# Palliative care for non-Western migrants in Denmark – towards a supportive intervention

# Colophon

Palliative care for non-Western migrants in Denmark –towards a supportive intervention ©2023, Jahan Shabnam

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# Preface

My curiosity about migrant palliative care started in 2017 when I was employed at REHPA, The Danish Knowledge Centre for Rehabilitation and Palliative Care to write an article on the palliative care service in Bangladesh. My visits to the Center for palliative care at Bangabandhu Sheikh Mujib Medical University, Dhaka, forced me to compare two incomparable palliative care service provisions: Bangladesh and Denmark. I talked to some of the family caregivers in Bangladesh who were spending their last penny in a palliative care ward, hoping for curative treatment for their loved ones. My stay in Bangladesh made me think about the people who migrate to the Western world from a country where palliative care is non-existent or perceived in a very different way compared to the world of the West.

As I reflect on my experiences and the emerging worries, I realise that these concerns come from my professional and personal position as a migrant in Denmark. As a professional, my physio competency did not allow me to register as a physiotherapist in Denmark due to poor language skills.

In my personal life, I lost my mother without even saying a formal goodbye. It has been a decade since we three siblings were together. I gave birth to two boys in Denmark. They have known Denmark as their home and Danish as their first language, while my Danish is horrible. Although I don’t speak fluent Danish or look, dress or eat like most people around me, I have developed a sense of belonging after living so many years in Denmark. Reflecting on my positioning makes me aware of several assumptions I hold. One of the assumptions is that patients with life-threatening diseases from non-Western backgrounds may need extra support in the system. Another assumption is that non-Western migrant families do not know what they are missing or what they do not know. These assumptions made my path to this PhD.

# Academic supervisors and assessment committee

## Academic supervisors

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Thanks to all migrant families and health professionals who participated in the interviews and workshops. My collaboration partners are the Migrant Health Clinic (MHC) Odense, the Palliation Department of Herlev and Gentofte Hospital, and the Oncology department, Department R, who put enormous energy, time, and effort into collecting informants for my PhD. Without you, the PhD would have never seen the light.

I want to express my sincerest gratitude to my principal supervisor Professor Mette Raunkiaer, for her expertise, patience, wise advice, and continual encouragement. Mette, you have always surprised me with your intellectual understanding. It was a great honour to conduct my PhD under your supervision. It was a privilege to know you not only as my supervisor but also as a person. Thank you for all our formal and informal talks, for pushing me out of my comfort zone and making me capable of conducting interviews in Danish when needed. You have seen the potential in me that I did not see. Thank you for everything.

I want to express my honest gratitude to my co-supervisor Professor Helle Timm, for her academic support throughout the PhD. Helle, I have known the palliative care world by holding your wise hands. Thank you for being my mentor even before starting my PhD.

I want to say special thanks to my second co-supervisor Professor Dorthe Nielsen. Thank you, Dorthe, for your enormous knowledge and experience in migrant research. You have opened the door of the Migrant Health Clinic for me and introduced me to your network for collecting informants. Getting to know and participate in your PhD group discussions was a pleasure.

Thanks to REHPA, The Danish Knowledge Centre for Rehabilitation and Palliative Care, for providing me with the platform. Thanks to all my colleagues, former and present at REHPA, for their continuous support, suggestions and advice. Thanks to my former PhD colleagues at REHPA for inspiring discussions. Thanks to  Äldreforskning Syd (Vov-gruppen) at Lund University for allowing me to join your research discussions during COVID while other opportunities were closed.

I acknowledge the funding I received from The Danish Cancer Society and REHPA for conducting this PhD.

Thanks to all my family, especially my sister, for always encouraging me.

Thanks to all my friends back home and in different parts of the world, Reshma, Trisha, Nipa, Sonia, and Jamal, you are the gem in my life.

Thanks to my lifetime best friend, my husband, Sayed. Thanks for always being supportive, encouraging and lifting me up when I was down and to the coolness of my eyes, my precious Umar and Usman.

# Contents

# Abbreviations

| | |
|---|---|
| **ACP** | Advanced Care Planning |
| **COPD** | Chronic Obstructive Pulmonary Disease |
| **CVD** | Cardiovascular Disease |
| **DPD** | Danish Palliative Care Database |
| **DMCG-PAL** | Danish Multidisciplinary Cancer Group of Palliative Care |
| **D.N.** | Dorthe Nielsen |
| **EAPC** | European Association for Palliative Care |
| **GSF** | Gold Standard Framework |
| **HIV** | Human Immunodeficiency Virus Infection |
| **IAHPC** | Association for Hospice and Palliative Care |
| **ICUs** | Intensive care units (ICUs) |
| **MHC** | Migrant Health Clinic |
| **MRC** | Medical Research Council |
| **M.R.** | Mette Raunkiær |
| **NICE** | National Institute for Health and Clinical Excellence |
| **OUH** | Odense University Hospital |
| **PPI** | Patient and Public Involvement |
| **REHPA** | Danish Knowledge Centre for Rehabilitation and Palliative Care |
| **SPC** | Specialised Palliative Care |
| **SPICT** | Supportive and Palliative Care indicators Tool |
| **UK** | United Kingdom |
| **USA** | United States of America |
| **WHO** | World Health Organization (WHO) |

# Publications and manuscripts in this thesis

This PhD thesis is based on the three following manuscripts:

## Study I

**Paper 1.** Shabnam J, Timm HU, Nielsen DS, Raunkiaer M. Palliative Care Utilization Among Non-Western Migrants in Europe: A Systematic Review. Journal of Immigrant and Minority Health. 2021:1-19.

## Study II

**Paper 2.** Shabnam J, Timm HU, Nielsen DS, Raunkiær M. Palliative Care Utilisation Among Non-Western Migrants in Denmark: A Qualitative Study Of the Experiences of Patients, Family Caregivers and Healthcare Professionals. OMEGA-Journal of Death and Dying. 2022:00302228221111933.

## Study III

**Paper 3.** Shabnam J, Timm HU, Nielsen DS, Raunkiaer M. Development of a complex intervention (safe and secure) to support non-western migrant patients with palliative care needs and their families. European Journal of Oncology Nursing. 2023;62:102238.

# 01 Introduction

## 01.01 Overall aim

This PhD thesis aimed to develop a supportive palliative care intervention towards non-Western migrant patients with a life-threatening disease and their families in Denmark (See page 29 for the definition of non-Western migrants). This thesis combines a systematic review, a qualitative study, and a description of developing a supportive palliative care intervention informed by the Medical Research Council (MRC) guidance involving patients with/without life-threatening diseases, family caregivers and health professionals. See table 1, on page 50, for an overview of the three studies.

## 01.02 Background

Based on this PhD's overall aim, this section explains palliative care concerning migrants in the western world and palliative care in low-and-middle-income countries. This section concludes with a short review of why palliative care research is essential for migrants in Denmark and how it leads to supportive intervention towards the migrants that this study investigates.

### 01.02.01 Migrants and palliative care in the western world

We will continue to see migration as an essential and growing aspect of our societies, affecting migrant and host communities equally. Approximately 101 million international migrants live in the World Health Organization (WHO) European region, more than 13% of the population (1). Some general values and beliefs about life, health, illness and death among the migrants are very different from those in western culture (2-5).

Death is an inevitable process for all, regardless of background. It is estimated that almost half of the individuals who die each year around the globe meet “serious health-related suffering” that might benefit from palliative care (See “Conceptual framework” on page 22 for the definition of palliative care) (6). Global migration, therefore, needs a better understanding of palliative care practice among migrants. Evidence suggests that the quality of and access to palliative care services, such as health and social services at home or hospices, differs due to unique cultural, spiritual and existential practices among migrants living in western societies compared to their natives (2, 4, 7-10). Culture and religion are interwoven; it can be hard to tell whether current behaviour and responses result from either (11). However, all humans are cultural beings; some are religious, and some are not, but culture determines how religion or irreligion works (12). Thus, understanding the cultural background can help to understand patients, family caregivers and any cross-cultural connectedness to religion and spirituality (11). Of note, multiple factors influence the palliative care preferences, attitudes, values and beliefs of the migrants.

It is crucial to remember that cultural background influences how patients respond to life-threatening illnesses, as well as their beliefs, whether religious or, more generally, spiritual (11). For example, talking about death is taboo among many migrant groups (13). The ‘good death’ concept may not be perceived similarly among migrants (14), such as a ‘good death’ is considered a quick, unexpected death, while a ‘bad death’ is lengthy, conscious and dependent (7). Discussing death is often related to a fatal prognosis, fear of losing hope and hastening death (3, 15). Patients with palliative care needs and their family members try to protect each other by avoiding discussing death. Family members of the patient often make decisions on the patient's behalf without involving them in the decision-making process (3, 15). Such cultural practices are associated with ‘filial piety’, part of adult children’s responsibility to provide care (16-18). It is mainly women who care in the home while the men maintain contact with the outside world and protect their parents from the ‘bad news’ (18, 19). Hence, for many migrants, breaking bad news is not only about telling about their illness but also the timing, manner, phrasing, amount of information and attitude with which the message is conveyed (20, 21). Inconsistency in delivering information may cause mistrust, poor satisfaction and conflict between families and health professionals (20, 22). The concept of filial piety among migrants often creates misconceptions among health professionals that family caregiving is widely available among migrants, mainly Asian families. They prefer to ‘‘look after their own’’, which is not always accurate (23). Several factors challenge the assumption, such as the breakup of traditional large family groups, the increased number of women working outside the home and migrants living for extended periods in the host country (8, 23, 24).

Besides personal issues, migrant families usually experience systemic barriers in the host country due to culturally insensitive medical care, poor language skills, lack of information about the healthcare system, and eventually navigating it (2, 25-27). Healthcare services in the host country may not adequately address the needs and preferences of migrants and may lack the flexibility to adjust (28). Lack of time and institutionalised strategies may make health professionals unable to manage challenging situations, leading to perceiving migrants as a burden in healthcare (29, 30).

It is inevitable to consider the diversity that exists across and within different groups of migrants to offer more responsive healthcare services towards migrants. Migrants are a heterogeneous population with a variation in their culture, religion, language, ethnicity, country of origin, social class and purpose of migration (5). Nevertheless, migrants often share a similar perspective on family caregiving, shared decision-making by involving other relatives and the preference to die at home (2, 3). Nationwide surveys showed different migrant groups are more likely to use intensive care units (ICUs) near death and generally die in a hospital than at a hospice or home (31-33). Despite these findings on ethnic and cultural differences, no attempt has been made to date to explore the challenges or facilitators of migrant families accessing and utilising palliative care more systematically in a European context.

### 01.02.02 Palliative care in low and middle-income countries

Palliative care research of non-Western populations often includes background discussion on palliative care in the country of origin. It is essential to understand how palliative care is organised at the country level, practised at the healthcare services and perceived by individual patients, thus, families in their country of origin. Understanding palliative care in the country of origin is the first step to putting in perspective the palliative care utilization among migrants in the host country. Thus, in this section, I will discuss palliative care in low- and middle-income countries, although not all non-Western countries are listed as low- and middle-income countries. I chose low and middle-income countries as most of the migrants in Denmark are from this area. The largest national groups of migrants in Denmark come from (Turkey, Pakistan, Ex-Yugoslavia, Iraq, Lebanon, Somalia, Eritrea, Afghanistan and Syria) (34, 35).

About 78% of adults needing palliative care live and die in low- and middle-income countries (6). The massive burden of life-threatening diseases, including cancer, cardiovascular disease (CVD), human immunodeficiency virus infection (HIV), and others, such as sickle cell disease, associated with physical and psychosocial suffering, illustrates the need for palliative care in this area of the world (36). Despite the documented need, palliative care is either limited or not integrated into the national health systems of low- and middle-income countries, restricting access to palliative care in countries that need it most (37). Even though successful palliative care exists, there are different service delivery models in low- and middle-income countries compared to the West. For example, in India, Kerela has shown significant progress in primary palliative care over the past three decades. In India, where millions live without access to primary healthcare, Kerala's community participation model shows an efficient, low-cost, low-technology and equitable palliative care service provision (38). Generally, access to essential pain control medicines, particularly oral morphine-equivalent opioids, is minimal and fails to meet international conventions in low and middle-income countries (36).

Moreover, improving access to and using opioids has been primarily ignored among regulators, health professionals, patients and their families due to the misconception and fear that will result in non-medical use and opioid addiction

(6). There is a general lack of national policies recognising palliative care as an essential component of healthcare. In addition, there is inadequate or non-existent palliative care training for health professionals (37). According to WHO, inequalities in palliative care are caused by limited awareness about the benefit of palliative care among policymakers, health professionals and the public (36). Finally, social and cultural barriers, i.e. disclosure of life-threatening disease to the patient and connecting palliative care with death and dying (36, 39, 40). Even Cicely Saunders recognised the risk of perceiving palliative care negatively due to its association with death: “How could we make sure the hospice was not seen as a death house'?” (41). Despite the WHO's definition being 20 years old, palliative care tends to stay related in the minds of health professionals and individuals as entirely related to the last weeks of life (36). This connection to death leads to difficulty with timely access to palliative care and acceptance among patients with palliative needs and their families.

The inequalities in the palliative care service provision eventually reflect the research contributions. Therefore, most research on palliative care has been carried out in high-income countries. A previous study documented an enormous deficit in the palliative care research output between high-income and low-and middle-income countries (42). As a result, the palliative care practice, preferences and challenges of patients in low and middle-income countries are not as well recognised as in high-income countries. Indeed, it is essential to increase awareness of palliative care; otherwise, it may hinder public acceptance of evidence-based care service provision. Limited research activity in low and middle-income countries explains the unfamiliarity or unwillingness of potential participants from migrant backgrounds to participate in research projects (43, 44).

Palliative care has been recognised under the human right to health since 2000 (45). Eventually, many countries have integrated it into universal health coverage, including Denmark (37). However, non-Western migrants in Denmark experience barriers to accessing palliative care services (7, 8). Standardised palliative care interventions in Denmark are generally directed with limited relevance to this group. The current palliative care practice in Denmark challenges non-Western migrants with limited Danish proficiency, limited information about the existing services, and culturally different view regarding palliative care treatment close to death (7, 46). Migrant patients with palliative care needs are less likely to receive equal healthcare when one-size-fits-all approaches are used for palliative care interventions (4, 7, 8). Thus, attention to migrants and their palliative care in this research was warranted to ensure equal care service provision. To ensure equality, palliative care intervention needs to be better tailored for this group considering context, need, focus, flexibility, and social and cultural relevance (28, 47, 48). To date, several Danish research projects have shown that engaging individuals, family members, patients, community groups and organisations in decision-making about their health can potentially reduce health inequalities (49-52). However, in Denmark, there is a lack of palliative care practice and research on intervention development engaging respective health professionals and non-Western migrants. Thus, in this PhD thesis, a supportive palliative care intervention was developed by engaging non-Western migrant patients with/without life-threatening diseases, family caregivers and health professionals. The intervention development process directs to the subsequent section, where the overall aim and research questions are presented.

## Overall Aim, specific aims and research questions

The overall aim of this PhD thesis was to develop a supportive intervention towards non-Western migrant patients with a life-threatening disease in need of palliative care and their families through three studies with the following aims and research questions consequently:

- **Study I**

  **Aim of study I** - To identify and describe the European evidence on opportunities and barriers to access and utilisation of palliative care among non-Western migrants

  **The research question of study I** - What is the European research-based knowledge about care experiences and perspectives of non-Western migrant patients with palliative care needs, family caregivers and health professionals?

- **Study II**

  **Aim of study II** - To explore the care experiences while utilising palliative care services of non-Western migrant families from the perspectives of patients, family caregivers, and health professionals in Denmark.

  **The research questions of study II**

  a. What do non-Western migrant patients and family caregivers find important and challenging while using institutional palliative care in Denmark?

  b. How do health professionals experience possibilities and challenges in providing palliative care for non-Western patients and family caregivers in Denmark?

### Study III

**Aim of study III** - To describe the development process of a theoretically informed, evidence-based intervention for non-Western migrant patients with palliative care needs and their families in Denmark.

**The research question of study III**: What is the process of developing supportive palliative care intervention for non-Western migrant patients with the life-threatening disease and their family members?

# 02 Conceptual Framework

This section follows an examination of the overall conceptual framework that guided this PhD study, following definitions of significant concepts: Palliative care – concept and context, Contextualisation of migrants in Denmark, Culture and palliative care, Inequality, Patients in palliative care, Stakeholders, Family caregivers, and Person-centeredness.

## 02.01 Palliative care – concept and context

Following the Danish national board of health, palliative care is a multidisciplinary approach which aims to relieve physical, psychological, social and spiritual symptoms resulting from the onset of life-threatening diseases (53). Balford Mount developed modern palliative care from its roots in the hospice movement founded by Cicely Saunders, St Christopher's Hospice in England, in 1967. Cicely Saunders was a nurse and social worker who later trained as a physician and described the concept of ''total pain'' as a holistic approach to a patient's pain and suffering. It is about understanding pain as one complex phenomenon and interaction between physical, psychosocial, social and spiritual dimensions (40, 54). She aimed to improve the quality of life of the dying by providing relief of the ''total pain'' through the interdisciplinary model of palliative care by emphasising the importance of clinical care, training, and research (40, 54). Inspired and informed by the hospice in the United Kingdom (UK), Balford Mount created a hospice-style inpatient unit in a Canadian hospital and first coined the English term ''Palliative care''(40) in 1974. The success of St Christopher's Hospice led to speared hospice development within the UK and the rest of Europe around the 1980s. In Denmark, palliative care has been an emerging arena since the late 1980s, and the first Danish hospice was established in 1992 (55). Historically Danish palliative care evolved and, until now, primarily focuses on cancer patients, among other reasons, because it is easier to identify the transition from curative to palliative care among these patients (56). However, since 2017 Danish national board of health has extended palliative care to anyone with a life-threatening disease (57). Therefore, it remains suitable for cancer patients, and still, it includes people with other life-threatening illnesses, such as CVD, chronic obstructive pulmonary disease (COPD), and dementia.

The European Association for Palliative Care (EAPC) distinguishes palliative care into two levels - specialised and general palliative care (58). Specialised palliative care (SPC) is care provided by health professionals with specialised training. They provide palliative care exclusively, with a multidisciplinary approach and mainly to patients with complex needs, e.g., hospices, palliative care teams, and palliative care units in hospitals and nursing homes (58). Health professionals provide general palliative care with basic competence in palliative care. It occasionally serves patients in the palliative phases of their diseases, e.g., nursing homes, general hospital wards and home care (58). Palliative care includes different types of services, though the structure of these services may differ across countries (59). In Denmark, like many other countries, palliative care service provision is organised in specialised and general settings (57). Health professionals in general settings ideally relieve symptoms and address the needs of the patient and family members from the time of diagnosis (57). Patients with complex needs which are not adequately managed by other treatment options are referred to SPC (57). In Denmark, around one-third of patients receive SPC, and most (89%) have cancer (60). Thus, the majority of palliative care efforts should be directed towards the general level, making palliative care a task almost all health professionals should be able to perform (61).

Danish healthcare settings follow the WHO definition of palliative care from 2002, which is based on the concept of ''total pain''. According to the definition, palliative care is an *''approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering through early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual*'' (62).

Since 1974, the term ''Palliative care'' has evolved in its definitions and thus in its tasks and goals. There remains a lack of consensus on the definition. The Lancet commission of pain and palliative care mentions that the WHO 2002 definition is inappropriate for low- and middle-income countries and limited resource settings. Thus, they recommended revising the definition by including three specific features, 1. Not to limit access to palliative care based on prognostic limitation, 2. Consider all settings and levels of care, including general and specialised care, and 3. To include care for complex acute or chronic life-threatening or life-limiting illnesses (6). Following the recommendation, the International Association for Hospice and Palliative Care (IAHPC) developed a global consensus-based new definition of palliative care. The new definition of "*Palliative care is the active, holistic care of individuals across all ages with serious health-related suffering due to severe illness, especially those near the* *end of life. It aims to improve the quality of life of patients, their families and caregivers*" (63). Moreover, according to the consensus, palliative care "*can be provided by professionals with basic palliative care training,*" but "*complex cases need a referral to specialist palliative care with a multi-professional team*" (63). The new definition was developed primarily to increase the relevance of palliative care for low and middle-income countries (6, 40). Though developed with consensus, concern was expressed that the definition is too broad and failed to emphasise early palliative care (40). Thus, EAPC has preferred to continue with the WHO 2002 definition, despite its recognised limitations (58), and so did Denmark until now.

In 2020, the WHO made an effort to simplify the language and wording of the 2002 definition to make it easier to translate into different national languages ''*Palliative care is an approach that improves the quality of life for patients (adults and children) and their families who are struggling with life-threatening illnesses. It prevents and alleviates suffering through early identification, proper assessment, and treatment of pain and other physical, psychosocial, or spiritual* problems'' (36). The most common conditions that may need palliative care are also listed in the comment section of the 2020 version, which was missing in the 2002 definition (62). Although, the list is neither exhaustive nor limits the criteria for qualifying patients for palliative care.

I acknowledge that an accurate and consistent definition of palliative care is essential globally. It will provide a common understanding of palliative care concerning defining the population needing palliative care, setting a goal and finding ways to achieve them via clinical practice, research and service development (40). Consecutively, this understanding could be the basis for health and social policy decision-making in palliative care service provision across settings (64). Similarly, I recognise that it might be impossible to have a consensus on the definition of palliative care, irrespective of context. For example, other factors, including culture, resources, and healthcare delivery system, outline how palliative care is perceived, delivered and defined in a certain situation (65, 66). Considering this, I have chosen that this PhD study builds on the WHO's definition of palliative care from 2002.

Different organisations worldwide have used the terms 'palliative care', 'end-of-life care', 'hospice care' and 'terminal care' in different definitions (40, 64). Fadul and colleagues have even suggested changing the name ''palliative care'' to ''supportive care'' to avoid the stigma around palliative care associated with end-of-life (67). The EAPC states supportive care includes "*prevention and management of the negative effects associated with cancer and its treatment*", and it is not a synonym for palliative care because supportive care is a component of oncology care that includes survivors of cancer (58). Considering this, I will not use the term ''supportive care'' instead of palliative care, not even as a synonym. The definitions of ''supportive care'' vary widely, including symptom management in the time of care treatment to survivorship care (68).

Palliative care has evolved (41). Today, in an ideal world, regardless of age and diagnosis, everyone with a life-threatening disease is covered by palliative care (6). It is essential to integrate assessments and support skills early, following the patient's needs and objectives so that patients remain hopeful throughout the trajectory (69). Early integration of palliative care has received more attention in the last decade after Temel and colleagues published their Randomized Controlled Trials (RCTs), which confirmed that early integration of palliative care improves the quality of life of patients with palliative care needs (70, 71). The care can be delivered at any time throughout the disease trajectory, from diagnosis to death, along with curative treatments and rehabilitation (6, 36). By now, it is evident that early palliative care is beneficial and reduces avoidable hospital admissions and the use of health services (36). However, integrating early palliative care into the patient's journey remains challenging.

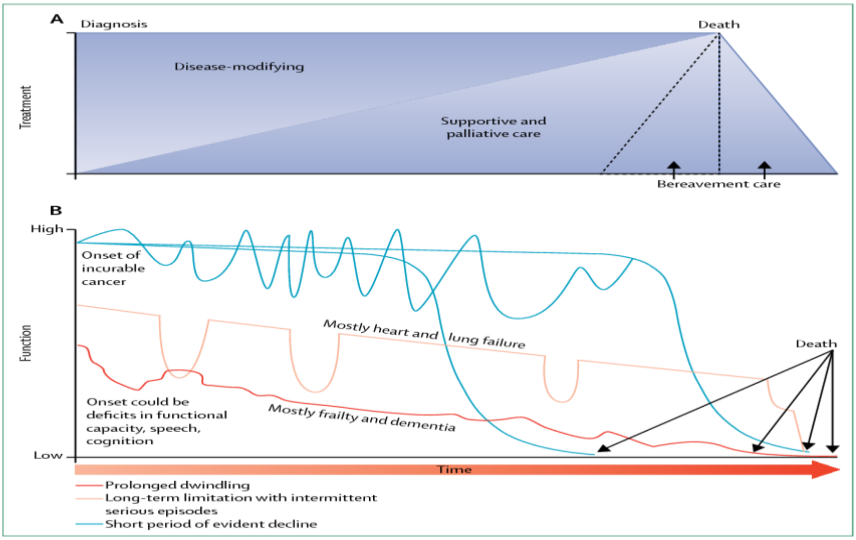

***Figure 1:*** **Integrating palliative care across illness trajectories**

Reprint from The Lancet, Knaul, Felicia Marie, et al. "Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage: the Lancet Commission report." *The Lancet* 391.10128 (2018): 1391-1454, with permission from Elsevier (6).

Figures illustrate although widely accepted models demonstrate a single, linear trajectory from diagnosis to death, patients move in and out of palliative care determined by the disease trajectory around cure, survivorship, and death (6). International development is also clearly reflected in the Danish context. The first national guidelines on palliative care from 1999 focused on care for the seriously ill and dying. Here, the target group was patients with life-threatening cancer in the last phase of the patient's life (53). In the revised recommendations in 2011 and the current one in 2017, the target groups and the time for integrating palliative care have expanded (53, 57). After the Danish Palliative Care Database (DPD) introduction, it is possible to monitor how many patients are referred or admitted to SPC, which is recommended to last more than three months (72). A Danish study reveals that only one out of three patients survived the suggested three months after starting SPC (73). A nationwide cohort study from the DPD confirms that only 37% of all patients dying of cancer are admitted to SPC (74). Thus, a considerable knowledge gap remains about general palliative care and when and how well it is integrated into the patients’ trajectory of life-threatening diseases.

## 02.02 Contextualisation of migrants in Denmark

This PhD thesis focuses on non-Western migrants, as considered in the choice of terminology. I use migrants as an overreaching term, including migrants and descendants comprising refugees and asylum. Considering the context of this study, Denmark, I used the definition of the Danish ministry of immigration and integration regarding descriptions of migrants, descendants, non-western migrants and persons of Danish origin.

*A migrant is defined as a person born abroad. None of the parents is born in Denmark and has Danish nationality. If no information is available on any of the parents and the person was born abroad, the person is also defined as a migrant (34).*

*A descendant is defined as a person born in Denmark. None of the parents is born in Denmark and has Danish nationality. If no information is available on any of the parents and the person in question is a foreign citizen, the person is also defined as a descendant (34).*

*Non-western migrants refer to the group of people originating from countries other than 28 European countries as well as Andorra, Iceland, Liechtenstein, Monaco, Norway, San Marino, Switzerland, Vatican City State, Canada, USA, Australia and New Zealand (34).*

*A person of Danish origin is defined as a person who, regardless of their place of birth, has at least one parent born in Denmark and has Danish nationality (34).*

In Denmark, like other European countries, the number of migrants has been growing steadily over the last half-century, shifting the relatively homogenous society to a gradually progressive heterogeneous society (75). According to Denmark's statistics report published in 2021, migrants contribute 14% of the population. Among them, more than two-thirds originate from non-Western countries (35), and the number will increase in the coming years. Migrants in Denmark tend to settle in major metropolitan cities, including Copenhagen, Aarhus, and Odense (76). I considered concentrating on non-Western migrants as they have increased by six-fold in the Danish population since 1980 and contribute as the majority (64%) of migrants in Denmark (76). Moreover, non-Western migrants mainly originate from low and middle-income countries where palliative care service provision is integrated differently into the healthcare system than in Denmark (77). Finally, non-Western migrants' cultures differ most from native Danes, which may affect health and hinder access to palliative care services (78).

Non-Western migrants in Denmark are a very heterogeneous group. They vastly differ in linguistic, cultural or religious backgrounds and with equally different health, social and economic needs and resources (78). Migrants' socioeconomic status varies and is often linked to their country of origin, but migrants in Denmark generally have a lower socioeconomic status than native Danes. For instance, around 40% of migrants do not have any education beyond compulsory schooling (79). However, this changes very significantly for second-generation migrants. In particular, women who are descendants of refugees or migrants are more likely to enter higher education than ethnic Danes (80). Some migrants came here at an early age, between 1960 and 1970, among others, Turkey and Pakistan as so-called "guest workers", while others came later as family reunified parents or as refugees from, e.g. Bosnian, Syria, Yugoslavia, Iran and Iraq (78). Therefore, migration background and basis for residence in Denmark are also very different (78). Non-Western migrants, however, also have a lot in common, which makes them in need of support in several areas than the majority of the population in Denmark. For instance, their physical and poorer mental health status than most ethnic Danes (78, 81-83). They are often affected by life-threatening, chronic and infectious diseases such as

CVD, diabetes, bloodstream infections and psychological disorders such as anxiety and depression (78, 82-84). The exposure to different risk factors at different migration phases may explain the reasons behind poor health. Pre-migration factors may include poverty, lack of access to healthcare, and refugees witnessing war, trauma, violence and torture (78, 85, 86). During the migration process, it may also include mental and physical stress. Those who migrate willingly for higher education or as skilled worker may be safe for many of these factors (78, 85, 86). However, regardless of migration history, all migrants experience common challenges after migration while starting life in a new country, such as social marginalisation, isolation, loss of identity, or with issues linked to social status, such as discrimination and racism (78, 85, 86). In the healthcare system, all migrants may face challenges associated with 'newness' such as language and communication barriers and service provider factors such as stigmatisation and lack of cultural competencies, which might delay diagnosis and treatment (78, 85, 86). To address the palliative care needs of migrants, understanding differences in disease and illness patterns is essential. However, alone they do not deliver an in-depth understanding of how the lives of migrants affect health and illness. Indeed, these experiences are most appropriate for understanding the ethnic patterning of disease and how palliative care services are needed and used. For example, within one or two generations, cancer incidence rates among migrants are similar to those of the host population (87).

There are some exceptions, though generally, the group of migrants with poor economic conditions and limited Danish language skills are growing in number. A significant increase must be expected to lead to increased demand for public care and concern (88). In addition, the beginning of a breakup in the traditional family patterns, integration of the adult children into Danish society and general orientation towards a more western lifestyle means that families might have more difficulties covering family members' palliative care needs without outside help (7, 8, 88). Therefore, there might be an increasing need for palliative care to be supplemented with and perhaps replaced by public assistance (7, 8, 88). In a time when resources are scarce, priorities are often razor-sharp in municipalities and regions. There is a need to consider how the care can be organised intersectoral (e.g. combining hospitals and municipalities). Thus, the health sector is inclusive for non-Western migrants, for the benefit of non-Western migrants, their families and the municipal economy in the long term.

As mentioned earlier, this population is at increased risk of developing advanced life-threatening diseases (non-malignant and malignant), bringing about physical, psychological and social needs which could benefit from a palliative care approach. As this population continues to diversify, increase in number and age, profound issues like palliative care are becoming significantly crucial to investigation among this population.

## 02.03 Culture and palliative care

Culture is becoming increasingly crucial concerning palliative care in the context of globalization, migration and European integration (89). Culture is "*dynamic, adaptive, ecologically based multilevel and multidimensional system for a population group that creates a social structure. The structure provides its members with beliefs, expectations, and tangible means to achieve a sense of safety, identity, and meaning of and for life" (90).* Cultures are constructed by language, knowledge, beliefs, assumptions, and values that shape how one perceives the world and relates to it. A person's unique characteristics are described by gender, age, race, ethnicity and socioeconomic status (11). Culture and religion are interconnected (11). Religious beliefs and practices can also be a significant element of our connection with others, along with shared values, behaviours, rituals, and symbols. A person's beliefs and values are vital to their sense of identity and may also be expressed in a broader spiritual sense outside formal religious contexts (11). However, not necessarily all members of a group that share practices, language and expressions of belief spontaneously share the same value (91). Therefore, culture does not associate merely with ethnic identity, nor does it simply refer to groups of people with the same ethnic background (91). It is often associated with social stratification, mainly in multicultural societies, that the dominant culture adversely affects life opportunities in lower socioeconomic groups and individuals (90). Considering financial limitations, socioeconomic status produces security and insecurity in every culture that intersects with nationalities, ethnicities, genders, and political ideologies. Thus economic equity is a massive part of cultural representation (91).

Research indicates that differences in cultural attitudes, values, perceptions, experiences and preferences are significant regarding palliative care across and within societies (90). Preferences are complex and influenced by cultural and structural features, e.g., availability, acceptability, accessibility, and knowledge about available services. Besides forming preferences, religion and culture influence how we see the world, thus guiding the decision-making related to palliative care (2, 90, 92). That might lead to ethical dilemmas if palliative care is delivered to diverse populations through the local clinical and ethical framework (93). As the Danish population becomes more diverse, the need to offer culturally competent palliative care increases. Cultural competence is the *awareness of the cultural factors that influence another's views and attitudes and assimilating that awareness into professional practice* (91). Thus, health professionals need curiosity, humility, willingness and flexibility to understand and respond to patients' beliefs and how they want to be treated (94). For some patients, it may be inappropriate to inform them in detail about the truth about their life-threatening disease or to ask openly about treatment planning (94). The meaning of truth is relative and exit in many forms, depending on what an individual perceives as true. Thus, one of the first steps of the patient-provider encounter is asking questions about a patient's cultural background to understand how they perceive their situation, how they learn to make decisions, and what kind of care they would like to receive (95). Thus, there is a need for culturally sensitive and competent cross-cultural communication (90). Although cultural specifics may generally apply to people with similar cultural backgrounds, health professionals should acknowledge that cultural and religious groups are not homogeneous, with beliefs varying within families or across generations (90, 95).

As mentioned, culture is dynamic, merging and changing; cultural diversity ensures that different lifestyles and beliefs exist, providing distinct, autonomous systems of value (90, 91). Therefore, culture is not only habits and beliefs about perceived well-being but also political, economic, legal, ethical, and moral practices and values (91). Most people are unaware of the cultural influences on their moral perspectives. Most people only recognize their cultural influences when the values they ascribe differ from or conflict with those of others (91). For example, in Denmark, patients have a legislative, ethical,  and culturally conditioned right to know about their diagnosis, even if it is life-threatening and thus make an informed decision about palliative care (94). Therefore, the health professionals assume the truth is clear and the patient has ‘’the right to know’’. However, in many societies, the patient has ‘’the right not to know,’’ which health professionals in Denmark find an ethical dilemma challenging to accept (94). Culture can also influence the role of the family in palliative care in other ways. For example, in some cultures (e.g., Asian), the family is the smallest unit, and individual family members cannot autonomously make decisions about illness, treatment, or death (3, 94).

Therefore, patient empowerment and shared decision-making strategies are helpful for patients who believe they can positively change their health by taking responsibility for themselves. Different approaches are required for patients who are not empowered to improve their health. These strategies are generally based on opportunities for engaging with person-to-person and building trust (94). However, culture is not limited to the direct action of health professionals. It

also comprises the priorities of policymakers, researchers and collective behaviours founded on social agreements and assumptions (91).

Using ethnic background as a simplified, straight, and definitive indicator of faith or behaviour leads to risky stereotyping and culturally insensitive palliative care for the individual (94). Culture is meaningful when it is understood in light of the individual migrant patient’s history, family structure, patterns of decision-making, and socioeconomic status (94). Predicting a patient’s preferences and values is impossible by classifying the individual into an ethnic group (94). For diverse communities, cultural consideration can include but is not limited to the preferred language used, disclosure of diagnosis and prognosis, the role of family and their involvement in decision making, preferred setting of care, personal care rituals, diet and food choices, ways of conceptualizing and customs around death, burial and bereavement (95).

Everyone is influenced by their cultural background (96). Avoiding cultural conflicts does not require that health professionals be experts in a wide range of cultural beliefs and practices (91, 94). Professionals can listen to patients and their families from different cultures to learn about their attitudes, preferences, and practices and incorporate them into an appropriate care plan (91). Achieving equitable and high-quality care for people with life-threatening diseases requires acknowledging cultural systems of value and understanding and respecting cultural diversity in research and palliative care practice (90, 91).

## 02.04 **Inequality**

The Nordic welfare states of Denmark, Iceland, Finland, Norway and Sweden have been recognized for their active labour market policies, high similarity, and universal approach to delivering and financing welfare benefits and services, including healthcare (97). The universal approach allows the migrants with legal residence to have equal access to healthcare in the country as other citizens (97). However, legal rights often differ from what is in practice or functioning in the real world (97). Previous literature has mentioned several factors that may have contributed, such as language difficulties, poverty, poor knowledge of the system, and cultural, spiritual and existential differences that hinder access, consequently indicating that the outcome might not be equal (85, 97).

