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DOI:  
[10.1111/jan.14509](https://doi.org/10.1111/jan.14509)

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*Document Version*  
Publisher's PDF, also known as Version of record

*Citation for published version (Harvard):*  
Clancy, M, Taylor, J, Bradbury-jones, C & Phillimore, J 2020, 'A systematic review exploring palliative care for families who are forced migrants', *Journal of Advanced Nursing*, vol. 76, no. 11, pp. 2872-2884.  
<https://doi.org/10.1111/jan.14509>

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## REVIEW



WILEY

# A systematic review exploring palliative care for families who are forced migrants

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## Funding information

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

## Abstract

**Aims:** To explore the palliative care experiences of forced migrant children, families, and healthcare professionals (HCPs) highlighting successes, challenges, and associated practice implications.

**Design:** Systematic literature review.

**Data Sources:** The following search engines were searched from 2008 - 2018: Allied and Complementary Medicine Database, Cumulative Index to Nursing and Allied Health, MEDLINE, Embase, ProQuest, Scopus, Psycinfo, and Web of Science. Extensive reference and citation checking were also conducted.

**Review Methods:** Systematic review followed PRISMA guidelines with prepared PROSPERO registered protocol #CRD42019129200. English language qualitative, quantitative, or mixed methods studies were eligible for inclusion. Study quality was appraised using the Mixed Methods Appraisal Tool (MMAT).

**Results:** Eighteen studies (reported in 20 articles) met the final inclusion criteria. Most focused on challenges to care provision. Thematic analysis following methods proposed by Braun and Clarke was undertaken. Five themes were identified: (a) divergence of beliefs and expectations; (b) communication; (c) navigating health-care systems; (d) burdens and coping strategies; and (e) training and knowledge. A compassionate, collaborative approach with mutual respect crossed themes and was linked to high-quality care.

**Conclusion:** Forced migrant families have multiple needs including physical and emotional support and help in navigating complex systems. Professional interpreters can ease communication barriers when resourced appropriately. Individualized care is crucial to addressing the intricate mosaic of culture such families present. A cultural sensitivity/insensitivity framework is presented that may help guide future interactions and priorities for those working in children's palliative care.

**Impact:** This systematic review explored the international experiences of palliative care for forced migrant families. The findings highlight the plight of families who experience multiple traumas and increased levels of grief and loss through their migration experiences and when caring for a child with a life-limiting condition. This

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research has potential to have an impact on professionals working with culturally diverse families in all palliative care settings.

#### KEYWORDS

children's palliative care, cultural humility, cultural sensitivity, forced migration, nursing, refugee, systematic review

## 1 | INTRODUCTION

International epidemiological data on child mortality and morbidity highlight an increasing need to focus on children's palliative care (CPC) services as an estimated 20 million children worldwide could benefit from unrestricted access to medical facilities and resources (Institute of Medicine, 2003; International Children's Palliative Care Network, 2019). Connor and Bermedo (2014) estimated that of the children in need of palliative care, 98% belong to low- and middle-income countries and with 83% found in the lower income groups. The African Region covers almost half of this need closely followed by Southeast Asia and Eastern Mediterranean Regions. Children in need of palliative care for progressive non-malignant disease represent the highest proportion for all regions (84.08%), whereas palliative care for cancer (5.69%) and HIV/AIDS (10.23%) is distinctly lower. While the actual numbers of forced migrant children requiring CPC are unclear, the World Health Organization (WHO, 2020) reports higher prevalence of accidental injuries, burns, gastrointestinal illness, respiratory infections, cardiovascular events, nutritional disorders, higher newborn mortality, and other non-communicable diseases. The key issue for forced migrant families appears to be poor access to care in their countries of origin and interruptions to care during migration, which can exacerbate chronic conditions (WHO, 2020).

The philosophy of CPC is to promote the best possible quality of life for children living with severe and incurable conditions through holistic care embracing physical, emotional, social, and spiritual elements (Together for Short Lives, 2018a). CPC is complex, multifaceted, and frequently misunderstood. Taboos surrounding child death can make open and honest conversations between healthcare staff and families difficult. Global CPC is compromised by a lack of specialist staff and resources, negative public perceptions, and limited healthcare provider education and research (Collins, McLachlan, & Philip, 2018; Connor, Downing, & Marston, 2017; Friedrichsdorf & Bruera, 2018).

Forced migrant children and families are under-represented in the literature surrounding children's health (Flanagan & Hancock, 2010). Forced migrant families are compelled to flee their homeland often facing intense physical and mental trauma including imprisonment, torture, violence, and loss. When arriving in a country of refuge, families may experience severe social isolation and be subject to hostility and discrimination (MIND, 2009; Parhar, 2018).

Little is known about the experiences of CPC for forced migrant families, but it is clear that the combination of trauma before, during,

and following migration coupled with the complexities of life with a severely ill child results in multifaceted needs. Consequently, this review fills an important gap in identifying the current state of knowledge surrounding the experiences of CPC for forced migrant families and considers how this can inform practice and research priorities.

### 1.1 | Background

Children's palliative care demands a holistic approach beginning with diagnosis and continuing through life, death, and bereavement (Together for Short Lives, 2018b). The WHO (2018) argue that CPC involves an ethical responsibility for health providers, and that a multidisciplinary, cross-setting, and cross facility-based approach offers the best use of resources.

