data available shows a considerable delay. It has been estimated that the Roma children who do not attend compulsory schooling number about 20,000. At the same time, an inquiry by the Red Cross in the Roma camps showed that more than 40% of the Roma residents did not have any degree of education, about 8% had elementary education, 13% held a middle school diploma; little more than 1% held a secondary school diploma and less than 0.50% held a degree<sup>184</sup>. The causes are numerous, and many are certainly to be traced to the socio-economic difficulties, the widespread illiteracy, particularly amongst the women and the irregularity in which many children live, especially in the illegal nomad camps.

The situation of the Roma communities with regard to access to work appears equally complex. The Red Cross inquiry in the nomad camps in Rome showed that more than 70% of the residents did not have a job of any kind and that the most common jobs were collecting waste metals, housewife, and peddler. Clearly, the widespread irregularity makes it difficult for these people to find regular work<sup>185</sup>.

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## Chapter Three

### Mother and Child Welfare

#### 1. Sexual and reproductive health

Adopting an approach based on human rights implies considerable awareness of the conditions of the more vulnerable groups and the development of strategies that guarantee equitable conditions and promote

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<sup>177</sup> President of the Council of Ministers, Ufficio per la promozione della parità di tratta-mento e la rimozione delle discriminazioni fondate sulla razza o sull'origine etnica, *Strategia nazionale d'inclusione dei rom, dei sinti e dei caminanti. Attuazione Comunicazione Commissione europea* N. 173/2011, February 28th 2012, pages 16-20.

<sup>178</sup> *Fourth ECRI report on Italy*, (fourth cycle of monitoring), CRI (2012) op.cit., pages 73 and 88-90. See also Law N. 94, July 15<sup>th</sup> 2009. *Disposizioni in materia di sicurezza pubblica*, *Gazzetta ufficiale* N. 170, July 24th 2009, ordinary supplement N. 128.

<sup>179</sup> *Ibidem*, paragraph 89.

<sup>180</sup> Law N. 482, December 15th 1999, *Gazzetta Ufficiale* N. 297, December 20<sup>th</sup> 1999.

<sup>181</sup> *Fourth ECRI report on Italy*, (fourth cycle of monitoring), op. cit. pages 32-33.

<sup>182</sup> It is estimated that the number of Roma killed during World War II ranges from 500,000 and 1,500,00. See Italian Senate, Extraordinary Commission, op. cit., page 36.

<sup>183</sup> Law N. 211, July 20<sup>th</sup> 2000, *Gazzetta Ufficiale* N.177, July 31<sup>st</sup> 2000.

<sup>184</sup> Italian Senate, Extraordinary Commission, op. cit., page 61 onwards.

<sup>185</sup> Italian Senate, Extraordinary Commission, op. cit., pages 73 onwards.

principles of parity and non-discrimination. Amongst the groups most notoriously exposed to violations of the right to health are, in fact, women and children.

A fundamental tool for clarifying the content of the right to health is, as we have seen, the General Comment 14<sup>186</sup>, which dedicates particular attention to women and minors. With regard to women, this document emphasises that they must enjoy the right to health without discrimination. It is therefore necessary to develop a national strategy that guarantees the realization of this right throughout life, eliminating the obstacles that hinder access to health services, to education, to information and to protect women from the dangers of traditional practices (paragraph 21). Particular emphasis is placed on safeguarding sexual-reproductive health, the reduction of the main health risks, of maternal mortality and the protection of women from domestic violence.

With regard to the minors, the need to reduce infant mortality and encourage the healthy development of children and adolescents is emphasised. Also, on the basis of the other international agreements – such as the International Convention on the Rights of the Child – the need to guarantee access to essential health services is stressed, including pre- and post-natal services for the mothers. The principle of non-discrimination also demands that all children be guaranteed adequate nutrition, healthy and safe environments and services for physical and mental health (paragraph 22).

At present, the situation relating to mother and child health generally appears good. In fact, the Italian situation is cited in the report *Women's and Children's Health: Evidence of Impact on Human Rights* as an example of the efficacy of health policies that, in explicit or implicit forms, are based on human rights<sup>187</sup>. The initiatives for the protection of maternity, a general improvement in the living standards of the citizens, the adequacy of the services for the needs of the territory, have allowed, through the setting up of family clinics, a national vaccination plan, prevention campaigns and NHS paediatricians, a considerable improvement in life expectation at birth. During the last century, the rate of infant mortality has also fallen considerably, and is now one of the lowest in the world, although as we will see later, there are significant differences between Italian children and foreign children<sup>188</sup>.

Despite this generally positive picture, there are still criticalities. Amongst these, we can list the north-south gap, the worrying conditions of Roma and Sinti minorities<sup>189</sup> and the need to guarantee adequate assistance to foreign women and minors. This chapter will concentrate on the last point, with particular reference to mother and child health in Torino. Our aim is to reconstruct the experience of migrant women in their path from birth, the postpartum period and the first years of their children's lives. Before dealing with this topic, however, it is necessary to emphasise the profoundly heterogeneous nature of the category

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<sup>186</sup> United Nations Committee on Economic, Social and Cultural Rights, *General Comment 14. The Right to the Highest Attainable Standard of Health*, UN Doc. E/C.12/2000/4, August 11<sup>th</sup> 2000.

<sup>187</sup> S. Longhi *et al.*, *Women's and Children's Health in Italy*, in *Women's and Children's Health: Evidence of Impact of Human Rights*, ed. F. Bustreo, P. Hunt *et al.*, Geneva, World Health Organization, 2013.

<sup>188</sup> According to the ISTAT report, *La mortalità dei bambini ieri e oggi in Italia*, published on January 15<sup>th</sup> 2014 and relating to data from 1887-2011, in 2011 the infant mortality rate amongst children resident in Italy was 2.9 per 1,000 born alive. This figure is lower than that registered for foreign children resident in Italy, which was 4.3 per 1,000. This rate is lower than the European and the American rates.

<sup>189</sup> United Nations Committee for the Elimination of Racial Discrimination (CERD) *Concluding Observations on Italy*, UN Doc. CERD/C/ITA/CO/15, May 16<sup>th</sup> 2008.

“migrant women”. This expression, in fact, gathers women with different stories and different socio-economic situations, who emigrated from their countries of origin for various reasons, bringing with them different beliefs, cultures and visions of the world and many different representations of maternity. In these circumstances, every generalisation risks being nothing more than a stereotype and caution is necessary.

The words of the foreign women and their daily experiences, gathered through narrative interviews and periods of participant observation, speak of a difficult situation that presents numerous challenges in the field of human rights.

Discrimination of gender, economic dependency, asymmetries in working life, domestic violence and the lack of recognition for the strain of caring for children are problems that still affect women whatever their nationality. In the case of migrant women, these problems are aggravated by the economic and social conditions, frequently underprivileged, the lack of information on social and welfare services and a lack of availability of the family networks and social buffers in case of need. Therefore, we can speak of a “twofold vulnerability”, which is particularly acute in the early phases of the migratory path, in the illiterate women, in situations of extreme poverty and in other cases of social marginalization and suffering.

Awareness of sexual and reproductive health is one of the most important aspects of the right to health of foreign women and minors. This health-welfare area is a priority need and is the first cause of hospitalisation for the female migrant population. In 2010, in Piemonte, the percentage of obstetric hospitalisations against the total number of hospitalisations for women in their childbearing years (from 15 to 49 years old) amongst resident women from countries with a strong migratory pressure was 64.38%, while for Italian women or those coming from advanced countries it was 39.38%<sup>190</sup>.

The first definition of “sexual and reproductive health” in the field of human rights was adopted at the international conference on population and development of 1994, and included questions that went beyond the strictly clinical field, such as prevention, information, free choice and sexual education.

Reproductive health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity, in all matters relating to the reproductive system and to its functions and processes. Reproductive health therefore implies that people are able to have a satisfying and safe sex life and that they have the capability to reproduce and the freedom to decide if, when and how often to do so. Implicit in this last condition are the right of men and women to be informed and to have access to safe, effective, affordable and acceptable methods of family planning of their choice, as well as other methods of their choice for regulation of fertility which are not against the law, and the right of access to appropriate health-care services that will enable women to go safely through pregnancy and childbirth and provide couples with the best chance of having a healthy infant<sup>191</sup>.

Bearing in mind these criteria, the Italian Ministry of Health established the following five areas for priority intervention for the population in general<sup>192</sup>:

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<sup>190</sup> Epidemiology service, Regione Piemonte, indicator 13: number and proportion of obstetric hospitalisations of resident women in their childbearing years (15-49) for the resident population in the year 2010. Source: hospital records (Sdo).

<sup>191</sup> Report of the International Conference on Population and Development, Cairo 5-13 September 1994. *Program of Action*, paragraph 7.2. <http://www.un.org/popin/icpd/conference/offeng/poa.html>

<sup>192</sup> Italian Ministry of Health: <http://www.salute.gov.it/portale/temi/p25.jsp?lingua=italiano&area=Salute%20donna&menu=sessuale>

- a) The protection of the woman throughout the process of birth, from the pre-conception phase to the postpartum, and the protection of the new-born child<sup>193</sup>;
- b) The education of young people regarding the topics of sexuality and reproduction<sup>194</sup>;
- c) The reduction of pregnancies in adolescents and contraception<sup>195</sup>;
- d) The prevention of sexually transmitted diseases, in particular HIV<sup>196</sup>;
- e) The prevention of carcinoma of the uterine cervix and breast cancer<sup>197</sup>.

In the case of foreign women, to these priorities, we must add the need to work on the prevention of abortions. In fact, amongst these women we find a high level of recourse to abortion, equal to 34% of the national total: this percentage initially increased, later stabilized and in the last two years the absolute number has decreased<sup>198</sup>.

Table 1 shows the principal causes of obstetric hospitalisation amongst women from countries with advanced development, including Italy; amongst resident women from countries with high levels of migration and amongst the non-resident women coming from the latter.

While for the first two groups, the prime cause of hospitalisation is childbirth; in the case of non-residents, abortion is the prime reason. The greater recourse to abortion is therefore one of the main problems in the field of sexual and reproductive health for migrant women, above all the non-residents, at national level<sup>199</sup>.

The epidemiological data suggest different models of recourse to abortion amongst foreign women, with respect to Italian women. While for the migrant women abortion is more common amongst married women who have reached the desired number of children, amongst Italian women, in recent years, there has been a reduction in recourse to abortion amongst married women and nowadays it is more common when the woman does not yet have children and has not yet constructed a personal and family life project<sup>200</sup>.

Table 1. Number and proportion of obstetric hospitalisations in childbearing years (15-49 years old) according to cause, by citizenship.

	Advanced countries resident		Countries high migration resident		Countries high migration non-resident	
	N.	%	N.	%	N.	%
Childbirth	28,535	64.90	8,021	56.44	540	31.65
Abortion	6,168	14.03	3,258	22.93	793	46.48
As	4,306	9.79	1,131	7.96	185	10.84
Other	4,956	11.27	1,801	12.67	188	11.02
Total	43,965	100.00	14,211	100.00	1,706	100.00

Commento [KMCI]: A cosa si riferisce?

<sup>193</sup> Italian Ministry of Health *Piano sanitaria nazionale* (national health plan) 2011-2013, pages 84-86.

<sup>194</sup> Italian Ministry of Health *Piano sanitaria nazionale* 2006-2008.

<sup>195</sup> Italian Ministry of Health *Piano sanitaria nazionale* 1998-2000, Progetto obiettivo materno-infantile, adopted with D. M. April 24th 2000.

<sup>196</sup> Italian Ministry of Health *Piano nazionale di prevenzione* 2010-2012, page 23.

<sup>197</sup> *Ididem*, chapter 4.

<sup>198</sup> Italian Ministry of Health Report, *Relazione sull'attuazione della legge contenente norme per la tutela sociale della maternità e per l'interruzione volontaria di gravidanza* (legge 194/1978), National Project, Agreement Ministry of Health-Agenas, October 2013, page 25.

<sup>199</sup> Regione Marche, *La salute della popolazione immigrata: il monitoraggio da parte dei Sistemi Sanitari Regionali*, National Project, Agreement Ministry of Health-Agenas, October 2013, page 25.

<sup>200</sup> E. Coffano, M. Del Savio and L. Mondo (ed.), *Report: Stranieri e salute*, Regione Piemonte, Assessorato alla tutela della salute e sanità, politiche sociali e politiche per la famiglia, 2012, page 2. Cfr. also Italian Ministry of Health Report, *Relazione sull'attuazione della legge contenente norme per la tutela sociale della maternità e per l'interruzione volontaria di gravidanza*, op. cit.

*Source:* The data presented was processed on the basis of the indications given by the following report: Italian Ministry of Health Agreement and Ccm. *La salute degli immigrati: metodologia di analisi, Progetto Promozione della salute della popolazione immigrata in Italia*, Regione Marche (Direzione generale prevenzione sanitaria, Ufficio I, N. DG/PREV/I 3488/P/F 3 ad, 2007), May 2009. The class of the countries with a strong migratory flow (Pfp) includes according to the *Rapporto Sviluppo Umano 2007-2008*: developing countries, countries with medium/low income (according to the classification of the World Bank, July 1<sup>st</sup> 2006, on the national gross pro capite income), countries of central and eastern Europe and of the Community of Independent States (CIS) or in the lists of developing countries. The countries classified as Psa are: Andorra, Australia, Austria, Belgium, Canada, Denmark, Finland, France, Germany, Greece, Ireland, Iceland, Israel, Italy, Japan, Liechtenstein, Luxembourg, Monaco, Norway, New Zealand, Netherlands, Portugal, San Marino, South Korea, Spain, Sweden, Switzerland, United States, and Vatican City.

The cases of two women, both mothers with two children, who made opposite choices, may be useful to illustrate the decision-making process faced by migrant women when they discover an unplanned pregnancy:

I am waiting for an abortion. This time it is the only choice. I already have two children, I haven't managed to get my documents in order, so I can't have another baby. How could I? There is no work, I can't... it is already difficult as it is... two children are all right, but I can't have another at the moment. I am not happy, but I can't see any other solution. (Nancy, 34 years old, Nigeria).

It takes courage to have children in a country that is not yours. We wanted the first two, but with the third, we asked ourselves, "What shall we do?" I was confused and I tried to do something stupid, then in the end I said, "No, stop!" When I found I was pregnant for the third time I was frightened and I thought about an abortion. My husband saw me crying every evening, but I didn't talk to him about it, I considered not telling anyone. Then he found out and he went personally to find out about an abortion, but they told him that they couldn't give him much information and that they had to speak to me directly, to know whether I wanted to do it. Then, on the way home, he saw a young couple like us with two children and he was shocked. He came home and he said, "Where two can grow up, so can a third." (Adriana, 36 years old, Romania).

As can be seen from the interviews, and as a now consolidated literature on the topic shows<sup>201</sup>, recourse to abortion is not a cultural decision, but an extreme solution, motivated above all by economic pressures and the impossibility of facing the birth of another child. Abortion is also linked to social factors such as a low level of education, the lack of adequate knowledge regarding contraception and the absence of female empowerment.

In 2009, the Regione Piemonte took part in the project *Prevenzione dell'Ivg nelle donne straniere: per una maternità responsabile e la prevenzione dell'aborto, la tutela della maternità e la prevenzione dell'abbandono del neonato* (prevention of abortion in foreign women: towards responsible maternity and prevention of abortion, safeguards for maternity and prevention of abandonment of new-born children) promoted and financed by the Italian Ministry of Health and the national centre for the control of disease (CCM) and coordinated by the Regione Toscana, in cooperation with the Istituto Superiore di Sanità (National Institute of Health) and the "La Sapienza" University in Rome.

This initiative, which ended in December 2012, aimed to prevent unplanned pregnancies through training and experimental ways of improving access to and availability of services and information on reproductive sexuality. Within this project, numerous local initiatives were undertaken and two multilingual leaflets were printed. The first, *Conoscere per scegliere: quando avere un figlio*, responds to the need to offer migrant women more information on contraception and the physiology of reproduction. The second, *Salute: un diritto per tutti, L'assistenza sanitaria in Italia*, is available in eight languages and summarises the

**Commento [KMC2]:** Presumo che questo pieghevole avrà una versione inglese, inserire il titolo ufficiale in inglese.

**Commento [KMC3]:** Come sopra.

<sup>201</sup> Cfr. A. Spinelli et al. (ed.), *Istituto Superiore di Sanità. L'interruzione volontaria di gravidanza tra le donne straniere in Italia*, Rapporti Istituzionali 06/17, 2006.

regulations that govern access to the health services for foreign citizens according to their country of origin and legal status. Both leaflets are currently available to users of the clinics in Torino.

Evaluation of the results of the project is still underway, but the initial outcome seems to be positive. Moreover, the decrease in the number of abortions amongst migrant women observed recently is a positive signal, that shows the importance of this and other national initiatives and the work on health education carried out by the clinics and the territorial networks at local level<sup>202</sup>.

## 2. *Pregnancy and immigration*

One consequence of the economic crisis that has marked Europe is a reduction in the funds available for welfare, an increase in unemployment and poverty and economic hardship for some middle class families. These phenomena have not been without consequences on the demographic plane. ISTAT<sup>203</sup> has in fact shown a new phase of considerable reduction in the birth rate. Although the foreigners have a higher birth rate than the national average, for the first time the fall in births has also involved children with at least one foreign parent, or with two foreign parents. Of the 514,308 births in Italy in 2013, 104,000 equal to 20.2% of the total, have at least one foreign parent (26.4% in Piemonte) and 77,705, 15% of the total (19.7% in Piemonte) have two foreign parents.

The average number of children per woman, considering the entire population, is 1.39, a lower figure than in previous years, which shows one of the lowest levels of fecundity in Europe. There are, however, significant differences between Italian women and foreign women: while the former have, on average, 1.29 children, the latter have, on average, 2.10. The highest rate of fecundity amongst migrant women is also due to their younger age at the time of the first pregnancy. In fact, the average age of Italian women at the birth of the first child is 32.1 years, compared with the 28.5 years of foreign citizens.

Considering the composition by citizenship of the foreign mothers, in first place for the number of children we again find Romanian women (19,492 births in 2013), in second place Moroccan women (12,778) in third place Albanian women (9,966) and in fourth place the Chinese (4,969). These four communities include almost 45% of the births to foreign mothers in Italy.

In Torino, in 2013, 63.5% of the mothers of newborn children were Italian, while 36.5% were foreign. Table 2 shows the ten most-represented nationalities and the total number of live births to foreign parents in this city.

The foreign women, overall, have more children and are on average younger than the Italian women. In this general framework, it is worth considering the meaning of the decision to face a pregnancy in the host country and the implications of this choice within the migratory project. The sense of maternity is subjective and is only partly moulded by the culture. Pregnancy, in particular the first, implicates a profound transformation in the woman, in her body, her psyche, her social and family role, her identity itself. In the

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<sup>202</sup> Italian Ministry of Health Report, *Relazione sull'attuazione della legge contenente norme per la tutela sociale della maternità e per l'interruzione volontaria di gravidanza*, op. cit., page 28.

<sup>203</sup> ISTAT Report, *Natalità e fecondità della popolazione residente: caratteristiche e tendenze recenti*, published on November 27<sup>th</sup> 2013, data relating to 2012.

case of a foreign woman, the birth of children leads her to reconsider the life project and is, in many ways, a vector of rooting, which opens the prospect of permanency in the host country and averts the project (or the desire) to return to the homeland.

Table 2. *Children born to foreign parents by nationality of the mother*

Nationality	Number of births	%
Romania	779	34,47
Morocco	485	21,46
People's Republic of China	135	5,97
Nigeria	134	5,93
Egypt	117	5,18
Peru	114	5,04
Albania	94	4,16
Moldova	90	3,98
Philippines	47	2,08
Other	265	11,73
Total	2.260	100,00

Source: *Processing of the data from the Annuario Statistico della Città di Torino*, 2013, chapter 3, pages 124-128, <http://www.comune.torino.it/statistica/osservatorio/annuario/2013>.

The words of Sadia, who speaks of the history of her family, while she is in hospital for the severely premature birth of her third child, reflect this attitude.

My first child is called Adam. The second is called Amin, which means, “so be it”. The third is called Salah-al-din (righteousness of faith), because he needs the help of a prayer, may God help him, he was born at five months, so God help him! At first, my husband only looked at the letters, the sound, that it was a good name. Later, people said “How nice!” But for me, what mattered is that, at school, the children should not feel different, because, you know, if you have a difficult name, perhaps the other children can't say it and they feel bad. The first two are easy names, but for him, even if he has a longer name, we wanted to call him that. In these years, many things have changed. Everyone would like to return to their own country, but when you have children here, you don't think about going back: you have built a life here. I feel that my life is here. I arrived thirteen years ago, this is our home, and my husband has a job here. Back home we have nothing. Of course, all my family is in Morocco and I miss them a lot, above all my mother, I wish she was here, especially now that the baby has so much need of God's help. (Sadia, 36 years old, Morocco).

The choice of the children's names is important: parenthood makes it necessary to mediate between the host country and the country of origin, which in this case is shown in an attempt to balance the desire to give a traditional name and that of not weighing down the children with “being different”. This balance is only broken in the case of the last child, where the religious content of the name and the wish that it may be a good auspice in a moment of worry and uncertainty prevail.

The woman who faces pregnancy in a place that is “other” must deal with a break in the continuity of the cultural references and re-elaborate the understanding of maternity that she has acquired so far. In such cases, there is an active search for strategies to combine the techniques of the body<sup>204</sup> and the methods of assistance during birth learned in the country of origin with the methods foreseen in Italy. This process is not reduced to a linear opposition

<sup>204</sup> M. Mauss, *Les techniques du corps*, in «Journal de Psychologie», vol. 32, n. 2, 1936, Italian translation *Le tecniche del corpo*, in *Teoria generale della magia e altri saggi*, Torino, Einaudi, 1965, pages 386-409. English translation at <http://quod.lib.umich.edu/d/did/browse.html>

between tradition and modernity; it is rather a comparison, often critical and aware, between the different systems of childbirth<sup>205</sup>.

I am not very expert – this is my first child – and I wish I could have had someone to follow me more personally during the pregnancy. I would also have liked to do a pre-birth course, but it was impossible to book one: there is a very long waiting list and there was the question of the summer, because my son was born on August 30<sup>th</sup>. Anyway, I have an aunt who is a midwife, who lives in Colombia. She helped me a lot. We were in contact through Skype throughout the labour: she told me how to move, she showed me how to breathe and she helped me to understand when it was time to go to hospital. (Ruth, 35 years old, Colombia).

However, it is not always possible to combine the two realities. The distance from family can cause a sense of disorientation and the weight of solitude is considerable. In addition to seeking healthcare from the consultancies and clinics, it is not rare for the women to feel the need to find a space where they can share experiences and find someone to listen.

Sometimes, the women come here because they want to be looked after during the pregnancy, or because they would like to go to the gynaecologist, because they want to get pregnant, but often a gynaecological visit is not sufficient... I will explain... the gynaecologist examines them, prescribes medicines if necessary, but the women often feel the lack of a place to let off steam. Many women, from different countries, come here, sometimes they are alone, they have no family, they don't have many friends... this is also a place where they see a person that represents their culture. Sometimes, however, we find ourselves in a situation where there are a lot of patients to see and the time available is not sufficient. Sometimes I feel guilty because I can't listen to them all. (Moroccan cultural mediator, Associazione Camminare Insieme).

### 3. *The childbirth process*

According to the Istitisan (National Institute of Health) estimates, in 70% of the cases the pregnant foreign women are assisted by a public service, while 75% of Italian women turn to a private gynaecologist<sup>206</sup>. Our observations confirm this tendency; in fact, the family clinics are the reference point for the majority of the women we interviewed.

I came here to work, like all young people, to improve my life and maybe to change something, and that is what happened. I worked and later I found a boyfriend. He is Moroccan, too. We got engaged, we married and we had this child. When I found out that I was pregnant, I turned to my sister, because they are women's questions and I was still uncertain. So, when I began to talk to my sister about how I felt, she said to me "There is something the matter, perhaps you are pregnant." So, then about two weeks passed, I don't remember. Then I did a urine test and I found out that I was pregnant. But my sister did not know what to do, it's a long time since she had children and her children were not born in Italy, so I asked my sister-in-law, who was about five or six months pregnant at the time, and had some experience. She explained to me that she went to the nearest family clinic and they gave me the pregnancy diary with everything I needed to get started. (Halima, 35 years old, Morocco).

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<sup>205</sup> The concept of "birth systems" proposed by the anthropologist Brigitte Jordan who carried out in-depth transcultural research in this field, refers for example to an integral set of practices and representations regarding the management of childbirth. Cfr. B. Jordan, *Birth in Four Cultures: A Crosscultural Investigation of Childbirth in Yucatan, Holland, Sweden, and the United States*, Montreal, Eden Press Women's Publications, 1980, Italian translation *La nascita in quattro culture. Atteggiamenti e pratiche ostetriche a confronto*, Milano, Emme Edizioni, 1983.

<sup>206</sup> L. Lauria and S. Andreozzi (ed.), *Percorso nascita e immigrazione in Italia: le indagini del 2009*, Roma, Istituto superiore di sanità, Rapporti Istitisan 11/12, 2011

The family clinics (*consultori*) were founded under Law N. 45, July 29<sup>th</sup> 1975, and are structures that offer integrated health and welfare outpatient services, in order to promote the health of women and children in paediatric age.

The family clinic is a basic structure that responds to the needs of the territory and can count on professionals and operators with multidisciplinary skills (doctors, nurses, midwives, social workers, psychologists and cultural mediators). They guarantee services of contraception, plan pre-conception visits and assistance during pregnancy and they offer numerous initiatives in the field of prevention, counselling and health education. In Piemonte, the family clinics distribute the 'pregnancy diary', which includes prescriptions for basic tests and useful information. The experience of the majority of our interviewees was positive.

When I found out that I was pregnant, I went to the family clinic: I went to all the appointments and had all the tests done. Everything was normal, regular. I had blood tests, ultrasound scans, everything. The help from the clinic was good. Since I have been here in Italy I have felt respected by the health services, very much assisted, very much helped. Maybe there were some difficulties, but nothing serious. In the end, we see a lot of things on the TV news, perhaps they are true, but we must say that the entire system is not rotten, that is not true. (Astrid, 32 years old, Dominican Republic).

I went to the family clinic during my first pregnancy and I came back this time. In both cases, I was treated well. I have been to two different clinics, first the one in Lungo Dora Savona, then I moved house and I went to the one in Via Pacchiotti, where they still assist me. I found helpful people there. The gynaecologist has a very direct manner, perhaps it may seem a little brusque, but she is very competent and I like her very much. She also helped me to book the ultrasound scans and the test... the integrated test; I think it is (prenatal screening, NdT.). (Anita, 27 years old, Peru).

The few negative experiences can be traced to the overload of work at some structures, which makes it difficult to book appointments and considerably limits the time dedicated to each patient.

When I realized I was pregnant, I was in my home country and when I came back to Italy, I was a bit late for some appointments. It was a mess. I immediately called the family clinic, but they told me that they couldn't assist me anymore because the pregnancy was too far gone and I had to contact the hospital. So I called the hospital and I insisted, but there was nothing to be done, they told me it was the duty of the family clinic and that I must go there. At that point, I tried to contact the family clinic again, I got angry, I pleaded and, in the end, they gave me an appointment. The beginning was not very good, but once we were underway, I had no more problems. (Natalie, 36 years old, Colombia).

The women who are most integrated in Italian society, who know the language well, who have better economic conditions and greater familiarity with the procedures and the mechanisms of the health services, are less prepared to put up with deficiencies in the public system and seek private alternatives, which often represent a considerable expense.

I went to that place, what is it called? The family clinic. There were lots of foreign women. There were always very long queues. I noticed that the gynaecologists there are always tired, sometimes they treat you... I don't know... I didn't have a good impression. There was a female doctor, the first time, who seemed already tired, annoyed. They treated me as if I had only just arrived in Italy, they hardly spoke to me, I received almost no information on my clinical condition. I have a very narrow pelvis, very small, it is a problem that I had with my first daughter, at twenty-two years old, and I knew that it would be a problem this time with the second, at thirty-five years old. I tried to explain the situation, but they didn't listen to me. They were always in a hurry and they only spoke to me to give instructions: "do this", "do that". Then I had complications, discharges, and I was taken into hospital because I had a

fibroma. After the hospitalization, I preferred to go to the gynaecologist at the Sant'Anna Hospital, privately. I felt more protected and, even though it was very expensive for me, I think it is worth it when it is for your health. (Maria, 35 years old, Peru).

The generally positive perception of the activity of the family clinics is an important aspect that contrasts with the results of the first phase of the research. In this first phase, in fact, the vision of the family clinics as health services of inferior quality, destined to serve mainly the foreign population, emerged repeatedly<sup>207</sup>. The data that emerged from the interviews is therefore to be considered positive, since the family clinics are seen as valid tools for guaranteeing the sexual and reproductive health of the migrant women.

From the normative standpoint, the right to health during pregnancy is widely safeguarded and is extended to all women, Italian and foreign, whatever their legal status. The free assistance includes regular examinations, ultrasound scans, blood and urine tests, pre-birth courses, assistance during labour and the birth, support with breastfeeding and the first care for the newborn child, and the specialist treatment for the mother<sup>208</sup>. The woman also has the right to a residence permit for medical treatment during the pregnancy and during the six months following the birth of the child.

The national picture shows a substantial equivalence in the indicators of assistance during the birth, but reveals significant disparities between Italian women and foreign women in assistance during pregnancy and postpartum<sup>209</sup>. The criticalities are manifest above all amongst women with illegal status, who live in marginal situations, come from rural contexts and have a low level of education, with little or no understanding of Italian. The category “foreign women” is, as we have reported, very heterogeneous and includes a variety of living conditions and migratory stories: when they come from an urban context, have a high level of education and of health literacy, they tend to be more aware of their rights and begin the assistential process sooner.

Table 3 examines some of the indicators found by the Epidemiology Service of the Regione Piemonte, which make it possible to evaluate the quality of assistance during pregnancy, in particular: *a*) the age of the foetus at the first visit; *b*) the number of ultrasound scans; *c*) the invasive prenatal tests and *d*) the number of caesareans carried out.

The data shows a considerable difference in the number of women who are more than twelve weeks pregnant at the first visit: while amongst the women from advanced countries (including Italy), it is only 2.93%, amongst the resident women from countries with strong migratory pressure it is 10.82% and 18% amongst the non-resident women. Of the latter two categories, 38.7% have less than three ultrasound scans during the pregnancy and invasive prenatal tests are rare, only 1.33% of the women undertake them.

Table 3. Assistance during pregnancy by citizenship, Regione Piemonte

Indicators	Citizenship
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<sup>207</sup> I. Biglino and A. Olmo, *Health as a fundamental right: a study on migration and healthcare in Turin*, op. cit., page 97.

<sup>208</sup> Article 1, paragraph 5, letter *a*) D. Lgs. N. 124, April 29th 1998, *Gazzetta Ufficiale* N. 99, April 30<sup>th</sup> 1998, excludes the sharing of the cost of treatment aimed at the protection of maternity.

<sup>209</sup> L. Lauria et al., *Indagini sul percorso nascita delle donne straniere*, in *Percorso nascita e immigrazione in Italia*, op. cit., pages 65-115

	Advanced countries	High migration resident	High migration non-resident
Number of births	27,430	8,804	300
Average age (standard deviation)	32.5 (5)	28.8 (5.5)	27.2 (5.7)
Age of foetus at first visit > 12 weeks (%)	2.93	10.82	18.00
Less than three ultrasound scans in pregnancy (%)	14.71	25.48	38.67
At least one invasive prenatal test (%)	15.55	4.65	1.33
Births by caesarean section (%)	31.29	26.77	25.33

The delay in the first visit and the lower number of checks during the pregnancy compromise the possibility of promptly carrying out prenatal diagnostic tests or screening and increase the risk of a late diagnosis of complications or congenital problems, thus preventing recourse to therapeutic abortion. The lower number of births by caesarean section amongst resident and non-resident foreign women is a positive factor, which indicates less medicalized pregnancies<sup>210</sup>. The number of caesarean sections is, in any case, higher than the recommendations of the WHO and the Italian Ministry of Health.

The lack of knowledge regarding access to the assistance available may represent a serious obstacle in safeguarding the health of foreign women during pregnancy. Access to adequate information in this particularly delicate phase of the woman's life, is an essential element for guaranteeing them full enjoyment of the right to health. Although steps forward have been taken with respect to the past, the problem must not be underestimated, because it could be the reason for the delay in seeking assistance.

My first pregnancy was very different from this one. Now, my daughter is six years old and everything has changed. When I found I was pregnant, that time, I was very pleased but also worried; instead, we tried for this baby. The first time I cried a lot. I had no documents, no work, not even a home. My husband was working, but he had no contract, we were staying with his friend, who arrived in 1992, I think, and he had been given a council flat. I came a bit later. I had never been ill and I didn't know about the family clinics. I knew I should go for tests, but I didn't know what to do. I was very upset. My husband had been here longer, but he didn't know what to do... of course, men don't know these things. I had some female Italian friends, but they asked me "who is your gynaecologist?" They all had a private gynaecologist, but I didn't even have the money for the rent... how could I go to a private gynaecologist?

Everyone took it for granted that I knew what to do. People assume you know. They didn't realise that I was still a kid. I often met other people from my country, we went to the church youth club, sometimes we went to the Pellerina Park on Sundays, but I didn't talk about the situation, because I didn't want people to know I was in difficulty. Anyway, at one point, I decided to ask a Peruvian friend for help and she said, "Are you crazy? Go to the family clinic... you don't even need to have documents and you don't pay for anything!" (Anita, 27 years old... Peru).

The decision to wait until the end of the first trimester before going to the doctor is, in some cases, a voluntary decision made by the woman. There are a number of reasons, including uncertainty about procedures; fear that the diagnostic tests may give results that present them with decisions that are difficult to take or incompatible with their religion; the idea that a pregnancy cannot be considered certain before the twelfth week, or the desire to put off communicating the news at work for fear of the consequences.

For the first three months, I kept quiet. I didn't tell anyone and I didn't even go to the doctor, because I didn't want it known... then, working at the bar, I couldn't carry on, because it was tiring to carry the water up and down, and I said "That's it. Now I will go to the doctor's and I will tell my employers that I am pregnant."

<sup>210</sup> The reduction in caesarean sections is one of the objectives of the national health plan 2011-2013, which states: "With respect to the threshold of 15%, which according to the WHO guarantees the maximum benefit for the mother and the foetus, Italy is the European country with the highest number of caesarean sections, with values of 38.3% in 2008, an absolutely inverse trend (we have moved from 11.2% in 1980 to 29.8% in 1996) and extreme variability by geographical area". The percentage of caesarean sections is higher at accredited private structures (61%) and the non-accredited (75%) compared with public structures (34%). Italian Ministry of Health, *Piano sanitaria nazionale 2011-2013*, op. cit., page 84.

They weren't very pleased, but I said, "This is my life, and it is my first child, I couldn't care less what you think." (Gina, 30 years old, Romania).

These situations indicate a pregnancy faced in a more fragile position and more subject to external pressures. In fact, procreation cannot be considered a merely biological process; it is a relational experience, moulded by social forces that converge in the female body.

In some cases, the reason for delay in seeking medical care can be a representation of the pregnancy as an event that must be safeguarded not only from a bio-medical standpoint, but also on the symbolic plane. Amongst the Senegalese women, for example, the secrecy can be part of a strategy for hiding their belly from other people's glances, which could be charged with envy and harm the foetus<sup>211</sup>.

Culture profoundly influences the way the pregnancy is experienced and affects the perception of the body and the relationship that forms between the woman and the healthcare system. In the case of migrant women, the cultural differences can lead to a different approach to medical care.

The lower number of checks is sometimes associated with the idea that pregnancy is a state that in itself indicates good health and there may be a more or less explicit disassociation from an excessively medicalized management of the nine months.

I find that here, pregnancy is experienced in an extremely stressful manner. There are too many checks and they make you anxious. With regard to weight, for example, they are very severe. The doctor scolded me every time and when I left the surgery, I felt totally inadequate, incompetent. Then they tell you to do this, do that, what you can and cannot eat. They practically limit you in everything. Some things are all right, you accept them for the good of your child and then, after all... this is a pregnancy that we wanted and tried for really hard, but there are other things that upset you because you don't know why, they don't explain the reason to you. And all those invasive tests made me very anxious... I don't know... I was frightened of the amniocentesis, so I decided to do the integrated test. You do it because you know it is important, but you spend ten days in hell waiting for a phone call, also because I knew from my friends that at our age, the result is often positive, and I said, "If it is positive, what do I do? Shall I do amniocentesis or not?" Every time I got a call from an unknown number... I was terrified... (Ileana, 37 years old, Romania).

This approach to pregnancy is not in itself negative, on the contrary, the demedicalization of pregnancy and birth is one of the explicit objectives of the *Progetto obiettivo materno-infantile* (Pomi)<sup>212</sup>. A medicalized approach to physiological pregnancy, in fact, does not represent greater safety for the woman and the child, but on the contrary implies a higher exposure to practices such as invasive tests and caesarean section, which involve a certain level of risk and should be limited to cases in which there is an effective need<sup>213</sup>.

The foreign women have different attitudes towards medicalization; some women come from urban contexts, where there is an equally medicalized approach to birth, others, although they come from more "traditional" environments, in which it is still common to give birth at home or in which the women are mainly assisted by midwives or other similar figures in the community, welcome this model, which they see

<sup>211</sup> . Quagliariello, *Dal Senegal migrare in Valdelsa. Modelli di nascita a confronto*, in *Stranieri in Italia. Figli, lavoro, vita quotidiana*, ed. A. Colombo, Bologna, Il Mulino, 2013, pp. 117-149

<sup>212</sup> The Progetto obiettivo materno-infantile (Pomi) [mother and child project] was adopted with the decree of the Italian Ministry of Health, April 24<sup>th</sup> 2000, *Gazzetta Ufficiale* N. 131, June 7<sup>th</sup> 2000, ordinary supplement N. 89, and it is a plan of action that gives normative and organizational references for the protection of mother-child health.

<sup>213</sup> L. Lauria et al. (a cura di), *Percorso nascita: promozione e valutazione della qualità di modelli operativi. Le indagini del 2008-2009 e del 2010-2011*, Roma, Istituto superiore di sanità, Rapporti Istituzionali 12/39, 2012.

as efficient and reassuring. In other cases, the medical procedures are accepted as a fact, although they are not fully shared. More rarely, there is an explicit critical attitude and the desire to give birth with traditional techniques is even more rare and elitist. With few exceptions, the rites, the traditional therapies of the countries of origin and the alternative forms of assistance during pregnancy find little space in the hospital environment and, if practised are limited to a more intimate sphere, within the family or the community.

In the face of a plurality of representations of pregnancy that underlie the assistential choices of the migrant women, it is necessary to find a balance that takes into account on the one hand the need to protect the health of the mother and the child; on the other to recognize the independence of the woman and respect her choices. This balance is still a distant goal and only in the presence of adequate information and a reciprocal openness to equal and bi-directional dialogue will it be possible.

#### 4. *Assistance during childbirth: a strength*

Assistance during the birth, with few exceptions, is seen positively by the women interviewed. The birth clinic for *Barriera di Milano* and the districts in which our research was carried out is the obstetrics and gynaecology ward at the *Maria Vittoria Hospital*, which assists a very high percentage of foreign women and in which, to quote one of the midwives interviewed, “cultural difference is not experienced as exceptional, interculturality has become the usual way of acting”. On the ward, the contact between Italian women and foreign women is constant: the rooms house three or four patients, often of various nationalities, and a relationship of support and cooperation is created between them during their stay, which sometimes continues after they leave. Amongst the many women interviewed, who expressed satisfaction for the care they received, the words of Sara are interesting.

I have lived in Italy for four years and my son, the youngest, was born here, in this hospital. They gave me help with everything, they were very kind. What can I say? Wait, I don't remember the word... yes... there... the midwife was modest, and the female doctor, yes, modest... although they were qualified people, they didn't rub it in... they treated me... I don't know how to say it... from person to person. (Sara, 29 years old, Morocco).

The choice of the word “modest” is not casual and it emphasises the operator's capacity for making their patients feel comfortable, without assuming a position of superiority. The assistance thus moves away from a paternalistic model and is open to a greater participation by the user.

Participative welfare means that it is the duty of the operator (in the multidisciplinary team) to interact with the person in a relationship based on respect, kindness, empathy, compassion and humility [...]. Humility is essential in order to question one's world vision and to avoid falling into the self-referential trap of blaming the victim, the true tomb of professionalism and, consequently, of the public health service<sup>214</sup>.

My wife never felt she was treated badly because she was a foreigner. She only said that she was sorry, because sometimes she didn't understand what they said. To ask for information about the pregnancy and breastfeeding, she had to make herself understood with gestures, or she had to wait for me. When there were

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<sup>214</sup> L. Lauria e S. Andreozzi (ed.), *Percorso nascita e immigrazione in Italia*, op. cit., page 6.

urgent matters, she called me and I translated over the phone. We had to do this with our first child, when she needed to know how to breastfeed.

*Have you ever had the information leaflets with the translation in Arabic?*

No, but they would be no use to her. She has problems because she never studied even down there. Now there is also Italian to deal with, she must learn it sooner or later. (Ahmed, 30 years old, Morocco).

The case of Ahmed's wife is not at all uncommon. The presence of the cultural mediators is guaranteed, on request, in situations where it is necessary to organize specialist examinations or supply information need for the signing of an informed consent form, in particular with regard to screening and prenatal diagnosis, for ultrasound scans in the first and second trimesters and any planning for a caesarean section. In many circumstances, however, the translation is carried out by a close relative who speaks Italian and not by the cultural mediator of the hospital. On the wards, then, it is not easy to have a cultural mediator always available and it is necessary to channel informal communication to transmit information on daily tasks, such as postpartum hygiene, the care of the child, the hours and the organization of visits, the organization of the day, diet and many other questions that are important, although perhaps not directly clinical.

In order to resolve, at least in part, the communicative difficulties, at times posters or informative leaflets in a number of languages are used. These are undoubtedly useful, but they cannot replace direct interaction and they are quite useless in the case of lack of education or illiteracy in the language of origin. The lack of education is, in fact, a problem that affects above all the illegally resident foreign women: in the Regione Piemonte the percentage of low-level education amongst the Italian women who gave birth in 2010 is 0.64%, while amongst the resident foreign women it is 6.74% and amongst non-resident women it reaches 10.33%<sup>215</sup>.

The communicative difficulties negatively affect the relational climate and worsen latent problems. While none of the women interviewed encountered problems of acceptability relating to obstetric and gynaecological assistance, some difficulties were evident in the daily interaction with other figures on the ward.

I see a lot of difference in the way they treat the foreign women... I often heard the auxiliaries comment, for example, "We work our asses off... we are paid peanuts and do shitty work... Why? For the migrants and the gypsies". It is true that there are a lot of us foreigners on the ward, but that is not a good reason to be offensive. Also at the registration desk of the A&E, I heard the same complaint. Perhaps they think that I am Italian because I have lived here for many years and I speak the language well. The woman at the reception, I don't know if she was a nurse, started the usual conversation. "The foreigners are the worst... They come here and they want to be taken care of immediately, they call 118 (the emergency service, NdT.) when they shouldn't, they take advantage... The Romanians and the gypsies, well... etc. etc." Then I say, I have lived in Italy for fifteen years, I work, I pay my taxes... And the taxes are not low... Why are you complaining? What does it matter if I am Italian or foreign? Anyway, if I weren't here, who would look after all the old people? What should I say? I am here to clean the backsides of the aged parents of the Italians! You can't look at it like this. The doctors and the midwives have a different attitude. They are much more respectful and they don't differentiate, but sometimes we only see one doctor in the entire day and hours go by before we see the midwives, at the shift change, for example... when your only reference is the auxiliaries, who are often really fed up and tell you so. Things have got much worse in the last two years. (Gina, 30 years old, Romania).

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<sup>215</sup> Information supplied by the Epidemiology Service of the Regione Piemonte. The table relating to indicator 17 is published in part: socio-demographic characteristic of the mothers and assistance during pregnancy by citizenship. Source: Cedap, 2010.

This interview clearly shows irritation with the healthcare workers that seems to contradict the positive evaluation of the assistance expressed by the women in the previous interviews and is a new element with respect to the findings of the first phase of the research. In order to adequately clarify this point, it is necessary to distinguish between the various levels of assistance and see the wards as complex units, in which various figures interact in offering assistance and care. In fact, the patient meets operators “with” and “without” a doctor’s coat, who have very different professional profiles, roles, skills, training, levels of education and responsibility.

The auxiliary nurses (*operatore socio-sanitario*, OSS) are figures who have basic training, centred on practical aspects of care of the person in their primary needs. In order to become an auxiliary nurse it is necessary to have completed compulsory schooling and attended a training course that leads to a regional qualification<sup>216</sup>. It is therefore a professional figure with a medium-low level of education and does not have any form of specific training with regard to intercultural communication.

On the ward, the OSS carry out simple tasks in support of the nursing services, they deal with a series of essential duties, such as assistance with personal hygiene, food and the cleaning and management of the rooms. They are also responsible for initially answering the patient’s call for assistance, administering therapies and they are often the mediator between the women on the ward and the medical staff. Therefore, their duties not only require close physical contact, they also involve creating a communicative relationship that must work sufficiently well to ensure that the ward runs smoothly.

Since the presence of the cultural mediator is not constant and is generally limited to specialist visits and meetings with the doctors, the communication between the OSS and the foreign women, even when they do not speak Italian, occurs without any intermediation and incomprehension, misunderstandings and mistakes are frequent. What is more, hygienic habits and diet call into play incorporated actions<sup>217</sup>, behavioural schemes learned and then naturalised, whose culturally based nature is generally not recognized. They are, in fact, sensitive areas, where diversity can be easily read in negative terms.

To this we must add the high rate of burnout, a pathology that involves all the professions with a high relational input, but which is particularly insidious in the categories that receive poor or inadequate wages, that carry out tasks with little creativity, repetitive and tiring, those that do not enjoy an adequate involvement in decision-making and that are often subject to work overloads.

The dissatisfaction that the women report does not therefore relate to the clinical aspects, but rather to the relationship with the OSS. It is essential to propose specific training, which takes into account the level of education and the specific competencies of this figure, with the aim of limiting burnout and the gradual development of a more open attitude towards diversity.

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<sup>216</sup> The ruling of the regional authorities N. 46-5662, March 25<sup>th</sup> 2002, enacts the agreement ratified by the *Conferenza Stato-Regioni* in relation to the job description of the *operatore socio-sanitario* and approved the guidelines for basic training leading to the qualification. An *operatore socio-sanitario* is “the operator who, following qualification after specific professional training, carries out activities designed to meet the primary needs of the person, in the area of their competencies, in both a social and a healthcare context; facilitating the well-being and the independence of the user”. In Great Britain the role corresponds to an ‘auxiliary nurse’, NdT.

<sup>217</sup> Cfr. T.J. Csordas, *Embodiment as a Paradigm for Anthropology*, in «Ethos», vol. 18, 1990, n. 1, pages 5-47; M. Lock e N. Scheper-Hughes, *The Mindful Body: A Prolegomenon to Future Work in Medical Anthropology*, in «Medical Anthropology Quarterly», 1, 1987, n. 1, pages 6-41.

One element that emerges clearly from the interviews and the direct observations on the ward is the frequency of negative stereotypes linked to the place of origin. Also in this case, it is amongst the OSS and the personnel responsible for the initial admission, that we find the most obvious criticalities.

The stereotypes are linked to processes of construction of the social and identity categories, which lead to labelling a particular segment of society as “different” from what is, in opposition, defined as “us”. Generically negative characteristics are ascribed to this “other” category, through a process of construction of hyper-simplified mental images<sup>218</sup>, based on prevalently unconscious mechanisms: in fact, if they are asked, the majority of people will not recognize the prejudices they hold, which they will rather tend to see as knowledge confirmed by the empirical experience<sup>219</sup>.

The stereotypes do not have a casual origin; they are linked to asymmetrical relationships of power and political dynamics that shape the relationship between the various social groups. They accentuate the internal cohesion, shift the attention towards hypothetical external threats and can legitimate policies of exclusion. The migrant is perceived not as an individual, but as a member of a given culture and, as such, the carrier of an intrinsic diversity. An ethnicization of otherness therefore occurs which, parallelly, leads to ignoring one’s own cultural particularity, as the anthropologist Fabio Dei wrote, “we have never been ‘ethnic’, and the great culture, the dominant one, never is. Ethnic means *others*, the most backward or the poorest, the minorities”<sup>220</sup>.

Also in this case it is essential to provide specific training, aimed at all the categories of operators, without neglecting the OSS and the personal who take in the patients, at triage or with administrative duties, in order to develop greater awareness of the cognitive functioning of stereotypes and prejudices, encouraging instead a more fluid intercultural communication. Finally, we cannot end a paragraph about assistance during birth without considering infantile mortality.

The rate of infantile mortality amongst resident Italian children is 2.9 per thousand live births, while that of the resident foreigners is 4.3 per thousand<sup>221</sup>. Table 4 shows the data regarding the neonatal births and deaths in Piemonte.

Table 4. *Number of births and characteristics of the newborn children by mother’s citizenship*

Indicators	Psa	Resident	Pfpm	Non-Resident Pfpm
Number of births	27,715	8,888		303
% born	75,10	24,08		0,82
Number of stillbirths	71	30		1
% underweight				
< 1,500g	0,91	1,15		0,99
< 2,500g	7,34	6,14		6,95
Rate of stillbirths (per 1,000)	2,56	3,38		3,30
% Apgar < 8 (at 5 min.)	3,69	4,44		2,65
% need for reanimation	3,79	4,58		3,97

Source: Information supplied by the Epidemiology Service of the Regione Piemonte, Indicator 24: the number of births and characteristics of the newborn children by mother’s citizenship (excluding stillbirths). Cedap, 2010.

<sup>218</sup> H. Tajfel, *Human Groups and Social Categories*, Cambridge, Cambridge University Press, 1981.

<sup>219</sup> For a summary of some important works on the topic, see: A. Alietti and D. Padovan (ed.), *Metamorfosi del razzismo. Antologia di testi su distanza sociale, pregiudizio e discriminazione*, Milano, Franco Angeli, 2005.

<sup>220</sup> . Dei, *Razzismi vecchi e nuovi*, article published online in the Blog *Fareantropologia*, 2009, available online at: [http://www.fareantropologia.it/sitoweb/index.php?option=com\\_content&view=article&id=130:razzismi-vecchi-e-nuovi&catid=48:testi&Itemid=61](http://www.fareantropologia.it/sitoweb/index.php?option=com_content&view=article&id=130:razzismi-vecchi-e-nuovi&catid=48:testi&Itemid=61)

<sup>221</sup> ISTAT, *La mortalità dei bambini ieri e oggi in Italia*, op. cit.

The national data shows a greater incidence of perinatal death and stillbirths amongst the foreign women, and although it is less marked, this difference can be seen also in the regional data. While at national level this tendency is present in particular amongst non-resident women, in Piemonte the phenomenon is present equally in resident and non-resident foreign women.

The mortality of the children under five years old is an important indicator of the overall well-being of a population and is closely linked to the environmental, health and social conditions. Consequently, the disparity in the rate of mortality between Italian and foreign children is a worrying signal, that cannot be ignored and that bears witness to the ongoing inequalities that affect the health of the migrants.

Of the deaths in the first year of life, amongst the resident foreigners, 27% occur at birth, 39% between one and twenty-nine days and 34% between the first and the eleventh month. Amongst the children of Italian citizens, the temporal distribution emerges significantly: 24% occur at birth, 49% between one and twenty-nine days and 27% between the first and the eleventh month. According to ISTAT, the gap is not due to different causes of death, but “can in part be explained by the lower rate of therapeutic abortion (that is more than 90 days after conception) amongst the foreign women (1.5% of all abortions) with respect to the Italians (4%).” Consequently, amongst the foreign women there is a higher number of births of deformed children, who can survive for one month, but not more. This data therefore allows us to identify two major causes that lie behind the differing rates of perinatal and infantile mortality: on the one hand, the delay in prenatal tests and on the other, the combination of social hardship and protection of health.

