

An Urgent Human Health Dilemma Facing Refugees and their Host Caregivers?

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Abstract

The continuous waves of refugees from Africa and the Middle East to Europe present major inter-cultural challenges to European health professionals and to society at large. A recent workshop in Sicily brought together local physicians, nurses, psychologists and managers of governmental agencies, along with representatives from Lebanon, Israel, Iraq, Iran, Sudan, Tunisia, Jordan and the European Society of Medical Oncology (ESMO) to develop training programs aimed at formulating dialogue between regional professionals and refugees. A major barrier refugees face is a lack of verbal and cultural communication, which hinders their smooth absorption into the new society. Cultural mediators who speak Arabic and Italian and understand the refugees' faith, tradition and beliefs are vital to successfully build bridges of trust between caregivers and refugees. Most asylum seekers experience anxiety, fear, and depression upon arrival in Europe. To achieve trust, all workshop participants agreed to develop a palliative care model that would best suit the unique circumstances now facing some Mediterranean countries and assist in overcoming the suffering of refugees during their initial stay in Europe. Such a model would include bio-psychosocial elements, essential for a culturally sensitive approach and based on core ethical principles.

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Citation: Michael Silbermann, Lea Baider, Daniela Respini, Paolo Tralongo, Michel Daher et al. (2018) An Urgent Human Health Dilemma Facing Refugees and their Host Caregivers?. *Journal of Human Health Research - 1(2):10-17*. <https://doi.org/10.14302/issn.2576-9383.jhhr-18-2111>

Keywords: Palliative care, Refugees, Middle East, North Africa, Europe.

Received: May 02, 2018

Accepted: May 19, 2018

Published: May 22, 2018

Editor: Jong In Kim, Wonkwang University, Korea.

Introduction

Refugees and migrants arriving in Europe seek a reasonable quality of life, after leaving their families, belongings and traditional existence.¹ Due to the new environment, language and life styles, many refugees suffer emotional, psychological and spiritual distress.² Hence, a high percentage of these newcomers face severe challenges throughout their acclimatization process in the host communities. These emotional disorders do not require hospitalization but can be treated effectively in the community.

According to the most recent data processed and published by ISTAT, there were 5,029,000 foreigners residing in Italy as of 1 January 2017. They constitute 8.3% of the total number of Italian residents. From the same data, it is recorded that are 2,425,000 families registered with at least one foreign member. Three quarters of these families are composed exclusively of foreigners. In 2016 foreign citizens numbered 92,000 (2.2% less than the previous year). Of these, 61,000 had foreign partners and 31,000 had Italian partners. Newborn babies born in 2016, where both parents were foreigners, numbered one/seventh of all births of the year, and one in five children had a foreign mother. 72.7% of foreign minors were born in Italy. According to 2015 data, there were almost four million non-EU foreigners residing in Italy, an increase of 55,000 compared to 2014. The flow of new entries of non-EU citizens to Italy has been decreasing since 2014. During 2015, 238,936 entry permits were issued, a 3.8% decrease compared to the previous year.

Unemployment rate of foreigners (~17%) is decreasing, but continues to be higher than that of Italians (~12%).

The level of educational achievement of

foreigners is slightly lower than that of Italians: among foreigners aged between 15 and 65 almost 50.0% have at most a middle school education, 40.1% have a high school diploma and 10.1% a college degree (in contrast to 15.5% among Italians).

Concerning the geographical origin of foreigners, while sufficiently precise data are available on residents and applicants staying abroad (for different periods of time), it is more difficult to monitor passing migrants and asylum seekers. More precisely, those who applied for a residence permits in 2015 came mainly from West Africa (21.8%), South Asia (19.6%), and Europe (19.2%). The first ten groups of immigrants present in Italy are the following: Romania 22.9%, Albania 9.3%, Morocco 8.7%, China 5.4%, Ukraine 4.6%, Philippines 3.3%, India, 3.0%, Moldova 2.8%, Bangladesh 2.4%, and Egypt 2.2%.