Children with palliative care needs have a primary, multifaceted, life-limiting, or life-threatening condition (Thompson, 2015). The numbers of children with such needs are increasing as is the severity of need because of cutting-edge clinical developments which prolong the lives of even those with the most complex needs (Mitchell, Slowther, Coad, & Dale, 2018; Thompson, 2015).

Parents' needs may be varied but recent literature reviews highlight the need for genuine communication, sincere relationships, respect as an expert, alleviation of suffering, and support (Melin-Johansson, Axelsson, Grundberg, & Hallqvist, 2014). In addition is the need for good multidisciplinary working and continuity of care (Van der Geest et al., 2014). Community-based trials have identified increased parental physical and social isolation, exclusion from the workforce, and pervasive grief (Collins et al., 2016). Liben, Papadatou, and Wolfe (2008) describe parental and staff challenges such as how to best control physical symptoms, difficulties when communicating with children (who may also be disabled), how to appropriately involve them in decision-making, and ensure that efforts to prolong life do not increase suffering.

This review focuses on forced migrant children and their families. The term forced migrant includes asylum seekers who have lodged an application for protection from persecution (The Refugee Council, 2013) and refugees whose asylum claim has been successful or who have been given refugee status by the United Nations Refugee Agency (UNHCR, 2016).

Poor access to health and social care in a country of refuge is commonly documented. Most research seems to concur that barriers are extensive and include financial insufficiency, administrative problems, lack of knowledge or understanding of the healthcare

Population (P)		Exposure (E)		Outcome (O)
Refugees including Asylum seeker/seeking	AND	Terminal care/terminally ill patient	AND	Infant
OR		OR		OR
Transient and migrants		End of life care		child
OR		OR		OR
Displaced persons		Palliative care		Pre-school child
OR		OR		OR
Emigration and Immigration		Life limiting		adolescent
OR		OR		OR
Undocumented child		Life threatening		Health care/treatment barrier
		OR		OR
	Death and dying	Health care professional/personnel		
	OR	OR		
		Disabled child		Parent
				OR
				Health service accessibility
				OR
				Health care utilization

**FIGURE 1** Key words/search terms

system, and rights to care and communication barriers (Maffia & Conway, 2008; Simonnot et al., 2016).

Forced migrant families who have children with palliative care needs have experienced the trauma of migration and of grief, fear, and loss associated with their child's diagnosis. They may have reduced agency and feel disempowered. Being forced to leave family, belongings, support, and all sources of familiarity often leaves them feeling displaced. Their child may not have a diagnosis, parents may have to undertake invasive medical care for their child, and they have to deal with uncertainty, critical illness, and periods of instability while living in fear of their child's inevitable death (Verberne et al., 2019). Additionally, the resources to provide adequate care and support may be limited or lacking. For healthcare professionals (HCPs), the diversity and differences in cultural, spiritual, and religious need may be bewildering and confusing.

There are no data on the numbers of forced migrants with CPC needs; however, there is little doubt that palliative care coupled with forced migration is likely to exacerbate already complex problems and have an impact on parental health and the provision of care.

## 2 | THE REVIEW

### 2.1 | Aims

The aim of this systematic review was to examine the palliative care experiences of forced migrant children, families, and healthcare providers. A secondary aim was to identify current challenges, barriers, and successes in care provision and to make practice implications for multidisciplinary CPC teams working with forced migrant families. This review addressed the following question: What is known about the experiences of children's palliative care for forced migrant families and their healthcare providers?