The case of Gabi<sup>222</sup> helps us to illustrate this phenomenon. Gabi is a Romanian Roma woman who lives in the Lungo Stura camp, she is thirty-four years old and she is pregnant for the fifth time. During one of the routine examinations (carried out relatively late, she was already in the third month of pregnancy) a foetal malformation was discovered. Thanks to the two social workers, the case was taken up by the Sant’Anna Hospital. A gynaecologist and a surgeon were contacted; it would be necessary to operate on the baby as soon as it was born; it would be a desperate attempt to save its life and there was no guarantee of success. The operators wrote out a certificate that the woman carried with her, so that in case there were complications, the doctors could operate immediately. However, two days before the birth, the woman lost all her documents. One night when she went into labour, a neighbour at the camp called for an ambulance. Following the indications of the 118 operator on the telephone, the woman managed to look after the mother and keep the child alive until the ambulance arrived. The ambulance finally arrived, but the child was already born, “it all happened in five minutes,” say the women at the camp. Because she had lost her documents, the woman was taken to the Maria Vittoria Hospital and not to Sant’Anna Hospital. The baby girl lived for just 45 minutes after the birth. In the following days, various tests were carried out, as is usual, to ascertain the cause of death, which created difficulties for the women at the camp and the mother. The case was clarified thanks to the intervention of the operators.

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<sup>222</sup> The case was gathered by Aurora Lo Bue, anthropologist and social worker, who cooperated as an intern with the research project.

This case highlights some of the specific assistential criticalities for the Roma population, which we covered in depth in the second chapter. Amongst these, in particular, we must emphasise the lack of suitable living spaces and the difficulties for the emergency services in reaching the camp in time in an emergency. The case also allows us to show the serious consequences of delay in the first visit and the importance of integration between the hospital and the territory which, in this as in other situations examined, seems to be insufficient. Finally, we must mention the fundamental role of the social workers, who did everything possible to guarantee prompt and optimal assistance during the birth.

##### 5. *The postpartum, a critical moment*

The postpartum is a delicate phase, to which many cultures pay particular attention. In the early days, support is fundamental to allow the woman to recover, so that mother and child can gradually get to know each other and form a bond.

Difficult economic and social conditions and the lack of a network of feminine support on which to count in the early months of the child's life are common problems for the immigrant women. However, some traditions are maintained and renewed in the country to which they migrate. Amongst the Chinese women the practice of *zuo yuezi*, also called 'quarantine' is usual. During this period, the woman must remain at home avoiding, as far as possible, any activity. She must follow a specific diet and not wash, to avoid dispersing the heat of the body and to allow the hot and cold components of the body to re-establish a balance.

In some areas of Morocco, it is the custom that during the first forty days after the birth, the woman will stay in bed as much as possible, while the mother and the other relatives do the daily tasks. In Italy, where it is not always possible to count on the presence of one's family, friends accompany and help the new mother in this period.

In the majority of the Latin American countries, the postpartum period is known as "diet", a period of forty or forty-five days during which the mother must rest, avoid leaving the house, pay attention to the wind and the humidity and follow a substantial diet based on broths and hot drinks.

These customs, at times not appreciated by the operators, because they interfere with the periodic checks planned for the first month, are in fact aimed to protect the mother and child in a moment of fragility, allowing the mother to concentrate on the needs of the new-born child and encouraging a good start to breastfeeding.

As the World Health Organization recommends, today mothers are encouraged to breastfeed and, in almost all hospitals practices such as rooming-in or early skin-to-skin contact between the mother and the newborn child are now the norm. According to ISTAT data the foreign women tend to breastfeed more than Italian women (89.4% against 84.6%) and to prolong the duration of breastfeeding (9.2 months on average, against 8.1 for the Italians)<sup>223</sup>.

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<sup>223</sup> ISTAT, *Gravidanza, parto e allattamento al seno*, published Tuesday December 9<sup>th</sup> 2014 with reference to the year 2013

In Piemonte, the mothers who clinically find it impossible to breastfeed, on the request of the paediatrician or the birth clinic, will be supplied with artificial milk free of charge. Breastfeeding is absolutely not advised for women who have HIV or AIDS, breast cancer, postpartum psychosis, bilateral herpes of the nipple in an acute phase, drug addictions, for alcoholics or those who are taking medicines incompatible with breastfeeding. There are not, however, any exemptions foreseen for women in economic difficulty, with no income or with a low income. The decision to limit the benefits exclusively to biomedical difficulties, without considering social aspects, penalises the migrant women living in poverty who, although they do not fall within the cases described, have difficulty in beginning exclusive breastfeeding, or must integrate the child's diet with artificial milk so that they can return to work as soon as possible.

For many women, in particular those working in the care field, it is impossible to combine their duties with the task of looking after their children, particularly when they are very small. The private social associations and the projects for mothers are a fundamental resource for the age range that suffers from a lack of public initiatives.

When I finished my training course as a cultural mediator, I looked for work, I looked for work... I sent hundreds of applications and I managed to find a job immediately. Then I got pregnant, the baby was born and I couldn't work. I couldn't work because I didn't know what to do with the baby, I was alone with the baby and I couldn't. In the meantime, I began to follow some projects of the associations here in Torino, in activities dedicated to the mothers, in the places where I first found a good welcome. I began as a volunteer, and then it became a job. (Latifa, 32 years old, Morocco).

Overall, it is necessary to encourage the integration between the social-welfare services, in order to guarantee more safeguards on the social plane for the new mothers and during the first months of the child's life.

The case of Elisa allows us to illustrate the impact of social factors on the well-being of a woman during the postpartum phase. Elisa had a negative experience during the birth and she attributes to what she sees as a genuine violence, the sense of sadness and incapacity that pervades her arrival at home.

I had a terrible birth, that is, put yourself in my place... having to beg them to give you an epidural, or to decide to do a caesarean. I knew that there was something wrong, because I had been in atrocious pain all day, as if someone was pulling my guts out. I told them a thousand times, but no one listened to me. I was crying, I was hurting and the labour didn't make any progress, in the end they had to do an emergency caesarean, but they waited too long and there was foetal distress. The problem, in my opinion, is that I went to the family clinic and so I didn't know the doctors, I had no reference point. Many other women went privately and they had their gynaecologist present on the ward, they had someone to talk to... I didn't. It was a terrible experience, to the point where I wanted to do something, to complain, but everyone advised me not to say anything. Afterwards, during my hospital stay, I don't want to seem a grumpy person, I don't consider myself either more or less than someone from here, but the nurse that looked after me seemed fed up with her work... tired of the foreign women... I don't know... she complained about everything... On the other hand, I had very kind and very competent midwives. (Elsa, 39 years old, Peru).

As in other interviews, we see a difficulty in "getting someone to listen" which affects the independence and the decision-making capacity of the foreign patient. Brigitte Jordan showed that there are various forms of knowledge relating to birth that enjoy various levels of recognition. While some knowledge

is little appreciated, others are officially recognised as authoritative. The “authoritative knowledge”<sup>224</sup> on the basis of which operative decisions are taken and clinical choices are made, in the context we analysed is ‘owned’ by the gynaecologists and the midwives and is mediated by the guidelines and the procedures adopted in each hospital. The knowledge regarding birth ‘owned’ by the women themselves and which circulates through informal channels of sharing of experience, finds little room in the physiological pregnancy and an even more restricted role in the management of a pregnancy at risk.

Many of the anthropologists who have studied the models of assistance during birth in the contemporary world have emphasised the fundamental role of the active participation of the woman in the demedicalization of the birth<sup>225</sup> and in the gradual affirmation of the holistic and humanistic models<sup>226</sup>, which emphasise the mind-body connection and the unique nature of every single experience during the birth.

The experience of Elisa shows that it is necessary to listen more carefully to the patient when they perceive that “something not quite right” is happening in their body and seek a response to their pain in the biomedical procedures.

In 2001, the national committee for bioethics ruled on the use of epidural analgesics during the birth, they also reported a delay in Italy in the use of analgesics and stated that “the right of the mother in labour to choose an efficacious anaesthesia should included amongst those guaranteed free of charge in the “essential levels of assistance”<sup>227</sup>. In 2008, the government attempted to introduce this amendment<sup>228</sup>, but the regulation was not enacted, so the possibility of using epidural analgesics during labour exists only on paper and this form of pain relief is still used only sporadically. According to two inquires carried out by the ISS in 2008-2009 and in 2010-2011, it was shown that of all the natural births, an epidural analgesic was used only in 14.6% of the cases. In general, therefore, for both Italian and foreign women, “the opportunity of a painless birth is still strongly denied in Italy”<sup>229</sup>.

The question of elective caesarean section is more delicate and complex, since it is a surgical procedure that involves risks for the mother and the child. The question was dealt with in the recent revision of the guidelines *Taglio cesareo: una scelta appropriata e consapevole* (caesarean section, an appropriate and aware choice) which aims to combine “the appropriateness of the clinical practice, which valorises the

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<sup>224</sup> R. Davis-Floyd and C. Fishel Sargent, *Childbirth and Authoritative Knowledge: Cross-Cultural Perspectives*, Berkeley, University of California Press, 1997.

<sup>225</sup> S. Kettler, *Preparing for Motherhood: Authoritative Knowledge and the Undercurrents of Shared Experience in Two Childbirth Education Courses in Cagliari, Italy*, in «Medical Anthropology Quarterly», 14, 2000, n. 22, pages 138-158

<sup>226</sup> R. Davis-Floyd, *The Technocratic, Humanistic, and Holistic Paradigms of Childbirth*, in «International Journal of Gynecology & Obstetrics», 75, 2000, pages 5-23.

<sup>227</sup> Presidenza del Consiglio dei ministri and Comitato nazionale per la bioetica, *La terapia del dolore. Orientamenti bioetici*, document approved March 30th 2001.

<sup>228</sup> D.P.C.M., April 23<sup>rd</sup>, Article 37, paragraph 3: “The national health service guarantees the analgesic procedures during labour and the vaginal birth in the structures identified by the regional authorities and within specific programmes aimed at the diffusion of these procedures.” The D.P.C.M. was withdrawn by the government before it could be published in the *Gazzetta Ufficiale*.

<sup>229</sup> *Nascere sicuri: an inquiry into birth procedures and the situation in the birth clinics with the aim of identifying specific criticalities regarding the mother and the foetus and the ways in which the woman can determine the choice between caesarean and natural birth*. The inquiry, presented by the Senator Fiorenza Bassoli and Laura Bianconi, was deliberated by the *Commissione Sanità* (healthcare commission) on September 21<sup>st</sup> 2010. The full text is online at: <http://www.senato.it/leg/16/BGT/Testi/Allegati/00000101.pdf>.

role of the healthcare professionals” with greater awareness and active participation by the women in decisions regarding the pregnancy and the birth<sup>230</sup>.

In order to allow active involvement of the foreign women it is necessary to encourage a more fluid and bi-directional communication and greater recognition of their capacity for self-determination, which seems to be lacking in the relationship with Elsa. Although it is an experience that can happen to any woman, whatever her nationality, many of the migrant women interviewed had the feeling that because they were foreigners, uncertain in their use of the language, were cared for at a family clinic and not by a private gynaecologist and their lack of knowledge about medical structures negatively influenced the operator’s perception of them as competent patients<sup>231</sup>.

After she was discharged, renouncing the right to complain or report her dissatisfaction in any way, our interviewee returned home, but the situation was not similar to her first pregnancy and the symptoms of psychological discomfort became worse.

When I arrived home, I hoped I would feel better, but I didn’t. I cried, I couldn’t sleep, I trembled and I ran a temperature, I was really ill, I tell you, really ill. I was losing my hair, I was becoming bald, I wept all the time, I wept. (Elsa, 39 years old, Peru).

As the weeks passed, the situation worsened so Elsa decided to speak to the gynaecologist at the family clinic, when she met her at the forty-day check-up.

“Is your husband present? Does he help you with the baby?” the gynaecologist asked me. “No,” I said, “he has to work almost all the time, I am always alone at home.” “Have you got any other relatives, your mother or your sister who can give you a hand?” “No,” I tell her. “It is important for you to rest... can’t you ask someone – a friend or a babysitter – to take care of the child, even just for a few hours a day?” “Of course I can’t. I can hardly cover my own expenses, let alone pay a babysitter.” “Then the only thing to do is to call the social services.” At that point, I said “No! never mind, thanks a lot, perhaps it is not so serious...” and I never went back. I thought, even if I am ill, I will never go there. Perhaps it is usual for them, I mean, to call the social services when you feel ill or alone, I don’t know. But I was afraid... I don’t know, you hear so many things... I was afraid they would say “she is mad, she can’t keep the child.” (Elsa, 39 years old, Peru).

The overall picture suggests a mood change associated with the pregnancy, which, however, was neither diagnosed nor treated adequately. Not finding any other solutions, Elsa tried to solve her problems alone and decided to return to Peru for a number of months, where finally she managed to overcome her depression.

The World Health Organization has recently recognized the role of psycho-social factors in maternal mental health, correlating them with poverty, the absence of social support networks, sexual or domestic violence, the stress of immigration, the development of pathologies such as the ‘maternity blues’, postpartum depression and puerperal psychosis<sup>232</sup>. Postpartum depression, in particular, is the most common

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<sup>230</sup> Ministero della salute and Istituto superiore di sanità, *Linea guida 22. Taglio cesareo: una scelta appropriata e consapevole*, 2012.

<sup>231</sup> It must be said that there is no quantitative data that allows us to evaluate how generalized these impressions are and how far they correspond to personal opinions based on dissimilar expectations of assistance or objective differences in the relationship between doctor and patient.

<sup>232</sup> Cfr. J. Fisher *et al.*, *Prevalence and Determinants of Common Perinatal Mental Disorders in Women in Low- and Lower-Middle-Income Countries: A Systematic Review*, in «Bulletin of the World Health Organization», 2011, online at: [http://www.who.int/mental\\_health/maternal-child/maternal\\_mental\\_health/en/](http://www.who.int/mental_health/maternal-child/maternal_mental_health/en/); E. Robertson, N. Celasun e D. Stewart, *Risk Factors for Postpartum Depression*, in *Postpartum Depression: Literature Review of Risk Factors and Interventions*, ed. D. Stewart *et al.*, Toronto, University Health Network Women’s Health Program, 2003.

complication of the postnatal period. Until the nineteen-eighties and nineties the research into this disorder was mainly concentrated in the industrialized countries and some authors considered it a disease that was absent in non-Western societies. Later studies, however, showed that it is a picture closely linked to social suffering, which presents transversely, although appearing in different ways and with symptoms that show a strong cultural variability.

This problem is currently widely underestimated and both specific research on the Italian situation and planned intervention that takes into account the needs of the migrant women and the need to recognize the risk factors and the difficulties they encounter in the postnatal period are lacking.

Elsa's experience also leads us to consider the profound fear that many migrant women feel when it is suggested that they may be reported to the social services and the widespread diffidence with regard to this service. Elsa's fear is widely shared amongst the mothers and sometimes means they renounce the forms of support necessary or assistance that could contribute to preventing situations of physical, psychological and social hardship. There is a strong need to safeguard their "invisibility" which, even in this case, speaks of a more vulnerable maternity, at risk, more marked by doubts and diffidence towards the institutions.

This is a complex topic, which requires targeted investigation and here we will merely mention it. The social services can intervene in various ways towards minors and families in situations of serious difficulty. In certain situations, the solution is support within the environment to which they belong, through daytime care or other projects for the support of the family group. In the more serious cases, the child is removed from the family. This latter choice is extremely delicate; it demands careful evaluation of every single case.

The causes that most frequently lead to drastic intervention are abuse; the lack of necessary care in primary and evolutionary relationships; serious neglect or socio-cultural and relational deprivation; the disability of the minor or specific relational pathologies and, finally, extreme poverty. The latter is a condition with respect to which the Roma and foreign families, especially when they are illegal residents, are particularly exposed. Without going into detail, the organization Save the Children mentions in the report *I minori stranieri in Italia. L'esperienza e le raccomandazioni di Save the Children*, that they "received testimonies from social workers and lawyers regarding cases in which the children were removed from their families following reports to the competent social services. From these cases it is clear that there is a situation of economic and social hardship that is determinant for the purposes of reporting and later removal"<sup>233</sup>.

The situation, for those who are irregular, is aggravated by the impossibility of getting onto the waiting lists for council housing in emergency situations, which requires three years of continual residence or the payment of welfare contributions, which shows continual working activity in this period of time.

In addition to the fragility on the economic-social plane, there is the difference in the educational models and the cultural context, which makes the procedures for evaluation of parental suitability particularly complex. During the interviews with the operators and in the patients' records, which it was

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<sup>233</sup> Save the Children, *I minori stranieri in Italia. L'esperienza e le raccomandazioni di Save the Children*, 2010, page 72.

possible to consult thanks to the cooperation with the Centro Frantz Fanon, there emerges a still insufficient or superficial attention for the migratory history and the cultural background of the parents. Frequently, the exploration of these aspects is limited to a few lines and is based on the work of specialists in other fields, who have no specific competencies in the anthropological field<sup>234</sup> or who do not have in-depth knowledge of the geographical area of reference of the user. An emblematic element of this situation is the acritical use of psychological testing. These instruments, which are often distant from the universe of references of the foreign user, are quite useless for understanding the psychic world of the user and for the psychologist it is necessary not only to introduce “some device that increases the legitimacy [...] but [also] to critically analyse their tools, highlighting limits and contradictions”<sup>235</sup>.

In recent years numerous criticisms of an approach to the safeguarding of the minor according to which “the family was judged to be inadequate and considered the cause of the traumas suffered by the minor, therefore seen as a merely negative element, from which the child must be separated” and there has been a tendency within the social services to see opportunities for “collaboration with the family of the child as an important objective to reach”<sup>236</sup>. This new approach, largely still to be constructed, appears particularly promising, since it shifts the focus of the intervention to the entire family group and develops the relational network of the foreign minor as a resource for the management of criticalities.

#### 6. *The right to health of the foreign minor and the paediatrician*

Children have needs that are particularly linked to their physical and psychological development and, more than other groups of the population, they have precise housing, hygienic and nutritional needs, essential to prevent diseases that could represent a serious threat to health and affect their physical and psychological development. Italy has ratified the international agreements on children’s rights and introduced specific regulations for the protection of minors, including the legal or illegal foreign minors<sup>237</sup>. The category “foreign minors” is very heterogeneous and includes both children born in Italy to foreign parents, and minors born abroad. The latter can be “accompanied”, legally entrusted to parents or relatives to the third degree, or “unaccompanied”, arriving in Italy without parents or other adults who are legally responsible for their assistance.

The foreign minors, and in particular the illegal minors and the unaccompanied minors<sup>238</sup> are a category that is adequately protected from the legislative standpoint, but extremely vulnerable on the social plane. From the standpoint of the right to health, the legal minors are obliged to enrol with the national health

<sup>234</sup> For an in-depth see S. Taliani and F. Vacchiano, *Altri corpi. Antropologia ed etnopsicologia della migrazione*, Milano, Unicopli, 2006, page 92.

<sup>235</sup> I. Biglino and A. Olmo, *Health as a fundamental right: a study on migration and healthcare in Turin*, op. cit., page 100.

<sup>236</sup> D. Bramanti and E. Carrà (ed.), *Buone pratiche nei servizi alla famiglia. Famiglie fragili e famiglie con anziani non autosufficienti*, Roma, Osservatorio nazionale per la famiglia, eBook, 2011

<sup>237</sup> Foreign minors, like Italian minors, are guaranteed all the rights foreseen by the New York Convention on Children’s Rights of 1989, in which the principle of the “greater interest of the minor” is established.

<sup>238</sup> In some cases, the young people who declare themselves to be underage have no identity documents. It is therefore necessary to ascertain their age, in order to guarantee the rights of the underage child, for whom placement in a safe home, non-expulsion, the granting of a residence permit for minors, the possibility of being entrusted to a relative to third-degree of kinship or to a community. However, these checks have numerous implications. For a detailed analysis of the limits and the perspectives for the procedures for determining age, see E. Coffano, M. Del Savio and L. Mondo (ed.), *Rapporto: Stranieri e salute*, op. cit., pages 310-313.

service (SSN) and have access to all the services guaranteed by the health system<sup>239</sup>. Until 2012, pursuant to Article 35, paragraph 3, D. Lgs. 286/1998<sup>240</sup>, the illegal minors who were not able to enrol with the national health service and had access to the healthcare structures only for urgent and essential treatment, including vaccinations and interventions of prevention, diagnosis and treatment of infectious diseases.

The State-Region agreement recognised the right of enrolment with the regional health services for all minors, therefore including the irregular minors, thus fully realizing what was foreseen by the Convention on Children's Rights of November 20<sup>th</sup> 1989, which ordered the nations to guarantee access to healthcare for all minors, whatever their legal status. Some Italian regions ratified this point of the agreement, but not all. SIMM (*Società Italiana Medicina delle Migrazioni*), Oisg (*Osservatorio Italiano sulla Salute Globale*), Asgi (*Associazione studi giuridici immigrazione*) and other associations that operate in the field of protection for the health of minors, have launched the initiative "*Appello per una pronta applicazione in tutta Italia dell'accordo Stato-Regioni sulla tutela sanitaria degli immigrati a partire dal diritto di ogni minore ad avere il suo pediatra*" (an appeal for the application of the State-Regions agreement on the safeguards for the health of the immigrants, starting with the right of every minor to have their own paediatrician). When we were carrying out the research project in Piemonte, measures had not yet been taken to guarantee the enrolment with the national health service of minors without a residence permit. Nonetheless, on March 16<sup>th</sup> 2015, the regional council approved a ruling that recognized the registration of illegal minors in the regional health service circuit and guarantees to possibility of access to a paediatrician, thus fully enacting the aforementioned State-Regions agreement<sup>241</sup>.

In Italy, the NHS paediatrician,<sup>242</sup> is the first point of reference for the protection of the health of children from birth to fourteen years old. In 1978, the law N. 833, which set up the Italian National Health Service, set out the principles for global protection of the health of the child until puberty, identifying in the paediatric specialist the professional figure most suited to play this role. They were to work in close contact with the family, to represent the link between the families and the SSN and to guarantee access to all the services and treatments including basic levels of treatment. Therefore, this figure guaranteed continuative assistance and made it possible to accompany the minor and the family throughout the stages of development, not only when there was a pathology underway. Being able to count on an NHS paediatrician is an important result for the protection of the health of illegal minors and, at the same time, is a measure that has overall positive effects on the healthcare system, since it encourages a more coherent and aware use of the emergency services, avoiding gridlocks.

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<sup>239</sup> *Testo unico delle disposizioni concernenti la disciplina dell'immigrazione, norme sulla condizione dello straniero* (consolidated legislation on immigration), D.Lgs. N. 286. July 25<sup>th</sup> 1998, *Gazzetta ufficiale*, N. 191 August 18<sup>th</sup> 1998, ordinary supplement N. 139, Article 34. See also Italian Ministry of Health, Circular N. 5, March 24<sup>th</sup> 2000, *Gazzetta ufficiale*, General Series N. 126 June 1<sup>st</sup> 2000.

<sup>240</sup> Article 35, paragraph 3 foresees that the foreign minors without a residence permit cannot enrol with the national health service, but in any case have the right to outpatient care and urgent or essential hospital treatment, also continuative, for disease and accident and to programmes of preventive medicine.

<sup>241</sup> Regione Piemonte, Deliberazione della Giunta regionale 16 marzo 2015, N. 34-1198, *Bollettino Ufficiale*, 11S1 March 19th 2000.

<sup>242</sup> The first convention for the *pediatra di libera scelta* (in effect an NHS paediatrician) was signed in 1979 and entrusted to the paediatrician the care of children up to age 12, rather than exclusively to the GP as occurred in the past. In later years new agreements between the *Federazione Italiana Medici Pediatri* and the Italian authorities contributed to defining the role of the NHS paediatrician, establishing that the health of the child is their exclusive field of expertise from 0 to 6 years old, and extending the paediatric age to 14.

The relationship of the foreign mothers interviewed, with the NHS paediatrician varied: some mothers reported excellent experiences, others many dissatisfactions. Some problems that frequently arise concern the difficulty in obtaining a home visit in the case of need, the bureaucratic obstacles in procedures that should be simple and immediate, and the difficulty in having immediate contact, especially when the child has a temperature or an illness.

I have had two paediatricians. With the first, I had a very bad experience, with the one I go to now I get on very well, she is very competent and she is a nice person. I will tell you what happened, although it was three, almost four years ago. I didn't know anyone and I chose just any paediatrician. I chose the surgery that had room for more patients, although it wasn't very near home. One day – the baby was very small, perhaps eight or nine months old – he began to have a very high temperature, didn't move, he was sick, he was ill. I was really frightened and the next morning I called the doctor asking for a home visit. It was winter and I didn't have a car, so I didn't want to take the baby out of the house, I was afraid that I would make things worse. He answered, quite annoyed, he asked for the address and he came here. He examined the baby, it took two or three minutes, not more, then he said "Madam, what do you want from me, this is influenza, it is quite normal. It is no good asking for a home visit for something like this." He was probably right, but my child had a high temperature and I was worried. I tried to explain, but he wouldn't listen and didn't let me say anything. Then he had to give me a prescription, no? We live in a very small flat, one bedroom and a living room-kitchen... he went away in a rage and he said very rudely, "how can you live like this! There's not even room to sit down and write out a prescription!" I was humiliated. After that I changed the paediatrician and anyway I prefer to go to the A&E. (Angela, 26 years old, Ecuador).

The limited visiting times, the lack of availability during the weekends, the long waiting times at the surgeries and the need to book appointments many days ahead, are some of the problems mentioned by our interviewees. These problems do not specifically concern the foreign families, but when combined they may represent the greatest obstacles to the right to health, due to the lack of an extended family network that allows better management of the family timetable; working conditions that allow less freedom for the parents in the case of a sick child and lower income, which makes it difficult to use private services. In this case, the voluntary associations and the private social clinics represent a fundamental resource for the migrant families, integrating the service offered by the public system, in order to answer the needs of users, who by their very nature, need greater flexibility.

I have worked very little here in Italy; I haven't found a permanent job. I only have work by the hour and I have to be available when they need me, otherwise they don't contact me again. My working hours vary, at times I have to work all day, at times only in the morning, sometimes in the afternoon... any day of the week. That is why I bring the children here, it is basically a problem of our schedule. Our paediatrician takes appointments for two hours and you have to book, so I can't organize that. Sometimes I go to the A&E, the last time they were kind, they understood our problem, because the little girl had a fever and it was the weekend: the paediatrician was not available and we don't have her phone number... we didn't know what to do (Elvira, 42 years old, Peru).

The cases mentioned represent specific experiences, which as we have seen, are occasional and cannot be generalized. The opinions gathered, both positive and negative, represent individual situations and experiences that allow us to illustrate the vicissitudes of the families we contacted, but which do not necessarily correspond to general tendencies.

Amongst the NHS paediatricians, moreover, there is a growing awareness of the need to actively organize themselves to meet the specific needs of migrant children and their families. Training in the intercultural field which we will discuss in chapter seven, represents one of the most common and most efficient tools for acquiring the necessary skills and for understanding the needs of the foreign users.

## 7. The health needs of foreign minors

From a hospital point of view, there are no significant differences between Italian and foreign children. Table 5 illustrates the reasons for hospitalization between 329 and 365 days<sup>243</sup> for citizens of the Regione Piemonte. The principal reasons for hospitalization for both groups are respiratory diseases, congenital malformations and infectious or parasitic diseases.

Although the general picture is similar, the greater presence of infectious and parasitic diseases and respiratory diseases amongst foreign children or those from Fpm countries can be linked to less favourable living conditions and social inequality. Nonetheless, the effects of this inequality is not easily demonstrable if we start from this single datum. In fact, many problems, although they compromise the overall well-being of the child, do not reach a level of urgency that requires hospitalization.

Table 5. Distribution of hospitalization by cause, age: 29-365 days, by citizenship

Main reasons ICD9CM	Advanced countries		High migration	
	N.	%	N.	%
Infectious and parasitic	287	7.25	95	9.31
Tumours	60	1.52	10	0.98
Glandular, endocrine diseases, nutrition, metabolism and immune diseases	360	9.10	76	7.45
Diseases of the blood and the blood-forming organisms	71	1.79	19	1.86
Psychological disorders	17	0.43	5	0.49
Diseases of the nervous system and the sense organs	204	5.15	41	4.02
Diseases of the circulatory system	37	0.93	7	0.69
Diseases of the respiratory system	987	24.94	306	30.00
Disease of the digestive system	240	6.06	54	5.29
Diseases of the genital-urinary system	401	10.13	87	8.53
Diseases of the skin and the subcutaneous tissues	41	1.04	15	1.47
Disease of the osteomuscular system and the connective tissue	11	0.28	3	0.29
Congenital malformations	470	11.87	118	11.57
Pathological conditions of perinatal origin	108	2.73	27	2.65
Undefined symptoms, signs and pathological conditions	385	9.73	88	8.63
Trauma and poisoning	115	2.91	29	2.84
Factors that influence the state of health	164	4.14	40	3.92
Total	3.958	100.00	1.020	100.00

Source: Information supplied by the epidemiology service of the Regione Piemonte, indicator 26b: distribution of hospitalization by cause, age: 29-365 days, by citizenship. Year 2010.

<sup>243</sup> In the first month, the majority of hospitalizations are linked to the condition of the child at birth, while from the twenty-ninth day onwards complications become more important.

The private social paediatric clinics are a good observation point for understanding the health needs of illegal foreign minors, or those in conditions of social hardship. As the volunteer paediatrician of the Association Camminare Insieme explains.

Amongst the children who come to us it is difficult to be certain whether the illness is the result of poverty and which are normal pathologies of the paediatric age. Anyway, there are many colds and respiratory infections that I feel are linked to the lack of proper heating: it is cold in my house, so I can imagine what it is like for them. I have also noticed that there are often problems of children who don't grow properly, and there could be nutritional problems. The first months, while the mothers are breastfeeding, are alright, then when they begin weaning, the growth slows... it is possible that it is due to the weaning methods, but I am afraid that it is above all due to a lack of financial means: I am afraid that their food is not of the best quality. It seems to me that the problem of underweight children is quite widespread and the doctor at the ISI paediatric clinic confirmed this. It seems that the problems are not linked to incorrect eating habits, but to social problems.

A further problem found above all amongst the children who did not have basic paediatric assistance, is the delayed diagnosis of learning difficulties, cognitive retardation, or rare and chronic diseases that began in childhood. In fact, since there is no continuity in the relationship with the doctor it is difficult to note the first signs of anomalies or evaluate whether a symptom is cause for concern or if it is something that will be resolved spontaneously over time.

Amongst the children, we see here, we notice cognitive retardation, but we have few elements to go on and, if we suggest to the mothers that they see a specialist, we don't know if the child is effectively treated and if these questions are looked into. The fact is that some problems, if caught in time, can be managed much more easily and there is a greater chance of recovery. (NHS paediatrician and volunteer, Associazione Camminare Insieme).

The weight of the social determinants also affects the cost of Group C medicines, a problem that is particularly serious in paediatric age. Many of the necessary medicines such as paracetamol or milk enzymes must be paid for and they are expensive for the families. This is one of the reasons that many of the mothers enrolled with the SSN, who have an NHS paediatrician, go to the private social clinics.

We have a paediatrician, but for me the problem is the medicines. I don't work and my husband works, but he doesn't earn much, so for me it is a help to know that they will give me the medicines. The child had a cough and I had to buy a syrup that cost 15 euros at the pharmacy. It doesn't seem much, but it is a lot for us. This time I took the little girl, who is small and has dermatitis, she has to use a cream every day, but it is expensive, so I come here. (Halima, 33 years old, Morocco).

Also in this case, it is not a problem that concerns the foreign minors as such, but a consequence of the economic inequalities and of poverty, two conditions that, as we saw in the second chapter, principally affect the migrant families.

Finally, we must not underestimate the problems of mental health. The associations that operate in the field of ethnopsychology and transcultural psychology, such as the Centro Frantz Fanon, Mamre and the Centro Marco Cavallo, have developed projects in support of the families and the foreign minors, with particular attention to the critical situations, such as the women who are victims of trafficking, unaccompanied minors and minors who are joining their families.

Family reunification is in fact difficult to attain and is a moment keenly awaited and longed for, with many expectations. Nonetheless, it is not easy to recompose the family group: the reunification may worsen existing or latent problems and it is very difficult to rebalance the family roles, particularly after long

absences. For the children, moreover, the reunification may involve a traumatic confrontation with a new reality that is often more hostile than they imagined and a second separation from the persons who, after the departure of the parents, cared for them and with whom they formed an affective bond. These circumstances may have important effects on the psychological well-being of the child or adolescent and increase the conflicts within the family group.

The challenges on the relational plane are numerous also for the families on their way<sup>244</sup>, who are facing together the first stages of the migration: the radical transformation of the social context, the passage from an extended family network to a nuclear family and the frequent phenomena of the inversion of roles, which occur when the children acquire greater competence than their parents in the place of arrival, undermining the equilibrium of the nucleus may all cause forms of psycho-social upset in the children and adolescents.

The material conditions, whether favourable or adverse, affect the overall well-being of the minors directly or indirectly. The quality of life significantly influences the development and the problems that occur during the most precocious phases of life can be correlated to forms of physical and psychological suffering in adult life. In addition to medical assistance, protection for the right to health requires an active intervention to encourage inclusion and reduce social asymmetries that affect the well-being of women and children. As Margaret Whitehead and Göran Dahlgren wrote, “Three distinguishing features, when combined, turn mere variations or differences in health into a social inequity in health. They are systematic, socially produced (and therefore modifiable) and unfair”<sup>245</sup>.

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<sup>244</sup> S. Taliani and F. Vacchiano, *Altri corpi*, op. cit.

<sup>245</sup> M. Whitehead and G. Dahlgren, *Concepts and Principles for Tackling Social Inequities in Health: Leveling up Part I*, Copenhagen, WHO Regional Office for Europe, 2006.

## Chapter Four

### Health and work. The vulnerability of foreign workers and access to healthcare

#### 1. *Migrant workers as a vulnerable category: what are the implications for health?*

Work represents one of the hinge pins of the migratory project. In the Italian context, in particular, the participation of foreigners in the employment market – expressed by the employment rate – is one of the highest in Europe, both because the majority of the immigrants come seeking work, and there is a lower number of refugees or asylum seekers, and because in this country there is a high rate of employment also for those who initially arrived through family reunification<sup>246</sup>. For this reason, it is important to take into consideration the health of immigrants as workers.

Amongst the social determinants of health, the workplace relationships (between the employer and the employee), the conditions of employment (recruiting, contractual conditions, placement in the company, integration in the place of work, etc.) and the working conditions (duties, organization of work, working environment, technologies used, etc.) play a fundamental role<sup>247</sup>. Those who are unemployed, or underemployed, or who do stressful or unsafe work are in fact more subject to poor health. On the contrary,

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<sup>246</sup> A. Cangiano, *Immigration Policy and Migrant Labour Market Outcomes in the European Union: New Evidence from the EU Labour Force Survey*, Torino, Fieri Working Paper, 2012.

<sup>247</sup> I. Biglino and A. Olmo, *Health as a fundamental right: a study on migration and healthcare in Turin*, Bologna, Il Mulino, 2014, page 10

people who have greater control over their working situation, in terms of contractual and working stability, and less stress in the workplace are healthier and have a greater life expectancy than the former.

With regard to the employment situation in Italy, the data available shows a distribution and a placement in the labour market with considerable disadvantages compared with autochthonous workers. In fact, the immigrants are more concentrated in specific sectors and in activities with low productivity and low technological value. Almost half the immigrants in employment (49.7%) against one fifth of the Italians (17.5%) are employed in three macro-sectors: building, tourist services (hotels, restaurants, catering and entertainment) and personal services<sup>248</sup>. The distribution of the workers on the basis of gender shows a further occupational segregation. Amongst the men, we see a strong concentration in employment in the manufacturing industry, in construction and in hotels and restaurants, while women work in social services and personal care.

Within these sectors the foreigners, although they (more than the Italians) often have qualifications superior to the position they hold, work above all in roles of medium or low specialisation and in jobs with a high intensity of work, in which, generally speaking, strength and resistance is required, working hours are long or unsocial, involving fatigue and risks for health. According to the data elaborated by the Fondazione Moressa<sup>249</sup>, more than one immigrant out of three (37.7%) is employed in unqualified work. Models elaborated by the Italian Home Ministry show that the probability of carrying out unqualified work is three times higher for a foreigner than for an Italian with the same social status<sup>250</sup>. The foreign workers are mainly employed in small and micro companies. These are still largely based on traditional production systems and make greater use of 'off the books' work or partially regular work; they have lower safety standards in the workplace and limited resources for prevention and information for the workers. They offer less training opportunities, poorer promotion plans to their employees, are less unionized than the medium and large companies, and are less subject to checks and inspections.

It must also be said that the migrants form the component of the workforce that has been most affected by the crisis. Recent data on the dynamics of the labour market in Italy show a reduction in the employment rate between 2008 and 2013, which has affected above all the male migrants (-14%) and, to a lesser extent, the foreign women (-3.4%)<sup>251</sup>, due to the differing distribution of men and women in the labour market and a different impact of the crisis on the respective sectors in which they are employed<sup>252</sup>.

The impact of the crisis on the migrant workers has not only reduced the occupation rates for the foreigners, but has also accentuated their disadvantageous conditions, increasing the concentration of the foreign work force in poorly qualified positions (from 29% in 2008 to 34% in 2012), with a parallel reduction in the number of migrant workers in qualified positions (from 8.2% in 2008 to 5.9% in 2012) and

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<sup>248</sup> Cnel, *Il ruolo degli immigrati nel mercato del lavoro italiano*, Roma, Onc and Cnel, 2012, page 31.

<sup>249</sup> <http://www.fondazioneleonemoressa.org>.

<sup>250</sup> L. Zanfrini, *La partecipazione al mercato del lavoro*, in *L'immigrazione straniera in Lombardia. La decima indagine regionale, Osservatorio regionale per l'integrazione e la multiethnicità*, ed. G.C. Blangiardo, Milano, Regione Lombardia and Fondazione Ismu, 2011, pages 83-125.

<sup>251</sup> Istat, *Rapporto annuale 2014. La situazione del paese*, 2014, page 85.

<sup>252</sup> F. Pastore, E. Salis and C. Villosio, *L'Italia e l'immigrazione «low cost»: fine di un ciclo?*, in «Mondi Migranti», 19, 2013, n. 1, pages 151-172.

an increase in the gap between the average income of the foreign workers and the Italian ones. In recent years, the increase in the disparity in income has been recognized as one of the principal effects of the crisis, and the cause of the increase in what are known as the *working poor*<sup>253</sup>.

This chapter takes into consideration the health of the immigrants as workers and analyses the health-work binomial in its bi-directional relationship. Work and the occupational conditions of the foreigner are in fact first examined as determinants of health. As will be recalled, the right to health includes the right to the preconditions underlying health or the so-called determinants of health<sup>254</sup>. This chapter will concentrate on one of the most important determinants for the migrant population; that is, working conditions and health in the workplace. Secondly, we will analyse how work can, at the same time, constitute an obstacle to access to health and appropriate treatment, taking into account in particular the caring professions, which represent the main sector of employment for foreign women in Italy, and highlighting an area of potential conflict between the right to health and the right to work.

In order to deal with these topics, we will illustrate individual cases; although they cannot be considered representative of the phenomena in question, they allow us to highlight some of the key questions in the analysis of occupational health in more generalizable terms and offer a narration and a subjective perspective of access to healthcare and the obstacles found. The cases and the stories of the immigrants interviewed have been combined with the literature on occupational health and the perspective of privileged witnesses who work to offer healthcare services (associations, trade unions, social workers, medical staff, and cultural mediators) and who have contributed to offering a more complex picture of the phenomenon.

## 2. *Accidents in the workplace and illegal workers: safeguards and risks of extreme marginalization*

According to the consolidated legislation on compulsory insurance against accidents in the workplace and occupational illnesses,<sup>255</sup> an accident in the workplace is “a traumatic event that occurs for a violent reason during work, and makes it impossible to carry out the working activities for at least three days.”

During 2012, INAIL (national institute for insurance against accidents in the workplace) recorded 3,486 accidents involving foreign workers in the province of Torino, with a drop of 7.7% with respect to the previous year and an incidence of 14% of the total number of accidents in the workplace that occurred in this area<sup>256</sup>. Since 2008, in correspondence with the crisis, the absolute number of accidents in the workplace involving foreign workers has fallen, as an effect of the reduction in the number of foreign workers in the region, while their proportion in the total number of accidents has increased.

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<sup>253</sup> E. Galossi, *L'impatto della crisi sulle condizioni di vita e di lavoro degli immigrati: un'indagine dell'Associazione Bruno Trentin*, Roma, Associazione Bruno Trentin, Ires, 2013.

<sup>254</sup> Cfr. the first chapter of this volume. For more detail, see also I. Biglino and A. Olmo, *Health as a fundamental right: a study on migration and healthcare in Turin*, op. cit.

<sup>255</sup> DPR N. 1124, June 30<sup>th</sup> 1965, *Gazzetta Ufficiale*, N. 275, October 13<sup>th</sup> 1965, Article 2.

<sup>256</sup> M. Maltana, M.L. Tomaciello and A. Congia, *Lavoratori stranieri e infortuni sul lavoro*, in *Osservatorio Interistituzionale sugli stranieri in provincia di Torino: rapporto 2012*, Prefettura di Torino, 2013, page 263.

An analysis based on longitudinal data Whip (Work Histories Italian Panel)<sup>257</sup> showed that the risk of accidents involving immigrant workers is 45% higher than for national workers. The analysis of the more serious events showed an even higher risk for foreign workers, 56% greater than for Italian workers<sup>258</sup>. Then, if we take into consideration that these results relate to the period 2000-2005 and that they exclude irregular work, we can theorize that these indicators have worsened in recent years, since the crisis negatively affected the employment situation for foreign workers in Italy. However, we must bear in mind that the immigrants, also those who have regular work, tend, more often than native workers, not to report minor accidents and consequently the incidence of serious accidents on the total number of accidents registered is higher.

Foreign workers who are victims of accidents in the workplace are above all males aged between 30 and 40, employed in the construction sector, transportation and business services, coming mainly from Morocco, Albania and Romania<sup>259</sup>. There has also been, in recent years, a constant increase in the average age of the victims of accidents, but above all an increase in the incidence of injured female foreigners and in the sector of personal services, which include healthcare workers and carers. Amongst the domestic personnel, (maids and carers) 77 accidents out of 100 involve immigrant workers, mainly women<sup>260</sup>.

Various factors combine to determine the higher level of accidents amongst foreigners. As already highlighted, the immigrants tend to find work in activities with a low level of specialisation and a high level of danger, often in unfavourable conditions and unsocial working hours. More often than the Italians, they accept risky duties and offer to work overtime<sup>261</sup>, also because they need to increase their income. They work above all in micro and small companies, which have less resources and awareness regarding safety in the workplace<sup>262</sup>. The widespread system of subcontracting in certain sectors, such as the construction industry<sup>263</sup>, and the higher incidence of temporary work or the high turnover of foreign workers, makes it difficult to give correct access to information regarding safety in the workplace. The fact of continually starting a new job is in fact associated with a higher risk of accident<sup>264</sup>.

In addition to a lower average age (a characteristic of the injured workers overall), the foreigners also have a lower length of service compared to their Italian colleagues, which translates into less experience of specific working environments in Italy, which are often very different from the ones in which they were employed in their country of origin. It has also been shown that in some of the countries of origin, different safety regulations are applied, with lower standards and there is a different perception of risk by the

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<sup>257</sup> The Whip databank includes the individual stories of approximately 15 million workers in the private sector who worked only or partly in Italy. The dataset was developed starting from the management archives of the national welfare institute (Istituto Nazionale della Previdenza Sociale, INPS) and the historical series covers the period 1985-2005.

<sup>258</sup> A. Bena and M. Giraud, *Occupational Injury Risk in Immigrant Workers in Italy: Differences in Work Characteristics and Age*, in «Epidemiologia e Prevenzione», 38, 2014, numbers 3-4, page 213.

<sup>259</sup> M. Maltana, M.L. Tomaciello and A. Congia, *Lavoratori stranieri e infortuni sul lavoro*, op. cit., page 284.

<sup>260</sup> Inail, Dipartimento di Medicina del lavoro, *Immigrazione, salute e lavoro*, 2012, page 1, [http://www.inail.it/internet\\_web/wcm/idc/groups/internet/documents/document/ucm\\_portstg\\_100854.pdf](http://www.inail.it/internet_web/wcm/idc/groups/internet/documents/document/ucm_portstg_100854.pdf).

<sup>261</sup> Castagnone, *Il lavoro immigrato: la prospettiva delle imprese*, in *Non solo braccia. Un'indagine sull'impiego di lavoro immigrato nelle imprese del torinese*, Torino, Fieri-Cciaa, Camera di Commercio di Torino, 2012.

<sup>262</sup> G. Mosconi e M.M. Riva, *Immigrati e salute in edilizia: risultati di una indagine sanitaria su un campione di lavoratori edili della provincia di Bergamo*, in «Giornale Italiano di Medicina del Lavoro ed Ergonomia», 33, 2011, N. 2, page 36.

<sup>263</sup> R. Bichi and R. Bracalenti (ed.), *Il lavoro che ferisce. Esperienze di riabilitazione degli immigrati in Lombardia*, Quaderni Ismu, 2, Milano, Fondazione Ismu, 2012, page 8.

<sup>264</sup> A. Bena and M. Giraud, *Occupational Injury Risk in Immigrant Workers in Italy*, op. cit., page 216

immigrant workers, above all during their first years in Italy. Finally, the linguistic barrier, above all amongst the immigrants who have arrived most recently and amongst those who have a medium-low level of education, is one of the most important limits in access to information on the prevention of accidents in the workplace, confirming – also with respect to this category – the importance of information in guaranteeing, *inter alia*, the right to health.

Various studies have shown, moreover, that even now many accidents in the workplace are not registered and remain underestimated. There are a number of reasons for this. First, the migrants are often not aware of their rights, of the existence of INAIL<sup>265</sup> and the possibility of being safeguarded, even if they are employed irregularly. Thanks to the principle of automaticity of the services, the worker has the right to be safeguarded by INAIL, even if the employer has not insured them or if they are not in order with INAIL contributions<sup>266</sup>. Then, there is the fear of losing the job or being reported to the police and deported from Italy, for those without valid residence permits. It has also been testified that migrants can be particularly reluctant to report accidents that occur at the companies of relatives, friends or countrymen.

Moreover, as already mentioned, the foreign workers tend to report above all the more serious accidents, neglecting to report minor accidents and those that do not invalidate, which are lost to the registers of INAIL – and they show a greater incidence of rejected cases. The greater frequency of accident reports not approved by INAIL amongst foreign workers is a structural datum. In 2012, the percentage of cases relating to the foreign workers accepted by INAIL in the province of Torino was about 65% of those reported, against an overall rate of approximately 70%. The foreign workers often find greater difficulty in managing the bureaucratic procedures involved in reporting an accident for linguistic reasons, understanding of the procedures and the concept of availability, so they are more frequently rejected for lack of the legal requisites<sup>267</sup> (see box 3 for the procedure for reporting and recognition of accidents in the workplace).

These elements contribute to making a significant part of the immigrants in Italy a vulnerable category from the employment standpoint – and consequently from a social and economic one – making it difficult for this category to realize their right to health. The immigrant workers are, in fact, particularly exposed to health problems, because they are more likely to be employed in sectors particularly “at risk”, and because the working conditions guarantee a lower level of protection (illegal contracts, limited prevention in the workplace, etc.).

From the interviews we held it was evident that the most vulnerable category of foreign workers who have suffered an accident in the workplace are those who are employed without a regular work contract and who are often without residence permits. In these cases, the A&E department is the most important hub in the process of emergence and reporting of traumas in the workplace. According to a recent survey carried out

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<sup>265</sup> INAIL (Istituto Nazionale per l'Assicurazione contro gli infortuni sul lavoro) operates as a 'global' (safeguarding Italian and foreign workers, regular and irregular) and 'integrated' (ranging from prevention in the workplace to health and economic services, treatment, rehabilitation and return to work and social life) system of protection in the case of accidents in the workplace, or occupational illness. See: <http://www.inail.it/internet/default/INAILcosafa/Attivitsanitaria/index.html>.

<sup>266</sup> INAIL is a health and insurance system that accepts injured workers on the principle of universality (healthcare is guaranteed without distinction of individual, social or financial conditions), equality (according to which everyone has an equal right to the same treatment in parity of need) and globality (according to which it is not the illness that is taken into consideration, but in general the person implying a link between all the health services for prevention, treatment and rehabilitation).

<sup>267</sup> M. Maltana, M.L. Tomaciello and A. Congia, *Lavoratori stranieri e infortuni sul lavoro*, op. cit., page 290.

in Lombardia, about half the foreign workers who have suffered an accident in the workplace (47.4%) were put in contact with INAIL by a doctor at the A&E department, compared with 20% of cases (23.8%) by the employers and 10% (11.8%) by their GP<sup>268</sup>. Irregular workers who are victims of serious accidents requiring urgent treatment at a hospital, generally follow two paths, which lead to two distinct results for treatment of the trauma and access to the healthcare services.

In the first case the emergency services are called to the place of work and the injured worker is taken directly to the A&E department. In these cases, the police or the *carabinieri* are required to inspect the place the accident occurred. In this context, the report on the accident is completed at the workplace and sent to SPreSAL (Servizio prevenzione e sicurezza negli ambienti di lavoro – service for prevention and safety in the workplace)<sup>269</sup>. As soon as possible, the patient completes the accident report for INAIL, which will register the event as an accident in the workplace and will protect the worker throughout the process, in the same way as a legal worker. The employer will be reported to INAIL and will be fined.

In the second case, the illegal worker who has an accident in the workplace goes independently to the A&E department, without being accompanied by the employer. On these occasions, as many of those interviewed reported, foreigners are reluctant to report the origin of the trauma, which is often declared to have occurred in the home. This fact is confirmed by the high rate of anamnesis incongruent with the nature of the event registered, which emerged from an analysis of the A&E registration cards of non-Italian patients, who declared the traumatic event to be “other type of accident”<sup>270</sup>. Often it is the employer who exerts pressure, and in some cases even blackmails the worker so that they will not report the accident.

Here at the CTO Hospital (Centro Traumatologico Ortopedico – trauma and orthopaedic hospital in Torino) we have seen many accidents not reported by the workers. We have had various obvious accidents, in which all the colleagues denied the evidence, said they had seen nothing, that they weren't present, out of fear. We have had a Romanian patient who went back to Romania; he told us he had hurt himself at home. He arrived here covered in whitewash. I encouraged him to report the accident, but he kept on denying it, except that he told me in the last days before he returned to Romania, that they had threatened his family at home. (Social worker, CTO and Spinal Unit).

The employers promise them ‘back pocket money’ in addition to their pay packet, because if they are reported, they have to pay fines. It is a pity that this money is never handed over, so in the end the people who suffer the accidents don't get the money from either side. It is difficult to convince them to report an accident. Many keep quiet, they don't file a report. (Social worker, CTO and Spinal Unit).

Despite the fact that in many cases the medical staff realizes (due to the nature of the symptoms and the causes of the trauma) that the accident probably occurred at work, without the compliance of the worker in reporting it as an accident in the workplace, there are no other ways to prove the nature of the accident,

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<sup>268</sup> R. Bichi and R. Bracalenti, *Il lavoro che ferisce*, op. cit., page 65.

<sup>269</sup> SPreSAL is a local health authority service responsible for safeguarding the health and safety of workers through prevention, supervision and monitoring in the workplace. The activity is destined for all workplaces, both public and private and for building sites and consists of monitoring correspondence to regulations and current legislation on hygiene and safety in the workplace. SPreSAL also carries out criminal investigations into work-related accidents and occupational illnesses.

