

**Palliative Care Utilization Among Non-Western Migrants in Europe
A Systematic Review**

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Palliative care utilization among non-western migrants in Europe: A systematic review

Introduction

International migration is increasing globally, with an estimated 272 million people (3.5% of the total world population) living outside their country of origin [1]. Since the Second World War, the continent of Europe has become more ethnically and culturally diverse [2]. In 2019, 21.8 million people (4.9 % of the total population) living in Europe were born elsewhere [3]. As a result, the European healthcare system is serving an increasingly diverse population of patients [4]. All migrants in Europe have the right to equal access to health services from prevention to treatment, rehabilitation and palliative care (PC) without discrimination. This common goal of the continent towards provision of PC among migrants motivated our search to be conducted within Europe [5, 6]. Since palliative care is multidimensional, multiple settings including home, hospitals, long-term care facilities, cancer centers, and hospices are involved in the provision of care [7]. In Europe, migrants are defined diversely within several categories, including labour migrants, refugees and asylum seekers, family members of existing migrants, victims of trafficking, and returnees [4, 8]. In this review the term ‘migrants’ will be used as an overarching term inclusive of refugees, asylum seekers and other migrants [4] (table 1). Due to different welfare systems within Europe, the right to access health care varies according to the migration status of the migrant. Within Europe, for example, undocumented migrants have the right to access free of charge, more than emergency care in five countries, only emergency care in twelve countries and only first aid in ten

countries [9]. It is anticipated that legal aspects of migration status can influence access to and provision of palliative care among various migrant groups within Europe [10]. Although in this review non-western migrants will be named as a common group, they represent a variety of languages, religions and cultures originating from different continents of the world [11]. Migrants will not be categorized according 1st generation or 2nd generation migrants in this review.

The process of migration often leads to health problems among migrants [12]. Moreover, it has been documented that life threatening and chronic disease burden is highest among ethnic groups, especially among non-western migrants [13-15]. Furthermore, non-western migrants have a tendency for lower utilization of hospice and PC at the end-of-life (EOL) [16-20]. The lower utilization of PC among non-western migrants living in Europe could be explained by significant differences in spirituality, culture and religious beliefs emanating from the country of origin [21, 22].

Empirical research on non-western migrants' PC has been conducted within national contexts [19, 23]; however, we did not find a systematic review on current practice, facilitators and barriers of utilizing PC services among the non-western migrant population living in Europe. Therefore, this systematic review was conducted to systematically summarize and present the available published European literature on utilizing PC services among non-western migrant population living in Europe.

Aim

The aim of this systematic review was to identify and describe the European evidence on opportunities and barriers to access and utilization of PC among non- western migrants.

Methods

The review was conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines for systematic reviews. The review is registered in PROSPERO, reference number CRD42020193651, an international prospective register of systematic reviews.

Inclusion and exclusion criteria

Study selection criteria are presented in table 2.

Three articles did not clearly state the ethnic background of the migrants [24-26]. Hence, emails were sent to the corresponding authors to obtain this. One author did not reply and two others confirmed that they had not asked the relevant professionals about the demographics of the migrants; still they stated that it would likely be the same group of migrants as in this systematic review [24, 25]. All three articles were included.

Search strategy

An electronic search was conducted on the 22nd of June 2020. Prior to the search, a librarian was consulted to review the search strategy. The primary databases used were: Medline, Embase, PsycInfo and CINAHL. Furthermore, manual searches of the reference lists of identified articles were performed, and through citation tracking in Google Scholar.

All documents were considered for relevance based on titles and abstracts. When the information was not sufficient to decide on inclusion or exclusion, the full text was evaluated. EndNote was used to keep track of the selected literature and to remove duplicates. Table 3 shows the search words with number of results obtained.

Quality appraisal

Each of the included studies was evaluated for methodological quality by first author based on a tool developed by Hawker [27], which assesses the quality of heterogeneous study designs. Confusions and uncertainties were continuously discussed with last author. The tool is scored on ten areas ranging from 1 (very poor) to 4 (very good). Components of the scale were: 1. title and abstract, 2. introduction and aims, 3. method and data, 4. sampling, 5. data analysis, 6. ethics, 7. bias, 8. results, 9. transferability and generalizability; and 10. implications and usefulness. Scores range from 10 to 40 with higher scores indicating higher quality [27] (table 4).