The health and well-being of an individual is a complex interplay of genetics, upbringing, social relations, environment, experiences, and social living conditions, and the help an individual can receive from the welfare state when needed, for example, education, health and social support (94). Dissimilarities in these elements generally result in alterations in health status. Health inequalities defined as "*Social inequities in healthcare is a systematic difference in health status among diverse socio-economic groups. These inequities are socially produced, unfair and therefore modifiable*" (98). However, the definition is not universal. Definitions, thus understanding the concept of health inequalities, varies across continents. Such as, in the USA, health inequalities apply to the differences in health status between groups that are not necessarily unfair, such as the probability of death being higher among the elderly compared to young adults. ‘‘Health inequity’’ is linguistically the correct term to define unfair dissimilarities resulting from social injustice. According to WHO, equity is the absence of unfair, avoidable differences among different groups defined by their social, economic, geographical and/or other aspects of inequality (e.g. ethnicity, sex, disability) (99).

Further confusion may arise with the term ‘health disparities’, described as the differences in opportunities to achieve optimal health usually experienced by socially vulnerable populations (100). Thus, health equity and health disparities are connected. Health equity is the social justice in health, and health disparities are the standards to measure improvement towards achieving health equity. Consequently, health equity is achievable by reducing health disparities (99). In Europe, health inequity is not usually used, and health inequalities are used instead, or both terms are used interchangeably (101). In this PhD, the term health inequality is understood in the light of the definition on page 37. It briefly and effectively represents the basic principles of health equity and health disparities and why it is inevitable to eradicate them.

## 02.05 Patients in palliative care

There is no consensus about the definition of the patient population in palliative care (102). Therefore, it is difficult to define the patient population in research and clinical practice, thus to decide when patients need palliative care in their illness trajectory. There has been an effort to describe palliative care in terms of phases and trajectories of a patient's illness to understand better the target group and timing of palliative care (103). Early-phase patients have incurable illnesses that have low symptom burdens and receive active curative treatment and palliative care; late palliative patients have incurable illnesses with less than one year to live. Progressive symptoms and curative treatments may be offered in addition to palliative care (103). Those who are expected to die within days or weeks are in the terminal phase after curative treatment is completed and palliative care has been provided (103). The Gold Standard Framework (GSF) developed three proactive identification guidelines for care providers to identify patients in the last year of life for better provision of high-quality palliative care (104). These include a. the surprise question, ‘Would you be surprised if this patient were to die within the next few months, weeks or days?’, b. general indicators of decline and increasing needs and; c. specific indicators related to single/multiple organ failure, for example, supportive and palliative care indicators tool (SPICT) (104). Culturally adapted SPICT helps Danish health professionals to identify individuals at risk of deteriorating and dying with life-threatening diseases irrespective of the condition and setting (105, 106). In study II, non-Western migrant patients with palliative care needs were included. In this thesis, they will be referred to as patients.

## 02.06 Stakeholders

Engaging stakeholders is one of the core elements of the latest MRC framework (107). According to MRC, stakeholders are those affected by the intervention or policy and those involved in its development or delivery (i.e. those with a stake in the topic). Professionals, patients and the general public all are involved (108). It is suggested to engage stakeholders early in the research process and continue throughout the development, evaluation and implementation (108). Many stakeholder groups exist, e.g., patients, consumers, providers, researchers, the general public, and policymakers. In the updated version of the MRC framework, stakeholders from professional groups and Patient and Public Involvement (PPI) are described independently (108).

Similarly, within palliative care, stakeholders include professionals (e.g. service officials, health professionals and academics) and lay people (e.g. patients and their family caregivers) (109). Most literature focuses on engagement with the general public, patients, and community stakeholders. Within palliative care also in general, user involvement (In Danish: brugerinddragelse) has received considerable attention in Denmark and internationally in the form of other comparable initiatives such as PPI, participatory approaches and public engagement (110-113). However, there is no gold standard on who they are “stakeholders”, when to involve them in the research process and how to define their ‘‘involvement’’(112, 114). Depending on the context, other terms for involvement, such as participation, partnership, collaboration, engagement, and co-production, are also used in the literature (112, 114, 115). Following the MRC recommendation, in this PhD, multiple stakeholders, including patients, the public, and health professionals, were involved at different stages of the intervention development process (108).

In this PhD thesis, I used the term key stakeholders for the patients and the public. In studies II and III, key stakeholders include non-Western migrant patients with and without a life-threatening disease, respectively and family caregivers. In studies II and III, key stakeholders shared their lived experience of utilising health and social care services. In addition, I used the term professional stakeholders for the social and health professionals. In studies II and III, the professional stakeholders shared their clinical experience of providing palliative care towards non-Western migrants within the Danish health and social care system. The professional stakeholders include physicians, nurses, physiotherapists, health consultants, social workers and psychologists. I have discussed how stakeholders helped to develop the intervention in the co-production via workshops in study III under methods of data collection.

## 02.07 Family caregivers

Within the scientific literature, family caregivers are called family members, informal caregivers, caregivers, relatives or careers (116). They may or may not recognize themselves as family caregivers but are often involved in providing care and support.

The National Institute for Health and Clinical Excellence (NICE) states that family caregivers are people with a close social and emotional bond, not just those related by kinship or marriage (117). Family caregivers are crucial in palliative care and decision-making in different cultural contexts since they influence caregiving and dying experiences. In palliative care, family caregivers contribute to direct care, goal-setting, decision-making, and advanced care planning (ACP) (118). ACP is *"a process whereby a patient, in consultation with health care providers, family members, and important others, makes decisions about his or her future health care*" (119). Family caregivers have many tasks including, but not restricted to, providing physical, practical, and/or emotional care, social and financial support, being a spokesperson, and overall coordinating all aspects of the palliative care of the patient with a life-threatening disease (120). In addition to meeting physical and practical needs, they can also meet spiritual and existential needs, particularly when patients are experiencing spiritual and existential distress due to the nature of their illness (17). Family caregivers and health professionals often have a fundamental role in providing care, irrespective of whether the patient is in a formal healthcare setting or a home setting (121). Research among the migrant population indicates that family members wish to be involved in their loved one's palliative care. Although, how family caregivers are involved in palliative care also differs. Some cultures believe caring is the family's duty and obligation, so they actively participate in patient care. For example, in some cultural groups (e.g., Asians), extended family members may make palliative care decisions and provide care (3). Research reveals that migrant families from cultures that follow filial piety influence the patient's palliative care treatment options (13, 16, 17). However, the burdens caused by filial piety on the younger generation of migrants can create a set of uncertainties about how children want to involve in family caregiving in the context of palliative care (122). There are multiple existing synonyms of the term ’’family caregiver’’(116). This study defines family caregivers in a broad context (117). I have used “family members” and “family caregivers” interchangeably.

## 02.08 Person-centredness

Palliative care emphasizes holistic, personalized, family and team care and incorporates principles of person-centred care (123-125). Person-centred care identifies that patients are at the centre of care (123, 124). Being sensitive to patient circumstances and life stories, needs, preferences, and values, and incorporating knowledge of the patient and the health professional's competence to provide the best possible quality of life to the patient (and their families) (94, 123-125). In light of this, the palliative care and services that are provided to non-Western migrant patients with life-threatening diseases truly reflect the principles of person-centred care, for example, providing care for the individual and whole person in a dignified and humane way. Person-centred care with non-Western migrants with life-threatening diseases is to be open to how they describe, recognize, or interpret their illness. Therefore, person-centeredness concerns how cultural beliefs influence symptoms, distress, the pattern of help-seeking, and what constitutes a positive outcome for an individual (126).

In paper 3, I have used the term patient-centred. The discrepancy in terminology may be partly explained by the fact that the terms ‘patient-centred’ (125, 127) and ‘person-centred’ (36, 128) have been used in palliative care. Scholars found it challenging to entirely distinguish one from another as the key elements of the two care philosophies are similar, including a few differences (128). Despite differences, both terms are used interchangeably within palliative care (129). In light of this consideration, in this thesis, I will use ‘’person-centred’’. However, this does not exclude the view that all patients are persons.

# 03 Methods and Results

I arranged the section ‘’Methods and Results’’ inspired by Creswell and Creswell's ‘’three components involved in determining research approach’’(130). They mentioned that the research approaches (e.g. qualitative, quantitative) are the plan to conduct research. This plan involves the intersection of philosophical worldview (e.g. constructivist, pragmatic), research designs (e.g., qualitative, ethnographies; quantitative, experiments) and specific methods (e.g. data collection, data analysis) (130). They argue that the researchers must consider the philosophical worldview assumptions that convey to the study, the research design related to this worldview, and particular research methods that translate the approach into practice (130).

Creswell and Creswell used worldview (over paradigm or epistemology and ontology), which is ‘’a basic set of beliefs that guide action’’. They see **the worldviews** as philosophical aspects concerning the world and the nature of the research that researchers bring to the study (130). The second element, **research designs**, provide a particular direction for procedures in a research study based on the type of investigation. The final component of **research methods** includes data collection, analysis and interpretation that researchers intend for studies. In sum, the worldview, the designs and the methods all together contribute to a research approach that might be qualitative, quantitative or mixed (130). In the following section, I will explain the overall philosophical worldview of the PhD study. Next, the research design, methods and results will be presented for the three studies.

## 03.01 Philosophical worldview/Research paradigm

I approached this PhD study from a pragmatic worldview/paradigm, which provides an action-oriented framework for the researcher to discover the truth and reality about the investigated issue (131). The pragmatic worldview includes features of positivism/post-positivism and constructivism; and is often related to mixed-methods research (132-134). At the same time, researchers argue that for pragmatists, the suitable method is the most effective one in achieving the desired results of the investigation, whether it is a single method, multiple methods or a mixed-methods (135). Although born in the light of mixing qualitative and quantitative methods, pragmatism is applied in multiple methods, e.g. multiple qualitative methods (136).

Pragmatism is not committed to a system of philosophy but rather arises out of situations, actions and consequences (130). It rejects the traditional philosophical dualism of positivism or post-positivism and constructivism and permits researchers to abandon involuntary separations (130). The ontological assumption of pragmatism focuses on “what works at the time”, the problem to be investigated, and the value of the findings (130, 137). I combined multiple data sources and knowledge to answer the research questions, as I needed to comprehensively understand the phenomenon by exploring the issue from different directions.

Epistemology requires considering how the researcher knows the world and gains knowledge, the relationship between the researcher and that being researched (132). Thus, the worldview of this PhD thesis was concerned with solving practical problems in the “real world” to address the research question (137) rather than assumptions about the nature of knowledge. I valued practical solutions to the issues that suit the aim of palliative care, a problem-oriented and goal-oriented approach to assess and address the multidimensional needs of patients with a life-threatening disease and their family members, as addressed by WHO (36).

Within pragmatism, researchers can adopt a need-based methodological approach, including mixed or multiple methods, to conduct practical and relevant research (132, 134, 138). In essence, pragmatism as a research paradigm attracted me as a physiotherapist. Indeed, pragmatism focuses on practicality over philosophizing and advocacy for shared values, e.g. freedom, democracy, and equality (134, 139). According to Allemang and colleagues, pragmatism is suitable for addressing complex social issues as it is based on democratic values and collaborative approaches to problem-solving (131). Considering ontological, epistemological, and methodological orientations of pragmatism, I used a multi-method qualitative approach from secondary qualitative data analysis, engaging stakeholders to explore the experiences of receiving and providing care. Moreover, health professionals demonstrated which changes are possible in clinical practice, what interventions might work and how, thus, endorsing several realities and subjective viewpoints besides my values.

## 03.02 Research Design

The MRC framework for developing and evaluating complex interventions was applied as the overreaching framework for this PhD thesis (107, 140). The framework demonstrates a nonlinear, reasonably flexible and iterative approach that outlines four phases: development, feasibility testing and piloting, evaluation, and implementation (107, 140). A supportive palliative care intervention was developed following the steps recommended by the MRC framework in this PhD thesis, which is narrowly in the development phase. For the development phase, three stages are recommended: identification of the evidence base, identification or development of theory, and modelling process and outcomes (140).

According to MRC, a complex intervention have several interacting components, including outcomes, characteristics of target groups, and context and tailoring of the intervention is recommended (107). Palliative care service provision, including earlier steps such as identification of patients with palliative care needs, is by definition a complex intervention as it usually includes several components, such as symptom management and care planning (62). Thus, supportive palliative care intervention for non-Western migrants fulfils these criteria as mentioned by Sepúlveda, C. et al. 2002 (62). MRC framework guided the intervention development and helped make appropriate methodological and practical choices throughout this thesis. For instance, the MRC framework calls for integrating qualitative methods to design complex interventions (108). Multiple qualitative methods were used to develop this intervention, from secondary qualitative data analysis to interviews and workshops with stakeholders. By employing a qualitative approach, facilitators and barriers to access were identified, the complex and diverse needs of palliative care service users and providers were explored, and finally, the current practice and contextual factors and implementation challenges were discussed. Qualitative methods are consistent with pragmatism, where research questions can be answered using qualitative, quantitative, or mixed methods (137). Based on a pragmatic worldview and qualitative methods, this PhD study emphasizes participants' perspectives, uses inductive and deductive reasoning, recommends the researcher's role in guiding interpretations, and emphasizes context as recommended by Kaushik and Walsh; and Creswell and Creswell (130, 138).

## 03.03 Methods of data collection, analysis and trustworthiness

### 03.03.01 Systematic review: study I

Study I followed the systematic review methodology by identifying existing studies, selecting and evaluating contributions, analyzing and synthesizing data, and reporting the evidence that allowed us to reach reliable conclusions about what is known and unknown (141). This review protocol was registered with the PROSPERO, a prospective international register of systematic reviews (registration number: CRD42020193651, https://www.crd.york.ac.uk/PROSPERO/display_record.php?RecordID=193651. It is highly recommended that authors publish their protocols before submitting their manuscripts for publication (142). The protocol registered in advance supports transparency, helps to lessen the potential for bias, and assists in avoiding unintentional replication of reviews (143). The systematic review was conducted and reported according to Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) (144).

I searched in four databases: CINAHL, Embase, Medline, and PsycInfo the 22nd of June 2020. A hand search of the included articles and citation tracking in Google Scholar was also done.

The search process started with Medline, where keywords and the thesaurus were recognised, tested and adjusted. The keywords in the databases were discussed with supervisors and with an experienced research librarian (Anne Faber Hansen). Anne supervised testing new keywords and combinations; and suggested developing a board search strategy to have the most relevant hits in this area. This process was time-consuming and challenging. However, it allowed me to see if there is any existing palliative care intervention towards migrants. As mentioned, the systematic review was the first step aimed at developing a supportive palliative care intervention towards non-Western migrants in Denmark. The intervention was planned to be developed, eventually adjusted, and implemented in Denmark. Thus, Denmark's context was considered while conducting the review of the authors. Context is essential when conducting the study and implementing the intervention (145). Denmark is one of the five Nordic countries which adheres to the concept of a welfare state with healthcare as an essential element and equal and easy access to healthcare as a fundamental goal (146). Considering the similarities of the health system, the review initially searched for studies conducted in Nordic countries, but only four studies were found, so we decided to search for European studies.

| Paradigm worldview | Pragmatism | | |
|---|---|---|---|
| Research design | MRC framework | | |
| Methodological approach | Systematic review | Qualitative research design | |
| | Study I | Study II | Study III |
| Studies/Participants | Qualitative studies, n=29<br>Quantitative studies, n=6 | Patients with a life-threatening disease, n=8<br>Family caregivers, n=11<br>Health professionals, n=10 | User panel at the MHC<br>Health professionals |
| Methods of data collection | Medline<br>CINAHL<br>PsychINFO<br>EMBASE<br>Google Scholar | Individual interviews, n= 19<br>Joint interviews, n=3<br>Group interviews, n=1 | Workshops, n=3 |
| Data analysis | Thematic analysis of research articles | Thematic analysis of interviews | Thematic analysis of workshops |
| Results | 35 peer-reviewed articles<br>29 qualitative articles<br>6 quantitative articles<br>Four themes were identified as related to the utilization of palliative care services within Europe:<br>Communication and language<br>Knowledge and awareness<br>Patient preferences, cultural and religious issues; and<br>Lack of resources at different levels of palliative care service provision | 29 participants included<br>8 patients with a life-threatening disease<br>11 family caregivers<br>10 health professionals<br>The analysis identified three themes:<br>Communication between families and health professionals;<br>Building and lack of trusting relations, and feeling safe, and<br>Access to information and navigating in the healthcare system. | 11 participants included<br>5 members of user panel MHC, OUH<br>6 health professionals<br>The analysis identified the intervention including three components:<br>Education and training sessions;<br>Consultations with the health professional; and<br>Coordination of care |

Table 1. Overview of the three studies

However, the provision of palliative care varies between and within European countries (147-149). Still, the European human rights convention has common law to protect the dignity, equality, freedom of religion, and respect for self-determined choice for all citizens near death (150). The common goal of European countries is to provide equal palliative care to all citizens, directing the search for the entire of Europe. The review did not include studies outside of Europe, for example, from Australia or the USA, to avoid even more differences in healthcare compared to Denmark.

The search combined keywords for ''palliative care'' and ''ethnic groups''. After the first search in Medline, the search was adapted to the remaining databases. See **Paper 1, Table 3** for the search strategy in Ovid Medline. Mette Raunkiær (M.R.) and I screened n=6170 records for eligibility, screening titles and abstracts for relevance, inclusion or exclusion criteria and research question. See **Paper 1, Table 2** for inclusion and exclusion criteria. The titles and abstract screening were conducted in Covidence, a screening and data extraction tool for organizing and systematizing articles (151). Afterwards, 116 articles were included for the title and abstract screening and were imported to a classification system in EndNote (152). In EndNote, articles were grouped into include or exclude. The reason for exclusion was stated within EndNote. Moreover, EndNote was used as a reference manager to help format citations (152).

### 03.03.02 Recruiting participants (study II and III)

In concept, palliative care research has the potential to reduce ethnic inequalities. It can help to identify the reason behind inequalities, implement and evaluate interventions to reduce them, and thus support improving quality and innovations in palliative care (153, 154). Researchers must, however, be able to recruit study participants among migrant populations to reduce inequalities through research. In palliative care research, recruiting study participants is challenging due to ethical and methodological concerns surrounding working with patients with terminal illnesses (155). A study reports that recruiting participants with an ethnic minority background in palliative care research is even more challenging (156). I was aware of these challenges from my previous research experience of working with the south-Asian migrants in Denmark with palliative care needs (157). In that project, I failed to recruit a single participant for the qualitative part of the study. Being concerned about the scenario, before my PhD started, I planned to get in contact with the ‘’gate keeper’’. Gatekeepers in this study involved the individuals and/or groups of individuals who were important for gaining access to the research field due to their knowledge and formal or informal connections to the research population (158). I approached both formal and informal gatekeepers to recruit participants. Formal gatekeepers are the ones who have administrative authority to allow a researcher access (159). In this PhD, the formal gatekeepers are professionals working at hospitals, research centres, municipalities, and hospices. Informal gatekeepers are the ones who have no formal authority to allow or restrict the process; however, they can influence the recruitment of the project. In this PhD, informal gatekeepers are the community organizations, influential lead of the community, and respected members of the community, as it is suggested to contact community organizations that can facilitate access to the target population (160, 161). In my PhD, I contacted, e.g. Danish Pakistani Affairs Council. Apart from organizations, key people in the community can also help access, for instance, community leaders and religious leaders (160) f.x. Imam in the mosque. Coming from a Muslim background, I knew it was more appropriate to approach the imam via man. Therefore, my husband approached several Imams in the mosques. Key people in the non-Western community were approached directly to explain the study, including health professionals from the non-Western community and friends. I placed information leaflets (see attachment 1) in Turkish, Pakistani, and African shops, restaurants, and daycare institutions for my kids. However, I did not receive any feedback or enquiries from potential participants. The reasons for not responding are ambiguous and probably have multiple aspects, e.g. mistrust in research or researchers, lack of interest, fear of potential harm, lack of perceived benefit, stigma, mistreatment or exploitation (156, 161). Literature suggests that involving community groups is one of the solutions for recruiting participants from migrants (160-162). However, this strategy did not result in recruiting participants in my PhD study.

I went to present my study to several settings, e.g., departments of hospitals, municipalities and hospices for recruitment. Generally, health professionals agreed to work as gatekeepers to recruit families, which gave me access to potential participants. If any patient or family member showed interest, the gatekeeper conveyed their contact information to me. Of note, I combined different recruitment strategies to recruit participants for this study as suggested by the existing evidence (161, 163, 164).

### 03.03.03 Interviews: study II

Qualitative interviews allow understanding of the world from the interviewee's perspective, unfolding the meaning of their experiences and uncovering their lived world before scientific interpretations (165). In study II, semi-structured interviews were used to gather information from stakeholders (patients, family caregivers and health professionals) with personal experiences, views, perceptions, attitudes, and beliefs related to the research questions, as suggested by DeJonckheere and Vaughn (166). Here I used F for the family, Pt for the patient, R for the family caregiver and HCP for the health professionals with consecutive numbers. See **table 3** and **table 4** in **paper 2** for an overview of the participants.

Before conducting interviews, I was aware of ethical issues (see details on page 77 in the Ethical considerations section) and planned logistic aspects. For example, I distributed an information leaflet (see appendix 1) about this PhD study to get in contact with potential participants. I obtained informed consent (see appendix 2) and arranged and tested recording equipment before the interviews. I was flexible about the interview's time, location and preferred language. I could conduct interviews in Bengali (my first language), Danish, English, Hindi and Urdu. I contacted an interpreter in advance if any participant wanted to be interviewed other than in these five languages. Being able to conduct interviews in five different languages gave me the freedom to conduct most interviews (but one) without the presence of a third party (interpreter). The literature suggests that conducting interviews via interpreters might result in different styles of interpretation and miscommunication with interpreters (167). Moreover, participants might not open up during interviews in the presence of an interpreter

(167). In study II, I avoided using an interpreter at the request of a participant (Pt 3). See table 3 in paper 2 for an overview of the migrant families. The example of the Pt 3 participant is discussed in detail on page 56.

Under the supervision of my three PhD supervisors, I developed a semi-structured interview guide. The interview guide includes three types of questions: introduction, follow-up and probes (168). I initially developed the interview guide toward migrant families based on findings of the systematic review (study I) and other reviews (2, 3, 25) on the experience of migrant families in accessing and utilising local palliative care services. See Appendix 3 for an interview guide for patient and family caregivers and Appendix 4 for health professionals. As a relatively inexperienced researcher, the semi-structured interview guide initially helped me focus on the interview questions. Gradually when I became more familiar with the field, I was better off conducting the interviews spontaneously and still being able to maintain the essential research queries. As the data collection progressed, new questions and additional probes evolved to explore unique aspects introduced by participants in earlier interviews (166). The boundaries of my understanding of the research questions expanded as I investigated further the interviews with the stakeholders. I started interviews with a general and context background question before I moved to more complicated or in-depth questions, as suggested by Britten N. (169). The interviews are a special human relationship where the interviewer or researcher is the tool (166, 169). A qualitative interviewer requires the skill to establish rapport and trust so the participant can share their personal information (166, 169). Therefore, I was conscious of listening empathetically, respecting the participants' information, and encouraging them to share their perspectives. How these tools aided me during interviews is illustrated with a few examples.

In the interviews with patients and family caregivers, I used individual or joint interviews. I chose individual interviews, as I was particularly interested in detailed information about the individual patients’ and family caregivers’ perspectives and experiences with access to and utilization of palliative care. However, families 5 and 15 preferred to be interviewed together, as they wished to supplement each other during the interview. I showed respect for their preference. Indeed, both couples helped each other during the interviews to supplement events. To this end, I did not consider group interviews as an option, as it will risk the participants opening up fully due to the type of sharing of sensitive personal experiences.

DeJonckheere and Vaughn described that awareness of contextual or cultural factors that influence participants' perspectives might be helpful as background knowledge (166). Therefore, being a non-Western migrant helped me understand the factors affecting the informants' perspectives. For example, one of the participants (Pt 3) was offered the option of an interpreter, as I do not speak his language. He refused to use an interpreter and preferred to be interviewed in English, although he was not fluent in speaking. I respected his choice of preferred language and interviewed him in English. I could sense that he refused the presence of an interpreter, as he was afraid of leaking personal information in his community, which he confirmed during the interview. The interview lasted for 104 minutes, giving me a sense that he opened up his personal information, as he was not afraid to share sensitive information. I planned to conduct face-to-face interviews with migrant families. However, after the outbreak of COVID-

19, many families preferred to be interviewed online due to the risk of spreading. It had both positive and negative sides (170). The opportunity to conduct interviews online allowed me to collect data, which was impossible otherwise. However, when collecting data online, I did not have the chance to have an idea of the contextual factors—for example, the living condition of the participants.

A different interview guide was developed for the health professionals. The interview guide was developed based on the interviews conducted among migrant families and the systematic review (study I). Various issues mentioned by the families were raised as an example while interviewing health professionals. Initially, I chose group interviews with health professionals. The emphasis of group interviews has not been on the interaction and dynamics of the informants, as in traditional focus groups (171). Rather the mutual interaction and individual informants' experiences have been given a voice and the opportunity to be elaborated on, as in individual interviews (172). I wanted to explore how participants shared views and experiences to explore further their perceptions of providing treatment/care towards patients with palliative needs from non-Western countries and their families. However, for two reasons, I wished to restrict the group interviews to health professionals from the same department. First, I wanted health professionals from each department to discuss their shared experiences and thus reflect upon their organization’s role in mitigating challenges. Second, I did not want different departments to affect participants’ participation and interaction. For example, mixing health professionals from different departments can restrict the discussion to opening up in fear of sharing internal organization information with other health professionals. As I was concerned that health professionals from different departments might not open up to each other, I considered interviewing professionals and their peers. Although I planned group interviews, I conducted individual, joint and group interviews (2-5 people) face-to-face or online. This was a pragmatic choice based on what was practically possible under COVID-19 and what informants preferred. Thus, I conducted four individual interviews, one joint and one group interview with the health professionals. Except for one, all other interviews with professionals were conducted online. For health professionals, participating online was a time saver in a busy working day.

At the beginning of the interview with health professionals, I welcomed participants, introduced this PhD study, and described the population of interest, patients with life-threatening diseases from non-Western countries and their families. I did this to make the participants consider this specific population when sharing their thoughts and experiences. The group interview was conducted with health professionals during their working time. M.R. and I conducted the interview. During the group interview, I asked questions and facilitated the interview. M.R. acted as a co-moderator by monitoring time, taking notes, and asking follow-up questions. All interviews were audio-recorded.

### 03.03.04 Co-production: study III

Co-production in public services is about "*the involvement of users and public sector professionals in the delivery of public services*". Co-production refers to various relational interactions between service providers and users operating at different levels (individual, group, collective) (173). Moreover, it may comprise several dimensions (e.g., dialogue, practical matters, and cooperation) at different phases of a service cycle (commissioning, design, delivery, and assessment) and aids in generating personal and/or societal benefits for all parties involved (173, 174). Co-production is increasingly being recognized as a reasonable approach to developing intervention, including migrants (47, 175-178). Developing partnerships with stakeholders through co-production is a valuable way to move from research-driven interventions to interventions developed in collaboration with stakeholders (179). It is vital to involve stakeholders with knowledge and experience of existing interventions, the target population and delivery settings to develop a high-quality intervention suitable to the implementation context (175). For example, engaging targeted service receivers during co-production has the potential to confirm that intervention will be developed to address their needs and is acceptable (175). Moreover, engaging service providers help the intervention by addressing practical agendas as they know the delivery setting and have experience implementing previous interventions (175). Increasingly, academics, practitioners, and policymakers are interested in co-production as an innovative way to address the growing burden on welfare states, provide public services tailored to all citizens' needs, and address democratic deficits and inequalities (47, 180-182).

In this PhD, an intervention development group including the research team (the PhD student and supervisors), key stakeholders and professional stakeholders was established to coproduce the intervention content in study III. In the next section, I will describe the co-production workshops in study III.

### 03.03.05 Workshops: study III

Three workshops with key stakeholders (migrants, n=5) and professional stakeholders (social and health professionals, n=6) were conducted, and each workshop lasted two hours. See appendix 7 and 8 for the program of workshops II and II, respectively. I started each workshop with an introduction to the research team, the project, and the workshop's aim. It was necessary to start the workshop with basic knowledge about life-threatening diseases and palliative care among user panel members from Migrant Health Clinic (MHC) at Odense University Hospital (OUH) (see the following paragraph for user panel members). Then, I presented the results of prior research on the systematic review and interviews among patients, family caregivers, and health professionals. During the workshops, participants discussed the applicability of intervention components, activities, and intervention and training materials relating to their experiences as professionals or migrants and community representatives. Participants generated numerous ideas in the workshops. They jointly developed the logic model (See Paper 3, Table 2 for the logic model) and modified it by the research team (consisting of my PhD supervisors and me). After each workshop, I created a draft summarizing the discussion and adjusted intervention components accordingly. Thus, drafts were sent to the other research team members by e-mail. Research team members added, adjusted, and the consensus agreed upon the final draft. Thus, the revised draft guided the next workshop or discussion. The research team discussed and reviewed the formulation and content of the intervention. Two out of three (workshops II and III) workshops were audio-recorded.

Workshop I and II (named Workshop 3. a and 3. b in paper 3) was conducted with a user panel at the MHC at OUH. The MHC is an outpatient clinic that treats migrant and refugee patients suffering from complex, chronic, and unexplained symptoms, often associated with language barriers and compliance problems (183, 184). The MHC initiated a user panel of members from diverse countries of origin, social backgrounds, languages, gender, and age in January 2017. The user panel meet every second month for two hours, with the presence of the clinic's staff, to discuss potential improvements in practice (183). The panel members provide suggestions by focusing on the collective well-being of the migrants rather than making an effort to deal with their concerns. If needed, the interpreter is also invited to meetings at MHC (183, 184). I invited the user panel to their planned meeting to participate in workshops as an advisory group for developing an intervention for this PhD study. Invitations were sent to the members in their e-boks, messages on their mobile phones, and a reminder message on the workshop day. See appendix 5 for participant information and invitation letter for user panel members at MHC – Study III. One of the clinic's staff, Dorthe Nielsen (D.N.), also a co-supervisor in my PhD, attended workshops I and II. The user panel members knew each other and D.N. from their earlier meetings or previous visit to MHC, which facilitated the conversation and enriched understanding. Five and three user panel members participated in workshops I (26.10.2021) and II (29.03.2022). In workshop II, M.R. was also present. Both M.R. and D.N. facilitated workshops and took relevant notes while I was leading the workshop.

Workshop III was conducted on 04.05.2022 (workshop 3.c in paper 3). Health professionals who participated or were approached to participate in study II were invited to attend workshop III on confirmation workshop.  Six professionals involved in palliative care, including three nurses, one health consultant, and two physiotherapists' participated in workshop III. See appendix 6 for participant information and invitation letter for health professionals in workshop III.

In workshops I and II with user panel members, I encouraged them to suggest the health professionals' affiliation in providing supportive intervention. They expressed feeling safer and more secure with health professionals from the hospital rather than the municipality. They told migrants generally lack trust in municipal support due to previous negative experiences. They further suggested that the health professional affiliated with their own doctor could be trusted and helpful.

During workshop III with social and health professionals, I raised the issue of missing trust among migrants from workshops I and II. Social and health professionals could recognize the problem from their practice. Thus, they suggested that collaboration between general practitioners, professionals at the municipality, and the hospital could be a solution to gain trust among migrant families. They also affirmed that continuity of care is especially important among migrant families as it has the potential to facilitate communication and build a trusting relationship.

Moreover, the participants in workshops I-III expressed the need for training among existing health professionals and to engage more health professionals from different cultural backgrounds to embrace cultural diversity. Besides, the involvement of volunteers from the same cultural background to help navigate the healthcare system was discussed. Participants shared the pros and cons of involving volunteers from the same cultural background. Finally, they stressed the need for a volunteer with a professional background who is knowledgeable about the existing healthcare system. Nevertheless, panel members expressed their concern about engaging volunteers from their same original background in fear of leaking family information within the community.

In workshops I-III, participants valued the need for a professional interpreter during the conversation, especially among recent migrants. According to the panel members, recent migrants need the maximum support regarding language, healthcare, and other practical information. Thus, they suggested assessing the individual family's needs through an assessment by the respective health professionals.

Participants of panel members were asked about the language preferences of the intervention material to improve their knowledge of palliative care. All members expressed the need for information. However, they suggested that the information leaflets should be in simple Danish, with and/or without their language. The participants explained that migrants often lack primary education from their home country. Thus, reading information material in their language is inconvenient. Rather information material written in simple Danish would be helpful as the children at home can help to read the leaflet for parents. The social and health professionals also knew that the migrant families with family and social support could better manage the palliative trajectory.

### 03.03.06 Identifying theory: study III

The use of existing theory assists in identifying what is essential, relevant, and feasible, guiding the intervention's objectives and informing its content and delivery (185). I identified a conceptual framework for complexity in palliative care established by Pask and her colleagues (186). Although developed based on specialized palliative care, I found it relevant for general palliative care as the framework is patient-centred and contextualizes how a patient with a life-threatening disease interacts with their context and environment (186). An example of how the theory is applied in the analysis procedure to develop the intervention components is shown in **Table 3**, **paper 3**. The process is uploaded as a supplementary document in **Table S 3**, **paper 3**.

Contextualizing the framework within this PhD study refers to the fact that at the individual level, the migrant patient and family caregiver lives in and interacts with their other immediate family members. Thus, it highlights the characteristics, needs, and migration history of the patients and family caregivers, which might have eventually affected the experiences of access and utilization and/or seeking institutional palliative care services amongst migrant families. For example, a refugee patient from a war region has a different migration history than those migrating to Denmark for education or a better job. At the interpersonal level, it refers to the connections or interrelationships among various individuals, such as patients, family caregivers and health professionals. Therefore, it focuses on the interaction between the patient and family caregivers at home, the patient and their close social network - family members, friends, other support groups and their health professionals. For example, a lack of communication and trusting relationships between migrant families and hospital staff might negatively impact the patient's disease trajectory. The service level is not directly connected to the patient or the family. It still influences how a migrant patient receives palliative care in the Danish healthcare system. These factors might include issues related to the service provision and system, for example, coordination between health professionals at various levels of the health and welfare system or resource availability to provide skill-based training towards health professionals involved in palliative care.

### 03.03.07 Data management

I transcribed all the interviews in the primary language in which the interviews or workshops were conducted. Then I imported the transcripts into NVivoTM, a computerized qualitative software package, to manage and analysis qualitative data. A manual data coding process was also conducted in addition to the transcribed data to have a complete picture.

I wanted to transcribe all the interviews (study II) and workshops (study III) myself to ensure the transcription was close to the participant’s expression and to get familiar with the data material, as suggested by Braun and Clark (187). I transcribed all the qualitative data with a clear marking of the date of the interview or workshop, type of informant (patient or family caregiver or health professional) and context. During transcription, I preserved the participants' choice of words and formulations verbatim. I analyzed transcripts in the interview/workshop language because qualitative data is better analyzed in the source language. However, I slightly changed a few selected quotations for readability when the text had to be translated into English for publication in the journal. A native Danish speaker and a native English speaker checked my translations to minimize the loss in the translation (188, 189). Expressions for laughter, crying, pauses, sighs etc., was marked clearly in the interview or workshop text. It was marked when something appeared indistinct, so I had the opportunity to go back and re-listen to these passages. I used the method in several interviews. I anonymized all interview transcripts and workshops and gave them identification codes. In study II, I used F for the family, Pt for the patient, R for the family caregiver and HCP for the health professional with consecutive numbers.

### 03.03.08 Data analysis

The analyzes in the systematic review, study I are based on a secondary analysis of others' qualitative or quantitative data.

A thematic analysis technique proposed by Braun and Clarke was used to extract the main themes for studies I-III (187), under which the result of the studies are presented. The analysis followed the steps : (a) reading and re-reading articles/transcripts, (b) assigning initial codes to the individual findings of the articles/transcripts, (c) arranging similar codes together under some potential themes, (d) reviewing themes to ensure representation of codes, (e) defining and naming themes and (f) finally presenting the results (187).

In study I, despite including any study design in the review, data was only extracted by qualitatively derived themes from the included studies. The review aims to describe in detail the information on migrants’ facilitators and barriers to access and utilisation rather than the proportions of participants utilizing palliative care facilities.

In study III, to develop the final intervention, I analysed all data materials under the structure of a scheme. I developed the scheme to plot facilitators, barriers and suggestions from study I, transcripts from study II, factors related to this study based on the framework of complexity in palliative care, and transcribed data and notes from workshops. See **Table 3** in study III for an example of the analysis procedure. See the supplementary file (**Table S3**) in **paper 3** for the entire process.

