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Compassionate care provision: an immense need during the refugee crisis: lessons learned from a European capacity-building project

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Abstract

Background: The refugee crisis has resulted in massive waves of migration towards Europe. Besides sufficient and appropriate healthcare services, these vulnerable populations need kindness, respect, acceptance, empathy, and attention to basic needs. Healthcare professionals ought to have a respectful and compassionate approach to safeguard the dignity and interests of the people they care for.

Aim: The overall aim of the European Refugees-Human Movement and Advisory Network (EUR-HUMAN) project was to provide good and affordable, comprehensive, person-centred, integrated and compassionate care for all ages and all ailments, taking into account the transcultural settings and the needs, wishes and expectations of the newly arriving refugees. This paper reports on findings to help establish what the nature of compassionate care for refugees consists of and implies and how its implementation could be promoted across European countries and healthcare settings.

Methods: A two-day Expert Consensus Meeting (ECM) took place in order to reach consensus in different thematic areas including cultural issues in health care, continuity of care, information and health promotion, health assessment, mental health, mother and child care, infectious diseases, and vaccination coverage.

Results: Notably, all experts stressed the need to address mental health problems. Interactions and input received during the meeting highlighted the urgent need for compassionate care for these vulnerable populations. Additionally, the needs reported by refugees and other migrants helped identify a serious gap in terms of compassionate attitudes exhibited by healthcare workers. Linguistic and cultural barriers exacerbate the effect of the lack of compassion, especially where healthcare information and psychological support are urgently needed but an appropriate supportive framework is missing.

Conclusions: This European collaborative capacity-building project attempts to develop a long-term strategy to tackle this issue, focusing in particular on the design and delivery of appropriate person-centred and compassionate-based primary healthcare (PHC) services. A list of recommendations developed by this consensus panel may facilitate the design and implementation of similar capacity-building efforts, as well as the design of educational intervention programmers for a person-centred and compassionate PHC for vulnerable populations.

Keywords: Refugee crisis, Compassionate care, Empathy, Cultural competence, Healthcare services, Primary health care (PHC)

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Background

During the past few years, many countries in the Middle East and North Africa are facing political crisis, disputes and riots. As a result, thousands of people have been displaced from their home countries and risk their lives in an effort to find a safe place to live in Europe. More than 1 million refugees and migrants have reached European shores during 2015 and around 1,2 million people applied for asylum in European Union countries during the same year [1].

The escalating refugee crisis requires an immediate response. Lack of relevant policy framework and low-level preparedness of the hosting European Union (EU) countries regarding refugee and migrant needs pose great challenges for both newly arriving refugees and local healthcare professionals [2]. In addition to the provision of adequate healthcare services for these vulnerable populations, it is important to include compassion and empathy as core elements of the care provided to establish an optimal approach to enhance quality and improve outcomes [3]. There are multiple definitions of compassionate care; a general definition adopted as an operational definition for the purposes of the European Refugees-Human Movement and Advisory Network (EUR-HUMAN) and, consequently, of this debate article has as follows: "[…] *the humane quality of understanding suffering in others and wanting to do something about it*" [4].

Upon arrival, refugees reported with many physical and psychosocial issues, including mental health (MH) problems, trauma, dehydration, etc. A lack of access to and a lack of information about health systems and treatment possibilities are perhaps the most significant barriers for the vulnerable subgroups of these populations, including women, the elderly, the very young and children, as well as those previously suffering from ill health [5, 6].

It is generally accepted that Primary Health Care (PHC) could be considered as the basis of the healthcare pyramid for refugees and other migrants [7]. Building a strong PHC service model, with responsibilities for the full spectrum of care for refugees, migrants and communities is essential to improving care to particularly vulnerable subgroups. However, compassion, empathy and humanitarianism should be central principles in the PHC model of healthcare [8–10]. According to Ticktin [11], the dominant definition of humanitarianism is "[…] *to 'do good' or to improve aspects of the human condition by focusing on suffering and saving lives in times of crisis or emergency".*

Enhancing the cultural competencies, competencies for caring for vulnerable groups, and developing the communication skills of interdisciplinary teams offering care and support to refugees represent some of the most pressing needs encountered by the host countries. Escalating costs, medical errors, and lack of compassion are common issues in many healthcare systems across the world. It is widely accepted that compassion, kindness, respect, acceptance, empathy, attention to basic needs, and attention to dignity, are crucial in alleviating pain, prompting fast recovery from acute illness, assisting in the management of chronic illness, relieving anxiety, but, also contribute to better resource management and to reducing costs [3].