Data extraction and analysis

Data was extracted by first author and reviewed by last author if necessary. Data was extracted from each paper including information on year of publication, study aim, sample characteristics, method and/or design, and main findings. Included articles were read and assessed by first author and subsequently checked by last author. Any disagreements on eligibility and quality of each article were discussed and agreed upon between first author and last author.

A thematic analysis technique proposed by Braun and Clarke was used to extract main themes [28]. Detailed examples demonstrating the process of data extraction and data

analysis are shown in tables 4 and 5. Despite including any study design in this review, only data on qualitatively derived themes was extracted from the included studies, as the aim of this review was to describe information on migrants' facilitators and barriers to access and utilize PC rather than the proportions of participants utilizing these care facilities.

Results

As can be seen in Fig. 1, the search yielded 8431 articles of which 35 were relevant to this review. None of the studies were excluded on the basis of methodological quality. All studies provided adequate information related to the study question. There was considerable heterogeneity among included studies in the review.

Thirty-five original articles from 21 studies were included. The following references originate from the same studies [24, 25], [29-31], [32, 33], [34-37] and [38-40]. The articles varied in respect to the number of participants, research design, locations, settings, and ethnicity of migrants. Studies have been carried out in various settings across nine European countries. Nineteen articles were conducted in the United Kingdom (UK) (n=19) and the remainder in Germany (n=3), the Netherlands (n=4), Belgium (n=3), Sweden (n=2), Norway (n=2), Austria (n=1), and Denmark (n=1). The majority of the articles followed a qualitative design (n=29) with a small number of quantitative studies (n=6). The number of participants in the qualitative studies ranged from two [41] to 106 [42] and in the quantitative studies from 34 hospice and PC institutions [43] to 2,820,283 individuals [44]. The included articles involved migrants originating from the continent of Asia and Africa. Participants in the studies were citizens [45], health professionals (HPs) [24, 25, 46], volunteers [47] non-western migrant patients with PC needs and/or

their family caregivers [33, 48]. The thematic analysis revealed four main themes concerning barriers to migrant utilization of PC:

1. Communication and language
2. Knowledge and awareness
3. Patient preferences, cultural and religious issues
4. Lack of resources at different levels of palliative care service provision.

Articles included in this review use various terms to describe the subjects of research for example, Black, Asian and other minority ethnic groups, immigrants, migrants, South Asians, ethnic minorities and/or non-western migrants. All subjects are described as non-western migrants in this review.

1. Communication and language

Poor communication among migrants and HPs is identified as a problem in seventeen of the articles included in the review [10, 24-26, 29, 32, 33, 35-40, 42, 45, 49, 50]. This was associated with proficiency in the local language [26, 36, 37, 40, 42, 45, 49], involvement of family members (as interpreter/interrupter) [33, 38, 39] , or HPs' poor cultural understanding [24-26, 33, 34].

Poor communication leads to poor satisfaction among both the users and service providers [24, 25, 33, 38-40, 45]. Patients feel isolated and have poor mental health due to limited opportunities for interaction and conversation during their stay in hospital [10, 40]. To facilitate communication, healthcare facilities provide support through interpreters, internet services and/or by family members are working as interpreters [26, 34, 36, 37,

42, 45]. Users and service providers experience challenges in both scenarios [26, 34, 36, 37, 42, 45]. According to HPs, interpreters are not translating properly [42]. Moreover, patients and their family members are not comfortable with using an interpreter in fear of conveying bad news to the patient [33, 42]. Using a family member as an interpreter creates several other issues for HPs who can be afraid that family members are holding back information and interpreting only partially or improperly [26, 34, 36, 37, 42]. Interpreters and HPs therefore both acknowledge a dearth of understanding and training for working in collaboration [33, 42].

Apart from verbal language, barriers sometimes extend to body language and non-verbal communication [10, 25, 42]. HPs find it difficult to deal with both verbal and non-verbal communication with patients from migrant backgrounds, resulting in short conversations rather than deep discussion [25, 36]. According to HPs, patients are over expressing pain and families are dramatic when expressing their emotion towards their dying relative [10, 24, 25, 38]. The absence of proper communication encountered by HPs can lead to uncertainty and dissatisfaction while caring for migrants [42, 46]. Poor communication is reported to cause negative feelings and distancing of HPs from patients, which may result in failure to provide best care [24, 25, 38].