### 03.03.09 Trustworthiness or Rigour

In this section, I will discuss the terms *credibility, dependability, confirmability, transferability* and *authenticity* under *trustworthiness* or *rigour*, inspired by the understandings described by Lincon and Guba (190); and Polit and Beck (191). Several diverse terms are available in the literature to describe trustworthiness in qualitative research, such as rigour, quality, and credibility (191-195). To develop trustworthiness in qualitative research, Lincoln and Guba primarily introduced four criteria, including *credibility, dependability, confirmability and transferability*; they later added *authenticity* (190). However, Morse and colleagues argue that even though reliability and validity are commonly used in quantitative research, researchers should not abandon these terms while discussing rigour in qualitative research (196). Although there are variations in terminology, the soundness and worthiness of the study is the point that all authors address in trustworthiness, rigour, quality, and credibility (196). In this section, I will discuss the concepts and some of these strategies employed during my own research to ensure rigour or trustworthiness in my PhD, including *credibility, dependability, confirmability, transferability* and *authenticity*. The strategies I used to enhance quality within each criterion are not exclusive. Many strategies simultaneously address several criteria. For example, data triangulation addresses *credibility*, *dependability* and *confirmability*. However, I will only describe data triangulation strategies concerning *dependability*.

Credibility refers to the truth and confidence in the value of data, interpretation of data and representation of the data by the researcher. It is one of the most important criteria in qualitative research (191). Strategies to enhance credibility include, e.g. reflexibility, prolonged engagement, data and method triangulation, member checking, audio taping and verbatim transcription, peer reviewing and debriefing and so on (191). Reflexivity is an integral part of this PhD study, as it produces knowledge in a collaboration between the research team and the research subjects. In a comprehensive definition, reflexibility is ''*a set of continuous, collaborative, and multifaceted practices through which researchers self-consciously critique, appraise, and evaluate how their subjectivity and context influence the research processes*'' (197). Throughout the process, researchers need to be conscious about their ''own projections, attachments, agendas, and biases – like an eye that sees itself while simultaneously seeing world'' (198). The concept of reflexibility is often considered a repetitive internal dialogue and critical self-evaluation of the researcher's positionality (199), while actively acknowledging and recognizing this may affect the research process and outcome either positively or negatively (200). Therefore, I needed to reflect on my own position as a migrant researcher. My positionality was not limited to my socio-demographic characteristics, e.g., age, race, gender, ethnicity, and religious belief. My position was also informed by my appearance, migration status, professional and personal experiences, language, beliefs, biases and preferences. During this PhD study, I was conscious that the practical focus and substance of this work might reflect some of my interests and experiences of being a physiotherapy graduate from Bangladesh, working in a spinal cord injury hospital and never hearing the term ''palliative care''.

I did informal patient observation at MHC, OUH and the Palliative treatment clinic at Herlev hospital to gain insight into the research field. I went to patients' homes with respective health professionals and was present during patient consultations at the hospital. A prior agreement was made with respective patients and their families regarding my presence. With prior arrangements with the respective health professionals, I filled out the permission document to observe certain patients. The observation data is not included in the analysis, neither the participants of the studies II and III observed. I did the observations to get familiar with the hospital schedule of the patients, families and health professionals, as I lacked clinical experience in the Danish healthcare system or specific data collection settings. During analysing data, the informal observation helped me to put the role of different stakeholders into perspective.

I started my PhD study eleven years after I left Bangladesh, three years as a student in Sweden and the rest as a migrant worker in Denmark. As mentioned earlier, I never worked as a physiotherapist in the Danish healthcare system. At that time, I was coping with the hardship of my professional identification, facing the world's most rigid naturalization laws in Denmark (201) and learning to live in the Danish language, which seemed far from reality. During my PhD study, I gave birth to our second child and received a permanent residence permit, which gradually shifted my position as a migrant and belonging to Denmark. Having shared the migration experience with the study participants (migrant families), I was positioned as the role of the ‘insider’. That allows easier entry into the field, knowledge about the topic and familiarity with the culture to some extent (202). Being a migrant greatly facilitated my data collection. For example, the families I reached were receptive and cooperative. The migrant families were happy to help me in my PhD study to achieve my goal. They expressed confidence that being a migrant myself, I will be able to recognize and represent their experiences, perspectives, and cultural and religious preferences better than a native Dane. It increased their and my level of comfort and assisted in better communication. During interviews, they often expressed the notion of ‘’our/us’’ for me, contrary to ‘’they’’ to refer to Danish people. However, it also affected interviews, e.g. during interviewing R1 (study II), her father-in-law dropped in the middle of the interview and started to ask me personal questions, which he would not do to a native Dane, I assume. As I was familiar with the culture of how an elderly treats a fellow, I stopped interviewing and continued the conversation with him.

Like my migrant background, wearing a headscarf as a symbol of practising Islam as a religion also paused challenges during interviewing families. For example, in study II, while discussing religious beliefs, I could sense that family 5 became a little uncomfortable at sharing that they are Muslim believers but not practising. Maybe because of my headscarf, they perceived me as more religious than them. Therefore, they were trying to compensate by describing that their parents are very religious. I could sense they felt it occurred for not practising religion. On the other hand, in the same study, while interviewing family caregiver R (3), she shared her religious acts in detail, thinking that I would understand her coping mechanism. For example, she explained how reading The Quran helps her to find peace in her hard time. Therefore, I assume it may be showing my religious identity made some participants from sharing or withholding their position about religion.

My data collection was paused for a while due to my maternity leave. During the leave, the world experienced the coronavirus (Covid-19) pandemic, which shifted most of the data collection from face-to-face to online as described by Coates and Aston (203), and recruitment went slow. The difficulties in recruitment helped to immerse me in the data. I was concurrently analysing the collected data and looking for new participants. My insights, reflections and understanding of the data were slowly changing as my migration status. COVID-19, permanent residency, a newborn and a school-going child developed my belonging to Denmark and my way of interpreting data. Before my own belonging to Denmark, maybe I viewed families' experiences through judging lenses, such as asking myself why don't they go back to their own country of origin if they are struggling here. However, my migrant positioning facilitated my data collection and challenged my analysis. I was aware that the insider's position and familiarity with the researcher bring the risk of placing own values, beliefs and perceptions, and prediction of biases as suggested by Drake (204). As a research team, we represent the combination of migrant and native Danes. Thus, I analysed (Danish and English) content with M.R. As an ethnic Dane, M.R. could see there are more similarities than differences at a personal level, e.g. families wanting to take care of the elderly at home or continuity of care. Our discussions also made me to see the issues embedded in the organisational level of the healthcare system in the provision of palliative care rather than personal, e.g. lack of resources.

In contrast, I was positioned as the role of the ''outsider'' while recruiting participants. Not being a health professional in the Danish health system greatly challenged my recruiting participants (both families and health professionals). It requires enormous time, sufficient resources and huge networking (43). I had to use all my professional and personal networks to recruit participants.

As an outsider to the health professionals', I had a feeling that my migrant background made them withhold from making any comments against migrants in front of me. Ahmed et al. 2011 reported a similar issue; here, the religious view of the researcher (perceived by participants) refrained participants from making comments in front of her (205). I was aware of my limitation in professional experience in the Danish healthcare system. In studies II and III, M.R. helped by asking probing questions during group interviews (HCP1) and workshops (3. c) with health professionals. Moreover, my position as an outsider without experience of having a life-threatening disease or being a family member may have forced me to overlook the experiences migrant families meet in the utilization of palliative care.

My previous experience of conducting qualitative interviews helped me obtain rich information in this study (206). In particular, my ability to speak several languages (Danish, English, Urdu, and Bengali) allowed me to communicate with study participants and ask probing questions. I trained myself to talk to Danish to collect data for this PhD. My Danish colleagues helped me in the process. As literature suggests linguistic diversity gives flexibility in the interview process (207). The participants chose their preferred language for the interview and workshops, mostly Danish. For example, R 2 (study II) migrated to Denmark as a child. Although he speaks Vietnamese with his parents, he preferred to be interviewed in Danish. Unlike recent migrants, the participants who lived in Denmark for longer were more expressive in speaking Danish than in their mother tongue. My imperfect Danish accent was not a barrier while collecting data (study II and III). As the researcher needs to be aware of maximising the space for participants to share their experiences rather than telling their own (202).

As a migrant researcher, I took strategies to reduce my own biases. First, I used triangulation by comparing the same content analysis by my principal supervisor M.R. I wanted to ensure that the data analysis was a trustworthy illustration of the themes in the articles/interviews/workshops rather than the image of my biases. Moreover, my co-supervisors were continually consulted to reflect on the accuracy of the analysis.

Secondly, in this PhD study, knowledge production was interactive rather than one-way. During Study III, I presented the result of studies I and II to participants to reflect on themes related to their personal and professional experiences. Participants could recognize the results, and knowledge was produced neutrally in collaboration with participants, free from my own biases.

Thirdly, during data collection, I asked probes for clarification and summarized the content to the participants at the end of data collection. It allowed migrant families and health professionals to verify and explain any misconceptions or additional information.

Finally, I kept a reflective diary throughout my PhD to document my reflections, assumptions and decision-making, especially after each interview and workshop. It helped me to be more responsive towards differences and similarities between the participants and me. Thus, recording helped minimise the gap between etic (outsider) and emic (insider) perspectives (208).

The *study's dependability refers to the consistency of the data over time and* similar contexts (191). That means a study is dependable if the results are repeated when the investigation is replicated with similar participants in a similar context. Credibility is not achieved in qualitative research until the findings are dependable (191). The dependability of a study is achieved, for example, by data and method triangulation. *Triangulation* is the use of several referents to determine what constructs truth. Triangulation aims to overcome intrinsic bias by involving multiple investigators, data sources, methods and theories. To ensure data triangulation, I involved other researchers in different steps of this study (e.g., data collection and analysis) by peer reviewing and debriefing. For instance, in studies II and III, I recorded reflexive notes after each interview that outlined details about the interview (e.g., strengths and weaknesses), including my own reflections while conducting an interview. Afterwards, I conducted physical meetings with my main supervisor every two weeks and virtual meetings with the entire research team, including two co-supervisors, every three months. Here, I shared issues written in the reflexivity note, and we devised strategies to collect rich data. Moreover, I discussed the analysis of my data related to the research questions with PhD (and other) colleagues at REHPA, *The Danish Knowledge Centre for Rehabilitation and Palliative* Care (studies I-III) and Äldreforskning Syd (Vov-gruppen) at Lund university (study II). Engaging in these discussions allowed me to probe my results and analytical process. To ensure person and space triangulation, I collected data from patients with/without life-threatening diseases, family caregivers and health professionals from different sites in studies II and III. Collecting data on the same phenomenon from different sources gave me the opportunity to validate data through multiple perspectives. To ensure method triangulation, within PhD, I used multiple methods to collect data, e.g., interviews and workshops, to develop a complete understanding of the phenomenon. For example, in study I, I analyzed data from secondary sources. In study II, I collected data through individual, joint and group interviews. The main data source in study II was the

15 migrant families, and then I triangulated these data with the interviews conducted with health professionals.

*Confirmability* refers to the neutrality or the researchers' ability to demonstrate the data representing informants' response free from the researcher's biases, motivation or perspectives (191). Qualitative researchers use several methods to ensure confirmability, e.g., detailed notes of their decisions and the analysis process, audit trial of analysis, peer review and peer debriefing. Peer debriefing refers to meetings with peers to review and explore different features of the investigation (191). In this regard, I discussed the entire research process, including my studies I-III with my PhD supervisors and colleagues at REHPA. Additionally, study II with Äldreforskning Syd, they made important discussion in my written summary of data. Additionally, I used NVivo software. This program helped to organize and manage all data, including a detailed audit trail.  Finally, as a testament to the high-quality research and peer review, three studies from my PhD are published in international peer-reviewed journals.

*Transferability* refers to how findings can be applied to other settings or groups (191). Within the qualitative study, researchers focus on the participants and their experiences without saying this is everyone's experience. The transferability of the study is strengthened by the researcher providing a detailed description of its context, location, and participants and being transparent about the study's analysis and trustworthiness. This vivid picture lets the reader decide if the findings are transferable (192, 193, 195). Therefore, in study II, I provided simple and textured descriptions carefully combined with verbatim quotes from the study participants (see paper 2). Throughout this study, I wanted to provide a detailed and thick description of the research context and the data collection procedure while drawing results. However, there were limits to these descriptions due to word counts in studies I - III. Thus, writing this PhD dissertation allowed me to describe the thesis and the analytical process in detail across studies (I-III), reinforcing the transferability of the findings. For instance, I provided a more nuanced description of the context of palliative care in relation to non-Western migrants in Denmark and their country of origin, eventually, how their background affects ethical considerations; these aspects influenced the data analysis and results.

*Authenticity* is the extent to which researchers fairly and faithfully express various realities and accurately convey the feelings and emotions of informants' lives (191). Qualitative researchers select appropriate study participants to ensure authenticity, providing rich and detailed descriptions (193). The quotes of participants provide readers with a sense of the experience through this descriptive reporting (192). I ensured authenticity in this study by using purposeful sampling to select appropriate participants, and the data collection was participant-focused. To encourage rich data, I asked probing questions for clarification and depth information during interviews and accurate transcription of audio recordings.

Additionally, I used the source language to analyze data recognizing the challenges (e.g., meaning loss, trustworthiness) connected with translation (209). I only translated the representative quotes from the source language, e.g. Danish, to English in this manuscript. M.R. then checked the quotes if the meaning was lost in the translation or expressed the real meaning.

# 04 Ethical considerations

In this section, considerations of ethics across studies II and III are outlined. Study I was the secondary analysis of studies conducted by others, so I did not collect ethical permission from the participants. However, ethical consideration was shown while analysing, interpreting and representing secondary data. I did not want to either over-interpret, misinterpret or manipulate data through the research process. I had some responsibilities while conducting a systematic review, including acknowledging contributors, declaring potential conflicts of interest, and avoiding plagiarism, as suggested by Wager and Wiffen (210). The following section is organised into three overall headlines informed consent and ongoing consent, privacy and confidentiality and risks and benefits.

This section will describe my ethical conduct concerning study II and II participants, including migrant patients with/without life-threatening diseases, family caregivers and health professionals. Although I followed overall ethical considerations for all participants while explaining concerns, I will mainly refer to migrant patients and family caregivers. As evidence suggests that migrant families with/without life-threatening diseases are even more vulnerable because of physical symptoms and emotional status (156, 211). Thus, in my study I needed to pay more attention to the ethical rules regarding the participant migrant families.

The Region of Southern Denmark ethics committee assessed that according to Danish legislation, the study was not subject to ethical notification (journal number 61269). The PhD study was recorded with The Danish Data Protection Agency (journal number 10.109). This PhD study's ethical considerations are based on the Helsinki Declaration (212).

There is no doubt that palliative care poses ethical challenges for researchers, primarily because of the vulnerability of those receiving treatment and the difficulties related to the disease trajectory (155). For example, in study II, participant patients receiving palliative care were vulnerable because of their physical or other symptoms, and the patient's family members were vulnerable due to their experience of severe mental distress.

It was even more challenging for me to define ethical considerations in this study as it involves patients with life-threatening diseases, family caregivers and health professionals from different cultures with a unique and often conflicting definition of ''what is ethical''. Thus, the complexity was impossible to solve with the help of existing ethical principles and guidelines (39, 43). It is the ethical responsibility of the investigator to ensure scientific rigour while considering the significance of the issue and the need to come up with valid data to inform the research process (213, 214).

## 04.01 Informed consent and ongoing consent

In studies II and III, oral (for online) and/or written (for face-to-face) informed consent was obtained from participant stakeholders, depending on the mode of data collection. Like many other migrant groups, non-Western migrants may face language barriers, particularly in written comprehension. Inspired by van den Muijsenbergh and collegues, the informed consent form was written in simple language, using short sentences, without any references to legal issues and finally was piloted (215). The consent form was in Danish and was translated into the preferred language for those who do not understand (see appendix 2). The word selection of informed consent was challenging because patients and family caregivers often associate palliative care with terminal care and death. Thus, I had to search for ways to diminish the emotional impact of the patient information material. The wording of the information material was chosen to be easily understandable. The precaution was taken so that the wording did not convey a negative feeling among the patient and the family members, as evidence shows that non-Western migrant patients and family members are highly sensitive towards words like cancer, death, dying, and terminally ill (13, 94, 164).

During my PhD, I learned that informed consent is a process in human research rather than a one-time endeavour, requiring planning, enough time and resources. I carefully constructed the informed consent process and was engaged in discussions with the participants (patients and family caregivers) who did not know about the research process. For instance, after receiving personal information from the gatekeeper health professional, I visited or called the patient or the family caregiver. I talked to them casually to build up rapport and made an effort to explain the interview process eventually and how their experiences would contribute to the research. These procedures were time-consuming. For example, I sent out an information leaflet in Danish and English to explain the project's aim (see appendix 1). I added my photo purposefully to inform that a migrant conducts the research following the suggestion within migrant health issues. Literature suggests that including research team members who share aspects of the lived experiences and the cultural and linguistic background of the migrants can enhance recruitment and the overall research process (43, 202, 216, 217).

Although informed consent lies at the heart of ethical guidelines that researchers follow, there is still ambiguity about whether and how it is accomplished in practice, particularly for different cultures (156, 211). For example, in one case, I called a family caregiver, and we talked for 45 minutes. He spoke openly about his situation and heard about the project but did not want to participate. I assured him that the information would be kept confidential; still, he was not convinced to provide informed consent. I sensed that he lacked trust and knowledge of the research project. He kept asking if it would positively change her mother’s treatment. When he was assured that participation would not directly affect his mother’s treatment, he declined to participate.

In most non-Western cultures, usually, the male, e.g. husband, makes decisions for his wife (218). Thus, the gatekeeper health professionals in this study need to obtain consent from the relevant decision-maker in the family first before approaching the potential participant. For instance, during recruiting participants for study II, a wife was diagnosed with a life-threatening disease in one family. The gatekeeper had the cultural sensitivity of working with individuals from different backgrounds. Thus, the gatekeeper approached the husband for his consent if the wife could participate. The husband was already disappointed that the health professionals had disclosed the life-threatening disease to his wife. Conveying bad news to the patient is often considered to accelerate death in many cultures (94). He was afraid that participating in my PhD study would make the wife more exposed; he did not allow his wife to participate. In western ethical research, it may be a dilemma where a potential participant is excluded from information and decision-making.

Before conducting the interviews, group interviews and workshops, I mentioned the purpose of the study, the types of questions participants are supposed to answer during interviews and group interviews (families and health professionals), including the potential risks and benefits of participation. Considering the physical and mental state of the participant patients and family caregivers, I asked participants on an ongoing basis if they wished to continue to be in the study and allowed enough time for participants to review the consent form and answer any queries they had during interviews. It was challenging during video interviews. To solve the issue, I sent a brief interview guide and the consent form to the participants in advance, so they could think about it and give consent eventually. During video interviews, participants gave verbal consent, and consents were audio recorded before initiating any interviews.

## 04.02 Privacy and confidentiality

I explained the issue of privacy to all the participants before data collection. In study II, during individual interviews, I explained to the participants that I would prefer to talk to them individually. The preference was made based on the result of study I, which shows that talking about life-threatening diseases or death is not expected within migrant families to protect others from mental distress (219). Therefore, I was careful that their concern for each other might affect the data quality. However, I was flexible. Patients and family caregivers in study II were interviewed in families (no. 5 and 15). They expressed the need to be interviewed together so that they could refer to each other for support. In another case, in study II, family members were around while interviewing Pt (7). The patient expressed the need for family members around him for mental support.

Health professionals' mostly participated online from their workplace or home.

I clarified to the participants that I would like to interview them in privacy; however, it was challenging for one relative, R (1), in study II. We chose a time for the interview when no one else but the patient was at home to ensure privacy. So, the patient was in the room during the interview as she (R1) was the only caregiver for her mother-in-law. It was interesting to note that, after 28 minutes of the interview, the father-in-law dropped into the home without notice. I could see the participant was uncomfortable talking in front of the father-in-law. For example, suddenly, her answers were short and went in the opposite direction from our previous conversation. So I stopped the interview and clarified the issues privately with the participant afterwards.

By reflecting on the importance of my data material, I considered privacy. I was open to meeting participants outside their homes if necessary. I knew that it might be difficult for both patient and family caregivers to share experiences in front of each other. For example, in study II, Pt (6) was interviewed in a shopping centre. While conducting my PhD, I established a sophisticated understanding of the original issues so that I could negotiate creative solutions to resolve them. For example, in study II, R (9) wanted to participate in the interview but pushed the appointments thrice. I have been to their home to interview his father, so I knew that the apartment was tiny, and there were many people around, so it might be difficult for him to maintain privacy. I offered to come to my place so we could talk in privacy, and then he accepted my offer and came to my home. However, I was open to conducting interviews at the preferred site of the participant. The participant could not tell me he did not want to be interviewed at home. I had to sense the issue and come up with options for him. Confidentiality poses challenges while researching some small communities among non-Western migrants (43). For example, Pt (3), in study II, refused to use an interpreter during the interview. He was afraid of spreading his private information in the community in the presence of an interpreter. We agreed to interview in English, although English is not his first language. Considering the privacy and confidentiality of the participant's personal information, I interviewed them in their preferred languages.

All of the collected data were stored strictly confidential. All the electronic data and audio recordings were saved in a password-protected folder. I assigned a unique identifier code to ensure privacy and used pseudonyms in all written materials (i.e., transcripts and research reports) that were produced from the data collection. I anonymized transcripts by removing identifying information such as people's names and places.

## 04.03 Risks and Benefits

The researcher needs to considered the risks and benefits the study might give the participants (220). Some participants had individual benefits from participating in this study. Some described how sharing experiences via interviews made them reflect on issues in palliative care they had not previously discussed. Families and health professionals might have felt contentment and satisfaction with the possibility that their contributions will inform how the Danish healthcare system might better support palliative care for migrant families. The potential risks in this study could be that some questions may provoke feelings of sadness, vulnerability, or frustration in study II. The potential risks in this study were minimal, and I continually tried to balance them.  For example, in study II, family caregiver R (3) expressed her frustration during explaining how her husband was informed about the life-threatening disease diagnosis in a hospital unit without the presence of any relative. She started to cry while telling the story. I stopped the interview and tried to comfort her by holding her hands. However, comforting and solidifying the participants with physical support was not always possible. Due to COVID-19, several interviews were conducted via video call. During video conversations, I made every effort through my communication to ensure that participants felt comfortable and safe. I informed participants that they could skip any question they felt uncomfortable with or did not want to answer.

Moreover, I was cautious of the language used during interviews, particularly concerning death, dying, and cancer. Furthermore, I paid close attention to the language used by participants to talk about death and dying. I actively avoided it if the participants did not mention those words.

Indeed, I did not have enough knowledge of the method, data collection and analysis, so I was supervised by experienced supervisors Mette Raunkiær, Helle Timm, and Dorthe Nielsen during my PhD study. In the presence of all supervisors, the authorship roles and order in each study were discussed and agreed upon before the article writing process in the PhD meetings. Moreover, in all three articles, each author's role in the “Author contributions” section was mentioned to ensure transparency.

# 05 Results

In this PhD thesis, three studies were conducted. The first was a systematic review (Study I), the second was a qualitative study (Study II), and the third was the development of a supportive palliative care intervention (Study III). In particular, the findings of study I informed the interview guide for study II and contributed nuance to the empirical data of my subsequent studies (Studies II and III). The findings of studies I and II directed the workshops with stakeholders. Moreover, results from studies I and II, inspired by the theoretical framework of complexity in palliative care (186), shaped the basic foundation of the logic model and components of the intervention ''Safe and Secure''.

**Study I**, the complete results of this study, are presented in **Paper 1** (219). This result section consists of a summary of the main results. Of 6170 records, n=116 were initially read, and of those in total n= 28 articles were included. Further, Seven (7) articles were identified from searching the reference list of the identified articles. See **Paper 1**, **Figure 1** for the flowchart. For the review, n=29 qualitative and n=six quantitative articles were eligible. None of the included articles was excluded based on the quality appraisal. See **Table 4** in **Paper 1** for a short overview of the included articles and results of the quality appraisal. Four main themes were identified in the data analysis: 1) *Communication and language*; 2) K*nowledge and awareness;* 3) *Patient preferences, cultural and religious issues;* 4) *Lack of resources at different levels of palliative care service provision.* The systematic review (**Paper 1**) is based on a secondary analysis of studies conducted by other researchers. Therefore, the definition of migrants in paper 1 varies from article to article.

In summary, the results demonstrate how non-Western migrants face diverse interrelated factors contributing to their lower utilization of palliative care services in Europe. For example, sub-optimal communication between migrant families and health professionals were a combination of language differences, unskilled interpreters, and different cultural background that led to dissatisfaction among both parties. Communication (verbal and non-verbal) was often interrupted by patients' preferences and religious and cultural views contradicting health professionals' principles, e.g. disclosure of life-threatening disease prognosis. The availability of relevant information on palliative care services in local languages was perceived as a barrier to knowledge and awareness among migrants. Moreover, barriers were also related to inflexibility and poor adjustment of healthcare services for migrants due to inadequate resources, e.g. time and/or cultural competency training for health professionals. The focus, therefore, should be on improving palliative care service provision at the system, community and individual levels. Considering non-Western migrants as a heterogeneous group, the current practice needs to provide support based on their necessities in accessing and utilizing palliative care services.

**Study II,** the complete results of this study are demonstrated in **Paper 2** (221). This result section includes a summary of the main results. In total, eight patients with life-threatening diseases, eleven family caregivers and ten health professionals were interviewed.

See **Paper 2**, **Table 3** for presentations of patients' and family caregivers’ characteristics, and **Table 4** for presentations of health professionals’ characteristics.

A total of 31 participants, consisting of 15 families and ten health professionals, participated in nineteen individual semi-structured and four group interviews. Three themes emerged from the data analysis: 1) *Communication between migrant families and health professionals*; 2) *Building and lack of trusting relations and feeling safe; and* 3) *Access to information and navigating in the healthcare system*. Moreover, ‘‘*language and culture*’’ appeared as transaction themes that are not mutually exclusive, though they interconnect across the three abovementioned themes.

The study findings show that a trusting relationship is often missing among migrant families and health professionals due to language differences and a lack of cultural competency among health professionals. Moreover, social networks (family members, relatives, friends, and colleagues) are central to caregiving, navigating the health system, and decision-making in palliative care. Thus, findings suggest that migrant families – like everyone else - need individualised palliative care based on their specific needs and available resources.

**Study III,** the complete results of this study are demonstrated in **Paper 3** (222). The result section includes a summary of the main results.

A logic model of general palliative care service intervention for non-Western migrants was developed by synthesising evidence from a systematic review on facilitators and barriers to accessing and utilizing palliative care services, findings from qualitative interviews with stakeholders on their experiences of utilizing/providing palliative care services, and results from three stakeholder workshops. See **Paper 3**, **Table 2** for the logic model.

The research team developed the intervention components by combining study I and II results, the framework for complexity in palliative care and the logic model. The final intervention components included the following three components:

1) Education and training for health professionals involved in palliative care at a hospital or a municipality on person-centredness and culturally competent palliative care. The education and training aim to ensure a better quality of palliative care and to improve professionals' skills and confidence in providing care towards patients from diverse backgrounds.

2) Consultations with the respective health professional in the healthcare setting or at home. The patient and the family will be assigned to a health professional, where the professional will introduce herself/himself and explain the ‘’Safe and Secure’’ intervention. Following this initial visit, the health professional and the patient will plan further consultations on their preference, e.g., at home or in a health setting. The frequency of visits is scheduled to be at least once a month.

3) Coordination of care between general practitioners, health professionals at the hospital, and/or the municipality. The assigned health professionals are encouraged to establish multidisciplinary and multi-professional collaboration and coordination by considering individual patients and families. This comprises, e.g., the organisation of a multidisciplinary meeting with other health professionals involved in individual patient care.

# 06 Discussion

The following section will start with a synthesis of findings and, finally, a discussion of the strengths and limitations considerations from three studies. Based on the above-mentioned results and results presented in the three papers, I have identified three key areas in my PhD thesis that provide a structure for the discussion in the next section. These areas are non-Western migrants as a group, the organizational structure of palliative care and finally comparing the intervention and its components with existing literature.

## 06.01 Non-Western migrants as a group

Considering non-Western migrants with palliative care needs was warranted to ensure equal access to palliative care. However, viewing migrants based on origin should not lead to unwanted stereotyping and unclear diversity. In developing this supportive intervention, it was not intended to create a stigmatising us/them dichotomy or to label migrants as a vulnerable group. Indeed, not all migrants in Denmark are vulnerable. Migrants, like ethnic Danes, are usually diverse regarding their, e.g. socio-economic condition, jobs, education, and availability of family caregivers. In addition, the needs and wishes of patients with palliative care need with a migration background are often similar to those without a migration background (28). Therefore, a question might arise, if the problems are so generic, why is it essential to study non-Western migrants as a group? Since migration is an independent social determinant of health risk, even when the usual socioeconomic risk factors are considered (78, 94, 223). In addition, diverse migration-specific aspects, such as migration history, Danish language proficiency and length of stay in Denmark, and cultural and religious preferences, can influence the access to and utilisation of palliative care services.

In papers, 1 and 2, cultural differences' translational and relational nature emerged as significant factors. Culture is translational and relational. Thus cultural differences and stereotypes are constructions that only come into play when two or more perspectives meet, e.g., in encounters between service providers and service recipients (91). Therefore, interpretations of differences reveal as much about the observer as they do about the culture. When participants talked about cultural differences and cultural stereotypes, they did so concerning their own experiences, knowledge and positioning.

First-generation non-Western migrant patients and their family members are pioneers in their communities in finding appropriate palliative care services in Denmark. They often lack role models, partly because they have left the care of their parents and elderly family members to relatives who have remained in their country of origin. Studies in the USA have documented that second-generation migrants are more likely to be prepared towards their end of life by participating in discussions and completing ACP (224, 225). A study conducted among second-generation Chinese migrants has documented that the meaning of care has changed over generations. The traditional form of practical support for parents in the activities of daily living (e.g. cooking, shopping, washing) is now being changed by language support, orientation in the health system, home visits, help and social support (122). The Danish health system does not yet have experience using palliative care services for second-generation migrants. The results of this doctoral thesis provide a basis for sharing evidence-based knowledge while considering palliative care services for the next generation of migrants in Denmark. As this thesis encompasses experiences and views of second-generation migrants, nevertheless, mainly as family caregivers. Further research could explore how the trend of using palliative care services changes across generations among those who were not as close to the home country's traditions as their parents.

The systematic review of European evidence (paper 1) and the empirical studies in Denmark (papers 2 and 3) have shown differences within the study population, e.g. family members make different palliative care decisions depending on their cultural and religious preferences. In addition, migrants with more resources, e.g. relatives, higher education and income, more extended residence in the host country and knowledge of the local language, cope better in their palliative course than new migrants or migrants living alone. These findings are confirmed by several previous studies conducted in different contexts among similar populations, such as the UK, Australia, Canada, and the USA (2, 156, 226, 227). The diversity within the group supports the implementation of person-centred palliative care in practice as recommended in the ‘Safe and Secure’ intervention.

The interviews with health professionals in papers 2 and 3 also showed differences and similarities in how they understood and treated non-Western migrants compared to their Danish compatriots. It was not only cultural, religious and language differences that contributed to poor consultations or lack of consensus, but also health professionals' poor understanding of the individual patient or family in care management. Health professionals in other European countries have reported similar confusion around the role and structure of the family among migrants (93, 228, 229). Although the structure of the families can be complex, patients with palliative care needs and their family members are central to palliative care (36). In studies II and III, it seemed easier for health professionals to help Danes as they understand Danish family relationships and care decision-making. The composition of the care group is familiar to health professionals. However, pre-migration history, resource availability and complex family roles are not exclusive to the culture, religion or ethnicity of non-Western migrants. Studies conducted in Sweden, Netherlands and Belgium reported similar findings (19, 29, 93). Palliative care health professionals expressed that interacting with patients and families from other cultural backgrounds carries conflicts, uncertainty, stress and frustration (19, 29, 93). Therefore, this PhD study advocates for considering the whole context of each patient and family, consequently paying attention to cultural specificities. As evidences emphasize, culturally competent care is one of the most important aspects of person-centred care (2-4, 96). Looking at each patient based on their resources or perceived needs could also help to put the person in perspective across cultures, regardless of their background. Through this PhD study, I have gradually learned that the supportive intervention we have developed might not be unique to meet the specific needs of non-Western migrants in Denmark. It might apply equally to a frail elderly native Dane from a low socio-economic condition, living alone in a remote area. Irrespective of ethnic background, patients encounter particular challenges in accessing palliative care due to, e.g. low health literacy, lack of family caregivers, and communication difficulties between healthcare providers (230, 231). In line with this finding, two Danish studies suggest that under-prioritised cancer patients could benefit from additional support to access and use palliative care and developed tools to identify the patients in need (230, 231). Thus, this ‘’Safe and Secure’’ intervention can potentially support patients irrespective of their ethnic background. This intervention might, therefore, also be a model of palliative care that is transferable to other populations and contexts, although this requires further research.

## 06.02 The organizational structure of palliative care

Combining the findings presented in this thesis shows that organisational structure is important to approach palliative care towards non-Western migrants, for example, the collaboration between migrant patients, their family caregivers, professionals, and healthcare organisations. According to previous literature, it is significant to understand the barriers to and facilitators of change so that organisational improvements can be tailored to meet individual and organisational needs (232). In paper 1 and paper 2, the lack of resources (e.g., time) at different levels of palliative care service provision was found to be of great importance, which leads to limited access, utilisation and consequently, satisfaction with care. For example, to reduce the extra burden on the health system, Danish health authorities have decided that migrants living in Denmark for more than three years must pay for their interpreter service (233). This interpreter fee can have consequences, especially for those with limited financial resources, such as delays in diagnosing life-threatening diseases. Likewise, a study in Germany mentioned that the inflexibility of organisational strategies hinders access to palliative care among migrants (28).

Unlike Germany, Danish studies found that migrants were more likely to use specialised palliative care than native Danes (234-236). The findings suggest a greater need for hospital and home-based services towards migrants (234, 235). Likewise, Danish researchers found that migrants had more face-to-face contact with general practitioners in the last 90 days of their lives than native Danes (237). Explanations of the extra visits near death, might be often explained by delay in diagnosis, ignorance of the system and the poor ability to follow medical instructions or the doctor's advice (238). Although, international evidence revealed that early integration of palliative care benefits patients and reduces unnecessary hospital admissions and healthcare costs (6).

In papers 2 and 3, migrant families and health professionals especially valued the necessity of continuity of care, as building trusting relationships was important. Moreover, participants expressed the need for training to discuss palliative care. A Danish study of health professionals' experience with palliative care in patients (irrespective of ethnicity) with COPD reported similar organisational challenges, including lack of time and continuity of care, lack of opportunities for discussing palliative care, and lack of peer learning (239). A study including five European countries (England, Germany, Italy, Norway and the Netherlands) indicates that some of the barriers and facilitators, for example, lack of skill among health professionals, time constraints, and financial aspects, were experienced by health professionals in almost all countries (232). In light of the common organisational challenges of palliative care, policy makers should consider new organisational structures that support tailored interventions to improve the organisation of palliative care and meet challenges beyond those typical of health care reform implementation (232).

Inter-professional approaches to palliative care are an integral part of the care provided in Denmark. In 2016, the Danish Multidisciplinary Cancer Group of

Palliative Care (DMCG-PAL) published their findings on mapping current inter-professional collaborations in general and specialised palliative care (240). The results indicate that there will be increasing demand for cooperation between the general and the specialised level as more patients with palliative care need stay home (240). The findings suggest developing and eventually evaluating different intersectoral collaboration models to ensure better patient care regarding safety, minimising breaks in the patient palliative trajectory and readmissions (240). In line with the results of papers 2 and 3, the health professionals expressed the need for intersectoral and inter-professional collaboration, reducing fragmentation of care. Lack of coordination of palliative care across medical specialities and healthcare services conflicts with the holism of palliative care. Suppose the ‘’ Safe and Secure’’ intervention proved to be successful in attaining the proposed outcomes. In that case, it will contribute to meeting the holistic palliative care needs of non-Western migrant patients and their families. Undeniably, the organisational structure of palliative care needs flexibility and extra resources to provide care for individuals with diverse backgrounds.