Early experiences of individuals and of groups upon arriving in a new land, country, and upon entering a different society and, indeed, a healthcare system, represent a crucially formative experience to the narrative developing for a refugee or migrant. In other words, by ensuring quality and relevant care provision, we establish better experiences and overall satisfaction for all involved, thus, decreasing fears, dissatisfaction, unidentified health issues and issues contributing adversely to the overall wellbeing of individuals. We also ensure higher motivation and satisfaction for healthcare professionals regarding the relevance of the work they do.

For all these reasons, despite the challenges facing EU countries affected by the refugee crisis, it is critically important to ensure compassion and humanity in the delivery of healthcare services to refugees. This would ensure the needs of the vulnerable populations are better met, whilst, at the same time, benefit our society ensuring the wellbeing of all the citizens. This would help also in better and swifter integration of refugees in their new countries.

The EUR-HUMAN (http://eur-human.uoc.gr/) project was a 12-month project, in operation throughout 2016, to respond to the aforementioned needs in the context of rapid capacity-building. It proposes an agile PHC model for refugee care with an emphasis on compassionate care. The main objective of the project was to contribute to the provision of good, affordable, compassionate, comprehensive, person-centred and integrated care for all ages and all ailments, taking into account the transcultural setting and the needs, wishes and expectations of the newly arriving refugees. All the tools, guidelines, recommendations and implementation strategies selected or developed in the context of the project were intended to be used by authorities, health policymakers and other stakeholders to rapidly increase capacity, so as to enhance overall PHC provision for refugees and migrants at both first arrival centres and in transit or long-term reception centres.

The overall aim of this paper is to report the key messages of the two-day Expert Consensus Meeting (ECM) hosted by the Coordinator, the University of Crete, mid-cycle in the project to establish what the nature of compassionate care for refugees implies and what it consists

of, to identify barriers encountered on its provision, and to explore how its implementation could be promoted across European countries and healthcare settings.

Included in the objectives of this meeting were the identification of relevant tools, and the development of guidelines and recommendations in order to provide compassionate training material for PHC providers and to raise awareness about the relief of suffering of refugees and other newly arriving migrants, its importance and manners to achieve it.

Focussing on compassion

Reaching consensus in compassionate care - EUR-HUMAN workflow - issues on approaches and methods

The two-day ECM hosted by University of Crete, was attended by sixty-nine (69) international, regional, and local experts, across disciplines, and with a focus on refugee and migrant care from fourteen (14) countries. Participants were chosen on the basis of their experience and knowledge in the field of primary care and/or care for refugees. Several participants were also invited given their involvement in other EU projects in the same Consumer, Health, Agriculture, and Food Executive Agency (CHAFEA) cluster of activity (migration/capacity-building).. A migrant, who is currently living in a European country and is involved in academic research and teaching activities, was invited to the expert meeting in order to express the experiences (including wishes, needs, preferences) *encountered* as a refugee from the moment of leaving their home country *until arrival at their* final destination in Europe. Prior to the ECM, relevant material was identified and retrieved through *various sources, including a* literature review that has been *conducted along with an* online survey among healthcare experts and practitioners. Experiences that were gained from 98 refugees and migrants, as well as stakeholders throughout participatory and learning actions approaches were disseminated to the participants.. This material was shared with all expert participants ahead of the meeting to help them prepare for an effective dialogue. According to findings, an 'ideal' and theoretically driven process /workflow of healthcare services for refugees and other migrants from the moment of arrival in a European country was developed, the EUR-HUMAN Workflow, and this was also shared with the expert participants prior to the group discussions. The expert participants were invited to discuss in small groups (5–10 persons per group) the element of compassionate care across selected thematic areas, to identify barriers in its provision, as well as to develop guiding statements and recommendations for designing primary care interventions for refugees. The thematic areas were grouped as follows: i) cultural issues in health care, ii) continuity of care, iii) information and health promotion, iv) health assessment (triage), v) mental health, vi) mother and child care, vii) infectious diseases and vaccination coverage. Each group defined one coordinator and one rapporteur; both having the responsibility to keep notes, to structure them and report the key messages and recommendations into the extended plenary meeting upon completion of all subgroup discussions.