<sup>270</sup> Ispesl, *Indagine pilota conoscitiva sulle condizioni di salute e sicurezza negli ambienti di lavoro relativa ad una realtà regionale: Veneto*, Roma, Ispesl, 2006, page 135.

nor to guarantee the safeguards to which every worker, whatever their nationality, the legality of their contract and their legal status, has the right.

The report must be made by the patient. No one can stand in for the patient. We can only stand in for the patient when the police or *carabinieri* are called to the place where the accident happened. In that case, the patient that had the accident is present, the emergency services arrive, the police arrive, there is a report to the Public Prosecutor's Office and then to SPreSAL (Servizio prevenzione e sicurezza negli ambienti di lavoro – service for prevention and safety in the workplace). In such cases, the patient cannot refuse. However, when they arrive here directly, and I realize that it is a work-related accident, he or she is the only person who has the right to report that event, no one else can do it for them. (Head of the Public Relations Office, CTO Hospital).

Amongst the patients who have suffered an accident while working illegally and who do not have a residence permit, those who do not report the accident are therefore the most vulnerable group. In fact, while the irregular workers who report the accident fall within a protocol of legal safeguards and healthcare, those who do not report the accident to INAIL encounter considerable problems in accessing the necessary treatment during their recovery. As the head of the Public Relations Office at the CTO Hospital told us, while for the latter urgent treatment is guaranteed, in the absence of a report to INAIL, the impairments that may be a consequence of the event are not recognized by INAIL and are therefore not covered by healthcare plans. This means that the operations, the appointments and the therapies that follow treatment at the A&E are not guaranteed by INAIL and must be paid for by the patient.

In these cases, amongst the solutions enacted by the health and welfare workers who look after the patient, it is possible to register the foreigners with the ISI Centres (immigrant health information centres), thus obtaining an STP code for them (temporarily resident foreigner). Nonetheless, the STP code<sup>271</sup> does not guarantee full coverage of the follow-up medical care and the physiotherapy. Moreover, the paradox, according to the head of the PRO at the CTO Hospital, is that together with the ISI code the patient is attributed the status of 'indigent person'; however, this does not give exemption from the fee (ticket) to be paid by the patient<sup>272</sup>. This is a problem that involves irregular migrants in conditions of poverty and working marginalization in general, but can also have particularly serious consequences for those who, being illegal workers and injured in the workplace without filing a report, and therefore without safeguards, risk falling into a spiral of economic, employment and social marginality that it is difficult to get out of.

We take care of those who arrive accompanied and are then abandoned, and who do not report the work-related accident. If they are admitted, after various attempts – not usually successful – to encourage them to report an accident in the workplace, we send a request for registration at ISI and they send us a regular enrolment. We have continual reminders from foreign citizens in this situation. Because first they are operated on urgently, then perhaps there are further operations for reconstruction [...] The ISI doctors are GPs. Anyone who has had a serious accident needs specialist treatment, rehabilitation, reconstructive surgery, which the indigent cannot pay for. The fee for physiotherapy has gone up recently. So, they refuse the treatment. After the visits immediately following A&E treatment (removal of stitches and things like that), they give up on the

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<sup>271</sup> As we have seen, the ISI Centre supplies a card with an alphanumerical regional code (STP code) necessary for accessing healthcare. The STP card is valid for six months and can be renewed. The foreigner who holds this card is exempt from fees, like an Italian citizen, with regard to first level or urgent treatment, pregnancy (services foreseen by DM September 10<sup>th</sup> 1998), treatment and medicines for chronic pathologies and rare and acute invalidating conditions. (See: S. Dacquino and A. Bergallo, *Guida ai servizi sanitari per immigrati*, Torino, LDF and Regione Piemonte, 2012).

<sup>272</sup> Health services are granted without a fee for the patient, except for the share foreseen (ticket) with equal treatment to Italian citizens. The STP foreigner is exempt from the ticket for: 1) first level treatment, direct access without booking and a prescription; 2) pregnancy and maternity; 3) interventions of collective prevention; 4) pathology; 5) age less than 6 or more than 65. If the STP foreigner does not have sufficient funds to pay the ticket, it is possible to apply for exemption X01, which is valid exclusively for the single treatment (*ibidem*).

appointments and the treatment. The result is that we have people who abandon the health services and are not treated completely. (Head of the Public Relations Office, CTO Hospital).

As we already mentioned, in addition to protecting health for economic and legal reasons, there is also the problem of the return to the labour market following an accident. The obstacle in this case is twofold and concerns, firstly, the consequences of the accident in terms of placement following the trauma, and in particular the capacity for carrying out a given activity, above all when the accident was of a serious and invalidating nature.

It is necessary to consider whether the handicap of a person who has suffered an invalidating trauma will allow them to return to work. Many accidents involve the hands and the hands are an important tool for any worker. This is already a serious limit. (Head of the Public Relations Office, CTO Hospital).

Apart from these circumstances, the irregular workers who have suffered an accident do not have the immediate possibility of finding regular work, since they lack a valid residence permit. This situation has led them, in some of the more serious cases, to obtain a visa for medical reasons<sup>273</sup>. Although this visa grants a residence permit for Italy, it does not, however, resolve the problem of the expense of medical treatment, which the patient must undergo during the rehabilitation process.

The patient who receives a visa for medical purposes must pay all the medical expenses and the cost of the treatment is equal to that charged to an Italian citizen, but as soon as there is a problem (they can't pay the expenses) they let the visa for medical reasons expire and return to being illegal residents. (Head of the Public Relations Office, CTO Hospital).

For some permanent invalids who do not have family members in Italy, plans are made for them to return to their country of origin. In these cases, INAIL continues to pay the disability benefit and to guarantee the supply of medical goods necessary for the home visits abroad, providing the person maintains their residence in Italy. Nonetheless, the projects for a return home are not always welcomed by the patients and they are not always successful. The environmental and medical standards in the country of origin may be particularly unfavourable. We must also take into account the problems of a cultural and social nature, associated with the condition of disability, which may represent an obstacle to the condition of disability, which may represent an obstacle in the social reintegration of the patient in their country of origin.

There was an Egyptian for whom we had organized a re-entry plan with the social workers at INAIL. INAIL sent to his home in Egypt all the sterile material for his catheter and they had even organized for the shipping and maintenance of a replacement wheelchair. However, the patient decided not to return home, because living in a hot country puts the paraplegic person at risk of urinary infections. The patient was rehabilitated and is now self-sufficient with regard to his disability, but as far as the urinary function is concerned, he has never reached full autonomy, because there is a continual need for check ups. (Head of the Public Relations Office, CTO Hospital).

### 3. *Permanent invalidity and the organization of the rehabilitation process*

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<sup>273</sup> The entry and residence permit for medical care is a document attained thanks to: a declaration by the chosen health structure indicating the type of treatment and the duration; certification of a deposit equal to 30% of the presumed cost of the treatment; documents proving that the patient can pay the expenses at the healthcare centre, and the expense for the return home for the patient and the person accompanying them (if any). It is not possible to enrol with the SSR. Residence permits are valid for a duration equal to the presumed duration of the treatment and can be renewed as long as the documented treatment lasts.

In the province of Torino, the incidence of serious injuries within the total number of accidents – those which cause permanent invalidity of more than 6% – and fatal accidents, is double amongst foreign workers with respect to those registered amongst Italians, with a percentage of 0.42% amongst the former, against 0.22% amongst the latter and a fatality rate respectively of 0.09% and 0.05%<sup>274</sup>. This is a phenomenon that, although limited with respect to the total number of accidents compensated, implies high social and human costs.

While the studies carried out so far have concentrated on the characteristics and conditions in which the serious work-related accidents have taken place, following a mainly statistical-epidemiological approach, the post-trauma phase of this type of accident is still little studied in its articulation and its implications. In particular, the foreigners who have been victims of invalidating accidents face complex problems that are interconnected and linked to their condition as immigrants. There is the specifically medical sphere, the medical-legal sphere, the economic and employment dimension and finally, the social and psychological aspects. The harmonisation of the procedures in these various spheres contribute to a successful rehabilitative result, or its failure.

The case of Nasser, aged 42, who came to Italy from Egypt in 1995, clearly exemplifies the complexity of these various dimensions, offering a subjective perspective of his experience. In 2004, Nasser suffered a serious accident in the workplace, at the factory where he worked with a contract and a regular residence permit.

One morning they called me early, about half past five in the morning. I had my cell phone on all the time because if there were problems on the production line, they called me. I went in because a machine was blocked, I opened it and while I was removing the blockage, the machine started up. It was faulty. In a second, it had almost cut my left hand off. I immediately put my other hand in front of the photocell to stop it, but this machine works with belts and it takes time to stop. The helicopter came to the factory and they didn't know what to do, whether to amputate immediately, or not. So, the helicopter went back to fetch the doctor, who operated on the spot. They amputated immediately and then we went to the hospital, where the doctor told me that I had lost my hand. (Nasser, 45 years old, Egypt).

Nasser's medical progress was reasonably simple. After about forty days from the accident and the first aid, through INAIL he was put into contact with the centre specialized in mechanical prostheses in Bologna. He underwent physiotherapy and recovered satisfactory use of the damaged limb. The assistance supplied by the local health authority and the rehabilitation went well, with the sensitivity and attention necessary, as Nasser himself says.

I was very satisfied with the Italian health service. They treated me really well. They looked after me. When I went to the local health authority for the therapy, they gave me precedence; I was treated before many other people, when they heard about my case. (Nasser, 45 years old, Egypt).

Nasser's experience is in keeping with the experiences gathered during a survey recently carried out by Fondazione Ismu<sup>275</sup>, which reviewed the stories of healthcare for foreigners injured at work and

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<sup>274</sup> M. Maltana, M.L. Tomaciello and A. Congia, *Lavoratori stranieri e infortuni sul lavoro*, op. cit., page 291.

<sup>275</sup> R. Bichi and R. Bracalenti, *Il lavoro che ferisce*, op. cit.

investigated their perception of the medical and legal results. The research showed that the majority of the patients expressed a good level of satisfaction regarding the services offered by the local health authorities and the hospitals. The Italian health system overall, in the perception of the interviewees, as in the experience of Nasser, was seen as open and receptive, capable of safeguarding the health of the foreign worker, with particular attention for the specific nature of the individual cases, but at the same time, in conditions of absolute equality with respect to the rest of the population.

At the same time, Nasser's medical-legal procedures continued. The process begins with the report on the accident. In the case of Nasser, the company was cooperative. The responsibility for the malfunction on the machine that caused the accident was traced to the company that supplied the machine. Nasser therefore began the process for ascertaining the degree of invalidity suffered. This is a process in which the invalidity rate is renegotiated in stages.

At first they gave me 40/100 invalidity points. However, then I spoke to some people who suggested that I get a lawyer. So, a colleague helped me to find one, took hold of the situation and negotiated with the company lawyers. They reopened my case and I had another meeting with the forensic physician, and I was given three more points. Things went on like this for years [...]. After a while, I went to INAIL to ask for a certificate of invalidity. Only that time, the lady who was dealing with my case stamped the certificate of another person by mistake. When I got home, I realized that it was not my document. It was a request for the same reasons, a case identical to mine. However, I saw that this document had an invalidity rate of 50%, while I had 43%. When I went back to INAIL to get a copy of my certificate, this lady compared the two cases and helped me to apply for another examination. They sent all my documentation to the doctor, who said that I had the right to 50 points. And that is how it went: quite by chance. And then they calculated the difference between 43% and 50%, also for the time that had gone by, for the previous years. (Nasser, 45 years old, Egypt).

The bureaucratic and administrative dimension is what causes, in the case of Nasser but also in many other similar situations, the greatest problems, like the lack of guidance or information, the complexity of the procedures, the difficulties in establishing a dialogue with the various offices and players involved in the medical-legal procedures.

The world of work is an equally important aspect of the rehabilitation of the patients, which however presents considerable difficulties and obstacles. The working hours are often too long for a person in a wheelchair, with the relative risks of bedsores, or it is too difficult for them to get to the place of work, after various hours of preparation. In many workplaces, there are still numerous architectural barriers that make services such as the canteen and the bathrooms inaccessible. Nonetheless, as the social worker at the Spinal Unit of the CTO Hospital says "returning to work is essential if they are to recuperate an identity and a role in society and the family. The INAIL benefits or the carer's allowance sometimes correspond to the wages prior to the accident, but often they are lower because the person worked in unskilled employment. However, some prefer to renounce this income, in order to return to work." In fact, this was Nasser's choice, he returned to work just three months after the accident.

They told me I could stay off work for a year, that it would be the same, there would be no problem. But my head was bursting with thoughts; I needed to go back to work. I could have stayed home for a year, and earned the same amount without working, because mine was a serious case. But at home I felt heavy, and my head was full of thoughts. I thought, 'if I go to work, at least I will have less worries'. So, they had me sign a paper, and I did it under my own responsibility. After three months exactly, I returned to work [...] Now I work on the electrical panels, they are all digital, and if there is something I can't do, I explain it to someone and he does it for me. Since the accident, I have also continued travelling abroad. (Nasser, 45 years old, Egypt).

The psychological-social condition of the permanent invalid is equally important in the phase of rehabilitation and reconstruction of a new equilibrium following the accident. One of the recurrent problems is solitude and isolation, a condition that involves above all foreigners without relatives in Italy. More than one out of five injured foreigners (21.5%) does not have a family member in Italy. In these cases, the urgency of reuniting the family in Italy<sup>276</sup> is dictated by the patient's need to receive assistance at home from the moment they are discharged from hospital, and the psychological risks associated with the physical trauma. Thanks to the central role that the family can play in the rehabilitation process, the reunification of the family is encouraged and supported by the medical structures themselves, in cooperation with other institutions, as a social worker at the Spinal Unit of the CTO Hospital tells us, and as happened in the case of Nasser.

Generally, we get organized to bring the family from the country of origin to Italy. We write detailed reports about the fact that a family presence is necessary, even just from the psychological point of view. We contact consulates and embassies to get them over here. (Social worker, CTO Hospital and Spinal Unit).

When the accident happened, my family was in Egypt. I spent almost one month in hospital, then they told me not to go home, to stay in hospital until someone from my family came. They helped me a lot [...]. When the accident happened, I had been married for one year. I had applied for family reunification a year ago, but it would be some time before my wife could come over. So, when I left the hospital, they speeded up our application for reunification and they pushed it through immediately. The social worker sent a letter to the Italian Consulate in Egypt to have my wife sent over, and they gave her a passport within a week. Then she bought a ticket and five days later, when I left the hospital, my wife arrived from Egypt. (Nasser, 45 years old, Egypt).

After the reunification with his wife, their first child was born, an event that assumed a fundamental role in accepting and symbolic rebuilding after his accident:

In May, on May 7<sup>th</sup> 2004, I had the accident. The same day and the same month in 2005, exactly one year later, my first son was born. That was a wonderful thing, to celebrate the birthday of my son on the day of the accident. I took this accident to be a sign: he took my forearm, he could have taken all of me, and instead, after one year exactly he made me a whole man. What more could I want, it was fate. It was simply fate; I have got on even better than before. (Nasser, 45 years old, Egypt).

Nasser's case can be considered one of the success stories of our health service and of the integration of the service with the more general welfare services. In the case in question, Nasser not only received the most suitable care, he was also able to return to work quite quickly and, more generally, he was able to recuperate his life, and they were also able to bring his wife home, a crucial aspect of his process of recovery.

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<sup>276</sup> *Ibidem*, page 58.

#### 4. Occupational illnesses: a little-known phenomenon

An occupational illness is “a pathology whose cause acts slowly and progressively on the organism”<sup>277</sup>. In occupational illness – unlike an accident, in which the event is sudden and violent – the causes are slow to act and diluted over time. Moreover, in occupational illness, the cause must be “direct and efficient”, that is capable of producing infirmity in an exclusive or prevalent manner. Therefore, for the occupational illness to be recognized, the place of work is not sufficient, as it is for an accident. There must be a causal, or concomitant link between the professional risk and the disease (see box 4 on the procedure for reporting occupational illness).

While the number of immigrant workers who are injured in the workplace has increased at approximately the same rate as the increase in the number of foreign workers, and settled following the economic crisis, that of occupational illness shows a much slower rate of increase, above all due to the period of latency (at times many years) of these diseases. While at the beginning of the new century, occupational illnesses that affected foreign workers in the province of Torino were mainly isolated cases, in the last fifteen years there have been around one hundred cases a year and the numbers have begun to increase, although they are still much lower than the number of accidents. In 2012, for the first time, they were more than 10% of the total number of cases reported in the province of Torino<sup>278</sup>.

As in the case of accidents in the workplace, also the number of occupational illness reported to INAIL seems to be greatly undersized<sup>279</sup>. In this case, there is a problem of non-notification caused, unlike work-related accidents, by the long period of latency of some pathologies, which tend to appear after many years<sup>280</sup>. Due to the period of time, which may be considerable, between exposure to the risk and the appearance of the pathology, the procedures for reporting occupational illness are much more complicated than those for accidents. Often it is only possible to complete them after a number of years and the majority of such cases is concluded without it being possible to recognize the disease as effectively being linked to the workplace. Also for occupational illness, the number of cases rejected is greater amongst foreign workers than amongst Italian workers, with a much wider gap compared to accidents (82% against 64%)<sup>281</sup>. The responsibility for the low rate of recognition of occupational illness is to be attributed to the difficulty in showing the causal link between the working activity and the lack of knowledge amongst GPs of the possible correlation between the risks present in the workplace and the number of pathologies that may derive from it. According to Anmil (Associazione Nazionale dei Mutilati e Invalidi del Lavoro – National Association for Mutilated and Invalid Workers) there are particular difficulties in dealing with recognition of the causal link between disease and exposure in the workplace in the case of pathologies with multi-factor exposure, causing a certain margin of uncertainty and ambiguity in determining the professional causes of a disease. The development of a disease contracted for professional reasons can only in certain cases be attributed to

<sup>277</sup> INAIL, *Malattie professionali. Indirizzi operativi per l'emersione e la prevenzione*, INAIL, Azienda ULSS 12 Veneziana, 2013

<sup>278</sup> M. Maltana, M.L. Tomaciello and A. Congia, *Lavoratori stranieri e infortuni sul lavoro*, op. cit., page 262

<sup>279</sup> Italian Senate, Report of a Parliamentary Commission on accidents in the workplace, *Relazione intermedia sull'attività svolta*, Relatore Senatore Oreste Tofani, Approved by the Commission on October 7th 2009, XVI Legislature, Doc. XXII-bis N. 1, page XXX.

<sup>280</sup> M. Maltana, M.L. Tomaciello and A. Congia, *Lavoratori stranieri e infortuni sul lavoro*, op. cit., page 263.

<sup>281</sup> INAIL, Direzione Regionale Piemonte, 2012.

a single cause or a set of specific causes linked to the workplace; while it may, on the other hand, depend on numerous individual environmental and/or lifestyle factors that contribute to causing the harm.

This research took into consideration two sectors, very different in the type of duties carried out, the working context and the level of formality of the sector, which register a high number of foreign workers and which are characterised by a high intensity of work and physical effort: the transport sector and care of old people. In both sectors, muscular-skeletal disease – back pain – emerges as a recurrent pathology, although it is sometimes difficult to prove report and see recognized as an occupational illness. It is one of the most common occupational pathologies, although with variable levels of gravity, amongst the foreign workers, representing almost 54% of the total number of occupational illness<sup>282</sup> and according to ISTAT data<sup>283</sup> particularly involves foreign workers (42.1%) compared with Italian workers (28.5%). This type of condition is undoubtedly linked to the wearing working conditions and the uncertainty that often characterizes the employment of the foreigners. However it must also be considered, from a strictly epidemiological standpoint that, since migration for employment is a relatively recent phenomenon, amongst the foreign workers pathologies with relatively brief periods of latency prevail, with respect to other pathologies, such as professional tumours.

From the testimony of Carlos, a Peruvian worker who came to Italy in 2002 and has been employed in the transport and logistics sector at Torino Airport since 2005, it is evident that the majority of the workers at the cooperative for which he works, who are 80% foreigners and Peruvians in particular, suffer from back pain caused by the constant physical strain and are subject to repeated accidents.

We are apron workers; we load and unload the planes by hand. And we also operate the unloading machinery, conveyor belts, tractors or carts. We also work in the goods sector; we work with forklift trucks. The accidents that happen most often are caused by the effort we have to make. They involve your back, above all. About 60%-70% of the workers has back problems. You start with pain, then suddenly your back locks and you can't move. (Carlos, 38 years old, Peru).

A representative of the CGIL (trade union) in the transport sector says that the union encourages workers with technopathies<sup>284</sup> to gather the relative documentation on the occupational hazards, reporting and documenting every single incident, so that they arrive with a file that documents all the incidents in the workplace. From an operative standpoint, the INAIL procedure in the case of occupational illness finalized in the verification of cause-effect between the working activities and the pathologies reported is based on the medical-legal examinations and the acquisition of all the proof of exposure to professional risk. This appraisal is based on a working anamnesis designed to investigate every possible factor of professional risk of the pathology reported, by identifying information on previous incidents or technopathies. An interview with the CGIL shows how the occupational illness can be easily identified and therefore recognized as the result of various incidents.

Our offices always advise the workers to report the various incidents to one of the *patronati* (trade union offices that carry out various administrative procedures on behalf of workers, NdT.). If they keep a clear

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<sup>282</sup> M. Maltana, M.L. Tomaciello and A. Congia, *Lavoratori stranieri e infortuni sul lavoro*, op. cit., page 262.

<sup>283</sup> ISTAT, *Salute e sicurezza sul lavoro*, Statistiche Report, Anno 2013, 2014, page 262

<sup>284</sup> Technopathy is a professional illness due to a harmful, slow and protracted risk factor in the workplace.

record, if a person reports 10-11 incidents of the same kind, it is more likely that the occupational illness will be recognized. In this way, the health problem related to the work is somehow monitored. Otherwise, it is very difficult to demonstrate. (Representative FILT CGIL, Torino).

The problem highlighted, which is common to both Italian and foreign workers, is that the incidents reported are often not accepted as such, and therefore risk being catalogued as ordinary illness. In this way, the cause of the pathology is not traced to the work carried out.

When I had my accident, I was seen by a doctor at the airport. From there they sent everything by computer to INAIL. They only gave me an appointment for a check-up. I remember that I had backache and I my back 'locked' when I was in the hold of the plane, but they didn't recognize this as an accident, just as an illness. INAIL does not consider this problem sufficiently serious to be considered a work-related accident<sup>285</sup>. We are quite capable of knowing what to do in these cases. Do we have to lose an arm in order to have an accident recognized? We don't understand why our work-related accidents are not recognized. (Carlos, 38 years old, Peru).

Often, INAIL tries to pass off occupational illness passed as an illness *tout court*. This is a problem, because if an accident passes as a common illness paid for by INPS (the national welfare system) then it is no longer an accident and cannot be linked to occupational illness. This is the worst risk, because often the doctors at A&E are careful. Usually, when the workers hurt themselves in the airport, where there is an A&E department, they are seen first at the airport A&E and then they go to the hospital in Ciriè. However, for example, the workers don't know that they must be careful what the doctors write, because if the doctor writes that this is a person who came from home with backache, and not that they tore a muscle at work, it is no longer a work-related accident, they tick the box 'illness' and not the box 'accident'. We have taken up lots of certificates written like that; in these cases, INCA intervened, reporting the error. (Representative FILT CGIL, Torino).

While the transport sector has a high level of contractual employment and regulation of the duties carried out, above all in contexts such as airports, where the safety standards and the controls are severe, the working conditions of those employed in the health and care sectors are very different. This sector has become, in the last decade, the main area of employment for women who have immigrated to Italy. In 2011, more than one foreign woman in two (51.3%) in Italy was employed as a domestic worker or a carer<sup>286</sup>. In the same year out of a total of 881,702 domestic staff, more than 80% were foreigners (Fondazione Leone Moressa on INPS data). This is a sector in which, more than in others, the concurrent interest of the employer – the families – and the domestic worker make recourse to unregistered work more common: according to recent estimates produced by the national statistics office<sup>287</sup>, about half the domestic staff in Italy was employed on an irregular basis during the last ten years.

From the standpoint of occupational health, the social-healthcare workers in family contexts are often not equipped for managing bed-bound persons. Prolonged strain, if not managed through adequate training, can be harmful for the health of the workers. Back strain is the most common pathology amongst carers, which, according to a CENSIS study<sup>288</sup> affected 61.3%. The interviews carried out as part of the LDF research with the associations ASAI<sup>289</sup> and Alma Mater<sup>290</sup> who operated in support of the female workers in the care sector, highlighted this problem.

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<sup>285</sup> The days of temporary absolute inability to work must be in excess of three, before a report can be filed with INAIL.

<sup>286</sup> CNEL, *Il ruolo degli immigrati nel mercato del lavoro italiano*, op. cit.

<sup>287</sup> ISTAT, *La misura dell'occupazione irregolare nelle stime di contabilità nazionale*, 2011, [www.istat.it/it/archivio/39522](http://www.istat.it/it/archivio/39522).

<sup>288</sup> Censis, *Percorsi di prevenzione per la messa in sicurezza dei lavoratori domestici*, 2009, page 64.

<sup>289</sup> <http://www.asai.it/sportellolavoro>.

<sup>290</sup> <http://www.almaterratorino.org/it/home>.

Backache is a considerable problem, the effort needed to lift a sick person from their bed to the wheelchair, the movement and transportation, etc. That is true for the auxiliary nurses (OSS) in the nursing homes, who suffer from slipped discs, crushing of the vertebrae and chronic back pain. In fact, some of them say, “I will work, but not for an old person who needs lifting, because I just can’t do it.” (Head of ASI job centre).

Many of these people have slipped discs or symptoms that require surgery, or they even lose their jobs because they can’t go on working. (Alma Mater job centre).

While in 45% of the cases, the symptoms appear suddenly and can be traced to a traumatic episode, in the remaining cases the commencement is silent and latent<sup>291</sup> and can therefore assume the characteristics of an occupational illness, which is “a harmful event for the person that appears in a slow, gradual and progressive, involuntary way and during work”. Also in this sector, backache and pain linked to the prolonged physical effort remain, nonetheless, they are difficult to document as occupational illnesses. Since the working relationships are not continuous, from the medical-legal point of view, it is in fact more complicated for the social and healthcare workers to demonstrate a period of exposure to risk sufficiently long to be associated with the symptoms.

Years ago, we decided to carry out a survey with **Alma terra**, asking the workers to bring in their x-rays, so that we could make a comparison.... Because there is nothing scientific in hearing someone say, “I have backache”. You must have data if you are going to carry out a serious investigation into occupational disease [...] The objection the forensic physicians make is, “What was the condition of the spinal column before they began working as carers?” The fact is that we have no idea. (Head of ASAI job centre).

**Commento [KMC4]:** Si intende Alma Mater, l'altra associazione menzionata?

##### 5. *Stress related to work: burnout and domestic work*

In recent years, numerous studies on domestic work<sup>292</sup> have shown that there are a series of specific vulnerabilities associated with this work<sup>293</sup> and with the working conditions and the lifestyle it implies, above all in co-residential mode. Those who work and live with the person they look after are often dealing with a person who is old or not self-sufficient, with various degrees of physical or mental disabilities, or cognitive problems<sup>294</sup>. It is physically hard work and emotionally draining. This form of family assistance involves a considerable level of promiscuity between work and personal life, a lack of privacy, inadequate living conditions and at times exposes the women to the risk of harassment or sexual abuse<sup>295</sup>. Moreover, the way this assistance is given can easily transform the working context into a surrogate family for the workers<sup>296</sup>, leading to asymmetrical “semi-familiar”<sup>297</sup> relationships, where the professional relationship and the relative,

<sup>291</sup> M. Giovannone and S. Spattini, *Lavoro in ambiente domestico, telelavoro e lavoro a progetto: linee guida e buone prassi per la prevenzione dai rischi, anche in chiave comparata, alla luce della riforma del mercato del lavoro in Italia*, research project financed by the Italian Ministry for Labour and Social Policies. Adapt, 2009, page 307, [http://www.lavoro.gov.it/SicurezzaLavoro/Documents/08\\_RAPPORTO\\_IT.pdf](http://www.lavoro.gov.it/SicurezzaLavoro/Documents/08_RAPPORTO_IT.pdf).

<sup>292</sup> See: M. Tognetti Bordogna, *La realtà delle badanti, criticità e prospettive nell'assistenza agli anziani*, in «Rassegna di servizio sociale», 1, 2006, pages 43-56; G. Lazzarini, M. Santagati and L. Bollani, *Tra cura degli altri e cura di sé. Percorsi di inclusione lavorativa delle assistenti familiari*, Milano, Franco Angeli, 2007; G. Lazzarini and M. Santagati, *Anziani, famiglie e assistenti. Sviluppi del welfare locale tra invecchiamento e immigrazione*, Milano, Franco Angeli, 2008.

<sup>293</sup> A. Triandafyllidou (ed.), *Irregular Migrants Domestic Workers in Europe. Who cares?* Aldershot, Ashgate, 2013.

<sup>294</sup> S. Pasquinelli and G. Rusmini, *Badanti: la nuova generazione. Caratteristiche e tendenze del lavoro privato di cura*, Milano, Istituto per la Ricerca Sociale, 2008.

<sup>295</sup> Agenzia europea dei diritti fondamentali, *Migrants in an Irregular Situation Employed in Domestic Work: Fundamental Rights Challenges for the European Union and its Member States*, Luxembourg, Publications Office of the European Union, 2011.

<sup>296</sup> A. Triandafyllidou (ed.), *Irregular Migrants Domestic Workers in Europe. Who cares?*, op. cit.

<sup>297</sup> M. Romero, *Maid in the USA*, New York, Routledge, 1992.

reciprocal rights and duties are often not formalized, or clearly defined. The domestic workers in co-residence work long hours and are often required to be available also outside the hours agreed with the employer<sup>298</sup>. In some cases, the latter ask the migrant worker to give up their rest day in exchange for extra payment. This request, which is often accepted by the workers, can generate psychological and physical stress<sup>299</sup>. Studies in the field of occupational medicine have shown that prolonged working hours, night-time work and shifts that foresee an irregular distribution of the working hours, have negative effects on the psychological conditions of the workers<sup>300</sup>.

Often the co-resident domestic workers are implicitly seen as not having the right to a family life<sup>301</sup>, despite the fact that 80% of them are women, many in their childbearing years. Nonetheless, while their work allows the employers to conciliate caring for relatives with professional activities, these workers often find it difficult to conciliate their own work with starting or looking after their own family<sup>302</sup>. Globally, more than a third of the domestic workers is excluded from the social protection norms such as maternity leave and integration of income during maternity leave. Moreover, pregnancy can often lead to the loss of the job for domestic staff<sup>303</sup>.

In the majority of cases, the workers who act as domestic workers or carers for aged or disabled persons are newly arrived immigrants. They often do not have a residence permit or have precarious legal status; they have weak networks and limited access to information on their rights, on the structures and the services for integration<sup>304</sup>. Moreover, many of them have come to Italy in order to allow their children to study in their country of origin. The need to quickly find work in Italy, in order to send money back to the family they have left behind, is a further element of psychological pressure on the women, while their condition of legal, economic and social precariousness and their weak contractual power makes them more likely to be employed in this area of assistential work, and to accept unfavourable conditions. The fact that they have weak links, limited professional experience in the sector and poor linguistic skills, prevents these foreign domestic workers from acquiring adequate knowledge of the services for home care for old people, the regulations and the social and occupational rights relating to this profession and makes them particularly vulnerable to abuse.

Even following the processes of regularization and increased mobility of migrant domestic workers in Italy, attaining a job with a regular contract does not necessarily correspond to a significant improvement in the working conditions. The content and the methods of work are negotiated within the family and the

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<sup>298</sup> International Labour Office *Decent Work for Domestic Workers*, International Labour Conference, 100th Session, Report IV(1), Geneva, International Labour Office, 2011; E.G. Rodriguez, *The «Hidden Side» of the New Economy. On Transnational Migration, Domestic Work and Unprecedented Intimacy*, in «Frontiers», vol. 28, 2007, N. 3, pages 60-83.

<sup>299</sup> Agenzia europea dei diritti fondamentali, *Migrants in an Irregular Situation Employed in Domestic Work*, op. cit., page 28.

<sup>300</sup> Tucker and S. Folkard, *Work Scheduling*, in *The Handbook of Operator Fatigue*, ed. G. Matthews, P.A. Desmond and P.A. Hancock, Burlington, Ashgate, 2012.

<sup>301</sup> A. Triandafyllidou (ed.), *Irregular Migrants Domestic Workers in Europe. Who cares?*, op. cit.

<sup>302</sup> ILO, *Domestic Workers across the World: Global and Regional Statistics and the Extent of Legal Protection*, Geneva, International Labour Office, 2013.

<sup>303</sup> ILO, *Domestic Workers across the World: Global and Regional Statistics and the Extent of Legal Protection*, Geneva, International Labour Office, 2010

<sup>304</sup> See E. Castagnone, E. Salis and V. Premazzi, *Promoting Integration for Migrant Domestic Workers in Italy*, International Migration Papers N. 115, International Migration Programme, Geneva, International Labour Office, 2013; M. Ambrosini, *Dentro il welfare invisibile: Aiutanti domiciliari immigrate e assistenza agli anziani*, in «Studi emigrazione», N. 159, 2005, pages 561-595.

relationship between the employer and the domestic workers tends to remain asymmetric. The permanent situation of insecurity, deriving from precarious work or the condition of irregular legal status, can in fact generate stress and fear of being dismissed and deported.

All these elements affect the physical and mental health of those who work in these professions. Nonetheless, despite the increasing number of workers in this sector and their specific characteristics, there is still little literature on the ways in which the health of these workers is linked to their work and their living conditions and to their access to healthcare.

In particular, burnout<sup>305</sup> has emerged in recent years as the most common occupational illness amongst domestic workers. In recent years, researchers have attributed to the syndrome various meanings that can be summarized in a single definition of burnout as ‘a set of symptoms that bear witness to the presence of a behavioural pathology, typical of all the professions with a high relational investment’.

Burnout has elements in common with numerous illnesses of a depressive nature, linked to the stress of work; however, it is configured as a phenomenon with specific characteristics. The most important is that it occurs in professions linked to care (doctors, psychologists, nurses, social workers, carers), all jobs that involve a dimension of help, of intense contact, and which are based above all on the relational skills<sup>306</sup>. A further cause of burnout is linked to the working times and the organization of the work, to the interpersonal relations with the persons assisted and with their relatives. The majority of the studies has concentrated on the professional category of nurses, studying the harmful effects of burnout on the individuals and on the institutions of the health sector, almost completely ignoring the category of carers. In this latter sector burnout is still a little-known phenomenon, which does not fall within the area of legal responsibility of the employer to compensate the worker for harm that was caused in the workplace, although it is becoming increasingly important in the sociological and medical field<sup>307</sup>. While some working conditions may be associated with specific causes of psychological upset, in general the line between occupational illness and everyday illness, for these problems, is not clearly drawn and is difficult to diagnose. In the year 2011, about 600 cases were reported to INAIL, with a percentage of compensation of less than 10%. These were above all for “chronic disturbances of adaptation” and “work-related post-traumatic stress”, more commonly known as mobbing<sup>308</sup>. The percentage of compensation for these occupational illnesses is low, because it is difficult to verify the origin of occupational illness.

In order to highlight some of the problems of access to healthcare in this sector and in relation to this specific occupational illness, we give the case of Irina, a Romanian woman who arrived in Italy in 2002, for a brief substitution as a carer; she has since remained in Italy. The experience of Irina is unique and as such not representative of the domestic workers who suffer from psychological problems overall, and whose

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<sup>305</sup> The term burnout was coined for the first time in the USA by Herbert Freudenberger, who in 1974 defined the syndrome as “state of mental and physical exhaustion caused by one’s professional life”. Later, in 1976, Maslach described burnout as a specific occupational illness of carers, which affected above all the more motivated and those with higher expectations from their work. See ISPESL, *Stress & Burnout: come riconoscere i sintomi e prevenire il rischio. Guida per operatori sanitari*, Roma, Dipartimento di Medicina del Lavoro, Centro Ricerche di Monte Porzio Catone, 2008, page 11.

<sup>306</sup> S. Ferrua and M. Giovannone (ed.), *Salute e sicurezza dei lavoratori: il caso dei servizi sanitari di assistenza alla persona*, Modena, Dossier Adapt n. 12, 2009, page 6.

<sup>307</sup> M. Giovannone and S. Spattini, *Lavoro in ambiente domestico, telelavoro e lavoro a progetto*, op. cit., page 275.

<sup>308</sup> Inail, *Rapporto annuale 2011*, part IV, 2012, page 27.

stories remain submerged and are unlikely to result in access to healthcare. Nevertheless, her case highlights some important points of the genesis, the process of recognition and the treatment of psychological illness linked to the condition of worker in the family care sector. Irina began her story like this, emphasising two aspects of her experience at the time of her arrival in Italy: the solitude in the country of immigration and the social isolation caused by her work on the one hand and by the servile relationship that forms with the person assisted on the other, which imposes a relationship of asymmetric power.

When I arrived in Italy, I found myself in a totally unknown environment, with completely different rules, without any friends or relatives. You come to work [as a carer] for a person, who does not see you as a person, but as a tool to be used as they wish. This often happens. It is a job in which you are, in any case, in a servile position. [The old person] considers you almost an object when you are in the house. I remember that I was working for this old woman. She shouted orders and she insulted me. She humiliated me in every way. It was difficult. Even if there is not much to do in the house, it is difficult if you have no contacts, with all your social links cut off. You are closed in a house with an old person, and you are absolutely at their beck and call. (Irina, 36 years old, Romania).

As Alina, another domestic worker interviewed for this research project, says, the stress of the work does not show evident symptoms and the problem of its recognition concerns both the workers themselves and the medical-legal and health institutions.

There are illnesses that can be seen and others can't. Stress can't be seen [...] I want to talk about the hidden things, the ones that are not visible. When you fall, you can see the results of the accident and its effects, the pain in your back. But I think that there should be more attention for this aspect, for what is not visible. It is necessary to speak of the stress related to the work. (Alina, 45 years old, Romania).

The recognition of burnout is first of all linked to the recognition of the psychological illness as such, but also to its acceptance, to overcoming social and cultural prejudices linked to it, to the awareness of the need to ask for help and be treated, to the acceptability of the treatment and psychological support, in moral, cultural and social terms. As already mentioned in the research carried out by LDF in 2011<sup>309</sup>, for many cultures psychological illness does not exist as such, or is only defined in the presence of very serious conditions, while psychological upset tends to be considered part of normality, rather than a pathology and is often less medicalized than in the Italian context. For this reason, the problems of mental health are easily stigmatized amongst the migrant populations. This makes it even more difficult to identify them and deal with them, also when they are quite mild. Suffering a psychiatric pathology is considered by many carers an embarrassing and socially unacceptable fact.

I didn't have the strength, or the culture to go to the [mental health] services. I think it is a cultural question. Because we Romanians only go to the doctor when we are really ill. We don't have a culture of prevention. I didn't want to go to the doctor and say 'I am crazy' or something like that... (Irina, 36 years old, Romania).

Consequently, access to health care in this sector requires specific cultural tools. As a cultural mediator from the association Mamre, an ethnopsychological and psychotherapeutic centre, explained, the

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<sup>309</sup> I. Biglino and A. Olmo, *Health as a fundamental right: a study on migration and healthcare in Turin*, op. cit.

migrants often do not have a culture that allows them to recognise their emotions, to give them a name and build a period of analysis.

At times, a person manages to find Mamre, coming into contact with the reality of psychological work and they realize that this work, based on words, is a surprise, that it is not easy. It depends where they come from but the foreigners are quite diffident. They do not recognize their emotions, they don't know how to work with that part of themselves. It's not that they don't want to, it's that they are not capable. They can't give it a name. So it is difficult at first. Then, very slowly, as they move forward, they realize that it is extraordinary to have a space where you can unlock your thoughts, where you can talk. They didn't know that it was possible for this type of work to allow them to reorder everything around them. Then, there are people with whom we can't do anything, because they remain on the surface and we can't reach them, because it is very painful, it's hard work. There are people who refuse. They have enormous problems. (Cultural Mediator, Mamre, Romania).

What is more, for those who have arrived only recently in Italy and have illegal status, with a weak network in the place they have arrived, there is only limited access to information and the fear of being reported and losing their work. Despite the fact that there are services available to migrants without a residence permit, the irregular residents generally do not have the means to ask for help and indications of where to find adequate services and they often do not know about the services available. Consequently, they are not able to deal with the health problem and often turn to other systems, like self-medication, or go to a pharmacy, as Irina did.

After working with this lady for eight months, I had my first panic attack. At least, I realize now that that is what it was, now that I have been treated. I felt awful. I was also an illegal resident. There was a friend of mine, I went to the pharmacy, and I said, "I feel bad, really terrible," and they gave me a mild anti-depressive. They simply gave me an anti-depressive. I was afraid and I took half the pill, because I was afraid I would mess things up. (Irina, 36 years old, Romania).

Irina found out about her depression and the psychological trauma caused by her work and the living conditions when she was a carer only some years later. A number of years after she left domestic work, she began a course of psychological, non-medical treatment. Irina began individual psychological therapy at the cooperative where she was working, where she met a psychologist, who then treated her at her private office.

I dealt with my problem many years later. My psychological disorder came out while I was working at a social cooperative, three years ago. With our work there were a lot of disagreements in the team and we all got very upset. So they brought in a psychologist who monitored our work group. There I began individual treatment, that way I could afford it, because psychologists are expensive. At the cooperative there were sessions for our work, but there were also individual sessions, that lasted for two years. Then the psychologist left the cooperative, she set up her own private office and I went there, because I didn't want to change my therapist, or I would have had to start everything all over again. (Irina, 36 years old, Romania).

In the case of serious illness, which requires access to psychiatric assistance and the prescription of psychotropic drugs, or in the case of the degeneration of a mental disorder, the psychological support is insufficient. Irina's experience with the CSM (*centro di salute mentale* – mental health centre) of the national health service was problematic from the first visit, as she told us. Nevertheless, turning to a private specialist in alternative to the public service is often considered too expensive.

That was a really bad moment for me. I had no money and no work. From one day to the next, I found myself idle. From the chaotic life that I had been living, I found myself without work. I went to ask for an appointment at the CSM. The person who received me at the centre asked some questions. I only understood later that he

was a nurse at the CSM (and not a doctor). He said, “Phone on Thursday, when the doctor is here, we will take your records into the meeting, then when the doctor is here, he will interview you and we’ll decide whether you need to take something or not”. (Irina, 36 years old, Romania).

Irina’s evaluation of the assistance received from the national health service is not positive. When she finally managed to fix an appointment with a doctor at the CSM, not only was the session useless because it was delayed with respect to the acute phase of the depression, but also due to the way it was conducted, as she will explain. Irina also reported the inadequate use of the cultural mediation service, which was called on during the second telephone contact with the CSM. The intervention of cultural mediation was supplied in her case on the basis of an arbitrary evaluation – the fact that she was Romanian – and not on the basis of effective need or usefulness, nor even on the basis of an explicit request by the patient.

It is already difficult to contact a doctor for mental health problems. I phoned the CSM and when they realized that I am Romanian, they handed me over to a Romanian woman who spoke Italian worse than me. I explained to her that I had already spoken to a nurse, that he had written everything down on a piece of paper and that he had told me to phone for an appointment on that day. She said I didn’t have an appointment with the doctor. She said that the nurse was on holiday and there was no sheet of paper. I was furious. Then I said, “You are crazier than me. Ciao!” Then I calmed down and I went back to my psychologist to finish the treatment. And so, in my opinion, the CSM is useless. It is for those who are in serious difficulty. I believe that only 1% of those who are really ill get treatment from the CSM. (Irina, 36 years old, Romania).

Once the date for the clinical interview fixed by the CSM arrived, Irina went anyway, finding a public service with poor quality assistance<sup>310</sup>. Irina feels that the services offered by the CSM are not acceptable either from the cultural standpoint (in relation to the inappropriate use of cultural mediation in her case), nor in professional terms (that is the quality of the service offered, from the time she first contacted the CSM and during the session with the specialist).

Then, when the time came, I went to the appointment, because I couldn’t just say “I’m not going”. In the end I managed to get an appointment. I went, but I didn’t need the treatment any more. It was embarrassing. I found it difficult to tell everything. You have to tell your private thoughts to a person you don’t know. It’s one thing to talk to my psychologist, who I have known for some time and with whom there is a bond created through the psychotherapy. But here I found myself with a person I was meeting for the first time, with my piece of paper in his hand, and I said “This, that, and the other”. He took the piece of paper and began reading out loud. I felt out of place. It was embarrassing to hear those things read out, those things that I had written. And the tone was... (monotonous). It was a very embarrassing moment. (Irina, 36 years old, Romania).

Ironically, Irina’s experience can be considered a positive case, in which there is a growing awareness of the psychological problem and where the meeting between the need for healthcare and the offer lead to a successful cure, although with certain limits. The public health system was revealed to be inefficient and inadequate, that is it acted late and badly and was not able to create a bond with the patient. Moreover, the emergence of psychological upset and the start of treatment, in Irina’s case, began through the private system, many years after she left domestic work and in a very different working context.

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<sup>310</sup> Previous studies reported the difficulties found by the CSM in supplying adequate services in qualitative and quantitative terms. See: I. Biglino and A. Olmo, *Health as a fundamental right: a study on migration and healthcare in Turin*, op. cit.

## 6. *Treatment or work? When the right to health is in conflict with the right to work*

The health problems generated in a working context are difficult to identify report and recognize as such, as we said before, but they can also be a threat to current employment or represent an obstacle to access to future employment. The state of a worker's health has an effect on the possibility of being employed, and it can be said that it plays a decisive role in the case of domestic work.

At the time of recruitment, for the family who is seeking a domestic worker or carer, the worker must have certain human and professional characteristics. Amongst the qualities required, the worker must also be in good health and efficient, be psychologically healthy and resistant<sup>311</sup>. We have already mentioned the physical effort required of workers in this field, often without adequate help (patient lifts and slings) and in unequipped settings, (the homes of the persons assisted). If the worker's physical capacity is lessened, they are less able to carry out the more tiring work and their efficiency is affected. The carers are required to look after their own relatives, but it is preferred if they are not needy, since this would limit or complicate the management of the patient. If the worker is ill, or has health problems, they may be absent from work, in order to receive treatment or care, or there may be specific conditions for the co-residence with the patient, which complicates the situation for the standpoint of the family that employs them, the working relationship or introduces limits to the services offered. From the interviews, it is clear that many women tend to omit their physical limits in carrying out their duties, or to keep quiet about certain pathologies, that will limit the management of the co-residence.

[At the interview] one of the questions was about our health. What do you eat, what don't you eat? They want us to be perfect. If you don't tell the truth at the start "I can lift one thousand kilos"... then you don't know how you will manage later on. Today, to get a job you have to hide your situation. Life forces you to do that, if you are going to feed your family. (Nicoleta, 45 years old, Moldavia).

They are afraid to declare their state of health, because (the workers) they know that if they declare some physical difficulty, they will not get the job, so they don't mention it at the interview. But perhaps they have serious problems. Also, it is necessary to work in order to keep the residence permit... so it is a very delicate situation. (Cultural Mediator, Mamre, Romania)

I have always had this problem with my back, so they know about that. I have always had to 'jump through hoops'. They don't want me because I can't put their relative to bed. Because I have a problem with my bones, even the slightest effort hurts me. So I refuse. This is a major problem, this way of living where we always have to hide, because that way the family likes you. You must always be smiling. (Nicoleta, 45 years old, Moldavia).

The need to find work and not be unemployed in many cases leads the workers to putting their own health aside, with the main aim of finding or keeping a job. They are aware that the supply exceeds the demand in this sector and that the families can therefore choose from a vast pool of workers, easily rejecting the candidates who do not meet their expectations.

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<sup>311</sup> A. Sarli, *Il disagio della cura. I vissuti professionali delle assistenti familiari occupate in Italia*, unpublished doctoral thesis, Università degli Studi di Modena e Reggio Emilia, 2011, page 37.

The workers (domestic workers and carers) are often desperate women who will accept any job. Rightly, when they arrive they are ready to do anything, they never object ('look, I can't do this or that), they don't consider their limits and therefore they accept any work. There are people who go on for a long time, trying to put up with certain conditions... at times there are also sick people. (Cultural Mediator, Mamre, Romania).

Finally, the work of co-residential care is very precarious by its very nature: the turnover is high, also due to the conditions of the old people they are looking after, whose health may suddenly worsen. The new demand for immigrant domestic workers finds a response above all in the immigrants who have arrived most recently, who are most willing to accept difficult working conditions, in the absence of better opportunities. The short-term nature and the high intensity of this work tends to cause a high rate of turnover.

If you say no (you don't agree to lift weights) due to a bad back, they will get someone else. When they look for a carer from 30-40-50 people, they choose one. In any case, they will find someone willing to do what they ask. And you, if your fridge at home is empty, will say yes. You already know that you will not be able to do it, but what can you do? You say yes. Perhaps you last one month, perhaps two. (Alina, 45 years old, Romania).

In a similar manner, but with an inverse mechanism, for the migrants who find work, the fact that they are employed becomes an obstacle to accessing appropriate medical care. Research in this sector has shown how the initial "health capital" of the migrants employed in the domestic sector is exhausted or strongly eroded over time. The immigrants who are healthy when they arrive in Italy, during the years they work in the domestic sector are often exposed to physical traumas, stress and anxiety, conditions made even more problematic by the lack of sleep, the impossibility of controlling the rhythms of work and life, the isolation and the lack of privacy.

The national contract guarantees domestic workers recognition of illness and accidents in the workplace<sup>312</sup> and paid leave for medical treatment during working hours. However, when health problems arise, the possibility of taking a few days holiday from work or getting leave for medical reasons is not always guaranteed. According to an ISTAT study, more than 16% of the foreign workers say that it is difficult to organize medical tests or appointments due to working hours. The possibility of organizing medical tests or appointments on the basis of personal or family commitments is present for 8.6% of the foreigners<sup>313</sup>. The commitment with the family for whom they are working makes it difficult to contact the health services. The obstacles to this service are caused by the lack of flexibility of the employers regarding the schedule of the workers.

Many of the (workers) in order to keep their jobs, put up with the situation, until they get to the point where they can't go on. And then, they have to go for treatment, creating an upset, because the relative of the person they look after has to find another person to take their place. Often, in order to avoid creating an upset, they keep quiet and soldier on. In this kind of work you can't say "I have the right to treatment", without losing

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<sup>312</sup> In the case of accident or occupational illness, domestic workers have the right to have their jobs guaranteed for ten working days, if they have more than six months of service – for forty-five days if they have between six months and two years service and for one hundred and eighty days for service over two years (Article 28). Workers must be guaranteed full salary for the first three days. Furthermore, pursuant to Article 28.3 CCNL, domestic workers have the right to the measures set out in DPR N. 1124, dated June 30<sup>th</sup> 1965<sup>312</sup>. These measures include compensation for temporary inability, income for permanent inability, contributions for continuative personal assistance, contributions for survivors and a payment in the case of death, medical care or surgery and the supply of prostheses.

<sup>313</sup> Istat, *Cittadini stranieri: condizioni di salute, fattori di rischio, ricorso alle cure e accessibilità dei servizi sanitari. Year 2011-2012*, Istat, Ministero della salute, 2014, page 1.

your job, or “Anyway, I am covered by the SSN”. That’s not the way it is. This is an enormous problem! Let’s hope it will be recognized! (Cultural Mediator, Mamre, Romania).

Therefore, the majority of these women continues to work in order to keep their wages. This problem is present for both those who do not have a work contract and for those who have regular employment, since, as we said, not all those who have a regular contract have full access to their rights.