In 2016 in Italy most migrants landed from Africa, in particular from Nigeria (21%), Eritrea (11%), Guinea (7%), Ivory Coast (7%), Gambia (7%), Senegal (6%), Mali (6%), Sudan (5%), Somalia and Bangladesh (4% each). In the first six months of 2017, the nationalities and percentages of immigrants disembarking in Italy are approximately the same, with some variations (for example, the number of migrants from Bangladesh is on the rise). In Europe, the countries most represented in 2016 were Syria (23%), Afghanistan (12%) and Nigeria (10). However, the number of migrants from Syria and Afghanistan declined sharply over the course of the year, as they previously had generally entered Europe via Greece, where it had now become much more difficult to enter.

It may also be interesting to consider religious affiliation, at least taking into account estimates for residents and applicants for residence permits: the distribution is as follows: Christians 53.8%, Muslims

32.2%, adherents to oriental religious traditions 6.7%, others 1.7% (and 4.4% includes those who called themselves atheists/agnostics).

Essential elements in achieving a successful operational model include variations in refugee populations, clinical and geographic settings. The workforce is clearly the key for a successful community-based model. Physicians, nurses and social workers, experienced in providing palliative and supportive care, are considered appropriate professionals in these situations. They form an interdisciplinary team that focuses on improving quality of life for people suffering from physical and emotional trauma.³

The health condition of refugees reaching Europe must be addressed by professional caregivers, spiritual leaders and policymakers.⁴ Refugees generally seek support and reassurance from these trained personnel. If they need a medical consultation, it is usually because they are in crisis. As stated, the involvement of local caregivers is critical for any success in efforts to alleviate the suffering of the refugees and their families. To achieve this goal, local physicians, nurses and psychologists should always consider how to apply the right care to the right persons at the right time. Further, the caregivers need to develop a primary palliative care approach and to preserve the continuity of relationships with the primary care team. Also, it is highly advisable that the caregivers try to build relationships with refugees being treated.

Providing Support

During the past decade, the Middle East Cancer Consortium (MECC) has focused its activities on developing palliative care services for cancer patients in the Middle East, through training courses for healthcare professionals (physicians, nurses, psychologists, social workers and spiritual counselors). Onlus Association Center for the Management of Human Relations and Spiritual Resources was founded in Sicily in the year 2004 to promote social solidarity, psychological, and spiritual assistance to cancer patients, who for the most part were not Italian, but refugees and migrants from the Middle East and North Africa.⁶ Because of varied cultural and religious backgrounds, these patients had different spiritual needs and perceptions of disease and death. Hence, MARELUCE's primary objective was to promote, coordinate and implement initiatives to provide

spiritual care and support. For this purpose, the MARELUCE Onlus Association and the Vatican have disseminated a culture that encompasses strong humanistic elements. This culture tries to integrate traditional practices into conventional, mainstream oncology treatment modalities. Recently, we appraised that such approaches would be applicable when managing health problems in refugees arriving in Europe.⁷

Characteristics of Health Service of Host Countries to the Immigration Population

The foreigner will then apply conditions of access to essential and continuous care that are not differentiated from those insured to the citizen.

By registering with the (SSN) National Health System, the foreigner enjoys total equal treatment, in rights and duties, with respect to Italian citizens in health care, including the choice of a primary care physician or pediatrician, access to family counseling and mental health departments, emergency services, access to forensic services, without ticket.

At sea, before landing, emergency health care should be readily available,

After disembarkation, migrants are housed in first aid and assistance centers (CPSA Centro di primo Soccorso e Assistenza) located near landing sites, where they stay only for the time necessary for their transfer to other centers (approximately 24/48 hours).

In this phase called first aid, there is a first health care and the possibility of transfer to hospitals.