## 06.03 Comparing the intervention and its components with existing literature

A recently published Danish study among migrants highlighted the importance of coproducing health care with migrants (241). The study findings focused on the significance of flexibility among service providers' practice for showing compassion and accepting the vulnerability of the diverse population (241). However, the service providers without proper training cannot ensure equal and equitable health care service towards migrants (242). Thus, the first component of the ‘’Safe and Secure’’ intervention highlights the importance of education and training on person-centred, culturally competent palliative care towards health professionals. Previous palliative care interventions in other European settings have mentioned the importance of health professionals’ training. For example, a RCT in Belgium aimed to investigate the effect of early integration of palliative care compared with usual care among advance cancer patients (243). Therefore, the training of the health professionals included information about cancer treatments early in the disease trajectory (243). Another palliative care intervention towards COPD patients stressed the importance of training health professionals with the care and knowledge for patients with end-stage COPD (244). Noticeably, the training content depends mostly upon the aim of the investigation and the target population.

According to a Danish study, cultural factors significantly influence migrants' access to dementia care services (245). The study suggests a need to raise awareness of dementia and the availability of dementia care services among migrants, reduce stigma and develop culturally appropriate interventions (245). Several Danish and international literature showed evidence of studying and providing tailored interventions towards migrants. For example, in the USA, an intervention was designed to increase African American patients' opportunities to use palliative care services by improving patients' and physicians’ motivation and capacity (48). Similarly, a Danish study reports that migrants only open up when they feel safe and comfortable with the health professional (246). It could be derived from the evidence that assigning a health professional to the patient and his family can improve the professional-patient relationship, irrespective of ethnicity or disease conditions. A Danish study showed that assigning a health professional to a COPD patient improved the quality of care and made patient and family caregivers feel safe, enhancing their confidence in self-management abilities (247). Indeed, it is anticipated that the consultations with assigned trained health professional (second component of '' Safe and Secure'' intervention) have the prospective to address needs of the migrant families based on their preferences. Connecting a health professional with a migrant's family have the potential to maintain continuity of care, thus building trusting relationship with migrant families.

Similar to the final component of the ''Safe and Secure'', previous palliative care intervention studies have mentioned the significance of coordination of care between involved health professionals (70, 71, 244, 248). Palliative care service providers might be benefited from the inter-sectoral management strategy throughout the life-threatening disease trajectory, which includes coordination of care between health professionals for migrant families and in general. One might argue that coordination of care might not be unique to the migrants or any disease group but for all in general. I completely agree that the components of this intervention are broad and could benefit those with special needs and preferences, irrespective of their ethnicity. WHO recommends that healthcare towards migrants may sometimes need to be delivered parallel to the respective national health system. However, in the long term, migrants' health needs to be mainstreamed in the existing services (249). Thus, this supportive palliative care intervention component is modelled flexibly and generically to be introduced as parallel to the current palliative care service provision, which could still be adopted in the Danish health care system in the long term.

## 06.04 Strengths and Limitations

The following section includes discussions of the methodological strengths and limitations of this PhD study, a reflection on pragmatism as the paradigm, the intervention development, followed by thematic analysis, and finally, involving stakeholders for this PhD study.

### 06.04.01 Pragmatism as the paradigm

One can discuss if pragmatism can be considered a paradigm as it concerns practicality over philosophical foundation. Followers of pragmatism paused questions on the term “paradigm” and indicated different meanings within the literature (134, 250). Pragmatism does not overlook ontological and epistemological issues, as it maintains its connection with the methods used to produce knowledge (134, 250). Pragmatism, however, focuses mainly on exploring the nature of human experience, in which the beliefs and actions of the researcher constantly interact to generate meaning and motivate the production and philosophy of knowledge (134). Thus, pragmatism is not missing a philosophy of knowledge. Instead, it goes beyond problem-solving and practicality (134).

Another critique of pragmatism is the confusion around its basic features or the failure of pragmatists to be specific about their assumptions (139). For instance, pragmatists are criticised for not stating whose values are involved in the investigation and what they mean by practicality or workability (139). For this PhD study, my own values and the values of stakeholders were comprised to produce knowledge, while workability includes the ability to integrate this intervention within basic palliative care. Another critique is that pragmatism is exclusively associated with mixed methods research (134, 137, 139). Indeed, pragmatism embraces a “what works at the time” approach to research methods. Thus, investigators can use quantitative, qualitative, or mixed methods based on their research question (132, 134, 139).

### 06.04.02 Intervention development

The ‘‘Safe and Secure’’ intervention was developed based on participants' opinions. A limitation of this thesis is that the data depend on the subjective experiences and responses of the participants, which may have been influenced by social desirability. This study did not include participant observation in data collection and analysis. The combination of participant observation and interview and including different stakeholders' perspectives on palliative care practice could have strengthened this project. The participant observations have the potential to provide a nuanced illustration of the phenomenon (251). It could rise to elaborations of what was observed and the informants' own words and interpretations. Not including participant observations concerning the context of receiving palliative care (migrant families) and clinical practice (service providers) weakens the project's empirical basis and analyses.

A strength of this study was the commitment to a well-established framework, for example, the MRC framework (185). The results from each study phase informed the following phase, which resulted in gathered evidence that led to the development of an evidence-based intervention ‘‘ Safe and Secure’’. The MRC framework helped to inform the research approach (qualitative methodology) and offered a structure for the systematic development of the intervention by involving multiple stakeholders. However, the time taken in developing the intervention stage of the MRC framework has been discussed within palliative care (252). Investing in developing the intervention is important to avoid the ethical and practical problems within palliative care research and consequently develop a more feasible, implementable intervention to reduce research waste (140). An additional concern is the generic nature of the MRC framework. However, this was lessened by using the framework for complexity in palliative care, which provided important aspects specific to the context (186).

### 06.04.03 Thematic analysis

One critique of thematic analysis is related to its flexibility. It poses a challenge in achieving coherence between the research objectives, philosophical and theoretical assumptions, and chosen methods and could affect the research's methodological integrity (253). I want to argue that the flexibility of thematic analysis gave strength to my PhD study, fits with the pragmatic worldview and are appropriate to answer my research question. It is also criticized for its lack of interpretative depth and descriptive focus, but the thematic analysis is not necessarily simple or complex; it depends on how it is applied (254). There is a misconception that thematic analysis is an atheoretical method. Instead, it is theoretically flexible since investigators select the theoretical framework most appropriate to answer their research questions (255, 256). Finally, thematic analysis is criticized for being a poorly defined and unstructured method (254). In recent years, however, several papers have offered distinctive methods and tools for rigorously conducting thematic analyses, including Braun and Clarke's six-phase process (187, 257). I have used Braun and Clarke's six steps in studies I and II to develop themes. See Paper 1, table 5 and Paper 2, table 2 for the analysis process.

### 06.04.04 Involving stakeholders

One of the strengths of this thesis is involving multiple stakeholders in developing the intervention. Involving stakeholders is significant in designing interventions according to their needs (185). Involving migrant patients with palliative care needs contributed insights into living with and caring for the ones with life-threatening diseases, adding unique perspectives to the research. Though, one of the limitations of this thesis was the challenges of involving migrant patients with palliative care needs and their family members as true co-researchers throughout this project. Research showed that involving stakeholders in migrant palliative care can improve patient-physician interpersonal communication (48). Stakeholders would ideally have been involved from the very beginning of this thesis for them to be involved in essential components such as generating research questions, prioritising, designing, conducting and interpreting data. However, as mentioned earlier, I experienced challenges such as gaining access, ethical concerns and logistical issues that delayed the involvement of the stakeholders and hindered my ability to participate.

Moreover, as a naïve researcher in co-production, I possibly underestimated the time required to establish and build trusting relationships with stakeholders. An additional limitation was stakeholders were involved from the micro level, for example, the patient, family caregivers, and healthcare professional levels, with less focus on the macro level, for example, collaboration between hospitals and community services. Nevertheless, the limited involvement of stakeholders at the macro level is justifiable, as the involvement of all stakeholders is neither feasible nor necessary (108).

# 07 Conclusion

This thesis presents a comprehensive and novel body of research exploring palliative care among non-Western migrants in Denmark. The overall aim of this thesis - to develop a supportive palliative care intervention towards non-Western migrant patients with a life-threatening disease and their families in Denmark - has been successfully achieved.

The study has offered a glimpse into the complexity of the utilization of palliative care among non-Western migrants and merely scratched the surface of the supportive intervention towards migrant families. Indeed, palliative care towards migrants is an emerging research field in Denmark, which is increasingly recognized as a way to ensure equitable health service. Different chapters presented in this thesis have provided a deeper understanding of the phenomena of palliative care among different parties involved in care (patients, family caregivers and health professionals). It is documented that migrant families value palliative care near death, although; it is evident that the group is under-represented in palliative care according to their needs. The current thesis has identified several facilitators and challenges hindering this group's utilization of palliative care. The current thesis has come up with several strategies to overcome the difficulties, to make the path of palliative care easily accessible for those in need.

Thus, the study suggests that non-Western migrant families and their health professionals must be proactive in building collaboration and forming a collective effort to support greater demand for patients with palliative needs. Health professionals can help families and patients with palliative needs by organizing, training and disseminating relevant information about different opportunities available in the Danish healthcare system and how to access them. In addition, the results of this thesis should be seen as a contribution to organisational change, as the findings suggest improving palliative care for migrants; it is not sufficient to address the individual or service level.

Finally, several topics and knowledge gaps that warrant further research can contribute to achieving a greater match between the values set in the Danish health system and reality by providing insights that inform research and practice. Taken together, collective efforts from different stakeholders working with palliative care and their families have the potential to facilitate access to available supports, which, in turn, would increase their access to palliative care, thus achieving the goal of equal health care.

## 07.01 What this PhD project adds

This PhD project describes how and to what extent palliative care research has been conducted among non-Western migrants in Europe, and possible barriers, enablers, and suggestions to enhance their access to palliative care. Moreover, this project informs practice and provides evidence on non-Western migrant palliative care in Denmark. The findings of this project advocate for focusing on person-centredness towards the patient and the entire family while providing palliative care services for non-Western migrants. This project adds to the knowledge that focusing on the individual level is insufficient. Instead, coordination and changes need to be made at different levels of the care system to ensure better palliative care for non-Western migrants. This study also proves that by devoting efficient strategy, sufficient time, resources and energy, it is possible to recruit non-Western migrants with palliative needs for a research project. However, an important lesson learned through this PhD has been to allow more attention to the priorities and resources of the organization. As I tried to build a collaboration with four different municipalities in Denmark to deliver the intervention, each municipality recognised the importance of reaching out to this group and their needs, even though they lacked time and resources.

## 07.02 Implications

From this PhD study, there are different implications essential to utilise to improve current palliative care service provision, here among non-Western migrants. Below implications will be elaborated on:

- Implication for research
- Implication for practice

### 07.02.01 Implication for research

Research on non-Western migrants' palliative care and developing palliative care interventions for them is limited, particularly in the Danish context. To my knowledge, this is the first study that developed supportive palliative care intervention towards non-Western migrants that involved different stakeholders in Denmark. This thesis mainly adds to the literature on palliative care needs related to supporting patients with life-threatening diseases and family members by exploring the topic from different angles, including the evidence, service users' experiences, and service providers' perspectives. The themes that emerged from secondary data and empirical data shared by service users and providers help us understand the complexity of palliative care in light of the theoretical framework (186). However, the socio-economic characteristics of this population related to their barriers to accessing palliative care remained unknown. Further research is needed to reflect on the demographic profiles of the migrant population.

Moreover, the policy-related factors affecting the palliative care provided to non-Western migrants remained relatively unexplored. Further studies are needed to capture the voice of policymakers to expand the understanding of this phenomenon. Moreover, research is needed regarding how socioeconomic conditions, legal status, housing problems, and education affect the palliative care utilization of non-Western migrants.

### 07.02.02 Implication for practice

The findings from this thesis suggest a health professional-led intervention is likely to be able to facilitate a care system that provides more collaborative, unified palliative care for non-Western migrant families. Although the importance of coordinating intervention was evident, underlying concerns remain over the applicability of such a model of palliative care for non-Western migrants and the feasibility of implementing the higher-order organizational adaptations within the well-established Danish healthcare system. These questions might be addressed in future work around the feasibility study.

Besides other reasons, the Danish healthcare system is under considerable stress in the world's current economic situation after COVID and the war in Ukraine. As I have seen through the thesis, the flexibility of funding, workforce, and resources is already significant. Furthermore, it is hard to consider implementing a new intervention outside the existing healthcare structure. Danish municipal palliative care evidence shows that complex interventions must be incorporated into existing organizational structures such as meetings, IT and interdisciplinary/cross-sectoral documentation systems (110). In line with the existing evidence, this study's findings advocate for implementing interventions within the existing structure to ensure sustainability.

The ‘’Safe and Secure’’ intervention or the logic model developed for this intervention is context specific. The logic model (see paper 3, Table 2) is used to specify the resources and activities that lead to the outcomes so that the interventions can be easily adapted. A visual representation of the hypothesised mechanism of change allows a scientific readership in other contexts to assess the usefulness of the identified resources, activities and outcomes for their health system and determine which elements can be transferred and which need to be further tailored. Some aspects of the developed intervention model are transferable to other countries, especially Nordic countries where palliative care is available in primary care.

## 07.03 Future perspective

Several questions are yet to answer about the intervention ‘’Safe and Secure‘’ after this PhD study and are food for future research:

- How will the intervention be organised, e.g. within the hospital or in the municipality, and who will identify and recruit the patients who need additional support?
- What is the optimal structure and frequency of consultations between health professionals and patients?
- What level of care coordination is most likely to be achieved, and what is required to achieve it?
- How can this intervention be integrated into the ongoing palliative service provision structure to achieve sustainability?

Further research using focus groups with service users and health professionals may help generate more critical discussion around the model of care, its likely acceptability, utility, and feasibility in current Danish healthcare settings. After the conceptual model is revised based on feedback, feasibility studies and pilot trials will be conducted. The feasibility study is completed to answer the question, 'Is it feasible?' It includes reviewing the uncertain parameters of an intervention and describing methods to improve its accuracy (258). A feasibility study for the ''Safe and Secure'' intervention will involve developing training materials to facilitate the training of health professionals as described in the logic model (222). Following training, health professionals will be responsible for delivering the ''Safe and Secure'' intervention over six months to 30-35 migrants with palliative care needs and their family caregivers. During the feasibility study, I will collect data on the implementation and procedures of delivery. It will also concern recruiting and retaining migrants with palliative care needs and their family caregivers. A feasibility assessment might involve collecting qualitative data from various stakeholders to determine difficulties and ways to overcome them, views on facilitating factors and patterns to incorporate them, and whether further modifications are required.

A pilot study can be conducted following the completion of a feasibility study and any changes or refinements. As a next step, a pilot study might be appropriate, as pilot studies are smaller versions of the main study to test whether the components and process of the study can work together (258). Pilot studies focus on smooth processes such as recruitment, randomisation, treatment and follow-up assessments. Often, pilot studies are the first phases of more extensive studies that measure primary outcomes (259). Following promising results

from a piloting stage, the ‘’Safe and Secure’’ intervention will be introduced to a large scale over multiple hospital or municipality centres. A draft of the information leaflet of the intervention is attached in appendix 9. The folder is possible to download via this link
https://www.rehpa.dk/wp-content/uploads/2023/05/Tryg-og-Sikker-folder.pdf
I did not investigate this intervention's economic benefit and fidelity due to limited resources within the PhD thesis regarding time and funding. These are essential topics that should be further researched. One way of measuring economic benefit could be to examine whether the intervention enabled patients to remain in their homes instead of being admitted to the hospital.

The final stage in implementing complex interventions is to examine how they are implemented in practice, particularly in terms of acceptance rates, stability of the intervention and possible adverse effects (108). This PhD thesis did not examine the implementation processes of this intervention, so further investigation is needed.

# 08 English summary

### Background

International migration is increasing globally. In 2021, 14% of the population in Denmark had a migration background. Many work migrants who migrated between 1960 and 1970 are now ageing. Therefore, an increasing number of migrants are expected to be benefited from the palliative care approach. There have been calls to understand better the barriers and facilitators to access and use palliative care services among non-Western migrants with a life-threatening disease and their family members. Still, there is a lack of knowledge on the effectiveness of palliative care interventions for non-Western migrants, and there are currently no tailored interventions towards them in Denmark. This PhD thesis endeavours to mitigate these gaps in the current evidence base through three studies.

### Aim

This PhD thesis aimed to develop a supportive palliative care intervention towards non-western migrant patients with a life-threatening disease and their families in Denmark.

### Methods

The Medical Research Council (MRC) framework for developing and evaluating complex interventions guided the approach to this multiple qualitative methods research. First, a systematic review of opportunities and barriers to palliative care access and utilisation among non-Western migrants in Europe was conducted (study I). Next, eight non-western migrants with life-threatening diseases, eleven family caregivers, and ten health professionals were interviewed on their experiences while utilizing and delivering palliative care services in Den-

mark (study II). Finally, the findings of studies I and II were discussed with stakeholders via three workshops to develop a supportive palliative care intervention towards non-Western migrants in Denmark (study III).

**Results**

The systematic review (study I) identified barriers to migrants' utilization of palliative care in Europe and possible suggestions to overcome the barriers recommended in the included articles. The main barriers to access to and utilization of palliative care are poor communication, lack of knowledge and awareness among migrants about the existing palliative services, differences in religious and cultural preferences, and lack of resources at different levels of the health systems and palliative care providing organisations. The interview study (study II) identified determinants influencing palliative care experiences in Denmark from the perspectives of service receivers and service providers, e.g., trusting relations between families and health professionals, feeling safe in the healthcare system and language and cultural differences. Based on the findings and underlying theoretical framework for complexity in palliative care, ''Safe and Secure'' complex intervention was developed (study III), including three components: education and training sessions, consultations with the health professional, and coordination of care. The ''Safe and Secure'' is a health professional (for example, nurse, physiotherapist, or occupational therapist) led person-centred palliative care intervention at the general palliative care level.

**Conclusion**

This PhD thesis has contributed to knowledge by providing a much-needed conceptual understanding of this complex issue and towards supportive palliative care intervention development for non-Western migrants in Denmark. The intervention focuses on the holistic palliative care approach by providing person-centred care towards non-Western migrant patients and families with palliative care needs. Further research is needed to assess the acceptability and sustainability of this novel intervention through a feasibility study.

# 09 Danish summary

**Bagrund**

International migration er stigende globalt. I 2021 havde 14 % af befolkningen i Danmark migrationsbaggrund. Et betydeligt antal arbejdsmigranter, der migrerede mellem 1960 og 1970, ældes nu. Derfor kan et stigende antal migranter forventes at få gavn af en palliativ indsats. Der har været opfordringer til bedre at forstå barriererne og facilitatorerne for at få adgang til og bruge palliative ydelser blandt ikke-vestlige migranter med livstruende sygdom og deres familiemedlemmer. Der mangler dog viden om effektiviteten af palliative indsatser for ikke-vestlige migranter, og der er i øjeblikket ingen skræddersyet indsats til  dem i Danmark. Denne ph.d.-afhandling bestræber sig på at afbøde disse videnshuller gennem tre undersøgelser.

**Formål**

Det overordnede formål med denne ph.d.-afhandling var at udvikle en støttende palliativ intervention til livstruede syge mennesker med ikke-vestlig migrantbaggrund og deres familier i Danmark.

**Metoder**

Medical Research Council (MRC) dannede ramme for udvikling og evaluering af en komplekse intervention til i, hvori der indgik flere kvalitative metoder. Først blev der gennemført en systematisk gennemgang med fokus på muligheder og barrierer for adgang og udnyttelse af palliativ indsats blandt ikke-vestlige migranter i Europa (undersøgelse I). Dernæst blev otte ikke-vestlige migranter med livstruende sygdomme, 11 pårørende og 10 sundhedsprofessionelle interviewet om deres erfaringer i forhold til at modtage og yde palliation i Danmark (undersøgelse II). Endelig blev resultaterne af undersøgelse I og II diskuteret med interessenter via tre workshops med henblik på at udvikle en støttende palliativ indsats over for ikke-vestlige migranter i Danmark (undersøgelse III).

## Resultater

Det systematiske review (undersøgelse I) identificerede muligheder og barrierer i forhold til palliativ indsats til migranter og deres familier i Europa. Hovedbarrierer for adgang til og udnyttelse af palliativ indsats er dårlig kommunikation, manglende viden og bevidsthed blandt migranter om de eksisterende palliative tilbud, forskelle på religiøse og kulturelle præferencer, mangel på ressourcer på forskellige niveauer af de sundhedssystemer og organisationer, der leverer palliation.  Interviewundersøgelsen (undersøgelse II) identificerede forskellige forhold, der påvirker de palliative ydelser i Danmark fra familiernes og de professionelles perspektiver f.x. tillidsfulde relationer mellem familier og sundhedsprofessionelle, tryghed i sundhedssystemet og sproglige og kulturelle forskelle. Baseret på resultaterne og en underliggende teoretiske ramme om kompleksitet i palliation, blev en kompleks intervention "Tryg og Sikker" udviklet (studie III), hvori tre komponenter indgår: uddannelse og træningssessioner, konsultationer med sundhedspersonalet og koordinering af den palliative indsats.

## Konklusion

Denne ph.d.-afhandling har bidraget til viden om, hvordan det er muligt at forbedre den palliative indsats til mennesker med ikke-vestlig migrant baggrund og deres familier gennem en konkret intervention. Interventionen indeholder og fokuserer på en holistiske palliative tilgang, herunder at yde personcentreret indsats til ikke-vestlige migrantpatienter og familier med behov for palliation.

Yderligere forskning er nødvendig for at vurdere acceptabiliteten og bæredygtigheden af denne nye intervention gennem en forundersøgelse.

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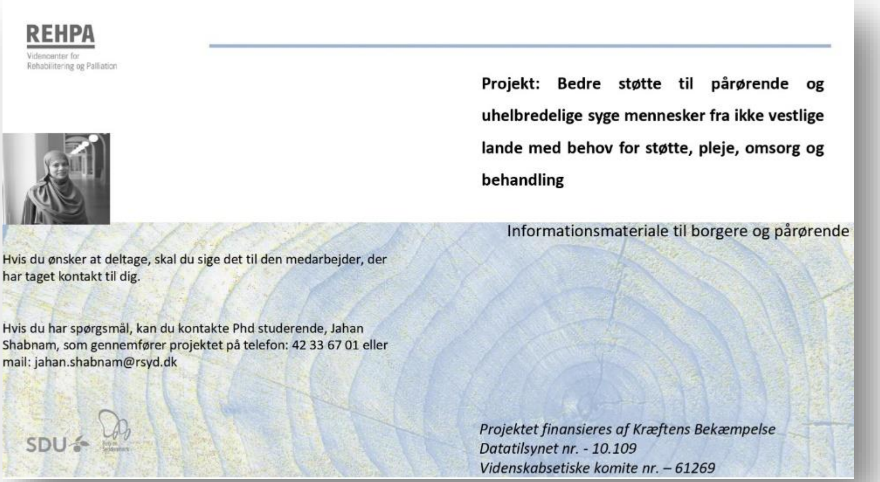
# 11 Appendices

## 11.01 Appendix 1 – Information leaflet



REHPA
Videncenter for
Rehabilitering og Palliation

**Projekt: Bedre støtte til pårørende og uhelbredelige syge mennesker fra ikke vestlige lande med behov for støtte, pleje, omsorg og behandling**

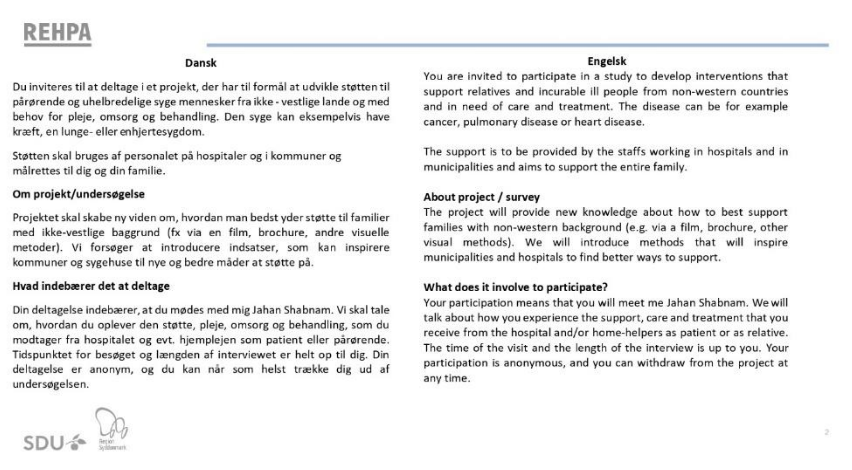
Informationsmateriale til borgere og pårørende

Hvis du ønsker at deltage, skal du sige det til den medarbejder, der har taget kontakt til dig.

Hvis du har spørgsmål, kan du kontakte Phd studerende, Jahan Shabnam, som gennemfører projektet på telefon: 42 33 67 01 eller mail: jahan.shabnam@rsyd.dk

*Projektet finansieres af Kræftens Bekæmpelse*
*Datatilsynet nr. - 10.109*
*Videnskabsetiske komite nr. – 61269*

SDU



REHPA

**Dansk**

Du inviteres til at deltage i et projekt, der har til formål at udvikle støtten til pårørende og uhelbredelige syge mennesker fra ikke - vestlige lande og med behov for pleje, omsorg og behandling. Den syge kan eksempelvis have kræft, en lunge- eller enhjertesygdom.

Støtten skal bruges af personalet på hospitaler og i kommuner og målrettes til dig og din familie.

**Om projekt/undersøgelse**

Projektet skal skabe ny viden om, hvordan man bedst yder støtte til familier med ikke-vestlige baggrund (fx via en film, brochure, andre visuelle metoder). Vi forsøger at introducere indsatser, som kan inspirere kommuner og sygehuse til nye og bedre måder at støtte på.

**Hvad indebærer det at deltage**

Din deltagelse indebærer, at du mødes med mig Jahan Shabnam. Vi skal tale om, hvordan du oplever den støtte, pleje, omsorg og behandling, som du modtager fra hospitalet og evt. hjemplejen som patient eller pårørende. Tidspunktet for besøget og længden af interviewet er helt op til dig. Din deltagelse er anonym, og du kan når som helst trække dig ud af undersøgelsen.

**Engelsk**

You are invited to participate in a study to develop interventions that support relatives and incurable ill people from non-western countries and in need of care and treatment. The disease can be for example cancer, pulmonary disease or heart disease.

The support is to be provided by the staffs working in hospitals and in municipalities and aims to support the entire family.

**About project / survey**

The project will provide new knowledge about how to best support families with non-western background (e.g. via a film, brochure, other visual methods). We will introduce methods that will inspire municipalities and hospitals to find better ways to support.

**What does it involve to participate?**

Your participation means that you will meet me Jahan Shabnam. We will talk about how you experience the support, care and treatment that you receive from the hospital and/or home-helpers as patient or as relative. The time of the visit and the length of the interview is up to you. Your participation is anonymous, and you can withdraw from the project at any time.

SDU

2

# 11.02 Appendix 2 – Informed consent and participant information – Study II

Samtykkeerklæring ” **Bedre støtte til pårørende og borgere med livstruende sygdom fra ikke vestlige lande med behov for pleje, omsorg og behandling**”

Jeg skriver under på, at jeg har modtaget skriftlig og mundtlig information om undersøgelsen og er villig til at deltage

Jeg har på ethvert tidspunkt ret til at afbryde deltagelse

Navn:_____________________________________________

Adresse:___________________________________________

Dato og underskrift:______________________________________

Jeg erklærer, at skriftlig deltagerinformation er udleveret og fulgt op af mundtlig information:

Navn:___________________________________________________

## Du inviteres til at deltage i et projekt

- Projektet skal skabe ny viden om, hvordan man bedst yder støtte til pårørende og til borgere med livstruende sygdom med ikke-vestlige baggrund.

- Vi skal tale om, hvordan du oplever den støtte, pleje, omsorg og behandling, som du modtager fra hospitalet og evt. hjemmeplejen som patient og/eller pårørende.

- Tidspunktet for besøget og længden af interviewet er helt op til dig.

- Din deltagelse er anonym, og du kan når som helst trække dig ud af projektet.

- Hvis du ønsker at deltage, skal du sige det til den medarbejder, der har taget kontakt til dig.

- Hvis du har spørgsmål, kan du kontakte Phd studerende, Jahan Shabnam, som gennemfører projektet på telefon: 42 33 67 01 eller mail: jahan.shabnam@rsyd.dk

## 11.03 Appendix 3 - Interview guide for qualitative interviews with patient/family caregivers – study II

**Aim – lines of inquiry**

**Introduction -** Introduction of the interviewer and the research project

**Background information** (may follow up during the interview) **-** Diagnosis, age, ethnicity, primary needs (physical, psychological, social), when they moved to Denmark, cause of migration (asylum/refugee/migrant worker). Language proficiency in Danish and language of communication with health professionals.

**Theme 1 – Social and personal relationships**

**Broad question**

Can you please describe your life after being a patient/ caregiver?

**Probing questions –**

- Can you please tell me about yourself and your every say after being a patient/caregiver of an ill relative?
- Would you please tell me about your relationship with your family members in Denmark and your homeland?
- Please tell me about your relationship with health professionals at hospitals/homes.

**Theme 2 - Knowledge, experiences, and perspective**

**Broad question**

What do you think about the services such as hospital/at-home/ hospice care?

**Probing questions –**

- How much do you know about the service provided at home/in the hospital for very ill persons (in terms of availability, appropriateness, and accessibility) offered by the state for citizens in Denmark?

Please tell me about your experiences of being patient/caring for your family member at home/hospital (challenges/facilitators). How does it vary from your own country of origin/culture? Can you please compare or evaluate?

**Theme 3 – Needs**

**Broad question**

What are your needs right now?

**Probing questions -**

- Can you please tell me about your care preferences as a patient/relative and how well they are met?
- Is there anything else that you would like to ask me
- Thanking participants for sharing ideas

**Ending the interview**

- Is there anything else that you would like to ask me?
- Thanking participants for sharing ideas.

## 11.04 Appendix 4 - Interview Guide for qualitative interviews with healthcare professionals - study II

**Aim – lines of inquiry**

- **Introduction -** Introduction of the interviewer and the research project (and the target group)
- Let the informant(s) present themselves very briefly and their place of work

**Theme 1 – Experiences** - What experience do you have with providing palliative care for non-Western migrants with life-threatening diseases such as cancer, COPD, heart disease, etc.? (With examples)

**Probing questions**

- Can you describe a situation from your practice where all parts were successful and/or challenges arose?
- Do you pay special attention to migrant families compared to ethnic Danes? If so, describe how. If not, why not?
- What concerns or considerations arose when you provided palliative care for migrant families?

**Theme 2- Access to palliative care -** How do non-Western migrants with life-threatening illnesses and their relatives access palliative care with you?

**Probing questions**

- Do you experience barriers to access concerning palliative care (possibly health professional services in general)? If so, describe which ones. (With examples)
- Do you have any experience or ideas for how it is possible to improve access to palliative care for non-Western migrant families? Describe why no / yes.

**Theme 3 - Ideas or strategies to improve palliative care efforts for non-Western migrant families -** Have you specifically developed or worked with any ideas, initiatives, and/or more individual professional strategies to provide care towards non-Western migrant families? Explain why / why not.

**Probing questions**

- Can you describe a situation from practice where these ideas/initiatives/strategies were used / not used?
- How is it possible that the application of these ideas/initiatives/strategies can be improved?

**Closing**

Is there anything else related to what we have discussed today that you would like to share with me?

Thanking participants for sharing ideas

## 11.05 Appendix 5 - Participant information and invitation letter for user panel members at Migrant Health Clinic – Study III

### Invitation til at deltage i en workshop, der skal bidrage til udvikling af palliativ indsats til familier med ikke-vestlige baggrund

Jeg håber, at du har tid og lyst til at deltage i en workshop, hvor vi skal drøfte en nyudviklet intervention, der skal bidrag til at støtte ikke-vestlige migrantfamilier med behov for palliativ indsats.
Interventionen er udviklet på baggrund af et litteraturstudie samt interviews med patienter, pårørende og sundhedsprofessionelle.
Workshoppen afholdes den 29. marts 2022 fra kl. 14:00 til 16:00 på Indvandrermedicinsk Klinik, indgang 112, Kløvervænget 10, stuen, Odense Universitetshospital.
Workshoppen vil bl.a. indeholde:

- Præsentation af resultater fra de to studier.
- Præsentation af komponenter i interventionen. Herunder og diskussion af spørgsmål som: Hvordan er det muligt at nå familierne? Hvordan og hvilke professionelle skal følge familierne? Hvordan er det muligt at sikre at samme fagperson følger familien? Hvor ofte skal familierne besøges?
- Hvem og hvordan skal samarbejdes?
- Kompetenceudvikling for professionelle med henblik på at sikre bedre interkulturel kommunikation med familierne.
- Derudover skal vi også drøfte muligheder og begrænsninger i forhold til at pilotteste og implementere interventionen.

Jeg håber, at høre fra dig.

Med venlig hilsen
Ph.d. studerende Jahan Shabnam, SDU
Hvis du har spørgsmål, kan du kontakte mig på telefon: 42 33 67 01 eller mail: jahan.shabnam@rsyd.dk

## 11.06 Appendix 6 - Participant information and invitation letter for healthcare professionals – Study III

**Invitation til at deltage i en workshop, der skal bidrage til udvikling af palliativ indsats til familier med ikke-vestlige baggrund**

Jeg håber, at du har tid og lyst til at deltage i en workshop, hvor vi skal drøfte en nyudviklet intervention, der skal bidrag til at støtte ikke-vestlige migrantfamilier med behov for palliativ indsats.

Interventionen er udviklet på baggrund af et litteraturstudie samt interviews med patienter, pårørende og sundhedsprofessionelle.

Workshoppen afholdes den 4 maj 2022 fra kl. 13:00 til 15:00 virtuelt.

Workshoppen vil bl.a. indeholde:

- Præsentation af resultater fra de to studier.
- Præsentation af komponenter i interventionen. Herunder og diskussion af spørgsmål som: Hvordan er det muligt at nå familierne? Hvordan og hvilke professionelle skal følge familierne? Hvordan er det muligt at sikre at samme fagperson følger familien? Hvor ofte skal familierne besøges?
- Hvem og hvordan skal samarbejdes?
- Kompetenceudvikling for professionelle med henblik på at sikre bedre interkulturel kommunikation med familierne.
- Derudover skal vi også drøfte muligheder og begrænsninger i forhold til at pilotteste og implementere interventionen.

Jeg håber, at høre fra dig.

Med venlig hilsen
Ph.d. studerende Jahan Shabnam, SDU
Hvis du har spørgsmål, kan du kontakte mig på telefon: 42 33 67 01 eller mail: jahan.shabnam@rsyd.dk

## 11.07 Appendix 7 – Program of workshop II

REHPA
Videncenter for
Rehabilitering og Palliation

### INVITATION TIL AT DELTAGE I EN WORKSHOP, DER SKAL BIDRAGE TIL UDVIKLING AF PALLIATIV INDSATS TIL FAMILIER MED IKKE-VESTLIGE BAGGRUND

**Formål med dagen:** At diskutere komponenter til en intervention, der skal forbedre den palliative indsats for familier fra ikke-vestlige lande. Interventionen er udviklet på baggrund af et litteraturstudie og kvalitative interviews med patienter, pårørende og sundhedsprofessionelle. Interventionen skal pilottestes på hospital og i kommuner.

**Tid: [Den 29. marts 2022, kl. 14.00—16.00 ]**

**Sted: [Indvandrermedicinsk Klinik, indgang 112, Kløvervænget 10, stuen, Odense Universitetshospital]**

**Tilmelding: [Senest den 25. marts 2022 til ph.d. studerende Jahan Shabnam, jahan.shabnam@rsyd.dk, tlf. 42336701 ]**

| | |
|---|---|
| **14.00 - 14.30** | Velkomst og Jahan Shabnam's præsentation af resultatet fra litteraturstudiet, interviewundersøgelsen og interventionens komponenter |
| **14.30 - 14.45** | Pause med te, kaffe og kage |
| **14.45 - 15.45** | Fælles drøftelse af studiernes resultater, interventionens komponenter samt idéer og udfordringer i forhold til at pilotteste og implementere interventionen i praksis. |
| **15.45 - 16.00** | Opsamling og tak for i dag |

Vel mødt, Jahan Shabnam.
Hvis du har spørgsmål, kan du kontakte mig på telefon:
42 33 67 01 eller mail: jahan.shabnam@rsyd.dk

## 11.08 Appendix 8 – Program of workshop III

REHPA
Videncenter for
Rehabilitering og Palliation

### INVITATION TIL AT DELTAGE I EN WORKSHOP, DER SKAL BIDRAGE TIL UDVIKLING AF PALLIATIV INDSATS TIL FAMILIER MED IKKE-VESTLIGE BAGGRUND

**Formål med dagen:** At diskutere komponenter til en intervention, der skal forbedre den palliative indsats for familier fra ikke-vestlige lande. Interventionen er udviklet på baggrund af et litteraturstudie og kvalitative interviews med patienter, pårørende og sundhedsprofessionelle. Interventionen skal pilottestes på hospital og i kommuner.