Plenary sessions followed, which provided opportunity for discussion and agreement supported by the great majority of the participants (voted by more than two thirds of expert participants) on the major principles and recommendations for a model of integrated and person-centred and compassionate-based PHC services delivery for refugees and other migrants in European countries.

Highlights from the ECM: The need for compassionate care

We clarify that before the ECM, group sessions with refugees were held with the main aim to identify their wishes, preferences and needs in terms of services. During these meetings, refugees reported that during their journey, and in the centres (in European countries), travelling and living conditions cause or aggravate injuries, disabilities, and mental health problems, whilst at the same time increasing the risk for certain infectious diseases. Furthermore, women reported pregnancy-related issues. Core knowledge and key messages were extracted from these meetings, and were further utilised to stimulate the discussion among the participants during the ECM that is presented in this paper.

Among the problems reported, the lack of medical examination, accessible toilet facilities and dehydration were frequently referred to. Most health problems reported in these meetings were related to the lack of access to adequate healthcare. For example, wounds, mostly having been sustained as a result of extensive travelling under adverse conditions, often exacerbated having been left untreated, and either not being detected given lack of doctors or thorough examination, or because refugees themselves neglect to seek care. Dental problems and the lack of continuity of care for chronic diseases and injuries were also highlighted.

A critical need identified by refugees was improving communication for adequate healthcare information and psychological support, an issue that is exacerbated by linguistic and cultural barriers, and directly correlated with the provision of compassionate care. The lack of continuity of care and the lack of information on medical history and previous treatment (i.e., by means of personal health record); lack of information regarding regulations and procedures in the EU countries and difficulty understanding them were also mentioned. However, during the meetings, many refugees expressed their wish and hope for the healthcare personnel to be

friendly and to have a respectful attitude. In different settings, refugees expressed the need for more respect, smile, kind words, attitudes generating a feeling of being accepted, etc.

Finally, the lack of knowledge among PHC personnel, especially on cultural and religious issues creates difficulties in providing compassionate care. Most significantly, all refugees considered that the most important element defining their experience was the way they are approached by healthcare workers. Appropriate training in communication would provide tools and empower healthcare professionals to better address this issue and transform the way they approach these vulnerable people. This would create the basis and establish the first steps towards allowing them to build trust with the teams caring for them. Healthcare workers also reported these aforementioned issues.

Highlights from the ECM: Barriers for providing compassionate care

From the patient side, the limited understanding and knowledge, and the lack of awareness regarding available health services result in exacerbated disparities and low uptake of care. Educational programs to inform about health issues and available care can increase acceptability and uptake of care. The provision of translated information, tailored to the health literacy levels of the refugees, and appropriate cultural mediator services could further reduce these barriers and could significantly contribute towards building a trusting relationship.

Additionally, patient factors that hindered the implementation of health programs and interventions are: forced lifestyle changes, unfamiliarity of patients with the healthcare system, fear of deportation, fear of persecution in their home country and passive attitudes towards treatment. Moreover, an unfavourable social context that imposes exclusion and isolation may have an adverse impact on the implementation of prevention and adoption or application of treatment strategies.

An important barrier in the provision of health care is the lack of relevant knowledge and/or skills among healthcare professionals. The literature search and interviews with experts found that in order to provide compassionate care crucial problems and barriers occur at the levels of professional, patient, and organisation. Many studies identified the training of professionals in culturally sensitive aspects of care as a core enabler or a critical element of improvement interventions [6, 12–15].