Also available and provided by the government are the Reception Centers (CDA), which guarantee a first reception to the non-regular foreigner to Italian territory, for the necessary time, in order to carry out the necessary operations to define the legal position of the foreigner concerned

All the government centers offer health support, consisting of medical entrance screening and compilation of a health card for each guest, also aimed at an immediate assessment of the psycho-social profile, to identify particularly vulnerable subjects; first medical aid, which includes a medical facility for urgent outpatient treatment, with the presence of medical and paramedical staff; any possible necessary transfers to hospital.

There is always the presence of a cultural mediator.

Many of women migrants are victims of violence. In this respect, the information network has a great importance in the field of subjective rights and support. Many of the local associations, structures and organizations with different strategies and initiatives fight to help migrant women in difficulty.

Collaborative efforts between European caregivers and their Middle Eastern colleagues would be significant in overcoming the psychological-social-cultural-spiritual gaps, thereby enhancing provider-patient communication with a culturally sensitive approach. Such a Euro-Middle Eastern interaction will undoubtedly facilitate the integration and absorption of refugees after their arrival in Southern Europe. In these places any medical care needs to take into account the refugees' faith, cultural beliefs and spiritual needs. The initial triage at the port of entry will be carried out by a physician and a cultural mediator before referring the refugees to a shelter. Thereafter, the acculturation process may involve treatment of non-communicable diseases such as cardiovascular, diabetes, cancer and pulmonary disorders. With the years, we have learned that three pillars of palliative care are critical for improved outcomes that cause dramatic changes in human lives, including those of refugees: namely, communication, collaboration and coordination.

The Value of Palliative Care

Palliative care is a healthcare specialty that is both a philosophy and an organized, highly structured system for delivering care. Its services are significant in realizing the most ancient mission of medicine: "to care even when it cannot cure." Palliative care is provided through comprehensive management of the physical, psychological, social and spiritual needs of suffering people, while remaining sensitive to their personal spiritual, cultural, and religious values and beliefs. By experience, we have learned that increasing numbers of people seek spiritual care, especially when their situation approaches hopelessness. From the onset of palliative care practice, spirituality has been understood broadly, where religion is just one element of a spiritual life. Spirituality encompasses the individual's search for meaning and purpose in life and the experience of the transcendent. It also refers to communication with

others, nature and the sacred realms inside and outside traditional religion. In refugees suffering from isolation, spirituality is an important component of quality of life and may be a key factor in how people cope with frustrations. Unfortunately, such dimensions are not always understood and accepted by healthcare professionals.

Work with refugees tries to discover what their sense of hope is for that day, for the near future, or even for the more distant future. Hope can also be a healthy sense of surrender to the flow of life, not from defeatism, but rather from a feeling of faith and confidence that enables them to waive the desire for complete control. Expressing feelings of hope and love serves as a supportive resource to help refugees cope.

Behavioral health of refugees should always be taken into consideration. A large portion of them have some behavioral health comorbidity, such as anxiety or depression, which is often undiagnosed and therefore untreated. The outcome of a spiritual Intervention, as part of the overall palliative care program, includes calming down a frustrated refugee, which in turn enables an enhanced level of communication that is essential when administering palliative care. The second key to improved communication is the question of truly expressing oneself. By facilitating self-expression, the level of stress is taken off the persons involved; they realize that they are not the only ones struggling with such issues, and that they have been heard and understood, while the caregiver shares their struggle.

For Refugees who might have Mental Illness, Nurses, Physicians, and Social Workers must know how to Cope with this Issue

The guidelines provide assistance to victims, starting from early detection of this type of situation, which is not always easy, until rehabilitation. Points of attention are the certification, which is essential in the asylum process, and cultural mediation, which is indispensable for the construction of the relationship. A specific focus is dedicated to women and children who, as is known, represent two particularly vulnerable subgroups.