### 2.2 | Design

#### 2.2.1 | Systematic review

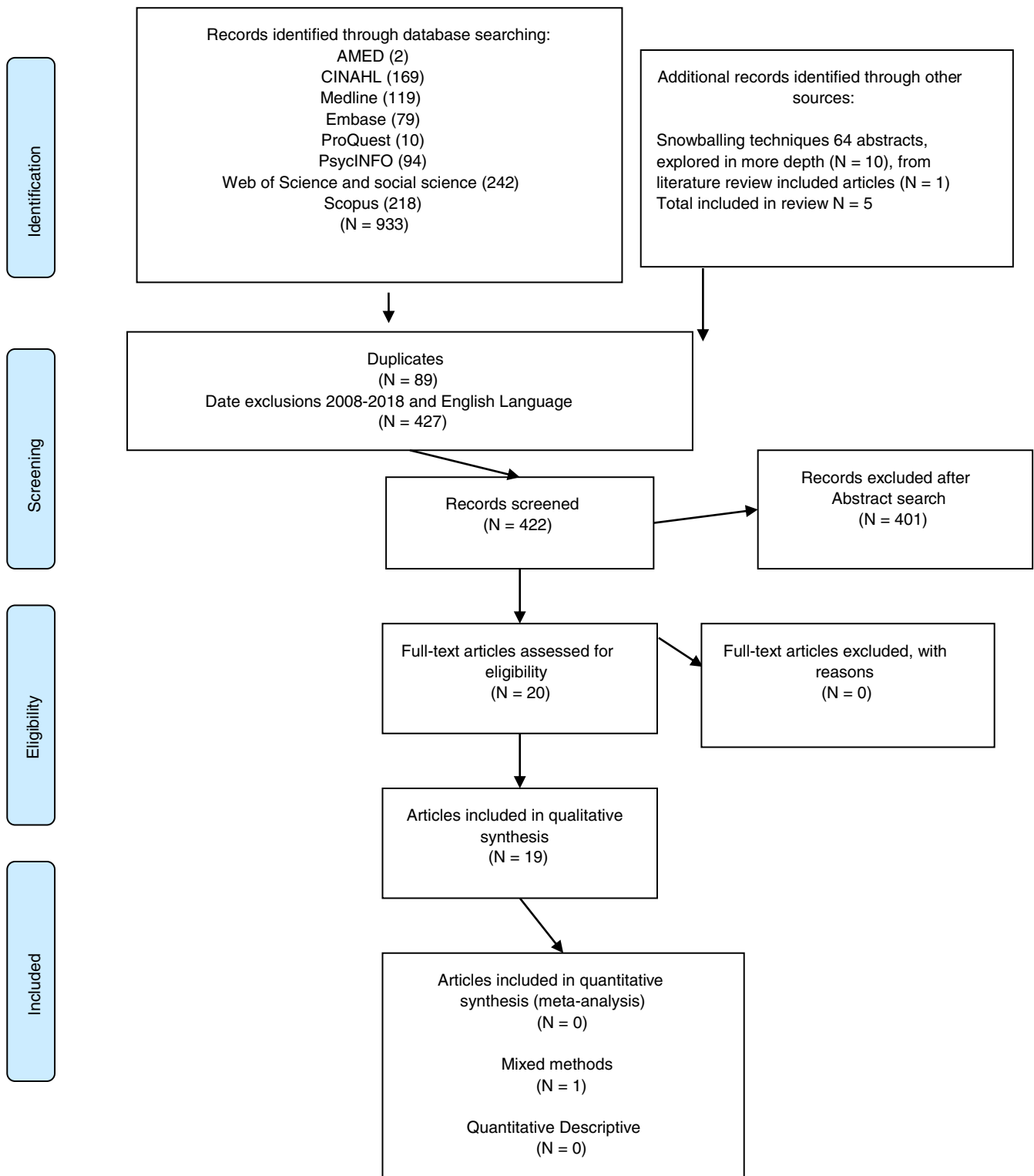
This systematic review aimed to identify and appraise all the literature on CPC for forced migrant children, using explicit, rigorous, and transparent methods as outlined by the NHS Centre for Reviews and Dissemination (2009) and Search, Appraisal, Synthesis, and Analysis (SALSA) methods (Grant & Booth, 2009). These frameworks aid the identification, selection, and critical appraisal of existing knowledge, enabling a synthesis of data from included studies (Nicholson, 2007; Ten Ham-Baloyi & Jordan, 2016).

Methods included a broad search strategy using PEO (Population, Exposure, and Outcomes) variables, predefined search terms, and uniform inclusion and exclusion criteria (Ten Ham-Baloyi & Jordan, 2016). The use of the PRISMA tool aided the review process ensuring articles were selected for sensitivity and specificity (Moher et al., 2009). Furthermore, registering the review in Prospero (#CRD42019129200) enhanced the justification for the study as it emphasizes the gap in the current literature, reduced duplication, and provided methodological transparency. The review protocol was developed iteratively refining processes and clarity as work progressed.

The review research team has a range of skills and experience surrounding systematic review methods, information retrieval, topic/clinical expertise, and methodology, which have enhanced the quality of this review.

#### 2.2.2 | Search methods

The databases searched were: Allied and Complementary Medicine Database (AMED), Cumulative Index to Nursing and Allied Health (CINAHL), MEDLINE, Embase, ProQuest, Scopus, Psycinfo, and Web



**FIGURE 2** Search outcome – PRISMA diagram [Colour figure can be viewed at [wileyonlinelibrary.com](http://wileyonlinelibrary.com)]

of Science. Snowballing techniques and searching of the Cochrane Database, Summon, and Google Scholar were also used to identify any potentially relevant grey literature. We sought to offer a diverse and comprehensive range of literature from across disciplines, as the topic connects different fields of study, such as the social sciences to health and nursing disciplines.

English language format records were searched for peer-reviewed empirical primary research for the period covering January 2008 to October 2018 (Table S1 for inclusion/exclusion criteria and rationale).

The search strategy involved the initial use of Mesh headings (database taxonomies) to commence the search, adding full-text

terms to capture additional material. Search terms were refined following each search as terminologies surrounding CPC and migration are extensive and differ internationally. New terms were added with searches rerun and the process repeated until no new articles were identified (Figure 1).

### 2.2.3 | Search outcome

A total of 422 articles were retrieved from the databases with hand searching/snowballing revealing a further five (Figure 2). Following the exclusions outlined, 18 studies reported in 20 articles were critically appraised using the Mixed Methods Appraisal Tool (MMAT) (Hong et al., 2018). From the 18 studies, 20 articles were produced because two authors – Kvarme et al. (2016), Kvarme, Alebertini Früh, & Lidèn (2017), and Wolff, Pak, Meeske, Worden, & Katz (2010), Wolff, Pak, Meeske, Worden, & Katz (2011) – used the same data set to publish two separate articles with differing findings.

### 2.2.4 | Quality appraisal

The use of a quality appraisal tool was important as the effectiveness of interventions can be masked or exaggerated by studies that are not rigorously conducted (NHS Centre for Reviews & Dissemination, 2009). The MMAT appraisal tool (Hong et al., 2018) enabled the appraisal of empirical studies using qualitative, quantitative, and mixed methods. The tool offers clear steps to the appraisal process and explanations which aid decision-making processes. To ensure the robustness and reliability of the review and the MMAT process, all authors appraised each study and two authors (JT and CBJ) randomly checked for consistency in four papers. Differences were discussed until consensus was reached.