Finally, the lack of a comprehensive monitoring system, insufficient funding, limited supply and equipment, poor coordination, unclear division of roles, lack of capacity in terms of time and resources and staff changes are found as main barriers in providing compassionate care. Policymakers should work with all relevant stakeholders, adopting recommendations from capacity-building efforts, to address these issues in a prompt and relevant manner, and in order to facilitate the role of healthcare personnel in the provision of compassionated services.

Highlights from the ECM: Solutions for providing compassionate healthcare

Refugees and other migrants have been exposed to severely adverse and often life-threatening experiences. Notwithstanding such experiences, there is ample evidence indicating that they are reluctant to seek help for psychological problems unless or until such issues have a debilitating effect [16]. Therefore, there is a need to develop a model that will foster person-centred, integrated, coordinated, compassionate and multifaceted support for these groups of people. The model that the ECM proposed is based on three key assumptions:

(1). If highly distressed refugees and other migrants are identified early and receive appropriate initial care, these will be more likely to seek assistance for mental health problems later on, if and as needed;
(2). Refugees at high risk of developing mental health issues should receive appropriate, person-centred and compassionate care over time, based on Psychological First Aid (PFA) principles;
(3). Continuity of care should be enhanced through appropriate procedural adjustments.

Following the well-established principles in the provision of Mental Health and Psychosocial Support (MHPSS), the ECM proposed a stepped model of rapid assessment and care. The purpose of the stepped model of assessment and care is to provide MHPSS services on the basis of different levels of individual needs. In the proposed model, both the assessment of MH needs and the overall MHPSS provision are integrated in healthcare provision in a seamless manner. There are several arguments substantiating such an approach. Firstly, integrating mental health care in overall healthcare provision reduces the stigma usually attached to mental health issues. Secondly, people are often not aware of the strong connection between body and mind symptoms. Finally, although there is a substantial rate of psychiatric disorders present in PHC, individuals may not be willing or able to accept a referral to a mental health provider in a different location, making PHC the most appropriate setting for effectively and efficiently addressing mental health problems.

Recommendations formed by the ECM: How to provide compassionate care for refugees and other migrants

Based on the discussions made in the plenary and the agreements reached, a set of recommendations where formulated.

Table 1 summarises the recommendations formed during the consensus meeting.

In order to provide culturally adapted health assessment and compassionate health care services, a trained multidisciplinary team (consisting of physicians, nurse, midwife, social worker, nutritionist and mental health professionals) is needed. The team requires the support of an interpreter and, where possible, this ought to be combined or supplemented by cultural mediation. All healthcare services (HCS) need to be culturally adapted in an appropriate manner, holistic and person-centred under the prism of compassionate care. To achieve this, a trusting relationship ought to be built. More specifically, ensuring familiarity with personal and country-of-origin background, awareness and early recognition of signs of compassion fatigue (secondary traumatic stress), and making available appropriate training to PHC professionals to equip and empower them to provide compassionate care. PHC professionals need to gain knowledge on health systems, asylum procedures, signs of vulnerability and knowledge regarding vulnerable groups and the needs thereof. Specific knowledge pertains to tasks in triage, assessment, initial treatment, extends to health promotion and its content ought to encompass all related aspects of healthcare for refugees. Instruction on a team-based approach is essential to facilitate and promote interdisciplinary collaboration in addressing important refugee and migrant healthcare needs [17, 18]. Use of protocols adjusted to the need of refugees and migrants may also, further enhance the quality and effectiveness of care services provided by PHC professionals.

Table 1 Key Recommendations formed during the ECM

•All healthcare professionals need to be prepared to deliver culturally competent, compassionate and person-centred care. The content of this care should involve a trained multidisciplinary team by using proactive outreach to identify vulnerable refugees.
•The assessment of health needs and personal preferences should be done at all stages and settings, in conjunction to applying diseasespecific recommendations for evidence-based care.
•Quality interpretation services must be provided, by avoiding as much as possible informal interpreters and using children as interpreters.
•Health information and all services needed to be tailored and suitable according to the level of refugee health literacy.
•Refugee values, societal beliefs, wishes, experiences and particularities needed to be assessed by well-trained and empowered on cultural competences and compassionate care PHC professionals.