Various possibilities to improve communication among HPs and migrant families are found in the literature, for example, to involve both the patient and family members in the medical discussion [32, 39]. Moreover, HPs should be trained to work in cooperation with professional interpreters [33, 42]. Involving professional interpreters rather than family members or an ordinary interpreter could be a possibility to facilitate communication [10]. Other suggestions are to employ migrant HPs in the care team [26],

ensure that HPs are sensitive, less judgmental, open to discussion [10, 33, 41] and encouraged to take part in culturally sensitive communication training [39]. Sometimes, just showing interest in/or respect for the culture or religion of the patient, has been seen as helpful to ensure good communication [49].

2. Knowledge and awareness

Sixteen articles included in this review [10, 24, 25, 34, 36-39, 43, 45, 47-52] discuss inadequate knowledge and poor awareness among non-western migrants and their families about the existing healthcare system in the host country and how to navigate it. Poor awareness among migrants is often linked to poor expertise in the local language. Thus, it becomes troublesome for them to gather information about the healthcare system [10, 37].

According to HPs, lack of awareness among this group is a result of poor education [26, 34, 39, 49]. Moreover, in gathering information, migrant families have exhaustive medical queries for their HPs [38, 39, 41]. Thus, HPs need to be prepared with information for migrants [25]. Better understanding of the provided PC services in the host country is also influenced by the acculturation of migrant families [37, 45]. It has been documented that younger generation migrants have better knowledge and awareness about existing PC compared to the older generation [37].

The articles mention the need for improved knowledge among migrants, through training and education within the migrant communities to facilitate access to PC [10, 45, 49]. One way could be to use volunteers from the same community [47]. Other suggested methods

include using information leaflets in the different languages [49], using local television channels or use of audio/video materials, website based information, using social media such as Facebook and/or involvement of religious and recreational authorities [10, 49]. Indeed, information on PC is seen as a way to empower the migrants [49].

3. Patient preferences, cultural and religious issues

The concept of “filial piety” is often discussed in articles [10, 29, 45, 50]. Most of the elderly migrants expect their families, especially children, will take care of them [10, 45]. The entire family agrees upon the concept of ‘family caregiving’, i.e. duty towards family, both to avoid extra expenses and due to their poor knowledge about available professional help [50]. Caring for the sick family member at home is also highly respected by community members and they may be criticized if this does not happen [49, 50]. The decision to be cared for at home is often inspired by the need for religious practice, which is more feasible at home [31]. The decision of being at home is also motivated by the strong desire to be surrounded by family and friends until the very last moment of life [48]. However, retrospective studies on place of death reveal that non-western migrants are more likely to die in hospital than at home or in a hospice [53-56]. One survey came up with possible explanations for differences in care and decision-making, at patient level (for example, preferences related to culture and religion, language proficiency, health literacy) and at provider level (for example, responsiveness, cultural competence) [55]. The reason for hospital deaths may be associated with a perception that deaths are better managed in hospitals compared to at home [31]. Moreover, medical care is a way of sustaining the hope that a patient will be cured [57].

After diagnosis, disclosure of the incurable disease, prognosis and treatment of the patient are discussed in some articles [24, 26, 42, 49]. Inspired by the cultural values of the country of origin, migrant patients often lean on the family members especially on the children for proactive healthcare decision-making [30]. The family members try to keep hope alive for the patient and often the patient is not informed about the diagnosis or poor prognosis [10, 33, 39, 40, 42, 46, 57]. The culture of disclosing the diagnosis to patients is practiced differently in Europe, although the patient has the right to be informed about the medical condition [24]. However, it should not be taken for granted that all migrants want to be in the dark about the diagnosis or prognosis [24]. Migrants are a heterogeneous group in terms of educational level, economic level and social class [10, 26, 44]. Thus, there are suggestions that HPs initiate an open discussion with the patient about their preferences on the level of information they receive. These preferences must then be respected and documented, to avoid conflicts in professional practice [10].

The culture of being surrounded by many visitors is preferred by patients, although not supported by the HPs or the rules of the hospital [24-26, 38, 39, 49]. For visitors, the act of visiting a sick person may be a part of a religious practice [38]. While for professionals, too many visitors are noisy, disturbing for other patients, and time consuming [24]. One suggestion is to extend hospital visiting times and official routines [26].