In the case of lengthy absence from work, there is the danger that the family will find a substitute, who can take the place of the former worker and cause the loss of the job. This risk, associated with the suspension of wages in the case of lengthy absence, leads the domestic workers to work even when they are ill<sup>314</sup>. Due to inadequate access to the health services, the immigrant domestic workers do not seek treatment rapidly and in an appropriate manner. This may lead to permanent invalidity or chronic illness<sup>315</sup> or prevent the workers from receiving the appropriate treatment, as occurred in this case reported by Alma Mater.

In this job you can’t get ill. We have a friend, for example, who thought she had a cold, then she found it was much more than a cold, it was cancer... For fear of losing her job, she didn’t stay at home to rest and have treatment... So she neglected it, she had this continual cold and she kept coughing, she had a temperature and she continued to go to work. Then one day she was sacked. This contract doesn’t protect domestic workers. She had worked and now she was ill, she was unemployed, she had no money to pay the rent, she had no one to help her. (Work Group, Alma Mater).

While the working conditions of the foreigners can be the cause (literally determining health problems) of work-related accidents or occupational illnesses, their work is, at the same time, a potential obstacle to access to health and a barrier to appropriate treatment. In this sense, there is a twofold conflict between the right to health and the right to work: on the one hand, health problems, whether caused by the working environment or not, may constitute an important limit for access to work, in particular when the person is looking for work. On the other hand, once the position has been acquired, the job itself may become an obstacle in access to appropriate treatment, both due to the difficulty in obtaining paid leave for medical reasons, and for the fear of losing the job when declaring health problems and the consequent limits in carrying out the duties required in an efficient manner.

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#### Box 2. *Health of migrant workers: the international legislation*, Anthony Olmo

This box presents the most important international tools on human rights concerning the category of migrant workers.

The main tool in this sense is certainly the international convention on International Convention on the Protection of the Rights of All Migrant Workers and Members of their Families (Convention on Migrant Workers)<sup>316</sup>. This was adopted by the General Assembly of the United Nations in 1990 and

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<sup>314</sup> *Migrants in an Irregular Situation Employed in Domestic Work: Fundamental Rights Challenges for the European Union and its Member States*, Luxembourg, Publications Office of the European Union, 2011.

<sup>315</sup> *Ibidem*.

<sup>316</sup> International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families, Adopted by General Assembly resolution 45/158 of 18 December 1990. See also, *inter alia*, *Migration for Employment Convention (Revised), 1949 (No. 97), Convention Concerning Migration for Employment*, Geneva, July 1<sup>st</sup> 1949.

came into force only 13 years later, on July 1<sup>st</sup> 2003, twenty years after it was ratified. Italy, like the majority of European countries, has not ratified this convention.

The main objective of the convention is not so much to ratify the specific rights for the category of migrant workers, as to ensure equal rights and equal working conditions for migrant and native workers. Amongst these rights are, *inter alia*, the right to life, the right not to be subjected to torture or to inhuman or degrading punishment, the right to not be held in slavery or servitude, the right to freedom of thought, of conscience and religion, the right to expression, the right to respect for a private and family life, the right to private property, the right to freedom and security, the right to a fair trial<sup>317</sup>. There are also a range of strictly economic, social and cultural rights such as the right to health, the right to education, the right to respect for cultural identity<sup>318</sup>.

As far as the questions relating to the working conditions are concerned, the convention specifies that the migrant worker has the right, *inter alia*, to benefit from a treatment not less favourable than that enjoyed by workers who are citizens of the state with regard to matters of remuneration and other working conditions (such as overtime, working hours, weekly days off, paid leave, safety, health, termination payments, and all the other working conditions that, according to national legislation and practice are covered by this term) and the other employment conditions (such as minimum age for employment, restrictions on home work and all the other questions that, according to national legislation and customs, are considered terms of employment)<sup>319</sup>. Migrant workers also have the right to trade union membership<sup>320</sup> and to the right to equal treatment with other native workers, with regard to social security<sup>321</sup>.

Finally, the convention sanctions further rights with regard to those migrant workers who have legal status with regard to entry into the country and residence permits<sup>322</sup>. Amongst these are, for example, the right to leave the country temporarily without effects on the residence or work permits, the right to move freely around the country, and to choose the place of residence, the right to take part in public affairs in their country of origin, the right – extended also to family members – to access to educational services, professional, social, health and cultural guidance<sup>323</sup>.

A further international tool to which we can refer is the General Comment 1 on migrant domestic workers, drawn up by the United Nations Committee for the rights of migrant workers and members of their families<sup>324</sup>. The Committee, taking note of the large number of migrant workers employed in the sector of domestic work and the lack of specific references in the main international documents, decided to dedicate the General Comment to the International Convention on the protection of the rights of the migrant workers and the members of their family precisely to domestic work.

This recognizes, first of all, that the category of migrant domestic workers lives in conditions of particular risk, which exposes them to various forms of exploitation and abuse. The main causes of this vulnerability are to be traced to the isolation and the dependence that characterizes this work. The sudden vulnerability, moreover, is not limited to the job, but usually emerges at the origin of the migratory process, already in the homeland<sup>325</sup>. The Committee emphasises that there are various shortcomings in the network of protection for this category of worker. Amongst these limitations, some are of a legal nature (for example, due to problems relating to legal status, on the basis of the legislation that governs immigration)<sup>326</sup>, others are of a more functional and practical – some of which were emphasized also in the fourth chapter – such as the isolation or the contractual weakness that characterizes the relationship of domestic work<sup>327</sup>.

The Committee, in the light of this situation, drew up a detailed list of recommendations for the member states of the Convention, in order to assist them in guaranteeing the enjoyment of their rights for migrant domestic workers. These recommendations range from information and awareness

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<sup>317</sup> International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families, Articles 8-24.

<sup>318</sup> *Ibidem*.

<sup>319</sup> *Ibidem*, Article 25.

<sup>320</sup> *Ibidem*, Article 26.

<sup>321</sup> *Ibidem*, Article 27.

<sup>322</sup> *Ibidem*, Articles 36-56.

<sup>323</sup> *Ibidem*, Articles 36-56.

<sup>324</sup> International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families, General Comment N. 1 on Migrant Domestic Workers, UN Doc. CMW/C/GC/1, 23, February 2011.

<sup>325</sup> *Ibidem*, paragraph 8.

<sup>326</sup> *Ibidem*, paragraph 18 *et seq.*

<sup>327</sup> *Ibidem*, paragraph 25 *et seq.*

raising projects in the phase prior to departure, to cooperation between nations, the role of job centres, working conditions, social, welfare and health services, the right to collective contracting, access to legal assistance, the specific need to guarantee the rights of minors and gender equality.

A further international tool is particularly important for the category of domestic workers, migrants and non: the Domestic Workers Convention from the International Organization of Work on N. 189 (ILO Comment)<sup>328</sup>, which gives the most complete and detailed international normative framework on domestic work. The Conventions was signed in 2011 and came into force on September 5<sup>th</sup> 2013. Italy ratified the document on January 23<sup>rd</sup> 2013. Although the Convention was drawn up by ILO – an agency that, as is known, concentrates on international working standards – it was strongly inspired also by an approach based on human rights<sup>329</sup>.

The Convention states that countries must adopt measures to ensure that the domestic workers, like all other workers, can enjoy conditions of fair employment, and adequate working conditions<sup>330</sup>. In particular, the minimum salary must be guaranteed<sup>331</sup> and the wages must be paid to them in cash<sup>332</sup>. Countries must also guarantee a minimum age for domestic workers<sup>333</sup>, guaranteeing that they enjoy adequate protection against every form of abuse, harassment and violence<sup>334</sup>, guaranteeing them a safe and healthy working environment<sup>335</sup>, and finally, guarantee equal safeguards in the field of welfare, above all with regard to the protection of maternity<sup>336</sup>.

The Convention was accompanied by a further measure, Recommendation N. 201, June 2011<sup>337</sup>. This Recommendation is not legally binding, but is in any case important because it supplies interpretative support for the Convention. In fact, it further explains some delicate aspects dealt with by the ILO Convention, such as working hours, wages, medical examinations, residential conditions, board and firing of co-resident workers.

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Box 3. *The procedure for reporting and recognition of work-related accidents: a brief review*, Eleonora Castagnone

In order to attain recognition and compensation for work-related accidents from INAIL, it is necessary to report the accident, following a standard procedure. The procedure foresees that the worker immediately advise the employer – also in the case of a minor injury – and that they contact the company doctor or the A&E department of the nearest hospital, or the GP. The doctor who carries out the first examination will issue a certificate, indicating the diagnosis, the number of days of temporary absolute inability to work (which must be more than three, if the accident is to be reported to INAIL). On receiving a copy of the certificate, the employer has two days in which to report the accident to INAIL (in the case of the decease of the worker or danger of death, the deadline is 24 hours). If the employer does not report the accident to INAIL, the worker can do so directly, by sending to the Institute a copy of the medical certificate. The law foresees that companies who employ workers must underwrite a compulsory INAIL insurance policy to compensate the workers who are involved in accidents. If the employer has not paid this insurance, the worker is still protected and the employer will have to pay a fine.

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<sup>328</sup> ILO, C189 – *Domestic Workers Convention, 2011 (No. 189), Convention Concerning Decent Work for Domestic Workers*, Geneva, International Labour Office, June 16<sup>th</sup> 2011.

<sup>329</sup> A. Albin and V. Mantouvalou, *The ILO Convention on Domestic Workers: From the Shadows to the Light*, in «Industrial Law Journal», vol. 41, 2012, N. 1, pages 67-78.

<sup>330</sup> ILO Convention, Article 6, op. cit.

<sup>331</sup> *Ibidem*, Article 11

<sup>332</sup> *Ibidem*, Article 12

<sup>333</sup> *Ibidem*, Article 4

<sup>334</sup> *Ibidem*, Article 5

<sup>335</sup> *Ibidem*, Article 13

<sup>336</sup> *Ibidem*, Article 14

<sup>337</sup> ILO, R201 – *Domestic Workers Recommendation, 2011 (N. 201), Recommendation Concerning Decent Work for Domestic Workers*, Geneva, International Labour Office, June 16<sup>th</sup> 2011.

In the case of more serious accidents, which are destined to interfere significantly with the working and non-working life conditions of the injured person, and their economic capacity, current legislation foresees the possibility of family, social or working rehabilitation of the workers. The methods for rehabilitation are evaluated jointly by various professionals working at INAIL (social-educational, administrative and medical-legal) who, in a multidisciplinary procedure take on the case of the invalid worker, identifying the most suitable personalized solutions for each case. The aim of this project, organized with the involvement of the worker and his family, is to define the overall medium- and long-term objectives and identify the action to be taken, which will also be integrated with any therapeutic and rehabilitation projects organized by other institutions.

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Box 4. *The procedure for reporting occupational disease: a brief review*, Eleonora Castagnone

The worker is responsible for reporting an occupational disease within fifteen days of its appearance, otherwise the right to compensation is no longer guaranteed for the time prior to the report. The worker's intention to apply to INAIL must be clear and declared. This intention is finalized in the safeguarding of the worker's job, since, if the occupational illness is confirmed and employer is unable to guarantee conditions of employment that will not determine further problems for the worker's health, this may determine dismissal for just cause. The employer must send the report to INAIL, with the medical certificate, within the five days after receipt of the medical certificate<sup>338</sup>. In the case of inaction of the employer, the worker can send the report to INAIL with the medical certificate for occupational illness.

Once the occupational illness has been recognized, INAIL compensates the lack of earnings of the injured worker by paying a daily benefit, calculated on the basis of the effective wage, until they are well, and economically compensates permanent invalidity, including biological harm, or death. For invalidity between 6% and 15%, a sum is paid forfeit as compensation of biological harm; for invalidity between 16% and 100%, a lifetime annuity is foreseen for the invalid worker<sup>339</sup>.

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Box 5. *Focus on domestic work: a comparison between the Italian legislation and standard international legislation*, Anthony Olmo

In this chapter, we can clearly see the influence of the working conditions of domestic workers on the realization of their right to health. As we have often mentioned, the degree of health that they can enjoy, and the possibility of access to health services, are strongly influenced by the peculiarities of the profession and the conditions that characterize it. For this reason, it appears opportune to investigate the working conditions guaranteed to them by current legislation, with particular attention for that which, more than others, can have an impact on their health and the possibility of access to the services.

For this reason, this section will be dedicated to comparing the relevant legislation for domestic workers in Italy with the standard international labour legislation, the Convention N. 189<sup>340</sup> and the Recommendation N. 201 (ILO Recommendation)<sup>341</sup>, both adopted in June 2011 – with particular attention to regulations relating to working conditions. This will make it possible to evaluate the correspondence between national legislation and the main international legislation, in order to highlight any deficiencies.

With regard to the national legislative framework, the most important tool is the Contratto Collettivo Nazionale del Lavoro (CCNL – National Collective Labour Contract)<sup>342</sup>. The CCNL identifies the essential regulations – from a legal and an economic standpoint – that must necessarily regulate the

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<sup>338</sup> DPR 1124/1965, article 53

<sup>339</sup> INAIL, Direzione Regionale Piemonte, 2012.

<sup>340</sup> See *supra*, box 2.

<sup>341</sup> See *supra*, box 2.

<sup>342</sup> Federazione italiana datori di lavoro domestico, Associazione nazionale famiglie datori di lavoro domestico, Federazione italiana lavoratori commercio, turismo e servizi, Federazione italiana sindacati addetti ai servizi commerciali e affini e del turismo, Unione italiana lavoratori turismo commercio e servizi, Federazione sindacale dei lavoratori a servizio dell'uomo, *Contratto collettivo nazionale di lavoro sulla disciplina del rapporto di lavoro domestico*, July 16<sup>th</sup> 2013.

contractual relations between domestic workers and their employers. The CCNL, with other legislation<sup>343</sup>, give the basic legislative framework for the category in question. The CCNL currently in force was signed in July 2013 by representatives of the main associations of employers and workers and replaced the previous contract, signed in 2007. The CCNL of 2013 will remain in force until the end of 2016. Finally, it must be said that the CCNL 2013 was finalized a few months prior to the enactment of the ILO Convention and is strongly influenced by it.

#### *The regulations concerning the domestic environment*

The CCNL states that all domestic workers have the right to healthy, safe working conditions<sup>344</sup>. In particular, these must respect the legislation on domestic environments<sup>345</sup>. The CCNL also specifies that employers must guarantee the presence of an efficient earth leakage circuit breaker on the electrical system and inform the worker of any possible risks those deriving from the use of equipment and exposure to chemical, physical or biological agents<sup>346</sup>.

The impression is that these measures are somewhat limited, an evaluation that is true also for the measures set out in the ILO Convention. Article 13 of the Convention simply states that “Every domestic worker has the right to a safe and healthy working environment” and that “each Member shall take, in accordance with national laws, regulations and practice, effective measures, with due regard for the specific characteristics of domestic work, to ensure the occupational safety and health of domestic workers.”<sup>347</sup> The extent of this measure, which is rather vague, is further reduced in the successive paragraphs which state that “The measures referred to in the preceding paragraph may be applied progressively, in consultation with the most representative organizations of employers and workers and, where they exist, with organizations representative of domestic workers and those representative of employers of domestic workers.”<sup>348</sup>

#### *The number of working hours and rest time*

Article 15 of the CCNL identifies the number of working hours. Co-resident workers can work for a maximum of ten non-consecutive hours per day, for a total of fifty-four hours per week. With regard to non-resident workers, the working hours cannot exceed eight hours per day, for a total of forty hours per week.

Pursuant to Article 15.4 of the CCNL, the co-resident workers have the right to eleven consecutive hours rest each day and a two-hour break during the working day. Moreover, the employees who work in the house for at least six hours have the right to a meal, or to an equivalent compensation, in accordance with Article 15.8 CCNL.

With regard to the daily rest, the CCNL specifies that co-resident workers have the right to at least eleven hours consecutive rest and at a least two-hour break when the working hours are not completely within the hours 06:00-14:00 and 14:00-22:00. Finally, according to Article 15.6, the work carried out between 22:00 and 06:00 is to be considered a night shift and must be paid 20% more per hour.

Domestic workers can be asked to do overtime, both in the day and at night. Pursuant to Article 16 of the CCNL, overtime must be paid with an hourly wage increase (between 25% and 60% according to the hour of the day in which the work is done) and it must not interfere with the daily rest period.

As far as the weekly rest days are concerned, Article 14 of the CCNL states that, for co-resident workers, the weekly rest period is at least thirty-six hours, of which twenty-four must be on a

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<sup>343</sup> See in particular the Italian Civil Code on the specific nature of domestic workers with respect to the general category of employees. Italian Civil Code, Book V, Title IV, Articles 2240-2246. There are also other specific laws, such as the laws on the workplace.

<sup>344</sup> CCNL, Article 27.1.

<sup>345</sup> See Law N. 493, December 3<sup>rd</sup> 1999, *Gazzetta Ufficiale* N. 303, December 28<sup>th</sup> 1999.

<sup>346</sup> See: CCNL, Articles 27.1 and 27.2.

<sup>347</sup> See ILO Recommendation, Article 19 a. “Members, in consultation with the most representative organizations of employers and workers and, where they exist, with organizations representative of domestic workers and those representative of employers of domestic workers, should take measures, such as to: (a) protect domestic workers by eliminating or minimizing, so far as is reasonably practicable, work-related hazards and risks, in order to prevent injuries, diseases and deaths and promote occupational safety and health in the household workplace.”

<sup>348</sup> ILO Convention, Article 13.2.

Sunday. The remaining twelve hours must be taken during the rest of the week. For workers who are not co-resident, the weekly break is twenty-four hours, which must be taken on Sunday.

According to the CCNL, the Sunday break – for both categories of domestic worker – is compulsory. The work carried out during the Sunday break must be remunerated with an hourly salary increase of 60% and an equivalent number of rest hours, to be taken the next day. If the worker is of a religion that celebrates a day other than Sunday, the parties can reach an agreement regarding another day, in accordance with Article 11.2 of the Recommendation dated 2011, which requires that “The fixed day of weekly rest should be determined by agreement of the parties, in accordance with national laws, regulations or collective agreements, taking into account work exigencies and the cultural, religious and social requirements of the domestic worker.”

The regulations on working hours, rest and overtime appear to be in line with the ILO Convention. Article 10 of the Convention requires, above all, “Each Member shall take measures towards ensuring equal treatment between domestic workers and workers generally in relation to normal hours of work, overtime compensation, periods of daily and weekly rest and paid annual leave in accordance with national laws, regulations or collective agreements, taking into account the special characteristics of domestic work.” Moreover, Article 10 of the 2011 Recommendation specifies that “Members should take measures to ensure that domestic workers are entitled to suitable periods of rest during the working day, which allow for meals and breaks to be taken.”

The criteria set out for weekly rest periods are also respected. Article 10 of the IOL Convention requires at least twenty-four consecutive hours weekly rest, a standard that is clearly respected by the CCNL.

The only profile for which the Convention seems to foresee greater protection regards being on call. Article 10.3 states that “Periods during which domestic workers are not free to dispose of their time as they please and remain at the disposal of the household in order to respond to possible calls shall be regarded as hours of work to the extent determined by national laws, regulations or collective agreements, or any other means consistent with national practice.”<sup>349</sup> In the CCNL, there is no trace of a similar measure.

#### *Paid leave*

According to the CCNL, domestic workers have the right to paid leave for medical appointments during their working hours<sup>350</sup>. Moreover, domestic workers who have a monthly salary have the right to twenty-six days paid holiday per year<sup>351</sup>, in addition to the national holidays identified by Article 17 of the CCNL. The right to enjoyment of holidays cannot be renounced<sup>352</sup>. The ILO Convention does not foresee any measures on this matter.

#### *Accommodation and food*

With regard to accommodation and food, the employer must guarantee adequate nutrition and adequate lodgings that guarantee the worker’s dignity and privacy<sup>353</sup>. In this sense the ILO Recommendation gives more detailed instructions and in particular requires that the worker be given “ a separate, private room that is suitably furnished, adequately ventilated and equipped with a lock, the key to which should be provided to the domestic worker; access to suitable sanitary facilities, shared or private; c) adequate lighting and, as appropriate, heating and air conditioning in keeping with prevailing conditions within the household; and meals of good quality and sufficient quantity, adapted to the extent reasonable to the cultural and religious requirements, if any, of the domestic

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<sup>349</sup> With regard to Article 9 of the ILO Recommendation, which specifies that “Members, to the extent determined by national laws, regulations or collective agreements, should regulate: (a) the maximum number of hours per week, month or year that a domestic worker may be required to be on standby, and the ways they might be measured; (b) the compensatory rest period to which a domestic worker is entitled if the normal period of rest is interrupted by standby; and (c) the rate at which standby hours should be remunerated.”

<sup>350</sup> CCNL, Article 20.

<sup>351</sup> *Ibidem*, Article 18.

<sup>352</sup> *Ibidem*, Article 18.4

<sup>353</sup> *Ibidem*, Article 35.

worker concerned.<sup>354</sup> It is clear that the framework set out by the ILO defines the requisites for accommodation and adequate meals in more detail.

#### *Ordinary illness, accidents and occupational illnesses*

In the case of illness, all domestic workers have the right to maintain their jobs for ten days, if they have more than six months of service; for forty-five days if they have between six months and two years' service and for one hundred and eighty days for service over two years<sup>355</sup>. In the case of oncological diseases, the periods are 50% longer<sup>356</sup>.

In the case of accident or occupational illness, domestic workers have the right to have their jobs guaranteed for ten days, if they have more than six months of service – for forty-five days if they have between six months and two years' service and for one hundred and eighty days for service over two years<sup>357</sup>. Workers must be guaranteed full salary for the first three days.

Furthermore, pursuant to Article 28.3 CCNL, they have the right to the measures set out in DPR N. 1124, dated June 30<sup>th</sup> 1965<sup>358</sup>. These measures include compensation for temporary inability, income for permanent inability, contributions for continuative personal assistance, contributions for survivors and a payment in the case of death, medical care or surgery and the supply of prostheses.

Article 29 of the CCNL states that all domestic workers must enjoy the guarantees foreseen by the law, in terms of welfare and social services. In particular, domestic workers must be guaranteed the conditions set out in DPR N. 1403, dated December 31<sup>st</sup> 1971<sup>359</sup>, such as invalidity insurance, seniority, sick pay, accident insurance and paid maternity leave.

The IOL Convention does not include specific regulations on the matter.

#### *Maternity*

According to article 24, domestic workers enjoy the safeguards normally guaranteed by the law for pregnant women and mothers. In particular, the women cannot be asked to work during the last two months of pregnancy (and up to the effective date of birth) and for three months after the birth. From the day the pregnancy starts, the worker cannot be dismissed without just cause.

The level of protection guaranteed to pregnant women and mothers has been a controversial topic for the employer associations and the workers' associations. On the one hand, the former emphasise that the regulations of the CCNL guarantee the standards required by the OIL Convention<sup>360</sup>. Article 14.1 of the Convention states, in fact, that "Each Member shall take appropriate measures, in accordance with national laws and regulations and with due regard for the specific characteristics of domestic work, to ensure that domestic workers enjoy conditions that are not less favourable than those applicable to workers generally in respect of social security protection, including with respect to maternity." On the other hand, the representatives of the workers say that this protection is insufficient compared to other labour sectors. For example, it is not specified that the worker cannot be dismissed during the year following the birth, a safeguard generally foreseen by regulations on maternity<sup>361</sup>.

#### *Conclusions*

Generally speaking, the level of protection guaranteed by the CCNL appears to respect the international standards and substantially enter into more detail.

From the analysis we have carried out, this does not seem to be the case only in the matter of regulations regarding accommodation. As we explained above, the ILO regulations set out in detail the characteristics that the accommodation must have. Considering the importance of this topic, also

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<sup>354</sup> ILO Recommendation, Article 17.

<sup>355</sup> CCNL, Article 26.

<sup>356</sup> *Ibidem*, Article 26.7.

<sup>357</sup> *Ibidem*, Article 28.

<sup>358</sup> See Note 10.

<sup>359</sup> *Gazzetta Ufficiale* N. 94, April 10<sup>th</sup> 1972.

<sup>360</sup> ILO Convention, Article 14.1: "Each Member shall take appropriate measures, in accordance with national laws and regulations and with due regard for the specific characteristics of domestic work, to ensure that domestic workers enjoy conditions that are not less favourable than those applicable to workers generally in respect of social security protection, including with respect to maternity."

<sup>361</sup> Dlgs N. 151, March 26<sup>th</sup> 2001, *Gazzetta Ufficiale* N. 96, April 26<sup>th</sup> 2001, Ordinary Supplement N. 93, Article 54.

in the light of the aspects revealed by this research, it would be opportune for the CCNL to specify this characteristic in more detail.

Finally, it must be said that the CCNL and the ILO documents give an insufficient framework with respect to the criteria of a safe and healthy working environment. They both tend to simply confirm the right to safe and healthy working conditions, without specifying precisely the minimum criteria to be respected.

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## Chapter Five

### Infectious diseases, the syndrome of the plague spreader. The social stigma of the infected foreigner and perception amongst patients

#### 1. *The presence of infectious diseases. Foreigners and natives compared*

The area of infectious diseases is one of those in which the foreign citizens' rights are most seriously at risk<sup>362</sup>. The migrant population is in fact more vulnerable than the autochthonous one: they are more exposed to infection (in particular infection from HIV and tuberculosis) which may derive from episodes of violence and abuse and from the conditions of vulnerability that they face during the travel. The most affected by infectious diseases are the migrants with a high risk of social exclusion, for whom the health conditions are aggravated by a high level of mobility, irregular status, economic difficulties, exploitation, lack of work, or work in areas of considerable risk, such as prostitution. These factors are often intensified by living conditions, but also by disinformation, which in turn is linked to a low level of education, lack of access to health services, prevention and reduction of harm<sup>363</sup>. To these dynamics, we must add the

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<sup>362</sup> I. Biglino and A. Olmo, *Health as a fundamental right: a study on migration and healthcare in Turin*, Bologna, Il Mulino, 2014, page 70.

<sup>363</sup> A.A. Agudelo-Suárez, D. Gil-González and C. Vives-Cases, *A Metasynthesis of Qualitative Studies Regarding Opinions and Perceptions about Barriers and Determinants of Health Services' Accessibility in Economic Migrants*, in «BMC Health Service Research», 17, vol. 12, 2012, N. 1, page 461.

mechanisms of stigmatisation of the illness that increases, as we will see later, the vulnerability of the patient.

Although, in the collective imagination infectious diseases are often associated only with immigrants, their diffusion in Italy remains a problem that affects the entire population and contrasting them remains a priority in the planning of healthcare policies. In its social-health plan for 2012-2015 Regione Piemonte identified infectious diseases as one of the most important health problems for the population; emphasising that there is still room for improvement in the system of control and that it is essential for the main regional hospitals to carry out monitoring activities, in order to establish the effective entity of the phenomenon. For the control and correct treatment of these infections, it is also necessary for these institutions to set up an infectious disease service, either their own or under contract, and that they should foresee the presence of a specialist in infectious diseases<sup>364</sup>.

From the epidemiological standpoint, the situation appears to be under control, since there has not been a noticeable increase in reports of infection over the years, neither for tuberculosis nor for HIV, and the efficacy of the therapies has improved, significantly reducing the mortality rate. However, there has been a change in the social-demographic characteristics of the patients: the number of migrants has increased and the number of persons who identify the infection only in an advanced stage is higher.

The Piemontese territory shows data mainly in line with national figures. In 2012, in Italy, 3,853 new diagnoses of HIV were reported, 6.5 cases every 100,000 inhabitants, a rate basically unchanged with respect to previous years. The data gathered by the Ministry of Health Institution for AIDS, COA (*Centro Operativo Aids Istituto Superiore della Sanità*) clearly shows how the patient profile has changed over the years. Contagion has fallen amongst drug addicts (from 47.9% in 1998 to 5% in 2013) and today the majority of infections is linked to unprotected sexual relations (25.3% in 1998, approximately 80% in 2013). The incidence rate of AIDS has also progressively fallen over the years, reaching 1.7 cases per 100,000 inhabitants in 2012<sup>365</sup>.

In 2013, in Piemonte the new diagnoses of infection were 7.2 cases every 100,000 inhabitants<sup>366</sup>. The Province of Torino (7.6) together with Novara (10.4) have the highest average rates in the region for the last three-year period. The proportion of foreigners amongst the new diagnoses of HIV rose from 11% in 1992 to 24% in 2013. The infection mainly concerned men, although the female component is particularly relevant amongst foreigners, where the women are 62%, while amongst Italians the women are only 11%. Although the rate amongst foreigners is much higher than amongst the indigenous population, it must be stressed that it has slightly decreased over the years and is distributed in a very dissimilar manner amongst groups with different origins. The rate for migrants from the sub-Saharan area (228.2 cases per 100,000) is ten times higher than the overall rate for foreigners. The main methods of transmission were, also in Piemonte,

<sup>364</sup> Regione Piemonte, *Piano socio-sanitario regionale 2012-2015*, 2012, page 86.

<sup>365</sup> Istituto superiore di sanità, *Aggiornamento delle nuove diagnosi di infezione da Hiv e dei casi di Aids in Italia al 31/12/2013*, in «Supplemento del Notiziario dell'Istituto superiore di sanità», vol. 27, 2014, N. 9.

<sup>366</sup> Data relating to cases of AIDS is available for Piemonte from the early eighties, while the HIV surveillance system gives data for new diagnoses of infection as from 1999. C. Pasqualini, C. Di Pietrantonio and V. De Micheli, *HIV e AIDS in Piemonte, Rapporto 2013*, Alessandria, Servizio di riferimento regionale di epidemiologia per la sorveglianza, la prevenzione e il controllo delle malattie infettive (Seremi), ASL Alessandria, 2013

unprotected sexual relations, 90% in 2013. A last aspect to emphasise is that the number of diagnoses in an advanced state of HIV was very high, in particular for those who caught the infection through unprotected heterosexual relations. In 2013, the seventeen women in Piemonte who found that they were HIV positive during routine pregnancy tests were all of foreign origin, showing that this group is particularly vulnerable. In conclusion, from the analysis of the epidemiological data it is clear that there are some important risk factors that are found in particular amongst the foreign population: origin from a country with a high endemic, the prevalence of young and sexually active people, insufficient information, lack of awareness of prevention and the presence of prostitution.

The other infectious disease we considered was tuberculosis. The epidemiological data is also available by citizen<sup>367</sup>. In Torino, the rate in 2012 was 17 cases per 100,000 inhabitants, double the regional rate (8.4 cases per 100,000 inhabitants). This value is not alarming since it is in line with other European cities (Milano: 18.6; Barcelona: 24.3; Paris: 23.4). There has been, as for HIV infection, a reduction in the number of cases reported compared with 2011, 13.8% less amongst foreigners and 6.7% less amongst Italians.

What is striking is the preponderance of cases reported amongst the foreign population, which in 2012 were 70% of the cases diagnosed in Torino (103 cases). The number of cases of tuberculosis amongst foreigners is approximately fourteen times higher than those registered amongst Italians; they are above all respiratory tuberculosis, which involves three quarters of the total cases. The foreigners with a diagnosis of tuberculosis in 2012 came from forty different countries, with a prevalence from Romania, sixty-nine cases and Morocco, forty-three cases; these numbers can, however, be traced to the numerical prevalence of these two communities. The differences between foreigners and natives emerge when we observe the distribution of the positive results of the therapies: in Torino, the positive results concern 80% of the Italian patients and 67% of the foreign patients, while in the rest of Piemonte they are 82% of the Italians and 66% of the foreigners.

The main risk factor for tuberculosis concerns the provenance from countries with a high tubercular endemic, due to the presence of active or latent infections, which are reactivated by the environmental conditions that weaken the immune system; in some cases, the appearance of tuberculosis is linked to the presence of HIV infection. The risk factors that are most common, as for HIV, are precarious living conditions, malnutrition, living in crowded, poorly ventilated spaces with poor hygienic facilities, conditions to which the foreign citizens are more likely to be exposed. As a doctor at city service for infectious diseases said.

These diseases are the diseases of poverty, of the wretched. What is more, the most vulnerable people, in today's world, are often the immigrants. Where there is great social fragility the need for health is not seen as a

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<sup>367</sup> C. Pasqualini, M. Bugiani and V. De Micheli, *La tubercolosi in Piemonte, Rapporto 2013*, Alessandria, Servizio di riferimento regionale di epidemiologia per la sorveglianza, la prevenzione e il controllo delle malattie infettive (Seremi), ASL Alessandria, 2013.

priority, and this aggravates the situation. My patients, when they come to me, say, 'my real need is a home, a job, documents!'

## 2. *The syndrome of the plague spreader. The stigmatization of the infected foreigner and the perception amongst patients*

One of the main problems that emerged with both the operators and the foreign patients, when speaking of the question of disease, was the stigma. Infectious diseases have a very strong symbolic value and are dense with moral significance; public opinion associates them with deviant and socially unacceptable behaviour, such as sexual promiscuity, homosexual relations, prostitution or conditions of extreme hardship, such as drug addiction. When it is a foreigner who is infected, the social stigma is even stronger.

Recently, in the public discourse, various voices have been heard pointing at the foreigner as a danger, an incubus, assimilating the foreigner with an extraneous and diseased body that penetrates our society, infecting and destroying it from within. This is not a new attitude, in fact, diseases such as tuberculosis have always been charged with other meanings that transcend their seriousness. The link between disease, poverty and prostitution has, since the first British industrial revolution, given tuberculosis the negative significance that was previously attributed to leprosy and would later, although with different characteristics, be attributed to mental illnesses and HIV. Stigmatizing discourses linked to health scares reappear in correspondence with political and social events, during election campaigns and as a response to increasing economic insecurity. In May 2014, the secretary of the Lega Nord (right-wing Italian political party, NdT) Matteo Salvini, in keeping with the anti-immigration rhetoric of his party, accused irregular foreigners of being a threat to public health, stating,

Ask the doctors who brings scabies and tuberculosis. They don't come from Switzerland, but from Africa. In Africa there is a backward healthcare system. But these diseases come here, just speak to a doctor from Milano to Taranto. Then there is Ebola, which is in central Africa and let's hope it doesn't come here. There is an alarm at the airports<sup>368</sup>

In September 2014, the general secretary of the police trade union CONSAP launched a class action against the Italian Home Ministry for having exposed the colleagues involved in the *Mare Nostrum* operation in rescue operations without healthcare precautions, after forty of them resulted positive during screening for tuberculosis bacteria. The secretary of the Movimento Cinque Stelle (political "free association of citizens", NdT), Beppe Grillo, immediately picked up on this report stating that, "We want to re-import tuberculosis, let's re-import it! But let's do so in the light of day, informing the population that the police are not even given minimum protection."<sup>369</sup>

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<sup>368</sup> Matteo Salvini contro gli immigrati: «Darei a loro il Daspo: portano scabbia, tubercolosi ed ebola», 6 maggio 2014, [http://www.huffingtonpost.it/2014/05/06/salvini-immigrati-malati-daspo\\_n\\_5274621.html](http://www.huffingtonpost.it/2014/05/06/salvini-immigrati-malati-daspo_n_5274621.html).

<sup>369</sup> Grillo-shock sui migranti «Portano la tubercolosi» il Viminale lo smentisce, 3 settembre 2014, <http://ricerca.repubblica.it/repubblica/archivio/repubblica/2014/09/03/grillo-shock-sui-migranti-portano-la-tubercolosi-il-viminale-lo-smentisce20.html>.

Various authoritative voices have been raised to contrast these distorted views, which nonetheless have had a very strong impact on the (easily influenced) public opinion. The president of SIMM (Società Italiana Medicina delle Migrazioni), Mario Affronti, emphasised that the health of immigrants arriving in Italy is generally good, since they are young and healthy when they start out, and that the health problems derive from the conditions that have stressed them during the voyage: dehydration, sunstroke, heatstroke, hypothermia, bedsores due to the forced positions on the boats, aggravated by chemical agents such as seawater or diesel fuel<sup>370</sup>. In the analysis of 25,000 immigrants who landed on Lampedusa during 2011, for example, it was shown that less than 2% of the population observed was affected by a contagious disease<sup>371</sup>.

Despite this evidence, the stigma continues to manifest itself with force and must be considered an important determinant of health; it is necessary to invest energy and resources to uproot it, if we want to affirm the full right to health. In fact, as Olmo and Biglino remind us: “The discrimination and the stigma are a failure with respect to human dignity; they increase the vulnerability with respect to health problems and limit the efficacy of treatments”<sup>372</sup>.

The stigma cannot be considered an individual phenomenon; it is rather a social process to be seen within the complex mechanisms such as economic inequality, relations of power, domination and oppression. As medical anthropology reminds us stigma is enacted by concrete, identifiable social players who are trying to legitimate their dominant status within structures of existing inequality<sup>373</sup>. The persons stigmatized are subject to a process of impoverishment of their identity in which they are fitted into a totally *other* social category, different from “normality”. The stigma is manifested on two levels: there is a perceived and feared stigma, which corresponds to specific actions carried out towards the stigmatized persons<sup>374</sup>. Often the choice of the sick people to keep their illness a secret reflects the desire to avoid hostile behaviour towards them. During the meeting at a Torino Islamic centre with a group of volunteers it became clear that in Italy the migrants often preserve the feeling of social shame for the illness that was already strong in their country of origin,

It takes courage, a lot of courage to come out. Some things are seen as taboo. The people in Egypt even avoid going to the doctor's for fear of being judged. The opinion of others frightens them, because people think, “He's got HIV! That will show him! He has left God's way and that is why he is being punished!” With this vision of blame and sin, people will never manage to face their illness serenely. (Nader, 50 years old, Egypt).

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<sup>370</sup> Simm: «Immigrati, basta con la sindrome dell'untore», 10 giugno 2014, <http://www.ilcitta-dinoonline.it/nonsolosiena/simm-immigrati-basta-con-la-sindrome-delluntore.html>.

<sup>371</sup> T. Prestileo *et al.*, *Salute e malattie infettive nella popolazione migrante: l'esperienza della «Coorte di Lampedusa 2011»*, in «Le Infezioni in Medicina», 2013, n. 1, pages 21-28

<sup>372</sup> I. Biglino and A. Olmo, *Health as a fundamental right: a study on migration and healthcare in Turin*, op. cit. page 163.

<sup>373</sup> R. Parker and P. Aggleton, *Hiv and Aids-related Stigma and Discrimination: A Conceptual Framework and Implications for Action*, in «Social Science & Medicine», 57, 2003. As Castro and Farmer state, social stigma is rooted more forcefully in social contexts where the inequalities are more evident. “In societies marked by profound racism, it is expected that people of color with AIDS will be more stigmatized than in societies where racism is more attenuated. Similarly, gender inequality determines the extent to which sexism will mark the course of HIV disease. In highly sexist settings, the disclosure of HIV infection is more likely to provoke stigma and threat of domestic violence than in environments where women enjoy gender equity.”. A. Castro and P. Farmer, *Understanding and Addressing Aids-Related Stigma: From Anthropological Theory to Clinical Practice in Haiti*, in «American Journal of Public Health», vol. 95, 2005, N. 1, pages 53-59.

<sup>374</sup> A. C. Vargas, *Avere paura, fare paura: stigma e discriminazione nell'esperienza dei giovani sieropositivi*, in C. Di Chio, A. Fedi and K. Greganti (ed.), *Vivere la sieropositività: i giovani, la comunità, l'aids*, Napoli, Liguori, 2013, pages 89-108.

The same point of view emerged strongly during the discussion with some female cultural mediators who work at the infectious disease clinic of an important hospital in the city.

I have to explain to people that HIV is what leads to the disease, but is not the **disease** itself, and therefore it must be kept under control. Like all other cultures, also amongst us Nigerians there is a terrible image of this virus, since the first time we spoke about it, it was a question of people without sexual control, like prostitutes. To say that I was HIV positive meant recognizing publicly that I was promiscuous, that I was amoral. (Nigerian cultural mediator, Amedeo di Savoia Hospital).

The dreaded stigma generates the fear of remaining completely isolated and this is what keeps people from facing the screening, they don't want to have to admit to themselves or to others their status as "different". The places set up for analysis and treatment, like the infectious disease clinics, are considered by some to be contaminating places. The simple fact of entering the hospital is interpreted by acquaintances as proof of the disease.

Because there are also people who are infected who try to tell you a fine story, without recognizing the truth, so that they won't create a vacuum around themselves. Amongst the Nigerians, there is a rumour that all the people who come here have AIDS. That's what a young man told me when he came here to see his girlfriend who had been admitted. He wanted to find out from me if his girlfriend was HIV positive. The girl did not want him to know... I told the young man, "Well, if you think that everyone who comes in here is sick, believe what you want, from this moment on, so are you!" (Nigerian cultural mediator, Amedeo di Savoia Hospital).

While fear may be an obstacle to recognizing one's state of health, once this first step has been taken and the presence of the virus has been diagnosed, many people live for years keeping their condition a total secret. One example is that of a Moroccan girl with HIV discovered in 2010, following a voluntary abortion. The girl worked regularly at the market and lived with her partner. She did not want to tell anyone about her condition, not even her partner, and this made it very difficult to keep up the therapy, based on the regular dosage of antiretroviral medicines twice a day, morning and evening. The girl told the healthcare workers that she was keeping up the therapy, although the blood tests often showed that this was not true. The girl had elaborated a total refusal of her condition, presenting to the world an image of self that was quite unreal. The operators are carrying out a very complex procedure of psychological support in order to allow her to overcome these anxieties, but without the support of a social network, it is very difficult to reach a result.

Fear of the stigma is experienced towards members of the majority society as much as towards members of the personal social group. All this makes it particularly difficult to deal with the various phases of the illness: the diagnosis, the planning of the therapy and continuation of the therapy over time, above all because the community support that would in many other situations be a fundamental resource is lacking. In this sense the healthcare operators, more than in other situations become fundamental figures, the only ones who share the secret and to whom the fears, but also the hope of recovery are confided. The fear of social stigma means that in the case of infectious diseases, that patients rarely return to their country of origin, unlike immigrants who suffer from other diseases.

The patient does not see a reason for returning home. The disease is not a reason to return. Also because no one who left healthy wants to return with an illness... they had a plan when they left. To return home sick just creates more problems, and then with this disease, which people think is

**Commento [KMC5]:** Era richiesta (durante la traduzione) una differenziazione tra il linguaggio dei ricercatori e i 'testimoni'. Avevo scelto la parola 'illness' (meno specificamente medico di 'disease' per questo motivo. Vedere file separato con definizioni.

connected to immoral behaviour, it is absolutely impossible! (Egyptian cultural mediator, Amedeo di Savoia Hospital).

### 3. *The sick are made not born. The relationship between infectious diseases and conditions of life*

While it is true that very few migrants have arrived in Torino already infected, it is also true that the living conditions they have to face in the city are the cause of the infections, as are the difficulties encountered in recovering. In the case of tuberculosis, the precarious living conditions are one of the most important risk factors for exposure to the bacilli and for the progression once the disease is active. In a longitudinal study on the conditions of health in the Torino population between 1973 and 1999 it emerged that the probability of contracting tuberculosis and scabies has doubled for those who live in the poor districts and in precarious or abandoned structures<sup>375</sup>.

Amongst the stories of health that we gathered, one of the most symbolic concerns the vicissitudes of the asylum seekers and the political refugees who live in Torino, in abandoned buildings. The best-known case is that of the buildings in the MOI area, a complex built to house the athletes competing in the 2006 Winter Olympics. After the Olympic Games, the buildings were entrusted to the privately managed City of Torino Fund, but the conversion for residential use was never completed. The state of the buildings rapidly deteriorated and after seven years, in March 2013, three of the seven apartment blocks were occupied by refugees from the North African emergency, who were left without board and lodging or other support when the funds foreseen for initial assistance ran out. There were two hundred people, helped by a committee of volunteers from the district and activists from the local squats; during the summer of 2013, a fourth building was occupied, bringing the numbers to about seven hundred occupants. In addition to the first occupants who came through word of mouth and the social networks, political refugees from other areas of Piemonte and Italy arrived. For a long time the occupants had been homeless and this excluded them from enjoyment of many fundamental rights that should have been guaranteed by law. In the meantime, the network of support for the rights of the occupants was extended: in addition to the squats Askatasuna and Gabrio, the Pastorale Migranti, the Ingegneri senza Frontiere and Microclinica Fatih, the associations Frantz Fanon, Mamre, Gruppo Abele, Sermig and Anpi joined forces. Thanks to the continual activities of these organizations and of some residents in the district, in January 2014 the local authorities, with a ruling unique in Italy, granted all the refugees official domicile in the ex-Olympic village, attributing a virtual address “Via della Casa Comunale 3”. In order to register with the public records office (*anagrafe*) lacking any other identity document, it was considered sufficient to have a residence permit for reasons of international or humanitarian protection. The ruling therefore allowed them to be issued with an identity card and opened the way for a series of benefits foreseen by law for the status of refugee, the possibility of finding regular work, healthcare, and registration with the social services<sup>376</sup>. This situation of apparent stabilization of the risks

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<sup>375</sup> M. Demaria, *La gestione integrata dei dati demografici e sanitari: l'esempio dello studio longitudinale torinese*, in *Disuguaglianze sociali e di salute*, ed. A. Pullini, Quaderni Ismu, Milano, Fondazione Ismu, 2011, pages 101-128.

<sup>376</sup> With regard to access to the social services, equality with Italian citizens is foreseen by the consolidated legislation on migration (Testo Unico sull'Immigrazione) D.Lgs. N. 286, July 25<sup>th</sup> 1998, *Gazzetta Ufficiale* N. 191, August 18<sup>th</sup> 1998, Ordinary Supplement N. 139 (Article

however was once again jeopardized when the preventive seizure of the apartment blocks, ordered in January 2015 by the examining magistrate (GP) of Torino, foreshadowed a possible eviction<sup>377</sup>.

Life in the occupied houses has involved a series of important health problems, problems linked to overcrowding and the lack of heating and running water in many apartments. This situation has created a conflict between the occupants and the local authorities, since anyone resident in the city, in conditions of necessity, should have the right to use the public baths. The shower vouchers are issued by the district authorities, which should accept the cost directly, but Circostrizione 9 (district 9) in which the occupied buildings stand, has not been able to fund this service, without the city council setting up a special fund to deal with the emergency.

The lack of hygiene and the precarious nature of the living conditions have led to the appearance of infectious diseases, in particular tuberculosis, which was documented by a Somalian cultural mediator who looks after a number of patients at a public clinic.

Many Somalian young people come here. They are very young, they are between 20 and 23 years old, they are mainly men, but there are also some women. Almost all have refugee status. Many of them have tuberculosis. Some of them caught it in Somalia and then it got worse when they came here. One girl of twenty-one has tuberculosis that has eaten away all her back, now she has to wear a corset, because she was walking about without realizing it; the pain grew until she fell down in the street, they took her to the A&E and then she was sent to us. Now, if a Somalian in Torino has a high fever, the first thing we do is check for tuberculosis. The Somalians live in squats and they get ill because they are underfed, they don't have anything decent to eat, one day they eat, the next they don't, and they drink dirty water. This already happened before they left, but now it is happening here: to eat they go to the church, but perhaps they are only given ham, and they don't eat it, they miss a meal... Then, in the squats, there is scabies. Those buildings were completely empty, so they found mattresses in the rubbish dumps and they brought them home, to have a place to sleep. The doctor told them that it is necessary to close them in a sealed plastic bag and use steam to kill the bugs in the mattresses, but how can they, in those conditions? The house is cold, in winter... five people in a tiny room! (Somalian cultural mediator, Amedeo di Savoia Hospital).

As this cultural mediator explained, it is very difficult to take preventive measures against the spread of infection when all the circumstances of life are exceptional. The needs of those affected by infectious diseases are not only healthcare, they are, above all, social needs. The discovery of the disease has a further series of implications that only aggravate a situation that is already precarious. The therapy, in the more serious cases, can involve hospitalization for more than a month and there are patients who have lost their jobs for this reason. The health workers are forced to carry out a complex procedure of mediation, not only regarding healthcare, but also social: they facilitate accommodation in hostels and at public canteens, they supply information and contacts with the social services available in the territory.

**Commento [KMC6]:** See above. Here 'disease could be appropriate.

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41, for permit lasting at least one year) and D.Lgs. N. 251, November 19<sup>th</sup> 2007, *Gazzetta Ufficiale* N. 3, January 4<sup>th</sup> 2008, Article 27. Since there have been cases where assistance was refused, it was requested that this refusal be set down in writing, in order to sue for discrimination through ASGI, the ombudsman or UNAR.

<sup>377</sup> Torino, il giudice sequestra l'ex villaggio olimpico occupato dai profughi: «Va sgomberato», 14 gennaio 2015, [http://torino.repubblica.it/cronaca/2015/01/14/news/torino\\_il\\_giudice\\_sequestra\\_l\\_ex\\_villaggio\\_olimpico\\_occupato\\_dai\\_profughi\\_va\\_sgomberato-104924110](http://torino.repubblica.it/cronaca/2015/01/14/news/torino_il_giudice_sequestra_l_ex_villaggio_olimpico_occupato_dai_profughi_va_sgomberato-104924110)

There are also cases of migrants who discover the disease in such an advanced state that they cannot be cured in any way. Amongst the many stories we heard, the one that struck us most concerns an aged Moroccan homeless man, for whom it was complicated even to start chemotherapy treatment.

After he came to us, with HIV, we found that he had lung cancer. The doctor at the hospital wanted to start chemotherapy but told us that it was crazy to administer chemotherapy to a homeless person. If he were to fall in the street, or if he vomited... He needed someone to look after him. But he had no one in Torino. We tried to find a place in a number of structures, and in the end we found room at the Cottolengo shelter, an exceptional place; there was a room where the priest stored clothes and other things that are donated, they put a bed in there and this man lived there until he died. (Egyptian cultural mediator, Amedeo di Savoia Hospital).

This story is an exceptional case, but there are many situations in which due to material problems, people put off the moment of the first medical visit, often meeting the doctors when the infection is in an advanced state and therefore very difficult to treat. In addition, for practical reasons, the therapies are often interrupted or carried out with extreme difficulty or discontinuously.

#### 4. *Communicating, understanding and accepting the illness*

A central aspect for prevention and treatment of infectious diseases is information. We asked ourselves how much the migrants know about the existence of certain illnesses, how aware they are of the risks they run when adopting certain behaviours and how much information they have on the existence of specific services in the territory for control and treatment. From the interviews we carried out with the operators, it was evident that, with regard to HIV, there is now widespread awareness within certain social groups: these people go for regular check-ups, above all thanks to word of mouth. Amongst the girls who work as prostitutes, especially the Nigerians, the practice of screening is now consolidated, as it is in the homosexual community, principally amongst Italians.

As a Nigerian mediator told us, her countrywomen are 'obsessed' with their state of health, they are very much afraid of the virus and for this reason, once they hear of the clinics, they become regular visitors and go for periodic screening. In choosing to attend the clinics, the fact that the service is free of charge is very important.

So... the Nigerian women, given that this is a specific clinic, when a doctor or an association sends her, or when she discovers that this service is available, what does she do? She phones her friend and says, "I went to do the test, and there is this and there is that. Why don't you come along?" And the friend goes; also because they have the feeling that they want to check their health continually. Because they are obsessed, they go regularly. If they don't have to pay, they will go. But if they think they have to pay, they will put it off, again and again. If they think it is expensive, they wait, they think about it for a bit. (Nigerian cultural mediator, Amedeo di Savoia Hospital).

There is still a lack of information that affects the more marginal migrants, those who are more difficult to reach through institutional channels. For these people, the arrival at the specialist clinic occurs after they have been to the A&E or other voluntary health structures, which give basic care and where they often arrive in emergency conditions. Many of these patients are irregular; therefore, they have no GP or

even an STP card, since they are often not aware of their rights. The first step, when these patients arrive, is to send them to the ISI clinics to be registered and receive the STP code: for the more complex cases, which require immediate hospitalization, it is now possible to register them by fax, with compulsory signing on by the patient after discharge.