There is more to say about the importance of communication in a refugee healthcare context. Communication skills are very important in intercultural relations. Effective communication and compassion are considered as important components of effective primary care [19]. Listening patiently and carefully to refugees expressing their concerns, as well as touching them carefully and showing them they care about their health problems is of paramount significance. Effective communication must be built in the framework of listening to them in an active way and posing questions by using the appropriate verbal and non-verbal communication skills [19].An initial step the PHC professionals may try to gain a better understanding and feeling of what these people have experienced and require, i.e., "getting into refugees shoes" is by specifically seeking their input asking them about their physical and emotional needs as well as their preferences of receiving health services. To successfully overcome language barriers, the PHC professional ought to consider the socio-cultural beliefs of the patient, as well as to overcome linguistic challenges [6, 12]. Here, an appropriate supporting network is needed for the PHC team, facilitating access to interpreting and cultural mediation services. Additionally, the PHC professional may often be required to tackle complicated issues, as for example the possibility of a latent infection being present or of a chronic disease requiring different management and self-management approaches [20]. Communication needs here extend well beyond ad-lib approach, and communication may need to be adjusted at an individual level. Of note, regarding linguistic barriers, healthcare professionals mostly use the services of lay interpreters and family members as interpreters who, in principle, facilitate communication. Studies have shown, however, that these can play an adverse effect [21, 22]. Training or actions incorporating scenario building, taking into consideration available resources, compliance patterns for the given group of migrants and refugees, considerations pertaining to planned and/or unplanned movement and relevancy in identifying culturally relevant practices prior to the consultation may prove invaluable. Online translation tools, handbooks and dictionaries still remain underutilised [23, 24]. Time pressure and limited interpreter availability are frequently cited as reasons for underuse or absence of professional interpreters during consultations, but erroneous estimates regarding patient and physician language proficiency may also play a role [25]. Regardless of the patient's cultural background and language barriers, the PHC team will greatly benefit from the development of a good relationship, with the experience at the receiving end also being enhanced and outcomes improved. Therefore, ensuring clarity of information and messages, and a respectful attitude as part of communication is

key in building trust from the very beginning. When providing care to migrants, the specific stress factors associated with migration and fleeing from one's home, along with the short- and long-term impact on the incidence of mental disorders and timing for detection thereof ought to be considered. Additionally, longer stay, of migrants and refugees in one or multiple host countries ought to be considered along with the conditions under which they live and/or are moved across settings and/or countries [26, 27].

Due to the fact that refugees are a population in transit, it is important to inform them about the provision of healthcare services across European countries. Healthcare professionals are called to not only inform, and potentially gain consent, about procedures, data provision, and the care they provide by acting as a source of information on the refuges' rights.. An additional challenge is the result of changes in cross-border agreements, local rules and regulations or even misinformation of the healthcare professionals themselves. Patient health records must be readable and in English (not only in patient's native language). Authors of the current paper propose English language because a large majority of healthcare professionals are likely to have the ability to read and understand it. In addition, every effort ought to be made to use international disease and vaccination classifications and coding. Therefore, applying an electronic patient record approach is the appropriate avenue to ensure error minimisation and patient safety, to increase effectiveness and efficiency, ultimately, to ensure cross-border continuity of care [28]. Along with ensuring continuity of care, an additional benefit at the system level would be the ability to monitor resource utilisation as these people move through the systems and across countries; such data can then be captured, analysed and evaluated to develop more resilient approaches on multiple levels, including local and European system levels. Of course, ensuring confidentiality and privacy is key, particularly for these vulnerable groups, therefore, the support of policymakers is needed with action pertaining to protection from compromising anonymity.