**Tid: [Den 4. maj 2022, kl. 13.00—15.00]**

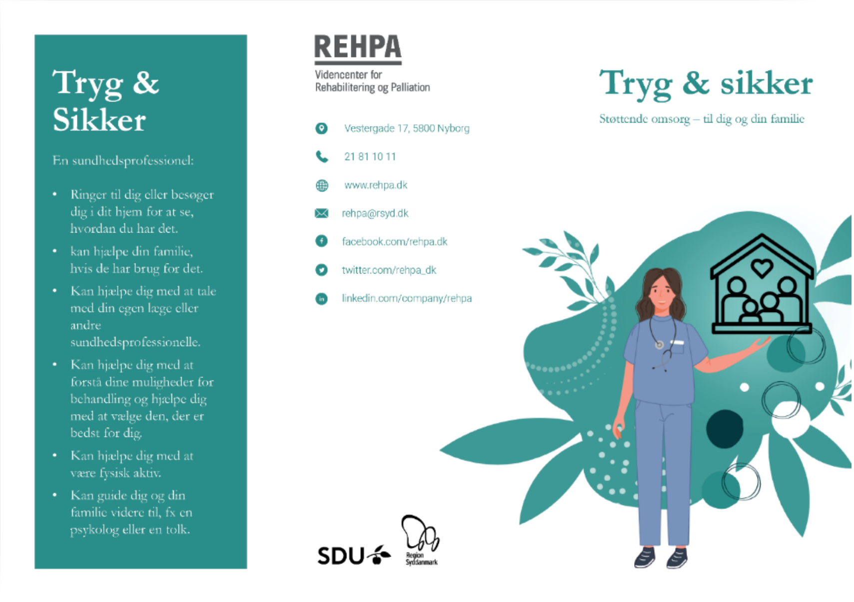
**Sted: [Virtuelt]**

**Tilmelding: [Senest den 29. april 2022 til ph.d. studerende Jahan Shabnam, jahan.shabnam@rsyd.dk, tlf. 42336701 ]**

| | |
|---|---|
| **13.00 - 13.30** | Velkomst og Jahan Shabnam's præsentation af resultatet fra litteraturstudiet, interviewundersøgelsen og interventionens komponenter |
| **13.30 - 13.45** | Pause |
| **13.45 - 14.45** | Fælles drøftelse af studiernes resultater, interventionens komponenter samt idéer og udfordringer i forhold til at pilotteste og implementere interventionen i praksis. |
| **14.45 - 15.00** | Opsamling og tak for i dag |

Vel mødt, Jahan Shabnam.
Hvis du har spørgsmål, kan du kontakte mig på telefon:
42 33 67 01 eller mail: jahan.shabnam@rsyd.dk

## 11.09 Appendix 9 – Information about the intervention ''Safe and Secure''



# Tryg & Sikker

En sundhedsprofessionel:

- Ringer til dig eller besøger dig i dit hjem for at se, hvordan du har det.
- kan hjælpe din familie, hvis de har brug for det.
- Kan hjælpe dig med at tale med din egen læge eller andre sundhedsprofessionelle.
- Kan hjælpe dig med at forstå dine muligheder for behandling og hjælpe dig med at vælge den, der er bedst for dig.
- Kan hjælpe dig med at være fysisk aktiv.
- Kan guide dig og din familie videre til, fx en psykolog eller en tolk.

REHPA
Videncenter for
Rehabilitering og Palliation

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linkedin.com/company/rehpa

SDU
Region Syddanmark

# Tryg & sikker

Støttende omsorg – til dig og din familie

### Hvad er Tryg & Sikker?

Tryg & Sikker er en indsats, hvis mål er at yde lindrende pleje, omsorg og behandling til mennesker med kronisk, fremadskridende, uhelbredelig sygdom og deres nærmeste. Indsatserne fokuserer på at lindre symptomer og løse probmlemer i forbindelse med sygdommen. Formålet er at forbedre livskvaliteten for både dig og din familie.

### Hvem yder omsorg og pleje?

Det afhænger af din situation, hvem du møder. Det er en sundhedsprofessionel, der yder omsorg i samarbejde med en frivillig, din egen læge, læger og sygeplejersker på hospitalet og andre specialister for at støtte dig og din familie. Den sundhedsprofessionelle tager sig ekstra tid til kommunikation og gennemgang af behandlingsmuligheder og hjælper med at navigere i sundhedssystemet.

"Tryg & Sikker" er egnet til alle voksne på et hvilket som helst tidspunkt i forbindelse med et fremadskridende, uhelbredeligt sygdomsforløb.
Du kan modtage indsatsen Tryg & Sikker sammen med rehabilitering og behandling målrettet din sygdom.

### Hvordan ved jeg, at Tryg & Sikker passer til mig?

Tryg & Sikker er for dig, hvis du lider af smerter, træthed, stress eller andre symptomer på grund af et fremadskridende, uhelbredeligt sygdomsforløb, som fx kræft, hjertesygdomme, lungesygdomme, nyresygdomme, demens, Alzheimers, Parkinsons, amyotrofisk lateral sklerose (ALS), multipel sklerose og mange flere.

### Hvordan får jeg Tryg & Sikker?

Du skal bede om det! Fortæl blot din læge og/eller sygeplejerske, at du gerne ønsker indsatsen Tryg & Sikker. Tilbuddet er gratis.

### Hvor modtager jeg Tryg & Sikker

Hjemme eller hvor du har brug for det, fx i forbindelse med din kommunale rehabilitering, hos lægen, på sygehuset, plejehjem eller lignende.

### Hvad kan jeg forvente?

Du kan forvente:

- Lindring af smerter, træthed, åndenød, kvalme, forstoppelse, appetitløshed og søvnproblemer.
- Hjælp til at fortsætte din daglige aktivitet.
- Understøttelse af din læge- og rehabiliterende behandling.

Indsatsen hjælper dig med bedre at forstå din helbredstilstand og dine muligheder for behandling og rehabilitering. Du kan kort sagt forvente at øge din livskvalitet.

# 12 List of papers

**Paper 1**

Shabnam J, Timm HU, Nielsen DS, Raunkiaer M. Palliative Care Utilization Among Non-Western Migrants in Europe: A Systematic Review. Journal of Immigrant and Minority Health. 2021:1-19.

**Paper 2**

Shabnam J, Timm HU, Nielsen DS, Raunkiær M. Palliative Care Utilisation Among Non-Western Migrants in Denmark: A Qualitative Study Of the Experiences of Patients, Family Caregivers and Healthcare Professionals. OMEGA-Journal of Death and Dying. 2022:00302228221111933.

**Paper 3**

Shabnam J, Timm HU, Nielsen DS, Raunkiaer M. Development of a complex intervention (safe and secure) to support non-western migrant patients with palliative care needs and their families. European Journal of Oncology Nursing. 2023;62:102238.

# Paper 1

Journal of Immigrant and Minority Health
https://doi.org/10.1007/s10903-021-01302-8

REVIEW PAPER

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

**Jahan Shabnam**[1] · **Helle Ussing Timm**[2] · **Dorthe Susanne Nielsen**[3] · **Mette Raunkiaer**[1]

Accepted: 22 October 2021

## Abstract

The paper aims to identify and describe the European evidence on opportunities and barriers to access and utilization of palliative care among non- western migrants. A systematic review in accordance with PRISMA guidelines was conducted in June 2020, searching Medline, CINAHL, PsychINFO and EMBASE databases. PROSPERO# CRD42020193651. Studies included empirical research published between 2011 and 2020. Search words were, for example, ethnic groups and palliative care. Thematic analysis was used to analyze data. Twenty nine qualitative and six quantitative studies were included. Four main themes were identified: communication and language; knowledge and awareness; patient preferences, cultural and religious issues; and lack of resources at different levels of palliative care service provision. Migrants' access to palliative care is impeded at system, community and individual levels, yet, recommendations are mostly at the individual level. Closer attention is required to these different levels when designing future palliative interventions for migrants.

**Keywords** Palliative care · Non-western · Migrants · Europe · 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.

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**Table 1** Definitions of terms

| Terms | Definitions |
|---|---|
| Culture | A dynamic framework that evolves and adapts within an ecologic and technical setting through historical, political, and social forces. The framework provides a structure that positions its subgroup members in juxtaposition. Each subgroup creates a dynamic system of beliefs, values, lifestyles, and opportunities that provide its members a sense of safety, identity, and meaning of and for life within the social, biologic, physical, and political niche [75] |
| Migrants | A person who have moved from the country of origin to reside somewhere else willingly or forcefully by finding work or better education or family reunion or other reasons [4] |
| Palliative care | Starting with the diagnosis of a life threatening disease and continuing along the entire trajectory of care, to hospice and end-of-life-care, and finally to family support after death of the loved one [69], [76] |
| Non-western | Non-western migrants refers to the group of people originating from countries other than 28 European countries as well as Andorra, Iceland, Liechtenstein, Monaco, Norway, San Marino, Switzerland, Vatican City State, Canada, USA, Australia and New Zealand [77] |
| Religious | A particular system of faith and worship expressive of an underlying spirituality and interpretative in terms of specific rules, regulations and practices, of what the named religion understands of 'God' or ultimate reality [78] |
| Spiritual | A search for existential meaning within a life experience, usually with reference to a power other than the self, not necessarily called 'God', which enables transcendence and hope [78] |
| Health literacy | Health literacy is linked to literacy and entails people's knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course [70] |

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.

**Table 2** Eligibility criteria

| | |
|---|---|
| Inclusion criteria | Peer reviewed research articles<br>Addressing data from at least one of the non-western migrants nations'<br>Focuses on end-of-life/palliative care<br>Research articles published in last 10 years<br>Non-western migrants living in Europe<br>Articles available free-of-charge or are available through university library services<br>Written in English/Danish/Swedish/Norwegian<br>Concerning adults 18 + as patients |
| Exclusion criteria | Case studies, reviews or non-peer reviewed documents, conference abstracts, editorials, report, quality improvement papers<br>Studies reporting data from people of non-western origin<br>Studies without focus on end-of-life care/palliative care<br>Articles published before 2011<br>Non-western migrants living outside of European setting for example USA/Australia<br>Require a fee OR not available through university library services<br>Resources in languages other than English/Danish/Swedish/Norwegian<br>Religious views without organizational palliative care at the end-of-life<br>Studies on euthanasia, organ donation, mourning or religious descriptions without focus on palliative care |

## 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.

**Table 3** Search words: Ovid Medline

| Searches | Result |
|---|---|
| 1. Exp Ethnic groups/ | 152,424 |
| 2. Exp Cultural diversity/ | 11,452 |
| 3. Exp ''Emigrants and Immigrants''/ | 12,296 |
| 4. Exp ''Transients and Migrants''/ | 11,542 |
| 5. Exp Human Migration/ | 26,237 |
| 6. Exp ''Emigration and Immigration''/ | 25,127 |
| 7. Exp Culture/ | 160,142 |
| 8. Exp Cultural competency/ | 5485 |
| 9. Exp transcultural Nursing/ | 3364 |
| 10. (Ethnicity or Ethnic groups or Cultural diversity or Immigrant* or Migrant* or Human Migration or Immigration or Emigration or Transients or Culture or Cultural competency or transcultural Nursing or cultural factor or culturally competent care or Multiculturalism or Acculturation or Fugitive*). ab,kw,ti | 738,864 |
| 11. 1 or 2 or 3 or 5 or 6 or 7 or 8 or 9 or 10 | 990,902 |
| 12. Exp Palliative care/ | 53,811 |
| 13. Exp Hospices/ | 5006 |
| 14. Exp Terminally ill/ | 6492 |
| 15. Exp Terminal care/ | 51,074 |
| 16. Exp Hospice care/ | 6453 |
| 17. (End of life or palliative nursing or cancer palliative therapy or palliative therapy or hospice care or hospice or hospice nursing or hospice patient or terminally ill patient or Life threatening disease or Life limiting illness or Terminal care or Terminally ill or hospice* or palliative). ab,kw,ti | 91,432 |
| 18. 12 or 13 or 14 or 15 or 16 or 17 | 141,447 |
| 19. 11 and 18 | 4642 |
| 20. Limit 19 to (humans and yr = ''2011 – Current'') | 1726 |

**Table 4** Description of studies

| Author(s), Year, References | Aim | Study design and method | Quality score | Location | Participants | Ethnicity* | Main findings |
|---|---|---|---|---|---|---|---|
| 1. Coupland et al. (2011) [53] | To investigate whether place of death from cancer differs between ethnic groups | Quantitative (retrospective cohort) | 39 | United Kingdom | Cancer patients n = 101,516 | White, Indian, Bangladeshi, Pakistani, Black African, Black Caribbean and Chinese | Place of death varies among ethnic groups. Asian and African patients are more likely to die in hospital |
| 2. Cowan (2014) [50] | To explore the experiences of the Sikh population caring for a dying relative at home without institutional support | Qualitative (semi-structured interviews) | 34 | United Kingdom | Careers, n = 6 | Indian (Sikh) | Lack of support provided by the health professionals was perceived resulting from lack of awareness of services among Sikh population |
| 3. Debesay et al. (2014) [46] | To explore the challenges faced by the community health nurse in providing home health care to minority ethnic patients | Qualitative (semi-structured interviews) | 35 | Norway | Community nurses, n = 19 | African (Islam believers), others are not mentioned | The community nurses were challenged when relatives were not willing to disclose the terminal illness of the patients for believing in the destiny of the God |
| 4. Fang et al. (2015) [45] | To explore the end-of-life (EOL) beliefs, values, practices, and expectations of Chinese women living in England | Qualitative (semi-structured interviews) | 33 | United Kingdom | Migrant women, n = 11 | Chinese | Participants discussed the cultural adaptation of norms, beliefs and values of the host country, language barrier limiting communication, family and health services differential beliefs and norms in providing care; and spiritual practices and beliefs after death, and the hereafter |

**Table 4** (continued)

| Author(s), Year, References | Aim | Study design and method | Quality score | Location | Participants | Ethnicity* | Main findings |
|---|---|---|---|---|---|---|---|
| 5. Finnvold (2018) [44] | To compare the variations in hospital admissions with a serious condition between immigrant and native-born by taking into account income, education and residential area characteristics | Quantitative (retrospective cohort) | 37 | Norway | Hospital admissions, n = 548,140 | Norwegian, Bosnian, Iraqi, Iranian, Somali, Turkish, Pakistani, Sri-Lankan, and Vietnamese | Non-Western immigrant groups' income levels were significantly below that of native Norwegians, the immigrants with lower levels of income or education used less somatic health care and have relatively low hospitalization rates compared to native-born Norwegians |
| 6. Graaff et al. (2012) [33] | To examine the factors influencing communication between care providers and Turkish and Moroccan immigrants in the palliative phase of cancer | Qualitative (interviews and focus groups) | 34 | Netherlands | Cancer patients, n = six, relatives, n = 30 and health professionals, n = 47 | Turkish and Moroccan | Communication between care providers and Turkish or Moroccan immigrants are often hindered by the involvement of family members |
| 7. Graaff et al. (2012) [32] | To explore the influence of different ways of care management on communication and decision making in PC between migrant families and Dutch professional care providers | Qualitative (semi-structured interviews) | 34 | Netherlands | Total, n = 83 patients, n = six, relatives, n = 30 and care providers, n = 47 | Turkish and Moroccan | 'Good care' is perceived differently among care providers and migrant families. Dutch PC providers prefer to focus on quality of life rather than on prolonging life, while Turkish and Moroccan families tend to insist on cure |
| 8. Gunaratnam (2013) [41] | To discuss the value of a stance of cultural vulnerability in intercultural social work | Qualitative (focus group discussions) | 27 | United Kingdom | Palliative care professionals, n = 56 | Indian, Black Caribbean, White (British, Irish, other) | Professional narratives are essential to support professionals to recognize the cultural vulnerability and to deal with thought-provoking emotions |
| 9. Henke et al. (2017) [43] | To present the utilization of hospice and PC facilities by different immigrant groups | Quantitative (cross sectional study) | 37 | Germany | Hospice and PC institutions, n = 34 | **For example Turkish, South Korean, Serbian | Utilization of hospice and PC is lower among immigrants in Berlin especially by the Turkish immigrants |

**Table 4** (continued)

| Author(s), Year, References | Aim | Study design and method | Quality score | Location | Participants | Ethnicity* | Main findings |
|---|---|---|---|---|---|---|---|
| 10. Islam et al. (2015) [47] | To describe the challenges of recruiting and training volunteers from Black, Asian and Minority Ethnic (BAME) community | Descriptive study and focus group | 25 | United Kingdom | Volunteers from BAME group, n = 25 | Black, Asian and Minority | The challenges of recruiting volunteers mainly included inconsistency throughout the training and misconceptions about idea of volunteering for PC. The volunteers who continued perceived their role of great importance thus gained high satisfaction |
| 11. Jansky et al. (2019) [10] | To identify possible access barriers, challenges, and helpful recourses to PC for terminally ill migrants | Qualitative (interviews) | 37 | Germany | Experts, n = 13 | Turkish and Arabs | Health care services do not address migrants. Therefore, patients may mistrust health care system and expect the family to care for them. Cultural conflict is present among patients, families and professionals. To overcome the challenges use of skilled interpreters and focus on cultural competence training are suggested |
| 12. Kai et al. (2011) [42] | To report on the practical challenges faced by professionals while conducting communication, disclosure and patient autonomy in providing cross-cultural cancer care | Qualitative (focus group interviews) | 33 | United Kingdom | Health professionals, n = 106 | White, South Asian, African Caribbean, Chinese, White European | Professionals find it challenging to communicate via a family member as an interpreter. Better understating of diverse culture and individual choices regarding disclosure of information, patient autonomy and patient-centeredness is required among professionals |

**Table 4** (continued)

| Author(s), Year, References | Aim | Study design and method | Quality score | Location | Participants | Ethnicity* | Main findings |
|---|---|---|---|---|---|---|---|
| 13. Koffman et al. (2014) [54] | To examine patterns in place of death among Black, Asian and minority ethnic groups who died of cancer | Quantitative (retrospective cohort) | 38 | United Kingdom | Cancer patients n = 93,375 | Black, Asian and ethnic minorities (BAME) | BAME people are more likely to die in hospitals and less likely to die in home or in hospice compared to those born in UK or other European countries |
| 14. Kristiansen et al. (2014) [57] | To explore the role of faith and religious identities in EOL experiences with life-limiting illnesses | Qualitative (semi-structured interviews) | 35 | United Kingdom/Scotland | Family members, n = 15 and health professionals, n = 10 | South Asian Muslims and Sikhs | It is challenging to maintain hope in illness trajectory of an individual. Clinical encounters and religious beliefs are source of hope among respondents to cope with personal and social consequences of illness |
| 15. Markham et al. (2014) [49] | To explore the reasons for not using hospice services by black, Asian and ethnic minorities (BAME) and possible solutions to improve access | Qualitative (informal discussions) | 34 | United Kingdom | Community people, n = 134 | Black, Asian and ethnic minorities (BAME) | Knowledge about PC was scarce. Participants were concerned about food in hospital. They also valued the provision of information on PC and hospice at different levels in different languages |
| 16. Milberg et al. (2016) [25] | To explore health care professionals' understandings of cross-cultural interaction during EOL care | Qualitative (focus group interviews) | 31 | Sweden | Health care professionals, n = 60 | Not mentioned | Informants mentioned several challenges to provide care towards migrant patients including communication barriers, \`unusual' emotional and pain expressions by migrants, the pre-conceived idea of migrant families are \`different' and anticipation that these patients and their families lack knowledge |

**Table 4** (continued)

| Author(s), Year, References | Aim | Study design and method | Quality score | Location | Participants | Ethnicity* | Main findings |
|---|---|---|---|---|---|---|---|
| 17. Paal and Bukki (2017) [51] | To explore the views and EOL care preferences of migrant patients | Qualitative (interviews) | 34 | Germany | Patients with advanced life-limiting disease, n = 37 | Turkey, USA, Indonesia Germany and other EU countries | Participants with migrant background have limited knowledge about PC, are reluctant to discuss as it is connected to suffering and the significance of individual's migration histories |
| 18. Raunkiaer (2012) [48] | To explore the experiences of elderly ethnic minorities everyday life near death | Qualitative (semi-structured interviews) | 33 | Denmark | Patients, n = 13 and relatives, n = nine | Iranian, Iraqi, Sri-Lankan, Turkish, Thai, Pakistani, Tanzanian, X-Yugoslavs, | Participants lack knowledge about PC. A good death is perceived as quick and unexpected on the contrary a bad death is prolonged, conscious and with dependency. Patients wish to die in the presence of family |
| 19. Samanta and Samanta (2013) [59] | To explore the values considered important by migrants in the context of EOL care | Qualitative (focus groups) | 27 | United Kingdom | Community people, n = 12 | South Asian | Informants expressed the importance of religious values, freedom of expressing faith at the EOL care. Western pattern of autonomous decision-making is not preferable by migrants; instead, they would like to put their trust on family for the decision-making at the EOL care |
| 20. Samanta et al. (2018) [52] | To ascertain faith based values, beliefs, views and attitudes of south Asians' in relation to their perception of issues pertaining to EOL care | Qualitative (focus groups) | 26 | United Kingdom | Community people, n = 12 | South Asian | Faith based values and needs of migrants at the EOL care should be accommodate within the normative structures of the host countries |

**Table 4** (continued)

| Author(s), Year, References | Aim | Study design and method | Quality score | Location | Participants | Ethnicity* | Main findings |
|---|---|---|---|---|---|---|---|
| 21. Schrank et al. (2017) [26] | To explore health care professionals experience of working with cancer patients from different cultural background | Qualitative (semi-structured interviews) | 35 | Austria | Staff members (physicians, nurses, psychologists, spiritual worker and volunteers) | Not mentioned but Muslim patients | Informants focused on culture specific differences due to consequences of multicultural care, and tools for culture-sensitive care. Study suggested strategies for improvement on an organizational level, team level and personal tools |
| 22. Sharpe et al. (2015) [56] | To determine the pattern of place of death from cancer by different ethnic groups and describe patient characteristics | Quantitative (retrospective cohort) | 37 | United Kingdom/ Scotland | Cancer patients, n = 117 467 | Scottish, South Asian, Chinese and African | Non-western ethnic groups represented small portion in all cancer death (0.4%), however, e.g. South Asian, Chinese and African origin patients were youngest at death (66, 66 and 65.9 years) |
| 23. Torensma et al. (2019) [58] | To develop a self-assessment instrument to help PC researchers to improve the responsiveness to diversity of the project | Delphi study | 35 | Netherlands | Expert researchers from Belgium and Netherlands, n = 22 | Non-western migrants | An instrument includes a list of 23 diversity responsiveness measures for migrants and other vulnerable groups. PC researchers to assess diversity responsiveness of their projects and instigate action for improvement can use this instrument |
| 24. Torensma et al. (2020) [55] | To gain insight into EOL care and decision making for non-western migrant patients and assess differences compared to Dutch or western patients | Quantitative (retrospective cohort) | 38 | Netherlands | Patients, n = 5327) | Non- western migrants | Non-western migrant patients are more likely to be admitted or die in hospitals than Dutch/ western patients; less likely to receive sedative drugs; and more likely to receive EOL care that, by physicians, is directed at curation for too long |

**Table 4** (continued)

| Author(s), Year, References | Aim | Study design and method | Quality score | Location | Participants | Ethnicity* | Main findings |
|---|---|---|---|---|---|---|---|
| 25. Torres et al. (2016) [24] | To explore the EOL care providers' understandings of patients need with migration backgrounds | Qualitative (focus group interviews) | 30 | Sweden | Health care professionals n = 60 | Not mentioned | EOL care providers facing challenges in treating patients with migration background for difference in expectations. The difference in expectations might bring misunderstandings and leave the patients' with unmet needs |
| 26. Van Keer et al. (2019) [39] | To explore challenges in delivering bad news to patients and relatives from ethnic minority groups in intensive care unit | Qualitative (observation, in depth interviews and patients' medical record) | 33 | Belgium | Nurses, n = 80, physicians, n = 12 and ethnic minority patients, n = 11 | Turkish, Moroccan, Congolese, Tunisian and Greeks | Challenges of delivering bad news included physicians' poor ethno-cultural understanding in choosing a suitable partner and place for conversation. However, health professionals are continually trying address problems in quick and pragmatic way |
| 27. Van Keer et al. (2015) [38] | To identify the factors contributing to conflicts between health professionals and families from ethnic minority groups in an ICU | Qualitative (observation, in depth interviews and patients' medical record) | 31 | Belgium | Ethnic minority families, n = 10, nurse, n = 80 and doctors, n = 12 | African, Turkish, and Southern European | The factors for conflict between two parties in the study were related to difference in participants' views on what is 'good care' based on different approaches for example biomedical care vs. holistic lifeworld-oriented approach |
| 28. Van Keer et al. (2017) [40] | To investigate the mental well-being of ethnic minority patients in a multi-ethnic ICU | Qualitative (observation, in depth interviews and patients' medical record) | 33 | Belgium | ICU staffs, n = 84, patients and families, n = 10 | Moroccan, Algerian, Turkish, Congolese and Portuguese | Patients in ICU have several needs, includes need for social contact, need to increase comfort, alleviate pain and to participate in EOL decision making |

**Table 4** (continued)

| Author(s), Year, References | Aim | Study design and method | Quality score | Location | Participants | Ethnicity* | Main findings |
|---|---|---|---|---|---|---|---|
| 29. Venkatasalu (2017) [29] | To explore older individuals view on dying at acute hospitals | Qualitative (focus groups and semi-structured interviews) | 35 | United Kingdom | Older adults, n = 55 | South Asian | Informants reported lack of trust for hospital care, family care was carried out to both protect and provide comfortable EOL care towards dying loved one |
| 30. Venkatasalu et al. (2013) [30] | To explore the perspectives of older South Asians towards discussing death and dying | Qualitative (focus groups and semi-structured interviews) | 35 | United Kingdom | Older adults, n = 55 | South Asian | Older south Asians avoids discussion on death and dying within family as a cultural norm and to protect family members from mental distress |
| 31. Venkatasalu et al. (2014) [31] | To explore beliefs, attitudes and expectations of older adults about dying at home | Qualitative (focus groups and semi-structured interviews) | 37 | United Kingdom | Older adults, n = 55 | South Asian | Physical place of death (home/hospital) is considered less important compared to be able to carry out the cultural and religious practices |
| 32. Wilkinson et al. (2014) [36] | To explore EOL care for South Asians with kidney disease, to identify inequalities in access and experience of EOL care | Qualitative (semi-structured interviews and focus groups) | 32 | United Kingdom | Patients, n = 16 and Care providers, n = 45 | South Asian | Lack of awareness about EOL care and communication barriers hinder the kidney patients' involvement in shared decision making in the EOL care |
| 33. Wilkinson et al. (2016) [34] | To reflect on the process to identify and recruit patients with ethnic minority backgrounds at the EOL for a research project | Qualitative (semi-structured interviews and focus groups) | 35 | United Kingdom | Patients, n = 16 and care providers, n = 45 | South Asian | Barriers to recruit patients included: difficulties in identifying the EOL phase; and lack of awareness of EOL care; family members' role in mediating communication; and contrasting cultures in EOL kidney care |

**Table 4** (continued)

| Author(s), Year, References | Aim | Study design and method | Quality score | Location | Participants | Ethnicity* | Main findings |
|---|---|---|---|---|---|---|---|
| 34. Wilkinson et al. (2017) [35] | To explore experiences of kidney patients' at the EOL care to inform delivery of care that can meet diverse patients' needs | Qualitative (semi-structured interviews and focus groups) | 35 | United Kingdom | Patients, n = 16 and care providers, n = 45 | South Asian | Lack of time and skill of nurses in the kidney care influence the access to EOL care of patients with migrant backgrounds |
| 35. Wilkinson et al. (2017) [37] | To report interviewer reflections of conducting interviews with South Asian kidney patients about their experiences of EOL care | Qualitative (focus group) | 35 | United Kingdom | Bilingual research interviewers, n = 7 | South Asian | Bilingual research interviewers reflected on the inequalities and access to EOL care that could contribute for the service development of South Asian kidney patients |

*Ethnicity here refers to the ethnicity which are studied or discussed in the article

**Polish, Turkish, Russian, South Korean, Serbian, Vietnamese, Austrian, Ukkranien, Croatian, Italian, French, Romanian, Libyan, Indian, Egyptian, Portugease and others

## 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, 29–37] 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.

### 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,

**Table 5** Data analysis

| Steps | Process | Example |
|---|---|---|
| Extracting data | Articles added in current review were read carefully to extract data by using a form developed by authors. Authors extracted data which seems relevant to the current review | Table 4 shows the extracted data |
| Coding data | Entire articles were read again and again to code according to the research aim. Line-by-line coding was done manually. Here in this table showing example from one article [35] | Need more time to allocate interpreter<br>Nurses lacked time to talk to patients<br>Lack of time and staff, less time available to talk<br>Culture of common decision making<br>Providers lack training to discuss EOL<br>Strategy to improve rapport is to involve family members<br>Involvement of family careers increase frequency of treatment [35] |
| Combining similar codes together | Similar codes from all of the articles were combined together | Need more time to allocate interpreter<br>Nurses lacked time to talk to patients<br>Lack of time and staff, less time available to talk<br>Providers lack training to discuss EOL |
| Themes | Similar codes were grouped together under themes. Themes were not included if they consisted of very diverse data. Themes with too little information were merged together under one theme | Lack of resources at different levels of palliative care service provision |

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].

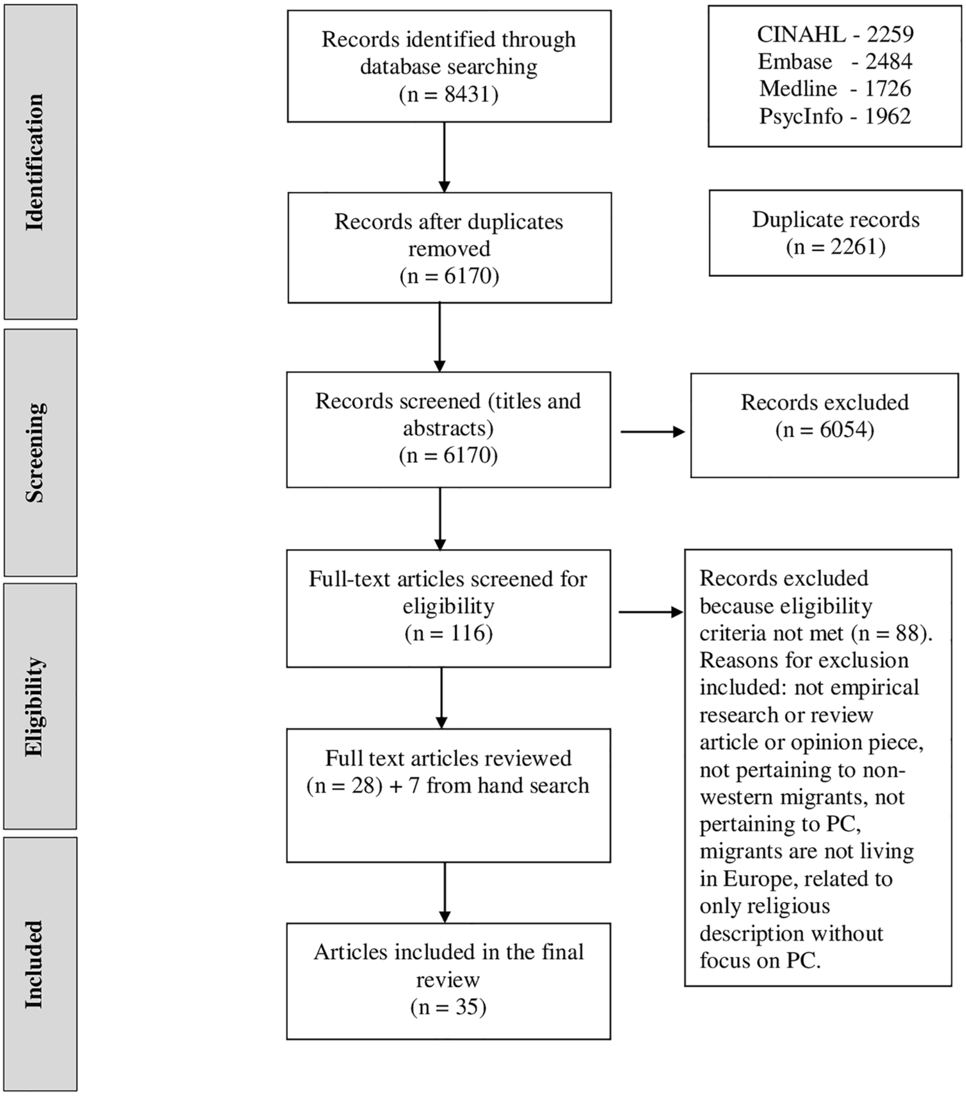
Various possibilities to improve communication among HPs and migrant families are found in the literature, for example, to involve both the patient and family members in the medical discussion [32, 39]. Moreover, HPs should be trained to work in cooperation with professional interpreters [33, 42]. Involving 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].

## 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

**Fig. 1** PRISMA flow diagram



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].

## 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].

### 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-existant 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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### Declarations

**Conflict of interests** The authors declare that they have no conflict of interests.

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# Palliative Care Utilisation Among Non-Western Migrants in Denmark: A Qualitative Study Of the Experiences of Patients, Family Caregivers and Healthcare Professionals

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## Abstract

This study explores care experiences while utilising palliative care services of non-western migrant families from the perspectives of patients, family caregivers, and healthcare professionals in Denmark. Twenty-three semi-structured individual and group interviews were conducted among eight patients with a life-threatening disease, 11 family caregivers, and ten healthcare professionals. Thematic analysis revealed three themes: 1) Communication between families and healthcare professionals; 2) Building and lack of trusting relations, and feeling safe, and 3) Access to information and navigating in the healthcare system. Moreover, "language and culture" emerged as transaction themes that are not mutually exclusive, however, interconnect across the

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mentioned three themes. Non-western migrant families can be supported by healthcare professionals' cultural competency training, negotiating on providing services concerning information, patient preferences, family involvement, and palliative care setting. This study findings urge inter-sectoral collaboration to ensure needs-oriented and linguistically and culturally appropriate palliative care services for non-western migrant families in Denmark.

**Keywords**
palliative care, transients and migrants, non-western, health services, Denmark

*Palliative care* has been recognised under the human right to health by the United Nations' International Covenant on Economic, Social, and Cultural Rights since 2000. Eventually, it has been integrated into universal health coverage in the healthcare systems in many countries (Powell et al., 2015). Ethnic inequalities in access to and utilisation of palliative care are well documented, and the reasons stated include lower awareness of the availability of palliative care services (Evans, Meñaca, Andrew, et al., 2012; Shabnam et al., 2020), language difficulties (de Graaff et al., 2012), lower rate of referral to palliative care services (Evans, Meñaca, Andrew, et al., 2012), and healthcare professionals' poor *cultural competency* (Jansky et al., 2019). Although barriers to access to and utilisation of palliative care among migrants are described as rooted at the system-, community- and individual levels (Jansky et al., 2019; Schrank et al., 2017), most recommendations are at the personal level (Shabnam et al., 2021). Palliative care services are well established and available for all Danish legal residents. G*eneral and specialised palliative* care are integrated into mainstream healthcare provision for patients with life-threatening diseases (Sundhedsdatastyrelsen, 2017). Concepts in italic are described in the concept section of this study.