All studies were scored separately for quality (judgements regarding research design, methods, and rigour) and usefulness (relevance to the subject area; Daniel, Taylor, & Scott, 2010, 2011; Taylor, Daniel, & Scott, 2012). For quality, scores of 1 indicated that the study was rigorous and bias had been addressed; scores of 2 showed agreement with design and methods and attempts to address bias; a score of 3 was applied when studies did not satisfy basic criteria of rigour, were flawed, or did not address bias. Usefulness and relevance to the subject was also scored using: 1 – to show extremely useful and relevant studies; 2 – some useful information, but not direct relevance; and 3 – very little of relevance. Any study that scored 3 for either quality or usefulness was excluded. Results can be found in Table S2.

### 2.2.5 | Data abstraction

The selection process aimed to minimize bias over inclusion/exclusion by making this explicit and free from any researcher pre-formed opinions (NHS Centre for Reviews & Dissemination, 2009). Initial decisions were based on titles and, where available, abstracts. The research

team examined these to ensure agreement around inclusion/exclusion. Where it was unclear if studies met the inclusion criteria, the full text was assessed to ensure there were no inappropriate exclusions.

A table was used to extract relevant information from each study (Table S3), providing consistency and improving validity and reliability (NHS Centre for Reviews & Dissemination, 2009). At the end of the process, a table was produced including all studies (Table S4).

### 2.2.6 | Synthesis

The next step in this review was identification of themes from each study followed by an analysis to identify relationships. Braun and Clarke (2006) guidelines were used to ensure that the themes accurately summarized findings. Following this, an analysis of the frequency with which themes appeared in different papers was conducted alongside a reflection of the significance and relevance of each theme. At this stage, themes that might be amalgamated were identified where they were similar or part of a pattern (Aveyard, 2019). Next, theme names were examined to ensure if they best fit the content included. Through 'dynamic working back and forth', robust themes were identified (Lincoln, Guba, & Pilotta, 1985, p. 342). Finally, themes were examined across the studies to look for similarities and inconsistencies.

## 3 | RESULTS

Table S4 provides an overview of the 18 studies included. Articles originated from a multitude of countries (America  $N = 6$ , Canada  $N = 7$ , Sweden  $N = 2$ , Australia  $N = 2$ , and Norway  $N = 1$ ). Seventeen were qualitative, with one mixed methods study. A diversity of approaches was evident in qualitative studies. While some research versatility can be helpful and allow for flexibility (Bradbury-Jones et al., 2017), such diversity was confusing as methodologies were broad in scope and offered limited detail about actual methods used. Without clear methodological justification, it was hard to identify sample size or know whether the methods employed were sufficiently rigorous to justify the claims made (Kim, Sefcik, & Bradway, 2017).

### 3.1 | Thematic development

A summary of the articles included in this review can be found in Table S4; following analysis, five main themes were identified:

#### 3.1.1 | Theme 1: Divergence of beliefs and expectations

A key theme was that of divergence of beliefs between HCP and families. These varied between different perceptions of

parenting (Brassart, Prévost, Bétrisey, Lemieux, & Desmarais, 2017), to conflicting perceptions of diagnosis (Brassart et al., 2017; Gulati et al., 2012; Sneesby, Satchell, Good, & Van Der Riet, 2011), systems (Fellin, King, Esses, Lindsay, & Klassen, 2013), non-acceptance of treatment (Brassart et al., 2017), truth-handling (Periyakoil, Neri, & Kraemer, 2015), and disability (Brassart et al., 2017; Lindsay, King, Klassen, Esses, & Stachel, 2012). Challenges around disclosure and consent were also identified (Sneesby et al., 2011).

Some families seemed to struggle with Western ideals of autonomous parents who advocate for their child and make decisions with HCP (Beatson, 2013; Fellin et al., 2013; Gulati et al., 2012; King, Desmarais, Lindsay, Piérart, & Tétreault, 2015; Pergert, Ekblad, Björk, Enskär, & Andrews, 2012; Periyakoil et al., 2015). One article highlighted a lack of family centred care and instead a reliance by families on medical authority (Fellin et al., 2013).

However, when differing beliefs were acknowledged by HCP, participants shared how an understanding of the child's disability, diagnosis, prognosis, and treatment helped them to prepare for the future and set goals (Brassart et al., 2017; Green, Jerzmanowska, Green, & Lobb, 2018). Collaborative working allowed the development of care that was tailored to fit individual family's situations (Green et al., 2018; King et al., 2015) and enabled accounting for different customs surrounding death, dying, and bereavement (Green et al., 2018; Sneesby et al., 2011).

Families discussed the importance of traditional healing strategies (Beatson, 2013). Physicians incorporating traditional healing were seen as helpful but those who did not, incited anger (Davies, Contro, Larson, & Widger, 2010). Families described the importance of incorporating faith and spirituality into care (Davies et al., 2010) with prayer as a common coping mechanism (Davies et al., 2010; Pinheiro & Jaff, 2018; Sneesby et al., 2011; Wolff et al., 2010).

In Periyakoil et al. (2015), patients' spiritual and religious beliefs about death and dying were seen as challenging, as doctors felt they led to a demand for futile treatments. Clinicians argued that families' hope for a miracle resulted in refusal to engage in end-of-life discussions. Some doctors believed that they had to reconcile religious 'obstructions' with a do not resuscitate status. These findings suggest a lack of empathy, with one study author observing that more collaboration with community spiritual leaders may enhance care.