A Dutch study concludes that patients with a non-western migration background prefer more, longer or maximum, curative treatment [55]. This is supported by other qualitative studies conducted in Belgium, the UK and the Netherlands [30, 32, 38, 39]. However, a contrary result is found in another qualitative study, where the nurses reported that the families of the non-western migrants asked them to stop intervening and let nature take

its course [46]. Some articles suggest that HPs should consider the cultural differences of migrant families in relation to their own preferences [10, 26, 32, 33, 45], thus creating a point of negotiation for both parties and acceptance of the differences [26, 33].

4. Lack of resources at different levels of palliative care service provision

Scarce resources in the care facilities at different levels is mentioned: at policy level, structural level and provider level [10, 33, 35, 38, 42, 52, 58]. Authors recognize a need for proper initiatives at the policy level. The existing healthcare system of host countries fails to address the need of the migrants [10, 26, 45, 52]. Moreover, as the migrant population is almost non-existent at the political level, the practice of shared medical decision-making remains unknown for this population [10]. Articles based on religious belief expressed the need for policy makers to address the role of faith-based values when providing EOL care for migrants [52, 59].

At a structural level, healthcare facilities do not have enough resources to support the diverse and complex needs of the migrants [25, 45]. The structures of the healthcare facilities should be more flexible to provide for the diverse needs of the migrants [10, 45], for example, availability of professional interpreters, spiritual care workers or a psychologist with different cultural origins [26].

At the healthcare provider level, there is a shortage of time, training, planning and resources to meet the unmet needs of the migrant families [10, 34, 35, 38, 42, 46]. Within the healthcare facilities, providers are under time pressure. There is no time left for them

to be emotional only rational [34, 38]. Moreover, they are expected to provide care for migrants without any proper prior training [10, 24-26, 35]. Thus, cultural understanding of migrant families' remains limited for HPs [24, 25]. This results in many migrants being considered as a burden to them [10, 25] and a tendency to generalize about 'migrants' [25]. Discrepancies between available resources and unmet needs [33, 38-40], for example, differences in expectations about what constitutes good care [29, 32, 38], results in conflicts between HPs and migrant families [33, 38-40]. Due to such conflicts, both parties develop negative feelings towards each other [38]. This conflicting position results in mistrust towards HPs in general [38-40]. To solve these conflicts, authors suggest that the HPs should follow the strategy of acknowledging differences and accepting them [26, 33].

In addition, HPs agree that professional interpreters could facilitate good communication, although there is scarcity of time, planning and resources to provide interpreters for migrant families [33, 35, 39, 42]. To provide appropriate care for the migrants, it is suggested cultural sensitivity training for HPs should begin in medical schools [10, 26, 35, 39, 46] .

Discussion

To our knowledge, this is the first systematic review of palliative care utilization among non-western migrants living in Europe. The themes that emerged from this review reflect several interrelated factors that restrict access to palliative care services for non-western migrants. An attempt was made to describe themes separately, though they sometimes remain difficult to separate from each other. For example, lack of language proficiency leads to poor knowledge and awareness. In addition, poor language skills also contribute

to limited communication and a sign of the preference of the individual (not to learn the local language). Thus, it is difficult to draw a line between each theme. It is also worth mentioning, one result of this review that highlighted the issue of poor language proficiency, knowledge, awareness among migrants or lack of cultural training among HPs are not the fault of any individual. It is not the responsibility of those individuals (migrants or HPs) to solve these problems. Rather, it is anticipated that the problems are embedded in the policy and/or in the system, where diverse needs of migrant families are overlooked in the PC trajectory.

The findings of this review are both consistent with and complementary to themes found elsewhere on migrants' PC in Europe and internationally [19, 23, 60, 61]. Articles included in the current review discuss more explicitly the challenges at an individual level) rather than how economic and/or structural factors influence the utilization of PC among migrants. Structural factors might include strict immigration policies in Europe and institutionalized discrimination towards specific religious, ethnic or cultural groups in the receiving European country [62]. At the policy level, inclusion of cultural/religious diversity practice at the time of illness and at the EOL in the curriculum of HPs could make a difference in professionals' way of perceiving patients and their families from a migrant background. Ideally, professionals should be trained in and confident about providing care for ethnically diverse migrants. Interestingly, ethnic diversity is only visible when the group is not completely integrated into society [63]. Integration into the host society also influences the modes of communication with migrants in health facilities. In spite of language differences, showing interest or respect towards each other, might be helpful to build trust and provide comfort towards the migrant families. In

addition, professionals and migrants should both endeavor to find a mutual point of negotiation to avoid conflict between the two.