In January 2020, 14% of the population in Denmark had a migration background (migrants and their descendants). Among all migrants, two out of three have a non-western origin (Indvandrere i Danmark 2021, 2021). Many work migrants, mainly from Turkey, Ex-Yugoslavia, and Pakistan who migrated in the 1960s and 1970s to take jobs as unskilled workers in Danish factories are now aging (Nielsen et al., 2021). An increasing number of migrants are at risk of developing life-threatening illnesses. Previous studies conducted among these groups show that despite the general availability of these services in Denmark, non-western migrants are less likely than ethnic Danes to use elderly care (Hansen, 2014), to participate in cancer screening (Frederiksen et al., 2010; Hertzum-Larsen et al., 2019; Kristiansen et al., 2012), and live in a nursing home (Stevnsborg et al., 2016). One of the factors limiting non-western migrants' interaction with healthcare services may be poor Danish language proficiency (Hansen, 2014). Another factor is the religious and cultural differences between the non-western migrants and the Danish community (Pentaris & Thomsen, 2020). For example, the traditional values held by some of the non-western migrants, such as filial piety and the collective well-being of families, can be seen to contradict the dominant cultural norm of public healthcare in Denmark (Hansen, 2014). Hence, when approaching death, non-western migrants may reasonably prefer adopting rituals practiced in the country of origin to those of the host country (Hunter & Ammann, 2016).

While the literature on the needs and barriers to access general healthcare services experienced by migrants has recently increased (Biswas et al., 2011; Lokdam et al., 2016; Nielsen et al., 2021; Villadsen et al., 2019), in Denmark, empirical data on non-western migrants' utilisation of palliative care is scarce (Pentaris & Thomsen, 2020; Raunkiær, 2012). Thus, little is known about what facilitators or barriers to; palliative care provided by healthcare professionals and receiving palliative care among non-western migrant families in Denmark. These insights may better support non-western migrant families with palliative care needs.

Therefore, this study aims to explore the care experiences while utilising palliative care services of non-western migrant families from the perspectives of patients, family caregivers, and healthcare professionals in Denmark. The research questions of this study are

1) What do non-western migrant patients and family caregivers find important and challenging while using institutional palliative care?
2) How do healthcare professionals experience possibilities and challenges in palliative care for non-western patients and family caregivers?

## Concepts Used in this Study

In this section conceptual and analytical framework that guided this study will be discussed by defining central concepts.

In this study, palliative care is understood as "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness through the prevention and relief of suffering through early identification, correct assessment and treatment of pain and other issues, whether physical, psychosocial and spiritual" (Palliative Care, 2020).

In Denmark, general palliative care is provided in organisations like nursing homes, home nursing care, general practice, and hospitals (Radbruch & Payne, 2009; Sundhedsdatastyrelsen, 2017). Specialised palliative care is meant for patients with life-threatening diseases with complex palliative care needs that require attention from professionals with specialist palliative care skills and knowledge (Radbruch & Payne, 2009; Sundhedsdatastyrelsen, 2017). The organisations providing this care are specialised palliative care teams, hospices, and palliative care units in hospitals (Radbruch & Payne, 2009; Sundhedsdatastyrelsen, 2017).

In this study, culture is understood as a dynamic framework that evolves and creates a dynamic system of beliefs, values, lifestyles, and opportunities that provide its members with a sense of safety, identity, and meaning of and for life within the social, biological, physical, and political niche (Cain et al., 2018). Moreover, culture is understood as the beliefs, traditions, practices, and characteristics of people that have been taught over time which guide their perceptions and health behaviours (Purnell & Paulanka, 1998). Cultural competency encompasses a set of values, behaviours, attitudes, knowledge, and skills that allow healthcare professionals to offer patient care which is respectful and inclusive of diverse cultural backgrounds (Evans, Meñaca, Koffman, et al., 2012).

Someone has a migration background if that person or at least one of the parents was born outside of Denmark (Indvandrere i Danmark 2021, 2021). Migrants are defined diversely within several categories, including labour migrants, refugees and asylum seekers, family members of existing migrants, victims of trafficking, and returnees (How health systems can address health inequities linked to migration and ethnicity, 2010; Mladovsky, 2007). In this study, the term 'migrants' will be used as an overarching term inclusive of refugees, asylum seekers, and other migrants (How health systems can address health inequities linked to migration and ethnicity, 2010). Non-western migrants refer to the group of people originating from countries other than 28 European countries as well as Andorra, Iceland, Liechtenstein, Monaco, Norway, San Marino, Switzerland, Vatican City State, Canada, USA, Australia, and New Zealand (Statistik, 2021). Although non-western migrants will be named as a common group in this study, they represent a variety of languages, religions, and cultures originating from different continents of the world (What are the 7 Continents of the World? 2021). Despite heterogeneity, in this study, non-western migrants are studied as a group due to their cultural values and beliefs tied to their country of origin in palliative care preferences and decision-making (Shabnam et al., 2021).

## Methods

### Study Design

The research questions call for a qualitative study, and semi-structured interviews were conducted, reports by using the Consolidated criteria for reporting qualitative research (COREQ) guidelines (Tong et al., 2007). Thematic data analysis was carried out (Braun & Clarke, 2006), and the analysis was inductive (Thomas, 2006).

### Participants and Setting

Participants were recruited purposively, non-western migrant patients with a life-threatening disease, family caregivers, and healthcare professionals. Inclusion and exclusion criteria for participants are mentioned in Table 1. From previous experiences and literature (O'Reilly-de Brún et al., 2015; Torensma et al., 2019), it is already known that recruitment among non-western migrants is challenging and time-consuming. Therefore, collaborations were made with different departments at four different hospitals and two organisations situated in two regions, the Capital Region of Denmark and the Region of Southern Denmark, respectively, to contact migrant families. Thus,

**Table 1.** Criteria for Participant Selection.

| Inclusion criteria | Exclusion criteria |
|---|---|
| For families | For families |
| • Patients and family caregivers (not necessarily from the same family) | • Family caregivers less than 18 years |
| • Adult (18 or older) | • Western migrants and their descendants |
| • Non-western migrants and their descendants living in Denmark | • Patients unable to communicate |
| • Patients with life-threatening diseases (Cancer, Cardio Vascular disease, Lung disease, Mental disorders, or any disease which might result in referral to palliative care) | — |
| • The family caregiver is a relative or family member who is/was (bereaved relative within last 2 years) related most closely to the patient in the palliative phase of the life-threatening disease trajectory | — |
| For healthcare professionals | For healthcare professionals |
| • Providing care for any patients with life-threatening diseases with a non-western background | • Providing care more than 2 years ago towards this study group |
| • Doctors, nurses, physiotherapists, occupational therapists, psychologists, social workers, and dieticians | — |

healthcare professionals gave information material about the project and information on participation, written in Danish and English, to potential participants. If a person showed interest in taking part in the project, the contact information was passed to the first author. Eight potential participants declined to take part in the interviews after the first author contacted them. Recruitment of families took place between 11.03.2019 to 25.06.2021 from six different settings of Denmark's capital region and Southern Denmark's region.

To inform the aim of the present study and get in contact with healthcare professionals, the first author presented the study in different collaborating healthcare settings. The first author approached healthcare professionals to take part in the interview. Healthcare professionals from five different settings in the capital region and region of Southern Denmark were interviewed between 15.04.2021 and 14.06.2021. There was no dropout among healthcare professionals.

## *Ethical Approval*

The Danish National Committee on Bioethics, number 61269, approved the study. The study was registered at the Danish Data Protection Agency (file number: 10.109) and performed following the Declaration of Helsinki (Association, 2001). The first author provided written and verbal information to participants that this study was part of a PhD study, the study purpose, the interview process, and the audio recording to the participants. The first author obtained consent (written or verbal) before each interview. Patients were asked to nominate a family caregiver involved in the support and care, and the caregivers included gave consent separately. All participants had information that their data would be retained and used confidentially, besides their right to withdraw from the study at any time. The participants' initials and personal details have been altered in this article to prevent the identification of individuals.

## *Data Collection*

The inclusion criteria of the families are shown in Table 1. The healthcare professionals, in collaboration with the first author, included the families. The 'Surprise Question'-Would I (healthcare professional) be surprised if this patient died in the next 12 months? (Moss et al., 2010) combined with supportive and palliative care indicators tool (Weibull et al., 2019) were used to identify patients eligible for this study. Culturally adapted supportive and palliative care indicators tool helps Danish healthcare professionals to identify people at risk of deteriorating and dying with life-limiting illness (Weibull et al., 2019). Surprise question was used as an initial screening, then supportive and palliative care indicators tool was used for detailed identification of patients.

The first author conducted semi-structured interviews in participants' preferred language at a mutually agreed date, time, and place. Interviews were conducted in Danish (14), English (1), Bangla (2), Urdu (1) (by the first author), and Arabic (1) (took help from an interpreter during the interview). Eight participants preferred to be interviewed via video conference as the data collection process intersects the COVID-19 period. Only verbal consent (8) was obtained from the participants in those cases. Written informed consent was obtained from 11 participants before the interview.

The inclusion criteria for the healthcare professionals are presented in Table 1 and as appears they were not necessarily providing care for the participant families in the present study.

The first author conducted individual (4) and/or group discussions (2) with healthcare professionals from five different settings situated in the Capital Region of Denmark and the Region of Southern Denmark. In the first group discussion, the last author helped to take relevant important notes and facilitate the discussion. Only one interview was conducted face-to-face; all other five interviews were conducted over video according to the preference of the healthcare professionals due to the Covid pandemic.

The interviewer had no prior relationship with any of the participants. However, to build rapport, only a one-time interviewer met or talked over the phone with participants and exchanged formal greetings before the actual interview. An interview guide was developed to explore families' experiences, based on the result of a systematic review (Shabnam et al., 2021) of evidence on palliative care utilisation among non-western migrants in Europe. AfterwarAfterwarded accordingly to the Danish healthcare system. The interview guide explored how migrant families encounter healthcare services and healthcare professionals in the disease trajectory (supplemental material). An interview guide was developed to explore the experiences of the healthcare professionals based on the interviews with the families, where the families discussed different aspects faced at different levels of palliative care. Thus, the interviews with healthcare professionals were complementary and supplementary to those with migrant families (supplemental material).

To enhance the credibility of the data, at the end of each interview, the interviewer summarised the interview to the participants. It allowed them (families and healthcare professionals) to verify and clarify any misconceptions or additional information. Data collection continued until saturation was reached, discussed with the last author. All the interviews were audio-recorded, anonymised, given identification codes, and transcribed verbatim to ensure confidentiality.

### Analysis

The first author transcribed the interviews. The interview data was not translated because qualitative data is better analysed in the source language to minimise the loss in translation (Chen & Boore, 2010; Smith et al., 2008). Selected codes were translated into English. The first author conducted analysis and later discussed with the last author until agreement was achieved on identified emerging themes, their conceptualisation, and coding. Findings were presented and discussed within the research group to enhance data analysis further. A thematic analysis was conducted by following the steps outlined by Braun and Clarke (Braun & Clarke, 2006) (Table 2). A combination of manual technique and software (NVivo 12) was used to manage data and organise codes, to have an overall perspective.

## Results

A total of 31 participants, consisting of 15 families (eight patients and 11 caregivers) (Table 3) and ten healthcare professionals were recruited (Table 4). The interviews with families lasted from 15 to 104 minutes and with healthcare professionals from 16 to 82 minutes. In two families (no. 5 and 15), the patient and caregiver wished to be interviewed together; the rest were individual interviews. As preferred by the healthcare professionals, two group interviews and four individual interviews were conducted.

Family XX was included by personal contact; still, it was known by the first author that the patient only had a few months left to live (declared by the healthcare professionals at a hospital).

**Table 2.** Example of Analysis Process (Braun & Clarke, 2006).

| Steps | Description of action | Example from the present study |
|---|---|---|
| Step 1. Familiarising with data | Transcribing data, reading and reading the transcripts, noting down the initial ideas | The first author transcribed data, read transcripts several times and noted initial ideas |
| Step 2. Generating initial codes | Identification of interesting features of data and collating data relevant to each code | If my mother or I am not here, and my father is alone, so I think it is very important that the sense of safety is there, if the same persons are coming to my father at home if the faces are known then father feels safer and also try to talk. So it is something when someone knows each other even if they do not speak the language they try to communicate with each other in other ways, so one tries to communicate with the faces one knows, the well-known relationship is important. On the point of language, it is so difficult when someone is elderly and has a life-threatening disease<br>Yes, yes, one can easily use the translator, so it could also be a little help. But I think the feelings of safety and security are very important, no matter how the language barrier is. I have experienced with my father that, the one who comes most often, the well-known, trusted relationship is important, my father is more comfortable talking in front of them. R - 2 |
| Step 3. Searching for themes | Collating codes into themes by organisingsimilar codes together | Migrant families needs of feeling safe |
| Step 4. Reviewing themes | Revisiting the themes to ensure that they are representing the codes identified previous step | Importance of non-verbal communication |
| Step 5. Defining and naming final themes | Generating clear definitions and names for each theme | Building and lack of trusting relations, and feeling safe |

*(continued)*

**Table 2.** (continued)

| Steps | Description of action | Example from the present study |
|---|---|---|
| Step 6. Producing the report | Interpreting findings with similar codes and writing the final findings | "The knowing relationship is important; my father is more comfortable talking in front of them. In general, if the same person comes, it gives the patient feeling of safety" R- 2<br>"To ensure the feelings of safety is the first and foremost for my father" R- 2<br>"All (doctors) say different things, they are alike at all, so we do not know whom should we trust" R –8 |

## Themes

Three main themes emerged from the data: 1. Communication between families and healthcare professionals, 2. Building and lack of trusting relations, and feeling safe, and 3. Access to information and navigating in the healthcare system. Language and culture are not mutually exclusive, however, they influence and interconnect in all three mentioned themes. Thus, culture and language are presented concerning all three themes (Table 5).

### *Communication Between Families and Healthcare Professionals*

Participants – patients, family caregivers, and healthcare professionals mentioned the importance of communication (verbal/non-verbal). Moreover, how culture influenced the communication between migrant families and healthcare professionals. While talking about communication, participants (F – 2, 3, 5, 7, 10, 13, 14) drew attention to the significance of Danish language proficiency at palliative care services in Denmark.

> *The first thing one should do while living in Denmark is to learn the language. If you cannot communicate, you cannot go further. I think doctors and nurses expect that I understand the language. (Pt – 5)*

Participants – especially healthcare professionals (1, 2, 5, 6) drew attention to the fact that lack of knowledge about the culture of non-western migrants influences their mindset, approach, and communication with migrant families. There was ambiguity among healthcare professionals if it was the person or his/her cultural background which made the difference. In ethnic Danish families, healthcare professionals could understand the reasoning behind a specific action. This current uncertainty made it difficult for healthcare professionals to further communicate with the family.

**Table 3.** Families at a Glance.

| Participant ID# (age) | Sex | Country of origin | Migration background (Lived in Denmark for years) | Language proficiency | Family caregiver of the patient |
|---|---|---|---|---|---|
| Family 1 Pt 1 (40) | Female | Turkey | Family reunification (21 years) | Communicates in Danish | Mother |
| Family 2 Pt 2 (52) | Male | Syria | Asylum seeker (5 years) | Uses interpreter | Wife |
| Family 3 Pt 3 (39) | Male | Nepal | Family reunification (9 years) | Communicates in English | None (lives alone) |
| Family 4 Pt 4 (37) | Male | Iraq-Poland | Family reunification 27 years | Communicates in Danish | None (lives alone) |
| Family 5 Pt 5 (41), R 5 (49) | Female | Iraq | Family reunification (17 years) | Communicates in Danish | Husband |
| | Male | Iraq | Family reunification (32 years) | Communicates in Danish | |
| Family 6 Pt 6 (39) | Male | Pakistan | Family reunification (17 years) | Communicates in Danish | Wife |
| Family 7 Pt 7 (72) R 9 (26) | Male | Bangladesh | Job visa (10 years) | Uses interpreter | Son |
| | Male | Bangladesh | Family reunification (10 years) | Communicates in Danish | |
| Family 8 R 8 (31) | Female | Turkey | Born in Denmark | Communicates in Danish | Daughter |
| Family 9 R 1 (45) R 4 (47) | Female | Turkey | Family reunification (23 years) | Communicates in Danish | Daughter in law |
| | Female | Turkey | Family reunification (25 years) | Communicates in Danish | Daughter in law |
| Family 10 R 2 (28) | Male | Vietnam | Family reunification (26 years) | Communicates in Danish | Son |
| Family 11 R 3 | Female | Iraq | Family reunification (27 years) | Communicates in Danish | Wife |

*(continued)*

**Table 3.** (continued)

| Participant ID# (age) | Sex | Country of origin | Migration background (Lived in Denmark for years) | Language proficiency | Family caregiver of the patient |
|---|---|---|---|---|---|
| Family 12 R 6 (50) | Female | Turkey | Family reunification (45 years) | Communicates in Danish | Wife |
| Family 13 R 7 (22) | Male | Iraq | Family reunification (5 years) | Communicates in Danish | Brother |
| Family 14 R 10 (29) | Female | Turkey | Family reunification (22 years) | Communicates in Danish | Granddaughter |
| Family 15 Pt 8 (73) R 11 (55) | Male<br>Female | Turkey<br>Turkey | Job visa (52 years)<br>Family reunification (21 years) | Uses interpreter<br>Uses interpreter | Wife |

**Table 4.** Healthcare Professionals at a Glance.

| Participant ID | Type of interview and setting | Workplace | Profession |
|---|---|---|---|
| HCP 1 (a,b,c,d) | Group interview in a hospital in the Capital region of Denmark | Specialist palliative care unit | Palliative nurse-1, social worker-1, psychologist-1, physiotherapist-1 |
| HCP 2 | Individual interview in a clinic in the region of Southern Denmark | Migrant clinic | Nurse - 1 |
| HCP 3 | Individual interview in a clinic in the region of Southern Denmark | Migrant clinic | Physician - 1 |
| HCP 4 | Individual interview in a research centre in the Capital region of Denmark | Specialist palliative care unit | Physician - 1 |
| HCP 5 | Individual interview in a hospital in the region of Southern Denmark, oncology department | Specialist palliative care unit | Palliative nurse - 1 |
| HCP 6 (a,b) | Group interview in a hospital in the region of Southern Denmark, oncology department | Specialist palliative care unit | Palliative nurse - 1 |

Initials for participant identification: Family – F, Patient – Pt, family caregivers – R, and healthcare professionals – HCP. All the healthcare professionals were ethnic Danes.

**Table 5.** Themes Derived from this Study.

| Transverse theme | Theme 1–3 |
|---|---|
| Language and culture | 1. Communication between families and healthcare professionals<br>2. Building and lack of trusting relations, and feeling safe<br>3. Access to information and navigating in the health care system |

A nurse explained:

> *After all, death is at the door. Our culture (Danish) is different. We (professionals) think maybe it is a barrier. I am confused. Is it culture or personality, or what is it all about? And, then maybe with a Danish family, I can sense the reason. (HCP-1(a))*

Only healthcare professionals (1, 2, 5, 6) and relatives (R – 1, 8, 9) talked about the clash between cultures, disclosing the actual situation to the patients.

One of the nurses explained:

> *Yes, I know some families have wished that patients should not know how seriously ill they were.* […] *one should know how to find a way where we can meet. We have, or the system must tell the patient. But sometimes it is also important how one tells it. One can say it the way the patient and family experience respect. One can also ask how much the patient would like to know. (HCP – 2)*

For relatives, this was a way of protecting their loved ones.

A son stated:

> *I hide information from my father, so he is not afraid and more worried. Doctors give a lot of information; if the doctors say something severe, I try to avoid that and say something else. So he does not get scared. (R-9)*

Participants from families (R – 1,2,5,7,8,9,10 and Pt – 1,2,3,5) highlighted how migrants' cultural understanding often combined with poor language proficiency could influence the palliative care decision-making.

> *Caregiver: When we think about her care at nursing homes, we think about language. The problem is she neither speaks nor understands it.*
>
> *Interviewer: So is it because of language you do not want to send her to a care home?*
>
> *Caregiver: It's not only language; it's something different. In our culture, it is not allowed to send her to a care home. We take care of our sick relatives at home for as long as we can. (R – 1)*

Participants with poor Danish language proficiency faced challenges in the disease and palliative trajectory to express their needs, so they needed help from a family caregiver or a translator to convey their messages further.

A wife said:

> *My husband uses a Turkish interpreter during the conversation with health professionals or his two sons born in Denmark to help with interpretation during hospital visits. (R-11)*

Most of the families (F- 2, 3, 7, 10, 13) and professionals (1, 2, 5, 6) were not satisfied with the available interpreter service, as the interpreters were missing skills concerning the disease-related translation. The issue of an interpreter was worsened when it was via telephone.

A brother and a nurse described:

> *It was an interpreter over the telephone; a doctor and a nurse had to explain to my sister what kind of cancer she had. The interpreter could not even mention what type of cancer. I could understand everything the professionals said. I could explain better than the interpreter did to my parents and sisters. (R – 7)*

> *I have used telephone interpretation on a few occasions, and then it is my interpretation, but I could see that the translation was poor in the family's face. I think the interpreter should facilitate the conversation, not the opposite. I am not defending the use of interpreters. Still, using an interpreter depends on the need of the patients or families. (HCP -5*)

However, healthcare professionals (3, 4) entirely depended on professional interpreters. A doctor explained:

> *We always have a professional interpreter if the patient does not speak Danish fluently. They cannot understand what we are talking about. We tell relatives that they can stay there and sit but interpret, and most accept it. (HCP-3)*

Healthcare professionals were satisfied when skilled interpreters were involved during the healthcare conversation.

### Building and lack of trusting relations, and feeling safe

All the migrant families expressed their overall satisfaction with the Danish healthcare system, especially compared to the healthcare system in their homeland. However, there could be challenges in the relationships between the families and the healthcare professionals (F – 3, 5, 7, 8, 11, 13).

A patient described:

> *If I compare Danish health facilities with my country on a one to 10 scale, my country is on two, and Denmark is on 10. But when they (healthcare professionals) have a lot of jobs, lots of patients they have stress, sometimes they cannot control, and they are showing their feelings (for example anger)* [...] *I understand. I never asked, and I never complained about the nurse. (Pt-3)*

Often lack of a trusting relationship was due to receiving different information from different professionals. Conflicting information from healthcare professionals generated confusion among families about the patient's actual situation.

As a daughter said:

> *All (doctors) say different things, and they are not alike at all, so we do not know whom should we trust. (R – 8)*

The feeling safe also depended on the attitude of the professionals. The migrant families appreciated the professionals who took their time to listen to them. According to the relatives (R - 3, 7, 8, 9), the Danish doctors are skilled enough, although they do not spend time listening.

One of the relatives explained:

> *Every time we go to the hospital for a consultation, we meet a new doctor. We need to tell him the history from the beginning, I know he can read the medical record, but everything is not in the record. After we have a permanent doctor, we feel safer* [...] *she is from Lebanon. I can see my father feels safer talking to her. She understands our mental situation and our feelings. All other Danish doctors are good too but they do not listen properly. (R – 8)*

In addition to enough time, the quote shows what was not in the medical journal, for example, cultural recognizability as they originate from the same cultural background, which might support the family's feeling of safety.

Both patient and relatives (P 2, 3, 5, and R 2, 3, 8, 9) mentioned that knowing a face in the health system increased the feeling of safety and comfort. Even for home visits, relatives preferred the same healthcare professionals to come. Continuity of care helped make a trusting relationship, especially when the verbal conversation was lacking due to poor language proficiency.

A son described:

> *The knowing relationship is important; my father is more comfortable talking in front of them. In general, if the same person comes, it gives the patient a feeling of safety, especially for those who do not speak Danish. (R- 2)*

Healthcare professionals (2, 3, 4, 5, 6) approved that building a trusting relationship was not always dependent on the verbal conversation but on showing respect.

One doctor described:

> *It is possible to provide complex palliative care services without talking. It is possible to have a respectful relationship without speaking the same language. It just needs to have some other resources, for example, time. If one cannot show respect with words, one can show respect with their care. It is possible to provide care without speaking the same language, and it is just difficult. (HCP – 4)*

According to healthcare professionals (1, 4, 5, 6), among non-western migrant families, most patients with life-threatening diseases try to manage the caring within the family by helping each other.

A doctor and a nurse stated:

> *They will often try to manage it themselves instead of seeking help in the system, which can be difficult as it requires extra energy. (HCP – 4)*
>
> *Many families try and manage on their own. And so actually, therefore, get help late in the disease trajectory. (HCP - 5)*

According to all healthcare professionals (1–6), the preferences and wishes of each migrant family were seen as paramount to building trust and feeling safe. Healthcare professionals highlighted the individuality of each family.

A nurse and a doctor described (subsequently):

> *I think we should not try to put patients into specific boxes, such as Asian, African, homosexual, or based on their religious beliefs. We provide care toward each individual as a human being. Of course, the previous history of a person's life impacts how and what decision he/she takes during their terminal illness.(HCP - 6 (a))*
>
> *I try to talk to them according to their level of understanding. Something works for one (patient and their relatives), and something different works for others depending on their background. Their education, their experiences, the most important thing is that healthcare professionals need to ask families about their needs. (HCP -3)*

As the quotes show, some healthcare professionals were aware of possible differences in patient preferences.

### *Access to Information and Navigating in the System*

Migrant families (F-2, 3, 7, 9, 11, 13, 14) told that, in general, they had poor knowledge about how to utilise the healthcare system in Denmark in the whole disease trajectory. The barrier was more prominent among recent migrants and referred, for example, to psychological challenges.

A son explained:

> *We do not know how the Danish health care system works. I have psychological problems after my father's cancer. I need some information. I need to talk to someone about my psychological issues, but I do not know how. (R – 9)*

Migrant families were aware of the life-threatening disease-based treatment provided at hospital departments. However, many of them (F – 2, 3, 7, 9, 10, 11, 13) were unaware of other available support services, for example, mental health counselling, leave of absence, taxi service, and personal advisor at the municipality.

A daughter-in-law stated:

> *I was at work and was sleeping while sitting like this (showing the position). I told my colleague that I was with my mother-in-law. I could not sleep at night. She told me, why don't you take a leave of absence? I replied I did not know. So, I applied, and it was approved. (R – 2)*

Healthcare professionals warranted the issue raised by migrant families. Most healthcare professionals (1,2,5,6) agreed that they were not good at delivering information to migrant families, including medical and practical knowledge.

A nurse described:

> *I think we are bad at providing information. For example, it is possible to get an interpreter for patients with life-threatening diseases free of charge. After all, this is an opportunity. (HCP-5)*

Apart from poor knowledge about available supportive services for relatives, migrant families (F – 1, 2, 5, 7, 9, 10, 14) told that reluctance to seek help hindered their navigation in the palliative care service.

> *In our culture, one does not ask for help. Others help the one in need. In Denmark, it is the other way around. One needs to be healthy to get the benefit of being sick. So I will have to have control over many things, to be able to call the municipality and say I have these problems., I need help with this, and so on. (R – 5)*

Professionals (1, 4, 5, 6) said that one needed to be familiar with the entire system to make the best use of the Danish health care system. The situation was more complicated due to poor referral systems at different levels of health system.

One nurse working in specialised palliative care stated:

> *People who have experience in getting help from us can better navigate. But if you have no idea,,,, The general practitioners do not always remember that we are also available in the system. So I think it is not about the patient or the family. They do not know where to go, what help they can get. (HCP – 6 (b))*

Families (F - 4, 5, 6, 9, 12) living in Denmark with other extended family members or for a longer period had more information about how and where to get help when needed. Moreover, relatives from the second generation migrants (R - 2, 8, 10) were relatively more knowledgeable and confident about using the system.

> *My grandmother or my parents do not know the system as I do. I am from the second generation of migrants. So, it depends on how much you know the system, how much you know your rights in the whole society. You must know the system. Otherwise, something can easily go wrong. (R- 10)*

To come up with solutions by themselves, families (F – 8, 9, 10, 11) took help from external sources like the internet (google), other family members, Danish friends/colleagues, medical students, or doctors in their home country for a better understanding of the situation.

A daughter told:

> *We know some medical students who would like to help us. So, we send medical reports to them, and they explain to us what it is. (R-8)*

Many participants – mainly family caregivers (F – 3, 7, 8, 9, 10, 11, 13), expressed their need for information from the professionals.

A relative described:

> *I think it is necessary for the patient, or there is a need for advice from the healthcare professionals about the crisis, which the patient or caregivers have never experienced before. Another kind of advice on how one can handle it. People gave different information, some were correct, and some were wrong. It was a little confusing to start with. (R – 2)*

Migrant families (F – 1, 2, 5, 7, 8, 9, 10, 11) and healthcare professionals (3, 4, 5, 6) valued the importance of a healthcare professional as the contact person for receiving disease-relevant and practical information to better navigate in the health system during the disease trajectory. They highlighted the need to discuss the challenges families will face in the trajectory after returning home from the hospital. It was much more acceptable and convenient for migrant families to receive information delivered via personal contact.

Two family caregivers and a nurse described:

> *Suppose one who can work as a link between the family and the health system. In that case, the link person can explain to the family and go through what will happen in the future and the opportunities from the hospital, and how the family can help themselves. It would have been very easy for our family if it had been done like this. (R – 2)*

> *There is enormous information showing on the internet, but one doubts where the information is coming from. If they come for a personal conversation to share information, then it is safer, more explanatory, more transparent, the best. (R – 3)*

> *For me, conversation and provision of information are important. I try to talk to them (migrant families) according to their level of understanding. (HCP -3)*

These quotes illustrate the need for conversations that will have the opportunity to provide relevant information and better navigation in the healthcare system for the migrant families according to the individual need of the family in the palliative trajectory.

## Discussion

This study explored one transverse theme and three themes of significance to the migrant families and healthcare professionals' perspectives on the possibilities and challenges of utilising palliative care services for patients with a life-threatening disease. In the first theme regarding communication between families and healthcare professionals, participants identified a complex interplay of differences in language that shape subjective experiences of interaction between healthcare providers and recipients. The second theme is building trusting relationships and feeling safe in the palliative trajectory. Participants valued the need for continuity of care, listening time, familiarity, and knowing healthcare professionals in clinical practice. Lack of feeling safe in the healthcare system mitigates the utilisation of existing palliative care. The final theme concerns access to information and navigating the Danish healthcare system. Informants mentioned the importance of personal conversation between healthcare professionals and migrant families to empower migrant families with relevant information and thus better decision making in the palliative trajectory. The transverse theme of language and culture illustrates how these two aspects form all participants' individual experiences. For example, Danish language proficiency and cultural background influence communication and the capacity to build trusting relationships with healthcare professionals, access information and navigate the system. Some of the illustrated issues do not seem to be explicit to non-western migrant communities, for example, showing respect, continuity of care, lack of healthcare professionals' time, difficulty navigating the healthcare system, and lack of knowledge regarding available services. Instead, reasonably replicate more general challenges embedded in the Danish healthcare system (Boye et al., 2021; Ikander et al., 2021; Mousing et al., 2018; Nielsen et al., 2021). However, the present study findings are generally in line with systematic reviews among migrants in other western countries (Rahemi & Williams, 2020; Shabnam et al., 2021), demonstrating that the mentioned challenges and other experiences are worsened by poor language proficiency, lack of need-oriented information, and cultural issues.

This study shows that non-western migrants generally only had the opportunity to utilise palliative care services that differ from their language and cultural background. The general lack of choice encountered by the families when approaching healthcare professionals was a significant challenge to utilise palliative care services. Similar to the studies in other European countries (Jansky et al., 2019; Weber et al., 2021), this study also highlighted mainstream services are generally perceived to lack cultural competency for interacting with non-western migrant families. Lack of cultural competency often resulted in a dilemma among healthcare professionals while interacting and further building trusting relations with migrant families. Moreover, according to this study, family preferences and cultural norms often shaped the practice of palliative care. For example, cultural norms of family caregiving often influenced to provide care for an ill relative at home, despite needing professional support. As reported in other studies, family caregiving is appreciated by the community, and failure to do this is often criticised (Cowan, 2014; Markham et al., 2014). However, higher dependence on family caregiving should not be taken to indicate that non-western migrant families do not need support and guidance from professional palliative care services.

Consistent with international studies (Kirby et al., 2018; Van Keer et al., 2015; Weerasinghe & Maddalena, 2016), a discrepancy has also been discussed between migrant families and healthcare professionals' preference on disclosure of the open dialogue and truth towards the patient. According to Danish laws, it is the right of the patient to know his/her condition, though the way of telling the truth might be not practised where the migrant families originate (Khalil, 2013). The belief that discussing death and dying will worsen the patients' situation contradicts the premise of western society (Venkatasalu et al., 2013). These different choices could be addressed according to the patients' needs, family preferences, and healthcare professionals' assessment, then integrating the understanding of such differences to provide individualised palliative care (Cain et al., 2018). Migrant families need individualised palliative care mainly because they vary in their migration history, acculturation, available resources, and socio-cultural background (Angelo & Wilson, 2014). Thus, both healthcare professionals and migrant families need to negotiate on their needs and preferences of information provision in the palliative trajectory.

A major challenge in the utilisation of palliative care identified in the present study was related to the limited Danish language proficiency of the migrant families, especially among recent migrants. As described in previous studies, poor local language proficiency leads to patchy access, limited utilisation, less involved healthcare decision-making, and consequently dissatisfaction with the end of life care among migrants (de Graaff et al., 2012; Jansky et al., 2019; Wilkinson et al., 2014; Worth et al., 2009). This study suggests that when professional interpreters were not used, patients and their migrant families had an inadequate understanding of diagnosis and symptoms. On the contrary, professionally trained interpreters could be effective mediators between the migrant families and healthcare professionals. The present study findings replicate findings from studies in other western settings among patients with poor English proficiency (Silva et al., 2016; Smith et al., 2009). While acknowledging the benefit of the professional interpreter, this study also advocates the importance of "intercultural communication" instead of just translating from one language to other. As the Lancet Commission on culture and health stated, 'Intercultural health communication is not only about language translation, but also situated beliefs and practices about the causation, local views on what constitutes effective provision of health care, and attitudes about agency and advocacy' (Napier et al., 2014). Previous studies documented that it is necessary to move beyond language to ensure equitable healthcare (Piacentini et al., 2019) and consider the emotional expressions of the non-verbal communication between patients and healthcare professionals (Flores et al., 2012). Non-verbal communication, including affective touch, looking, smiling, physical proximity, and careful listening (Araújo & Silva, 2012), can be challenging to read, primarily if the interpreter's presence draws the focus of the healthcare professionals away from the patient (Tribe & Lane, 2009).

Accordingly, in the palliative care setting, if the focus is on spoken language translation, with little acknowledgement of nonverbal body language, building a trusting relationship with the migrant family becomes more challenging (Green et al., 2018). Here, a patient's trust is understood as confidence in a healthcare professional's competence, including social and communication skills, technical knowledge, honesty, confidentiality, and empathy (Calnan & Rowe, 2007). Similar to a recent Danish study (Radl-Karimi et al., 2021), this study also highlights the importance of feeling safe and trusting relationships with healthcare professionals. Non-western migrants from different countries may have different degrees of trust in healthcare professionals because of their prior migration experiences, different degrees of familiarity with Danish culture, language competency, and communication skills. The level of migrant trust in healthcare professionals in the host country can affect the use of healthcare services, despite having free access to public health services in Denmark. For example, Lokdam et al., 2016 found that some migrants from Turkey and The Middle East went back to their country of origin to seek healthcare because they lacked trusting relations with Danish healthcare professionals and felt safe in the familiar healthcare system (Lokdam et al., 2016). At an interpersonal level, the present study shows a lack of proper communication regarding treatment, conflicting health information may lead families to perceive clinicians as un-trustworthy, which reinforces their perception of feeling safe in the system. The present study indicates that regardless of patients being treated at home or in a hospital setting, they feel secure about and value the involvement of family members in the decision-making process.

Parallel to international studies (Cheung et al., 2020; Czapka & Sagbakken, 2016; Goodall et al., 2014; Straiton & Myhre, 2017), findings from this study also highlighted the significance of social support or social network (family members, relatives, friends, and colleagues) in accessing health information, connecting to the right health facilities, and increasing access to the Danish healthcare system. In particular, the younger family members, who were brought up within the Danish system, play a significant role in how and when patients seek palliative care services. Thus, the patients or families who have extended families or friends, are educated in Denmark, and/or have younger family members have fewer problems in navigating the health system. On the contrary, families with a poor social network, poor language proficiency have limited information about available services. Findings from this study showed that, contrary to healthcare professionals' beliefs, delay to use institutional palliative care and provide "care for their own" might have little to do with a negative attitude towards palliative care. Instead, the families merely lacked informed choice and a sense of safety. Access to relevant health information directs ones' health-seeking and decision-making (Yashadhana et al., 2020). Gaining knowledge about the Danish healthcare system has been reported challenging among migrants as they lack experience and expertise in the formal Danish language, which is often used in medical information (Smith Jervelund et al., 2017). Thus, it is easily assumed that the families with accurate information about how to navigate the local healthcare system would have guided them for appropriate healthcare decision-making in the palliative care trajectory. This might also be applicable to ethnic Dane families. However, coming from countries with different healthcare systems, where palliative care service is still a new and emerging field (Clark et al., 2020), non-western migrant families may need extra support to navigate this system.