Gender bias and associated caregiving and decision-making expectations fall within this theme (Burnes, Antle, Williams, & Cook, 2008; Fellin et al., 2013; Khanlou, Haque, Sheehan, & Jones, 2015; Kvarme et al., 2016; Pergert et al., 2012; Wolff et al., 2010). Studies highlighted that mothers were expected to be the primary caregiver, often becoming consumed by the child's illness (Burnes et al., 2008; Khanlou et al., 2015; Kvarme et al., 2016). However, Burnes et al. (2008) argue that fathers may cope by distancing themselves as they struggle to accept the realities of their child's illness, or because they are discounted by HCP who focus on mothers (Wolff et al., 2010).

Some of the gender aspects discussed relate to the lack of fathers' perspectives. The ratio of mother to father participants was

70:30. The studies focusing on fathers detailed actions such as protecting mother's poor physical and mental health, flexibility in sharing care (Wolff et al., 2010), and fathers' increase in self-worth and social status through providing care (Wolff et al., 2011).

The challenges of collaborative care were complex relating to additional time (Beatson, 2013; Pergert, Ekblad, Enskär, & Björk, 2008) and balancing of patient safety versus preference and comfort (Green et al., 2018). Where conflicts were identified, parents reported feeling ignored and unable to make decisions (Davies et al., 2010), fearful of misusing hospital resources (Gulati et al., 2012), cultural misunderstandings, and perceptions of discrimination (Fellin et al., 2013) and racism (Burnes et al., 2008). Pinheiro and Jaff (2018) emphasized the significance of collaborative care as it directly correlated with the perceived quality of care received.

Positive facilitators to good care were described when divergent beliefs were acknowledged, respected (Brassart et al., 2017), navigated (Green et al., 2018), and families helped to advocate for their children (Lindsay et al., 2012).

### 3.1.2 | Theme 2: Communication

Language and communication barriers were explored by many of the studies from professional perspectives (Brassart et al., 2017; Green et al., 2018; Khanlou et al., 2015; Periyakoil et al., 2015) and those of the family (Gulati et al., 2012; Kvarme et al., 2016; Pergert et al., 2012). Issues identified included medical misinterpretation (Fellin et al., 2013), difficulties in building rapport (Lindsay et al., 2012), and a reluctance to use services. Lack of information meant families expressed feelings of powerlessness, distress, fear, and being overwhelmed (Wolff et al., 2011). In addition, Beatson (2013) comments that no words existed in the native language for the child's condition, so this was increasingly complicated.

Families also reported that they felt abandoned and that staff were sometimes self-interested, not tuned into patients' best interests, and less compassionate and sensitive to their needs than in their country of origin (Periyakoil et al., 2015).

Lack of access to professional interpreters was a key challenge (Brassart et al., 2017; Davies et al., 2010; Fellin et al., 2013; Green et al., 2018; Gulati et al., 2012; Wolff et al., 2010) with some parents unaware of interpreting services (Fellin et al., 2013). An overreliance on families for interpretation was acknowledged as raising ethical concerns around disclosure and accuracy of information (Green et al., 2018; Pergert et al., 2008; Wolff et al., 2011). At times, families elected to use relatives rather than an interpreter given concerns about confidentiality (Green et al., 2018).

Facilitators to good care included strategies to overcome communication barriers such as modifying the language used (Brassart et al., 2017) and using signs, charades, and picture charts (Pergert et al., 2008); however, this offered potential for misunderstandings (Pergert et al., 2008). Non-verbal communication, such as expressive eye contact (Khanlou et al., 2015), engagement (King et al., 2015), or human connection (Contro, Davies,

Larson, & Sourkes, 2010), were linked to empathy, trust (Khanlou et al., 2015), and open-minded, non-judgemental interactions (King et al., 2015).

Two studies described the value of listening to and understanding migration experiences to establish a trusting relationship (Green et al., 2018; Kvarme et al., 2016) and get a better understanding of past traumas (Contro et al., 2010).

Participants shared that when they felt understood, they felt respected and that HCP really cared about their child (Green et al., 2018; King et al., 2015) and this helped to decrease helplessness and uncertainty (Gulati et al., 2012).

### 3.1.3 | Theme 3: Navigating healthcare systems

Healthcare services were criticized by families and professionals for their limited scope, poor availability and accessibility, and often-dispersed nature (Burnes et al., 2008; Gulati et al., 2012; Khanlou et al., 2015; Kvarme et al., 2016, 2017; Pinheiro & Jaff, 2018). Rigidity and complexity of the system (Brassart et al., 2017; Gulati et al., 2012) were linked to parents' limited understanding of what was available (Fellin et al., 2013; Kvarme et al., 2016) and a lack of knowledge about their child's condition (Beatson, 2013; Burnes et al., 2008). Insufficient systematic resources decreased mother's ability to cope (Burnes et al., 2008). Furthermore, some families appeared to be missing out on services and resources (Gulati et al., 2012) and even struggling to get appropriate diagnosis and treatment (Pinheiro & Jaff, 2018).

Families discussed financial stresses, with limited time and unemployment appearing important factors within the structural challenges to care (Beatson, 2013; Brassart et al., 2017; Contro et al., 2010). Financial stressors sometimes related directly to the cost of medical care or lack of insurance and associated implications (Fellin et al., 2013; Pinheiro & Jaff, 2018; Wolff et al., 2010).

Families and professionals described how a lack of health literacy led to difficulty in navigating the complex healthcare landscapes. Facilitators were linked to an ability to understand healthcare systems which strengthened parents' confidence and reduced anxiety (Gulati et al., 2012). Services such as transport assistance (Beatson, 2013; Wolff et al., 2011) and provision of navigators such as community nursing care (Beatson, 2013; Burnes et al., 2008; Fellin et al., 2013) phone services and paediatricians with specialist knowledge (Burnes et al., 2008) also acted as facilitators.

