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Palliative care for older South Asian migrants: A systematic review

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Abstract

Objective. South Asian migrants have a higher burden of life-threatening diseases and chronic diseases compared to other ethnic groups. Yet, knowledge gaps remain around their palliative care needs in the host countries. The aim of the review was to present results from a systematic literature review of available international evidence on experiences with and perspectives on palliative care among older South Asian migrants, relatives, and healthcare providers.
Methods. A systematic review in accordance with PRISMA guidelines was conducted in February 2018, searching PubMed, CINAHL, PsychINFO, and EMBASE databases. PROSPERO #CRD42018093464. Studies included empirical research, providing international evidence on experiences and perspectives on palliative care of South Asian migrants and were published between 2000 and 2018. Thematic synthesis was used to analyze data.
Results. A total of 30 articles were included: qualitative (24), quantitative (5), and mixed methods (1). Three main themes were discovered: 1) palliative care practice within the family, 2) trust as a precondition of palliative care, and 3) the importance of knowledge and cultural competency. All the themes, to a greater or lesser extent, are related to access to and use of palliative care services by South Asian migrant families.
Significance of results. Involvement of family members in palliative care decision making could improve the satisfaction of South Asian migrant families toward the service. For example, Advanced Care Planning involving family members could be a possible way to engage family members in palliative care decision making. Supportive interventions, e.g. providing knowledge, aimed at patients and their family members might improve knowledge and increase awareness among South Asian migrant families of palliative care. Knowledge gained from this review could be implemented with other ethnic minority groups.

Introduction

World Health Organization guidelines on Palliative Care (PC) state that worldwide PC must suit the individuals' cultural needs and context (Sepúlveda et al., 2002). Consequently, the PC needs of ethnic minorities, those who have specific cultural and socio-demographic characteristics, have gained increasing attention from service providers and researchers aimed at providing equitable PC services to all in society (Periyakoil et al., 2016; Randhawa and Owens, 2004; Worth et al., 2009).

It has been documented that ethnic minorities in western countries have limited access to PC services (Ackroyd, 2003; Philips and Taylor, 2012; Worth et al., 2009). Among them, people originating from South Asia are one of the most significant and largest ethnic minorities in western countries (Gupta et al., 2006; Morency et al., 2017; SAALT, 2012). South Asian countries include Afghanistan, Bangladesh, Bhutan, India, Nepal, Pakistan, Sri Lanka, and the Maldives (Gupta et al., 2006; LeCroy and Stevens, 2017). South Asian migrants have been studied worldwide due to their higher burden of life-threatening diseases and chronic diseases compared to other ethnic groups (Nair and Prabhakaran, 2012) resulting from their lifestyle, intense cultural values, and beliefs tied to their country of origin (Salant and Lauderdale, 2003; Tiwari and Wang, 2008). In this review, the South Asian population will be referred to as a single group of people originating from the same continent, but still, it is important to recognize that the term, South Asians, represents a group, with a variety of languages, religions, and culture (Kristiansen et al., 2014; Worth et al., 2009).

Empirical research on South Asian migrants from the perspective of PC has been conducted within national contexts. However, we did not find a systematic review that accumulates the experiences (active participation in something) and perspectives (someone's view on something) on PC practices of older South Asian migrants in different countries. Therefore, this systematic review aims to systematically summarize and present the available international published literature on experiences with and perspectives on PC among older South Asian migrants, relatives, and healthcare providers. The terms, relatives and family

Table 1. Definitions of terms

Terms	Definitions
Palliative Care	Palliative care is the active, total care of the patient whose disease is not responsive to curative treatment. Control of pain, other symptoms, and social, psychological, and spiritual problems is paramount. Palliative care is interdisciplinary in its approach and encompasses the patient, the family, and the community in its scope. In a sense, palliative care is to offer the most basic concept of care – that of providing for the needs of the patient wherever he or she is cared for, either at home or in the hospital. Palliative care affirms life and regards dying as a normal process; it neither hastens nor postpones death. It sets out to preserve the best possible quality of life until death (Radbruch and Payne, 2009).
Hospice Care	Hospice care is for the whole person, aiming to meet all needs – physical, emotional, social, and spiritual. At home, in day care, and in hospice, they care for the person who is facing the end of life and for those who love them. Staff and volunteers work in multi-professional teams to provide care based on individual need and personal choice, striving to offer freedom from pain, with dignity, peace, and calmness (Radbruch and Payne, 2009).
End-of-life Care	End-of-life care may be used synonymously with palliative care or hospice care, with end of life understood as an extended period of one to two years during which the patient/family and health professionals become aware of the life-limiting nature of their illness (Radbruch and Payne, 2009).
Advanced Care Planning	Ideally, the patient, family, and palliative care team discusses the planning and delivery of palliative care, taking into account the patient's preferences, resources, and best medical advice. Palliative care should integrate means for advance care planning, so that these patients can receive palliative care according to their preferences, if they wish. Advance directives allow patients to retain their personal autonomy and provide instructions for care in case the patients become incapacitated and cannot make decisions any more (Radbruch and Payne, 2010).
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 (Cain et al., 2018).
Ethnicity	One's sense of identity as a member of a cultural group within a power structure of a multicultural society and identified so by others within a sociohistorical context of a particular geopolitical setting (Cain et al., 2018).
Culturally Competent Care	Cultural competency encompasses a set of values, behaviors, attitudes, knowledge, and skills which allow professionals to offer patient care which is respectful and inclusive of diverse cultural backgrounds (Evans, Menaca, Koffman, et al., 2012).

members, are used interchangeably in this review, and healthcare providers (HPs) include, for example, nurses, physicians, chaplains, nurse administrators, social workers, priests, and interpreters. Definitions of different terms used in this review are listed in Table 1.

Methods

This review was conducted following the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines. The protocol for this systematic review was registered with PROSPERO (CRD42018093464), an international prospective register of systematic reviews. Inclusion and exclusion criteria of the articles are listed in Table 2.

Studies were searched for in PubMed, EMBASE, CINAHL, and PsychINFO databases in February 2018, covering the period from 2000 to 2018. Studies published after 2000 were included to ensure that the results reflect current practice. With the assistance of an experienced information specialist, a search strategy was developed. Considering the aim, three focus areas were targeted for relevant studies: migrants, South Asian geographical area, and palliative care; combined with AND to retrieve relevant studies. The search profile used in PubMed is provided as an example of the strategy used (Table 3). In addition, the reference lists of reviewed articles were searched manually. Full texts of the articles were reviewed to discover if any of the titles in the reference list seemed relevant.

Data was extracted using a form developed for this review on study aim, author, country, study design, sample size, and main findings (Table 4). Articles were screened, read, and analyzed by J.S., afterwards overseen by M.R. Disagreement on selection, eligibility, and quality of articles were discussed and agreed upon subsequently.