A recent review conducted in the European context has found that palliative care services miss a balance between the challenges, wishes, and resources of migrant families (Shabnam et al., 2021). Thus, there is a need for a healthy political and professional effort in this area of palliative care service provision in Denmark (Raunkiær, 2012). The risk of imbalance between challenges and service provision around palliative care may grow with the increasing diversity of migrant groups; however, there is also hope for improved service provision and integration.

## Strengths and Limitations

One strength of this study may include the rigour of the methodological approach, which allowed this study to gather diverse interview data by involving different informants with different roles and responsibilities of providing and receiving palliative care (patients, family caregivers, and healthcare professionals). However, the interviewer's appearance (wearing a headscarf) may have influenced data collection. Moreover, the present interview findings may be influenced by her preunderstanding as a non-western migrant to a modest degree, as in any qualitative research (Malterud, 2001). Authors took the participant's personal experiences as the analytical point of departure, being fully conscious of preunderstanding of the topic and doing their best not to let this influence interpretation. On the contrary, the interviewer speaking and understanding several languages (Bangla, English, Urdu, and Danish) have been an asset for this study.

However, this study did not explore specific encounters between patients, their family caregivers, and their health professionals, as this was beyond the scope of the study. The present study has several limitations, including lack of participation from migrant families who never tried to utilise and who do not have access (for example, undocumented migrants) to palliative care in Denmark. By excluding their perspectives, it is admitted that subsequent data from such groups may differ from those collected in the present study. Future studies should explore the barriers for migrant patients who do not attempt or have access to palliative care services. Only one informant family had an asylum migration background. Including more informants from the recent asylum and refugees could shed light on the unique needs of these groups (Matlin et al., 2018). One interview was interrupted due to the language barrier. The interviewer asked the family permission to come up with an interpreter, which the family refused. However, the short interview adds essential insight to the result. Thus, the interview was included.

## Conclusion

This study highlighted how language and culture, communication, navigating in the existing healthcare system and feeling safe/unsafe influence the utilisation of palliative care among non-western migrants in Denmark. The present study findings identified strategies for supporting non-western migrant families in the palliative trajectory; through training healthcare professionals in intercultural communication/competence, identifying the individual family needs to create a shared understanding of palliative care concerning information, patient preferences, and family involvement and setting of care. To conclude, inter-sectoral collaboration among organisations at different levels is essential to implement strategies identified in the present study and to establish palliative care services that are need-oriented, linguistically, and culturally appropriate for non-western migrant families.

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### Ethical Approval

The Danish National Committee on Bioethics, number 61269, approved the study. The study was registered at the Danish Data Protection Agency.

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## Supplemental Material

Supplemental material for this article is available online.

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**Jahan Shabnam** – PhD student, MSc, MPH, area of interest palliative care among immigrants.

**Helle Timm** – Professor, PhD in Health Sciences, MSc in Cultural Sociology, area of interest palliative care and narratives.

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**Mette Raunkiær** – Senior Researcher, PhD Nurse, area of interest palliative care in the primary sector, children and their families.

# Palliative care utilisation among non-western migrants in Denmark: A qualitative study of the experiences of patients, family caregivers and healthcare professionals

## Supplementary materials

### Supplementary material 1

*Settings involved in recruiting and number of participants (n) from each setting*

| **Settings for migrant families** | **Settings for healthcare professionals** |
|---|---|
| *A national research centre, S, n - 4* | *A national research centre, S, n- 1* |
| Palliative treatment department at X Hospital, Copenhagen, n- 5 | Palliative treatment department at X Hospital, Copenhagen, n - 4 |
| P (Care home), Copenhagen, n - 1 | Oncological Department - Q X, n - 2 |
| Oncological Department Q X , n - 1 | Oncological Department Q Y, n - 1 |
| Oncological Department Q Y , n- 3 | Migrant health clinic, C, n - 2 |
| Migrant health clinic, C, n - 3 | |
| Personal contact, n -2 | |

### Supplementary material 2

Interview guide for qualitative interviews with patient/family caregivers

| **Aim – lines of inquiry** | |
|---|---|
| **Background information** (may follow up during the interview) | Diagnosis, age, ethnicity, primary needs (physical, psychological, social), when they moved to Denmark, cause of migration (asylum/refugee/migrant worker).<br>**Language proficiency** in Danish, and language of communication with health professionals. |
| **Theme 1** | **Social and personal relationships** |
| **Broad question** | **Probing questions –** |
| Can you please | • Can you please tell me about yourself and your every day after |

| | |
|---|---|
| describe your life after being a patient/ caregiver | being a patient/caregiver of an ill relative?<br>• Would you please tell me about your relationship with family members in Denmark and your homeland?<br>• Please tell me about your relationship with health professionals at hospitals/homes? |
| **Theme 2** | **Knowledge, experiences, and perspective** |
| **Broad question** | **Probing questions –** |
| What do you think about the services such as hospital/ at home/ hospice care | • How much do you know about the service provided at home/in hospital for the very ill persons (in terms of availability, appropriateness, accessibility) offered by the state for citizens in Denmark?<br>• Please tell me about your experiences of being patient/caring for your family member at home/hospital (challenges/facilitators). How does it vary from your own country of origin/culture? Can you please compare or evaluate? |
| **Theme 3** | **Needs** |
| **Broad question**<br>What are your needs right now? | • Can you please tell me about your care preferences as a patient/relative and how well are they met? |
| **Ending the interview** | • Is there anything else that you would like to ask me<br>• Thanking participant for sharing ideas |

**Supplementary material 3.** Interview guide for qualitative interviews with healthcare professionals

| **Aim – lines of inquiry** | |
|---|---|
| **Introduction** | Introduction of the interviewer and the research project (and the target group)<br>- Let the informant(s) present themselves very briefly and their place of work |
| **Theme 1** | **Experiences** |
| What experience do you have with providing palliative care for non-western migrants with | **Probing questions -**<br>• Can you describe a situation from your practice where all parts were successful and/or challenges arose? |

| | |
|---|---|
| life-threatening diseases such as cancer, COPD, heart disease, etc.? (With examples) | • Do you pay special attention to migrant families compared to ethnic Danes? If so, describe how. If not, why not?<br>• What concerns or considerations arose when you provided palliative care for migrant families? |
| **Theme 2** | **Access to palliative care** |
| How do non-western migrants with life-threatening illnesses and their relatives access palliative care with you? | **Probing questions –**<br>• Do you experience barriers to access concerning palliative care (possibly health professional services in general)? If so, describe which ones. (With examples)<br>• Do you have any experience or ideas for how it is possible to improve access to palliative care for non-western migrant families? Describe why no / yes. |
| **Theme 3** | **Ideas or strategies to improve palliative care effort for non-western migrant families** |
| Have you specifically developed or worked with any ideas, initiatives, and/or more individual professional strategies to provide care towards non-western migrant families? Explain why / why not. | **Probing questions –**<br>• Can you describe a situation from practice where these ideas/initiatives/strategies were used / not used?<br>• How is it possible that the application of these ideas/initiatives/strategies can be improved? |
| **Closing** | Is there anything else related to what we have discussed today that you would like to share with me?<br>Thanking participant for sharing ideas |

# Paper 3

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# Development of a complex intervention (safe and secure) to support non-western migrant patients with palliative care needs and their families

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ABSTRACT

*Purpose:* International evidence supports the benefits of early use of palliative care, although the best use of services is often under-utilised among Danish migrants. The study aims to develop a theoretically informed, evidence-based intervention to increase support in palliative care service provision among non-western migrant patients with a life-threatening disease and their families in Denmark.
*Methods:* The overall approach was guided by the United Kingdom Medical Research Council framework for developing and evaluating complex interventions by involving stakeholders for example patients, family caregivers, and healthcare professionals. The intervention was developed iteratively by incorporating theory and evidence. Evidence was synthesized from a systematic review, semi-structured interviews, and group discussions with patients ($n = 8$), family caregivers ($n = 11$), healthcare professionals ($n = 10$); and three workshops with migrants ($n = 5$), social and healthcare professionals ($n = 6$). The study took place in six different settings in two regions across Denmark.
*Results:* The safe and secure complex intervention is a healthcare professional (e.g. nurse, physiotherapist, or occupational therapist) led patient-centred palliative care intervention at the basic level. The final intervention consists of three components 1. Education and training sessions, 2. Consultations with the healthcare professional, and 3. Coordination of care.
*Conclusion:* This study describes the development of a supportive palliative care intervention for non-western migrant patients with palliative care needs and their families, followed by a transparent and systematic reporting process. A palliative care intervention combining multiple components targeting different stakeholders, is expected that safe and secure is more suitable and well customized in increasing access and use of palliative care services for non-western migrant families in Denmark.

## 1. Introduction

This study describes the development of a theoretically informed, evidence-based palliative care intervention to better support non-western migrant patients with palliative care needs and their families. The World Health Organization (WHO) recommended the early use of palliative care in the disease trajectory of patients with life-threatening illnesses (WHO, 2020). Based on the suggestion by WHO (Gaertner et al., 2010) and other organisations, e.g. the American Society of Clinical Oncology (Ferrell et al., 2017), over the past few years, an increasing number of trials have focused on the effects of early integration of palliative care in improving quality of life of patients and families, reducing symptoms, and being cost-effective (Temel et al., 2010, 2017; Bakitas et al., 2009, 2015; Higginson et al., 2009; Vanbutsele et al., 2018). Despite these findings, studies report lower usage of palliative care (Gani et al., 2018), especially among migrants (Henke et al., 2017; Carlsson and Hjelm, 2021). Palliative care usage is hindered among migrants due to multiple reasons, including sociocultural (Kai et al.,

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2011; Debesay et al., 2014; Venkatasalu, 2017; Van Keer et al., 2015), provider-level (de Graaff et al., 2012; Graaff et al., 2012; Wilkinson et al., 2017) and organisational issues (Markham et al., 2014; Venkatasalu, 2017; Jansky et al., 2019). These barriers often tend to be interlinked and interact on several levels, e.g. system, community, and individual levels (Shabnam et al., 2022a). However, palliative care service provision varies within Europe due to different welfare systems and palliative care integration within each country's healthcare systems (Sánchez-Cárdenas et al., 2021; Centeno et al., 2017).

The context of this study, Denmark is one of the five Nordic countries which adheres to the concept of a welfare state with healthcare as an important element and equal and free access to healthcare as a central goal (Lyttkens et al., 2016). In Denmark, migrants (migrants and their descendants) represent 14% of the total population, and two-thirds originate from non-western countries (Denmark, 2021). Like other Nordic countries (Carlsson and Hjelm, 2021; Finnvold, 2018), Danish non-western migrants are highly heterogeneous concerning their reasons for migration, their education, occupation, culture, and social resources, e.g. availability of extended family members and friends (Hansen et al., 2008; Bo et al., 2015; Rytter et al., 2021; Shabnam et al., 2022b). Systemic health inequalities exist within and between migrant groups and have become even more evident during the COVID-19 pandemic (Brønholt et al., 2021). Despite the diversity, several general differences in need, service usage, disease patterns, health-seeking behaviour, entitlements, and life expectancy between migrants and ethnic Danes have been documented (Bo et al., 2015; Hansen et al., 2008; Rytter et al., 2021). Language barriers, lack of trust, and culturally different understanding of the palliative treatment among non-western migrants near death often challenge ongoing palliative care intervention in Denmark (Raunkiar, 2012; Pentaris and Thomsen, 2020; Shabnam et al., 2022b). This calls for equal palliative care service provision towards non-western migrants. Therefore, interventions to improve palliative care among non-western migrants require being context-specific, need-based, focused, flexible, and socially and culturally oriented (Diaz et al., 2017; Kubi et al., 2020; WHO, 2018; Jansky et al., 2019). However, there is a gap in the palliative care literature on developing intervention in partnership with the health-service receiver (e.g. migrants) and service provider (professionals), although it is highly recommended (Diaz et al., 2017; Johnson et al., 2021; Chambers et al., 2019). Thus, this paper aims to describe the development process of a theoretically informed, evidence-based intervention for non-western migrant patients with palliative care needs and their families in Denmark.

## 2. Methods

### 2.1. Study design, including the development phase

The safe and secure intervention was developed following the United Kingdom's Medical Research Council (MRC) guidance on complex intervention design (Skivington et al., 2021b), as it provides a general framework to develop and evaluate complex interventions as an iterative phased approach (Skivington et al., 2021b). The phases include intervention development or identification, feasibility, evaluation, and implementation (Skivington et al., 2021b). This article concerns the development phase. Key stakeholders (public, patients, and family caregivers) and professional stakeholders (social and healthcare professionals) were involved in the development phase from problem identification to developing and shaping intervention via interviews and workshops. Although it is, challenging stakeholder involvement is recommended within palliative care and migrant research as it improves quality, relevance, and potential outcome (Brereton et al., 2017; Chambers et al., 2019; Diaz et al., 2017; Bradburn and Maher, 2005; Skivington et al., 2021b). Terminologies used in this study are mentioned in Table 1.

According to the MRC framework, a complex intervention is developed by identifying the evidence base, identifying/developing theory and modelling process and outcomes (O'Cathain et al., 2019). The different methods used and synthesis process for developing and modelling the logic model for intervention are presented in Fig. 1. The logic model is visualised in Table 2. Steps followed in collecting data and developing intervention from stages 1–4 (Fig. 1), took over the three years (February 2019–June 2022) in Denmark's capital region and Southern Denmark's region.

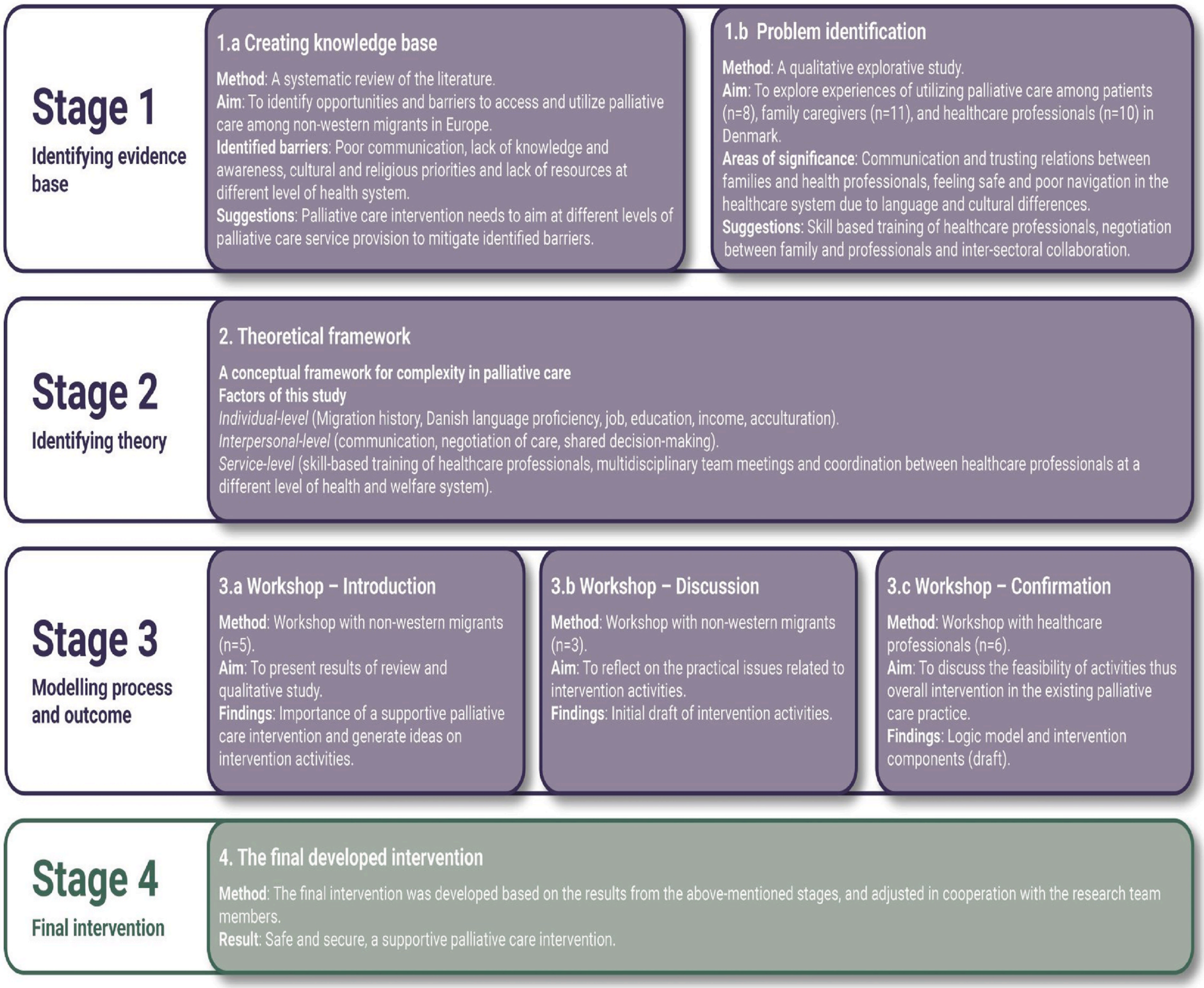
A logic model of basic palliative care service intervention for non-western migrants was developed by synthesizing evidence from a systematic review on facilitators and barriers to access and utilising palliative care services; findings from qualitative interviews and group discussions with stakeholders on their experiences of utilising/providing palliative care services; and findings from three workshops with stakeholders.

Stakeholders (stage1b, Fig. 1) were recruited purposively, non-western migrant patients with a life-threatening disease (8), family caregivers (11), and healthcare professionals (10).

In Stage 3a+3 b a user panel of five members in the Migrant Health

**Table 1**
The terminologies used in this study.

| Terminology | Description |
|---|---|
| Complex intervention | A complex intervention has multiple components or mechanisms of change, and/or the intervention generates outcomes dependent on exogenous factors, including the characteristics of recipients, and/or the context or system within which it is implemented (Skivington et al., 2021a). |
| Context | An intervention's context refers to the social, political, economic, and geographical circumstances in which it is conceived, developed, implemented, and evaluated (Craig et al., 2018). |
| Cultural competence | Refers to the knowledge, attitudes and skills necessary to provide good quality care for ethnic minority patients ( Seeleman, 2014). |
| Intercultural communication | The ability to understand, build a shared reality, and establish a satisfactory relationship between healthcare professionals and patients with different cultural backgrounds is part of cultural competence (Martin, 2015). |
| Intervention development | The term 'development' is used for the entire process of an intervention designing and planning from early conception through to feasibility, pilot or evaluation study (Skivington et al., 2021a). |
| Logic model | A method of visually representing some elements of the program theory, typically presented in a linear pathway. Simple logic models may include only observable inputs, outputs and intended outcomes (Skivington et al., 2021a). |
| Migrants | An overarching term inclusive of refugees, asylum seekers, and other migrants (WHO, 2010). |
| Non-western migrants | Refers to the group of people originating from countries other than European countries as well as Andorra, Australia, Canada, Iceland, Liechtenstein, Monaco, New Zealand, Norway, San Marino, the United States of America, Switzerland, the United Kingdom, and Vatican City State (Denmark, 2022). |
| Palliative care | An approach that aims improving quality of life of patients with life-threatening illnesses and their family members facing the problem associated with those illnesses by prevention and relieve of suffering through early identification, accurate assessment and pain management and other issues, such as physical, psychosocial, and spiritual issues (WHO, 2020). |
| Patient-centred approach | An approach based on identifying and negotiating different communication methods, decision-making choices, family roles, and mistrust, prejudice, and racism issues (Epner and Baile, 2012). |
| Stakeholders | The group of people targeted, involved in developing or delivering or, those whose professional or personal interests are affected by the intervention (i.e. who have a stake in the topic) (Skivington et al., 2021a). This study refers to non-western migrant patients with/without life-threatening diseases and/or their family caregivers, social and healthcare professionals. |



**Stage 1**
Identifying evidence base

**1.a Creating knowledge base**
**Method**: A systematic review of the literature.
**Aim**: To identify opportunities and barriers to access and utilize palliative care among non-western migrants in Europe.
**Identified barriers**: Poor communication, lack of knowledge and awareness, cultural and religious priorities and lack of resources at different level of health system.
**Suggestions**: Palliative care intervention needs to aim at different levels of palliative care service provision to mitigate identified barriers.

**1.b Problem identification**
**Method**: A qualitative explorative study.
**Aim**: To explore experiences of utilizing palliative care among patients (n=8), family caregivers (n=11), and healthcare professionals (n=10) in Denmark.
**Areas of significance**: Communication and trusting relations between families and health professionals, feeling safe and poor navigation in the healthcare system due to language and cultural differences.
**Suggestions**: Skill based training of healthcare professionals, negotiation between family and professionals and inter-sectoral collaboration.

**Stage 2**
Identifying theory

**2. Theoretical framework**
**A conceptual framework for complexity in palliative care**
**Factors of this study**
*Individual-level* (Migration history, Danish language proficiency, job, education, income, acculturation).
*Interpersonal-level* (communication, negotiation of care, shared decision-making).
*Service-level* (skill-based training of healthcare professionals, multidisciplinary team meetings and coordination between healthcare professionals at a different level of health and welfare system).

**Stage 3**
Modelling process and outcome

**3.a Workshop – Introduction**
**Method**: Workshop with non-western migrants (n=5).
**Aim**: To present results of review and qualitative study.
**Findings**: Importance of a supportive palliative care intervention and generate ideas on intervention activities.

**3.b Workshop – Discussion**
**Method**: Workshop with non-western migrants (n=3).
**Aim**: To reflect on the practical issues related to intervention activities.
**Findings**: Initial draft of intervention activities.

**3.c Workshop – Confirmation**
**Method**: Workshop with healthcare professionals (n=6).
**Aim**: To discuss the feasibility of activities thus overall intervention in the existing palliative care practice.
**Findings**: Logic model and intervention components (draft).

**Stage 4**
Final intervention

**4. The final developed intervention**
**Method**: The final intervention was developed based on the results from the above-mentioned stages, and adjusted in cooperation with the research team members.
**Result**: Safe and secure, a supportive palliative care intervention.

**Fig. 1.** The overall process of developing the intervention.

clinic was invited to participate in developing this intervention as an advisory group. The members were either patients, former patients or family caregivers to patients who have been treated and cared for in the clinic, who are experts by experience, and who provided advice to the research team throughout intervention development. Participant committee members were diverse in their age, sex, nationalities and educational level, e.g. illiterate to highly educated. Moreover, a group of professional stakeholders, including three nurses, one health consultant, and two physiotherapists involved in providing palliative care participated in stage 3c. Professional stakeholders provided expert opinions on how the intervention could be implemented in clinical practice. These stakeholders were professionally known to the research team, and approached face-to-face (key stakeholders) and/or via email (professional stakeholders). Thus agreed to become advisors in developing this intervention.

### 2.2. Ethical considerations

This study followed the declaration of Helsinki (Association, 2001). The region of Southern Denmark ethics committee assessed and accepted this study, journal number 61269 and this study was registered at the Danish Data Protection Agency, journal number 10.109. Written (face-to-face) or verbal (video conversations) consent was obtained from all participants before recordings who were interviewed (Stage 1 b), and participated in focus groups (Stage 1 b) and workshops (Stage 3).

## 3. Results

### 3.1. The process and stages of developing the intervention

Fig. 1 shows the four stages of this intervention development phase, and the following four stages are described and explained.

### 3.2. Identifying the evidence base – stage 1

Two methods were applied to identify the evidence base (Stage 1, Fig. 1). First, a systematic review was conducted of the European evidence about the barriers to and facilitators for non-western migrants to access and utilise palliative care (Stage 1a, Fig. 1). Considering the similarities of the Nordic welfare system, the review initially looked for studies conducted within Nordic countries. However, published studies in Nordic countries were limited (n = 4), so the review widened the horizon to all European countries. Although it is evident that provision of palliative care varies between and within European countries (Maetens et al., 2017; Pivodic et al., 2013; Beek et al., 2013). The relevant factors inhibiting or enabling palliative care service use and guiding the choice of intervention that could overcome the modifiable barriers and enhance facilitators were identified. Twenty-nine qualitative and six quantitative studies were included. The study revealed that barriers to access and utilising palliative care among non-western migrants are embedded at various levels of palliative care service delivery. Barriers are related to poor communication due to language differences, lack of knowledge and awareness among migrants about the existing

**Table 2**
The logic model of safe and secure intervention.

| Resources/Input | Activities | The hypothesised mechanism of change | Output | Outcomes | Impact |
|---|---|---|---|---|---|
| The project team includes researchers and healthcare professionals<br>Stakeholder advisory group including public, patients with/without life-threatening illness from non-western countries, family caregivers<br>Collaboration with a municipality, migrant clinic at Odense university hospital and a research centre<br>Facilities and funding to carry out training sessions, development of leaflet and/or video and development of training material<br>Evidence on the feasibility, the cost-effectiveness of the intervention and a qualitative study to capture the perspective of the intervention | Education and training sessions for healthcare professionals on<br>- Patient-centredness and culturally competent palliative care<br>-Information material<br>Consultations with the healthcare professionals in a healthcare setting or at home<br>- Engage patient and family in shared decision-making<br>- Arranging a professional interpreter if needed<br>- Providing knowledge and information (verbal + leaflet and or video)<br>- Providing emotional support<br>- Negotiation of care<br>Coordination of care<br>- Sharing knowledge and learning from each other's clinical practices<br>- Provision of care with an agreement and refereeing to relevant professional<br>- Uploading e-health record | Better communication, well-informed patient and family, and improved knowledge<br>▪ A better understanding of the progression of illness, signs, and symptoms (Graaff et al., 2012; Kai et al., 2011)<br>▪ Goal setting and follow-up plan (Scheerens et al., 2018)<br>▪ Shared decision-making and mutual plans to improve care (Jansky et al., 2019; Kai et al., 2011; Kaasa et al., 2022)<br>▪ Better navigation in the healthcare system (Jansky et al., 2019)<br>Emotional support<br>▪ Reduce anxiety and depression (Schrank et al., 2017)<br>Continuity of care<br>▪ Facilitating communication (Graaff et al., 2012)<br>▪ Building trusting relationship (den Herder-van der Eerden et al., 2017)<br>Collaboration<br>▪ Facilitating necessary referrals e.g. psychological consultation (Jansky et al., 2019)<br>▪ A shared understanding of patient and family's needs and wishes (Van Keer et al., 2015) | Healthcare professionals received education and training<br>Development of a culturally and linguistically appropriate informative leaflet/video<br>Development of a semi-structured protocol for every consultation<br>Development of training material for healthcare professionals to improve patient-centred cultural competency in palliative care<br>'X' number of patient and family members are included in this intervention<br>Patient and family members received 'X' numbers and 'X' hours of consultations<br>Action steps to improve the intervention and apply it to other populations | Improved intercultural communication and cultural competency skills among healthcare professionals<br>Improvement in the individual problems experienced by each patient with palliative care needs and their family members who participated in the intervention<br>Participants have increased knowledge and can better navigate the healthcare system relating to palliative care<br>Participants have an increased level of trust and feel better supported while receiving palliative care services | The best possible quality of life experienced by family caregiver and patient after being diagnosed with a life-threatening illness<br>Better access and utilisation of palliative care services by non-western migrant families<br>Healthcare professionals are more confident and satisfied during communication and delivering palliative care to patients and families with diverse cultural backgrounds<br>Increased job satisfaction among healthcare professionals<br>Implementation of early integration of palliative care tailored to the needs of non-western migrants in Denmark |

palliative care system, cultural and religious preferences of the migrants near death, and finally, lack of resources in health facilities, i.e., time, cultural competency training among healthcare professionals (Shabnam et al., 2022a).

Second, stakeholders were involved via an explorative qualitative study to understand the needs and barriers to utilising palliative care from the perspective of migrant patients with life-threatening diseases, family caregivers and healthcare professionals in Denmark (Stage 1 b, Fig. 1). A total of nineteen individual interviews and four group discussions were conducted, among thirty-one participants. It was identified that participants preferred continuity of care, and being listened to, which ensures feeling safe and secure while receiving palliative care. Participants also valued the importance of verbal and non-verbal communication during an encounter with healthcare professionals. Finally, participants identified the issues to access accurate information and navigation in the Danish healthcare system. Of note, participants' preferences were rooted in their individual needs, i.e., personal history of pre-migration and existing social resources (Shabnam et al., 2022b).

Overall findings at Stage 1 (Fig. 1): Results pointed to specific ideas to transfer initiatives, i.e., skill-based education and training towards healthcare professionals, provision of knowledge and awareness about palliative care among migrant families, and how to navigate the existing healthcare system. In addition, ensuring continuity of care and coordination among different healthcare professionals involved in palliative care builds a trusting relationship between migrant patients and family members.

### 3.3. Identifying theory – stage 2

A conceptual framework for complexity in palliative care, developed by Pask and colleagues as the theoretical framework for the intervention was chosen (Pask et al., 2018). Although developed in the light of specialist palliative care, the framework reasonably applies to basic palliative care. The conceptual framework is patient-centred and demonstrates how a patient living with advanced illness interacts with their context and his/her environment (Pask et al., 2018). They also argue that the complexity of palliative care goes far beyond recognised physical, psychological, social, and spiritual holistic domains. Pask and colleagues suggest that one need to reflect on pre-existing and cumulative complexity, the dynamic aspects of complexity, invisible complexity, service-/system-level factors, and societal influences to address patients' need comprehensively and effectively (Pask et al., 2018).

Overall findings Stage 2: Results of the systematic review (Shabnam et al., 2022a), findings from qualitative study (Shabnam et al., 2022b), and theory (Pask et al., 2018) were used for identifying activities of this intervention that would target specific barriers and facilitators for palliative care usage among non-western migrants in Denmark. The identified facilitators/barriers, e.g. knowledge, communication and trust guided the modelling process in Stage 3a+3 b (Fig. 1).

Although, inspired by the conceptual framework by Pask et al. society-level and changing needs over time were not aimed directly at this intervention development process. Thus, these systems and their factors are not applicable in this study. However, this intervention contributes towards achieving an impact on the macro-system in the long-term outcome.

### 3.4. *Modelling process and outcome – stage 3*

The stakeholder involvement (3a+3 b+3c) approach informed the design in Stage three.

The introduction workshop (Stage 3a), was held on 26.10.2021 at an interdisciplinary clinic for migrants and refugees at a Danish University Hospital. The identified facilitators and barriers based on the results of the review and qualitative study were presented among five participants from the user panel. The participants discussed the familiarity of the study results related to their own healthcare utilisation experiences as migrants/refugees in Denmark. The participants recognised the barriers mentioned in the presentation and acknowledged the need for a supportive palliative care intervention for the study group.

A discussion workshop (Stage 3 b), was held on 29.03.2022, at a Danish university hospital and three out of five participants took part from the user panel. The results of the previous studies were presented again to refresh the informants' memory. Moreover, initial ideas about intervention activities were presented to get suggestions from the informants. Here they discussed the study results one more time relating to their experiences as migrants/refugees and as community representatives. Eventually, they suggested intervention activities relating to the barriers. Suggested activities were the connection to a healthcare professional e.g. from the hospital, individual need assessment, goal setting, and provision of adequate knowledge to navigate the health system.

Confirmation workshop (Stage 3c), held on 04.05.2022, video conversations among six social and healthcare professionals. Here, participants discussed intervention activities suggested at the previous two workshops and came up with their suggestions for intervention activities. Here professionals also discussed the applicability, feasibility, and acceptability of intervention relating to their clinical practice. Suggested intervention activities at the confirmation workshop were providing education and training for healthcare professionals, organizing collaboration between health facilities and multidisciplinary meetings among healthcare professionals.

Each workshop lasted 2 h, and the first author led the workshops while other research team members took relevant notes. In the workshops, participants generated many ideas based on the results of the review (Shabnam et al., 2022a) and qualitative study (Shabnam et al., 2022b), and they jointly developed the logic model. However, modification in the content of the logic model was made until the research team reached a consensus, e.g. the mechanism of change column was added.

### 3.5. *Overall finding stage 3 - logic model*

The final logic model (Table 2) is the systematic and visual representation of the relationships between the planned work (resources and activities) and intended results (output, outcome and impact) (Foundation, 2004) of this intervention. Inputs are the resources needed to implement the intervention (e.g., collaborative partners, staff and cost). Activities describe specific procedures, processes, events or actions of the intervention (Foundation, 2004). Mechanism of change refers to the phenomenon responsible for the intended outcome (Bosqui and Marshoud, 2018). Outputs are the measurable product of activities or the results of the project. Outcomes are the changes due to the activities (Foundation, 2004). Impacts are the expected long-term changes at organisational, community, and/or system levels, resulting from intervention activities, e.g. improved conditions, increased capacity, and/or changes in the policy arena (Foundation, 2004).

### 3.6. *Final intervention – stage 4*

Facilitators, barriers and suggestions identified in the review (Shabnam et al., 2022a), transcribed data from qualitative interviews (Shabnam et al., 2022b), factors related to this study based on Pask et al., 2018 (Pask et al., 2018) frameworks and transcribed data and notes from workshops were plotted and analysed in a pre-determined scheme by the first author. An example of the analysis procedure is shown in Table 3, the entire process is uploaded as a supplementary file (Table S3). Carefully considering the analysis process as a whole, the research team agreed upon the following three components to achieve the hypothesised mechanism of change by accumulating intervention activities. The intervention consists of 1. Education and training sessions, 2. Consultations with the healthcare professional, and 3. Coordination of care.

The final intervention safe and secure is a healthcare professional (e. g. nurse, physiotherapist or occupational therapist) led patient-centred palliative care intervention at the basic level. After being diagnosed with a life-threatening disease, non-western migrant patients will be assigned to the healthcare professionals affiliated with the municipality, general practitioner's practice and/or a hospital. The research team developed the intervention by combining results from stages 1–3 and the logic model. Migrants have special characteristics and thus their needs (e.g. linked to their migrant history, culture, and language) are individual, still, there are universal needs, thus components of the intervention that are general.

#### 3.6.1. *Education and training sessions*

Education and training on patient-centredness and culturally competent palliative care will be provided to the healthcare professionals involved in palliative care at a hospital or a municipality who expressed the need for such training. Patient-centred palliative care intervention is particularly needed in migrant patients and families as they vary in their migration history, acculturation, available resources, and sociocultural background (Saha et al., 2008; Epner and Baile, 2012). Key and professional stakeholders expressed the need for such education and training. The training aims to ensure a better quality of palliative care and improve professionals' skills and confidence while treating a patient with diverse backgrounds. A combination of professionals with different skills and expertise be the most appropriate team to deliver education and training sessions (Ivers et al., 2012), e.g. a health consultant with expertise in migrants' health, a healthcare professional with expertise in palliative care and/or a researcher in migrants' palliative care.

Training will be, e.g. for two days, and there will be a follow-up session after three months for one day. Further, a plan for future sessions will be made in the follow-up session.