PHC professionals providing services to refugees should be trained on their own country's healthcare system, the healthcare system of the country of origin, as well as gaining some familiarity with the healthcare system of the countries that may be likely to be in the path as recipient hosts during the next movement of these groups. For final destinations too, it is of paramount significance that healthcare professionals are provided with information and gain knowledge regarding the care provided and the conditions of stay at the first-point-of-entry as well as in the transit countries. Additional facets also seem to be important; extended knowledge on political and legal situation, asylum process, entitlements and charges for accessing services or utilising healthcare service procedures after registration, and transportation from one country to another one (or within country) are also core issues of relevance for the wellbeing of these populations. As mentioned, to help healthcare professionals feel empowered and to ensure the overall frame of interaction is one of trust, they need to be able to provide information about basic human rights in Europe, gender equality, hygiene, healthy lifestyle choices and availability of services in the hosting centre, always taking into consideration the protection standards and security storage of patient records and data and transmission thereof. Information about privacy, data confidentiality, ownership of records, informed consent, right to treatment and right to refuse treatment is included in the extensive list of tasks assigned to PHC professionals when they address refugees and migrants.

It is known that the lack of a comprehensive monitoring and integrated PHC system, insufficient funding, limited supply and equipment, poor coordination, unclear division of roles, lack of capacity in terms of time and resources and staff changes are also key barriers in providing compassionate care [29]. To overcome all these barriers, many of which are relevant for migrant populations within Europe, i.e., EU citizens moving from one Member-State to another, policymakers need to urgently tackle these issues in order to support the operational framework of cross-border PHC delivery and to help train and empower the PHC professionals in their difficult task of providing compassionate services.

Conclusions

Compassionate care should not be separated from other types of care – rather, it ought to be acknowledged as representing a core and integral theme of the person-centred care provision [30]. Additionally, considering shared-decision making as a cornerstone of evidence-based practice, it can be examined as moving further beyond simply having empathetic conversations to developing a compassionate, evidence-based frame for safe and trusting interaction. Since providing compassionate care has an important impact on the reduction of anxiety, prevention of health problems, faster recovery and better adherence to treatment recommendations [31], this results in better outcomes, helping move teams and systems towards a more person-centred, yet, high value approach. The challenge is multi-prong, at the individual, team and system level, often starting with the PHC professionals having to accept and validate the values, beliefs, experiences, needs and wishes of these very different culturally vulnerable groups. Such an approach encompasses compassion, empathy and respect, which, despite the difficulties encountered in terms of implementation and

adoption, will help them improve their own motivation and performance [30–33].

Healthcare systems are currently confronting many challenges including rising financial pressures, depleted resources and severe austerity measures, as well as a refugee and humanitarian crisis [29]. The EU jointly with Member-States and other national, regional and local stakeholders' attempts to develop a long-term strategy to tackle this issue, focusing in particular on the design and delivery of appropriate person- and compassionate-based PHC services. Despite the well-recognised difficulties in teaching compassion and empathy, it is of paramount importance to empower the PHC healthcare professionals, in other words to make them aware of the deep suffering of refugees and other migrants and to equip them with the skills and expertise through training, as well as to cultivate the wish to provide relief to these populations and to demonstrate to them how this can be effected. The list of recommendations composed by this consensus panel may assist the design of educational intervention programmes to be used in enhancing existing modalities in relevant aspects, including ethics, of formal undergraduate, postgraduate and professional training.

Abbreviations

EU: European Union; EUR-HUMAN: EUropean Refugees - HUman Movement and Advisory Network; ICPC: International Classification of Primary Care; MHPSS: Mental Health and Psychosocial Support; PFA: Psychological First Aid; PHC: Primary Health Care

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Authors' contributions

CL contributed to study design and conception. EAM wrote the first draft. AA, EP, DSP, VEC, CD, KH, EJ, DRP, MD, IR, MvdM, TvL, DA and HB contributed to study design. In addition, EAM, AA, EP, DSP, VEC, CD, KH, EJ, DRP, MD, IR, MvdM, TvL, DA and HB contributed to writing the manuscript and to revising and approving the manuscript. CL contributed to revising the manuscript and checked and approved the final version. All authors read and approved the initial and revised manuscript.

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Competing interests

The authors declare that they have no competing interests.

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