The Torino medical personnel have long been aware of the criticalities of the information sector and for this reason they have organized ways of reaching the vulnerable sections of the population. The hospital for infectious diseases has opened decentralized consultancies at the Sermig and the Associazione Camminare Insieme clinics, which are well attended by poor migrants without documents. The operators meet people waiting for the distribution of food parcels or specialist visits and they show information videos on infectious diseases, provide information and offer them immediate screening examinations. On the basis of a similar philosophy, since summer 2014 volunteer doctors, following repeated reports of cases of scabies and tuberculosis, have set up an information desk and consultancy at the MOI buildings, where they direct the occupants to the various public services available in the territory. The health-training programme on infectious diseases, organized in some Islamic prayer centres in Torino, also derived from the need for more information reported by the healthcare operators working in this community. We will dedicate more space to this experience in the seventh chapter.

In order to attain a good level of efficiency in the activities, however, it is important not only to promote information campaigns, but also to understand how these campaigns are received by the persons for whom they are destined, within which systems of meaning the people place the experience of illness and what explanations they give for the causes and the consequences.

For the Nigerian women the weight of the system of traditional beliefs remains very strong, as a mediator told us.

Occasionally we meet a person who says that the disease is not theirs, because it is voodoo. The influence of voodoo is very strong and people are afraid. The girl tells us "it's nothing to do with me; it is other people who have given me the illness". Then, she doesn't follow the treatment and she won't take responsibility. We are also working on this. Another problem is the incorrect behaviour during pregnancy. The pregnant women, if they are infected, must be very careful. In Nigeria, when a woman is pregnant, she must move quickly, she must run every day, because she must prove that she is still a woman; that she is an active wife and mother. And this is a risk, because if they move about too much they can infect the foetus and it is complicated to explain to them why they must be very careful. (Nigerian cultural mediator, Amedeo di Savoia Hospital).

The discovery of infection is experienced as a tragedy, because its presence often conflicts with the ideal of maternity, which is very important for African women. The priority for these women is to show their reproductive capability.

There is a lot of work to be done with these women. Even more than the virus, what frightens them is the fact that the maternal role is at risk. If the father is not present, it is not a problem, they are happy to have the child on their own, the important thing is to have a child... because they think, my friend has a child and we are about the same age, so I must have a child, otherwise they will think there is something wrong with me. You know, there are a lot of people who say they want to get pregnant, but only because they must get pregnant, to be able to say that they can. (Nigerian cultural mediator, Amedeo di Savoia Hospital).

The idea that the disease appears as a punishment for immoral behaviour is recurrent and takes different forms according to the cultural context of the country of origin. Often the systems of religious belief contribute to endorsing and supporting mechanisms of blame and self-blame. The links between religion, morality and sexuality are complex. For example, in the Pentecostal religion, to which many African migrants have converted, HIV and AIDS are proof of the presence of Satan and are considered a challenge to the person's capacity to live as a good Christian. Often the infected are accused of deliberately plotting the infection of other people in order to drag them (with themselves) into sin, and even the use of a condom is implicitly considered an admission of immorality or promiscuousness<sup>378</sup>. The religious interpretation of sexuality proposes abstinence before marriage as moral behaviour and condemns the use of condoms even within "moral" sexual relations. Amongst the young people who are sexually active, these religious interpretations of the disease and these moral judgements on sexual behaviour create obstacles to the practical evaluation of health risks. Similar views are often found amongst the young migrants we met in Torino. Religious belief in fact, plays a fundamental role in accepting and overcoming the disease. For many patients the churches are the only places they can find a spiritual answer to the anxieties linked to the disease<sup>379</sup>. Their stories are very explicit on this matter.

When I was ill and they took me into hospital the only people who came to see me were the ones from my church, in particular the Pastor. I had been attending that congregation since 1999. They didn't bring me food because they knew that I received it in hospital, but they came to pray with me; the medicines were important, but also my faith was important. A lady from the church had to go to Jerusalem and I asked her to bring me some water from the Jordan River because I knew that Jesus was baptised there. The lady brought me the bottle of water and I drank it every day once I returned home. I also used this water to wash myself, because Jesus was baptised in this water. The doctors, in 2000, told me that I was almost dead, that I would not be here by the end of the year. But I am still alive, I have had a second child, I also take less medicines. Also thanks to this miraculous water! (Beauty, 35 years old, Nigeria).

This patient has never told the Pastor and the congregation exactly what her illness was, however she has harmonised modern medicine and spiritual belief. Although it is not a priority in safeguarding the right to health and at times, the spiritual strategies can conflict with the treatment proposed by biomedicine, the dialogue between the medical staff and religious leaders is very important.

Some interviewees were very critical of the behaviour of the religious leaders, because in their opinion they promote an exclusive and integralist approach.

There are priests who say, "If you want to get well, you *are* well, but if you don't... you will not get well". So everything depends on the will of the sick person. Now, while it is true that the psychological situation of the sick person is important, that is obvious, but not to the point where they will get well without taking medicines. I have an Egyptian friend and there are some Nigerians who came to her house, to pray, to read the Gospels. She had tuberculosis, she was dying, and they told her, "If you want to get well, you will." And when this friend of mine died, the answer they gave me was, "We knew she would die... because she did not want to live." (Amira, 50 years old, Egypt).

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<sup>378</sup> D.J. Smith, *Youth, Sin and Sex in Nigeria: Christianity and Hiv/Aids-related Beliefs and Behaviour among Rural-urban Migrants*, in «Culture, Health, Sexuality», vol. 6, 2004, n. 5, pages 425-437

<sup>379</sup> On the role that the Pentecostal religion and churches play in responding to the crisis of belonging linked to migration, amongst Nigerians in Torino see also: P. Cingolani, *Coming from Naija to Torino: esperienze nigeriane di immigrazione e di fede*, in *Più di un sud. Studi antropologici sull'immigrazione a Torino*, ed. P. Sacchi and P. Viazzo, Milano, Franco Angeli, 2003, pages 120-154.

The treatments can be very lengthy and require a high degree of awareness and acceptance. One instrument that has been elaborated and proposed to the patients, in the case of a positive response to screening, is the help of a psychologist. Nevertheless, this form of assistance is not always accepted by the patients, because they see it as an excessively ethnocentric approach. For some of the interviewees it is not a psychologist that is needed, but rather spiritual fathers and a community of friends.

It is necessary to know the person, then you can talk, you try to understand whether the person needs a psychologist or not. There is no universal rule. Because often, at least the Nigerians and other Africans, don't need the psychologist, they need a cultural father; psychology, even with all its specialisations cannot help. In my opinion, in these cases, it is necessary to put the person in contact with a group where they feel comfortable. In the sense that it is better to go to this church or that association where they feel at home. And in effect, I have seen that they go and they feel good, they feel at home. (Nigerian cultural mediator, Amedeo di Savoia Hospital).

The question of the cultural acceptability of the disease and the treatments is also closely linked to the question of cultural mediation, to the professional preparation and the skills brought into play. In this healthcare field more than in others, it was clear that the presence of mediators from the same cultural group as the patient could create considerable awkwardness, rather than facilitating the dialogue. People do not always want to meet a figure from "within" their community, because they fear they will be judged morally and above all, they fear that the secret of their disease will be betrayed.

At first, I didn't want the mediator because I could only tell the important things directly to the lady doctor, the doctor understood English and I understood Italian. That other Nigerian woman made me feel like it was an examination. And then, the world here is small and who could assure me that outside the hospital she wouldn't talk to others about me? It's better to tell my affairs to an Italian rather than to someone from my community. It would also be all right to talk to an Egyptian mediator, who can speak Italian, but not to a Nigerian one, absolutely not. (Beauty, 35 years old, Nigeria).

Despite considering all these criticalities, it is important to emphasise that all the patients interviewed, once the difficulties of access and the cultural obstacles were overcome, showed a high degree of satisfaction for the quality of the services received and for the relationship they built with the medical staff. One of the most significant stories is that of Alima, a Moroccan woman of thirty-four years old, who has had tuberculosis since she was seventeen. In Morocco the disease had not revealed particularly violent symptoms, but then, as the situation worsened, in 2010 it became necessary for her to join her parents and siblings who had been living in Torino for some time. Due to a crisis, her father took her to the A&E of an important Torino hospital and there she was sent to a specialist clinic. The tuberculosis diagnosed was lymphoid, with intermittent and unforeseeable symptoms, and it required treatment for much longer than that foreseen for respiratory tuberculosis. In Italy, the disease had compromised Alima's capacity for organizing her days independently, preventing her, for example, from holding down a regular job. After she met the personnel at the clinic, she became progressively more independent, for example, renouncing the mediation of her father during the appointments. Throughout the course of her illness, she has never had contact with her GP; the principle reference point is the personnel at the clinic. Only the family know about her disease and Alima has never spoken of it with people from her country of origin, showing a profound social shame;

she has built a strong relationship of trust with the medical staff and with the Arabic mediator and this has made it possible to carry out the treatment efficiently.

##### 5. *An integrated approach to sickness in foreign mothers*

As we have seen the infectious diseases represent an area of particular complexity since the people who suffer from them often suffer also from multiple forms of discrimination. These forms of discrimination are linked to the characteristics of the disease, difficult to identify and strongly stigmatized, to the subjective characteristics of the patient, often bearers of various fragilities, and to the characteristics of social contexts and material conditions of life. The interventions to safeguard the right to health of these patients should adopt an integrated approach that considers all these aspects.

One of the cases in which multiple discrimination is strongest is that of HIV positive mothers who find that they must face two courses in parallel, that of the illness and that of maternity, in conditions of considerable personal, family and social fragility. These women are, in part Italian, and come from the world of drug addiction, but the majority are immigrants, often irregular, who have contracted the virus sexually. The transmission from mother to child of the HIV virus occurs in 15-20% of cases, a percentage that increases to 30% if the mother breastfeeds. Thanks to specific interventions, that is the administration of medicines during pregnancy, caesarean section and avoiding breastfeeding, this rate of transmission can be reduced to 2%. In order to attain these objectives, it is important to facilitate access to the healthcare structures and to support the correct antiretroviral therapies. The right to have a serene maternity that does not put the baby's health at risk is often compromised by the socio-economic difficulties of the women.

In order to respond to these problems since the year 2000 OIRM-Sant'Anna Hospital, the regional centre for HIV in obstetrics, gynaecology and paediatrics, in cooperation with the Amedeo di Savoia Hospital for infectious diseases and Gruppo Abele has been running a programme for integrated assistance called *Mamma+*. This project is based on the awareness that "in order to safeguard and protect the mother-child couple correct healthcare is necessary to remove the social and cultural obstacles that risk compromising attainment of the health objective."<sup>380</sup>

The project was presented to the council department for health (Assessorato alla tutela della salute e sanità) of the Regione Piemonte, and has received funding from the national health fund in favour of persons affected by HIV/AIDS. This project, as shown in previous studies<sup>381</sup>, is based on contributions renewed annually, but cut by 50% in 2012; this reduction has affected the number of working hours of the social workers and the contributions for ordinary expenses of the mothers, such as help with rent or the cost of medicines.

Each intervention lasts between twelve and eighteen months and is developed by taking charge of the pregnant mother until the child is one year of age. A first phase is during the pregnancy and involves the personnel of the obstetric gynaecological clinic, the social worker at the Sant'Anna Hospital and the educator

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<sup>380</sup> Regione Piemonte, Assessorato alla tutela della salute e sanità, Ufficio Dipendenze e Aids, *Mamma+*. *Progetto di assistenza integrata alle donne gravide HIV+ e alla coppia mamma- bambino. Sette anni di attività e prospettive future*, Cuneo, Edizioni Publiedit, 2008, page 7.

<sup>381</sup> I. Bigliano and A. Olmo, *Health as a fundamental right: a study on migration and healthcare in Turin*, op. cit., page 88.

at Gruppo Abele. A second phase, after the birth of the baby, involves the personnel and the social worker at the department of infectious diseases at OIRM and the educator at Gruppo Abele. All these figures accompany first the mother, then the mother and the child, in a course of social-health integration, with appointments at the clinic and home visits. The methodology is based on teamwork, with monthly meetings and the supervision of the educational unit at the child psychology unit of OIRM. The initial work of the group was integrated in time with other professional figures with specific skills, such as the ethnopsychiatrists from Centro frantz Fanon for transcultural psychological assistance, lawyers for legal matters regarding documents and work-related matters for the professional inclusion of the women.

Over the years, there have been important changes with regard to the social-demographic characteristics of the users. In the first years of the project, the women were mainly Italian with experience of drug addiction, either previous or ongoing, 70% of the cases, while in recent years the majority of the women have been foreigners, 90% in 2012, with infections contracted almost exclusively through sexual relations. At first, the number of women who, having found out about the infection, decided to continue with the pregnancy was very low: in 1989 there were less than ten births in the city each year. Trust in the efficacy of the treatment, promoted also by the project, has meant that many women have decided to give birth, with more than thirty cases in 2005. The foreign women involved are mainly of sub-Saharan origin, without a residence permit, who live in conditions of strong isolation and social marginalization, with families far away, often without a partner, without stable employment and with precarious and poor living conditions. The words of an educator involved in the programme summarise this complexity well.

The objective of the project, apart from the strictly medical one, is to activate a support network in the widest sense. The right to health of mother and child is guaranteed only if we can satisfy a whole series of other conditions. For this reason, we accompany the mothers, with psychological support for her personally, and with help in the management of the child, through placement at nursery school, in some cases with the assistance of the child psychologist, help with finding work and support for the first year with everyday expenses, such as rent. In the first six months, the National Health Service guarantees powdered milk for all mothers with pathologies that risk infecting the child. After this period the contribution ends and we buy both the milk and the nappies, reimbursing the receipts from the pharmacies, we also help with food through the food bank. Also from the point of view of work, the situation is dramatic: the women, when they have a job, lose it because they are pregnant and after the birth they find it difficult to find another job. Some work on the streets as prostitutes, we don't know whether after the birth they continue, and only a few of them are involved in service cooperatives, some work as cleaners or carers. One example is that of an HIV positive Nigerian woman with three children, after the birth of the third child she lost her job: she was behind ten months on her mortgage and was about to be evicted. The company she worked for had a call centre that went bankrupt, then she took out a VAT number, but she has a debt of 3,000 euro to cancel it. The fact that she had a VAT number meant that this family was not considered by the local social services to be in a situation of need. We are desperately trying to find a way to cushion the effects of this situation, because this woman will be homeless, jobless and with all the expenses for the children... The final aim is to guarantee health and independence; it is not easy to become a mother nowadays and even more so if you are a foreigner and sick! (Educator from the project *Mamma+*).

The portrait of the persons assisted by the project once again illustrates a number of the problems that emerged from the interviews with other patients with infectious diseases, here aggravated by the fact that the patients are women with young children. In the first months of the child's life, these women must face profound solitude. Often they do not share with anyone, except the doctors and the educators, their health situation and this makes the appointments for assistance even more complex. The networking is partial

because it cannot include and valorise the relational resources from the community of origin of these women. The situation is even more complex when the partner is not present, or if present is not aware of the state of health of the woman and the child.

The story that Queen tells is particularly meaningful. Queen is a Nigerian woman aged forty, an Edo born in Benin City, in the southeast of Nigeria, and she grew up in the city of Lagos. In Nigeria, she worked as a dressmaker until 2000, when she had to emigrate due to the economic crisis, above all to help her younger brother and sister. In 2006, she obtained a regular work contract with a cooperative that cleaned campers and a residence permit. She kept this job until 2009, when she was dismissed. In 2007, Queen began a relationship with a Nigerian man, becoming pregnant twice and aborting both times. In 2009, at the third pregnancy, despite the fact that her companion did not agree, Queen decided to keep the child, but the man left. During the medical appointments for this pregnancy, Queen discovered that she was HIV positive and was sent to the Sant'Anna clinic and to the Amedeo di Savoia Hospital clinic for infectious diseases. After careful evaluation, she agreed to join the project *Mamma+*; the educator accompanied Queen to the appointments and mediated in both hospital contexts, in addition to putting her into contact with the local social worker. Queen refused the presence of a Nigerian cultural mediator, because she said she had no problems understanding Italian. The health situation worsened rapidly: during the pregnancy Queen lost a lot of weight, falling from 80 to 56 kilos, she refused food and was forced to spend long periods in hospital, where she was fed through a drip and given a strong antiretroviral therapy. Her daughter was born full term through caesarean section, without becoming infected; after the birth, Queen was assisted for another year. With the birth of the child, the socio-economic situation worsened and Queen lost her home. Thanks to the intermediation of the educator, she was taken into a residence for mothers and children in difficulty. At the age of four months, the child was placed at a nursery school and in the same period, Queen attained a work bursary in a large tailor shop, thanks to which she was able to pay the rent for a private apartment. Later she applied for and was granted an apartment in council housing, with a welfare benefit of €90 to help pay the rent. At present Queen has lost the benefit and is waiting for an answer from the Ufficio Pio, Compagnia San Paolo (corporate social assistance). She meets the daily expenses, for herself and for the child, thanks to the small income from dressmaking work that she does informally at her home. This is where I met her.

I really wanted this child, that is why I called her Blessing. My companion did not want a baby and that is why I left him. He lived off me; he did nothing. Men don't want to take responsibility. I worked, even when I was pregnant, and my companion did nothing, absolutely nothing and it is also for this reason that I never told him about my illness, because anyway he wasn't on my side. Without Maria, the educator, I would never have managed. She is like the father and I am the mother for Blessing, that's what I always say [...] The doctors also told me that my daughter is a miracle! It's not easy to raise a daughter alone, but God also helps me a lot. God says we must forgive and let things go, and not think about the difficulties. To cure myself I also tried other things, I used a root that I paid €6,000 for, they sent it to me from Nigeria, but it was no use. For my illness, only Italian medicine was any use, and prayer. Now I am at peace with myself and with my illness. (Queen, forty years old, Nigeria).

Commento [KMC7]: Come sopra.

In Queen's story, we find a number of interesting elements; first, there is the strong desire for motherhood, pursued alone and in the total absence of the paternal figure, substituted, in Queen's words, by the educator of the project. The network formed by the operators of the various services has been essential

for the health dimension and for the working situation, for finding a home and for the education of the child. The infection is a constant element in the background, which re-emerges strongly in the most critical moments, but with which Queen has learned to live, arriving at an intimate acceptance. This has occurred thanks to the combination of practical support from the social and healthcare operators of the project and from an emotional and spiritual support from her faith. Stories such as this one show the importance of an approach to the health of the migrants that is not limited to guaranteeing the right to health, but also tries to involve the wider social sphere.

## Chapter Six

### Intercultural mediation and training

#### 1. *Mediation and interculturality*

During the two phases of the research, intercultural mediation emerged as an essential resource in safeguarding the migrants' right to health. The importance of this instrument was highlighted by both the operators and the users who have encountered this professional figure while in Italy; nonetheless, there are still criticalities that put this figure at risk and there is still not sufficient clarity about the responsibilities and the role of the intercultural mediators.

The word "mediation" derives from the Latin *mediatio*, *-ōnis* and is linked to the word *medius* "in the middle, central", but also to "intermediate", "ambiguous", "neutral"; it is, therefore, a concept that opens up a vast semantic horizon. To mediate refers to the construction of meeting points between opposing

positions; to the art of conciliating divergent needs in a creative manner; to the possibility of generating relations between the parties and finding compromises that, in some way, can meet the various expectations; to the capacity for maintaining a neutral position, ideally equidistant between those for whom the mediator is acting, accepting the ambiguity intrinsic in this precarious balancing game.

Although other names have been given to intercultural mediation, nowadays this term is the most widely used and the most appropriate, since it emphasises the possibility of dialogue and reciprocal exchange between people from different cultures. The concept itself of ‘mediation’ calls on a relational and fluid idea of identity and a dynamic notion of culture, seen not as a reified, static entity with well-defined borders, but as a social construct, “a system of inherited concepts expressed in symbolic forms through which men communicate, perpetuate and develop their knowledge and their attitude”, to quote a definition formulated by the anthropologist Clifford Geertz<sup>382</sup>. Admitting that it is possible to “mediate between cultures” implies seeing these as open systems of operative knowledge that direct the actions and that can be modified, allowing the subjects to attribute a sense to a dynamic reality and adapt to change. Cultures, in a world increasingly characterised by mobility, can also be seen as transnational entities, “structures of meaning that travel on networks of social communication not entirely situated in any single territory”<sup>383</sup>.

**Commento [KMC8]:** Se possibile inserire la citazione originale.

**Commento [KMC9]:** Come sopra.

The concept of “interculturality”, nonetheless, must be problematized in the light of historical and political circumstances that condition relationships between countries and between cultures. In fact, we must not forget that the meeting between the migrants and the host society is not equal, nor neutral: it is intrinsically asymmetrical and is conditioned by historical inequalities in the distribution of the global resources, by the migratory policies and by the dynamics of power. The inclusion of the migrant often occurs in conditions of “subordinate integration” and fair conditions of cohabitation are not always guaranteed. As the sociologist Giovanna Ceccatelli Gurrieri states, “the conceptualisation and the experience of cultural mediation forces us to reflect on conditions that allow us to approach others; the different from ourselves, and, inevitably, leads to the construction of a concrete relation with the gap, the difference, the error which, after all, we believe they bring with them”<sup>384</sup>.

Intercultural mediation is first a communicative process that finds its basis in dialogue. It is a complex instrument that has been developed in Italy since the early nineties, in concomitance with the growing migratory flows, which made interaction with migrants from linguistic, cultural, geographical and social situations with which the operators are unfamiliar occurrences that are more common. Misunderstandings and conflicts are inevitably rife in fields often highly bureaucratic and frequently characterized by a strong structural rigidity.

<sup>382</sup> C. Geertz, *The Interpretation of Cultures*, New York, Basic Books, 1973, Italian translation: *Interpretazione di culture*, Bologna, Il Mulino, 1998, page 113.

<sup>383</sup> U. Hannerz, *Cultural Complexity: Studies in the Social Organization of Meaning*, New York, Columbia University Press, 1992, Italian translation: *La complessità culturale. L'organizzazione sociale del significato*, Bologna, Il Mulino, 1998.

<sup>384</sup> G. Ceccatelli Gurrieri, *Mediare culture. Nuove professioni tra comunicazione e intervento*, Roma, Carocci, 2003, page 27.

The presence of “others” – the foreigners – began to increase during that period and the more attentive operators became aware of the limits of the consolidated procedures and their own skills. The need to train figures capable of acting as linguistic-cultural mediators during the first phases of reception of the migrants and later in other situations, such as the health and welfare fields, was evident.

We took the course in 1996-97 and then we did an internship at the Amedeo di Savoia Hospital, where I still work, and at Sant’Anna and Regina Margherita hospitals. There was a great need for mediators, practically, anywhere you did an internship, they took you on afterwards. At that time there was no one to tell you what to do, because mediators did not exist, to some extent, we invented the job. We were linked to the social workers at first. In some hospitals these two offices are still together, but in others we are linked to the Public Relations Office, for example at the Molinette Hospital it is like that. (Albanian cultural mediator)<sup>385</sup>.

The intercultural mediator, already present in other European countries that had faced the migratory phenomena, had been an efficacious instrument in responding to the challenges posed by the new users. The private social associations and the local administrations had in fact activated this figure at an informal level even before it was announced for the first time at national level, thanks to the Law N. 40, March 6<sup>th</sup> 1998, known as the Turco-Napolitano Law.

The role of intercultural mediator is also foreseen by Articles 38 and 42 of D. Lgs, N. 286, July 25<sup>th</sup> 1998 (TUI immigrazione). Article 38 refers to the education of foreigners and intercultural education and at paragraph 7, letter b) foresees the adoption of “criteria for recognizing educational qualifications and studies carried out in the country of origin, for the purpose of placement in schools, and the criteria and the methods for communication with the families of foreign pupils, also through qualified cultural mediators”. Article 42, relating to the measures of social integration, enacted the Turco-Napolitano law and established that:

The State, the regions, the provinces and the *comuni*, within their specific responsibilities through cooperation with associations of foreigners and with the organizations working stably in their favour, and in cooperation with the authorities or the public and private bodies in the countries of origin, shall favour:

d) conventions with associations regularly registered, as per paragraph 2, for employment within their structures of foreigners who hold a residence permit or visa for not less than two years, as intercultural mediators in order to facilitate relations between the administrative units and the foreigners belonging to various ethnic, national, linguistic and religious groups.

Intercultural mediation is therefore included in the general framework of the measures that encourage social integration and is closely linked to the world of associationism amongst the migrants, which we will discuss in the next chapter. The consolidated legislation establishes minimum requisites for working as a mediator and proposes an initial operative sector – that of the public administration – but does not describe the training procedures, or define the duties, the skills or the role of these new figures<sup>386</sup>.

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<sup>385</sup> In this chapter, the mediators interviewed will be quoted with reference only to their nationality. This choice, which differs from the method used in other chapters in the volume, is motivated by two factors. In the first place, while in other parts of the research the mediators are called on as privileged observers or operators of particular services, in this part we asked them to tell us about their own experiences. We have therefore decided to quote the interviews using generic references, to safeguard their anonymity. Secondly, during the research we have noticed that, in the majority of cases, the mediators operate in more than one situation and they usually report working as mediators in a variety of contexts during their professional lives. To ascribe them to a single service would therefore be a stretch, in particular when speaking of transverse themes such as training or the role of this professional figure.

<sup>386</sup> The TUI (consolidated legislation) remains the principal legislative reference at national level.

At regional level the regulations that govern the recognition of the intercultural mediators varies considerably. In the Regione Piemonte, the professional profile of the intercultural mediator is established by the Determination N. 399/2000 “New standard denominations of the Regional direction for professional training and work”, according to which:

The intercultural mediator carries out activities of liaison between foreign cultures and the local and national structures, the services and the institutions, cooperating to give responses to the needs for integration of the immigrants. They work at the structures and services, both public and private (ASL, hospitals, clinics, schools, reception homes, social and welfare centres, prisons, public offices whether state-run or local authority). They cooperate with the operators of the public and private services, assisting them in their activities and participating in the planning of interventions in order to guarantee their efficacy. The students will be able to finalize the professional skills acquired in order to provide their professional services to the above public and private subjects, also promoting with other students the constitution of a service cooperative<sup>387</sup>.

In Piemonte, both public and private training courses that grant a qualification for working as a mediator in the public sector are available, nonetheless there is no deontological code regulating the profession and there is no professional roll or unified register of the mediators. In effect, there is no uniformity in the training courses: some of the mediators have followed unrecognized courses or have trained in the field. Many of the mediators have a university degree from their country of origin, which, however, is rarely recognized in Italy.

So, who are the mediators? Where do they operate and what are their specific functions? What are the aims of their interventions? What training is required and what should the professional profile be? What contractual profile should they come under and in which fields should they operate? What responsibility do they have towards the structure or institution that employs them and towards the foreign users? Should the mediators have a function of advocacy, becoming spokespersons for the demands and needs of the migrants, or should they be neutral? How is it possible to guarantee the correctness of the mediation? These and many other questions have guided research at national and regional level, in attempts to map the existing situation, to give coordinates for analysis and propose elements for the definition of a shared theoretical and operative framework.

In fact, in 1999, the Organismo Nazionale di Coordinamento per le Politiche di Integrazione Sociale dei Cittadini Stranieri (ONC – national body for coordinating policies for social integration of foreigners) of the Consiglio Nazionale dell’economia e del lavoro (CNEL – national council for economics and labour) set up a workgroup that drew up a document summarising the most significant experiences of training and work for intercultural mediators during the nineties, within private social associations and public bodies at local level. This document starts from the concept of integration seen as “The progressive acquisition of citizenship through a process of non-discrimination and inclusion of the differences, therefore of

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<sup>387</sup> Direzione regionale Formazione Professionale-Lavoro, Settore standard formativi, *Determinazione N. 399/200, Nuove denominazioni standard* (amendments to Dgr N. 184-2323/1995, enacting regional law N. 63/1995).

contamination and experimentation of new forms of relationship and behaviour, in the constant attempt to hold together universal principles and particularisms.”<sup>388</sup>

The document was later updated in 2009, in an altered social-political scenario, characterized by a high level of conflictuality and increased xenophobia, which was manifesting itself in Italy and other European countries. The emphasis consequently shifted to cohabitation and the principles of equal opportunities, active participation and interculturality<sup>389</sup>.

In the same year, the document “Riconoscimento della figura professionale del mediatore interculturale” (recognition of the professional figure of the intercultural mediator) was approved by the State-region conference. The document mentioned “the need to realize coherent, integrated governance between state, regions, independent provinces and local authorities on matters of foreign immigration”, confirming the competence of the regions in the area of intercultural mediation and validating the professional standard for the intercultural mediators<sup>390</sup>. In this document, the role of mediation as a vector of integration was also recognized. While in the nineties the main purpose of intercultural mediation was to facilitate the first reception of the migrants, facilitating access to the public services, as the migratory projects stabilized and the number of family reunifications increased, it became essential to work towards greater social cohesion and long-term placement in the various areas of daily life.

At regional level it is worth mentioning the volume *Promuovere la mediazione culturale in Piemonte. La valutazione di una politica regionale per diffondere la mediazione culturale nelle amministrazioni pubbliche piemontesi* (Promoting cultural mediation in Piemonte)<sup>391</sup> which, as the title suggests describes and evaluates the process of enacting a regional policy started in 2002 and finalized in promoting intercultural mediation. The interest in this report is twofold: on the one hand, it paints an overall picture of the Piemontese situation during the period in question; on the other it identifies the criticalities that the decision-making process did not consider when implementing the policies discussed in the volume. The offer of mediation was fragmented and the authors felt that the mediation services were generally insufficient and that in some situations there was an unexpressed need for mediation. “Many of the people interviewed felt that the financial resources currently available were very much inferior to the sums need to fulfil the demand for mediation within the administrations.”<sup>392</sup>

These difficulties (as we will explain in the next paragraphs) still persist to some extent. In recent years, however, awareness of the importance of intercultural mediation has grown and new initiatives have been set up to spread and valorise these professional figures. Important work in this direction has been

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<sup>388</sup> Consiglio nazionale dell'economia e del lavoro, Organismo nazionale di coordinamento per le politiche di integrazione sociale degli stranieri, *Politiche per la mediazione culturale, formazione ed impiego dei mediatori culturali*, 2009, [http://www.cnel.it/271?shadow\\_documento\\_altri\\_organismi=3010](http://www.cnel.it/271?shadow_documento_altri_organismi=3010).

<sup>389</sup> Consiglio nazionale dell'economia e del lavoro, Organismo nazionale di coordinamento per le politiche di integrazione sociale degli stranieri, *Mediazione e mediatori interculturali: indicazioni operative*, 2009, [http://www.cnel.it/271?shadow\\_documento\\_altri\\_organismi=3366](http://www.cnel.it/271?shadow_documento_altri_organismi=3366).

<sup>390</sup> Conferenza delle Regioni e delle Province Autonome, *Riconoscimento della figura professionale del mediatore interculturale*, Rome, April 8th 2009.

<sup>391</sup> E. Allasino et al., *Promuovere la mediazione culturale in Piemonte. La valutazione di una politica regionale per diffondere la mediazione culturale nelle amministrazioni pubbliche piemontesi*, Torino, Ires, 2006

<sup>392</sup> *Ibidem*, page 20.

carried out by the multi-ethnic association of intercultural mediators, Ammi<sup>393</sup>, born in Torino in 2005, on the initiative of a group of intercultural mediators with the aim of valorising and promoting their profession and encouraging, thanks to the association, safeguards for the rights of the migrants, their integration and their active participation. This association has contributed to giving a voice to the mediators themselves and is a professional reference point and interlocutor for the public institutions and other associations.

## 2. *The cultural mediators in the healthcare sector*

The effective presence of the migrants has made it necessary to rethink the model of healthcare provided by the National Health Service, which has had to deal with new needs and new problematics. Intercultural mediation has been a fundamental resource in the process of reorganization of the services and has, even today, an important role in safeguarding the migrants' right to health. As we will try to show in this paragraph, the role of the mediator is not limited to the task of facilitating access to healthcare or making health education for the communities possible<sup>394</sup>. In addition to these two areas, mentioned in the national health plan 2006-2008<sup>395</sup>, this figure also has considerable organizational importance, contributes to education regarding the right to health and is essential in the clinical sector and in planning initiatives for migrants.

The mediators who operate in the health and welfare sectors in Torino are generally foreigners who have personally faced the difficulties of the migratory experience and who, precisely for this reason, apart from knowing the language and culture of their country of origin, have experience and skills acquired in Italy, thanks to interaction and integration with the new reality. It is therefore a question of aware participation that allows them to develop a knowledgeable approach to the problems and the obstacles that the migrants encounter, conscious of their rights and sensitive to the process of inclusion in the society they have joined.

When we speak of cultural or intercultural mediation, it is often not so much a case of mediating the cultural situation of your area, so much as mediating the situation of that immigrant who perhaps does not have a home, who is in a new country and must relate... often from this point of view there is not much difference between an African and an Asian person. (Nigerian cultural mediator, Amedeo di Savoia Hospital).

Many mediators describe their role using the metaphor of a bridge "linking two worlds" and which "helps thoughts to move from one shore to another". As Roberto Beneduce says, starting from the experience of the Centro Frantz Fanon:

The metaphor that could be suitable for describing, in general, the role of the mediator is perhaps that of a bridge that must be incessantly crossed in order to ensure a satisfactory exchange between members of

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<sup>393</sup> For more information consult the association website <http://www.mediatorinterculturale.it>.

<sup>394</sup> Other mentions of the educational role of the cultural mediators can be found in *Linee guida destinate alle figure professionali sanitarie nonché ad altre figure che operano con le comunità di immigrati provenienti da paesi dove sono effettuate le pratiche di mutilazione genitale femminile per realizzare una attività di prevenzione, assistenza e riabilitazione delle donne e delle bambine già sottoposte a tali pratiche (art. 4 legge n. 7 del 2006)* del Ministero della salute, Direzione generale della prevenzione sanitaria, which deals with training of the professional figures, such as cultural mediators, who operate with the communities of immigrants from countries with rescissory traditions.

<sup>395</sup> Italian Ministry of Health, *Piano sanitaria nazionale 2006-2008*, page 78.

different cultures, between distinct logics and representations of health and treatment, between distinct universes of thought<sup>396</sup>.

The first and best-known task of the mediator is linguistic interpretation or translation, as the Lebanese mediator Kassida Kairallah explains, “it is not a literal translation”, although it is a faithful translation that maintains the content, at the same time setting in motion a process of bi-directional interpretation, which not only facilitates reciprocal understanding, but also aims to facilitate the relationship. “Unfortunately, the role of mediator is not well defined and there is no national roll or deontological code that allows us to set out our skills. At times we are considered interpreters, but this is not the kind of work for which we are trained.”

Using the mother tongue does not mean limiting communication to this vehicle. The patients may prefer to express themselves in Italian, in the language of the operators. The role of the mediator in this case is to offer support that does not “confine” the other in their diversity, but that facilitates the dialogue, creating a relational situation that encourages assistential continuity and improves the quality of the therapeutic relationship. The sharing of the mother tongue creates a situation of proximity and trust, which allows the mediator to access content that would be precluded also in the presence of a basic competence in Italian, as a mediator who works in the mother-child field explained.

For the parents it is very difficult to work with the Italian psychologist, in the sense that although they speak good Italian, they can only express themselves to a certain extent. You have to talk about yourself. Then there is the painful part. Certainly, the presence of a mediator is fundamental for the linguistic part, but not only... and it is all a question of entwined experiences, habits, customs, and cultural codes, that the person may even have difficulty expressing. With the help of another person, this becomes possible. (Romanian cultural mediator).

As mentioned in the second chapter, the communicative difficulties are amongst the most important problems faced by the patients and operators and are a serious obstacle to safeguarding the right to health. These difficulties lead, in domino fashion, to a series of negative consequences that have repercussions at various levels and which affect the accessibility, the quality and the acceptability of the health services. As we have documented, non-verbal communication, although important, cannot replace the possibility of having a common linguistic terrain, nor does it detract from the importance of the presence of the mediator. Finally, proxemics and gestures are not universal languages, but change their meaning significantly from one context to another.

At times, the doctors are confused because they see the patient nod, when they ask “did you understand?” and the patient nods... so, obviously, they think they are saying “yes, I understand”, but for Orientals, it is a question of courtesy to say yes to a question, even if they have not understood, they will never say “no”. (Chinese cultural mediator).

In addition to the language, the mediator must fully understand the cultural context of the geographical area of reference, which largely determines the semantic background of the words. The concept

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<sup>396</sup> R. Beneduce, *Frontiere dell'identità e della memoria. Etnopsichiatria e migrazioni in un mondo creolo*, Milano, Franco Angeli, 2004, page 235.

of culture, nonetheless, must be treated cautiously. The patients rarely express explicitly cultural needs. When they exist, the cultural differences are presented above all in an implicit manner and may also imply a degree of relationship and awareness that it is not always possible to reach. The category “culture”, in fact, is more often used by the operators than by the patients and is often called upon to explain problematic situations or attitudes that are not usually present in Italian patients. On many occasions, this term masks stereotypes and is used in an *a priori* and acritical manner.

A critical consideration of the concept of culture and its application to intercultural mediation has been matured above all in the field of ethnopsychiatry, which starts from the consideration that the gnoseological categories, the aetiologies, the therapeutic techniques and the forms of suffering are linked to the historical-cultural setting. An in-depth understanding of the cultural reality from which the patients come allows exploration of the way they articulate their psychic reality and their cultural reality and makes it possible to seek the roots of the processes of significance that make a symptom, a discomfort, a knowledge, a treatment intelligible.

With regard to the mediation service, I often find that I must choose the new mediators by geographical area and we realize that it is not easy to work in the psychological-clinical field. In my opinion, this is the place of the cultural mediator. Where you meet the cultural aspect in the most frequent, permanent and clear-cut manner. Where you are called upon to use the cultural part. While an intercultural mediator who [...] works as an interpreter in a court is quite different (Romanian cultural mediator).

The mediators who work in this field must deal with a further level of complexity, which makes them part of the therapeutic itinerary as subjects capable of acting as “guides” in the use of the culture to generate change. In this last sense, the mediator becomes a constitutive element of the therapeutic device<sup>397</sup>.

Also in other areas, the role of the mediator implies an active participation in the assistential course, and, in some cases, involves the practical, operative responsibility that goes beyond the tasks strictly linked to mediation. The presence of the mediator contributes to creating a relationship with a greater symmetry that encourages sharing of the treatment and the compliance.

The responsibility of assisting Arab women who have difficulty with the Italian language and encouraging them to attend the appointments, both prenatal and postnatal – such as appointments with the paediatrician, with the gynaecologist for the prescription of a contraceptive pill compatible with breastfeeding and other things, is mine. I am convinced that our presence can benefit the work of the doctors and nurses. Without the mediators, many operators would find it difficult to create a “therapeutic contract”, to share objectives, to receive informed consent and continue the interventions, actively involving the patients, making them not only adherent, but also aware and in agreement with the treatments proposed. For us, on the other hand, this is possible because the women trust us. (Moroccan cultural mediator).

The mediator facilitates the interaction with the local resources and specific associations from the country of origin of the migrant, contributing to recreating the bonds that can support them in times of difficulty and, in certain cases, play a therapeutic role. Overall, we can state that the mediator has a fundamental role to play in facilitating the communication at various levels and constructing a relational framework within which the specific health problem can be treated.

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<sup>397</sup> *Ibidem*, pages 241-243.

At times, a person arrives with a headache and they can only speak a few words of Italian, or they explain with gestures, you as the operator do your job; you give them paracetamol and you send them home, but maybe the headache was just part of the problem and there were many other things that they didn't want to tell you... so you haven't solved the problem and you may not even realize it. So there is something more that we can do, we can listen. (Jordanian cultural mediator.)

Sharing a language, a cultural origin and, above all, the asperities of the migratory experience opens the way for a relationship based on trust and closeness, which allows greater attention to the specific needs of each user.

I try to be near them, I give advice also on the basis of their needs, their history. They confide in me. At times, a woman will not dare to speak of a discomfort or a problem with others. At times, a woman has to come here to give birth and she has no one to leave the other children with. At times, I have to deal with women with a low level of education, they don't understand the reason for certain specialist tests and I try to simplify. (Moroccan cultural mediator).

In many situations, the mediator fully understands the regulations and the procedures for applying for specific rights and offers practical help to the patient in navigating a healthcare system that is not user friendly.

I don't only look after Albanese patients, but also other people who speak the language, because there are many bureaucratic procedures and no one knows the law for the foreigners... the clerks, the secretaries... they all call us, almost none of the Italian clerks knows the rules, and the laws change continually, so when a patient arrives with an irregular situation, they call us. Sometimes I accompany Nigerian patients, sometimes I help them with the admission procedures, because they don't know the hospital, they don't know where to go. So we explain to the patient how to get an ISI code, because there are a lot of people who have been here for six years and they have never applied for an ISI code. When you are both foreigners, you feel closer. We also came here without being able to speak the language. (Albanese cultural mediator).

A fundamental task of the mediators is to receive the informed consent of the patients and, in some cases, to explain the *concept* of informed consent, which is unfamiliar to many patients. This task is particularly delicate, due to its legal implications, and should be further investigated. Finally, the mediator is a fundamental support in planning the interventions: the initiatives that are rooted in the territory are in fact characterized by the participative and continuative presence of mediators in whom the patients place their trust and who have in-depth knowledge of the problems of a community.

### 3. *Obstacles and problems to be resolved*

Around the figure of the intercultural mediator, there are still many unsolved problems that were already examined in the first phase of the research<sup>398</sup>. Amongst these, we recall in particular the fragility of the profession of the mediators, which has insufficient formal recognition. Moreover, as already stated, non-EU citizens cannot be engaged as public employees, which further limits the contractual power and the employment stability of the mediators. There are still many deficiencies for those who must work in the

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<sup>398</sup> I. Biglino and A. Olmo, *Health as a fundamental right: a study on migration and healthcare in Turin*, op. cit. pages 101-110.

healthcare sector and need specialised, recognized, quality training. This need is now the object of interest at national level, thanks to the PASS programme (Promozione dell'accesso della popolazione immigrate ai servizi sociosanitari), coordinated by Inmp , which concluded in 2010, and which included a theoretical-practical course for linguistic-cultural mediators already working in the field, in cooperation with forty local health authorities throughout the country. In Torino, the San Giovanni Battista and Molinette hospitals took part, in the role of regional leader, with the local health authority ASL TO3. This course was the first step towards the specialization of those who work in the healthcare sector, but has not fully met the need for training and even today an adequate local response to the needs of the hospitals and the mediators themselves is lacking.

There is still a tendency amongst the services “to outsource the activities, rather than setting up specific services using employees”<sup>399</sup>. While the associations in the private social sector tend to establish working relationships with individual mediators, maintaining a lasting relationship with them the major structures use a system based on short-term contracts with cooperatives and associations. The mechanism of short-term contracts leads to the risk of encouraging a logic that prefers cost reductions rather than quality services and may eliminate the smaller associations, which are often managed by the foreigners themselves, because they are less competitive on the market, compared to the large cooperatives.

As already mentioned in the second chapter, the present situation is characterized by a general lack of resources and in recent years, there have been considerable cuts in public healthcare spending. In the first volume, in fact, we mentioned the need to monitor the initiatives for the protection of the migrants, given the tendency to reduce the social programmes and services for the more marginalized categories, who are more vulnerable in times of crisis<sup>400</sup>. Unfortunately, in some services we found a significant reduction in the funding destined for initiatives for migrants, which has had a negative effect on the availability of mediation. This is the case of the MISA clinic, which we discussed at length in chapter five.

The MISA was a new idea. It was a clinic only for foreigners, that wasn't just a clinic but also a reference point, a place to come to ask for information and guidance. At first they employed a lot of mediators... let's say, for many languages. Then with the cuts, we are just three poor things: Nigerian, Somalian and me. (Egyptian cultural mediator).

The attempt to save funds destined for the intervention of the mediators has also led some hospitals to propose solutions not coherent with the principles of this profession and which drastically reduce the efficacy of the work of the mediator. One example are the attempts to introduce telephonic translations, which may represent a solution in an emergency, but which do not replace the continuative and direct relationship with the mediators.

When the foreigner can't speak (Italian), they also have a lot of health problems. I will tell you about one case that I dealt with last week. An Egyptian man of 45 years old. He has diabetes and he must be operated for carpal tunnel, the carpal tunnel operation. He went to an appointment at the orthopaedic department of Maria Vittoria Hospital and since he didn't speak Italian, they said to him, “We can't give you an appointment unless

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<sup>399</sup> E. Allasino *et al.*, *Promuovere la mediazione culturale in Piemonte*, op. cit., page 5.

<sup>400</sup> I. Bigliano and A. Olmo, *Health as a fundamental right: a study on migration and healthcare in Turin*, op. cit. page 82.

you bring someone who speaks Italian.” And he said, “Who can I bring, I don’t have anyone, I can’t force my friends, I can’t ask a favour of my friends, if someone comes with me, he will come if he is free, if not, he will not come with me, and I can’t oblige him to come!” And then he came to me, because he is a Coptic Christian and I said to him, “You go and say to the doctors, respectfully, that you know there are mediators and that you need a mediator, a translator.” They pretended they did not understand. He was received and he went to the day hospital for the pre-operative preparation and they sent him to the specialist in diabetes – because he is also being treated by this specialist – and he takes insulin twice a day, morning and evening. The diabetes is not going well. So the specialist in diabetes added an injection in the afternoon and one before he goes to bed. And in front of the doctor, he called me to translate over the phone, as a friend, not as a mediator. I spoke to him, I told him everything, but because I am honest, I told him to come to me with the written piece of paper from the doctor. He came here, and he had not understood that he was to take the insulin four times a day! How can he understand when he finds himself in a situation like that? Pass me the phone... give me the phone back... pass me the phone again... (Egyptian cultural mediator).

As shown by the case described by our interviewee, an inadequate intervention of mediation can seriously compromise the quality of the assistance and may prevent understanding of the treatment to be followed. It must be said that there are no uniform regulations or guidelines regarding the methods of mediation and each hospital or service has developed its own operational methods.

In the meantime, a tendency for the hospitals to prefer the networks and the resources that the patient can activate independently has emerged, with the probable aim of limiting the number of hours paid for by the structure. This is not an isolated case, quite the opposite, the healthcare structures explicitly state that they cannot offer a service of mediation and they ask the patient, if they want an appointment, to find their own support for translation. This solution is certainly lacking from the standpoint of professionalism and privacy. As we explain in chapter seven the associations from the migrant community can offer an alternative channel and fill the gaps created by a lack of mediators in the public bodies.

The resistance to the use of mediators, which was already highlighted as a criticality in the first phase of the research, represents a serious obstacle to access to healthcare, above all specialist treatment, for the patients who do not have a sufficient knowledge of Italian. There is also an important qualitative difference between the translation and the assistance that a mediator with experience in the healthcare sector, who is competent in the technical language of the operators can provide, compared with the informal support of a family member or a friend.

In this second phase of the research, it was possible to see an unexpressed need for information on mediation and access to mediation services amongst GPs and amongst paediatricians. These professional categories meet an increasing number of foreign patients, of a heterogeneous nature, amongst which there are individuals and families with language skills that are not always excellent and with various degrees of knowledge about how the services work.

The intervention of a mediator could be resolute in the presence of linguistic and cultural barriers; however, there are no well-defined ways of activating this service.

In addition to the numerous situations of evident linguistic misunderstanding, there are more nuanced communication problems, which are rooted in different ways of representing the body and health. The case of Binette, a Cameroonian woman we met at the general medicine clinic of Associazione Camminare Insieme, may be useful to illustrate the misunderstandings that can occur even when the doctor has an open mind. In fact, the woman suspected that she was ill and, in order to ascertain her condition, she

asked for blood tests, but she had no money to pay the ticket and neither she nor the doctor can find a way to have her exempted. The doctor, probably with the best intentions, advised the patient to donate blood. As is well known to many Italians, blood donors are subjected to careful screening: although it was a loophole, in the eyes of the doctor, this was a valid way of managing the difficult situation. However, Binette was very frightened and during the interview she told us incredulously and fearfully what happened.

The doctor insisted that I should go and give my blood! He told me I had to do a... donation of blood first, to get the blood tests. Do you understand? Otherwise, they would not do the tests. I don't understand, I just don't understand why I have to give my blood to do the blood tests. I was afraid and I don't go there anymore. My brother told me to change... and I will change! No, no, no, I am not going there again! (Binette, 34 years old, Cameroon).

It is clear from her words that the patient does not understand the system for giving blood in Italy and she cannot understand why the doctor would give her such instructions. In her eyes, the suggestion assumes almost a commercial aspect (I give you my blood and you give me the blood tests) which is upsetting for her. It is possible that the fear is rooted at a more profound level, that we can only imagine because it is never stated, and that it has to do with the imaginary linked to witchcraft in the area the patient comes from, and to the role that blood and bodily fluids play in this context<sup>401</sup>.

Even without investigating the scenarios on which Binette's fears are based, the fact that the doctor has become a threat, in her eyes, reminds us of the fundamental importance of the context of signification, which goes well beyond the merely linguistic level of communication.

Even the occasional intervention of a mediator would have been useful in clearing up the misunderstandings and creating a positive relationship. Unfortunately, at present the doctors, as a category, do not actively demand this service, although some are individually aware of the usefulness of the resource. Many GPs, in fact, have never worked with a mediator and do not know their potential. The result of this gap is that some patients, being unable to build efficacious communication with their doctor, return to the ISI Centre or to the private social clinics to have their prescriptions read or to have an explanation of "what is happening". At the same time, the doctors who are more sensitive to the problems of foreign patients activate informal channels of cooperation with the associations or speak informally to their colleagues at the ISI Centre.

In the hospitals there is a well-established and organized mediation service, the resistances have given way to a relationship of cooperation and synergies between the various professional figures have been created.

In some situations in the public sector, also to overcome the chronic lack of personnel, the mediators are assigned tasks that go beyond their professional profile. This choice, on the one hand, has the advantage

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<sup>401</sup> The question of witchcraft is vast and complex and it is not possible to explore it thoroughly in this volume. In order to understand the symbolic content linked to the phenomenon of witchcraft in Cameroon, the representations of the person and the body it vehicles and the role of political, historical and social factors, see: R. Beneduce, *Corpi e saperi indocili. Guarigione stregoneria e potere in Camerun*, Torino, Bollati Boringhieri, 2010; S. Taliani, *Il bambino e il suo doppio. Malattia, stregoneria e antropologia dell'infanzia in Camerun*, Milano, Franco Angeli, 2006.

of making the presence of the mediator more stable, but on the other, it means that the mediator is no longer a neutral figure and tensions may arise between the mediators and the users.

I am deal with reception. When I am at the counter, I have responsibilities and I must follow the rules. Even when a rule does not seem fair to me, a person cannot say, "I will do it my way": as long as I am there, I will follow the rule, even if I don't agree with it. However, this creates many problems for me, because it is not understood by the others, and I am seen as a racist. At times, you have to say no, also to your fellow countrymen. If there are no places, there are no places, at present it is not possible (to give you an appointment)... so, either they tell you to get lost, or, if you don't help them they go to another mediator and then they say 'look, *she* is good and she helps her fellow countrymen, *you* don't, you are not here to help us'. (Moroccan cultural mediator)

Finally, it is worth looking in more detail at a topic already mentioned in chapter two, that is, the lack of knowledge regarding the figure of the mediator that we found amongst the foreign users. In the interviews with the patients who had arrived recently in Italy, or who, although they had been living in the country for some time, knew little about the resources available, we found a lack of understanding of the function and the potential of the figure of the mediator. The term 'mediator' itself is not always understood and during the interviews it was necessary to undertake an arduous and almost always unsuccessful attempt to find synonyms in order to verify whether the interviewees had actually been in contact with these operators. This problem is aggravated by the fact that the operators, above all Italians, tend to take for granted the fact that this type of information is circulating freely amongst the communities, and therefore there are few channels through which it is explained to the patients who the mediators are and what they do. During this research project, even the concept of community was shown to be an abstraction that does not correspond to the effective situation of the migrants, who can only rarely state that they are part of a close and organized social network, capable of offering practical support in the case of need.