Each study was evaluated for methodological quality. Studies were graded by the scheme developed by Hawker et al. (2002), because it provides a comprehensive and consistent framework to assess the quality of the entire research process and enables comparison of studies applying heterogeneous approaches. Ten areas were scored (title and abstract; introduction and aims; method and data; sampling; data analysis: ethics; bias; results; transferability and generalizability; and implications and usefulness). Each area was awarded grades ranging from 1 (very poor) to 4 (very good). The scale provides a maximum score of 40 and a minimum score of 10.

Analysis

A content analysis was performed to identify the main themes of the included studies (Elo and Kyngäs, 2008; Morris et al., 2015). Result and discussion parts of the studies were read and consequently coded. Similar codes were grouped systematically and identified sub-themes were listed. Thematic syntheses of the similar themes were grouped together under overarching themes (Table 5).

Results

A total of 1,031 articles were retrieved from the searches, of which 28 met inclusion criteria. Two more studies were obtained from the reference lists. A total of 30 studies were included in this review. The detailed selection process is shown in Figure 1, including reasons for exclusion. Descriptions of included studies are presented in Table 3. Thirty studies were graded for methodological rigor and scores awarded ranged from 23 to 39 out of 40 (Table 3).

This review included studies undertaking a range of methodologies: 24 qualitative, five quantitative, and one mixed method

Table 2. Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
Empirical studies (qualitative/ quantitative/mixed methods) and literature review	Letters/editorials, gray literature, conference abstracts, and publications focusing only on religious concern.
International sources	Articles focusing on South Asian migrants less than 50 years old. The age range of over 50 years was influenced by earlier research conducted among older South Asian migrant groups, which suggested that they have a sense of "early aging" (Patel, 1999).
Papers published between 2000 and 2018	Papers published prior to 2000
Articles were not excluded based on their methodological quality.	If it was not possible to identify results specifically for the South Asian ethnic group, for example, authors in one study defined Black and Asian Minority Ethnic patients (Markham et al., 2014) as one, as it was not possible to extract results specifically for the South Asian patients.

design. We did not find any review and/or meta-analysis that described South Asian migrants' perspectives and experiences on PC. The number of studies from each of the following countries was as follows: United Kingdom (UK) – 16, United States of America (USA) – 6, Australia – 3, Canada – 3, and Scotland – 2. Three main religious beliefs were discussed in the articles: Hindu, Muslim, and Sikh. The analysis revealed three themes, each with two sub-themes: 1) the PC practice within the family, 2) trust as prediction for PC, and 3) importance of knowledge and cultural competency.

1. The PC practice within the family

The literature search revealed studies discussing both the formal (professional) and informal (family) practice of PC in the migrant families. Fourteen studies raised the concern about preferred place of death and receiving care (Chattoo and Ahmad, 2008; Coupland et al., 2011; Cowan, 2014; Khosla et al., 2016; Owens and Randhawa, 2004; Radhakrishnan et al., 2017; Randhawa and Owens, 2004; Shanmugasundaram and O'Connor, 2009; Sharma et al., 2012; Venkatasalu, 2017; Venkatasalu et al., 2014; Weerasinghe and Maddalena, 2016; Wilkinson, Waqar, et al., 2017; Worth et al., 2009). According to these studies, preference was dependent on the interplay of various factors, for example, finance (Venkatasalu et al., 2014), availability of caregivers at home (Cowan, 2014), mistrust in institutional care (Venkatasalu, 2017; Weerasinghe and Maddalena, 2016), and the opportunity to perform religious practices (Venkatasalu, 2017; Venkatasalu et al., 2014).

1.1. Dying at home or in hospital

Home was considered the preferred place of care and death in several studies (Cowan, 2014; Doorenbos, 2003; Venkatasalu, 2017; Venkatasalu et al., 2014; Weerasinghe and Maddalena, 2016), as patients felt happier at home (Cowan, 2014). Some older migrants expressed their wish to go back to their homeland (country of birth) to die a peaceful death (Cowan, 2014). Spending the last days of life in one's homeland was preferable in terms of safety, space, time, caring persons, and practicing rituals surrounding death (Radhakrishnan et al., 2017; Venkatasalu et al., 2014).

Studies underlined that being cared for and to die in one's home was related to privacy (Shanmugasundaram and O'Connor, 2009), cleanliness, performing rituals, and most importantly, being surrounded by family (Chattoo and Ahmad, 2008; Venkatasalu, 2017; Venkatasalu et al., 2014). According to one study, while a person dies at home, he/she can complete responsibilities toward family, and relatives can show their respect toward the dying person (Venkatasalu et al., 2014). Another study mentioned that lack of culturally sensitive care in the hospital causes dissatisfaction among caregivers, which shifted the choice to home as the place of death (Weerasinghe and Maddalena, 2016). Despite the desire for comfort and peace from dying at home, due to the practicalities of older migrants living in the UK, many compromise and feel their death can be better managed in hospitals (Venkatasalu et al., 2014). According to older migrants, dying at home could be complicated (Radhakrishnan et al., 2017) and care could be an unbearable burden (Venkatasalu, 2017), often for their busy children (Venkatasalu et al., 2014).

1.2. Family caregivers

According to relatives, family care was named as the best option to retain dignity and comfort of the patients near death (Venkatasalu, 2017). Within families, most caregivers were female (children/ daughters-in-law, and spouses of the ill patient) (Chattoo and Ahmad, 2008; Cowan, 2014; Somerville, 2001). For caregivers, the main motivation for the caring role was love (Chattoo and Ahmad, 2008), respect, religious reward, (Chattoo and Ahmad, 2008; Cowan, 2014) and/or responsibility toward parents (Chattoo and Ahmad, 2008; Cowan, 2014; Radhakrishnan et al., 2017; Sharma et al., 2012) which often led to a decline in help from outside of the family (Somerville, 2001). Moreover, fear of being criticized by the same community restricted seeking professional help for the dying relative (Worth et al., 2009).

Studies mentioned that the caregiving role at home was physically, mentally, and financially burdensome for relatives (Chattoo and Ahmad, 2008; Shanmugasundaram and O'Connor, 2009; Somerville, 2001; Wilkinson et al., 2014). Often, family caregivers (mostly women) were struggling to manage household activities on top of caring for the dying relative at home (Somerville, 2001; Shanmugasundaram, 2015). Despite the extra burden, relatives were willing to care partly to avoid the extra cost of private care or just as a sign of being hopeful of possible recovery (Cowan, 2014; Shanmugasundaram and O'Connor, 2009; Wilkinson et al., 2016). Often, caregivers used to ignore their own physical health and struggled with normal life due to the demands of their role as caregivers (Chattoo and Ahmad, 2008; Shanmugasundaram, 2015; Somerville, 2001). Religious beliefs were found to be a common coping resource used by family caregivers (Khosla et al., 2017; Kristiansen et al., 2014; Somerville, 2001).