According to this review, preferences for PC are shaped by cultural and/or religious values, family involvement, trust/mistrust in institutional care, and the practice of care in the country of origin [10, 26, 29, 45, 49, 50, 55]. Similar factors are identified in a recent review conducted in the USA in which ethnic minorities mentioned the importance of spirituality, belief systems, acculturation, healthcare system distrust, and social networks in EOL care preferences and planning [64]. In addition, care preference is also influenced by economic conditions. Migrants are challenged in the ethnically, linguistically, and culturally segregated labour market [65]. Often, despite higher education, migrants have to choose low skill jobs because of proficiency in the local European language. Low socio economic status determines migrants' living conditions, eating habits, and health service affordability [65].

Non-western migrants are not a homogenous group; they have differences in care preferences and decision-making [10, 24, 26, 46]. It is noticeable that decision-making in PC is influenced by several factors, thus one should not stereotype by ethnic background [66]. Moreover, not all European countries have the same guidelines on provision of healthcare. For example, the norm of disclosing of life threatening illness or prognosis with patients varies within Europe [67]. Thus, the preference of the patient could be taken into account while disclosing diagnosis towards a non-western migrant patient.

The poor knowledge and awareness about PC has among migrants is probably caused by the lack of availability of PC services across the world. PC is a new and emerging field, particularly in Asian and African countries (origin of migrants in this review) [68]. Thus,

migrants originating from countries with little or no access to PC might find it difficult to accept such forms of care at the EOL. Particularly, they may not fully appreciate or accept the information that PC is not a curative treatment procedure, it neither hastens nor delays death but improves the quality of life of the dying individual and his/her family [69]. Articles mention the poor health literacy of the migrants, resulting in poor knowledge and awareness [25, 34, 39, 43, 48, 49, 51]. There are four steps in processing health information: access, understand, appraise and apply [70]. An individual must have sufficient relevant knowledge, motivation and competencies to successfully follow the steps [70]. Although educated migrants have the ability or health literacy to navigate the healthcare system in their country of birth, it may become complicated in the healthcare system of the host European country.

Mostly articles included in this review discuss barriers to accessing PC and possible measures for a way forward. To plan more responsive PC services for non-western migrants, one of the challenges is the diversity that exists across and within the different groups (for example, in terms of language, culture, religious beliefs or country of origin), thus, it is difficult to generalize [62]. In addition, different factors like migration background/status, length of the stay in the host country, language skill, and social class influence needs and PC service utilization among non-western migrants. Therefore, before planning any PC service for the non-western population, it is important to understand the migrant as a unique person with individual needs [71]. In order to better meet the diverse needs of the migrants, healthcare services and HPs, both should treat the individual patient and the family uniquely [72], by considering their linguistic, cultural and religious preferences and needs. Moreover, context should be considered carefully before planning and while implementing interventions for non-western migrants [73].

Such interventions need to take account of individual migrants' history, demographics, social class, education, language proficiencies, individual needs and the current context of implementation.

Strengths and limitations

This review included both qualitative and quantitative articles, providing insights from epidemiological, demographic, institutional, community and individual reasoning in relation to lower PC service usage by non-western migrants in Europe.

However, different studies have defined migrants differently or not at all; this heterogeneity was not considered during data analysis or when deriving themes. If the heterogeneity was considered this might have influenced the derived themes and, thus the overall results of the review. Furthermore, recent refugees and asylum seekers were considered part of the population of this review along with other migrants. Thus, the unique needs [74] of this group of migrants were not analyzed separately which could have influenced the results. Search terms were in English and included articles only in English, Swedish and Danish. Hence, there is the possibility that other relevant published literature in this topic area were not included in the study due to language restrictions.

Conclusion

This review showed that some of the reasons why non-western migrants find it difficult to navigate European PC systems, are related to structural barriers, lack of resources, as

well as issues of knowledge and awareness. Factors that are considered useful to help this group of patients are: flexibility of the healthcare system to address the diverse needs of the migrants, cultural training among HPs and empowering migrants by provision of relevant knowledge. As ethnic diversity is continually growing within Europe, it will become increasingly important to understand and modify our approach to the provision of PC both within healthcare systems and within the communities. Hence, recommendations are mostly at an individual level, as they are important to consider for policy makers and healthcare providers when designing future PC interventions for migrants.

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