As we have seen from the interviews, in some structures it is necessary for the patient to act independently and present an explicit request for the presence of a mediator, which obviously is not possible if one does not know that the mediators exist. This question is closely linked to the fact that many migrants have little understanding of their rights, as we have already shown. Not all the migrants have the same concept of healthcare. For some every free service is seen as "a favour" due to the benevolence of the person who offers it (whether it is the state or a voluntary association, it makes no difference) and for this reason it is necessary to express one's gratitude. In these cases, even when there were objective difficulties in accessing a service, the interviewees were reluctant to speak of them, or when comparing the system with their own country, they felt they were lucky to have the opportunities offered by the Italian health system. For other interviewees, the perception of health as a right is compelling and they do all they can to see it protected. Often these are people who have lived in Italy for some time and have a certain level of education, or who after repeatedly clashing with various types of administrative difficulty, to use the words of one of our interlocutors "have had to learn how to stand up for themselves". With respect to the possibility of access to mediation services there is, therefore, the problem of the availability of a right or a resource, and the channels through which a person can operate in case of need. It is still necessary to increase the awareness of the operators with regard to the role of the mediators and to increase the information available to the

migrants on mediation, through multi-lingual posters, for example, but above all through greater formal recognition of the mediators and development of their duties and their role in the various structures.

#### 4. *Training*

In recent years, in Torino, there has been a considerable increase in the intercultural training available, which responds to a need expressed implicitly and explicitly by the operators. During the research project, we saw a number of training projects as direct observers and in some cases took part as trainers.

An important element of these interventions is the variety of training needs and the activities available. On the basis of our observations, we can suggest, without claiming to be comprehensive, a classification of the types of training offered.

The first type, which we could call “formal”, involves training in intercultural communication formally recognized as part of the in-service medical training (ECM) planned by the health authorities, the private social associations or other public bodies. These events are destined for operators, are conducted by Italian and foreign experts, and deal with matters concerning immigration and health.

One of the most extensive initiatives of this kind is the *TakeEasy* project<sup>402</sup>, which promoted various methods of training and created a network of subjects involved in access to welfare-health services by immigrants: operators, heads of social and health services, bodies from the local network for intervention, university lecturers, trainers, associations, and private social organizations that deal with questions relating to interculturality, associations of foreign citizens, cultural mediators.

A second type, which we could call “reciprocal”, includes the training organized by the associations who operate in the field of interculturality, the local services and, at times, the hospitals, planned with the cooperation of the mediators, operators and foreign professionals, or migrant associations. This type of intervention is characterized by the involvement and active participation of the migrants themselves and is a mechanism for giving a response to the reciprocal expectations and training needs. In some cases, from this type of cooperation gives rise to networks of cooperation that last long after the training event. A first example is the agreement for cooperation between Angi<sup>403</sup> and the Torino-Asti interprovincial council for midwives (to which we will return in detail in paragraph 5 of the seventh chapter) with the aim of resolving the bilateral problems and guaranteeing better healthcare for Chinese women.

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<sup>402</sup> The project is funded by the EU and the Italian Home Ministry through the European fund for the integration of citizens from third countries and has been coordinated by Comune di Torino-Sfep, led in particular by the district social services, the Ufficio stranieri, the Ufficio Minori Stranieri, the health service of the intercultural centre Tavolo pediatria (and through them “Pediatria Interculturale”); the local health authorities ASL TO2 and ASL TO1, the University of Torino, faculty of medicine and surgery for coordination of the medical training and Cipes Piemonte.

The project involved: Comune di Chivasso, Comune di Settimo, Asgi, Associazione Mamre Onlus, NGO Centro Collaborazione Medica Onlus, NGO Mais, Rete Hph Migrant Friendly Piemonte, Associazione Frantz Fanon, Gris Piemonte and Laboratorio dei Diritti Fondamentali (LDF).

<sup>403</sup> Associazione nuova generazione Italo-Cinese.

As a second example, we can mention the project *Aracne*<sup>404</sup>, which concluded in the month of June 2012, and was aimed to promote the right to health of migrants by setting up a reception area within the Casa di Quartiere in San Salvario. In this space various training activities were presented, which involved the migrants, the mediators and the operators and a network of migrant associations and private social groups was created to operate in the district. The evaluation of the paediatrician Vittorina Buttafuoco on the need to create bi-directional training courses is particularly interesting.

I believe that it is important to consider the ways training on matters relating to the promotion of health is organized, above all when these topics touch on the grey areas of our paediatric knowledge, since the questions we deal with are mainly nutrition, sleep and personal hygiene. Often the people who come from cultures with “high contact” find themselves in a medical context, which for a long time has medicalized and westernized the practices of treatment and maternity and in this historical moment is trying to change its paradigm and recuperate a more “natural” model. In practice, mothers who find it difficult to breastfeed their children or who consider these practices “old fashioned”, not modern and scientific [...]. It is certain that we operators badly need training, training where our knowledge of health in the widest sense can encounter and be strengthened by anthropological and ethnopsychiatric knowledge.<sup>405</sup>

The third type of training activity concerns the health education projects for the community, which leave the institutional spaces to move into the daily life of the users. These activities require considerable flexibility of the organizers and a constant meeting with the diverse languages of healthcare and methods of transmission of knowledge. In fact, the authorities have the duty to offer health education as an important component of the right to health<sup>406</sup>. One example is the project *Idea Rom*, promoted by Associazione Camminare Insieme with the support of Idea Solidale.

The project was born to introduce the concept of basic paediatric care, the need for check-ups, going to appointments not only when it is essential because the child is ill, but also to monitor the growth of the child. We began with a series of informative and educational meetings for the mothers, we talked about access to the services, hygiene, weaning and other health questions, not only paediatrics... but they wouldn't come, we realized that it wasn't working. For the mothers of small children we offered free nappies, we thought that might be an incentive, but they still didn't come. So we reorganized the entire project and we said, rather than coming to the meetings, it would be right to get them to come and visit us here, at the hall, and while we are here, we will take the opportunity to introduce transverse education, in conversation, while we are talking about everyday things, we mention vaccinations, for example and we say “what do you think?”, and “what do you do about food?” We saw that this was a much more appropriate approach and much more educational. (Romanian cultural mediator, Idea Rom, Camminare Insieme project).

The educational meetings for refugee women, proposed by the Associazione CCM, are also an experience worthy of note, and a good example of health education that uses formative methods closer to the users. These meetings were destined for refugee women, almost all Somalian, and they were centred on contraception and the prevention of sexually transmitted diseases. They were organized by a Nigerian midwife, with the scientific support of MISA, and were held at the house where the women were staying. The language used was Italian, and a mediator was present to translate when necessary, to explain a concept or to emphasize the points made by the midwife using Somalian examples and popular sayings, with which

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<sup>404</sup> This is also an FEI project, coordinated by the medical cooperation committee, with the Associazione Mamre and the cooperative Tavola di Babele.

<sup>405</sup> CCM, Mamre, Tavola di Babele, *Progetto Aracne*: final report and research, 2012, pages 9-10.

<sup>406</sup> I. Biglino and A. Olmo, *Health as a fundamental right: a study on migration and healthcare in Turin*, op. cit. page 131.

the young women were familiar. The observations regarding the meetings show how efficacious this model was:

After a few minutes the women were gathered in a meeting room, some were sitting on the divan, others on the floor, one had brought her child with her. On the table, there was a projector and some material that the midwife had brought along to help the explanations. As usual, the meeting started with a round of introductions, but one of the young women, Halima, said she did not want to introduce herself and, pointing to the condoms, she added brusquely that she was not going to talk about “that stuff” which reminded her of very bad moments, because they were “the same that the soldiers used to rape her”. So the midwife, without getting upset and with a very strong and authoritative manners said, “I am African, too, and I know about these things... I am not here to teach you anything, nor to tell you what to do. I just want to share with you something that I have learned and I didn’t bring the condoms to annoy you. I respect and understand your experience and, if you are upset, you can leave when I get them out. Afterwards I will be happy to explain to you anything you want, without showing you anything. Now I will continue, because what I have to say is important, even if then you decide not to use them.” The atmosphere of the meeting changed and Halima decided to remain, becoming almost immediately the most active and participative of the women present.

The cultural closeness of the person leading the meeting and the mediator and their capacity to present themselves as equals and to place the information in the effective situation of the women was decisive in overcoming the initial resistances, which were openly manifested and to manage difficult moments linked to the story of suffering and violence that has marked the life and the journey of the refugee women. This allowed them to share sensitive content that it would not have been possible to discuss in other circumstances. It is therefore essential to guarantee the systematic nature of these initiatives, which is possible only with the constant and methodical commitment of the public authorities, which, as we revealed in the first phase of the research, is deficient<sup>407</sup>.

Finally, the last type includes the experiences of peer education. This method of construction of health literacy is still underdeveloped, despite its potential. Nonetheless, there are some projects amongst those organized by MISA and the Omar Ibn El Khattab mosque, and we will discuss them in more detail in paragraph five of chapter seven.

Although they do not replace other structural changes in the organizational methods and the treatment policies, training represents one of the tools for guaranteeing the quality and the acceptability of the services offered. It also offers good opportunities for meeting and discussion between the users and the services, which allow active participation of the migrants and encourage the coherence between the expectations of the foreign users and the healthcare available.

## Chapter Seven

### Inside the networks for migrant health: traces of community welfare

#### *1. The third sector in Torino: a tradition renewed*

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<sup>407</sup> *Ibidem*, page 131.

The considerations presented in this chapter were developed in close continuation with some of the content that emerged in the first LDF volume. From the foreword onwards it is clear that the city of Torino is characterized by a system that: [...] sees operating in synergy, although not always with ideal coordination, the structures of the public health service and private social or volunteer groups. [...] It is a gathering of reference points that now respond to the criteria of subsidiarity, although it was born in the environment of a typically nineteenth-century Torino.<sup>408</sup>

In the first report, this set of reference points was described as a “strong network” that assigns to the private social sector the role of integrating the public sector. Without ignoring the risks and the limits of this network, we highlighted its flexibility, a peculiar characteristic of voluntary work and the social private sector<sup>409</sup>. Observing this network, the authors asked themselves which were the most efficacious information channels for spreading information within the migrant communities and they identified word of mouth and peer education as the “information paths *par excellence*”<sup>410</sup>.

Synergies, networks, integration, word of mouth and peer education are the concepts on which we continue to ponder in this chapter. Thanks to the qualitative approach that has characterized the gathering of the data we will bring new elements to the description of the situation in Torino, without losing sight of a wider national and international debate on the role of the third sector (also known as the community sector, the voluntary sector, the not-for-profit sector, NdT) in the field of migrant health.

When we speak of the third sector, we mean a heterogeneous set of players who can be traced back to the four ideal types that Ambrosini calls:

- 1) *charitable associationism* characterised by direct assistance for persons;
- 2) *vindictive associationism*, which works for recognition of rights;
- 3) *entrepreneurial associationism*, which offers services and facilities;
- 4) *associationism promoted by the immigrants*, which gathers the experiences linked to precise contexts of origin or cultural groups<sup>411</sup>.

In recent years foreign associationism has attracted the attention of scholars for various reasons: first of all the growth in the associations in terms of numerical presence has made the phenomenon more visible<sup>412</sup>, secondly, the formalized groups of migrants were identified as subjects capable of mediating and creating a privileged channel of communication between the institutions and the communities of which they were intended to be an expression<sup>413</sup> and in the third place the presence of these associative realities has led

**Commento [KMC10]:**  
Inserire le citazioni esatte dal volume in inglese in tutto il capitolo.

<sup>408</sup> Biglino and A. Olmo, *Health as a fundamental right: a study on migration and healthcare in Turin*, Bologna, Il Mulino, 2014, page 10.

<sup>409</sup> *Ibidem*, page 89. For a consideration of the topic at national level see M. Tognetti Bordogna, *La salute degli immigrati e i soggetti di terzo settore*, in «Salute e Società», 2006, N. 1, pp. 187-207.

<sup>410</sup> Biglino and A. Olmo, *Health as a fundamental right: a study on migration and healthcare in Turin*, op. cit., page 134.

<sup>411</sup> M. Ambrosini, *Senza distinzioni di razza: terzo settore e integrazione degli immigrati*, in «Sociologia e Politiche Sociali», 2000, N. 3, pages 127-152

<sup>412</sup> M. Caselli and F. Grandi, *Volti e percorsi delle associazioni di immigrati in Lombardia*, Milano, Osservatorio regionale per l'integrazione e multietnicità della Regione Lombardia, 2011, page 20.

<sup>413</sup> M. Caselli, *Flussi globali, integrazione locale: il caso delle associazioni di migranti in provincia di Milano*, in «Mondi Migranti», vol. 2, 2008, pages 109-129.

to a questioning of the processes of participation and the nature of civil society.<sup>414</sup> The existing associations carry on a variety of activities that usually pursue the objective of facilitating and supporting the immigrants in their new lives, seeking space for cultural, identity and symbolic recognition.<sup>415</sup> Often these associations involve, or have amongst their founders, Italians with competencies or specific interests relating to a certain national group. A number of associations run information desks that receive inquiries about the services offered by the city, offer help with applications for documents, legal assistance, etc. Despite this, few of them have so far invested resources in the area of health. For this reason, the literature on the commitment to the third sector in favour of the foreigners' access to health has been concentrated in the work of the Italian associations and organisations that are based on a consolidated structure, and which over the years have matured sufficient competence to become stable reference points, recognized and appreciated by users and operators. Ethnic associationism – generally subject to a high turnover<sup>416</sup> – is, on the other hand, subject to a lack of stability<sup>417</sup>, which has made it marginal, so far, in the field of activities relating to health.<sup>418</sup>

Aware that these characteristics and certain limits of migrant associationism – often encountered during the research – we considered the role that the associations of foreigners play in the field of well-being and we decided to do this starting from the concepts we mentioned previously: synergy, networking, integration, word of mouth and peer education.

We talked to the heads of a number of migrant associations to identify situations with the following characteristics: presence of a statute that formalizes their presence in the territory and use of personnel in the field of health. We were able to identify five associations with which to undertake a process of understanding, which foresaw interviews with the operators – generally volunteers – and subjects who had turned to them to resolve health problems. The associative realities were therefore chosen not because they are representative or considered better than the others, but on the basis of their activities in the field of well-being, access to the health services and a significant and innovative practice in matters of health<sup>419</sup>.

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<sup>414</sup> V. Cesareo and F. Introini (ed.), *Istituzioni comunitarie e società civile. In dialogo per l'Europa*, Milano, Vita e Pensiero, 2008.

<sup>415</sup> M. Caselli and F. Grandi, *Volti e percorsi delle associazioni di immigrati in Lombardia*, op. cit. page 54.

<sup>416</sup> The author compares formal associationism with what he calls “informal networks on an ethnic-national basis” which are described as vital and functioning because they are the spontaneous expression of self-organization by immigrants. See: M. Ambrosini, *Scelte solidali. L'impegno per gli altri in tempi di soggettivismo*, Bologna, Il Mulino, 2005.

<sup>417</sup> Amongst the causes of the fragility of certain organizations, we can list the poor organizational capabilities, the tendency of many groups to have a highly personalized nature, the lack of funds, and the tendency to lean on existing local organizations. Cfr. M. Caselli and F. Grandi, *Volti e percorsi delle associazioni di immigrati in Lombardia*, op. cit., page 23.

<sup>418</sup> M. Tognetti Bordogna, *La salute degli immigrati e i soggetti di terzo settore*, op. cit., page 205.

<sup>419</sup> The associations contacted and which were studied were (in alphabetical order):

**Amece**, Association maison d'enfant pour la culture et l'éducation. The association was founded in 2000 with an educational mission. The projects underway are related to the following areas : education, sport, art, social sector, and are based mainly on voluntary work. Since 2003 the association has been part of a territorial network and has cooperated with Ufficio Stranieri, Centro Informagiovani, Centro interculturale Comune di Torino, Cultural Office and Social Services of the Moroccan Consulate.

**Angi**, Associazione nuova generazione italo-cinese. The association is formed of young Chinese and Italians with particular interests in or skills regarding the Chinese community. It was founded in 2007 by a group of Chinese immigrants with the aim to intervene in situations that could transform into social conflicts. The Association is active in various areas of social life and boasts numerous agreements with formal and informal realities in the area; in recent years it has been active in the field of health through an office in the association headquarters and the signing of an agreement for cooperation with the Torino-Asti interprovincial council of midwives.

**Acist**, Associazione culturale islamica San Salvario Torino. The association manages the prayer room in Via Saluzzo 18, in the San Salvario district. The main aim is the organization and management of religious activities, but there have also been projects in cooperation with local associations in the social field.

**San Lorenzo dei Romeni**. The Torino branch of the association was founded in 2011 and is headed by the national charity association of the Romanian Orthodox Diocese. In March 2011, the association officially opened a counselling centre, based in the church property, which

## 2. *New subjects in a welfare in transformation*

The studies that investigate the link between social condition and health form a vast bibliographical corpus within which we can identify two recurrent topics. The first is that of social capital<sup>420</sup>, which many authors have studied in relation to the conditions of health, finally stating that not only do the two variables have a close link, but also that it may be of a causal nature.<sup>421</sup> The second question is that of the inequalities expressed for example in terms of economic resources<sup>422</sup>, status or inequality of education<sup>423</sup>.

The ample discussion of the question of social determinants of health in the first volume is in line with the existing literature which, when speaking of migrants, concentrates mainly on inequalities. In this chapter, we propose some integrations, emphasising the strong link between inequality and social capital since the latter is seen as “relational inequality”<sup>424</sup>. The social inequalities may in fact be seen as objective and systematic disparities regarding the possession of resources and capabilities useful for obtaining a result<sup>425</sup> and often translate into social determinants for health.

The perspective adopted suggests that the foreign associations may be a place in which to grow social capital and influence the practices of the people who access them and that on the contrary, the absence of networks is a factor that increases the risks in general, and those connected to health in particular<sup>426</sup>. What is evident in the case of the associations is that – apart from being a place of aggregation and social and symbolic recognition – they are organized to offer a service. This is the case of the San Lorenzo dei Romeni association, which has founded a counselling centre, the association ANGI, which has a health office set up under an agreement with a clinic and other organizations that have opened information desks.

For some years, we have seen a reduction in certain state services<sup>427</sup> and the appearance of bodies of various kinds that offer additional services beside the ones offered by the state. To describe this situation the terms ‘welfare mix’<sup>428</sup>, ‘second welfare’<sup>429</sup> and ‘welfare system’ have been coined. Moreover, in the face of a

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receives requests of all kinds and works with the local services thanks to the presence of a **number of cultural mediators who work as volunteers**.

**Zhi Song**, Italo-Chinese cultural association. The association defines itself as socio-cultural, democratic, non-partisan, apolitical and non-profit. The purpose of the association is social solidarity and the promotion of intercultural relations between Chinese citizens and Italian society, with particular attention for young people, women and the disabled. Amongst the projects realized in these years are FEI projects (European funds for integration) which aim to improve learning of the Italian language and cooperation with the local health authorities on matters relating to the health of persons from non-European countries in the *Take Easy* project.

<sup>420</sup> Social capital indicates the resources that derive from civic participation, the relations of trust and the norms of reciprocity that characterize the social networks. Cfr. M. Minelli, *Capitale sociale e salute. Una bibliografia ragionata*, Perugia, Morlacchi University Press, 2007, page 9.

<sup>421</sup> I. Kawachi, *Social Capital and Community Effects in Population and Individual Health*, in «Annals of the New York Academy of Sciences», 896, 1999, pages 120-130.

<sup>422</sup> J. Lynch *et al.*, *Is Income Inequality a Determinant of Population Health? Part 2. US National and Regional Trends in Income Inequality and Age and Cause Specific Mortality*, in «The Milbank Quarterly», vol. 82, 2004, n. 2, pages 355-400.

<sup>423</sup> S. Geyer e R. Peter, *Income, Social Position, Qualification and Health Inequalities-competing Risk?*, in «Journal of Epidemiology and Community Health», vol. 54, 2000, n. 4, pp. 299-305.

<sup>424</sup> L. Rocco and M. Suhrcke, *Is Social Capital Good for Health? A European Perspective*, Copenhagen, WHO Regional Office for Europe, 2012.

<sup>425</sup> M. Tognetti Bordogna, *Disuguaglianze di salute e immigrazione*, Milano, Franco Angeli, 2008, page 10.

<sup>426</sup> *Ibidem*, page 21.

<sup>427</sup> M. Ferrera and F. Maino, *Il «secondo welfare» in Italia: sfide e prospettive*, in «Italianeuropei», 2011, N. 3, page 21.

<sup>428</sup> This term refers to the new form of the welfare system, which has developed over the last decade, determined by the passage from the concept of welfare system typical of the seventies – in which the state played a central role – to the present situation in which the realization

welfare with standardized services and impermeable to change<sup>430</sup>, there has been an increase in what is called ‘civil welfare’, a model of ‘welfare mix’ in which the third sector plays a central role. The public bodies themselves hope for a greater involvement of the third sector in social policies: in 2009 the Italian Ministry of Labour, Health and Social Policies published the *Libro bianco sul futuro del modello sociale. La vita buona nella società attiva* (White book on the future of the social model. A good life in an active society). The book proposes an integrated vision of social policies, that is, a vision of welfare as a system, strongly rooted in the context in which it acts and in the reference society, seen as an active society<sup>431</sup>.

The ‘welfare mix’ and ‘second welfare’ are therefore characterized by their roots in the context, greater flexibility compared with state bodies and spontaneous or ground roots development<sup>432</sup>. These traits characterize the associations of migrants and allow us to include them in our considerations on welfare mix, and in particular in what is known as ‘community welfare’. This includes what are called ‘proximity services’, or responses to needs that involve a strong relationship between those who offer the service and those who benefit from it (for example, youth clubs, day centres for the disabled and so on) and which are typically offered within a restricted territory, a circumscribed population and often run by non-profit bodies<sup>433</sup>.

Finally, this definition allows us to draw attention to the term ‘community’. It is a hotly debated concept in the social sciences<sup>434</sup> which emphasise that the communities must not be seen as homogeneous sets of persons. In line with the definition of proximity services, in this context we think of a community as a group which provides for effective needs and emphasises the practical dimension of use and frequency, rather than considering it as an ethnic group. It is worth remembering that the national groups present in the territory are often fragmented, when they are not riven by tensions of various kinds, and that the associations can be the means for certain exponents to consolidate or construct their leadership<sup>435</sup>. Despite this – above all in the Italian context where there is still little familiarity with the concept of community – the concepts of representativeness and that of community remain closely linked: the foreigners who live in the same context and share the same nationality are often erroneously called “community” and consequently the members of the associations are sometimes presented as representatives of the community<sup>436</sup>. Speaking of migrants it is

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of a welfare system is entrusted to a mixture of subjects/players who operate within the local community on the basis of principles of horizontal and vertical subsidiarity, of partnership, of participation, of integration, of networking, of concertation and negotiation to develop the well-being of a given local environment.

<sup>429</sup> This term refers to the heterogeneous activities that are private and prevalently use non-public resources. In effect, we are speaking of social projects and investments by companies, foundations, insurance companies and social cooperatives, where these make use of a mixture of public and private resources. Cfr. S. Pasquinelli, *Un sociale senza stato?*, in «Prospettive sociali e sanitarie», 7, 2011, available online: [http://www.qualificare.info/upload/Pasquinelli\\_PSS1107.pdf](http://www.qualificare.info/upload/Pasquinelli_PSS1107.pdf).

<sup>430</sup> M. Tognetti Bordogna (ed.), *I colori del welfare. Servizi alla persona di fronte all’utenza che cambia*, Milano, Franco Angeli, 2004.

<sup>431</sup> M. Caselli and F. Grandi, *Volti e percorsi delle associazioni di immigrati in Lombardia*, op. cit., pages 24-25.

<sup>432</sup> M. Ferrera and F. Maino, *Il «secondo welfare» in Italia*, op. cit., page 5. In the health services the flexibility of the third sector has been the characteristic that has allowed it to respond to emergencies from the seventies and eighties onwards, later consolidating and transforming the offer. Cfr. M. Tognetti Bordogna, *La salute degli immigrati e i soggetti di terzo settore*, op. cit.

<sup>433</sup> G. Marcon and C. Scilletta, *Il ruolo del welfare civile nel welfare mix*, op. cit., page 13.

<sup>434</sup> See for example: G. Baumann, *Contesting Culture. Discourse of Identity in Multiethnic London*, Cambridge, Cambridge University Press, 1996.

<sup>435</sup> M. Caselli and F. Grandi, *Volti e percorsi delle associazioni di immigrati in Lombardia*, op. cit., pages 24-25.

<sup>436</sup> With regard to this aspect it is useful to recall a certain influence that the Italian institutions and organizations have in managing the question of participation and representation when, for example, they present a migrant association as *the* representative reality of a national group. C. Mantovan, *Immigrazione e cittadinanza: autorganizzazione, partecipazione e rappresentanza degli immigrati in Veneto*, in

necessary to bear in mind that the idea of representativeness is fragile, because the concept of community is equally fragile.

In the light of a welfare that changes and the particularly lively associative fabric of Torino, the role of the associations is important to begin thinking of foreigners not only as users of the services, but also as suppliers, and to think of the associations not as ‘representatives of...’, but rather as a means for mediation between the foreigners and the institutions<sup>437</sup>. The work of the five associations mentioned will be analysed from a perspective that conjugates health and human rights, referring to the four basic criteria identified by the committee for economic, social and cultural rights, necessary if the right to health is to be realized<sup>438</sup>. Of these four criteria, we will analyse those on which the work of the associations could have a positive impact: they may influence the access to services and their acceptability – or cultural appropriateness – while, at present, they cannot influence the availability of structures and their quality<sup>439</sup>.

### 3. *Migrant associationism as an agent of accessibility*

At a formal level, the right to health is guaranteed equally to Italian and to foreign citizens, despite the fact that the effective possibility that the latter can enjoy this right varies considerably, as emerged from the first LDF report and from the earlier chapters in this volume. We use the term ‘implementation deficit’ to describe a situation in which a fundamental right exists, but its effective enjoyment is difficult to realize<sup>440</sup>. Some causes lie in what we can call accessibility of the structures, a complex concept that takes into account various dimensions: discrimination, physical accessibility, economic accessibility and accessibility of information<sup>441</sup>. Which of these dimensions can lie within the range of action of the associations? How can the associations of foreigners positively influence the structures, making them more accessible?

#### *Welcoming and discriminating*

The question of discrimination is very delicate, because it forces us to consider the relationship between effective practices of exclusion and perceptions of discrimination that we could call ‘imagined’. In fact, at times, the foreigners use the concepts of ‘discrimination’ and ‘racism’ to explain organizational elements that they do not understand.

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*Giovani sociologi 2005*, ed. Ais, Napoli, Civis, 2006, page 82; M. Caselli and F. Grandi, *Volti e percorsi delle associazioni di immigrati in Lombardia*, op. cit., page 23.

<sup>437</sup> M. Ambrosini, *Senza distinzioni di razza: terzo settore e integrazione degli immigrati*, op. cit.

<sup>438</sup> For a detailed discussion of this topic, see chapter one of this volume.

<sup>439</sup> The third sector already offers alternative structures to the public ones, it is sufficient to think of the clinics ‘Giovanni Paolo II’ and ‘Camminare Insieme’ in Torino. Nationally, there are other examples (see M. Tognetti Bordogna, *La salute degli immigrati e i soggetti di terzo settore*, op. cit.), but none of the cases we came across was founded by a migrant association, and certainly a similar reality was not present in the city of Torino at the time of this research project. However, we are aware of the desire to open a clinic at one of the prayer rooms. The idea was introduced by a Moroccan doctor, a member of Val Onlus (Volontariato assistenza socio-sanitaria mediterranea internazionale), a Milano-based association that offers integrated health and social services, prevention and training. As Tognetti Bordogna recalls “in addition to a historical and consolidated third sector, there is in the health sector, a less formalized, less continuous form of intervention and cooperation, which is however, capable of acting in response to particular needs.” (*Ibidem*, page 200). We registered the presence and the importance of the latter.

<sup>440</sup> A. Golini, *L’immigrazione straniera: indicatori e misure di integrazione*, Bologna, Il Mulino, 2006.

<sup>441</sup> Biglino and A. Olmo, *Health as a fundamental right: a study on migration and healthcare in Turin*, Bologna, Il Mulino, 2014, pages 37-38.

It happened to me twice, at the Molinette Hospital the first time. My knee hurt and I spent all the evening at the A&E department, no one paid me any attention because I can't speak [Italian] well, until a Moroccan arrived and he shouted at the nurses, and then they listened to me. Another time, I went to the Mauriziano Hospital where I had to make an appointment for a problem with my ovaries. They gave me an appointment for almost a year ahead, and they told me off when I asked for an earlier appointment. They said, "Take your piece of paper and go!" But at the Sant'Anna Hospital they gave me an appointment. The staff at the Sant'Anna Hospital is very good with foreigners. (Hasna, 55 years old, Morocco).

Hasna attributed to her condition of foreigner the treatment received, although we do not know the reasons for the delayed appointment. The context of the A&E, with the triage system<sup>442</sup>, which regulates access, is an example that clearly shows the combination of real and imagined discrimination. The perception of discrimination that the foreigners report with regard to this delicate topic may, in fact, be an erroneous reading – due to a lack of understanding of how the service works – or else, the symptom of a real problem. A study carried out at an A&E department in Venezia showed that the relation between insufficient triage (cases in which the code assigned underestimated the real problem) and high-risk pathologies appeared to be of concern above all in the case of foreign patients<sup>443</sup>.

The episodes of discrimination often emerge in situations of linguistic and cultural misunderstanding, as if the communication gap left a space that is filled by elements of an ideological nature that have to do with the social construction of "other" and with the prejudices linked to it. In these situations, the migrant associations can play a favourable role when they offer mediation and accompaniment to services, in effect bridging this communication gap. Referring to another experience, the same woman reports:

When I went to the tuberculosis centre, they didn't understand what was wrong with me and they called the social services. The social services called the association AMECE because there is an agreement between the city of Torino and AMECE. The association called my doctor and explained my problem and then a mediator from AMECE accompanied me when I returned to the centre. (Hasna, 55 years old, Morocco).

A situation in which misunderstanding, and consequently discrimination, can occur is (paradoxically) the ISI Centre, precisely the place designated for welcoming the more vulnerable and disadvantaged foreign users. As a Moroccan mediator told us, after accompanying a user to register with the service.

Sometimes it is not pleasant to deal with the personnel at the ISI Centre. I was upset and hurt. The lady doctor is very good and kind, but the assistants who hand out the appointments are not. In the morning there are a lot of people, too many, and they treat them badly, they shout at them when they don't understand and ask for information. (Moroccan mediator<sup>444</sup>, AMECE).

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<sup>442</sup> The term *triage* derives from the French verb *trier*, which means choose, classify. It indicates the method of evaluation and immediate selection used to assign the degree of priority for treatment when there are a lot of patients. *Triage* is carried out by the nurses who evaluate the signs and symptoms of the patient, identifying potentially life-threatening conditions and attributing a priority code for examination by a doctor.

<sup>443</sup> A. Da Lio and F. Spagna, «Un codice così bianco». *Aspetti antropologici del triage in una ricerca sulle «priorità» presso il Pronto Soccorso di un ospedale veneto*, in «Rivista della Società Italiana di Antropologia Medica», 35-36, 2013, pages 187-205.

<sup>444</sup> In this chapter, many of the volunteers at the associations with whom we spoke are known as 'mediators'. It is necessary to emphasise that some of them are formally mediators, having taken courses and carrying out their profession in structures, apart from their voluntary work at the associations. Others have taken a training course, but have never held professional positions in the sector, yet others do an internship at the associations and finally, there are those who have not received formal training and have learned their skills in the field.

With reference to some of the elements of criticality that emerged in the second chapter, we wish to emphasise that an unsatisfactory contact, often perceived as discriminatory, may result in a request for help to the third sector. People turn to the migrant associations for accompaniment – as in the case of the Moroccan woman who feared she had been infected by tuberculosis – or to a private social organization, which represents an alternative to the National Health Service.

At Camminare Insieme it is easy for me, I know everyone, at the ISI Centre they make you wait a long time. I went to the ISI only when I had to register, otherwise I go to Camminare Insieme, it is easier. There is a GP who sees you and gives you medicine immediately. [...] To register, a friend told me to go to the Romanian church. I came here and I met the counselling centre, step by step. The first thing I did was come here, then I went for the ISI card and they helped me. (Fabian, 47 years old, Romania).

At that time, I was sick with leukaemia, but I didn't know that and I didn't go for the blood tests. I had no contacts and so I had no doctor. When I felt ill, I fell down and once I went to Camminare Insieme because a friend told me about it [...]. I didn't know about the ISI Centres, no one told me they existed. I went where they opened their doors to me. (Viorica, 46 years old, Romania).

Many people say that they prefer the third sector because they feel they are listened to and they find a more welcoming atmosphere than the standardized environment of the National Health Service. When the reasons for lack of access can be attributed to the institutions which – originally designed to meet the needs of the native population – put other groups in a situation of disadvantage, it is a question of institutional discrimination. The discrimination therefore is not only the act of a single individual who takes a judgemental or racist position; it may also be the effect of structural inadequacy of the institution<sup>445</sup>.

#### *Linguistic accessibility*

In the discourse on institutional discrimination lies also the delicate aspect of linguistic accessibility, one of the main reasons the foreigners turn to the associations of their compatriots.

If it hadn't been for AMECE, I would have looked for a person to translate for me. At times I can't find anyone and so I give up and return home, above all if I have to go to the hospital, I try to find an appointment for another day and I get someone to come with me. (Hasna, 55 years old, Morocco).

When I have a problem, I don't go to my doctor, because I can't speak Italian very well. When I had to go I took my friend's son with me, but he is a child and he is not much help. The first person I speak to when I have a problem is the girl at the association. (Mei, 34 years old, China).

While all foreigners may encounter these difficulties, for those who come from linguistic systems very different from our own the obstacle can be unsurmountable. This is the case of the Chinese community, in which the language is identified as the first obstacle to access to the National Health Service<sup>446</sup> above all for the first generation, for whom it has been very difficult to learn Italian<sup>447</sup>. To this, we must add the fact that, even when the linguistic barrier is overcome, thanks to a sufficient command of the Italian language, the

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<sup>445</sup> Biglino and A. Olmo, *Health as a fundamental right: a study on migration and healthcare in Turin*, op. cit. page 163.

<sup>446</sup> T. Osteria, D. Carrillo and A. Sarli, *The Health Dimension of Asian Migration to Europe*, Manila, De La Salle University Publishing House for the Asia-Europe Foundation (Asef), 2013, page 515.

<sup>447</sup> L. Berzano, C. Genova, M. Introvigne, R. Ricucci and P. Zoccatelli, *Cinesi a Torino. La crescita di un arcipelago*, Bologna, Il Mulino, 2010, page 16.

exchange between Chinese patients and Italian doctors remains difficult and characterized by a mutual perception of distance and misunderstanding<sup>448</sup>.

The fear of not being understood, the absence of a cultural mediator<sup>449</sup> and the lack of information about the possibility of asking for one to be present can become obstacles to access, in addition to causing the failure of the treatment. Medical anthropology has shown that deficits in linguistic communication (both at the level of understanding and with regard to different cultural constructions of the clinical situation) represent the principal cause for lack of compliance with treatment by the patients<sup>450</sup> and that communicative inefficiency is destined to show itself in the therapeutic practice<sup>451</sup>. The non-access due to linguistic obstacles is therefore only the tip of the iceberg.

Generally, the doctor prescribes the treatment and everything goes well, then sometimes, we find out that the person is not following the treatment. Perhaps they phoned a relative or a friend in China who is a doctor and they discussed the situation with them on the phone. I normally don't accept this, if you want you can go to China to do the tests, but you can't ask for treatment over the phone. (Italian volunteer, Zhi Song).

We had the case of a man with diabetes, who did not understand what they told him at the Gradenigo Hospital. He went to the doctor and he was delighted, but when we gave him the translation of what the doctor had said and we explained it again and again in Chinese, he realised that he hadn't understood what the doctor said. His case wasn't serious, but it was essential to explain to him that he had to eat less, not three large meals a day, and it was essential to explain to him that he had to take the tablets. At times, when people speak only a little of a language, they don't understand what the illness is, what they have to do and how they can get help, when they have to go for blood tests. Even we Italians find it difficult to understand the doctor and if you have to understand it in another language and another logic with respect to your own, it becomes very complex. (Italian volunteer, Zhi Song).

When cases of incommunicability occur, the migrant associations can come into play, contacted by the users, who are seeking a translation/cultural mediation that was not available at the services. Sometimes it is the doctor himself who contacts them because they have previously encountered the association and consider it a reference point.

My husband had some tests done in China and when we returned to Italy we brought the translation with us and I spoke to the doctors, but the translation was wrong and the situation was getting worse. The doctor advised us to speak to the association, and he booked an appointment with the mediator at the association Zhi Song, so that he could explain better. (Suzi, 48 years old, China).

Another case of linguistic incommunicability in which the associations can play a role is the passage from a service with mediation to one without. This is the case of a pregnant Chinese woman who, during an appointment at the family clinic in Lungo Dora Savona, was informed by the mediator that the baby was in a breech presentation. She was sent to the Maria Vittoria Hospital, where a gynaecologist would turn the baby. At the same time, she was informed that there was no mediator available at the hospital and that she should arrange for a person who spoke Italian to accompany her. The patient said that she would ask one of the

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<sup>448</sup> A. Sarli and D. Carrillo, *Unasked Questions and Missing Answers: The Italian National Health System and Chinese Migrants in Milan*, *MPC Analytical and Synthetic Note*, Firenze, European University Institute, 2014, N. 1, page 5.

<sup>449</sup> For a detailed discussion of this topic, see chapter six of this volume, in particular paragraph 3.

<sup>450</sup> I. Quaranta, *Antropologia medica, i testi fondamentali*, Milano, Raffaello Cortina, 2006, page xi.

<sup>451</sup> <sup>44</sup> I. Quaranta and M. Ricca, *Malati fuori luogo. Medicina interculturale*, Milano, Raffaello Cortina, 2012, page 72.

mediators at ANGI to accompany her, finding in the association a response to the problematic situation of being sent to a service that did not foresee the presence of mediators.

It is precisely in the community where the problem of language is most felt that we found the phenomenon of payment between compatriots<sup>452</sup>. This type of accompaniment, like the assistance of friends or family members without payment; infringes the right of the person, does not guarantee a quality service and does not safeguard the confidentiality of the patient, who could even neglect to tell the doctor about a symptom or a problem, in order to avoid spreading the news amongst their compatriots. The work of the associations offers greater safeguards because anonymity and a reasonable level of quality of the service is guaranteed, although this may vary according to whether the association is manned by cultural mediators or volunteers who have trained in the field.

### *Economic accessibility*

Radu is a middle-aged Romanian. He has been in Italy since 2003, but since 2007 he has not held a steady job and he only does occasional irregular work. The loss of his job has also caused the loss of his residence permit, his home and the respectable conditions in which he lived, so he now sleeps in an abandoned factory with other Romanians. He has an ENI card and is registered with the ISI Centre, like all the people who live with him, because says Radu, “certain living conditions encourage health problems”. Despite this, not all of them have exemptions for medical treatment. When they first go to the ISI Centre, each foreigner signs a declaration of indigence, which allows them to pay only the ‘ticket’ rather than the entire cost of treatment. Foreigners who hold an STP/ENI card are exempted from paying for treatment, like Italian citizens, for first level treatment, urgency, pregnancy, treatment for rare or chronic pathologies and invalidating conditions. For other types of treatment, they must pay the ‘ticket’ – although they can apply for exemption – and this may be an obstacle to access to treatment for those who, although they do not hold an exemption, are in a condition of “medical indigence”<sup>453</sup>.

Radu has problems with his stomach and a hernia for which he must take medicines not prescribed through the National Health Service. A fellow countryman who sleeps in the same factory, advised him to contact the San Lorenzo counselling centre, run by the Orthodox Church. He already attended the church, but he had never heard of the counselling centre. When he first went to the Centre, Radu had two needs: to buy the medicines that had been prescribed for him and to pay a ‘ticket’ of €17 to collect the results of his blood tests. The operators at the Centre took a collection to pay the ‘ticket’ and sent him to Camminare Insieme, where he was given the medicines free of charge.

The work of most of the associations is based on the voluntary participation of the members and is characterised by a lack of funds. It is usually impossible for them to meet the users’ material needs, but at the

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<sup>452</sup> A. Sarli and D. Carrillo, *Unasked Questions and Missing Answers*, op. cit., page 4. The associations we worked with offer their support free of charge. In the case of Angi, access to the health desk, accompaniment and mediation are normally offered only to members, who pay an annual membership fee.

<sup>453</sup> For an analysis of this concept and some of the problems deriving from the assignment of exemption codes, see Chapter 2 of this volume, paragraph 5.

Romanian counselling centre they told me that in cases of extreme need they have contributed to some peoples' medical expenses.

Few people have come here asking for money to pay their 'ticket', but two weeks ago a man came who was desperate; he had to pay €20. We took a collection and we paid it immediately. It would be very difficult to do this for everyone, but this man was homeless, it was difficult for him to buy food, so it was almost impossible for him to find that money. He is one of the few who have come specifically to ask for help with health problems, usually they don't do that... they come for other reasons and then when we talk to them we find that they don't have a doctor, or that they have health problems and don't know where to go. (Romanian cultural mediator, San Lorenzo dei Romeni).

Although the migrant associations do not intend to be a solution to problems of economic accessibility, in cases of extreme necessity, thanks to their charitable and altruistic nature, they can be of help.

#### *Accessibility of information*<sup>454</sup>

The United Nations committee on economic, social and cultural rights indicated information as one of the most important elements of the normative content of the right to health<sup>455</sup>. Information plays a central role in the control that each individual has over their own health and the possibility of improving it, but social marginalization has numerous implications both on the efficacy of the communication and on the accessibility of the information.

Silvia is a Romanian woman, who has been living in irregular conditions for years<sup>456</sup>. She suffers from leukaemia. Finding work and a contract allowed her to regularize her presence in the country, and consequently gave her access to medical treatment. She had not known of the existence of the ISI Centre and therefore had not been able to enjoy her rights. When a person believes they have no rights, they cannot claim them, nor do they feel that they have been deprived of something that it was their right to have.

Many of them do not know about the services, and when they do know, either they don't trust them or they fear that they will not be listened to properly. So the users don't come, the service does not work correctly. Many come to the association before they go to the services. They are not integrated in the Italian community, so the information does not get through. Since they are in contact with their community, they take the children to the Arab school and the mothers talk to each other. They get more information from the Moroccan association than from the Italian services [...] They know they must go to the ASL (local health authority offices) for the health insurance card, to the police headquarters for a residence permit, to the town hall or the public records office for an identity card. They don't know anything else. (Moroccan cultural mediator, AMECE).

Accompanying their children to a language course, or after-school activities, going to pray or meeting fellow countrymen to celebrate a feast day linked to their country of origin, can be opportunities for asking for information. The informal networks of people of the same nationality is an important context for finding information and within these networks the associations can represent the place for the "first formal approach", above all when they are linked to the services. The associations themselves play a role that is

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<sup>454</sup> Here, by "information" we mean the notions necessary for dealing with the Italian institutions, defining information as "knowledge of the services". See paragraph 5, chapter 7 of this volume for an in-depth discussion linking information and training.

<sup>455</sup> Biglino and A. Olmo, *Health as a fundamental right: a study on migration and healthcare in Turin*, op. cit., page 127.

<sup>456</sup> She arrived in Italy before Romania joined the European Union.

formalized as time passes; many of them have institutionalized a service in terms of a counselling centre or an information desk, on the basis of an unofficial service they already offered to the migrant population for whom they were the reference point. One of the main reasons the associations can offer information is that they are part of the social reality of the community and can closely observe the problems of their fellow countrymen.

We did a survey after some Chinese women told the association that people were not following the correct procedures. In Torino, the Chinese have a high birth rate; about one hundred Chinese children are born every year. We carried out a number of interviews with hospitals like Sant'Anna and Maria Vittoria and we found that only 30% of these women follow the standard procedures with courses and planned appointments. This is a risk because it can cause problems with the birth. We decided to interview the Chinese women, to find out why this was so, and we realized that they found it difficult to access the services, even when the services were available. [...] Linguistic difficulties, problems with their working hours, difficulties in finding someone to accompany them who spoke the language. [...] Speaking to the people, we found that there was a widespread problem with healthcare, involving also men, old people and children. We asked ourselves what we could do. We couldn't just turn a blind eye. (Representative ANGI).

When a problem is found, the associations – if they are sufficiently strong – tend to enact resolute strategies. This is the case of the courses on infectious diseases held in some mosques in 2014. The year before, the Omar Ibn El Khattab mosque in Via Saluzzo organized a campaign for potential blood donors in cooperation with AVIS Torino. Many of the donors involved were found to be infected by pathologies linked mainly to hepatitis B (Hcb) and C (Hcv). The coherence between the results that emerged and the observations of the personnel at the MISA clinic<sup>457</sup> (with which the organizers of the campaign were in contact) encouraged them to discuss activities for prevention and containment of the problem. The willingness of the doctors to organize an awareness campaign gave the initial input, but a fundamental role was played by the presence of persons aware of the topic and convinced that the information *for* the community must come *from* the community itself<sup>458</sup>.

Often I went to pray and I was stopped by people who wanted to ask for a variety of information. For the simple reason that I speak Italian well, they think I know everything and, when they don't know where to go, they ask me. We must bring the answers to the places where the questions are asked. It is our responsibility. (Khaled, 36 years old, Egypt).

There was a similar perception amongst the volunteers at the Romanian counselling centre.

We are the largest community in Torino and therefore we certainly make considerable use of the services. The Italian volunteers have done a lot for us and I think that they were expecting a signal from us. We felt we had to do something. (Romanian volunteer, San Lorenzo dei Romeni).

Therefore, if they are well organized, the associations can intercept the problems and offer answers that take into account the linguistic difficulties and the cultural differences.

If we talk about the low number of pregnant women at the appointments, it is also a cultural problem, because in China there is no standard procedure like the one in Piemonte. There are not so many tests to be done. Therefore, we have to work on many aspects: information, language, culture, because we must also convince

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<sup>457</sup> Ambulatorio Migrazione e Salute, Amedeo di Savoia Hospital.

<sup>458</sup> We will discuss these educational activities in the last paragraph of this chapter.

the employers to give the workers time off for the visits. In China, there are many different tests and they are not all compulsory. We try to conciliate the two methods, so that the person's culture is respected, but also the methods existing in Italy are applied. (Representative ANGI).

The lack of information and the inability to find it may affect access to the health services in two ways: on the one hand, as in the case of Silvia, it prevents access and on the other creates erroneous access, which does not respect the procedures foreseen. One example is the incorrect use of emergency services: in the case of the Chinese, a massive use of the A&E department is often reported<sup>459</sup>, since the users go there when they should be contacting their GP. Often, the people do not seek information until they need it, or in an emergency, and the associations can play an important role in bridging this gap between the migrants and the National Health Service.

The first time they come to the centre, they fill in a form with their personal information. The form is used to create a computerised database and to begin to get to know the person. There are questions about their biographical information, the documents they hold in Italy and this helps us to find out whether they have a health insurance card or not. According to the documents the person has we can begin to understand their situation regarding their health. It is important to begin to understand the person's health condition and to give them information. Perhaps they didn't come here because of their health, but if we see that they don't have a health insurance card, we tell them to go and get one. (Romanian cultural mediator, San Lorenzo dei Romeni).

Finally, there are cases in which access is limited because it is obstructed by rules that are difficult to understand and sometimes the persons have become tangled in the bureaucracy, like Violeta. This woman has lived in Italy for five years, she worked as a domestic worker with a regular contract and was registered with the National Health Service. When her contract expired, she decided to return to Romania to be with her family. Some months later she returned to Italy to pay off a small debt with her bank and, during her brief stay, she felt ill. The first tests carried out at the Cottolengo Hospital<sup>460</sup> revealed a cirrhosis on which it was necessary to operate immediately. Although Violeta had not intended to remain in Italy, the appearance of the illness forced her to alter her plans and seek treatment. Violeta was obliged to wander around each day looking for a place in a dormitory, because she did not have a home and could not afford to rent a room. The expiry of her employment contract had terminated her registration with the National Health Service and as a "new entry"; Violeta could only obtain an ENI code if she had a residence. The woman was therefore in a difficult situation.

She can't go to Romania because she would not receive free treatment there, but she can't get treatment here because she is not registered with the National Health Service, because she is not resident... it's a bad situation... last time she came here she started crying. I told her that it is a good thing that she is here, perhaps someone up there decided it. That for that little debt, just a few euro, she should come here and then find out that she was ill, in Romania she would never have found out, or she would have spent thousands of euros in treatment. (Romanian cultural mediator, San Lorenzo dei Romeni).

In this difficult situation, the network that links the world of volunteers, private social bodies and public hospitals has worked in support of Violeta. The counselling centre, with the association Camminare

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<sup>459</sup> T. Osteria, D. Carrillo and A. Sarli, *The Health Dimension of Asian Migration to Europe*, op. cit. page 41.

<sup>460</sup> Violeta was sent to Camminare Insieme, which has an agreement with the hospital for persons without a health insurance card.

Insieme and the MISA clinic have taken up her case and found a stable place for the woman in a dormitory in the city. After a few days, Violeta was moved to a centre where she could stay also during the day and, thanks to a declaration of permanence in this structure, she has obtained an ISI card and begun more thorough tests at the Amedeo di Savoia Hospital. The results have not shown the need for medical treatment and so she has decided to return to Romania. A journey that was supposed to be for a few days was transformed into a “medical odyssey” which was managed thanks to the strong network that intervened.

One day, at the beginning of August, she told me she had booked a place on the bus to return to Romania. Since she insisted that the counselling centre should pay for the whole ticket, we collected a little money and paid part of the cost of the ticket. From Camminare Insieme and Sermig we managed to get some food for her to take home and we found a good supply of the medicines she took for her stomach and iron supplements, because she was very anaemic. Sometimes she calls me from Romania to thank me and she asks me to greet and thank all those who helped her. (Romanian cultural mediator, San Lorenzo dei Romeni).

#### 4. *Migrant associationism as an agent of acceptability*

The meeting between the foreign users and the Italian institutions is based on complex topics such as the conception of health, illness, body and healthcare<sup>461</sup>. Acceptability means that all the structures and the health services must respect medical ethics and be appropriate from a cultural standpoint. In the next paragraphs we will not deal with all the topics that could come within the theme of acceptability, but only those that emerged during the interviews with volunteers and users of the associations and which are useful for highlighting the way the associations can increase the acceptability of the treatment and the services offered.

##### *Waiting times as a cultural variable*

One criteria by which the users evaluate the National Health Service services is often that of waiting times. This is true for Italian and foreign users, but in the dialogues with the operators and the Chinese users the variable “time” emerged as crucial, as other studies on the relationship between the Chinese and the Italian hospitals also show<sup>462</sup>. The variable “time” is identified as the second cause that prevents the Chinese from using the Italian health services<sup>463</sup>.

The question of employment is often mentioned to explain why the Chinese would prefer shorter waiting times and avoid queuing at the GPs surgery: described as subjects totally dedicated to work, it is felt that they “have no time to waste” and that they put their work before their health.

There are many Chinese who go [to the surgery] to get a prescription, but the doctor does not fix appointments, so they have to wait in the waiting room. At times, just for a prescription they have to wait for half a day, they think that rather than wasting half a day, they can earn €30 and they don't bother. Perhaps it is also for this reason that they are prepared to go for examinations that cost a bit more. (Chinese cultural mediator, ANGI).

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<sup>461</sup> I. Biglino and A. Olmo, *Health as a fundamental right: a study on migration and healthcare in Turin*, op. cit., pages 92-98.

<sup>462</sup> . Osteria, D. Carrillo and A. Sarli, *The Health Dimension of Asian Migration to Europe*, op. cit.; A. Sarli and D. Carrillo, *Unasked Questions and Missing Answers*, op. cit.