Older South Asian migrants trusted in the culture of shared decision making by involving other relatives (Chattoo and Ahmad, 2008; Cowan, 2014; Ebrahim et al., 2011; Venkatasalu et al., 2013; Weerasinghe and Maddalena, 2016). Perhaps the eldest son held the role of decision maker in the family (Biondo et al., 2017; Ebrahim et al., 2011; Radhakrishnan et al., 2017; Sharma et al., 2012). Therefore, older migrants never felt the

Table 3. Search database, PubMed

Focus 1 Migrants	Focus 2 Geographical area	Focus 3 Palliative care
Emigration and Immigration [MeSH] Emigration [Title/Abstract, Other Term] Immigration [Title/Abstract, Other Term] Immigrant* [Title/Abstract, Other Term] Migrant* [Title/Abstract, Other Term] Transients and Migrants [MeSH] Transient* and Migrant* [Title/Abstract, Other Term] Emigrants and Immigrants [MeSH, Title/Abstract, Other Term] Fugitive* [Title/Abstract, Other Term] Ethnic group [MeSH Terms] Ethnic* [Title/Abstract, Other Term] Nationality [Title/Abstract] Nationalities [Title/Abstract] Religious beliefs [Title/Abstract, Other Term] Religion [MeSH] Hinduism [MeSH, All fields] Muslim [MeSH, Title/Abstract, Other Term]	Afghanistan/ethnology [MeSH] Bangladesh/ethnology [MeSH] Bangladeshi [Title/Abstract] India/ethnology [MeSH] Indian [Title/Abstract] Pakistan/ethnology [MeSH] Pakistani [Title/Abstract] Nepal/ethnology [MeSH] Nepali [Title/Abstract] Bhutan/ethnology [MeSH] Bhutanese [Title/Abstract] Maldives [Title/Abstract] Sri Lanka/ethnology [MeSH Terms] Sri Lankans [Title/Abstract] South Asian* [Title/Abstract, Other Term] South Asia [Title/Abstract] Western Asia [MeSH, Title/Abstract, Other Term]	Cultural competency [MeSH, Title/Abstract, Other Term] Cultural competence [Title/Abstract, Other Term] Culturally competent care [MeSH, Title/Abstract, Other Term] Cultural diversity [MeSH, Title/Abstract, Other Term] Multiculturalism [Title/Abstract] Transcultural nursing [MeSH, Title/Abstract, Other Term] Culture [MeSH, Title/Abstract, Other Term] Cultural [MeSH Terms, Title/Abstract, Other Term] Palliative care [MeSH] Terminal Care [MeSH] Terminally ill [MeSH] Hospice and palliative care nursing [MeSH] Hospices [MeSH] Palliative Medicine [MeSH] Palliative [title/abstract, other term] Hospice [title/abstract, other term] Hospices [title/abstract, other term] End-of-life [Title/Abstract, Other Term] Terminal care [Title/Abstract, Other Term] Terminally ill [Title/Abstract, Other Term] Bereavement [MeSH, Title/Abstract, Other Term] Critical illness [MeSH, Title/Abstract, Other Term] Life limiting illness [Title/Abstract] Life-threatening disease [Title/Abstract] Home care services, hospital based [MeSH Terms, Title/Abstract, Other Term] Home care services [MeSH Terms] Home care services* [Title/Abstract, Other Term]

need to discuss palliative care issues in advance (Venkatasalu et al., 2013). In the US, children often avoided discussing the topic of Advanced Care Planning (ACP) in fear of upsetting their parents (Radhakrishnan et al., 2017). Studies revealed that having collective decision making and filial responsibility within the family was hampering the completion of ACP among Hindus living in the US (Doorenbos, 2003; Radhakrishnan et al., 2017). However, due to the busy daily life of children in the Western world, some parents started to realize the need for discussing palliative care issues in advance (Radhakrishnan et al., 2017). Compared to older generations, younger generations and woman were more willing to discuss palliative care issues in advance to avoid difficulties in the future (Biondo et al., 2017; Doorenbos and Nies, 2003).

2. Trust as precondition for PC

The need for building trusting relationships among healthcare providers (HPs) and migrant families was mentioned in ten studies (Ackroyd, 2003; Cowan, 2014; Doorenbos, 2003; Khosla et al., 2016; Khosla et al., 2017; Radhakrishnan et al., 2017; Venkatasalu, 2017; Venkatasalu et al., 2013; Wilkinson, Waqar, et al., 2017; Worth et al., 2009). Despite this, a lack of trusting relationships with migrant families and the HP were often reported (Cowan, 2014; Doorenbos, 2003; Venkatasalu, 2017).

2.1. Trusting the staff

Patients and their families found themselves discriminated against during PC services of the host country in relation to their ethnic identity (Wilkinson et al., 2016). Although, studies did show that HPs with cultural and religious sensitivity were really appreciated by migrant families (Ackroyd, 2003; Owens and Randhawa, 2004). Some studies discussed the importance of partnership among HPs, patients, families, and community (Venkatasalu, 2017; Weerasinghe and Maddalena, 2016; Worth et al., 2009), while others described the importance of an individual approach (Randhawa and Owens, 2004) to building trustworthy relationships.

Patients and their relatives were afraid that staying in the hospital (Radhakrishnan et al., 2017; Venkatasalu, 2017) or hospice care (Weerasinghe and Maddalena, 2016) would make them feel alone. In addition, a lack of trust in hospital staff (Venkatasalu, 2017), perceived prejudice from HPs in regards to rudeness, and cultural insensitivity (Weerasinghe and Maddalena, 2016; Worth et al., 2009) restricted the wish to be cared for in hospitals among South Asian families (Worth et al., 2009). According to family caregivers, hospital staff ignored and failed to meet the physical and hygienic needs of their dying relatives (Venkatasalu, 2017). Mistrust was also expressed by older persons when having White ethnics as their personal caregiver in hospital (Worth et al., 2009). They believed White personal caregivers would not have the sense of privacy, cleanliness, and overall understanding of South Asian culture (Worth et al., 2009). Subsequently, dissatisfaction with hospital care led to mistrust of care in the hospice setting as well (Venkatasalu, 2017). However, previous positive experiences motivated people to be cared for in hospital (Radhakrishnan et al., 2017). Hospice care was really appreciated if it provided appropriate food, prayer facilities, Asian TV channels, and support for families and care after bereavement (Worth et al., 2009). Studies reported that South Asian families often expected to feed their relatives until the very end. Otherwise, they were not satisfied with the service (Venkatasalu, 2017; Weerasinghe and Maddalena, 2016).