On day one of the training session, professionals will *learn patient-centred intercultural communication skills, potential barriers to care* e.g. disclosure of life-threatening illness to the patient, and how to *engage patient and family caregivers in the shared decision-making* of palliative care. Here the healthcare professionals will learn *to negotiate care and provision of information according to the needs and preferences* of the patient and family, e.g. information on disease prognosis. Moreover, healthcare professionals also have the opportunity to have *knowledge about diverse cultural and religious preferences near death and dying*. After the end of the training on day one, professionals will develop skills in *providing emotional* support*, delivering knowledge about illness*, and *information about navigating the Danish healthcare system.*

On day two, the healthcare professionals will be trained on using *intervention materials* e.g. culturally and linguistically appropriate information leaflet/video developed (not yet developed). The training

**Table 3**
Overall analysis process of the safe and secure intervention.

| Facilitators, barriers and suggestions (references from articles in review) (Shabnam et al., 2022a) | Selected quotes from individual and group discussions via qualitative interviews (Shabnam et al., 2022b) | Applying the Pask et al. (Pask et al., 2018)framework in practice: factors of this study based on review, interviews and group discussions | Selected quotes from workshops (3a+3 b+3c) | Intervention activities | Intervention components |
|---|---|---|---|---|---|
| Stage 1a | Stage 1 b | Stage 2 | Stage 3a+3 b+3c | Intervention activities | Stage 4 - Intervention components out of several intervention activities |
| Barrier: Poor knowledge among healthcare professionals (Gunaratnam, 2013) (Milberg et al., 2016; Torres et al., 2016; Debesay et al., 2014; Graaff et al., 2012) | After all, death is at the door. Our culture (Danish) is different. We (professionals) think maybe it is a barrier. I am confused. Is it culture or personality, or what is it all about? And, then maybe with a Danish family, I can sense the reason. (HCP-1(a)) | Interpersonal-level<br>- Communication<br>Service-level<br>- Skill-based training of healthcare professionals | *I would like to have knowledge about the patient group I am providing palliative care. I do not want to play any guessing game (HCP 1 -Workshop 3c).* | Knowledge of diverse cultural and religious preferences near death and dying | Education and training sessions |
| Barrier: Cultural values and religious differences (Van Keer et al., 2015, 2017, 2019; de Graaff et al., 2012; Graaff et al., 2012) | Yes, I know some families have wished that patients should not know how seriously ill they were. […] one should know how to find a way where we can meet. We have, or the system must tell the patient. But sometimes it is also important how one tells it. One can say it the way the patient and family experience respect. One can also ask how much the patient would like to know. (HCP – 2) | Interpersonal-level<br>- Communication<br>- Negotiation of care<br>- Shared decision-making<br>Service-level<br>- Skill-based training of healthcare professionals | *We would like to know more about different cultural and religions' way of accepting death overall, we need a more open discussion around death and dying, but how? (HCP 2 – Workshop 3c).* | Education on diverse cultural and religious preferences near death and dying | |
| Suggestion:<br>Addressing individual/ diverse needs of migrant families (Schrank et al., 2017; Kai et al., 2011; Gunaratnam, 2013) | I think we should not try to put patients into specific boxes, such as Asian, African, homosexual, or based on their religious beliefs. We provide care toward each individual as a human being. Of course, the previous history of a person's life impacts how and what decision he/she takes during their terminal illness. (HCP - 6 (a)) | Service-level<br>- Skill-based training of healthcare professionals | I was thinking about skill-based training among healthcare professionals to improve shared understanding near death because often patients from this group have PTSD, other conditions (HCP 3 – Workshop 3c). | Training on how to engage culturally diverse patient and family in shared decision-making | |

HCP – Healthcare professional, P – Workshop Participant, Pt – Patient with a life-threatening disease, R – Relative of a patient with a life-threatening disease.
The safe and secure intervention procedures are as follows (intervention activities are italicised and underlined).

materials will be developed and conducted following the intercultural healthcare professionals (e.g. cultural coordinator at the hospital).

In the follow-up session, professionals can *share dilemmas and learn from each other's experiences* while providing care to the target group and how they have managed the situation. Here they will also have the chance to share experiences while using the intervention materials and the need for further sessions.

### 3.6.2. Consultations with the healthcare professionals

The assigned healthcare professional will arrange a *face-to-face consultation* with the patient and family caregivers at a health facility or home. The same healthcare professional will continue further correspondence and provision of care to ensure *continuity of care*. The importance of continuity of care is not explicit to migrants, however; professional stakeholders stressed the additional importance of knowing migrant patients and families in person to avoid confusion while providing care consequently *building a trusting relationship*. The healthcare professional is also responsible for *contacting and arranging a professional language interpreter* during sessions based on need (Danish language proficiency) and agreement with the patient and family to ensure optimum communication. The healthcare professional will *assess individual patient/family's needs* considering their migration history, job, education, available resources e.g. social network, and/or their overall acculturation in Denmark. The key stakeholders highlighted the importance of assessing individual patient and family as the need of migrants changes over time, e.g. Danish language skills changes over the years in Denmark. A *semi-structured protocol (not yet developed)* will guide the assessment of the individual need of the patient and family.

The frequency and type of consultations depend on the family's individual needs, and, on the agreement, the healthcare professional can also visit the patient at home if needed. Although evidence from Stage 1 (Shabnam et al., 2022a, Shabnam et al., 2022b), urges the need for emotional support and practical information for patients and their family caregivers right after being diagnosed with the life-threatening disease. Therefore, a systematic consultation with the healthcare professional a minimum of once a month is integrated to *provide practical information and emotional* support.

During the consultations, the healthcare professional will provide *relevant information about illness progression, signs and symptoms, and navigating the healthcare system*. The healthcare professional will also make the patient *aware of the emergency signs,* and *when, how and whom to contact* if needed. The healthcare professional and the patient will develop *shared decision-making* in receiving palliative care, considering the patient's and family's cultural and religious preferences. After each session, the healthcare professional will *make a future follow-up plan with the patient*. During the consultations, the healthcare professional will also *provide an information leaflet or video (not yet developed)*.

### *3.6.3. Coordination of care*

The current practice of palliative care in Denmark does not use standard reporting or collaboration procedures between general practitioners, migrant health clinics, healthcare professionals at the hospital, and/or at the municipality. Professional stakeholders stressed the importance of cross-sectoral and inter-sectoral collaboration while providing care to migrants, particularly in multidisciplinary team meetings as it will allow involved stakeholders to *share and learn from each other's experiences*. Moreover, it will allow stakeholders and healthcare professionals to gain a mutual understanding of migrant patients' needs and goals and mitigate confusion related to diverse cultural and religious preferences near death. To facilitate *intersectoral collaboration* the healthcare professionals will arrange *multidisciplinary team meetings* involving healthcare professionals from hospitals, migrant health clinics, municipalities, general practitioners and palliative care units. In addition, the healthcare professional *uploads e-health records* for general practitioners and other healthcare professionals (e.g. community nurses, physiotherapists, nutritionists), with an agreement with the patient and the family. Healthcare professionals will coordinate with the general practitioner and facilitate necessary referrals if any medical intervention is needed.

## 4. Discussion

This article describes the development of a supportive palliative care intervention for non-western patients with a life-threatening disease and their families. Following the MRC framework, this article describes the development of a complex intervention integrating evidence-based knowledge, theory and stakeholders' involvement. Throughout the entire process, it was an endeavour to accommodate different views on this topic as much as possible. Thus, the intervention development approach was guided by the lived experiences of the non-western migrant patients with/or without life-threatening diseases, family caregivers, healthcare professionals, and the research team (authors).

Some of the barriers identified at Stage 2, including lack of knowledge, resources or continuity in patient care (Mousing et al., 2018) are not specific to migrants. Still, they reflect more common problems embedded in palliative care in Denmark. Thus, one can argue how far it is important to introduce a supportive palliative care intervention for non-western migrants. It is acknowledged that several barriers to palliative care are similar between native Danes and non-western migrants. Perhaps, mentioned and other barriers are exaggerated near death by language and cultural differences, hostile migration history and lack of social networks in Denmark (Shabnam et al., 2022b; Kristiansen et al., 2015; Nielsen et al., 2021). Therefore, a supportive basic palliative care intervention for those who need it will ensure equality in service provision (Nielsen and Krasnik, 2010). The basic palliative care intervention consists of three components: education and training sessions, consultations with healthcare professionals and coordination of care.

The WHO European Region recommends reorienting health services (e.g. cultural competency training of healthcare professionals) as one of the important domains to consider before developing effective interventions for migrants (WHO, 2018) for achieving inclusive, peaceful, and equal societies for all.

Based on findings from the review, interviews and workshops, a patient-centred cultural competency training for healthcare professionals was designed. Evidence showed that it has the possiblity to improve the quality of healthcare for all patients by satisfying the needs of migrants and other disadvantaged groups, whose needs and preferences are often overshadowed by those of the majority (Saha et al., 2008). A core component of cultural competency is communication, which is often challenged in a cross-cultural clinical encounter by differences in language, health beliefs, concepts of illness, and role expectations, e.g., an apparent preference for an authoritarian approach or desire for a family-centred decision-making model (Suurmond and Seeleman, 2006; de Graaff et al., 2012). In line with the evidence, informants in this study reported similar challenges. Accumulated findings from stages 1–3 suggested the need for a skill-based training program for healthcare professionals to facilitate intercultural communication coherent with international recommendations (Suurmond and Seeleman, 2006; Semlali et al., 2020). Again during skill-based training, this intervention will connect patient-centredness with intercultural communication, as suggested by Paternotte and colleagues (Paternotte et al., 2015). They described it as an effective implementation strategy for equitable information exchanges, creating space for understanding and participation, improving communication quality and addressing migrants' biopsychosocial needs (Paternotte et al., 2015). Evidence showed communication skill training improved self-efficacy and empathy skills among healthcare professionals (Pehrson et al., 2016).

The findings from stages (1–3) showed that patients and family caregivers preferred a personal consultation with a healthcare professional focusing on knowledge about life-threatening diseases/palliative care, practical information on how to handle the transition process, and how to navigate the healthcare system. Kubi and colleagues have identified similar needs and preferences of patients and caregivers of African American communities with life-threatening illnesses, during the development of intervention via community health workers (Kubi et al., 2020). In Belgium, a palliative care intervention for end-stage chronic obstructive pulmonary disease patients emphasised the need for regular home visits by the palliative care nurse and the provision of an information leaflet on self-management (Scheerens et al., 2018). These suggest that patients' and family caregivers' needs are similar across contexts; however, unlike other studies, safe and secure intervention is patient-centred. Patient-centred palliative care was integrated as the core of this intervention; consequently, it aims improving the quality of life by focusing on the preferences and perceptions of the patient and his/her family. While providing palliative care to non-western migrant patients and families patient-centredness is especially important as it considers the importance of involving patients and families in the shared decision-making (Kaasa et al., 2022).

Findings from interviews and workshops suggest a lack of coordination among healthcare professionals involved in palliative care working at different levels and/or health facilities e.g. home and hospital. Thus, the final intervention component is coordinating care among multidisciplinary healthcare professionals. A similar need was identified by a short-term specialised palliative care intervention for the elderly with frailty and their family caregivers in Belgium (de Nooijer et al., 2021). Similarly, Lavesen and colleagues reported the need for multidisciplinary collaboration between healthcare professionals treating patients with chronic obstructive pulmonary disease in a Danish hospital (Lavesen et al., 2018). It suggests a targeted effort on organisational strategies of palliative care and highlights multidisciplinary and intersectoral collaboration.

Although the intervention components have been developed with non-western migrants, it can be argued that this intervention is not exclusive to supporting non-western migrant families. Therefore, this intervention might also be suitable for vulnerable families with palliative care needs irrespective of ethnic background, e.g. an elderly patient living alone.

After the intervention development process, sufficient knowledge of this intervention's rationale, supporting evidence, and theory were gathered. Although the training material for healthcare professionals, semi-structured protocol for assessing individual patient and family needs, an information leaflet and/or video, and indicators for measuring outcomes were not yet developed. The research team is considering patient-reported outcome measures as an outcome indicator tool. Evidence suggests that systematic-symptom assessment with patient-reported outcome measures is an inherent part of patient-centred care, is a low-cost quality indicator and is highly cost-efficient as it reduces unnecessary treatment and emergency admissions (Kaasa et al., 2022). The decision is yet to make as the patient-reported outcome measures is only available in Danish and the pilot testing phase in Denmark (Pro-Sekretariatet, 2022). Moreover, uncertainties remained concerning the frequency and/or length of the training, the convenience of intervention materials i.e. leaflet, and the acceptability and overall effectiveness of the intervention. The next step of this project is to develop the mentioned intervention materials and report the feasibility study of this intervention in line with the MRC framework (Skivington et al., 2021b).

### 4.1. Strength and limitations

A clear strength of this study is that the intervention was developed based on a broad range of sources: a systematic review of the evidence, qualitative interviews, group discussions and workshops with patients, family caregivers, and healthcare professionals, in an iterative process to develop intervention components and activities. These steps are in line with the recently published intervention development guideline (Skivington et al., 2021b).

This study has several limitations. Although the result of the interviews and group discussions with patients and family members tailored the development of intervention and findings were discussed during workshops, they did not participate in the workshops. Several invitations were sent still, but none of them agreed to participate.

Finally, the intervention development process crossed the COVID-19 pandemic, which resulted in a compromising mode of interviews or workshops. Although, it was planned to conduct all interviews and workshops face-to-face due to the pandemic research team had to comprise collecting data via video conversations. It is partly due to lower the risk of infection and the enormous work pressure of healthcare professionals, video conversation was more convenient to avoid travel time.

## 5. Conclusion

This study describes the development of a palliative care intervention for non-western migrant patients with palliative care needs and their families, followed by a transparent and systematic reporting process. The comprehensive description of this intervention development process, intervention components, and activities aims to increase replicability and comparability with other interventions. Moreover, involving stakeholders at different stages of the intervention development process is anticipated to generate ownership and feasibility among key and professional stakeholders. A palliative care intervention facilitated by skill-based training, patient-centred care, and coordination between different healthcare professionals is expected to be more suitable and well customised in increasing access and use of palliative care services for non-western migrant families in Denmark.

## Authorship contribution statement

Jahan Shabnam: Conceptualization, Formal analysis, Funding acquisition, Investigation, Methodology, Resources, Project administration, Writing – original draft, Writing – review & editing. Helle U. Timm: Conceptualization, Methodology, Writing – review & editing, Supervision. Dorthe S. Nielsen: Conceptualization, Methodology, Resources, Writing – review & editing, Supervision. Mette Raunkiaer: Conceptualization, Formal analysis, Funding acquisition, Investigation, Methodology, Resources, Project administration, Writing – review & editing, Supervision. The first author revised the manuscript after reviewers' comments on behalf of the research team.

## Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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## Appendix A. Supplementary data

Supplementary data related to this article can be found at https://doi.org/10.1016/j.ejon.2022.102238.

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# Development of a complex intervention (safe and secure) to support non-western migrant patients with palliative care needs and their families

## Supplementary material

Table S 3 Analysis of combined results

*HCP – Healthcare professional, P – Stakeholder Participant, Pt – Patient with life-threatening disease, R – Relative of patient with life-threatening disease

| **Facilitators, barrier and suggestions (references from articles in review)**[5] | **Selected quotes from individual and group discussions via qualitative interviews**[6] | **Applying the Pask etal** [2]**framework in practice: elements of this study based on the review, interviews, and group discussions** | **Selected quotes from workshops (3a+3b+3c)** | **Intervention activities** | **Intervention components** |
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| **Stage 1a** | **Stage 1b** | **Stage 2** | **Stage 3a+3b+3c** | **Several intervention activities** | **Stage 4 - Three intervention components out of several intervention activities** |
| Barrier: Poor knowledge among healthcare professionals[9] [10-13] | After all, death is at the door. Our culture (Danish) is different. We (professionals) think maybe it is a barrier. I am confused. Is it culture or personality, or what is it all about? And, then maybe with a Danish family, I can sense the reason. (HCP-1(a) | **Interpersonal-level**<br>- Communication<br>**Service-level**<br>- Skill-based training of healthcare professionals | *I would like to have knowledge about the patient group I am providing palliative care for. I don't want to play any guessing game (HCP 1 -Workshop 3c).* | Knowledge on diverse cultural and religious preferences near death and dying | Education and training session |
| *Barrier: Cultural values and religious differences* [13-17] | Yes, I know some families have wished that patients should not know how seriously ill they were. | **Interpersonal-level**<br>- Communication<br>- Negotiation of care<br>- Shared decision making | *We would like to know more about different cultural and religions' way of accepting death Overall; we need a* | Education and training on diverse cultural and religious preferences near death and dying, | |

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| | […] one should know how to find a way where we can meet. We have, or the system must tell the patient. But sometimes it is also important how one tells it. One can say it the way the patient and family experience respect. One can also ask how much the patient would like to know. (HCP – 2) | **Service-level**<br>- Skill-based training of healthcare professionals | *more open discussion around death and dying, but how? (HCP 2 – Workshop 3c).* | and potential barriers e.g. disclosure of life-threatening illness | |
| *Suggestion:* Addressing individual/diverse needs of migrant families [9 18 19] | *I think we should not try to put patients into specific boxes, such as Asian, African, homosexual, or based on their religious beliefs. We provide care toward each individual as a human being. Of course, the previous history of a person's life impacts how and what decision he/she takes during their terminal illness*.(HCP - 6 (a)) | **Service-level**<br>- Skill-based training of healthcare professionals | *I was thinking about skill- based training among healthcare professionals to improve shared understanding near death because often patients from this group have PTSD, other conditions (HCP 3 – Workshop 3c).* | Training on how to engage culturally diverse patient and family in shared decision-making | |
| Barrier: Poor language skills [20-22] | *My husband uses a Turkish interpreter during the conversation with health professionals* | **Individual-level**<br>- Danish language proficiency<br>- Acculturation | *It was very difficult to communicate with nurses and doctors at the hospital when we initially came to* | Training on patient-centered intercultural communication and provision of a professional | |

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| | *or his two sons born in Denmark to help with interpretation during hospital visits.* (R-11) | **Interpersonal-level**<br>- Communication | *Denmark. Interpreters with general knowledge did not help, because they lack knowledge about different diseases and symptoms (P 2-Workshop 3b).* | interpreter if needed | |
| Barrier: Lack of skill-based training and knowledge among healthcare professionals[9 10-13] | *I think healthcare professionals need some training on how to deliver bad news to the patient, I understand they are also human beings and they have feelings…(R-3)* | **Interpersonal-level**<br>- Communication<br>- Negotiation of care<br>**Service-level**<br>- Skill-based training of healthcare professionals | *I think it is difficult with this patient group is that I am not sure what do they want in their last days of life. As I work with the palliative team most of the patients are near to death. In Danish patients, I do understand what their wishes around death are but I wish there was anyone who could explain me what is preferable around death among this group (HCP 1 -Workshop 3c).* | Education and training on diverse cultural and religious preferences near death and dying | |
| Barrier: Lack of resources/ skill-based training and knowledge among healthcare professionals[9 10-13 22 23] | *I think we are bad at providing information. For example, it is possible to get an interpreter for patients with life-threatening diseases free of charge. After all, this is an opportunity.* (HCP-5) | **Interpersonal-level**<br>- Communication<br>- Negotiation of care<br>- Shared decision making<br>**Service-level**<br>- Skill-based training of healthcare professionals | *I think the health professional should be responsible for physical, psychological, social and existential needs. Moreover, communication should be one of the important issue and be curious for the patients' world of life and satisfaction.* | Training on negotiation of care and provision of information according to the needs and preferences of the patient and family near death | |

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| | | | *Because may be the understanding for satisfaction may differ near death compared to what we experience in our daily routine (HCP 4 – Workshop 3c).* | | |
| Facilitator: Providing culturally appropriate respectful care [9 19 23-25] | After we have a permanent doctor, we feel safer […] she is from Lebanon. I can see my father feels safer talking to her. She understands our mental situation and our feelings. All other Danish doctors are good too but they do not listen properly. (R – 8) | **Interpersonal-level**<br>- Communication<br>- Negotiation of care<br>- Shared decision making<br>**Service-level**<br>- Skill-based training of healthcare professionals | *I was thinking it will be a good idea if young generation from non-western migrant backgrounds are trained in caring for the patients in need, so they already know the culture, then it will be easier for them to understand the need of the patients from other ethnic backgrounds (P 3 – Workshop 3b).* | Education and training on diverse cultural and religious preferences near death and dying | |
| Barrier: Patient preferences and cultural issues [19 22 23 25] | In our culture, one does not ask for help. Others help the one in need. In Denmark, it is the other way around. One needs to be healthy to get the benefit of being sick. So I will have to have control over many things, to be able to call the municipality and say I have these problems. I need help with this, and so on. | **Interpersonal-level**<br>- Communication<br>- Negotiation of care<br>- Shared decision making | *Compared to Danish patients, non-western migrant patients have different expectations from us. They expect us to help them to go to the toilet even if they are capable of doing so (HCP 2 - Workshop 3c).* | Training on delivering knowledge related to illness and provision of emotional support | |

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| | (R – 5) | | | | |
| *Suggestion:* Addressing individual/diverse needs of migrant families [9 18 19] | I try to talk to them according to their level of understanding. Something works for one (patient and their relatives), and something different works for others depending on their background. Their education, experiences, the most important thing is that healthcare professionals need to ask families about their needs. (HCP -3) | **Individual-level**<br>- Migration history<br>- Job<br>- Education<br>- Danish language proficiency<br>- Acculturation<br>**Service-level**<br>- Skill-based training of healthcare professionals | *A structured questioner or a guideline could be a good idea for those who have less experienced working with non-western migrant patients with life-threatening disease near death. So healthcare professionals know how what to ask and how to go further in such a conversation (HCP 4 - Workshop 3c).* | Provision of training material towards healthcare professionals e.g. information leaflet/video, semi-structured protocol | |
| *Suggestion:* Addressing individual/diverse needs of migrant families [9 18 19 22] | There is enormous information showing on the internet, but one doubts where the information is coming from. If they come for a personal conversation to share information, then it is safer, more explanatory, more transparent, the best. (R – 3) | **Individual-level**<br>- Migration history<br>- Job<br>- Education<br>- Danish language proficiency<br>- Acculturation<br>**Interpersonal-level**<br>- Communication | *We have three main problems when we use the healthcare system in Denmark, first language, second lack of knowledge about the system and finally the problems we already have i.e. PTSD or coming from a war situation (P 4- Workshop 3a).* | Face-to-face personal conversation with healthcare professional to assess individual need of the patient and family | Consultations with the healthcare professional |
| Suggestion: Addressing individual needs[22 9 18] | The first thing one should do while living in Denmark is to learn the language. If you | **Individual-level**<br>- Migration history<br>- Job<br>- Education | *We always carry a backpack filled with our migration history… and we cannot run* | Assess individual needs and preferences of the patient and the family (via semi- | |

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| | cannot communicate, you cannot go further. I think doctors and nurses expect that I understand the language. (Pt – 5) | - Danish language proficiency<br>- Acculturation<br>**Interpersonal-level**<br>- Communication | *away from it (P 1 - Workshop 3a).* | structured protocol) | |
| *Suggestion:* Addressing individual/diverse needs of migrant families [9 18 19 22] | For me, conversation and provision of information are important. I try to talk to them (migrant families) according to their level of understanding. (HCP - 3) | **Individual-level**<br>- Migration history<br>- Job<br>- Education<br>- Danish language proficiency<br>- Acculturation<br>**Interpersonal-level**<br>- Communication | *Needs of the migrants are changed with the number of years they have lived in Denmark. After they live here in Denmark for a longer period they have problem with language, for example their interpreter cannot understand them,, (P-3 -Workshop 3b).* | Assess individual needs of language proficiency | |
| *Suggestion:* Addressing individual/diverse needs of migrant families [9 18 19 22] | It is possible to provide complex palliative care services without talking. It is possible to have a respectful relationship without speaking the same language. It just needs to have some other resources, for example, time. If one cannot show respect with words, one can show respect with their care. It is possible to provide care without speaking the same language, | **Individual-level**<br>- Migration history<br>- Job<br>- Education<br>- Danish language proficiency<br>- Acculturation<br>**Interpersonal-level**<br>- Communication<br>- Negotiation of care<br>- Shared decision making | *We need to understand the way a patient or family is thinking about the disease. How is their health care decisions are made is it more individualistic or more collectivist within the family. If they are in need of professional interpreter, even if interpreter is translating overall the responsibility lies with the healthcare professional. So, I want to say that we need to asses individual patient* | Assess individual needs and preferences of the patient and the family in shared decision making in palliative care | |

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| | and it is just difficult. (HCP – 4) | | *and his family's while providing care (HCP 5 – Workshop 3c).* | | |
| Barrier: Poor language skills and cultural differences[23 25 20 21] | Caregiver: When we think about her care at nursing homes, we think about language. The problem is she neither speaks nor understands it. Interviewer: So is it because of language you do not want to send her to a care home? Caregiver: It's not only language; it's something different. In our culture, it is not allowed to send her to a care home. We take care of our sick relatives at home for as long as we can. (R – 1) | **Individual-level**<br>- Migration history<br>- Job<br>- Education<br>- Danish language proficiency<br>- Acculturation<br><br>**Interpersonal-level**<br>- Communication<br>- Negotiation of care<br>- Shared decision making | *People are very different although they come from the same country, people have different way to understand things, and there is country's culture, certain areas culture and family's culture (HCP 3 - Workshop 3c).* | Assess individual needs and preferences of the patient and the family (via semi-structured protocol) | |
| Barrier: Lack of resources/ skill-based training and knowledge among healthcare professionals[9 10-13 22 23] | After we have a permanent doctor, we feel safer […] she is from Lebanon. I can see my father feels safer talking to her. She understands our mental situation and our feelings. All other Danish doctors are good too but they do not listen properly. (R | **Individual-level**<br>- Acculturation<br><br>**Interpersonal-level**<br><br>- Communication<br>- Negotiation of care<br>- Shared decision making | *Patients from non-western background have a different expectations towards Danish healthcare system compared to ethnic Danes. Ethnic Danes know the healthcare system so they are not surprised when they use the system. On the other* | Setting goals and follow-up plan with patients and family members by shared decision making | |

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| | – 8) | | *hand, no-western migrants have different expectations for example telling the medical history for several times at several healthcare settings or doctors are very authoritative in non-western culture … (HCP 2 -Workshop 3c).* | | |
| Barrier: Knowledge and awareness about existing healthcare system among migrant families [20 22 24 26 27] | I was at work and was sleeping while sitting like this (showing the position). I told my colleague that I was with my mother-in-law. I could not sleep at night. She told me, why don't you take a leave of absence? I replied I did not know. So, I applied, and it was approved. (R – 2) | **Interpersonal-level**<br>- Communication<br>**Service-level**<br>Co-ordination between healthcare professionals at different level of the healthcare system | *I have experienced many times that compared to ethnic Danes, this patient group does not get the aid they need, I do not know if it is because they are reluctant to say their needs, or they do not know who to ask or it the municipality who hinders. But it could be better…Unfortunately it happens many times (HCP 1 – workshop 3c).* | Provision of relevant information about progression of illness and helping in navigating the healthcare system | |
| Barrier: Knowledge and awareness about existing healthcare system among migrant families [20 22 24 26 27] | We do not know how the Danish health care system works. I have psychological problems after my father's cancer. I need some information. I need to talk to | **Interpersonal-level**<br>- Communication<br>**Service-level**<br>Co-ordination between healthcare | *Navigating healthcare system in Denmark is difficult especially for the recent migrants, because they lack experience, social network and local language skill. So they* | Helping in navigating the healthcare system for patient and family members | |

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| | someone about my psychological issues, but I do not know how. (R – 9) | professionals at different level of the healthcare system | *need special support from the healthcare professionals to get to know the system (P 2 – Workshop 3b).* | | |
| Facilitator: Trusting the existing healthcare system[28 20 28] | If I compare Danish health facilities with my country on a one to 10 scale, my country is on two, and Denmark is on 10. But when they (healthcare professionals) have a lot of jobs, lots of patients they have stress, sometimes they cannot control, and they are showing their feelings (for example anger) […] I understand. I never asked, and I never complained about the nurse. (Pt-3) | **Individual-level**<br>Migration history | *As patients, we feel we are in safe hands in the Danish healthcare system (P 2 -Workshop 3b).* | Building trusting relationship | |
| Barrier: Poor social network in the country of migration [20 24 29] | Many families try and manage on their own. And so actually, therefore, get help late in the disease trajectory. (HCP - 5) | **Individual-level**<br>Migration history | *Many patients from the migrant groups are very lonely, they do not have any social network in Denmark, they just need to talk to someone (HCP 5 – Workshop 3c).* | Provision of practical information and emotional support | |
| Barrier: Lack of open discussion on death and dying [15 19 24 30] | I hide information from my father, so he is not afraid and more worried. Doctors give | **Interpersonal-level**<br>- Communication<br>- Negotiation of care | *I think it is necessary to build up a trusting relationship. We should ask patients and their* | Negotiation on provision of information and building trusting | |

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| | a lot of information; if the doctors say something severe, I try to avoid that and say something else. So he does not get scared. (R-9) | - Shared decision making | *families about their needs time-to-time, beyond any survey because we may differ in cultural understanding (HCP 3 -Workshop 3c).* | relationship between patient and healthcare professionals | |
| Barrier: Lack of open discussion on death and dying [15 19 24 30] | Yes, I know some families have wished that patients should not know how seriously ill they were. […] one should know how to find a way where we can meet. We have, or the system must tell the patient. But sometimes it is also important how one tells it. One can say it the way the patient and family experience respect. One can also ask how much the patient would like to know. (HCP – 2) | **Interpersonal-level**<br>- Communication<br>- Negotiation of care<br>- Shared decision making | *I think communication is very important. Open discussion can help health professionals to come out from their self-justification and know what is important for the patient and his family. In this way one can also build trusting relationship (HCP 1 - Workshop 3c).* | Negotiation on provision of information and building trusting relationship between patient and healthcare professionals | |
| Barrier: Communication and language [19 31] | It was an interpreter over the telephone; a doctor and a nurse had to explain to my sister what kind of cancer she had. The interpreter could not even mention what type of cancer. I could | **Interpersonal-level**<br>- Communication<br>- Negotiation of care<br>- Shared decision making | *I can not read or write my own language. Information material in the simple Danish language is rather helpful than in my own language, so I can get help from my kids to read something written* | Provision of information in preferred language (via leaflet/video) and availability of professional interpreter | |

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| | understand everything the professionals said. I could explain better than the interpreter did to my parents and sisters. (R – 7) | | *in Danish (P 1- Workshop 3b).* | | |
| Suggestion: Availability of professional interpreter[13 15 18 19] | We always have a professional interpreter if the patient does not speak Danish fluently. They cannot understand what we are talking about. We tell relatives that they can stay there and sit but interpret, and most accept it. (HCP-3) | **Interpersonal-level**<br>- Communication<br>- Negotiation of care<br>- Shared decision making | *During COVID-19 we gathered many good experiences working with the non-western migrant group, it was helpful if someone could explain the restrictions and other information in their own language (HCP 2 – Workshop 3c).* | Provision of professional interpreter | |
| Barrier: Communication and language [18 19 31] | I have used telephone interpretation on a few occasions, and then it is my interpretation, but I could see that the translation was poor in the family's face. I think the interpreter should facilitate the conversation, not the opposite. I am not defending the use of interpreters. Still, using an interpreter depends on the need of the patients or families. (HCP -5) | **Interpersonal-level**<br>- Communication<br>- Negotiation of care<br>- Shared decision making | *It is like if one wants to interpret for an advocate he/she needs to know the language of the advocate. Interpreter without knowledge about health or disease is not useful (P 3- Workshop 3b).* | Provision of professional interpreter | |
| Barrier: Lack of | *Our nurse'X' is very* | **Interpersonal-level** | *It is because we are the* | Ensure continuity of | |

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| consistency in care personal [13 32] | *helpful after we went to her she helped my mother-in-law with her hard stomach before we went back and forth.. now....after the same physician 'K' and nurse 'X' it is much better now,,,,(R-1)* | - Communication<br>- Negotiation of care<br>- Shared decision making | *same professional during all the visits, so it gives us the opportunity to continue the care working as a physiotherapist I have the opportunity to come closer to patient and be involve in different discussions. Which in turn gives me the opportunity to open up for difficult issues like death and dying with the patient. (HCP 1 - Workshop 3c).* | care | |
| Barrier: Lack of consistency in care personal [13 32] | The knowing relationship is important; my father is more comfortable talking in front of them. In general, if the same person comes, it gives the patient a feeling of safety, especially for those who do not speak Danish. (R- 2) | | *I can understand patients need for continuity of care in general but among the patient group I think it is even more important to build the relationship with healthcare professional, and need to know them in person. In this way it is possible to go long (HCP 3 – Workshop 3c).* | Ensure continuity of care | |
| Barrier: Lack of communication between different levels of health and welfare system[18 22] | My immunity power is very poor so I need a clean place to work,,,,and back is very weak. The job center they force me to work, and a lots of | **Service-level**<br>**-**Coordination between healthcare professionals at different level of the healthcare system | *There exit also problem in Denmark, that is municipalities in Denmark. Municipalities are poisoned. Although doctors suggest the* | Cross-sectoral collaboration e.g. welfare and healthcare system | Coordination of care |

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| | things I forget,,,,I have problem,,, when I am taking I forget words (Pt-3) | | *patient have certain problem or needs something, when it comes to municipality, they ignore it (P-3 - Workshop 3b).* | | |
| Barrier: Lack of referral within healthcare professionals [24] | *I think they should be assigned to palliative care earlier in the disease trajectory. They are connected to us by a social-worker or psychologist very late, when they are seriously ill or dying HCP – 6(a)* | **Service-level**<br>- Co-ordination between healthcare professionals at different level of the healthcare system<br>- Multidisciplinary team meetings | *From migrants' health clinic, we arrange home visit for patients with migrant background but we do not have any cross-sectoral collaboration with other units of hospital (HCP 3 - Workshop 3c).* | Cross-sectoral collaboration e.g. different healthcare units in a hospital | |
| Barrier: Lack of referral within healthcare professionals [24] | They will often try to manage it themselves instead of seeking help in the system, which can be difficult as it requires extra energy. (HCP – 4) | **Service-level**<br>-Coordination between healthcare professionals at different level of the healthcare system | *I think it will be a good idea if clinics for migrants can work in collaboration with for example our specialised palliative care unit. It will give us a better understanding of the target group of patients and their family members (HCP 4 -Workshop 3c).* | Cross-sectoral and inter-sectoral collaboration | |
| Barrier: Lack of referral within healthcare professionals [24] | People who have experience in getting help from us can better navigate. But if you have no idea,,,, The general practitioners do not always remember that | **Service-level**<br>- Co-ordination between healthcare professionals at different level of the healthcare system | *I think most of the patients with palliative needs are still in the municipalities not with the specialised palliative team, so it is important to address the need of the patients* | Co-ordinate with general practitioners and assist in referrals to respective healthcare professionals or settings | |

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| | we are also available in the system. So I think it is not about the patient or the family. They do not know where to go, what help they can get. (HCP – 6 (b)) | | *in the municipalities (HCP 1 - Workshop 3c).* | | |
| Suggestion: Link workers between patient and healthcare system[19 24 27 33] | Suppose one who can work as a link between the family and the health system. In that case, the link person can explain to the family and go through what will happen in the future and the opportunities from the hospital, and how the family can help themselves. It would have been very easy for our family if it had been done like this. (R – 2) | **Service-level**<br>-Skill-based training of healthcare professionals<br>- Co-ordination between healthcare professionals at different level of the healthcare system | *We do a lot of teaching in different healthcare settings also in municipalities, but it will be nice if there is a way to coordinate our knowledge to the healthcare professionals working with the patients with palliative care needs in the municipality (HCP 3 -Workshop 3c).* | Sharing and learning from healthcare professionals with experience on migrant health and or palliative care | |
| Barrier: Lack of consensus among healthcare professionals[18 22] | Every time we go to the hospital for a consultation, we meet a new doctor. We need to tell him the history from the beginning, I know he can read the medical record, but everything is not in the record. (R-8) | **Service-level**<br>-Skill-based training of healthcare professionals<br>- Co-ordination between healthcare professionals at different level of the healthcare system | *I think it will be very helpful if there a health document regarding palliative care is uploaded somewhere in the system e.g. health platform, and all the health facilities and professionals have access to that. Because patient and family* | Co-ordinated e-health record | |

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| | | | *members are already tired in the palliative trajectory, when they need to answer the same questions in all the facilitates they are just frustrated. They wonder because they have already answered the questions several time in the trajectory (HCP 2 -Workshop 3c).* | | |
| Barrier: Lack of consensus among healthcare professionals[18 22] | All (doctors) say different things, and they are not alike at all, so we do not know whom should we trust. (R – 8) | **Service-level**<br>- Co-ordination between healthcare professionals at different level of the healthcare system | *I was thinking it would be nice if it were possible to ensure a collaborative network between different units working with palliative patients. Where a key person can share his/her experiences while working with migrants in the health system (HCP 4 - Workshop 3c).* | Healthcare professionals share and learn from each other's experiences via multidisciplinary team meetings | |
| Barrier: Lack of cultural flexibility in healthcare service [22 31] | My grandmother or my parents do not know the system as I do. I am from the second generation of migrants. So, it depends on how much you know the system, how much you know your rights in the whole society. You | **Service-level**<br>-Skill-based training of healthcare professionals<br>- Co-ordination between healthcare professionals at different level of the healthcare system | *We need a collaborative network among different professional groups. We need to also involve municipality because we would like to know what is happening in their real world. Initially patients might not trust municipality* | Multidisciplinary team-meetings | |

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| | must know the system. Otherwise, something can easily go wrong. (R- 10) | -Multidisciplinary team meetings | *as they think municipality is FBI. The system is very difficult and challenging for migrants, as they do not know the system well. However, we will gain real success in this network with home nurse for example from municipality (HCP 2 - Workshop 3c).* | | |

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