### 3.1.4 | Theme 4: Burdens and coping strategies

This theme relates to the challenges faced by parents which result from their care giving responsibilities and was only documented within the family perspective articles.

In terms of physical ill health, parents discuss pain, sleep disturbance, stress, and tension (Contro et al., 2010; Kvarme et al., 2016, 2017; Wolff et al., 2011). Further burdens included a lack of

leisure time, marital, and family conflict (Kvarme et al., 2016; Wolff et al., 2010), the unmet needs of siblings (Kvarme et al., 2016; Wolff et al., 2010) and for Mexican parents, a fear of not seeing other children who are left behind with relatives (Contro et al., 2010). These factors contributed to parental exhaustion (Burnes et al., 2008), loneliness, and isolation (Burnes et al., 2008; Davies et al., 2010; Kvarme et al., 2016; Wolff et al., 2010). Parents appeared reluctant to leave their child (Gulati et al., 2012) and struggled with uncertainty and lived in a constant state of fear due to the unpredictable nature of their child's condition (Burnes et al., 2008; Pinheiro & Jaff, 2018).

Forced migrant families suffered from additional hopelessness over the destitution of their country of origin with families detailing the difficulty in seeing their home lands destroyed by war and political injustice (Contro et al., 2010; Pinheiro & Jaff, 2018). Further to this, parents detailed the detrimental aspects of living in poverty (Pinheiro & Jaff, 2018), feelings of powerlessness, shame, and the effects of racism and discrimination on them and their families (Burnes et al., 2008; Pergert et al., 2012).

Coping strategies were undermined by a lack of tangible support including child care, respite services, and psychosocial support (Burnes et al., 2008; Khanlou et al., 2015; Kvarme et al., 2016). Families noted the absence of traditional support from partners, family, priests, and welfare services and struggled without these 'invaluable' support systems (Contro et al., 2010; Khanlou et al., 2015; Kvarme et al., 2017; Wolff et al., 2010). Coping strategies for families included love for the child which kept families going and the use of emotion-focused coping (mostly mothers) and problem-focused coping mechanisms (mostly fathers; Kvarme et al., 2017). Support in a refugee camp was also discussed as being forged by finding extended family and co-national assistance (Pinheiro & Jaff, 2018).

### 3.1.5 | Theme 5: Training and knowledge

A lack of HCP knowledge in culturally sensitive care was seen as a barrier to good care by HCP themselves (Brassart et al., 2017; Lindsay et al., 2012). Periyakoil et al. (2015) reported that an ignorance of patient's cultural beliefs, values, and practices was linked to a HCP lack of knowledge. A lack of public awareness of conditions was also highlighted and associated with cultural silence and uneducated notions (Burnes et al., 2008). The lack of investment in research and resources was also noted. Burnes et al. (2008) linked low levels of investment to sickle cell being a Black and thus marginalized disease. Conversely, facilitators to good care were linked to good theoretical knowledge, health professionals using reflection and the linking of staff with similar cultures, and ethnicities to families to share cultural expertise and understanding (Pergert et al., 2008).

It appears that the experiences of CPC for forced migrant families predominately relate to aspects which optimize or hinder culturally sensitive palliative care. From the review findings, we have



developed a framework to demonstrate the antecedents and consequences of care when it is seen as culturally sensitive or insensitive by families. The impact this may also have on HCP themselves is also presented (Figure 3). The discussion in the following section centres around the framework.

#### 4 | DISCUSSION

A definition for culturally sensitive care is found in Figure 3, but essentially this relates to an enhanced awareness and deepened understanding of cultural differences with an ability to apply these to