Table 4. Description of studies

Author(s), Year, Reference	Aim	Study Design /Methods	Quality Score	Location	Participants /Sample size	Main Findings
Jacqueline Somerville (2001), (Somerville, 2001)	To investigate the experiences of Bangladeshi informal carers caring for a dying relative.	Qualitative (Semi-structured interviews)	37	UK	Carers, n = 7	Poor communication, isolation, home care by relatives and declination of professional help, anxieties regarding housing and visa of relatives to visit dying one in UK.
Rajeena Ackroyd (2003), (Ackroyd, 2003)	To investigate the effect of a bilingual health care worker on PC of Bradford teaching hospital.	Quantitative (retrospective review of patient records)	30	UK	Minority ethnic patients, n = 47, out of 571 patients	The bilingual health care worker was involved in 41% of all referrals from ethnic minorities. The bilingual health care worker aided communication, acted as link between the community and the hospital, had role in bereavement and family support.
Ardith Z. Doorenbos (2003), (Doorenbos, 2003)	To determine if the causes of lower hospice use among diverse ethnic groups are also true for Asian Indian immigrants in USA.	Quantitative (Survey)	25	USA	Asian Indian immigrants, n = 43	Poor knowledge about hospice, cultural differences among hospice staff, although unlike diverse ethnic groups, financial resources were present among Asian Indian immigrants.
Ardith Z. Doorenbos and Mary A. Nies (2003), (Doorenbos and Nies, 2003)	To determine the rate of advance directive completion in Asian Indian Hindus and to explore the various cultural as well as other personal factors that may influence advance directive outcomes.	Quantitative (Survey)	28	USA	Asian Indian immigrants, n = 45	Forty-four percent of respondents wished to complete an advance directive; females and individualistic decision-maker style were more likely but strong religious affiliation and family decision-maker style were less likely to complete an advance directive.
Gurch Randhawa, Alastair Owens, Rah Fitches, Zafar Khan (2003), (Randhawa et al., 2003)	To explore the role of communication in delivering effective PC services to South Asians living in Luton, UK.	Qualitative (Semi-structured interviews)	35	UK	Family members and patients, n = 12 (10 + 2) and service providers, n = 10	Need to raise awareness about availability of PC services; need to improve communication between patients and service providers.
Gurch Randhawa and Alastair Owens (2004), (Randhawa and Owens, 2004)	To explore the meanings of cancer and perceptions of cancer services among South Asians living in Luton, UK.	Qualitative (focus groups)	32	UK	General public, n = 48, Healthcare Professionals, n = 10	Lack of information about available cancer services and desire to receive related information via their community social networks.
Alastair Owens and Gurch Randhawa (2004), (Owens and Randhawa, 2004)	To investigate the challenges faced by service providers trying to develop "culturally competent" PC for South Asian cancer patients in Luton, UK.	Qualitative (Semi-structured interviews)	30	UK	Service providers, n = 10	Difficulties and tensions were identified among philosophies of PC with models of cultural competence.
Sangeeta Chattoo and Waqar I.U. Ahmad (2008), (Chattoo and Ahmad, 2008)	The purpose of this study was to explore the dichotomous notions of caring, underpinning social policy and practice, within carer and care recipient.	Qualitative (Observations and in-depth interviews)	28	UK	Patients with cancer, n = 56 and family carers, n = 41	Ethnicity is not the only useful analytical concept to explore the illness and caring experiences of participants from minority ethnic backgrounds.

(*Continued*)

Table 4. (*Continued*)

Author(s), Year, Reference	Aim	Study Design /Methods	Quality Score	Location	Participants /Sample size	Main Findings
Ann Bowling, Steve Iliffe, Anthony Kessel, Irene J Higginson (2010), (Bowling et al., 2010)	To examine fears about dying in both homogenous and ethnically diverse population, group aged 65 and over.	Quantitative (Structured interviews)	34	UK	Total people, n = 989 (ethnically diverse group, n = 400, and homogenous group, n = 589)	Ethnically diverse group were more likely to express fears about dying compared to British population.
Sujatha Shanmugasundaram and Margaret O'Connor (2009), (Shanmugasundaram and O'Connor, 2009)	To investigate the experiences of the family members of terminally ill Indian migrants.	Qualitative (in-depth interviews)	23	Australia	Primary caregivers of terminally ill patients, n = 6	Families of Indian patients experience difficulties while receiving PC services, in terms of support system for Indian people, cultural issues, and caring experiences.
Allison Worth, Tasneem Irshad, Raj Bhopal, et al. (2009), (Worth et al., 2009)	To examine the care experiences of patients with life limiting illness and their families, and to understand the barriers and facilitators in accessing services and how the barriers might be overcome.	Qualitative (in-depth interviews)	36	Scotland	Patients n = 25, family carers n = 18, and key health professionals n = 20	Barriers to access included limited resourced services, discrimination, limited awareness, and understanding of hospices and difficulty discussing death.
Victoria H Coupland, Peter Madden, Ruth H Jack et al. (2011), (Coupland et al., 2011)	To investigate whether place of death from cancer differs between ethnic groups.	Quantitative (Population cohort)	39	UK	Cancer patients n = 101, 516	Place of death varies between ethnic groups. South Asian patients were more likely to die in hospital than White patients.
Shanil Ebrahim, Sheena Bance, Kerry W. Bowman (2011), (Ebrahim et al., 2011)	To explore the perspectives and attitudes surrounding death and end-of-life care of Sikh.	Qualitative (Semi-structured interviews and focus groups)	26	Canada	Total participants, n = 9 (community and religious leaders and representatives, n = 5; Sikh individuals, n = 5)	Participants mentioned the importance of praying, disclosure of prognosis, importance of organ donation and issues after death according to the Sikh religion.
Rashmi K. Sharma, Nidhi Khosla, James A. Tulsky, and Joseph A. Carrese (2012), (Sharma et al., 2012)	To examine the perspectives of end-of-life care among first- and second-generation South Asians.	Qualitative (focus groups)	32	USA	First-generation, n = 12 and second- generation, n = 11	Participants mentioned cultural challenges due to evolution of traditional roles, lack of communication between patients and family members about preferences and care expectations.
Munikumar R. Venkatasalu, Antony Arthur and Jane Seymour (2013), (Venkatasalu et al., 2013)	To report the perspectives of older (>50 years) South Asians about discussing death and dying.	Qualitative (focus groups and semi-structured interviews)	35	UK	Older adults, n = 55	Culturally older South Asians are not interested in discussing death and dying within their family members. Avoidance is a way to protect the family members from shortcomings.
Maria Kristiansen, Tasneem Irshad, Allison Worth et al. (2014), (Kristiansen et al., 2014)	To explore the role of faith and religious identities in relation to end-of-life experiences in South Asian Muslims and Sikhs with life-limiting illnesses.	Qualitative (semi-structured interviews)	35	Scotland	Family members, n = 15 and health care professionals, n = 10	Hope was identified as the central paradigm in the illness trajectory of respondents to cope with their personal and social consequences of illness. Clinical encounters and religious beliefs were the source of hope among respondents.

