Home-based end of life care for children and their families – a systematic scoping review and narrative synthesis

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Abstract

Problem: There is a growing international drive to deliver children's palliative care services closer to home. Families should have choice of where end of life (EOL) care is provided with home as one option. This review aims to establish the current international evidence base relating to children's EOL care at home.

Eligibility Criteria: A systematic scoping review was conducted in accordance with PRISMA-ScR reporting guidelines. Seven databases were searched to identify papers published between 2000-2018. Eligibility criteria included papers reporting children's EOL care with specific relation to: home being the preferred place of death; services providing EOL care at home; family experiences of receiving support when their child died at home and professionals' experiences of delivering this care.

Sample: Twenty-three papers met the eligibility criteria and were included in the review.

Results: Engagement of families in EOL care planning discussions was identified as a key factor to facilitate choice of setting. Consistent themes from the data suggest that providing access to care in the home 24/7 by a team of professionals with specialist paediatric palliative care knowledge is an essential aspect of any model of home-based EOL care.

Discussion and Application to Practice: This is the first comprehensive review of home-based EOL care for children which offers a valuable contribution to policy, practice and research. The evidence mapped and synthesised in this review can inform the development of services to facilitate the provision of EOL care at home in line with the unique wishes and needs of children and families.

Background

It is widely recognised that a premise of pediatric palliative care is to ensure care is planned and provided according to the wishes of children and their families. Facilitating choice of where end of life (EOL) care is provided is a key component of national policy within the United Kingdom (UK) (Scottish Government 2012; National Palliative and EOL Care Partnership 2015; Department of Health 2016) and advocated by leading children's palliative care charities and organisations in Europe and beyond (EAPC 2007; Together for Short Lives 2017).

If presenting families with choice regarding place of death for their child is to be prioritised, and home is to be offered as a potential setting, it is important that systems and services are in place to allow choice to be respected and families' wishes to be fulfilled. However, what provisions for EOL care of children within the home should entail or what examples of best practice might look like is not well documented. The dearth of research in this area is reflected in the National Institute for Health and Care Excellence (NICE) (2016) guidelines on planning and managing EOL care for infants, children and young people where supporting evidence for the clinical and cost effectiveness of home based programmes was based on four observational studies.

Scoping reviews, a form of evidence synthesis, can be influential in informing policy, practice and research (Colquhoun et al. 2014). This scoping review set out to establish the current international evidence base relating to children's[1] EOL care provided in the home setting. Specifically, it aimed to

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[1] The term children's palliative care is used throughout this manuscript with the understanding that it is inclusive of neonates, infants, children and young people.

identify and describe those models of care and services which enable EOL care to be provided at home, when home is the preferred place of care. In addition, it aimed to explore evidence surrounding the perspectives and experiences of families and professionals on EOL care and death at home.

Methods:

A protocol for the review was devised by applying Arksey and O'Malley's (2005) methodological framework and incorporating recommendations made by Levac et al. (2010). Reporting guidelines in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses statement for reporting scoping reviews (PRISMA-ScR) were followed (Tricco et al. 2018).

Stage 1 - Identification of research questions

The questions guiding this review were:

1. *What models of care or services provide access to home-based care for families who have identified home as the preferred place of death for their child?*
2. *What are families' experiences of receiving care and support when their child died at home?*
3. *What are professionals' experiences of delivering children's EOL care in the home?*

Stage 2 - Identification of relevant studies

A comprehensive and systematic approach to identifying evidence was adopted. The project team [CM, CT, KK] developed an initial search plan. To ensure rigour, the expertise of a senior subject specialist librarian was sought to further develop and refine the search strategy and carry out the electronic database searches.

Seven databases (MEDLINE, PubMed, PsycINFO, CINAHL, AMED, ASSIA, Cochrane Library) were searched in December 2018. Different combinations of search terms were used to reflect the core concept of children's EOL care and support provided in the home. Papers published in the English language between the dates of January 2000 to December 2018 were considered. This time period enabled a broad scope of evidence to be gathered reflecting any impact of the policy and guidance changes from that point on service delivery. No restrictions on study design were made, however, commentaries, editorials and opinion pieces were excluded. A sample of the MEDLINE search strategy is outlined in appendix 1. This strategy was adapted for the other databases where necessary.