<sup>463</sup> B. Wu and V. Zanin, *Healthcare Needs of Chinese Migrant Workers in Italy: A Survey Report on Chinese owned Workshops in Veneto*, University of Nottingham, China Policy Institute, Discussion Paper N. 48, 2009, page 15.

The question of employment is certainly central to Chinese emigration – which is described as “emigration with capital” because they seek independent work and economic success<sup>464</sup> – however we must not forget that being totally dedicated to work is a consequence of the status as a migrant, in addition to being a cultural trait. Employment is often precarious and lacking in trade union protection, requiring the migrants to safeguard their jobs at the cost of looking after their health<sup>465</sup>. In the case of the Chinese, this is added to a family-run production system in which the employer offers board and lodging to their employees and the work itself can become all-consuming<sup>466</sup>.

In the interviews with Chinese users it emerged that the linguistic difficulties and the lengthy waiting times are the elements that make access to healthcare most difficult. The Association ANGI offers its members a solution based on an agreement with a local structure.

We began with the question of mother and child, interviewing Chinese women, visiting hospitals, gathering statistical data and we saw that there was a health problem in the community. At the same time, we were contacted by an NHS contracted structure that offered us an agreement: they would send us all the forms and consent forms and we would have them translated into Chinese. Since when they go for an appointment, the patients must sign the forms and declare that they have understood, they will have a copy in Italian and one in Chinese, they know what the document says, they go to the appointment or for the tests and at the same time we build a databank for our studies [...]. We have opened a health information desk at the association, and we can see their situation (whether they are workers, have a card or not, and so on). If they have a health insurance card, we book at a public structure, if they don't we book at a private structure with a cost that is just a little higher than the 'ticket', because we have an agreement that gives a discount of 20% on the ordinary fees, and we don't have to wait. If I book today, I may have an appointment tomorrow. (Head of Association, ANGI).

This solution – designed for people who do not have access to the National Health Service, like the Chinese students who enrol at the Italian universities<sup>467</sup> – has also been useful in other situations: that of the migrant who, despite the possibility, has not registered with the NHS, and who prefers to pay a fee higher than the 'ticket' to obtain a swifter service.

When a friend introduced me to the association I had a gynaecological problem and I had to do some tests, but I gave up with the public hospital because the waiting times were too long. My friend gave me the phone number of the association and the first time we spoke over the phone, then they gave me the association card and we met for the first time in front of the hospital. (Li Ping, 34 years old, China).

It is necessary to consider that for many Chinese users the time variable is not only linked to the waiting times and the absences from work, but also to the type of treatment and the perception of its efficacy. Traditional Chinese medicine, based on herbs and natural remedies, is widely used both in China and in the Chinese diaspora, alongside Western medicine. In China, both medical traditions are accessible and, according to the type of problem to be solved, people decide which type of treatment to use.

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<sup>464</sup> A. Tassinari and L. Tomba, *Zhejiang-Pechino, Zhejiang-Firenze. Due esperienze migratorie a confronto*, in «La Critica Sociologica», 1996, N. 117-118, pages 27-38.

<sup>465</sup> A. Sarli and D. Carrillo, *Unasked Questions and Missing Answers*, op. cit., page 6. See also Chapter 4 of this volume.

<sup>466</sup> B. Wu and V. Zanin, *Healthcare Needs of Chinese Migrant Workers in Italy*, op. cit., page 32.

<sup>467</sup> Foreign students enrolled at Italian universities have the right to voluntary registration with the NHS, on payment of an annual fee, see Chapter 2 of this volume.

Chinese medicine is not specific for an illness, I use it in cases where I don't feel well, but I can't point to a specific problem, like when I feel weak and tired. On the other hand, if they find kidney stones, with traditional medicine they go away. Another example is back pain: here it is treated with tablets, but not in China, they will give you a natural herb and after six months or a year, you are cured. If you have a high temperature, though, you use European medicine, also if you have a serious problem that must be solved immediately. The Chinese remedies take longer to be effective. (Chinese cultural mediator, ANGI).

From these words it is clear that time is an element that comes into play when making a decision between the different medical systems: normally, when a rapid and immediate intervention is necessary, they turn to western medicine, which acts directly on the symptom. When a more profound treatment is needed, which heals not only the symptom but also acts in a holistic manner, they turn to Chinese medicine, which offers results only in the long-term. This is why one of the criteria that guides the choice of a medical system is the seriousness of the problem: serious illnesses or those in an advanced state in which it is necessary to act immediately are treated with western medicine. This also reflects a different organization of hospitals, coherent with the principle of rapidity attributed to western medicine.

In China, there are many hospitals. When you go in you ask for information, there is an information counter, you say what the problem is and they tell you where to go, and you do everything in one day, you have an appointment, do the tests, they don't make you wait for months. You see the specialist immediately, and 90% of the time, you can do everything in one day. (Suzi, 48 years old, China).

This concept of western medicine and the organization of the hospitals makes the long waiting times inconceivable and they are interpreted as “malfunctioning” and “lack of competence”<sup>468</sup>, causing an increase in the mistrust that the Chinese generally feel towards Italian doctors<sup>469</sup>.

The health desk at ANGI, run in collaboration with an NHS contracted clinic offers a solution for those cases in which the waiting times become an unacceptable element, transforming into a limit to access to treatment. Although the first thing they do is try to register the person with the National Health Service, the private sector is often the only resource in particular cases for which the public service is not considered efficacious. The solution offered by the association safeguards the right to health and can be considered an attempt to stem other types of response, such as incorrect use of the A&E department, the use of traditional medicine for self-medication<sup>470</sup>, the appearance of unqualified doctors and the search for a more acceptable cure elsewhere, with the consequent appearance of transnational therapeutic itineraries.

#### *Welcoming the expectations of health*

The acceptability of the service is a variable that can be measured on the basis of the patients' expectations of health, as shown in the case of the Chinese community. As we will see in the eighth chapter, dedicated to the topic of medical transnationalism, expectations of health often lead people to travel and to undertake therapeutic itineraries that cross the national borders in many directions.

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<sup>468</sup> T. Osteria, D. Carrillo and A. Sarli, *The Health Dimension of Asian Migration to Europe*, op. cit. page 511.

<sup>469</sup> *Ibidem*, page 41.

<sup>470</sup> In the case of the Chinese, self-medication often uses traditional medicines. This must not be considered a “cultural” attitude, or at least, this is not how the Chinese users to whom I spoke considered it. The principles mentioned to justify self-medication are efficacy (seeing that the medicine has the desired effect) and rapidity (acting on the illness without having to wait for appointments).

Viorel, a Romanian lorry driver, had an accident at work and fractured his femur. The two operations carried out in Bucharest only partly solved the problem and Viorel was destined to walk on crutches and remain unemployed, since the problem with his leg would make it impossible for him to return to work as a lorry driver. An acquaintance who was leaving for Italy, offered to accompany Viorel to Torino, where, in his opinion, it would be possible to solve the problem getting an implant. Soon, Viorel found himself in the nomad camp in Lungo Stura Lazio, trying to get by in a country where he did not know the language and with a health system that was equally foreign to him.

The first time he came to us, he had nothing, no contacts, no work, and no documents. He came here in the hope of solving his problem. He went to the church and then he came to us. We immediately told him it was not possible, we thought it was impossible to get a prosthesis for a person with no documents, but he was patient and in the end, he solved the problem. We looked after him: first, we took him to a community, because it was winter and it was a problem for him to sleep in the cold, then he got a health insurance card, did all the tests, in the end he was admitted to hospital, and they operated. (Romanian cultural mediator, San Lorenzo dei Romeni).

The initial fear that Viorel's request could not be accepted was unfounded. In fact, the regional ruling N. 6-3264/2006 states that temporarily resident foreigners have the right to have prosthetics fitted at the expense of the regional health service<sup>471</sup>.

For Viorel, the counselling centre was above all a place where he felt welcome and where he was able to recuperate a sense of dignity.

When you live in the street, you are nothing, you are nothing and you don't understand anything. You have dirty clothes; no one speaks to you, only *they*, that is the volunteers at the counselling centre, only *they* can help you. They don't care if you don't speak, if you don't shower, how you are dressed. They help you, they speak properly to you, they give you what they can. You are not patient in those cases, you can't talk, you hear a lot of different information, and they understand better than others. Before that, God helped me, then they did. (Viorel, 45 years old, Romania).

Secondly, the association was the context of practical help: Viorel was sent to Camminare Insieme to obtain free medicines, to the Madian<sup>472</sup> community so that he could have a place to stay and to the ISI Centre to register for healthcare. Assistance and mediation were the means of access to treatment.

The first time I went to the hospital I was with a friend. We did not know that it was necessary to do all those things, health insurance cards, prescriptions... in fact, at the hospital they told me I couldn't have the operation, the doctor told me I needed an ISI card. So I went with one of the people from the counselling centre to the ISI Centre in Lungo Dora Savona. [...] The doctor told me that he could operate only if I had my documents. He said that the ISI card did not cover such high medical expenses. So, I went back to the CTO Hospital a second time with the mediator from the centre, because at that time I couldn't speak (Italian) and I didn't understand properly. That time the doctor explained clearly to the mediator and I understood that it was possible to do the operation; it was just that I had to wait. I waited a year and four months, I had the operation last August and so far, everything has gone well. (Viorel, 45 years old, Romania).

Associationism and its networks have guaranteed Viorel the realization of his request for health. Without the intermediation of the association, Viorel would probably have received the prosthesis he needed,

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<sup>471</sup> On June 27<sup>th</sup> 2006, with ruling N. 6-3264, *Assistenza sanitaria agli stranieri tempora- neamente presenti sul territorio regionale. Diritto alle prestazioni integrative*, the regional council decided to include integrative services and prosthetics for STP. "It seems evident that the definition of treatment must include all types of healthcare and that prosthetics are an integral and indispensable part of therapeutic and rehabilitative cycles, and therefore lie within the field of essential services.

<sup>472</sup> Madian is a community that takes in foreign minors and sick foreigners and is run by the Ministers of the Infirm, The Camillian Religious.

but with greater difficulty, given the lack of a home, the impossibility of paying for medicines and his initial difficulty in dealing with Italian bureaucracy.

Accepting the expectations for health also means setting them against the cultural background of reference and, consequently, giving dignity to the subjects' requests. This element emerged in particular from the interviews with those who attended some of the mosques in the city. The importance of the place of cult – generally founded as cultural associations – is considerable precisely because they are also places where the cultural acceptability of certain practices is discussed.

If they have doubts, the people go to the mosque. There are cases in which a pregnant woman is told that the child could have illnesses; at times, the doctors advise the woman to have an abortion. In this case, for example, they ask at the mosque if it is *haram* [forbidden or proscribed by Islamic law or if they can do it. They ask the imam because he is the one who knows about these topics. Lately we have talked a lot about the donation of organs and brain death. Also in these cases, we ask the imam whether it is possible from a religious point of view. With regard to health, we seek answers at the mosque on the relationship between science and faith. (Khadija, 32 years old, Morocco).

In some cases, the religious discourse – as with other cultural references – can be used strategically to try to create bridges between the requests of the doctors and the beliefs of the people. This is what the cultural mediators do every day in their work, but it is also what many associations try to do, thanks to their religious and cultural background, shared with the people they are trying to help.

There was a woman who could feel lumps in her breasts, she didn't want to talk to her husband or the doctor about it, not to anyone, because she was afraid of what she would discover, afraid of her husband's reaction. Often, people come to us at the last minute, they don't want to know and they prefer to ignore the problem. In these cases, I introduce the religious aspect, because in the Qur'an there are a number of *surah* (verses) that invite people to be aware. So, the people are convinced that what will happen, will happen, and that it is better to discover the illness at the start. The *surah* speak in general, but we can also take them to mean discovering illness, because this means that people must know what is happening; in this way I can convince people to know. (Malika, 44 years old, Morocco).

The religious aspect is therefore a powerful vehicle of the messages, as well as acting as a social bond for the communities that gather on the basis of a common faith.

The good thing in church is that you find kind people. It was sufficient for the priest to say in church that a person who could repair a washing machine for a sick woman was needed and a man immediately offered to do it. The role of the church is very important and in cases of need, for example, we take a collection. For many reasons, the church does a lot and that is different from what I have seen in many churches in Romania, where charity, in such a corrupt country, almost no longer exists. (Romanian cultural mediator, San Lorenzo dei Romeni).

#### *Bridging the gap between cure and care*

The story of Viorel introduces the question of the gap between cure and care. While on the one hand the operators are invited to “keep their distance” from the patients' life stories and stories of health on the other they are urged to find ways to humanize the treatment, to welcome the person as a whole. Reaching a compromise between these two instances depends on the motivations of the individual operators since it is generally difficult to valorise the relational dynamics within relationships limited by rigid norms and economic logics. Consequently, the work of *care* is often invisible and in the hospitals, the procedures that

tend to rationalize the system and reduce costs generate a reduction of the spaces destined for the informal support of the patient<sup>473</sup>. This occurs in the case of Italian patients, for whom part of the activity of care is delegated to persons outside the institution, in particular to relatives<sup>474</sup>. In the case of migrants with weak family networks or few tools for dealing with the situation, the associations represent the social capital that influences the management of the care and of the illness.

In Torino in the third sector there are major experts who offer a service. We do not offer treatment, but we are the cultural mediators, or a channel, or a facilitator, we are not the replacement for a service. The mediator must be specialised in what they do, they must know the situation in which they are to act thoroughly before they intervene. I don't agree with the fact that the mediator is called upon to interpret for doctor and patient. If the mediation comes too late, it is useless; we have to accompany the patient from the start, know their story, know what that person is experiencing. From this point on, it is possible to build an intervention, you have to win the person over slowly [...] for example, Ahmed has changed from 'like this' to 'like that' (Italian expression accompanied by turning the hand palm down to palm up, to express change, NdT.) since we understood what he needed. He came to Italy seven months after his marriage. Soon after that, he became ill. We found him a council flat, but after six months, we discovered that he had a tumour. He knows he is going to die, but we found out his secret: he wants his wife to come here, but he does not have the necessary requisites. Thanks to Prisma,<sup>475</sup> we managed to speak to the chief of police and we found a way to help them reunite the family, so that he can have his wife with him. He found courage when we discovered that his secret lay in the family. (Moroccan cultural mediator, AMECE).

A woman came here because she was unemployed, she had discovered that she had a tumour and when she came to us, she was already very much tried by the treatment and in a very advanced state. She had no one in Romania; her only child was in Belgium. At a certain point, she had to ask for food from the food bank and we found that she couldn't even do the shopping and pay the rent. Through us she found that the landlord knew nothing about the situation. We made contact with the son, but it was difficult because she didn't want him to know. She said, "When I am better, I will call him." We managed to speak to the son, because we hoped that he could see her still alive, although when he arrived she was already in a coma. We took a long time to establish a relationship of trust, so that she would give us the keys to her home and let us contact her son; we had to look at her phone in secret (to find her son's number)... the best thing is that at the end she had begun to trust us and she called us her daughters. She had no one else; we did everything for her, even found someone to repair her washing machine. (Romanian cultural mediator, San Lorenzo dei Romeni).

From these testimonies, the role that the associations can play in terms of *caring*, or – to use the words of a volunteer at the association Zhi Song – 'social care' is clear. We can think of the concept of care as completely taking charge of the needs of the sick person.

The expression *care-mix* defines those situations in which the need for care are met by subjects of various kinds, whether they are public or private. The associations are a fundamental part of this fusion, in which they not only act as the social binding agent for the person's network, but they can even substitute the family if they are not physically present. When they are ill, the migrants are not only ill, they are "displaced sick people", first of all in the geographical sense – because they are far from their primary social context – and secondly in the personal and existential sense, because being ill also means that the migratory project could fail<sup>476</sup>. By calling the services, maintaining contacts with the doctors and with the other bodies of the

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<sup>473</sup> M. Tognetti Bordogna, *Disuguaglianze di salute e immigrazione*, op. cit., pages 219-220

<sup>474</sup> For a study on the welfare mix applied to the health sector see I. Ponzio (ed.), *Il nuovo care mix. Realtà e prospettive della cura agli anziani, tra pubblico (locale) e privato (transnazionale)*, Torino, Rapporti di ricerca Fieri, 2014, disponibile online: [http://fieri.it/wp-content/uploads/2014/04/Il-nuovo-care-mix\\_prefazione.pdf](http://fieri.it/wp-content/uploads/2014/04/Il-nuovo-care-mix_prefazione.pdf).

<sup>475</sup> The *Prisma* project offers support and help for foreigners with disabilities, through the disability and immigration service. It is a project founded by the Servizio Passepartout of the central direction for social policies, with a network of private social associations.

<sup>476</sup> I. Quaranta and M. Ricca, *Malati fuori luogo*, op. cit., page 9.

private social services, the associations try to meet the needs of the sick foreigner as a person, limiting as far as possible their sense of being 'displaced'.

##### 5. *Migrant associationism as an agent of health literacy*

The Recommendations of the European Union on migrant health have for many years emphasised the importance of the participation of the community in planning health measures. The World Health Organization has been moving in the same direction for some decades, with its principle of "health for all". This principle, adopted in 1984 and repeated in 1988, in *Health21: health for all in the 21<sup>st</sup> century*, drew attention to a series of actions that an efficient health service cannot ignore, including the promotion of health. It is realized by spreading a culture of health outside the hospitals, in the workplace and in free time, above all through the participation of civil society in activities that promote a culture of health. The accessibility of services, in fact, concerns not only their use, but also the promotion of health and prevention. There is now awareness that people from other cultures are not sufficiently reached by the preventive campaigns destined for the Italian population and that it is therefore essential to organize targeted campaigns<sup>477</sup>, which are more efficient in terms of reaching the population and of cultural appropriateness.

With regard to the topic of health, we have observed the project carried out thanks to cooperation between the MISA department and an Islamic prayer room in Torino from the start. In 2013, some members of the Omar Ibn El Khattab mosque in Via Saluzzo 18 began to promote a campaign for blood donors in cooperation with AVIS Torino. Many of the donors involved were found to suffer from hepatitis B and C. This information was a signal of alarm that led the organizers to contact the doctors at MISA. The discussion led to an activity of peer education mediated by the doctors of MISA who met with a group of volunteers from the various Islamic centres and trained them on the following topics: access to the NHS, infectious diseases, mother and child health and nutrition<sup>478</sup>.

In the first phase, the doctors and the representatives of the mosques drew up a calendar of eight meetings; the doctors prepared the informative material, while the organizers publicised the event amongst the various Islamic associations and created a group of about fifteen people to be trained as peer educators. The intention was to give the widest possible diffusion to the initiative, in order to then transmit the notions received contemporaneously in a number of different places. All the meetings were attended with a participative attitude and were appreciated by the group, who always emphasised the urgency of actions that would bring the hospitals closer to the users. The second phase, which began in September 2014, foresaw the diffusion of information by peer educators to the members of the mosques, but unfortunately, meetings were held in only five of the mosques involved. These moments were planned in continuity with the usual activities, for example, at the end of the prayers or during religious education for women.

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<sup>477</sup> Biglino and A. Olmo, *Health as a fundamental right: a study on migration and healthcare in Turin*, op. cit., page 126.

<sup>478</sup> The meetings were held twice a week from January to May 2014.

One of the first and most important observations concerns the setting up of the group that took part in the training with the doctors. The diffusion of the initiative to various mosques meant that people from the direction of every Islamic centre, identified as “best participants” were involved, and above all this gave them the chance to follow the entire cycle of lessons. The group was formed of men and women with certain characteristics: excellent competence in the Italian language, an interest in social and health topics, previous experience in voluntary work or cultural mediation and medium-high educational qualifications in Italy or in the country of origin. It is interesting to note that persons who were less well integrated, had less experience in the social field and an inferior cultural and linguistic level would have found it difficult to join such a project; this meant that the doctors were dealing with a group of people that have very different characteristics from those they meet daily at their surgeries. This fact may also offer points for consideration on at least two important questions: first of all, the constitution of the group represents a fundamental phase in projects of this type. Before starting a training activity aimed at creating *peer educators*, in fact, it is necessary to establish who the *primary beneficiaries* are and who are the *secondary beneficiaries*, at the same time considering whether there is a certain possible distance between the two categories. Secondly, it is necessary to consider the questions raised in the first chapter of this volume, with regard to representativeness: the community of religious, national and linguistic membership is not in itself a social bonding agent, just as attending the same mosque is not necessarily a social link. It is absolutely not certain, in fact, that this type of sharing leads to a greater awareness of other people’s problems or greater empathy. On this latter point, in particular, during the meetings we often discussed with the doctors the question of sexually transmitted diseases. To face such a topic in a mosque leads to a discussion of two fundamental points: firstly the possibility of non-judgemental acceptance requires a training and an attitude that cannot be taken for granted and secondly, it was clear that persons with certain problems flee from their community and prefer to find help in other sectors of society. Some people emphasised that the dominant moral opinion considers infectious diseases, and particularly those that are sexually transmitted, shameful. This is the reason the mosques receive many requests for help, but are rarely contacted by people who fear they will be judged and therefore marginalized (for example, prostitutes, alcoholics or drug addicts).

This is not the place for evaluation of the project; however, it is certainly useful to note the criticalities and the strengths.

One criticality is certainly the fact that many participants abandoned the project when it entered the second phase and they were required to participate more actively. The causes may lie in the commitment required of them, and perhaps in the attempt to unite various mosques in a single project. The various Islamic groups in the city are led by different associations and are linked to different nationalities, religious or political movements that implicitly characterize them. A collaboration on the basis of religious beliefs cannot therefore be taken for granted. The second phase, in addition to being more delicate, was not followed directly by the doctors, since the project only foresaw their participation in the first phase. The absence of anyone to monitor the progress of the activities and to set the pace made it difficult to continue the activities, perhaps also because the associations that run the mosques are not accustomed to organizing such projects.

The main strength was the intention of the doctors to take health education to places attended by the migrant communities. In the only centre where the project reached its conclusion, the results were good. The planning of the meetings with the peer educator, within the normal religious activities, made it possible to involve people who would otherwise have had little interest in taking part in meetings on health matters. This integration with the moments of prayer or religious education ensured that at times the meetings were held in the presence of the imam, which, in addition to giving the volunteers more authority, emphasised that ensuring the well-being of oneself and of others is one of the duties of a good Muslim. The context characterized by trust and the division of men and women allowed the users to ask questions and encouraged their interest in the project.

The element of division by gender is of particular interest. The sharing of information by the peer educators was carried out separately for men and women, since it was part of the normal religious activities (prayer, lessons) which are obviously held in different places. The meetings with the doctors, on the other hand, were held in front of a mixed audience. The “scientific” nature of the information transmitted by the doctors, the topic and the type of participant meant that no one questioned the presence of men and women in the same space. This organization was queried only with regard to two meetings on mother and child health and on sexual and reproductive health. When the doctors asked whether it was better to discuss these matters with a group of women or with a mixed audience, the majority of the women present were irritated by the position of the men, who took it for granted that they should not take part in meetings on what they considered to be “female topics” and they wanted these meetings to be held before a general audience. Only one participant out of five was against this option and her request was accepted to avoid her absence. However, the reaction of the other women showed that when such a project is organized, it is not possible to take anything for granted; on the contrary, the decisions must be taken systematically with the participants.

The genesis of this project also shows that in order to develop community welfare, it is necessary first of all to weave a network with formal institutions, to respond to a need that emerges from the community and attempt to encourage a passage from informality to formality. The birth of ground roots planning implies particular attention to actions that already exist, if only informally, which should receive attention from the institutions and be implemented. In this case, for example, the role of the mosques as places where people bring their problems and their requests was valorised. The attempt therefore was not to offload a model from above, but rather to develop an already existing practice.

The training and health literacy are not only a uni-directional process that foresees a passage of information from the doctors to the potential users, it must be seen as a bi-directional exchange that on the one hand foresees an increase in the users’ awareness and on the other an increase in the cultural competence of the service. By “cultural competence”, we mean the doctor’s capacity for interacting in an efficacious manner with patients from various cultures.

The associations can be the promoters of activities to increase cultural competence amongst doctors<sup>479</sup>. The association ANGI, for example, following the identification of a widespread problem in the

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<sup>479</sup> T. Osteria, D. Carrillo and A. Sarli, *The Health Dimension of Asian Migration to Europe*, op. cit., page 564.

mother and child area, in 2010 signed an agreement with the Torino-Asti interprovincial council of midwives in order to guarantee better services with regard to the health of Chinese mothers and children. Within this cooperation – prior to our research – there were periods of reciprocal training.

Starting from the health of women and children, we moved on to a phase of reciprocal training. We had two meetings with the council of midwives to discuss how to behave and what to do with Chinese patients. We went to them and they came to us and we organized two meetings for midwives on Chinese language and culture. We train each other. We found two teachers to explain the cultural profile, the role of the family, of work and the cultural aspects to be respected [...] They had had difficulty with the Chinese women, so they already wanted training and they found us. They agreed with us that by helping the users we are also helping them. (Head of ANGI).

Remembering the invitation to avoid homogenous visions of persons with the same origin, or considering an association the representative of a national group, we can say that the work done by the associations with regard to training, accessibility and acceptability is moving in the direction of training “community health educators”<sup>480</sup> and building the “profile of community health”<sup>481</sup> encouraged by the WHO.

## Chapter Eight

### Health crosses borders

#### 1. *From local health to transnational health*

The research that was presented in the previous chapters is strongly rooted in the city of Torino, where the hospitals, the associations and the clinics referred to are based. Torino is the landing point for people from other countries, who mainly came to Italy in search of work, intending to stay permanently or temporarily, but it is only one of the places mentioned in the interviews. The stories of health in this volume often evoke the country of origin or other stages in the migratory process and they acquire a sense within an imaginary made up of persons, languages and cultural concepts that frequently refer to a geographical ‘other place’.

In this last chapter, we have decided to follow up on these stories of health, in order to place them in a wider transnational context that will allow us to refer to the plurality of discourses of the migrants and

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<sup>480</sup> For an example of planning see the Artemis project (*Associazionismo e reti territoriali per la mediazione interculturale sulla salute*, a cura del Centro nazionale Aids, Istituto superiore di sanità (Iss), Organizzazione internazionale per le migrazioni (Oim), L’albero della Salute - Struttura di riferimento per la promozione della salute dei migranti e Regione To-scana (Ads).) The overall aim of the project was to improve the process of integration of immigrants through better health literacy of the associations of foreigners and the training of community health educators.

<sup>481</sup> The health profile is the description of the state of health of a population. It is constructed by gathering useful information at local level to take decisions on priority health problems. These can be gathered through interviews or focus groups with mediators or privileged witnesses of a certain social reality. The final aim is to identify the principle problems and then construct “a health pact” between the health services and the local administration.

understand the complexity of their geographical and cultural references. Unlike the pages that precede it, this last chapter does not deal with problems of access to specific treatment within the Torino context, but draws attention to dynamics that are only partly influenced by the context of the research<sup>482</sup>.

The aim is to take into consideration alternative and transnational forms of treatment to emphasise the fact that access to local services and crossing borders for medical reasons often ‘cohabit’ in the search for solutions to health problems. From the standpoint of the right to health medical transnationalism can be seen as an increase in the range of possible treatments, but also as opening to “competition” which may also be unfavourable to the patients and which may be called on to explain why some communities are poorly represented in the local health services.

In social research, to speak of transnationalism means referring to an approach in which the relations with the country of origin and the persons who live there become a key to reading the migratory experience. This is no longer seen as a definitive and unilateral move from one place to another, but rather as an event that creates a “transnational social field”<sup>483</sup>, crossing the national borders and in which the subjects interact, relate to each other and move. For a number of years we have spoken of “medical transnationalism” to refer to a perspective that describes the relationship between migration and health in a dynamic manner: if the migrants are persons contemporaneously rooted in more than one nation, then they are also linked to different health systems and different universes of knowledge and medical practices. If we recognise the social nature of health and illness, it is inevitable to use the term “medical transnationalism” when we speak of migrants<sup>484</sup>. Medicines, advice and their carers come from their country of origin; they remain in telephone contact with persons who live in other countries and ask them for advice about their health; Italy or a third country is the desired destination once an illness is diagnosed. Finally, they may send medicines to the country of origin or return there for diagnosis and treatment.

The subjective needs of the migrants – are rooted in a number of national territories – their twofold social and political origin and their diversified requests for participation affect the welfare systems, which are organized with reference to a national context<sup>485</sup>. The impact that migration has on the functioning of welfare in the places of destination, and on those of origin, is a new field that must be studied, trying to extend the horizons of action and fully understand the complementary, interlinked and communicating nature of the demands for social protection that emerge from the migrant population. These demands for protection may generate new forms of “DIY welfare” realized by the migrants themselves<sup>486</sup>, or find answers in a

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<sup>482</sup> We do not mean to suggest that the context of the research will not influence the results. The place is certainly significant because it influences the methods of access to health of migrants and therefore their choices of health. Despite this, we must emphasise that in this chapter the individual cases may represent the choices of migrants in general and not only those who live in Torino. For an example of how the context influences the health of migrants see: Y. Moullan and F. Jusot, *Why is the «Healthy Immigrant Effect» Different between European Countries?*, in «European Journal of Public Health», vol. 24, 2014, N. 1, pages 80-86.

<sup>483</sup> N. Glick Schiller, L. Basch and C. Blanc-Szanton, *Towards a Transnationalization of Migration: Race, Class, Ethnicity and Nationalism Reconsidered*, in «The Annals of the New York Academy of Sciences», vol. 645, 1992, pages 1-24.

<sup>484</sup> B. Bilecen and H. Tezcan-Güntekin, *Transnational Healthcare Practices of Retired Circular Migrants*, Comcad Working Paper, N. 127, Bielefeld, Comcad, 2014.

<sup>485</sup> F. Piperno and M. Tognetti Bordogna (ed.), *Welfare transnazionale. La frontiera esterna delle politiche sociali*, Roma, Ediesse, 2012.

<sup>486</sup> S. Ceschi, *Associazionismo migrante e welfare dal basso. Riflessioni di una conversazione con Hamat Diagne, presidente dell'Associazione Senegalesi Bergamaschi*, in *Welfare transnazionale. La frontiera esterna delle politiche sociali*, ed. F. Piperno and M. Tognetti Bordogna, op. cit.

legislative structure and a social protection system that mutates to try to offer suitable responses to changing needs.

By analysing the movement of knowledge, objects and persons within the legislative framework and a welfare system in transformation, we set ourselves the aim of showing how crossing a border in search of well-being and health is a dynamic and multidirectional phenomenon, and cannot be reduced to the label “health tourism”. In the common discourse, but also in that of some operators and politicians, this category is used to describe the experience of people who travel in order to obtain benefits for their health, using the services of countries other than their own. The corollary of this discourse is frequently expressed in terms of waste and incorrect use of resources. This study did not aim to calculate the percentage of the health budget dedicated to people who came to Italy for treatment, because this was not part of the approach adopted; we interacted with foreigners present in the city for various reasons (work, study, and family reunification) without asking them whether they left their country for health reasons. Persons with this profile, however, inevitably fell within the research area. Amira came to Italy to study and then did not return to Morocco because here it was possible to receive treatment not available in her own country. Radu left Romania with a friend seeking an implant that he could not afford in his own country; some migrants bring over their aged parents in order to access treatment of a superior quality or lower cost than that available in their country of origin. Despite this, we feel that the label “health tourism” is not useful because it greatly simplifies the numerous links existing between health and mobility.

One of the first scholars to deal with the many contemporary forms of this mobility was Henderson<sup>487</sup> who divided health tourism into subcategories according to the type of intervention sought: illness (check-up, screening, surgery for urgent reasons, transplants, orthodontic treatment, etc.), well-being (acupuncture, massages, spa treatments, etc.), aesthetic improvements (plastic surgery and cosmetic surgery) and the reproductive area (fertility treatments, assisted procreation). It is clear that these categories represent only in a very limited way the needs of the foreign patients present in Europe<sup>488</sup>, since medical tourism does not take into consideration the sense of inequality and the seriousness of the conditions that drive certain persons to seek treatment in a country other than their own. In the scientific literature, in fact, the term medical tourism is increasingly used to describe the growing industry involving patients who travel for non-essential services<sup>489</sup>. These are mainly patients from economically advanced countries who decide not to use the services offered in their country and turn to countries in Eastern Europe or South-East Asia where it is possible to obtain the same services at a lower price. According to Horowitz, this type of movement must be separated from another type of medical travel, in which the patients move from less developed countries to those with more numerous and more accessible services, seeking treatments that are not available in their own countries.

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<sup>487</sup> J. Henderson, *Healthcare Tourism in Southeast Asia*, in «Tourism Review International», 7, 2004, pages 111-112.

<sup>488</sup> T. Mainil, *Transnational Health Care and Medical Tourism: Understanding 21st Century Patient Mobility*, Nieuwegein, Nrit Media, 2012, pages 13-14.

<sup>489</sup> *Ibidem*.

The cases presented below – whether they are “health migrants” or immigrants who have fallen ill during their permanence in Italy – are radically different from those “health tourists”, in terms of possibility of patient choice, financial means and the type of treatment or service required<sup>490</sup>. We will not, therefore, speak of “tourism”, but of “mobility” or “therapeutic itineraries”. Therapeutic itineraries can be defined as the journeys made by the sick, and sometimes their families, in search of solutions to health problems; studying them makes it possible to highlight the plurality of therapeutic resources available and the ways they are used. The therapeutic itineraries observed fall within various moments of the migratory experience, but those who were ill at the time of leaving and whose journey was determined by the need for a therapy are a minority in the cases we encountered. The majority of the persons interviewed were healthy when they left and their pathology was diagnosed and treated in Italy. For some the illness determined the return to the country of origin and, at times, the result was the failure of the migratory enterprise. Finally, the term “itinerary” does not refer to a brief and temporary transfer (like tourism) but to a journey that can have various directions (in and out of Italy) and various destinations (Italy, the country of origin or third countries). This allows us to differentiate the categories of persons who move for reasons of health and at the same time to attribute weight to the social inequalities, also through a critical deconstruction of the concepts<sup>491</sup>.

## 2. *Transnational therapeutic networks: tourists, exiles and health pilgrims*

The relationship between well-being, health and mobility presents us with a variability of practices that it is difficult to summarize and organize. Patients in search of immediate intervention, the middle classes who move around seeking the least expensive versions of treatment or those not guaranteed in their home country; migrants who return to their country of origin for treatment. Various scientific contributions have tried to explain this complexity, by classifying in types<sup>492</sup> and trying to identify – as was done for other forms of mobility – the principle push and pull factors<sup>493</sup>. Glinos and colleagues, for example, have identified five main reasons that lead to the varying types of movement observable: availability, economic convenience, bioethical legislation, presumed quality and familiarity<sup>494</sup>. The anthropologist Kangas has described five elements that link all medical journeys, or border crossings in search of a solution to a problem. First of all, the journeys are preceded by a phase in which various possibilities are evaluated and they are motivated by the aim of alleviating suffering; often the treatment requires advanced technological competency and the

<sup>490</sup> M.D. Horowitz, J.A. Rosensweig and C.A. Jones, *Medical Tourism: Globalization of the Healthcare Marketplace*, in «MedGenMed», 9, 2007, N. 4, available online: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2234298>

<sup>491</sup> E.J. Sobo, *Medical Travel: What it Means, why it Matters*, in «Medical Anthropology», vol. 28, 2009, N. 4, pages 326-335.

<sup>492</sup> Glinos and colleagues propose a typology based on the meeting of two variables: why do people move to seek treatment? Who finances the trip and the medical expenses and how? See: I.A. Glinos *et al.*, *A Typology of Cross-border Patient Mobility*, in «Health Place», vol. 16, 2010, pp. 1145-1155. Manil, on the other hand, proposes a distinction based on the actors involved: *transborder access seeker* (the patient crosses the borders of neighbouring states); *receiving context actors*; *sending context actors*. By crossmatching these variables the author creates twelve types of transnational patients. See: Mainil, *Transnational Health Care and Medical Tourism*, op. cit., page 52

<sup>493</sup> V.A. Crooks *et al.*, *What is Known about the Patient's Experience of Medical Tourism? A Scoping Teview*, in «BMC Health Services Research», vol. 10, 2010, available online: <http://www.biomedcentral.com/1472-6963/10/266>; L. Culley *et al.*, *Crossing Borders for Fertility Treatment: Motivations, Destinations and Outcomes of UK Fertility Travellers*, in «Human Re- production», 26, 2011, pages 2373-3381.

<sup>494</sup> I. A. Glinos *et al.*, *A Typology of Cross-border Patient Mobility*, op. cit.

journey is undertaken because this treatment is inaccessible or non-existent in the place where the person lives. Finally, the journeys take place in a global arena and are facilitated by modern means of communication and movement<sup>495</sup>.

In addition to providing a typology capable of explaining the complexity of the phenomena involved in “medical tourism” and “medical exile”, the anthropologist must bring to light the lives of those who travel to resolve an illness<sup>496</sup>, examining how the models of treatment are transformed during the experiences of travel<sup>497</sup>, without losing sight of the comparison and the elaboration of the results, which offer an interpretative framework for the phenomenon. Starting from the cases that we encountered during our research, we will therefore try to answer these queries. Why do people move to resolve health problems? When do they begin to plan the move? What directions does this mobility take? What role do the social networks play in transnational treatment? How far and in what way can the right to health be guaranteed within this mobility?

In this paragraph, we will consider the various directions of border crossing for health reasons<sup>498</sup>, trying to propose a general consideration on mobility, beyond the rhetoric that often accompanies these topics. For the migrants who act in a social transnational field, made up of cultural relations and references set in more than one country, the possibilities of treatment are multiplied because people evaluate various possibilities, such as choosing between treatment in their country of residence or in their country of origin. Often, this latter option is preferred for treatment that is not considered essential, and for which a return to the country of origin can represent an economic alternative. Stan suggests that the Romanian migrants resident in Ireland compensate for their ‘neglect’ of the health services in the country of residence, with a considerable use of medical services in Romania<sup>499</sup>. For dental treatment, optical treatment or non-urgent specialist checks, it may be preferable to wait for the summer holidays or periodic visits to the country of origin. This means that there are countries, like Romania and probably geographically close, where the various “medical flows” intersect; wealthy immigrants who return home, foreigners who go there for treatment for economic reasons and Romanians who come to Italy for services not available at home. The story of Radu, told in chapter seven, is a clear example of the flows out, which in some ways can be read as a mirror image of the Romanians who return to Romania for treatment. While Radu could not afford the operation in Romania, in Ireland many Romanians cannot afford the treatment they need. At both poles of the process, therefore, the stimulus to mobility can lie in a variable degree of social inequality that, on the one hand, does not allow the migrants a satisfactory use of the services and on the other, does not include the poorer social classes in the services of their countries<sup>500</sup>.

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<sup>495</sup> B. Kangas, *Traveling for Medical Care in a Global World*, in «Medical Anthropology: Cross-Cultural Studies in Health and Illness», vol. 29, 2010, N. 4, pages 344-362.

<sup>496</sup> *Ibidem*.

<sup>497</sup> E.J. Sobo, *Medical Travel: What it Means, Why it Matters*, op. cit.

<sup>498</sup> I. A. Glinos et al., *A Typology of Cross-border Patient Mobility*, op. cit.

<sup>499</sup> S. Stan, *Transnational Healthcare Practices of Romanian Migrants in Ireland: Inequalities of Access and the Privatisation of Healthcare Services in Europe*, in «Social Science & Medicine», 1, 2014, pages 1-10.

<sup>500</sup> Many of the Romanians we met in Torino spoke of this social inequality in access to the health services, which are also confirmed by other studies. *Ibidem*, pages 5-6.

To this, we must add that the country of origin is often considered the place of acquisition of social recognition, which contributes to giving meaning to the migratory experience. This dynamic is known with respect to the economic investments of the migrants in the countries of origin, the matrimonial forms and the transnational links, and we cannot exclude that it also affects some choices in the health sector. To show the status reached abroad, in fact, some migrants choose treatment in their country of origin, often at private structures<sup>501</sup>, and the decision to have treatment at home<sup>502</sup> may be explained as a symbol of social mobility<sup>503</sup>, in addition to being a useful tool for re-establishing relations with the context of origin<sup>504</sup>. In addition to this type of motivation, other reasons range from dissatisfaction with the type of care received in Italy to the cultural dimension of the acceptability of the service and the trust.

I trust Italian internal medicine, and I trust Colombian surgery. In Colombia, they operate more, more quickly and with less scarring, so if I have to have minor operations, I wait until I go there. For example, during my last visit I had a chalazion removed, because in their opinion it was better to do so... there are many things I have had done there over the years, like dental treatment. It is a question of trust more than money, so for things like eye tests and in general minor things that you want to have done, although they are not essential, like dermatological examinations or a general check-up... I tend to have these things done there. The public costs here are comparable to the private costs over there, and I would say that it is also a question of trust. (Patricia, 40 years old, Colombia).

Often, to solve ordinary health problems (that is, those that don't need immediate treatment and do not represent a health risk for the person) they wait for a trip to the country of origin. In the case of Patricia, this dynamic is linked to a precise opinion based on a comparison between Italian and Colombian services, which leads her to identify which treatment to have in Italy and which, from her point of view, it is better to have treated in Colombia. In the case of Malika, on the other hand, a trip to Morocco was the occasion for solving a problem for which, in Torino, she would have to wait a long time, and for which the different ways of dealing with the problem in the two countries caused doubts and perplexities.

I had a fibroma in the uterus, which had to be removed. We saw it on the ultrasound scan. I went to the doctor because I had frequent haemorrhages and I didn't know what was causing them, and they were causing other problems like anaemia. The doctor told me that they had to operate to remove it and she put me on the waiting list. I don't know how long I had to wait, but it was a long time. They told me that to have the operation I had to sign a form where, if there were complications, I would allow them to remove the uterus. Honestly, I didn't want them to do that, because I am not young, but I don't consider myself old [...]. After a while, I went to Morocco and there I had the same problems with haemorrhages. I had a menstruation of about fifteen days and the women in my family recommended a private doctor. I went, I was examined and I decided to have the operation there. I paid what there was to pay and at least I solved the problem quickly. Of course, there was the risk of complications in Morocco, too, but there it is different. I didn't have to sign anything. For me, that is better, anyway, I would not have wanted to sign that document. (Malika, 43 years old, Morocco).

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<sup>501</sup> The question of use of private structures in their country of origin by migrants is a topic that can be seen from various perspectives. On the one hand, above all, in those countries in which access to public services are strongly marked by inequalities, this use accentuates the social inequality between those who benefit from ever better paid services and those who use the public services which have ever less resources (*ibidem*). On the other hand, however, the flow of resources that the migrants invest in the private treatment sector can drive improvement, invigorating the treatment sector (see E. J. Sobo, *Medical Travel: What it Means, Why it Matters*, op. cit. page 329).

<sup>502</sup> Here the term "home" is used in reference to all the literature on migratory phenomena, which has dealt with the relationships that the migrants maintain with their place of origin. By home, we therefore mean a set of social relations that involve shared meanings and which give the migrants a sense of belonging and identity. See amongst others: G. Valentine, *Social Geographies: Space and Society*, New York, Prentice-Hall, 2001 and H. Easthope, *A Place Called Home*, in «Housing, Theory and Society», 21, 2004, pages 128—138.

<sup>503</sup> S. Stan, *Transnational Healthcare Practices of Romanian Migrants in Ireland*, op. cit. page 12.

<sup>504</sup> E. J. Sobo, *Medical Travel: What it Means, Why it Matters*, op. cit. page 329.

In these cases, the trip and the mobility are seen as an element that extends the possibilities of choice of the migrants, who become subjects with agency and capacity for choosing in the health field, which, thanks to their own life experience, overcome the borders of the country in which they live<sup>505</sup>.

This type of return to the country of origin is opposed by that of persons who return because they do not trust the Italian health system and who do not have the linguistic and cultural tools for dealing with illness in Italy. In this case, as previously mentioned, the mobility is closely linked to forms of social inequality and exclusion.

When the doctor diagnosed the illness, the cancer was already advanced and we didn't know what to do. We phoned to China and my husband's parents said we should come home, to see whether what the Italian doctor had said was right, to see what could be done. In China, we received confirmation of the diagnosis and my husband underwent an operation. Afterwards he felt better, and we thought about the situation in Italy, about the factory, our work and all the rest and we came back. When we came back we immediately went to the Chinese doctor for Chinese medicines, and we also brought with us everything we had about the operation in China and the Chinese medicines he had taken. The idea was to return to China if anything happened, but in Italy, my husband got much worse and we were not able to leave. (Li Min, 45 years old, China).

The story of this widow reveals another side of transnationalism, that of persons who move due to a lack of trust and poor integration. The case of Li Min's husband leads to a consideration of a general nature on the phenomenon of medical transnationalism, but also and above all on the importance of guaranteeing culturally acceptable treatment. In the case of the Chinese community, it is common that, in the case of serious illness, people prefer to return to their country of origin, for reasons of waiting times<sup>506</sup>, of distance from the national health system and the impossibility of getting treatment from Chinese doctors when abroad<sup>507</sup>. These elements often lead them to choose a transnational solution to their health problems, which may be a "costrained choice". The tendency to turn to doctors from the country of origin – often seen as a lack of integration<sup>508</sup> - may however put the patient's health at risk. In fact, medical transnationalism on the one hand limits the use of the services in the host country<sup>509</sup> and on the other can be a risk because it is difficult to monitor. The translation of medical records written in another language and the continuation of therapies begun in a different country are elements that must not be taken for granted, which may compromise the success of the treatment<sup>510</sup>.

Border crossing for medical purposes can therefore be both an additional possibility and a lack of opportunity traceable to lack of documents, lack of trust, and lack of a social context suitable for the treatment. ResearSeveral research projects have in fact emphasised the importance of receiving treatment in

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<sup>505</sup> The migrants tend to compare the treatments they are offered in the various contexts to which they belong. This comparison often occurs informally and is part of the process of choice that the migrants activate when they choose where to be treated. See: B. Bilecen and H. Tezcan-Güntekin, *Transnational Healthcare Practices of Retired Circular Migrants*, op. cit. page 14.

<sup>506</sup> See paragraph 4, chapter 7 in this volume.

<sup>507</sup> A. Sarli and D. Carrillo, *Unasked Questions and Missing Answers: The Italian National Health System and Chinese Migrants in Milan*, MPC Analytical and Synthetic Note, Firenze, European University Institute, 2014, N. 1, page 14.

<sup>508</sup> T. Osteria, D. Carrillo and A. Sarli, *The Health Dimension of Asian Migration to Europe*, Manila, De La Salle University Publishing House for the Asia-Europe Foundation (Asef), 2013, page 615.

<sup>509</sup> *Ibidem*, page 44.

<sup>510</sup> A. Sarli and D. Carrillo, *Unasked Questions and Missing Answers*, op. cit., page 14.

a culturally and socially familiar context<sup>511</sup> and it is this element that some people mention to explain their choice of mobility. In some cases, the journey takes place because elsewhere there are answers that the Italian health system and biomedical approach cannot offer. A Roma woman whose daughter had a hearing problem explained,

If you get a bad illness, it is because you have done something bad. For example, if an ancestor committed a very bad sin, it may be that your daughter is born sick. In Romania I took my daughter to a woman, to have the evil eye taken off, there are *babeste* cures<sup>512</sup>. I believe in them, she told me that someone wishes her ill. (Tatiana, 41 years old, Romanian Roma).

This woman has perceived as useless the specialist visits in Italy and has preferred to make a transnational journey, to find in Romania a solution that Italian biomedicine could not supply and which she feels is useful for her daughter's problem<sup>513</sup>.

The intersection of the literature that deals with transnationalism, therapeutic space and health suggests that the decisions of the migrants were formulated starting from the interaction between individual and society, from which the preference for treatments carried out in a culturally familiar context derive. This can be translated into a link between health and place, which drives the migrants to seek a treatment that is not only efficacious, but also culturally acceptable. The relation between health and place is based on cultural, linguistic, religious and affective elements<sup>514</sup>.

I was working as a domestic worker; one day I sat on a chair that was broken and I fell suddenly. On that occasion, I found out that my vertebra were inflamed and the doctors said I must take bed rest and that the job I was doing was not helping [...]. I didn't know that I could report the accident I gave up my job [...]. At that time the only thing I could do was return home for treatment. In Peru, there are American chiropractors who solve the problem with just one session. One of the reasons I wanted to return to Peru was that my mother and my sister could be with me, look after me and take me to the doctor. (Cristina, 41 years old, Peru).

The choice of a transfer may also be based on the presence of family members in a certain context and on the perception that they are the people on whom to rely during an illness. Seeing the treatment as a collective responsibility and not merely as a personal commitment to one's well-being is important if we are to capture the social and affective side of the treatment, which it may be difficult to manage in families settled in different geographical contexts. The importance of an affective cure is more recognized in cases of a psychological nature. One of the volunteers involved in assisting Somali refugees and asylum seekers not included in official projects and residing in a squat told us the story of Abdou, a Somali man of twenty-five, who has been diagnosed as bipolar. For questions relating to appointments and medicines, Abdou was helped by the Somalis who lived with him and the volunteers who also helped him to maintain a relationship with his family of origin. His mother, with whom the volunteers spoke by phone thanks to a cultural mediator, said that she wanted her son to return home, even though she was worried about the lack of medicines in

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<sup>511</sup> M.C. Inhorn, *Diasporic Dreaming: Return Reproductive Tourism to the Middle East*, in «Reproductive BioMedicine Online», vol. 23, 2011, page 586.

<sup>512</sup> Literally, "old people's cures": this term refers to a wide range of therapeutic methods that can still be found in the rural contexts and which involve the use of herbs and other natural products, prayers and apotropaic rituals.

<sup>513</sup> The concept of usefulness is here clearly linked to the explanation that the interviewee gives of her daughter's illness.

<sup>514</sup> J.Y. Lee, R.A. Kearns and W. Friesen, *Seeking Affective Health Care: Korean Immigrants' Use of Homeland Medical Services*, in «Health & Place», vol. 16, 2010, pages 108-115.

Somalia. When the situation became more serious, due to a TBC infection – for which Abdou was hospitalized – his countrymen worked to find a way to allow the young man to return home. With the approval of the psychiatrist at the mental health centre where he was being treated, his countrymen helped him to return to Somalia. A Somali woman who was returning to Mogadishu agreed to take Abdou with her and he left with a suitcase full of medicines from the mental health centre. His return to Somalia is seen ambivalently by the people who were treating him: the fear that he may find it difficult to get adequate treatment is compensated by recognition of the social and affective context that has welcomed him. The case of Abdou attracted attention because of the characteristics of extreme social and health marginalization, which meant that the family were the most suitable context for treatment and for reaching a state of well-being.

The question of social networks as a context for treatment must be considered when speaking of management of illness, despite the fact that this area has so far been largely ignored by specialist literature. What responses can the transnational families bring in the case of health needs? What strategies can be activated in times of crisis? What role do the new technologies of treatment play? What does “treatment at a distance” and “treatment in proximity” mean?

### 3. *Crossing borders – from ordinary management to times of crisis*

Veronica is a Romanian domestic worker whose own family lives in Romania. In the ten years that she has lived in Italy, she has had to face the illness of her husband at a distance and, subsequently, her own illness. These two situations have altered the transnational structure of the family only for brief periods, like when Veronica asked for leave from work to help her husband in Romania after an operation. However, when she became ill in Italy no family member was available to help her, for practical and economic reasons. Veronica remembers these moments as very difficult, despite her constant contact with the family in Romania.

The studies on the migrations look at the ways people develop practices and processes for care at a distance, processes that are activated in various moments of the lives of the transnational families<sup>515</sup>. Baldassar and colleagues emphasised the importance of “moments of crisis”, that is moments in which care at a distance is not sufficient and a physical co-presence is required. In moments of acute illness or risk of death, the expectation of having family members nearby (parents and children above all) is particularly strong and a physical co-presence can replace care at a distance, when this is possible<sup>516</sup>. In this paragraph, we draw attention to the moments in which the choice of moving across borders in search of health, well-being and care must be made. In doing so, the multidirectional approach is kept intact (considering both the incoming flows and the outgoing) and the focus on the social networks involved in the phenomena of care.

