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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; Finnvoold, 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 (Brønholm 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 (Raunkjar, 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

**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.

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

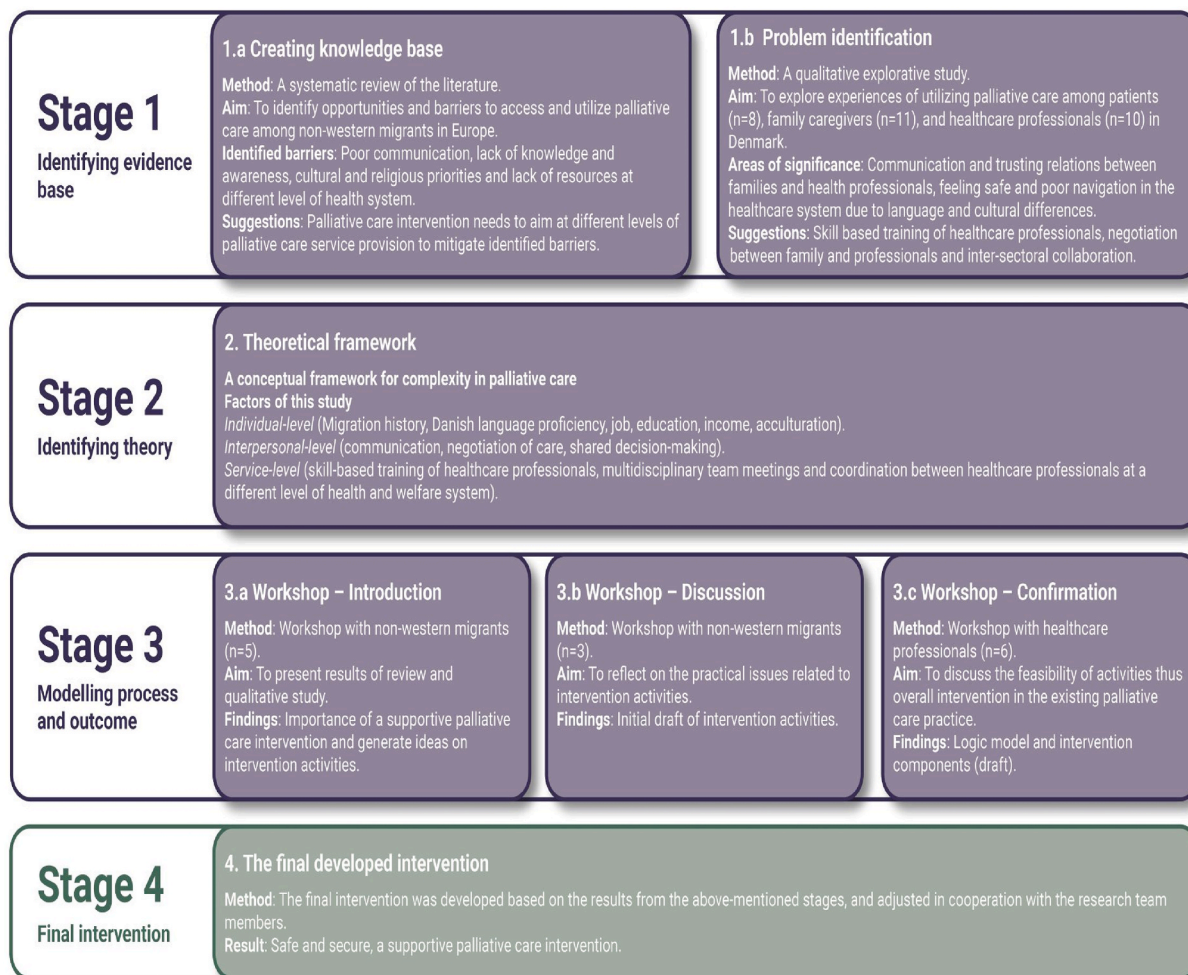


Fig. 1. The overall process of developing the intervention.