In addition, a manual search of reference lists for papers identified through database searches was performed to identify further relevant papers. Recent issues (January 2015 to December 2018) of key journals in the field (*Palliative Medicine, BMJ Supportive and Palliative Care, International Journal of Palliative Nursing, BMC Palliative Care,* and the *American Journal of Hospice and Palliative Care*) were hand-searched. References were managed using Endnote.

Stage 3 - Study selection

Papers were eligible for inclusion if they reported on any of the following: (i) services or models of care providing children's EOL care at home; (ii) family experiences of receiving care and support when their child died at home and; (iii) professionals' experiences of delivering home-based EOL care. Papers reporting on longer term palliative care in a home setting were included as long as they also reported on care during the final days of life or at the time of death.

Papers were excluded if they were not published in English or if the full text version of the paper was unavailable. Papers focused on EOL care at home for the adult population were excluded.

Two members of the project team independently reviewed the title and abstracts of identified papers to ensure the above inclusion and exclusion criteria were met. Full text papers were screened and through a process of consensus seeking by two reviewers, a final assessment of eligibility for inclusion in the scoping review was made. Any disagreements on paper inclusion between reviewers were resolved by a third reviewer.

Stage 4 - Charting the data

Relevant data was extracted from each paper. As suggested by Levac et al. (2010), two members of the project team undertook initial data extraction of the first ten papers independently and then met to confer and ensure that the data extraction was addressing the research questions posed in the review. Final data extracted included the following sections: author(s); year of publication; location of study; study population and design; methodology; and a brief summary of the main findings or recommendations.

Stage 5 - Collating, summating and reporting findings

A narrative synthesis approach was undertaken to present an overview of the evidence included in this scoping review. Using the qualitative data analysis software QSR NVivo 11 (QSR International PTY Ltd., Victoria, Australia), thematic content analysis was carried out to identify trends and patterns across the extracted data in line with approaches recommended by Levac et al. (2010). Project members (CM, CT) reviewed the data independently and engaged in critical discussions of the emerging topics and themes until consensus was reached. The themes were then reviewed with KK to reach team consensus. The final results were reported through a narrative description of themes and a table summarising the papers from which the data was synthesised.

Results

The search yielded 270 papers which were then screened by CM and CT resulting in the initial exclusion of 212 papers. The remaining 58 papers were read in full and assessed for eligibility following which 23 papers were included in the scoping review and the remaining 35 excluded with reasons given. The PRISMA flowchart (figure 1) illustrates the search strategy and paper selection process.