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<sup>515</sup> D. Bryceson and U. Vuorela (ed.), *The Transnational Family: New European Frontiers and Global Networks*, New York, Berg, 2002; K. Gardner and R. Grillo, *Transnational Households and Ritual: An Overview*, in «Global Networks», 2, 2002, pages 179-190; M. Madianou and D. Miller, *Migration and the New Media: Transnational Families and Polymedia*, London, Routledge, 2012.

<sup>516</sup> L. Baldassar, *Too Sick to Move: Distant «Crisis» Care in Transnational Families*, in «International Review of Sociology», vol. 24, 2014, N. 3, pages 391-405.

The family, in fact, is involved in the courses of treatment since it intervenes with suggestions, sending medicines, organizing strategies for care at a distance or travelling to guarantee physical co-presence in moments of need.

I came to Italy because my son was ill. He had a severe pain in his head, he went to the doctor who gave him medicines, but even after the medicines, nothing happened. He still had pain, even when he was sleeping. So they did a CAT scan and saw that he had a big mark on his brain that had to be removed. The doctor told him that he could do the operation, but it was risky, he could live or die. He asked whether my son wanted to do the operation, and he said yes, but that he wanted me to be present. "If I die, I want my mother to be with me." He phoned me and that is why I came. I prayed a lot and then I came. Now he has had the operation and it went well. To come here they gave me a family assistance visa. On the visa it says 'family reunification' and even if the situation was serious, it took some time to get the documents, about two months. I had a shop and I left it<sup>517</sup> [...] My son had been in Italy for nine years, he left Guinea when he was twenty. He was used to being here, I wasn't. I came here only to be with him, about one year ago. Here there are a lot of doctors, not like at home. This is a good thing, because at home, if you haven't got money, you die. If the same thing had happened to my son in Africa, he could have died. The good things I have seen in Italy are the schools, the food and the doctors. If I could find work, I could look for a home and stay here with my son. But here there is nothing for me, so now my son is better I think I will return to Guinea. (Adawa, 51 years old, Guinea).

Adawa is certain that if the problem had happened in Africa, her son would have risked dying. The perception that in one place it is possible to have free access to qualitatively better treatment than that available in many other countries means that the migrants resident in Torino feel a certain degree of responsibility towards those who have remained in their country of origin and face difficulty in getting treatment.

Odette's mother has suffered from heart disease for many years due to high blood pressure, but despite the appointments in Cameroon with a number of doctors, the problem remains. Odette, knowing the world of the private social sector, decided that her mother could come to Italy so that the diagnoses of the Cameroonian doctors could be confirmed or denied and she committed herself to getting a visa. The visa for family reunification was denied and Odette was forced to ask for a tourist visa. "I am sorry, to abuse the Italian services", she said, "but I had no choice. The visa is valid for three months and two have already passed. My mother will leave soon, because if she stays after the visa expires, she will not be able to get a visa for family reunification, if she applies for it." Odette's intention when she came to Italy fifteen years ago was to allow her mother to come and go from Cameroon, so that she could have periodic check-ups, since the contribution of the Italian doctors in identifying diagnostic and treatment errors made in Cameroon has been vital. Obtaining a visa would allow the woman to register with the National Health Service, which was not possible in this short period of time. The alternatives for Odette were the private social sector or private doctors, since a tourist visa did not allow her to register with the NHS<sup>518</sup>, nor with the ISI Centres<sup>519</sup>.

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<sup>517</sup> Wilding and Baldassar emphasise that the commitments linked to care at a distance can force women into temporary and precarious work, which allows them to leave when necessary. See: R. Wilding and L. Baldassar, *Transnational Family-work Balance*, in «Journal of Family Studies», 15, 2009, pages 177-187

<sup>518</sup> See the Circular N. 5 of the Italian Ministry of Health, March 24<sup>th</sup> 2000, *Gazzetta Ufficiale*, General Series N. 126, June 1<sup>st</sup> 2000, which states, "it is not possible for foreign citizens with a visa for reasons of health to register, pursuant to Article 36 TUI, and for tourist reasons pursuant to Articles 5, paragraph 3 TUI and 42, paragraph 6 of the regulation of enforcement".

<sup>519</sup> The possibility of using the ISI Centres is reserved, as previously mentioned, for foreign citizens present in the country, who are illegally resident, pursuant to Article 35, paragraph 3, D. Lgs, 286/1998.

Dissatisfaction with the treatment obtained is one of the reasons that explains the mobility in various directions, as when mistrust in the treatment provided in Italy drives the migrants to seek efficacious and culturally acceptable treatment in their country of origin.

After the second pregnancy, I had problems. For months, I lost blood and I had a lot of pain and problems like weakness and anaemia. I went to the hospital two or three times, I tried five or six doctors, I had all the tests done and they said everything was all right, but I still had pain. The doctor said there was nothing wrong, that everything was all right. I went to a private clinic in China, because I had no choice. I didn't go to the hospital, but to an older doctor who treats you with Chinese herbs. He is a very famous doctor, who works at his own home. A friend advised me to go to him when I couldn't get pregnant and with this doctor, I solved the problem. He told me immediately, when a woman has children, inflammations can occur afterwards that could be very bad if they are not taken seriously. With the Chinese herbs, I solved the problem. (Chie, 48 years old, China).

Another common condition both in the incoming and the outgoing flows is that of using the holidays as a moment in which to get treatment in a place where the migrant trusts the medical personnel. We have seen in the previous paragraph that this strategy is used by the migrants and the same may occur, in the opposite direction, in the case of families with a different transnational structure. The family reunification does not necessarily correspond to a choice of definitive rooting, since economic or cultural reasons may lead the families of the migrants (or some members of the family) to return to the country of origin<sup>520</sup>. Those who return to their own country after a long stay in Italy keep their Italian documents, which allows them a range of medical possibilities from which to choose<sup>521</sup>.

My wife and children have gone back to live in Egypt, but since May they have been here, and they will stay throughout the school holidays. The children have a paediatrician here, so when they come here, I always take them for a check-up. Last time they were here, they went to the optician and had the vaccinations that are compulsory here. (Ahmed, 47 years old, Egypt).

In addition to the economic dimension of the service, there are cultural and religious needs that can only be met in one of the poles of the migratory course.

Every two years I go to Senegal, I do a purifying bath, I say my prayers, and I put on the amulets for good luck, for defence and for long life. I do this when I return to Senegal; it is a psychological and cultural question in general, not only for illness. When I need prayers, faith, it is as if I were putting a protective shield in front of me. Last time I went to three marabouts, they prayed for me, one month ago. Now I am fortified. (Amadou, 35 years old, Senegal).

Besides being the situation in which choices are made, travelling back and forth can also be the solution to a problem, above all when the two contexts offer different resources, both useful for the person's health.

This friend of mine was twenty-four and he had serious problems with his feet, he scratched away the skin, it was awful. He had caught a disease in Africa. Then he had a really bad cough all night. He didn't want to go to the doctor because he had no documents, and that was the period when the doctors could call the police and report you. We tried to give him our African medicines, but they didn't work. In the end, we went to the hospital and the lady doctor told us he had a very serious problem with his heart, which gave him problems with his feet, because the blood did not arrive at the feet. She said, "We must operate on the heart, but it is very

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<sup>520</sup> L. Ferrero, *Generi, generazioni e famiglie in movimento tra le due sponde*, in *Transmediterranei. Generazioni a confronto tra Italia e Nord Africa* ed. P. Cingolani and R. Ricucci, Torino, Accademia University Press, 2014, pages 36-55.

<sup>521</sup> A similar form of "circular mobility" and its consequences on the health choices was investigated in relation to Turkish pensioners living in Germany, a case in which the free service was a determinant in deciding to live between the two countries. B. Bilecen and H. Tezcan-Güntekin, *Transnational Healthcare Practices of Retired Circular Migrants*, op. cit. page 14.

risky and he must have money for the treatment. A blood test costs €80 and we must do a lot of them, if we are to treat him, someone must take the responsibility. If we don't treat him, he will die within a month. I will not call the police, but someone must take responsibility for the treatment." [...] The operation went well and in the end, my friend had a residence permit for reasons of health. He had appointments every four months at the hospital, now he goes less, every seven months. He must not be in hot places, so when it is hot in Senegal, he stays in Torino and he works on a market stall. When it is cooler in Senegal, he goes to his family. Before he goes to Senegal, they give him the medicines he needs at the hospital. Of course, in Senegal, he also takes natural and traditional medicines, we all do, but for the problems with his heart, he does everything in Italy. (Babakar, 50 years old, Senegal).

The forms of circular mobility and border crossing in search of health solutions can be linked, as in the case Babakar recounted, to the phenomenon of poly-medication, that is, the migrant often uses different medicines at the same time to treat a pathology or a symptom. Turning to various medical traditions and different types of knowledge, the migrants may tend to combine allopathic medicine and traditional medicines, rather than sticking to a single type of treatment. Recourse to traditional medicine can also be the fruit of advice that emerged during meetings with the specialists in the country of origin, or a form of self-medication<sup>522</sup>.

To conclude these paragraphs, which have brought to light the moments in which mobility is useful or fundamental for health, we will describe three relevant phenomena to emphasise the variability of the link between health and movement. The first is that of "multiple border crossings"; in the majority of the cases reported people move between their country of origin and the country to which they have migrated. However, sometimes the trajectories are more dynamic and may touch on a number of countries. For those who arrived in Italy years ago and have Italian citizenship, mobility in Europe is a practical option<sup>523</sup>. One case of multiple border crossing is that of Costel, a Romanian man who, in 2012, while he was in France, had a bad accident. At the time he was working illegally on a farm, where he harvested vegetables and one morning, while he was cycling to work, he fell and fractured his leg. After being treated at a clinic managed by volunteers, he continued to work for a few days until the job ended. He then decided to return to Romania, where he was examined at the orthopaedic hospital in his hometown. The examination showed that it was necessary to operate, inserting an implant. This was an expensive operation and the waiting times in Romania were very long. In autumn of the same year, he returned to France where he underwent the operation. However, he was not guaranteed physiotherapy, which was very important to gain full rehabilitation of the limb. The situation worsened and Costel decided to join his brother in Torino. After receiving the ENI card, Costel went to see a specialist, and a further operation was carried out to remove the implant, which was positioned wrongly. The fact that the course of physiotherapy was also guaranteed in Italy was one of the reasons Costel decided to stay in Italy with his brother.

The second phenomenon is that of mobility as a "last choice". The country of origin remains for the migrant a very powerful symbolic and at times religious reference and it is for this reason that they often wish to die and be buried in their country of origin. When they are diagnosed with a terminal illness, with no hope of a cure, many migrants decide to return to their country of origin.

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<sup>522</sup> *Ibidem*, page 6.

<sup>523</sup> P. Cingolani and R. Ricucci (ed.), *Transmediterranei. Generazioni a confronto tra Italia e Nord Africa*, Torino, Accademia University Press, 2014, pages 78-79.

There was a man from my country – eight years younger than I am – who went to Egypt for a month’s holiday and he died, you see, fate let him die in his own land. Because if you die here it is different. Here there is an Islamic cemetery, but when we write our Wills we all say where we want to be buried: I want to be buried in an Islamic country and near my father, because if my relatives want to visit me, they can’t apply for a visa every time. (Nasser, 48 years old, Egypt).

Death is a moment to which various meanings are attributed, according to the culture and the religion and returning to the homeland may represent a major difference in awaiting this passage for the sick person and their family. In the case of the Senegalese population in Italy, for example, it is known that the associations are committed to a sort of ground roots welfare, gathering funds to send the corpses home<sup>524</sup>.

The third and last phenomenon is that of “moving without moving”. In a hyper-connected world, characterized by instantaneous and economical forms of communication, it is common for health problems to be discussed using modern means of communication and a form of poly-medication can occur even without returning to the country of origin. A volunteer at one of the Chinese associations told us, “At times, after a while, we find out that the person is not following the treatment prescribed by the doctor, probably they have phoned someone in China and discussed the situation on the phone.” Amongst the Chinese, cases of self-medication through the Internet were also reported; solutions are sought on Chinese websites and travel agencies offer trips for medical purposes to the communities resident abroad. Newspapers, telephones, social networks and Internet appear to be the global environment through which information is spread, including health information and therefore contribute to a perception of health and well-being that is increasingly less anchored to national borders.

#### 4. *Medicine and knowledge on the move*

The circulation of medicines and therapeutic knowledge within the social networks of the migrants is one of the fundamental aspects that characterize the spaces of transnational medicine<sup>525</sup>. This aspect emerged strongly also in our Torino-based research: the medicines follow multiple trajectories, they may be sent from the country of origin towards the place of immigration, or vice versa, but they may also travel through the global circuits of the Diasporas, from one country of immigration to another.

In order to understand this phenomenon it is necessary to recall the concept elaborated in medical anthropology of “medical pluralism”, that is the recourse to different practices that range from biomedicine to the therapeutic use of herbs, spiritual cures and alternative medicine<sup>526</sup>. Often people, rather than opting for a single course of treatment, follow various trajectories. For example, the Chinese woman Li explained how the passage from one therapy to another depends on the seriousness of the illness and the efficacy of the treatment:

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<sup>524</sup> D. Parkin, *Latticed Knowledge: Eradication and Dispersal of the Unpalatable in Islam, Medicine and Anthropological Theory*, in *Counterworks: Managing the Diversity of Knowledge*, ed. R. Fardon, London, Routledge, 1995, pages 143-164.

<sup>525</sup> G. Zanini et al., *Transnational Medical Spaces: Opportunities and Restrictions*, Göttingen, MMG Working Paper, N. 13-16, 2013.

<sup>526</sup> D. Parkin, *Latticed Knowledge: Eradication and Dispersal of the Unpalatable in Islam, Medicine and Anthropological Theory*, in *Counterworks: Managing the Diversity of Knowledge*, ed. R. Fardon, London, Routledge, 1995, pages 143-164.

If it is only flu, it is not serious, I can treat it myself with the medicines I buy from acquaintances, or that I bring over from China, they are quite 'light', natural products. If I don't get better, then I go to a Chinese herbalist. The herbalist can help you. Then if that doesn't work, I go to the family doctor. Only in the end, I go to the specialist doctor and if I still don't get better, I will go to the hospital for tests. Generally, a friend will find medicines from China for me, because I don't move around a lot, and I live outside the city centre. My friends have them, they know them, but they are only for minor things... We are used to them and we know what works and what doesn't, you can say that. For example, if a temperature is not very high, or for normal flu. We try to solve the situation at home; we don't go to the pharmacy. They are all natural things, for the chemical things it is better to go to the Italian pharmacy, or it is the same, you know chemical ingredients are all similar. They always ruin the body. (Li, 45 years old, China).

The Senegalese Amadou divides illnesses between those for which traditional medicine will work and those for which western medicine is considered the only remedy.

My brother had a shop in Torino and when he went to Senegal, he declared the plants he brought with him at customs. The local people knew that those plants cured certain illnesses, for tiredness one of them is good, for a cold, another. Using traditional medicine in Europe, like in Senegal, is not easy, it is different, we do it but for other illnesses and problems. There is trust in modern medicine in Europe, but for some illnesses the traditional medicine is better, like dermatological, allergies and things like that. For everything that comes out on the skin and that you don't know what it is, we use traditional medicine, also in Italy. If I have things I don't understand, like blotches, I call [someone in] Senegal and they send me the powder for the traditional treatment. (Amadou, 30 years old, Senegal).

So, what are the criteria according to which the migrants decide whether to use medicines that come from a cultural and geographical area that is not the country in which they are living? The choice is dictated by various motives, ranging from those of an economic nature, to those of an affective and cultural nature. They decide on the basis of accessibility, practical needs, social and cultural expectations and personal convictions regarding the efficacy of a cure. It is not easy to draw a clear line of demarcation, since these factors often influence each other.

One of the first criteria to influence the choice is economical. Medicines are imported from the country of origin or sent by relatives, because they are less expensive in one context than in the other. The Colombian Patricia, for example, brings to Torino both traditional medicines, because they are not available on the local market and western medicines, because in Colombia they are less expensive and are available without a prescription.

There are a lot of medicines that I bring with me from Colombia. At first I brought a suitcase of lotions and creams to help with my first pregnancy, this was more for care of the body than medical. These are typical medicines and there are also traditional Colombian medicines, and shamanistic gadgets. I brought an amulet to protect my son. You tie a large red seed with a black one on the child's wrist to protect him. Often I bring *mate de coca*, a traditional Colombian remedy for stomach ache, to relax, for PMT. My grandmother had coca plants at home and she made this tisane. Then there is equisetum (common horsetail), or *la yerba buena*, taken as a tisane and a gentle cure for purifying the liver... And then I bring western medicines, because there are no restrictions, even without a prescription you can buy them in Colombia. I still have a small surgical supply at home, where I keep some small scalpels. I have this heritage from Colombia, because both my grandparents were pharmacists. I bring medicines here for economic reasons, I think, at home medicines are much less expensive. (Patricia, 40 years old, Colombia).

The flows of medicines are also directed towards the countries of origin. Amira, from Morocco, began sending the medicines she found in Torino to her family thanks to the support of the voluntary associations. Over the years, she has altered this habit, because it became too expensive.

My mother has problems with her blood pressure, diabetes and many other health problems. There is no substantial difference in the cost of the medicines, for example, a pack of sprays, like Ventolin, costs 50 euro, both here and there... they cost the same. Only here I get the inhaler free of charge, with the NHS, the piece of paper from the doctor, because I have assistance, but there you have to pay, the doctor writes the name of the medicine and you go and buy it. Then, here there is an association that gives me the medicines to send to my sister and to my mother. For a while, I haven't sent any medicines, because I realized that it costs more to send medicines than other things. You know, there are these people who take the parcels, they leave here and they go by car to Morocco, and you pay them. But for every parcel, you pay 100-120 euro to be sure that it arrives, and they are always late. In Italy, there is total anarchy. They all come from Casablanca or Marrakesh and they have to go to my city... for this I pay more. When they arrive in Casablanca, perhaps they send the parcel with the bus and it is always difficult to find a responsible person and make sure that the parcel arrives whole and on time. So, I prefer to send money. Now, when I went to Morocco the last time, I came to an agreement with a pharmacy, and when my sister or my mother need medicines, they go to collect them and at the end of the month I send my family some money. (Amira, 37 years old, Morocco).

Some authors have spoken of the "social efficacy" of the medicines, placing the emphasis on the emotional component linked to the medicines that are sent. Sending medicines is a sign of attention and confirms an affective bond that is manifested also at a distance. As a tangible effect, a medicine can incorporate homesickness and makes it possible to highlight and strengthen the relationships that are considered important<sup>527</sup>.

I have responsibilities, because my family depend on me and I am proud to say so... my mother, my brother and two sisters. My mother and my sister are very ill: my sister has heart problems, she has asthma and diabetes, she spends about €200 in medicines every month, a lot of money for Morocco, and she has no welfare assistance. There is only me. (Amira, 37 years old, Morocco).

In the case of the young Roma, Ion, this manifestation of affection through medicines is reversed. His mother, who lives in Romania, has for a long time shown her affection for her son by sending expensive packs of food supplements, considered a miraculous treatment capable of improving the memory. The mother insisted that it was the only efficacious remedy for passing examinations at the driving school and holding off the psychological fatigue from which her son had been suffering for some time. Ion often took too many of these medicines, ignoring the suggested doses, but despite the lack of results and the negative effects on his health, he continued to take them considering them important, simply because they were sent by his mother.

The medicines that arrive in Torino from the countries of origin can travel by various channels. In some cases they are sent through word of mouth and personal networks. The migrants can obtain medicines thanks to the intermediation of friends or acquaintances who return to Italy after a trip home. The importation of these medicines, even for personal use, is not permitted and the migrants often encounter unpleasant situations, caused above all by cultural misunderstandings.

We have a type of powder that, if you are not well internally, you do like this with your nose, you breathe it up and you begin to sneeze, and that way, the illness comes out. A friend of mine from Senegal brought it from Africa, he arrived at Malpensa and the policeman sniffed it and he started sneezing; they took the policeman to hospital and sent the boy home, because he couldn't bring that stuff into the country and they didn't know what it was. There are things that don't work, if you don't know how they are used and you don't know the problem. Some people come here and they bring medicines from Senegal. They are always powdered; they are treated in that way... We are

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<sup>527</sup> S. Van der Geest, S.S.R. Whyte and E.A. Hardon, *The Anthropology of Pharmaceuticals: A Biographical Approach*, in «Annual Review of Anthropology», 25, 1996, page 168.

afraid that if I give you something and then you may be ill. If they ask you what you did at the hospital, maybe they come to get us and put us in prison! (Babakar, 50 years old, Senegal).

In other cases, these medicines can be found at the ethnic shops, above all at the Chinese herbalists. Unfortunately, it was not possible to interview the shopkeepers, but we gathered the accounts of some clients.

For small things I go to Chinese people who give me injections, I don't go to the doctor, because I don't speak [Italian] and I don't understand, even now. Also for the children. When someone in the family is ill, we go to the Chinese doctor who can explain everything well, it is easier to understand, we don't go to the Italian doctor. Many people in the community do this... I went to the pharmacy at Porta Palazzo, but now perhaps it has closed. There was a Chinese person who had a pharmacy where they sold both Italian and Chinese medicines. Usually the Chinese go there, but the Africans also go there to get medicines. (Chao, 41 years old, China).

From the research carried out in other Italian cities it is clear that many migrants prefer these herbalists since, unlike the pharmacies, the medicines are handed out without a prescription. The herbalists also supply basic medical treatment, such as injections and dental treatment. These shops are managed by persons who lack medical qualifications recognized by the Italian system. Inevitably, their professional qualifications are not subject to any form of monitoring, also because Chinese medicine is not recognized in Italy, nor are the qualifications that the doctors and pharmacists expert in allopathic medicine acquire in China. The migrants themselves have different opinions on these places: some express great trust, others abstain from expressing an opinion, and yet others express serious doubts regarding the preparations and those who manage the shops<sup>528</sup>.

Medicines have their own social life, which must be analysed by considering not only the moment of prescription, but also that of administration and assumption by the patient. The treatments do not involve only swallowing a substance; they also involve a wider sphere of practical and emotional meanings<sup>529</sup>. The efficacy of a medicine is linked to the social and cultural context in which it is produced and taken. For this reason, there are migrants who follow a therapy in Italy, substituting it for other therapies when they return to their country of origin.

In Senegal I had a terrible pain in my stomach that lasted for years. My father had a friend who told me "go to a tree that is called the mango, take the leaf and put it in water for a few days." I did this and I no longer had pain in my stomach, never. I said a prayer before I took the leaf. There are things you must know before using a tree, you must powder it, crush the dried leaves. There is a part of the tree to be used, the roots and the part above ground, and you have to know how each thing is done. But you can't do these things in Senegal and then send the medicine here, because it won't work. In Italy we use Buscopan. (Babakar, 50 years old, Senegal).

In analysing the flows and the transnational consumption of medicines, it is important not to fall into the classic dichotomization between western biomedicine and the traditional context of the countries of origin. In some cases the migrants come from more highly medicalized urban contexts than those they find in

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<sup>528</sup> For a more detailed analysis of this question see: T. Osteria, D. Carrillo and A. Sarli, *The Health Dimension of Asian Migration to Europe*, op. cit.

<sup>529</sup> . Van der Geest, S.S.R. Whyte and A. Hardon, *The Anthropology of Pharmaceuticals*, op.cit.; L.L. Schumaker and V.A. Bond, *Antiretroviral Therapy in Zambia: Colours, «Spoiling», «Talk» and the Meaning of Antiretrovirals*, in «Social Science and Medicine», 2008, N. 67, 2008, pages 2126-2134.

Italy: in these contexts of origin the use of modern medicine is dominant and has long replaced other forms of therapy. For example, Patricia explained that in Italy she has kept some Colombian customs. She has a medical cabinet well supplied with medicines and instruments, such as surgical forceps and anaphylactics:

There is a certain inertia in these phenomena; we continue to repeat behaviours that we learned in our own country. My relationship with the medical world in Colombia was much more direct, in Italy much less. In fact, my brother is a doctor and he recommends medicines and tells me to bring them to Italy. (Patricia, 40 years old, Colombia).

Similar considerations were expressed by Chao, who in Italy has found a more critical and parsimonious use of certain medicines.

At first I used a lot of antibiotics and I asked my GP for them, almost amazed because that is what I was used to. Now the approach to the use of antibiotics is changing also in China, but in the past for anything... straightaway, antibiotics. I was raised on antibiotics, on penicillin. Here in Italy I have learned that if we take too many they are not good for our bodies. (Chao, 41 years old, China).

##### 5. *Specialists on the move*

Within the transnational therapeutic networks not only medicines, but also specialists who know how to prepare and administer the treatments are circulating. They are persons with differing skills, some trained in the field of traditional medicine, others in biomedical sciences. The way these people come to Torino varies; there are persons who have come here for family reasons or to work, who have specific knowledge and informally make it available to members of their community. There are specialists residing permanently in the city who use these skills in a professional activity. Finally, there are specialists and healers who travel to meet the patients in the communities of migrants and stay for only short periods in the city.

The confines between these categories, between the expertise of traditional medicine and of modern medicine, and between formality and informality are often vague and a healer may move from one area to another according to the occasions and the opportunities, but also according to the structural limits with which he or she must deal. As a Senegalese migrant emphasised, there are various skills that a good healer must possess and these may belong to different areas.

There are many ways of healing. Some heal themselves only with prayer, others only with natural medicines, others go to the hospital. For all these things, it is necessary to have knowledge, to have learned them in the family, or at a school. The healers, for example, inherit their powers from a relative. At times, the first-born of a healer must emigrate and if he comes here he does not yet have the skills for healing, it is not his job, but occasionally he will practice, give advice, sometimes he will help and later he will become a healer in Europe. (Amadou, 48 years old, Senegal).

Babakar explained that when he is ill he turns to a marabout, but also to the traditional healers. Neither of these figures live permanently in Torino, but they visit periodically, hosted by the faithful and by their compatriots.

We believe in things that you Italians don't believe in. We Africans are different from you, you can't even imagine these things, trust me... Marabout means a clean person, who is close to God, who tells him a secret that only he can know. He looks and he sees all, no one can teach this at university, it is not in books, they are automatic things. They see everything, even when they sleep. The marabout, when he speaks to you says, "Your name is Babakar", he tells you your father's name and your mother's. How does he know? He knows, I swear it. Other marabouts tell you everything, what your house is like, or the television, or the colour of the furniture. And so they can see where your illness comes from. There are people in difficulty in life, who have

problems with their health, money or the family and the marabout explain everything. They do not stay here, they come from Senegal, only if they know that there are migrants who have problems and they come to calm the people. There is a queue; everyone wants to speak to them. (Babakar, 50 years old, Senegal).

The spiritual consultancy that the marabout offers does not only include physical health, but also social and psychological well-being. This great trust in the spiritual powers of the marabout is a response to the profound diffidence that many show towards the biomedical knowledge applied to the psychic sphere.

The people who go to the marabout are not really ill. They go for other reasons, to have high social status, money, or the drug dealer goes because he does not want to be caught by the police, to have protection. There are beliefs about the spirits; there are good spirits, there are bad ones, and sometimes they are in competition with each other. The marabout tells you to take baths because the evil spirit can ruin your life. When we go to them, we tell them what we need, how we feel. For the psychological part it is difficult to replace it with western medicine, if a Senegalese says he is going to a psychologist, the others will say he is mad. For them psychology and madness are the same thing. (Amadou, 40 years old, Senegal).

While the marabout uses words and prayer to treat people, the healers use above all natural substances and preparations.

The healer does different things from the marabout, he has his little bags and his medicines, while the marabout asks God, he is more spiritual. He is the intermediary between the patient and God, he is an interpreter. When a healer arrives, we spread the word. The healer goes to a hotel and he waits for the patients. I have seen a hotel in Corso Giulio Cesare where in the early morning, before people came, they had two or three powders that they mixed with water and they gave out prayers on the basis of these plants. The plant has the capacity to bring lots of good things, and they mix it with other things, without specifically going into the patient's problem, it is not a special cure, but it is given in general. (Amadou, 40 years old, Senegal).

As we have seen, one of the problems that emerged most frequently concerns the lack of spacious, hygienic and suitably equipped places where these specialists can meet their patients. This aspect is also linked to the lack of recognition of this knowledge in the Italian context, knowledge that remains for the moment condemned to semi-clandestinity. The places where they meet are hotels, private apartments or ethnic shops, which have a number of functions: supermarket, pharmacy, travel agency and meeting point for the healers. In Torino, this variety of functions has been documented, for example, with regard to the Nigerian barbershops, spaces where rich intercommunity relations are formed<sup>530</sup>. The question of the lack of suitable spaces for treatment is particularly evident when speaking of traditional Chinese medicine, a set of knowledge and therapeutic practice that increasingly attracts not only the Chinese migrants, but also Italians.

In Torino there is only one Chinese herbalist, they have closed all the others. There, a man from the north of China, who was already a doctor in China, has his practice. It is not that the Chinese trust him more than the local services, but they go there because it is convenient. They pay and he treats them immediately. He himself says that when he has to do a specialist test, he goes to the Italian doctor. He can't get all the herbs, once they took the medicines in the form of roots, now it is not possible because this kind of Chinese medicine cannot be brought into Italy. This person must practice unofficially, in a hidden manner; he does not have a licence. His qualification is not recognized. Anyone who practices does this, even though there are many doctors who recognize the value of traditional Chinese medicine, but it is a form of safeguard that is open only towards some countries. (Italian volunteer, Chinese association).

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<sup>530</sup> P. Cingolani, *L'imprevedibile familiarità della città: luoghi e percorsi significativi dei migranti nigeriani a Torino*, in *Stranieri in Italia. Reti migranti*, ed. F. Decimo and G. Sciortino, Bologna, Il Mulino, 2006, pages 59-88. Similar considerations were made for the Ghanaians living in London: K. Krause, *Transnational Therapy Networks among Ghanaians in London*, in «Journal of Ethnic and Migration Studies», vol. 34, 2008, N. 2, pages 235-251.

Many migrants criticise the approach of the Italian institutions towards traditional medicine. Without the recognition of these skills, it is impossible to certify and guarantee the quality and the professional competence of the traditional healers, at times putting the health of the users at risk<sup>531</sup>.

If by right to health we mean also the right to use culturally acceptable treatments, then it is essential also to recognize the titles and the qualifications of the migrants in the health sector. The migrants with specific medical training, not only in the traditional areas, but also in the biomedical field, could be the best references for their sick countrymen. Amongst the many stories we were told, we will report that of Marleni, a young Peruvian woman, who arrived in Italy in 2006. She had recently graduated in medicine from the University of Cuzco and emigrated in the hope of taking a specialisation and practising in Italy. Unfortunately, she has been overcome by the bureaucratic obstacles and she finally took up and developed another of her skills, that of natural medicine, enrolling in a course for professional naturopaths.

I come from Cuzco. I have a degree in medicine, I am a surgeon. This is the problem. I came here in the hope of taking a specialization and I found myself in a trap. When I went to the Order of Physicians in Como, they told me "you must apply to your professional Order in Peru". My cousin, with whom I was living in Como, did not know how to help me. In Milano, I had to meet other people to find out where there was an Order of Physicians. At the hospital, although it seems crazy, no one knew where it was. This also happened in Torino, and in the end I learned that there is an Order of Physicians and Surgeons there, too. At the Order of Physicians, they told me that I just have to do a refresher course; I don't have to take new courses, because I have worked in Peru. However, the list of requisites is long. First, I have to take my degree here. My visa expired and I was about to start work. I had already begun to gather all the documents from my country to see if I could get my qualification recognized. Now I am also thinking of returning to my own country. There it is easier in the private sector, but I also have to take back some studies that I have done in Europe. This course in naturopathy and Ayurvedic medicine lasts three years. I will stay for three years to see if the situation changes, or not. (Marleni, 35 years old, Peru).

Marleni's story raises a very important institutional problem, not only with regard to the health sector, that is the adequate recognition of the qualifications. In the health professions and above all in certain sectors, there is a prevalence of foreign operators in Italy, who, although they have excellent skills, work in less qualified and poorly paid positions. The recognition of these profiles would have effects not only in individual terms, but also for the collective well-being, since these operators would – more than their Italian colleagues – have the necessary cultural skills for looking after the majority of the patients.

#### 6. *Final considerations. Are we moving towards transnational systems of healthcare?*

In this chapter, we have seen that many therapeutic courses taken by the immigrant patients have intrinsic transnational characteristics. The mobility of the patients cannot be traced to a single model, but must be divided according to a number of variables, which range from the motivations (familiarity, perception of quality, availability, and economic accessibility), the distance to be travelled (from cross-border transfers to longer journeys), to the healthcare system within which the patients fall (public or private sector). In addition, the medicines, the knowledge and the specialists travel across borders and contribute to forming a dense network that extends globally, well beyond the local dimension. The foreign patients are rooted in multiple social contexts: they may valorise and follow either biomedical or non-biomedical paths

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<sup>531</sup> T. Osteria, D. Carrillo and A. Sarli, *The Health Dimension of Asian Migration to Europe*, op. cit.

and be involved in practices not confined within single territories. In fact, the migrants are transforming the borders of treatment and healthcare from below, introducing new practices and possibilities into their place of origin and that of arrival.

Nonetheless, this transnational perspective has not been sufficiently considered by either medical research, or the analysis of social determinants of health, or even professional practice<sup>532</sup>. This deficiency depends of a number of factors. It is not rare for doctors to find it difficult to recognize healthcare practices that derive from a multiple identity. Many operators do not take into consideration the possibility that their patients are following transnational treatments, or when they become aware of the fact, they find it difficult to fully understand them.

When there is no coordination between patients and medical operators and between medical operators from different countries, problematic situations can arise. For example, there may be problems of translation when a patient who is following a therapy in one country moves to another; the local medical operators may not be able to continue the course of treatment and the therapies may conflict, without guaranteeing the continuity of treatment.

The transnational courses of treatment are unlikely to be accepted also due to the organizational form of the healthcare sector, an area in which funding and services are offered exclusively on a territorial basis. The principle of territoriality has certainly made planning and sustainability possible, but has not been capable of responding to the mobility of the patients.

As we have seen, there is still resistance to recognition of the “other” competences brought by the migrants, since they are seen as incompatible with those of the western biomedical system. This resistance also affects the alternative medicines, which in order to be prescribed must be tested according to biomedical standards. The EU directive 2004/24/EC established that from 2011 onwards herbal products and all homeopathic medicines must be licenced, which however is very expensive and problematic for small producers. However, there is room for manoeuvre. Products are sold as food supplements for “traditional use” and it is in this grey area that many of the products imported and sold at the ethnic shops lie<sup>533</sup>. It is an adaptation but not a real solution, since these products are always at risk of being banned from the regular market.

During our research project we found, at institutional level, signals of awareness of transnational care and assistance: one example is the practice promoted by INAIL of sending medical supplies to the migrants who return to their country of origin after an invalidating accident in the workplace (see chapter four, paragraph 2 of this volume). The migrant in this case is considered the holder of certain rights and this option of activating projects for a return home represents an absolutely innovative transnational safeguard in a welfare system that is still mainly based on a national dimension.

Another institutional answer to the needs of the citizens who move from one country to another to resolve their health problems is that of attempting to standardize the quality of the treatment in the various

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<sup>532</sup> E.J. Murphy and R. Mahalingam, *Transnational Ties and Mental Health of Caribbean Immigrants*, in «Journal of Immigrant Health», vol. 6, 2004, n. 4, pages 166-178.

<sup>533</sup> G. Zanini *et al.*, *Transnational Medical Spaces*, op. cit., page 22.

countries. The European Union acted in this direction with the directive of March 9<sup>th</sup> 2011, enacted on October 25<sup>th</sup> 2013<sup>534</sup>. According to this directive, an EU patient has the right to be treated by the healthcare system of the country in which they find themselves, at the same conditions they would find in their own country. The opportunities and the progress in the field of healthcare foreseen by the directive are very important, although at the same time, the European legislators have emphasised that the individual countries remain responsible for the organization and financing of their health systems. There are still a number of shadowy areas, therefore, and above all it is necessary to recall that this directive concerns only migrants from within the European Union, while it excludes all non-EU citizens.

The transnationalism of healthcare is a central question for many migrants. The need for healthcare operators to understand these profiles and to be aware that there is “another” world to which their users turn, a world that is not always integrated with the biomedical approach of western medicine, derives from this fact.

## Conclusions

From the research thread of Laboratorio dei Diritti Fondamentali, within which this research project lies, it is clear that the vulnerability of the migrant population is a key concept for analysing the questions regarding health, since many aspects that make full realization of the right to health problematic derive from it. Another key concept that emerged strongly is the importance of social determinants in health, confirmed on the one hand by epidemiological data, the considerations of the professionals working in the hospital sector and the experience of the migrants.

The migratory experience is often associated with significant inequalities, poverty, residential hardship, lack of social recognition and numerous explicit and implicit forms of discrimination. In addition to battling with a considerable marginality on the political and economic plane, the migrant must also face “cultural marginality”, which implies a tiring process of adaptation to a new and often hostile reality. It is not by chance that migration can be considered a wound that, to paraphrase the words of the ethnopsychiatrists Roberto Beneduce, can be profound and dramatic, or minor and tolerable, according to the circumstances, but in any case, creates a discontinuity in the symbolic and relational references and leads to a profound identity transformation of the subject.

The asymmetries that mark the relationship between the migrant and the society he arrives in are a direct source of social suffering and lead to a process of incorporation: they assume concrete forms in pathologies related to poverty, to living conditions and employment, and to the physical and mental hardship which often affects the daily life of the migrants. The unfavourable conditions of life for the majority of the foreigners in the host society lie behind a form of “structural vulnerability” that negatively affects the right to

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<sup>534</sup> “This proposal followed a discussion on the ‘mobility of the patients’, which began in 1998 when the European Court of Justice added some principles to the EEC Regulation N. 1408/71 dated June 14<sup>th</sup> 1971, elaborated with regard to the application of the social security schemes for employees and to their families, who move within the EU.” (*ibidem*, page 21).

health. For these reasons, the link between marginality and vulnerability represents a primary thread in our research, which in both phases shows the mingling of the various forms of exclusion of the foreigner and his physical and mental well-being.

The right to health, as it is defined and interpreted at international level, represents the conceptual framework for our considerations and offers an interpretative structure for categorizing, problematizing and analysing the questions that emerged during the fieldwork. The right to health can be considered a combination of the two main categories: the right to medical assistance or to health services (generally seen as the supply of prevention, treatment and rehabilitation services) and the right to the underlying preconditions of health. The iniquity of the health conditions found in the testimonies gathered makes it essential to consider the right *to the best attainable conditions of health* an inclusive right, which cannot be reduced to prompt and adequate medical assistance, but also requires concrete attention to the social determinants of health.

The national legislation on health care and immigration are the first discriminant to determine the effective possibility of accessing health services for a migrant and, consequently, the possibility of seeing their right to health realized. These norms – which we examined in depth in the first chapter – guarantee the possibility of access to the health service and establish the type of service to which they have a right. The description of the norms – which foresee different action for foreigners with different legal status – faces us with the heterogeneous nature of the migrant categories. In fact, this expression, groups persons who have not only different migratory stories, but also varying legal status, who have diverse levels of social capital with which to face the adversity of emigration, who are bearers of cultures, convictions and visions of different worlds and diverse representations of the body and of health.

The economic inequalities represent the main determinant of the differences in health within the city of Torino. Amongst our interviewees, we met persons in conditions of extreme and relative poverty who represent the clearest examples of the weave of social marginality and the right to health. Poverty, in addition to directly affecting the quality of life, is linked to serious difficulties in the process of inclusion and integration that is manifested, for example, in the difficulty with acquiring good linguistic skills, in the reduced possibility of accessing spaces of participation and less access to information. These factors tend to restrict access to health services and compromise the quality of the clinical meeting, reducing at the same time, the independence of the sick person and their decision-making power. In these cases, there is also a serious lack of information about their rights, which inevitably becomes an unsurmountable obstacle to access to health services and the realisation of personal well-being.

The study clearly showed how the migrants could not be considered exclusively passive users of the health services. We saw the presence of an active involvement of the migrants in the search for solutions and strategies for the most common obstacles to the right to health. These responses may be individual (through recourse to intercultural mediators or to the development of transnational health strategies) or collective (through migrant associationism) and represent resources to be developed and promoted in order to construct a more participative and responsible approach to health.

The protection of the health of the migrants and the more vulnerable groups can be found in a situation of generalised scarcity of resources and cuts to public spending. Every consideration on the topic must take into account the present economic crisis and the ethical and political interrogatives raised by the choices regarding the allocation of the resources available. As found during the research, the migrants are often perceived as undesirable economic competitors in moments of crisis. This image can become a fear that the initiatives in favour of the migrants can in some way subtract funds that are necessary elsewhere, or which could benefit Italian citizens. These fears, however, are often based more on abstract ideological considerations than on specific economic evaluations, in which the cost of a given programme or project and the potential costs if action were not taken are compared. These evaluations should also take into account the efficiency of the initiative in question, the long-term benefits and the positive economic effects, with the aim of maximising the resources available within the limits of the budget. These aspects, which were not studied in this volume, represent an investigative thread of prime importance for future research projects.

During the second phase of the research project, we were able to confirm almost all the conclusions drawn at the end of the first phase<sup>535</sup>. Many of the problems that were identified as causes of the difficulties in realising the right to health were confirmed by the experiences reported by the migrant population and observed through research in the field. First, the problems regarding the availability and the quality of the health services were confirmed, as was the capacity of the health services to respond to the demand for health in a period of profound economic crisis and reduction of the resources. We noted that many services find it increasingly difficult to respond adequately to the health needs of the population in general, and to the vulnerable categories in particular. One example is the pressure on the ISI Centres, which are working with means insufficient to deal with the requests for assistance. Reference has been made to the effects of the budget cuts on the cultural mediation services. The mediators are often present in reduced numbers and with insufficient working hours, or in some cases they are replaced by telephone mediation or an appointment system, which are structurally incapable of offering effective assistance.

In the same way, many of the problems encountered with regard to cultural accessibility of the services were confirmed: the linguistic barriers, the difficulties in accessing a highly bureaucratic, user-unfriendly service and the relational difficulties with some figures operating in the health services. For example, in the first phase the frequent difficulties with the personnel in the Public Relations Offices emerged, while in this second phase we encountered a specific problem – particularly for women during their pregnancies – with the auxiliary nursing staff. Equally, this second phase of research confirmed the problems relating to the lack of information for the migrant population, which is found in various areas, such as information on rights, the existence of a health service, the ways of using the services, illnesses, prevention, treatment and lifestyles. In this complex framework, the question of cultural mediation remains a central topic.

It is worth emphasising that the use of two different approaches – centred on the suppliers of the services in the first phase and on the foreign users in the second – also brought to light important differences.

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<sup>535</sup> I. Biglino and A. Olmo, *Health as a fundamental right: a study on migration and healthcare in Turin*, Bologna, Il Mulino, 2014.

The use of an anthropological methodology led us to give importance to the categories used by the subjects and to note, for example, a different use of the category “culture” by the various actors involved. This concept, often used by the operators to explain the attitudes of the foreigners, is instead rarely used by the migrants themselves. The differences in the use of the term “culture” indicate two apparently opposite risks. The first is the risk of an excessive “culturalism” which explains all the differences in the light of cultural categories, neglecting the social variables, the conditions of poverty and social marginalisation. The second risk is that of ignoring the importance of an in-depth analysis of the culture, which is not manifested only in the sphere of explicit and observable practices, but also in the representations of the body, of health and illness that are, in the majority of cases, unconscious and implicit. The category “culture”, therefore has great importance in safeguarding the migrants’ right to health, but it must be seen in all its complexity and cannot be used acritically.

In the central chapters of the volume, we investigated the main areas in which the migrants’ needs are concentrated. In Italy the mother-child area, examined in the third chapter, the right to health is adequate from a normative standpoint; the assistance during pregnancy and birth is granted free of charge for a number of services and is extended to all pregnant women, Italian and foreign, whatever their legal status. From the clinical standpoint, the national framework shows generalised equivalence in the indicators of quality in childbirth, but shows significant disparity between Italian and foreign women in assistance during pregnancy and in the post-partum period. These differences cannot be explained either by the impossibility of accessing medical care for foreign women, nor by the criticalities regarding the availability of the services. They are, on the other hand, related to the social problems linked to the migratory experience, which we mentioned previously, such as lack of information on social-welfare services, lack of a family and social network capable of offering support in the more delicate phases, economic hardship, low level of education and lack of adequate knowledge or competence in health literacy.

The higher rate of maternal, perinatal, neonatal and infantile mortality amongst foreign women, compared to Italian women represents a worrying indicator of the persistent inequality between the two groups and a serious consequence of the “structural vulnerability” of the migrants. The combination of marginality and structural vulnerability can be seen clearly not only amongst those who live in a situation of extreme poverty, but also amongst those who live in a subordinate position in the labour market. For the migrant, work is not only a source of income and an important goal in their process of inclusion; it is often also a necessary condition for living legally in Italy. As described in the fourth chapter, the information available on the employment situation of foreigners clearly indicates a distribution in the labour market characterized by strong elements of disadvantage with respect to the autochthonous workers and with greater concentration of what (in Italian) are called 5P jobs (pesanti, precari, pericolosi, poco pagati, penalizzati socialmente – heavy, precarious, dangerous, poorly paid and socially inferior). In these circumstances, the foreign worker is more exposed to risks linked to working activities and encounters greater difficulty in reporting accidents and professional illnesses, above all if they are in an irregular situation. The study clearly shows that work can be an *obstacle* to the appropriate forms of treatment, since the workers neglect their

physical condition at the time of recruitment, or once they are employed, they are unlikely to seek treatment because this would mean being absent from work.

Also in the area of infectious diseases – examined in the fifth chapter – the link between social marginality and health emerged quite clearly. The immigrant population is particularly vulnerable because it must often cope with difficult living conditions, which can be seen in the precarious residential solutions, in the poor food, in the lack of work or in the jobs that expose them to a high risk of contagion, such as prostitution. These conditions contribute to the emergence of the diseases and, at the same time, are obstacles to healing, since they make it difficult to continue a therapy, which is essential if infectious diseases are to be overcome. Marginality also affects the relational plane: the strong moral stigma that surrounds these diseases means that people hide their state of health, preventing the possibility of relying on those social and community networks that in many cases are fundamental in the healing process. The meanings attributed to these illnesses by the migrants often diverge from those of the western biomedicine sphere; consequently, there is a serious problem of interpretation and communication between the health operators and the patients. Both the prevention and the treatment should be based on a complex process of cultural translation and a battle against social inequalities.

The sixth chapter is dedicated to a topic that emerged from both phases of the research as an essential resource in safeguarding the right to health of the migrants, intercultural mediation. The mediators have the task of realizing bi-directional interpretation that encourages reciprocal understanding and, in the end, facilitates the relationship. They fully understand the legislation and the procedures for obtaining certain rights and they give practical help to the patient in interacting with the healthcare system, facilitating accessibility and acceptability of the services.

Another subject that often carries out informal mediation are the migrant associations. They play a minimal role in the field of safeguarding health and well-being, despite the fact that first-hand observation of their work allowed us to identify them as agents of accessibility, acceptability and health literacy. Their role, discussed in the seventh chapter, can be seen as working in favour of social inclusion and a form of struggle against the marginality that can so easily be transformed into inequality of health. Despite their support being open to all, it is for the persons who are in the greatest difficulty that their presence can be essential. Some fundamental examples concern linguistic accessibility, economic accessibility, the offer of mediation, education and information. The work of the associations can positively influence the relationship between users and the service, contributing to making this more “accessible” and “acceptable”. Finally, the perspective adopted suggests that the associations can be places for increasing the social capital of the migrants, an element of fundamental importance, since the absence of networks has been identified as a factor that increases the risks, in particular those linked to health.

In the last chapter, we concentrated on the transnational trajectories linked to the search for health, a very delicate sphere of this right, since the relationship between mobility and treatment interrogates the welfare systems, organized according to a single national context. This topic was not central to our analysis, but drew our attention because it was frequently mentioned by our interviewees. Recalling the many

geographical references present in the experiences gathered was fundamental for doing justice to the complexity of the experiences of the migrants. The transnational mobility faced us with characteristics that are very different: on the one hand we find the mobility of the middle classes who move to find treatment, often non-essential, at a lower cost (medical tourism), on the other hand we find mobility as an extreme choice seeking treatment not available in the country of birth or residence, and finally we find mobility as a resource of the migrants who act in a transnational field, made up of cultural references and medical practices rooted in a plurality of contexts. The relationship that the migrants maintain with their country of origin with regard to medical questions shows that the journey and the mobility can be seen either as elements that extend the possibility of choice of the migrants, or as resources to be used in cases of extreme mistrust in the Italian healthcare system, or absence of the linguistic and cultural tools needed for facing an illness in Italy. In the latter case, the mobility is closely linked to forms of inequality, social exclusion and the impossibility of accessing culturally acceptable treatment. Both for those who leave their country in search of treatment and for those who return, the stimulus of mobility can lie in a variable degree of social inequality which, on the one hand, does not foresee forms of welfare for the poorer social classes of various countries in the world and on the other does not allow the migrants satisfactory use of the services in the country they arrive in.

Our research allowed us to gather numerous positive experiences and to identify good practices, some more recent and innovative, others better known and consolidated. Following the first research report, some changes to the legislation have improved the situation for the migrant population, in particular for the illegal migrants. We refer in particular to the State-Region agreement, which ordered the registration with the NHS of all minors, including irregular minors. We must emphasise the importance of an inclusive legislation in health matters, which finds its first and most important supporters in the health operators themselves and in the associations working in the sector.

It is also worth highlighting the efforts of the services to organize complex welfare assistance, which requires considerable flexibility by the operators. A very interesting example of this approach, which already emerged during the first phase of the research as particularly important, is represented by the integrated assistance project *Mamma+*, destined for HIV positive pregnant women and their children until the child's first birthday. The project was born from the cooperation between the institutions and various professional figures, such as doctors, social workers and educators, and foresees the registration and overall accompaniment of the mother and child. In the project attention is paid not only to health in the strictest sense, but also to all the dimensions that determine the patient's well-being, such as employment, residential solutions and the social-educational environment of the children.

Another good practice, again in the sector of mother-child health, is the *Salone delle Mamme*, a space managed by the volunteers of the association Camminare Insieme where mothers in situations of social and economic fragility can find paediatric assistance for their children. In this space, practical help is given in the form of nappies and medicines, and the women can discuss various aspects of daily life with their children. Amongst the most important results of the project is that the services have been brought closer to a

particularly marginalized group, the Roma women who live in the temporary nomad camps in the city. The Salone delle Mamme, is not intended to replace the public health services, but to work in a network and inform users, directing them to other services available free of charge in the territory.

It is necessary to emphasize the role of networking, which contributes to creating links between the various services and allows synergies between the public and the private social sectors, promptly recognizing the problems that have emerged in the territory and planning joint strategies for intervention. As we mentioned on many occasions, the immigration and health groups (GRIS) represent an excellent example of this operational model. Their work in a network in the city of Torino is characterized by a strong role of private social work, which, in addition to being a fundamental resource for guaranteeing free access to migrants, is an area of innovation and forward planning. Amongst the good practices, we can also emphasise the growing offer of education on immigration and health and, in particular, the reciprocal educational experiences and peer education, which encourages active involvement of the migrants.

These good practices represent important results in safeguarding the migrant's right to health and the construction of an inclusive healthcare system. However, what do we mean by an inclusive healthcare system? It is an open question and often taken for granted, but it is necessary to give it greater weight and importance. Although there are no univocal answers, we feel we can say that, during our research, the fundamental basis for inclusion are the possibility of access to the health services, attention to social determinants of health and the acquisition by the institutions of greater "cultural competence". The cultural and religious question is however still open, and may distance people from the healthcare system, or lead individuals to make choices other than those considered optimal by the WHO. In these cases, it seems necessary to reformulate, from time to time, the concept of inclusion and construct healthcare paths through the active participation of the migrants themselves.

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