(*Continued*)

Table 4. *(Continued)*

Author(s), Year, Reference	Aim	Study Design /Methods	Quality Score	Location	Participants /Sample size	Main Findings
Sujatha Shanmugasundaram (2014), (Shanmugasundara, 2014)	To explore the factors affecting access to PC services among Indian ethnic groups in Australia and to provide recommendations to improve access.	Mixed methods (descriptive statistics and semi-structured interviews)	24	Australia	Primary caregivers of terminally ill patients, n = 6	Respondents reported poor knowledge about PC services and overall health care system in Australia. Thus, challenges were faced by Indian ethnic minority group to access PC.
Margaret Mary Cowan (2014), (Cowan, 2014)	To explore and understand the Sikh carer's experiences of caring for a dying relative at home.	Qualitative (semi-structured interviews)	34	UK	Carers, n = 6	Family-led decision making, lack of support from health professionals was identified, which emerged from the lack of awareness of services among Sikh population.
Munikumar R. Venkatasalu, Antony Arthur and Jane Seymour (2014), (Venkatasalu et al., 2014)	To explore beliefs, attitudes, and expectations of older (>50 years) adults about dying at home.	Qualitative (focus groups and semi-structured interviews)	37	UK	Older adults, n = 55	Home is perceived more than a physical location for dying individual, as cultural and religious practices are possible to perform at home to achieve a peaceful death.
Emma Wilkinson, Gurch Randhawa, Edwina A. Brown et al., (2014), (Wilkinson et al., 2014)	To explore end-of-life care for South Asian kidney patients, to identify the inequalities in access and experience of end-of-life care.	Qualitative (action research design by conducting semi-structured interviews and focus groups)	32	UK	Patients, n = 16 and care providers, n = 45	Communication barriers hinder the kidney patients' awareness of their condition which results in less of their involvement in the end-of-life care decision making.
Sujatha Shanmugasundaram (2015), (Shanmugasundaram, 2015)	To highlight the needs of the family caregivers of Indian patients receiving PC services in Australia.	Qualitative (semi-structured interviews)	31	Australia	Primary caregivers of terminally ill patients, n = 6	Identified unmet needs of family caregivers are: lack of information, lack of financial and psychological support.
Nidhi Khosla, Karla T. Washington, and Hariharan Regunath (2016), (Khosla et al., 2016)	To investigate the perspectives of health care providers on the attitudes of South Asians toward pain management at the end of life.	Qualitative (focus groups and individual interviews)	37	USA	Health care providers, n = 57 (nurses, physicians, chaplains, and social workers)	In general, South Asian patients and their families are reluctant to use pain killers at the end-of-life, which is partly influenced by their spiritual beliefs, lack of knowledge about pain medication, and culture of morphine use in South Asia.
Swarna Weerasinghe and Victor Maddalena (2016), (Weerasinghe and Maddalena, 2016)	To explore the experiences of family caregivers' while providing end-of-life care for terminally ill South Asian immigrants.	Qualitative (in- depth interviews)	32	Canada	Family caregivers, n = 7	Use of family members as mediators could provide a partial solution to bridge cultural belief of immigrants and biomedical health care in Canada.
Emma Wilkinson, Gurch Randhawa, Edwina Brown et al., (2016), (Wilkinson et al., 2016)	To explore issues in recruiting ethnic minority kidney patients near end-of-life phase for a research project.	Qualitative (semi-structured interviews and focus groups)	35	UK	Patients, n = 16 and care providers, n = 45	Revealed issues were: difficult to identify patients with end-of-life needs, lack of awareness of end-of-life care, poor communication with patients and family members, and contrasting nursing cultures within end-of-life kidney care.

(Continued)

Table 4. (*Continued*)

Author(s), Year, Reference	Aim	Study Design /Methods	Quality Score	Location	Participants /Sample size	Main Findings
Patricia D. Biondo, Rashika Kalia, Rooh-Afza Khan et al. (2017), (Biondo et al., 2017)	To explore perspectives of South Asian community members toward participating in advanced care planning.	Qualitative (focus group, family interviews, community forum)	34	Canada	South Asian community members, n = 57	The concept of advanced care planning is unknown to South Asian community, though they are willing to learn about the concept. Barriers to participate in advanced care planning include cultural aspects, religious beliefs, and immigration challenges.
Nidhi Khosla, Karla T. Washington, Sara Shaunfield et al. (2017), (Khosla et al., 2017)	To examine the communication challenges and present strategies recommended by healthcare providers while caring for seriously ill South Asian patients and their families.	Qualitative (focus groups and individual interviews)	37	USA	Healthcare providers, n = 57 (nurses, physicians, chaplains, nurse administrators, medical social workers, priests)	Healthcare providers faced challenges in ensuring effective interpretation, identifying a spokesperson within family, and from being from different cultural norms. Recommended strategies are identifying patients' and families preferences and early appointment of a spokesperson in the family.
Kavita Radhakrishnan, Shubhada Saxena, Regina Jillapalli et al. (2017), (Radhakrishnan et al., 2017)	To identify barriers to and facilitators of older South Asian Indian Americans' engagement in advance care planning.	Qualitative (semi-structured focus groups)	36	USA	Older adults, n = 36, family caregivers, n = 10 and physicians, n = 4	Barriers to engage in advanced care planning includes lack of awareness, inability to access health literacy materials in own language, trust in family decision making, cultural assumption of filial piety, and fear of deprivation from after-death rituals.
Munikumar Ramasamy Venkatasalu (2017), (Venkatasalu, 2017)	To investigate older British South Asian views on dying in acute hospitals.	Qualitative (focus groups and semi-structured interviews)	35	UK	Older adults, n = 55	Participants reported "mistrust" for hospital care; family members acted as "protective shield" and were not willing to leave the dying one alone in hospital.
Emma Wilkinson, Gurch Randhawa, Edwina Brown et al. (2017), (Wilkinson, Randhawa, et al., 2017)	To explore end-of-life care of South Asian kidney patients to provide services that can meet diverse patients' needs.	Qualitative (semi-structured interviews and focus groups)	35	UK	Patients, n = 16 and care providers, n = 45	Limitation of time and lower level of confidence of nurses in renal care influenced the access to end-of-life kidney care services of patients.
Emma Wilkinson, Muhammad Waqar, Babir Gill et al., (2017), (Wilkinson, Waqar, et al., 2017)	To report interviewer reflections on conducting interviews with South Asian kidney patients about their experiences with end-of-life care.	Qualitative (focus group)	35	UK	Bilingual research interviewers, n = 7	Bilingual research interviewers identified points, gave insight to inequalities and access to end-of-life care that were accordingly important for service development for South Asians.