All the operators who, are involved in the activities of the Reception Center, should collaborate, taking into account the different tasks and skills, in these activities. In particular, it is believed that, after a

short specific training, social care workers, nurses, social workers, legal assistants, cultural mediators and possibly other operators, can be enabled to grasp and recognize some simple clues and signals (behavioral, relational, verbal and nonverbal communication, etc.) observable during the course of their work with the applicants and in various ways due to traumatic experiences. The narrative contents that, in a direct or indirect way, refer to traumatic experiences experienced by the applicant will be similarly enhanced.

The doctor and the psychologist of the host structure of the reception center, through some interviews and possibly with the support of specific tools for the early detection (questionnaires, semi-structured interviews, etc.), will assess the degree of vulnerability and the probability that the subject has experienced experiences of torture or other forms of extreme violence, as well as in indicating any urgency for the subsequent submission to specialist services.

Interviews will have to be managed in an empathetic way. The doctor and the psychologist of the Center, through the construction of a relationship that favors listening and creates the conditions that facilitate the emergence of suffering, begin a process of recognition of signs and symptoms attributable to traumatic events that may lead to the clinician-therapeutic treatment of the next phase.

It is important that there will be an integrated, multidisciplinary and multi-dimensional approach, with actions that are carried out in success stages: reception, orientation, and accompaniment.

The team must have a transcultural and multidisciplinary approach.

Refugees who reach a country with a new language and culture feel isolated and depersonalized and are in desperate need of a nurturing relationship, which subsequently enables them to feel a greater sense of personal value, and that they are not alone.

In recent research that the MECC conducted in the region, it was apparent while assessing professionals working on provision of palliative care, that nurses rather than physicians were more likely to provide supportive care. Of interest was the finding that in Middle East healthcare, professionals extended emotional care to 47% of their patients,⁹ a far higher figure than that shown in a parallel study in the USA,

where only 27 percent received this care.¹⁰ Our results also showed that staff members have real concerns about raising the topic of religion or spirituality with patients of different backgrounds than theirs, perhaps fearing it could lead to negative interactions. That finding was true even in countries with near uniform religious affiliation.

The palliative care team at the MARELUCE Association in Sicily comprises physicians, nurses, psychologists and chaplains forming an Interdisciplinary team, which provides the core values of palliative care — commitment and compassion — aiming to promote optimal care to patients, refugees, and their families living with a progressive life-threatening disease.

Role of Palliative Care in Facilitating the Integration of Sick Refugees in their New Countries

During the last MECC-MARELUCE workshop (Syracuse, Sicily, September 2017), the participants emphasized the need to further promote healthcare, especially mental care, in the refugee communities upon arrival in Europe. The first problem that host healthcare personnel face is the passive and fatalistic demand for the right of refugees to adhere to their culture and Identity, because refugees frequently experience normative cultural violations and identity crises, as well as strong ethno-cultural segregation. To overcome these barriers, refugees and their host countries should try to build adaptive mechanisms and a new language of interaction.

Furthermore, it is recommended that hosting communities leverage the refugees' physical surroundings to build continuity with their past, to provide them with a sense of power and endurance regarding their cultural values. The approach requires a generous human strategy, as initiated in the last Syracuse workshop. The initial step would be to develop a model of palliative care training aimed mainly at community volunteers and cultural mediators, preferably those with some medical or clinical background. As stated, many of the refugees have strong religious beliefs about illness and death, which are reinforced by cultural norms. Moreover, negative perceptions, misconceptions, and lack of awareness about palliative care, pain management and the use of opioids play an important role.¹² In order to enhance this approach, the European Commission, in April 2016, adopted the

slogan, "Lives with dignity: from aid-dependence to self-reliance," with the goal of strengthening the resilience and self-reliance of both the displaced and their host communities through a multi-actor approach from the onset of the displacement crisis. This approach aims to harness the productive capacities of refugees by helping them to access education, housing and livelihoods.¹³ Let us reiterate that military and social conflicts inflict more than short-term mental damage, as they might have long-term consequences on refugees' mental health and social functioning.¹⁴