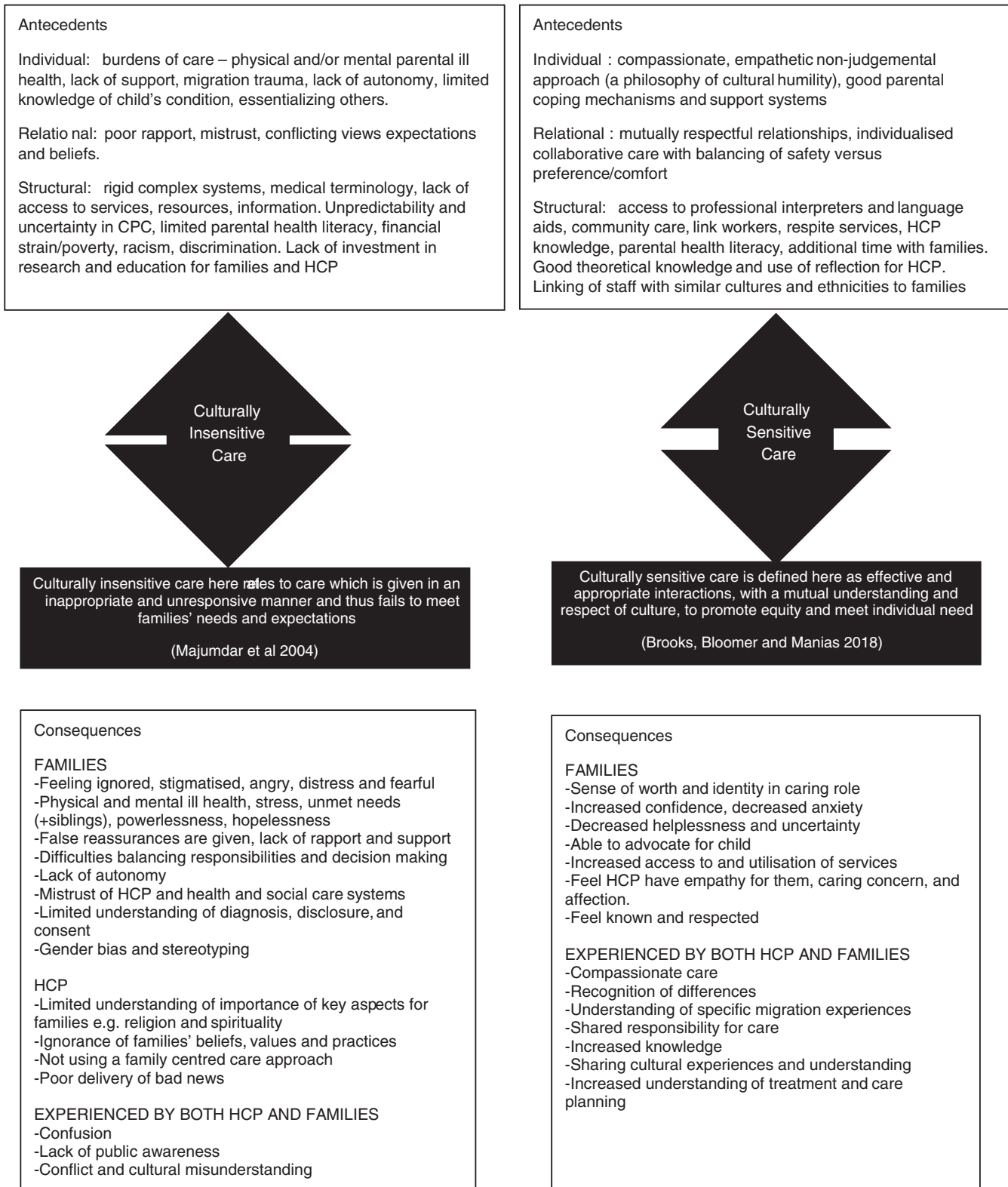


FIGURE 3 The cultural insensitivity sensitivity framework

practice appropriately (Evans et al., 2012). There are three overlapping factors which shape whether or not care is culturally sensitive: individual, relational, and structural aspects.

Individual aspects centre on the burdens to care faced by parents. The unpredictability and uncertainty of CPC lead to anxiety, as parents fear crisis, hospitalization, and their child's death. Anxiety can result in physical and mental ill health. The literature outside of this review details the consequences of caring for a child requiring palliative care and clearly documents the exhaustion, hyper-vigilance, and overwhelming burdens of responsibility (Carter & Bray, 2016; Limardi, Stievano, Rocco, Vellone, & Alvaro, 2016) which were also evident in our findings. Stresses for forced migrant families are compounded by a fragmented cultural identity, loss of belonging, and absence of a support network to provide support (Bhugra & Becker, 2005). Further to this is an apathetic view of migration trauma with the impact of displacement, enforced poverty, and elements of PTSD being frequently missed or minimized by HCPs.

Negative media discourse around migration, community antagonism, and a hostile environment further creates a sense of unease with the potential for forced migrants to be stereotyped or discriminated against (Manstead, Reicher, Greenland, & Nightingale, 2016; Weller et al., 2019). Forced migrant families particularly value those HCPs who offered them compassion, caring concern, affection, and empathy.

Relational aspects of the framework are primarily associated with communication difficulties, with insensitive palliative care being linked to poor rapport and conflicting expectations and beliefs. This is unsurprising as Bergstraesser et al. (2015) state communication is a central aspect of care for parents and linked to high-quality care. When there is a divergence in the views of families and HCP, families observe the cultural ignorance of HCPs, alongside feelings of unease and mistrust. Equally, when HCPs struggle to understand a family's values and practices, especially regarding spirituality, native healing, and gender roles, they feel conflicted.

Conversely, relationships based on mutual respect embodying a philosophy of individualized, collaborative care help parents to feel known and valued. Involving families and creating care pathways which fostered family centred care are linked to increased parental confidence and self-worth and an ability to advocate for their child. Helplessness, anxiety, and uncertainty are experienced when parents cannot have a negotiated caring role.

HCPs who embrace a 'one-size fits all' model move towards the culturally insensitive side of the framework as families feel ignored, stigmatized, and angry. Such 'clinician-directed care' was seen as oppositional to family centred care and linked to limited parental knowledge as their understanding appeared to diminish amid resulting disempowerment.

Individualized collaborative care is not new with NICE (2016) CPC guidelines recommending it and noting that its absence can negatively influence care. Given the traumatic experiences faced by forced migrant families, there is even greater need for collaboration. Their child's illness further removes a sense of normality and

diminishes agency (Verberne et al., 2019). The acknowledgement of such factors by HCPs contributes to empathetic, compassionate relationships essential for building trusting relationships, sharing cultural understanding, and meeting families' needs.

The importance of compassion crosses the five themes of this review and seems to relate to a two-way navigation where families and HCPs travel the road of CPC together. Suffering, past traumas, uncertainty, fear, and cultural differences are eased when they are faced together in a trusting, caring relationship (Awdish, 2018). However, being present takes time to listen, understand, and respect each other, acknowledging problems and a lack of knowledge for both parties. Cultural humility exemplifies such a philosophy as illustrated in a palliative case study by Cochran, Saleem, Khowaja-Punjwani, and Lantos (2017), which advocates an acceptance of difference and welcoming of diversity.