*Terms in the table are expressed as it was mentioned in the original article

Table 5. Data extraction and synthesis

Steps	Process	Example
Extracting data	Each study included in the review was read thoroughly to extract data relevant to the review. Important information from the studies was tabulated by using a form developed by the authors.	Table 4 shows the extracted data
Coding data	Results and discussion sections of the studies were read carefully to code according to the research aim. Line-by-line coding was done manually.	Preferred place of death and care Choice of care Family caregiving Burden of care
Sub-themes	Similar codes were grouped together under sub-themes. Sub-themes were not included if they consisted of very diverse data. Sub-themes with too little information were merged together under one sub-theme.	Dying at home or hospital Family caregivers
Overreaching themes	Sub-themes were presented under overreaching themes. Authors discussed and agreed upon codes, sub-themes, and overreaching themes.	Palliative care practice within the family

2.2. Language barriers and building up trust

It was revealed that often patients themselves were willing to discuss PC. However, they were not able to due to language barriers (Wilkinson, Waqar, et al., 2017). Older migrants were more likely to communicate in their own language although they could speak the language of the host country (Randhawa et al., 2003). To mitigate the language barrier, interpreters (in person or over the telephone) have been used in PC (Khosla et al., 2017). The role of the interpreter was praised by the patients and their families only if he/she was skilled (Somerville, 2001; Wilkinson et al., 2016). On some occasions, even HPs expressed their lack of trust toward interpreters (Khosla et al., 2017). It was also challenging for the HP to access and manage an interpreter on short notice (Wilkinson et al., 2016; Worth et al., 2009). Unavailability of interpreters (Randhawa et al., 2003) or family restriction led relatives to act as interpreter (Wilkinson et al., 2014) to maintain family privacy (Khosla et al., 2017; Wilkinson, Waqar, et al., 2017). Often as an interpreter, relatives modified, omitted, or miscommunicated to withhold medical information to protect patients or vice versa (Randhawa et al., 2003; Worth et al., 2009). Availability of link workers was valued as they had language skills as well as a religious and cultural understanding (Ackroyd, 2003). Link workers increased referrals to PC, facilitated communication, and maintained the link between the local community and the hospital (Ackroyd, 2003). However, there was a fear of breaking family privacy through the link worker who was often from the same community (Owens and Randhawa, 2004; Randhawa et al., 2003).

It was suggested by one study that appointing more HPs from South Asian ethnic backgrounds can help to build trusting relationships (Randhawa et al., 2003). HPs with the same backgrounds speak the same language and have cultural and religious understanding (Randhawa et al., 2003; Somerville, 2001). HPs were suggested for identifying a spokesperson within the family and being persistent in delivering care to build a trustworthy relationship with migrant families (Khosla et al., 2017; Randhawa and Owens, 2004; Venkatasalu, 2017).

3. Importance of knowledge and cultural competency

Twenty studies identified the issue of limited knowledge and partial awareness of PC as a term and of existing services available to the South Asian ethnic minority families (Biondo et al., 2017; Bowling et al., 2010; Chattoo and Ahmad, 2008; Cowan, 2014; Doorenbos, 2003; Ebrahim et al., 2011; Khosla et al., 2016; Owens and Randhawa, 2004; Radhakrishnan et al., 2017; Randhawa and Owens, 2004; Randhawa et al., 2003; Shanmugasundaram, 2014; Shanmugasundaram and O'Connor, 2009; Somerville, 2001; Venkatasalu et al., 2014; Weerasinghe and Maddalena, 2016; Wilkinson et al., 2016; Wilkinson et al., 2014; Wilkinson, Waqar, et al., 2017; Worth et al., 2009), which in turn affected access to and use of PC services.

3.1. Lack of knowledge and communication

The issue of poor knowledge was complicated by the lack of cultural equivalent words for palliative care and hospice care. Moreover, often these words were negatively connected to death (Cowan, 2014; Randhawa and Owens, 2004; Worth et al., 2009). One study revealed that better knowledge on available PC services was positively related to better cultural integration in the host country (Doorenbos, 2003). The same study reported that migrant families with longer stays in the host country had better language skills and consequently better integration (Doorenbos, 2003), although better integration did not always reflect the western way of PC decision making (Sharma et al., 2012). Yet compared to older people, younger people generations had better knowledge and more willingness to look for what more was offered within PC services (Randhawa et al., 2003; Sharma et al., 2012).

Nineteen studies identified the issue of communication between South Asian migrant patients/families and their HPs in PC (Ackroyd, 2003; Biondo et al., 2017; Doorenbos, 2003; Khosla et al., 2016; Khosla et al., 2017; Owens and Randhawa, 2004; Radhakrishnan et al., 2017; Randhawa and Owens, 2004; Randhawa et al., 2003; Shanmugasundaram and O'Connor, 2009; Sharma et al., 2012; Somerville, 2001; Venkatasalu et al., 2013; Weerasinghe and Maddalena, 2016; Wilkinson et al., 2016; Wilkinson, Randhawa, et al., 2017; Wilkinson et al., 2014; Wilkinson, Waqar, et al., 2017; Worth et al., 2009). Communication was identified as the key and most crucial factor in access to PC (Randhawa and Owens, 2004). Perhaps difficulties in communication were often increased by social patterns and family structures within South Asian migrant societies. Due to the gatekeeping nature of families (Wilkinson et al., 2016; Wilkinson et al., 2014; Wilkinson, Waqar, et al., 2017), direct communication between patient and HPs was often missing (Wilkinson, Waqar, et al., 2017). According to HPs, patients were reluctant to state their own wishes in front of other relatives (Khosla et al., 2017). Moreover, communication about the care was interrupted by the involvement of multiple relatives and friends. Consequently, it was complicated for the HPs to identify a particular spokesperson (Khosla et al., 2017; Wilkinson et al., 2014). Therefore, relatives with knowledge of health-related issues could work as mediators between HPs and other family members