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
<p>The project team includes researchers and healthcare professionals</p> <p>Stakeholder advisory group including public, patients with/without life-threatening illness from non-western countries, family caregivers</p> <p>Collaboration with a municipality, migrant clinic at Odense university hospital and a research centre</p> <p>Facilities and funding to carry out training sessions, development of leaflet and/or video and development of training material</p> <p>Evidence on the feasibility, the cost-effectiveness of the intervention and a qualitative study to capture the perspective of the intervention</p>	<p>Education and training sessions for healthcare professionals on</p> <ul style="list-style-type: none"> <li>- Patient-centredness and culturally competent palliative care</li> <li>- Information material</li> <li>Consultations with the healthcare professionals in a healthcare setting or at home</li> <li>- Engage patient and family in shared decision-making</li> <li>- Arranging a professional interpreter if needed</li> <li>- Providing knowledge and information (verbal + leaflet and or video)</li> <li>- Providing emotional support</li> <li>- Negotiation of care</li> </ul> <p>Coordination of care</p> <ul style="list-style-type: none"> <li>- Sharing knowledge and learning from each other's clinical practices</li> <li>- Provision of care with an agreement and refereeing to relevant professional</li> <li>- Uploading e-health record</li> </ul>	<p>Better communication, well-informed patient and family, and improved knowledge</p> <ul style="list-style-type: none"> <li>- A better understanding of the progression of illness, signs, and symptoms (Graaff et al., 2012; Kai et al., 2011)</li> <li>- Goal setting and follow-up plan (Scheerens et al., 2018)</li> <li>- Shared decision-making and mutual plans to improve care (Jansky et al., 2019; Kai et al., 2011; Kaasa et al., 2022)</li> <li>- Better navigation in the healthcare system (Jansky et al., 2019)</li> </ul> <p>Emotional support</p> <ul style="list-style-type: none"> <li>- Reduce anxiety and depression (Schrank et al., 2017)</li> </ul> <p>Continuity of care</p> <ul style="list-style-type: none"> <li>- Facilitating communication (Graaff et al., 2012)</li> <li>- Building trusting relationship (den Herder-van der Eerden et al., 2017)</li> </ul> <p>Collaboration</p> <ul style="list-style-type: none"> <li>- Facilitating necessary referrals e.g. psychological consultation (Jansky et al., 2019)</li> <li>- A shared understanding of patient and family's needs and wishes (Van Keer et al., 2015)</li> </ul>	<p>Healthcare professionals received education and training</p> <p>Development of a culturally and linguistically appropriate informative leaflet/video</p> <p>Development of a semi-structured protocol for every consultation</p> <p>Development of training material for healthcare professionals to improve patient-centred cultural competency in palliative care</p> <p>'X' number of patient and family members are included in this intervention</p> <p>Patient and family members received 'X' numbers and 'X' hours of consultations</p> <p>Action steps to improve the intervention and apply it to other populations</p>	<p>Improved intercultural communication and cultural competency skills among healthcare professionals</p> <p>Improvement in the individual problems experienced by each patient with palliative care needs and their family members who participated in the intervention</p> <p>Participants have increased knowledge and can better navigate the healthcare system relating to palliative care</p> <p>Participants have an increased level of trust and feel better supported while receiving palliative care services</p>	<p>The best possible quality of life experienced by family caregiver and patient after being diagnosed with a life-threatening illness</p> <p>Better access and utilisation of palliative care services by non-western migrant families</p> <p>Healthcare professionals are more confident and satisfied during communication and delivering palliative care to patients and families with diverse cultural backgrounds</p> <p>Increased job satisfaction among healthcare professionals</p> <p>Implementation of early integration of palliative care tailored to the needs of non-western migrants in Denmark</p>

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; Epler 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 - Communication Service-level - Skill-based training of healthcare professionals	<i>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).</i>	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 - Communication - Negotiation of care Service-level - Shared decision-making Service-level - Skill-based training of healthcare professionals	<i>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).</i>	Education on diverse cultural and religious preferences near death and dying	
Suggestion: 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 - Skill-based training of healthcare professionals	<i>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).</i>	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 possibility 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 inter-sectoral 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 measure 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 Raunkjaer: 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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