Moreover, a routine screening of psychological distress and cultural barriers, and effective interventions intended to support migrants psychologically, represent fundamental tools in promoting healthy integration into hosting communities and nations.¹⁵ The term palliative care is unknown to most refugees reaching European countries, and often they have difficulty in understanding the relevance of this relatively new subspecialty of their condition. Their embarrassment can be exacerbated by the doctor-patient communication gap. But despite such challenges, palliative care physicians in Sicily have succeeded in establishing a functional network within the incoming refugee and migrant populations.

To support the long-term sustainability of a migrant-friendly approach to palliative care, we need to involve local communities of resident foreigners and indigenous citizens as a crucial part of the communication processes we want to foster.¹⁶ Indeed, the healthcare process we plan to shape is, and must be immersed in the social and cultural texture of Europe.

Tailoring Palliative Care to the Changing Environment of People Facing a New World

Already in 2011 we asked ourselves whether palliative care principles can be applied to populations challenging a new world with its complexities and conflicts.¹⁷ As we are fully convinced that palliative care requires a tailored approach to meet the specific dynamic needs of each refugee group, one size does not fit all. The approach must involve two key methods: 1) developing dynamic palliative care integration models, and 2) exploring enhanced roles to meet refugees' changing needs.¹⁸ Palliative care not only improves quality of life but also improves symptom burdens. For example, patients who received early palliative care versus routine medical care reported improved quality of

life, less depression, better communication and adaptive coping with suffering.¹⁸ Overall, sick refugees, like cancer patients, find in palliative care interventions a useful tool in helping them to navigate uncertainties.¹⁸

As we look to the future, we will require new strategies and methods to effectively integrate palliative care within an evolving refugee landscape. Hence, we must tailor such care to meet their dynamic needs. To achieve this goal, organizations, scientific societies, public and governmental agencies need to increase time allotted for discussions, documentation systems, and communication between cultural mediators and the freshly arriving refugees, and allot more resources for targeted training on challenging communication scenarios.

The professional caregivers who are the first to examine the refugees along southern European beaches are well positioned to be primary palliative care providers. At a later stage, when refugees are provided with shelter, clinicians may approach the goals of care in discussions with patients and families from different cultures, while attempting to avoid potentially inaccurate perceptions of these differences. There is a desperate need for further research on palliative care at all levels, starting with refugees' arrival in their new country and continuing throughout their physical and emotional treatment interventions.¹⁹

Roles of Palliative Care in Mediating between Models of Healthcare

The MECC-MARELUCE workshop emphasized the need to promote palliative care in refugee communities in Sicily and elsewhere, with special emphasis on issues relating to mental health. In Europe, many refugees feel disappointed by the European approach to care, as they often face difficulties in understanding the relevance of the new types of interventions. Refugees' misgivings can often be exacerbated by the doctor-patient communication gap. We believe that palliative care is an ideal setting where the integration of a culturally sensitive approach can be of great benefit in absorbing refugees, and in aiding migrants fleeing from military conflicts and poverty in their native countries. As a starting point, workshop participants explained how they initiate educational and training courses for palliative care teams that include trained local personnel and representatives from refugee communities in Europe, the Middle East and Africa.

Conclusions

We hope to advance regional and international collaborative initiatives aimed at training physicians, nurses, psychologists and social workers from European, African and Middle Eastern countries, with a focus on palliative and supportive care protocols. It is hoped that this process will assist the first line of healthcare professionals to understand the newcomers' perceptions of health and disease, and that both groups will better comprehend their culturally based differences. Moreover, we strongly believe that palliative care is an expression of the truly human attitude of taking care of one another, especially of those who suffer.⁸

Conflict of Interest:

The authors declare that there is no conflict of interest.

Ethical Approval:

This article does not contain any studies with human participants or animals.

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