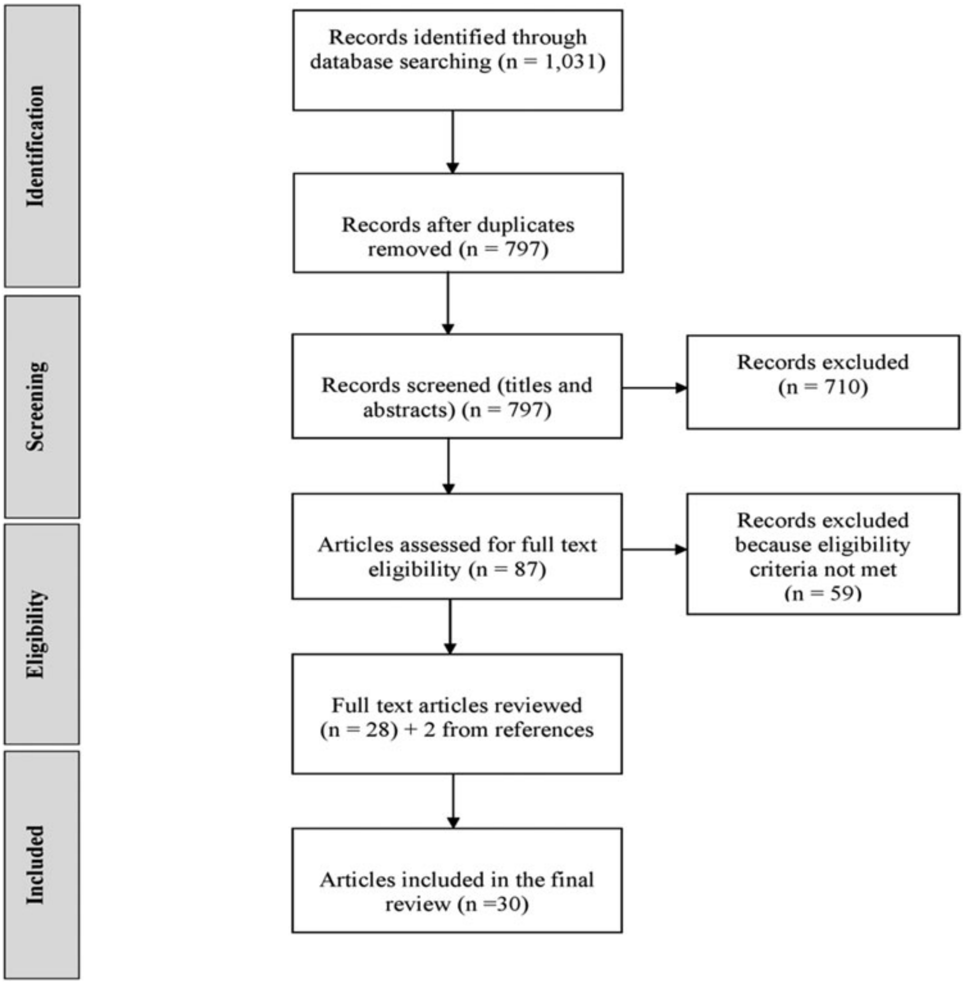

Figure 1. PRISMA Flow Diagram.

(Weerasinghe and Maddalena, 2016). Although involving relatives facilitated communication between HPs and family members (Wilkinson, Randhawa, et al., 2017), communication barriers also existed within the patients' family (Somerville, 2001). Relatives found it difficult to communicate the poor prognosis of the patient to other family members who knew less about the trajectory as a whole (Somerville, 2001). Apart from family, communication was also influenced by the patients' gender preferences for HPs (Khosla et al., 2017; Weerasinghe and Maddalena, 2016) and link workers (Randhawa et al., 2003). According to HPs, older South Asian migrant patients and their families were not really interactive with the opposite gender (Khosla et al., 2017). It was also suggested that the HPs should use less jargon while communicating with the migrant families (Khosla et al., 2017).

Several other factors were identified as reasons for not discussing PC with/within the family: culture (Radhakrishnan et al., 2017; Venkatasalu et al., 2013), religion (Khosla et al., 2017), ethnicity (Biondo et al., 2017), and/or poor language skill (Wilkinson, Waqar, et al., 2017). Although, one study contradicts this by stating that nothing but poor education among the group of ethnic minorities hinders the discussion (Wilkinson et al., 2016). Studies mentioned that discussions about death and dying were related to diminishing hope and would possibly hasten the process of dying (Biondo et al., 2017; Ebrahim et al., 2011; Venkatasalu et al., 2013; Wilkinson et al., 2016). To avoid the discussion, relatives wanted HPs to withhold discussion of a life-threatening diagnosis in front of the patient (Somerville, 2001; Weerasinghe and Maddalena, 2016; Wilkinson et al., 2016). However, provision of inaccurate information to the patient contradicted patients' autonomy (Weerasinghe and Maddalena, 2016). Thus, restricting the discussion on PC consequently led to a lack of knowledge about available PC services (Khosla et al., 2017). To improve awareness among patients and their families', emphasis was given on the provision of information, advice, and knowledge toward them (Wilkinson, Waqar, et al., 2017). The provision of information could be in the form of leaflets, posters, television programs, video, or audiocassettes in different South Asian languages (Randhawa and Owens, 2004; Randhawa et al., 2003).

3.2. Cultural competence among healthcare professionals and its significance

Providing care with cultural knowledge has been presented in several terms: cultural competency (Khosla et al., 2017; Owens and Randhawa, 2004; Randhawa and Owens, 2004; Wilkinson et al., 2016), cultural sensitivity (Weerasinghe and Maddalena, 2016; Worth et al., 2009), culture appropriate (Radhakrishnan et al., 2017), and cultural awareness (Worth et al., 2009). Studies urged the need for cultural education and training among HPs to facilitate access to services and to mitigate inequalities in care (Randhawa and Owens, 2004; Worth et al., 2009). Still, one study raised the issue that HPs were not aware of the available training (Worth et al., 2009). HPs with an understanding of the South Asian cultural context showed a positive influence during communication with individual patients and their families (Khosla et al., 2017). HPs were concerned that they found it difficult to understand the culture and communicate, while at the same time, provide PC services toward South Asian migrant families (Owens and Randhawa, 2004). Consensus was missing among HPs at different levels of PC concerning the proper time to start discussions on PC in the disease course and disclosure of illness to patients (Wilkinson et al., 2016). The misunderstandings were the result of time constraints, lack of confidence, skill, and cultural understanding in talking to patients and their families about PC (Radhakrishnan et al., 2017; Wilkinson et al., 2016; Wilkinson, Randhawa, et al., 2017). HPs with ethnicities other than South Asian ethnic backgrounds found it challenging to build emotional rapport with South Asian migrants due to a lack of knowledge about the culture (Owens and Randhawa, 2004).