Cultural humility aims to address the power imbalances which exist in health care by focusing on egoless dialogue, which is empowering and respectful, and with a commitment to lifelong learning and reflection (Tervalon & Murray-Garcia, 1998). Concepts of cultural humility may enhance traditional models like cultural competence which is said to be limited due to the broad, constantly evolving dimensions of culture (Foster, 2009) and fears too much focus on knowledge acquisition may lead to increased assumptions and stereotypical views (Evans et al., 2012).

Finally, structural antecedents were linked to access to interpreters, language aids, and other services, resources, and information. The link between good communication strategies and navigating access to care is widely reported in studies exploring forced migration and healthcare experiences (Morris, Popper, Rodwell, Brodine, & Brouwer, 2009; Sheikh-Mohammed, Macintyre, Wood, Leask, & Isaacs, 2006). Further to this, Finnström and Söderhamn (2006) suggest a link between a lack of cultural sensitivity and competence among HCP and less access to health care and pain treatment for minority groups. Consistent with the findings of this review, evidence suggests that optimal communication, patient satisfaction, and reduction in errors occur when there is access to professional interpreters and other supporting resources and services (Flores, 2005; Silva et al., 2016).

Families often have limited health literacy and appeared lost in medical jargon and the complex health and social care systems which held the key to accessing care. Families' lack of social support and problems identifying coping mechanisms meant community care, link workers, and respite services were crucial to maintaining their physical and mental health.

The use of link workers or cultural mediators who share language and culture is a strategy to improve communication and access with potentially an additional function of educating staff and supporting the development of trusting relationships (Finnström & Söderhamn, 2006; McGarry et al., 2018). However, the small number of forced migrant families receiving CPC and differences in their culture, language, and country of origin means it is frequently impractical to develop appropriate resources. Thus, collaborative resources may be supported by multi-agency working and shared

across services and settings which would reduce costs but may add logistical challenges.

Our framework enhances and highlights the distinctive insights offered from this review in terms of the experiences of families and HCPs working in CPC. Previous studies (Dewar & Nolan, 2013) have offered models in which to base compassionate relationship-centred care but none have yet focused on empathy and compassion in CPC for families who are forced migrants. These aspects of care were seen as particularly important in our thematic analysis given that challenges faced in accessing, giving, and receiving care are especially complex for forced migrants.

#### 4.1 | Limitations, strength, generalizability, and transferability of the evidence

Limitations to this review include the restriction to only English language articles which have limited the data set and may potentially bias findings towards Western nations (NHS Centre for Reviews & Dissemination, 2009). Translation of non-English language research was not feasible due to a lack of time and resources.

It was never the intention of this review to seek only qualitative studies, but our search and review processes did lead us towards a qualitative analysis. Had we known this in advance, it may have been advantageous to conduct a qualitative meta-synthesis (Sandelowski & Barroso, 2002).

The differences in terminology used in the papers reviewed proved challenging. Both CPC and migration were expressed in different ways which were not always clear from the outset. For CPC, the categories for palliative care were not always used and so examinations of the types of illness/disability had to be conducted to ensure these met inclusion criteria. For forced migration, the word migrant was used very broadly often without further explanations of who these populations were and so often full-text searching was necessary. However, this was enhancing to the study as the thorough approach it necessitated gave further confidence that all appropriate studies had been included in the review. A further strength lies in the international content of the articles included, which ensured generalizability and transferability.

#### 4.2 | Recommendations

Further research is needed to fill gaps in knowledge around CPC and forced migrant families. This review illustrated that child and young person perspectives are lacking. While this is not uncommon in the general population of children in palliative care and may relate to their illness (Ghirotto et al., 2019), other issues may be at play. Weaver et al. (2019) suggests that there is a tension within CPC research between collecting vital data and protecting vulnerable populations.

More work is thus needed to gather the perspectives of children and fathers. A wider range of settings should also be included,

such as hospices and respite care, as valuable perspectives surrounding pain and symptom control were missing from this review and research in such settings may aid understanding in these areas.

## 5 | CONCLUSION

This review has offered valuable insights into the experience of CPC for forced migrant families and contributed to existing knowledge in this area with the creation of a framework guiding HCP towards culturally sensitive care provision. CPC guidelines advise individualized care for all families but for forced migrant families, this is particularly important as experiences of persecution and displacement can reduce agency which needs to be fostered to rebuild self-worth and a sense of belonging. The 'normality' of parenting can be cultivated through a model of family centred care. There is a need for care which focuses on compassion, humility, and listening to individual experiences. This is imperative to building trusting relationships and increasing mutual respect and cultural understanding. Cultural humility may foster such an approach, so further research of its use in CPC would be beneficial.

The framework devised from this review is a useful tool for HCP to see how the antecedents and consequences of care relate to families' experiences. This unique insight into their world may help to improve knowledge, empathetic understanding, and the ability to facilitate future culturally sensitive CPC.

#### CONFLICT OF INTEREST

We have no conflict of interest to declare in the collaborative writing of this article.

#### PEER REVIEW

The peer review history for this article is available at <https://publons.com/publon/10.1111/jan.14509>.

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## SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

**How to cite this article:** Clancy M, Taylor J, Bradbury-Jones C, Phillimore J. A systematic review exploring palliative care for families who are forced migrants. *J Adv Nurs*. 2020;76:2872–2884. <https://doi.org/10.1111/jan.14509>

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