Although several studies were concerned with providing culturally competent PC toward South Asian migrant families, consensus was missing on how the aim would be achieved. Suggestions included: training of interpreters and advocacy workers in PC settings (Randhawa et al., 2003; Wilkinson, Waqar, et al., 2017), appointing bilingual health workers (Ackroyd, 2003; Randhawa and Owens, 2004; Wilkinson et al., 2016), cultural mediators (Khosla et al., 2017), and liaison officers (Randhawa et al., 2003). Among interpreters, concern was raised about their knowledge of the culture of the ethic group along with language proficiency (Khosla et al., 2017).

Discussion

This review has identified three themes from 30 articles globally concerning PC of South Asian migrants. The themes that emerged from the analysis of the articles were: 1) the PC practice within the family, 2) trust as a precondition for PC, and 3) importance of knowledge and cultural competency, each with two sub-themes. Several studies in this review discussed how the challenges of using professional care in the palliative stage was complex and not only connected to culture. Studies also mentioned that lack of competencies in local language resulted in poor communication, and consequently, difficulties in imparting proper information during the palliative stage. Most frequently mentioned barriers to accessing PC was lack of awareness and poor communication between HPs and migrant families. Communication was often hampered, particularly due to language barriers, differences in cultural norms, and the dominant role of relatives. The protective role of relatives and other barriers, e.g. language, was also mentioned in a review conducted among all ethnic groups living in the UK (Evans, Menaca, Andrew, et al., 2012). Patients with life-threatening diseases were rarely informed about their diagnosis, while HPs were willing to open up a discussion about the diagnosis and PC services. Relatives often prevented the open discussion on life-threatening disease to protect the patient until death, although patients wished to know the truth. This is a general challenge faced by the HPs working in countries without appropriate codes and legislation concerning the patients' rights to informed consent (Khalil, 2013). Consequently, a lack of open discussion on diagnosis resulted in poor knowledge and awareness about available PC services.

Themes that emerged throughout this review were the importance of family relationships, role of relatives as resources, and/or vice versa. Studies included in this review mentioned that the care burden was often too high, especially for female caregivers (Somerville, 2001; Venkatasalu, 2017). Jobs outside of the home, household tasks, providing care for young and older relatives at home burdens the female relatives (Kristiansen et al., 2014; Shanmugasundaram, 2015; Somerville, 2001). This scenario is in line with the results of a review conducted among Turkish and Moroccan incurably ill migrant families living in the Netherlands (de Graaff et al., 2012). Most of the Turkish and Moroccan migrants preferred to be cared for and die at home, even when home care became a severe burden for the female caregivers (de Graaff et al., 2012). The reasons for choosing home care over hospital were considerations including the culturally inappropriate PC services delivered at health facilities, financial constraints, and preference for family care (de Graaff et al., 2012). Despite the preference for home care over hospital, higher numbers of hospital deaths occur among South Asian migrants compared to the general population. A cohort study among cancer patients revealed that deaths in hospital were more likely to happen among South Asian migrants compared to their White counterparts living in the UK (Coupland et al., 2011).

Several studies in this review addressed the central role of the patient in the collective family, where he/she was not ready to make any medical decision that just affected him/her (Akter et al., 2017; Chattoo and Ahmad, 2008; Khosla et al., 2016; Sharma et al., 2012; Somerville, 2001; Venkatasalu et al., 2013; Wilkinson, Waqar, et al., 2017). Every patient and older individual was considering the burden/wellbeing of other relatives before making any PC decision. Often, the family of the patient in this minority ethnic group was not only referring to the immediate family but to an extended family as well, and often to the community at a large. Thus, PC practice was influenced by the judgement of the community. In general, it was difficult to separate the patients' individual wishes from his/her family. A study conducted among non-western migrants in Denmark also documented the collectivist idea in the family, which consequently resulted in stress and illness among family caregivers of the younger generation (Nielsen et al., 2018).

It is worth noting that consensus was missing regarding the definition of cultural competency, although several studies in this review mentioned the importance of cultural knowledge/training among HPs (Khosla et al., 2017; Owens and Randhawa, 2004; Randhawa and Owens, 2004; Wilkinson et al., 2016; Worth et al., 2009). Two systematic reviews on PC of minority ethnic groups in the UK confirm the variety of different terms used to describe cultural competency and a lack of clarity in the usage of cultural competency approaches (Evans, Menaca, Andrew, et al., 2012; Evans, Menaca, Koffman, et al., 2012). Certainly, it is challenging for the HPs to provide culturally competent PC services for a diverse population. As mentioned earlier in this review, South Asian migrants are diverse in their cultural and religious practices, so the HPs would have to keep this in mind while delivering care toward this group. Therefore, it is suggested not to generalize the care toward migrants as a whole (Calanzani et al., 2013). A study conducted among older migrants in Denmark suggested that it is also important for the HPs to consider the issue of the individual's life history to provide optimal support (Nielsen et al., 2017).

Limitations and strengths

The articles in this review were mainly about migrants from India, Pakistan, and Bangladesh, and to a lesser extent, Sri Lanka. Studies concerning migrants from other nationalities in South Asia were not found in this review. This is due to the history of early migration from the aforementioned nationalities. Though a large number of Nepalese and Bhutanese are migrating to western countries in recent years, the age group of the migrants has yet to reach the age that requires PC services (SAALT, 2012). Finally, combining qualitative, quantitative, and mixed method studies made it difficult to synthesize the data.

Despite these limitations, the findings of this review suggest that involvement of relatives in PC decision making would improve communication and build trustworthy relationships with HPs. Considering the burden experienced by migrant families, it would be worth providing supportive interventions for migrant families both in hospital and at home. The intervention should be adjusted according to the needs of the migrant families and their existing healthcare system. This review also reveals suggestions for future research. Studies included in this review discussed the various challenges faced by migrant families and their HPs. The mentioned challenges in this review can be used to assist researchers when planning an intervention toward migrant families. Therefore, further research is required to explore how to support migrant families with interventions at the PC stage.

Conclusion

This review is the first to systematically identify studies and summarize the experiences and perspectives of PC among older South Asian migrants, relatives, and HPs from all over the world. The limited access to PC services among this patient group seems to be related to the dominant role of family caregiving, the lack of communication with professionals, and poor knowledge among migrant families about PC services. However, there is no universal guide to follow, so the policies and practices of HPs need to be particularly sensitive while providing PC services to migrant families. Considering the multi-ethnic nature of the world today, culturally competent PC may be applicable to other migrant populations beyond South Asians migrants.

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Reasons for exclusion: participants were not >50 years old (13), migrants did not originate from South Asia (9), participants were not migrants (8), conference abstract (8), not about palliative care (7), only cultural and religious description (6), gray literature (4), full text unavailable (2), and editorial (2).

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