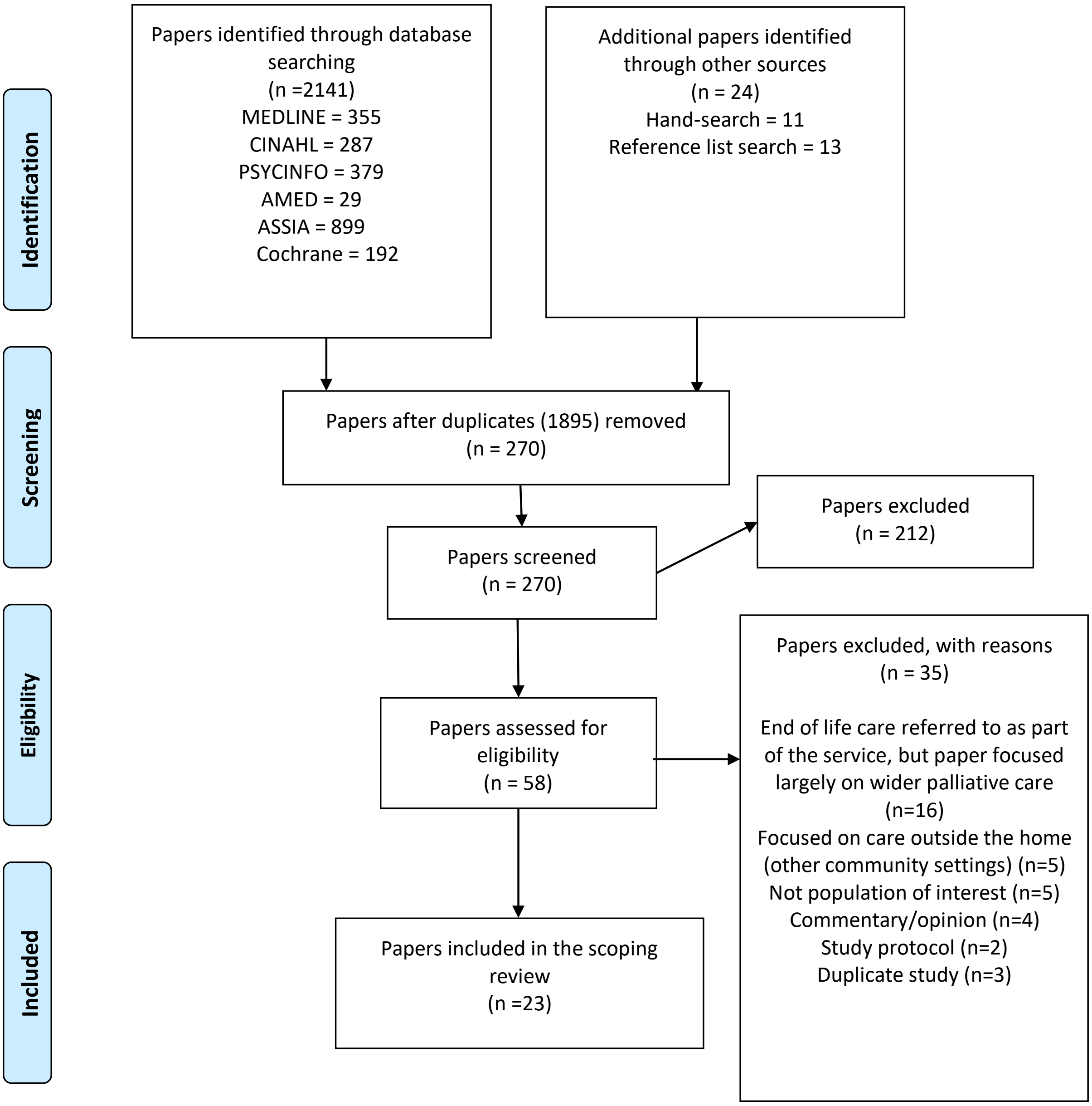

Figure 1. PRISMA flowchart illustrating the search strategy and paper selection process.

Characteristics of the included papers

The majority of papers originated from countries within Europe with nine arising from the United Kingdom (UK) (Vickers & Carlisle 2000; Hannan & Gibson 2005; Neilson et al. 2010; Reid 2013a, 2013b; Maynard & Lynn 2014, 2016a, 2016b; Bennett et al. 2016), four from Germany (Wolff et al. 2010; Vollenbroich et al. 2012, 2016; Bender et al. 2017), and one from each of the following countries: Switzerland (Eskola et al. 2017), Sweden (Lovgren et al. 2016), Poland (Dangel et al. 2000), the Netherlands (Kars et al. 2011) and France (Sentilhes-Monkham et al. 2003). In addition, four papers originated from the United States of America (USA) (Weidner et al. 2011; Arland et al. 2013; Niswander et al. 2014; Friedrichsdorf et al. 2015), and one from Canada (Zelcer et al. 2010).

Seven of the 23 papers focused exclusively on children with cancer (Vickers & Carlisle 2000; Hannan & Gibson 2005; Neilson et al. 2010; Zelcer et al. 2010; Kars et al. 2011; Arland et al. 2013; Friedrichsdorf et al. 2015), 12 papers included both children with cancer and children with a range of other life shortening conditions (LSCs) (Dangel et al. 2000; Wolff et al. 2010; Weidner et al. 2011; Vollenbroich et al. 2012; Niswander et al. 2014; Maynard & Lynn 2014, 2016a, 2016b; Bennett et al. 2016; Vollenbroich et al. 2016; Bender et al. 2017; Eskola et al. 2017), and one paper reported on children with spinal muscular atrophy (SMA) (Lovgren et al. 2016). Three papers did not specify the diagnosis (Sentilhes-Monkham et al. 2003; Reid 2013a, 2013b).

Twelve papers reported on a palliative care programme, model of care or service providing EOL care to children at home (Dangel et al. 2000; Wolff et al. 2010; Arland et al. 2013; Vollenbroich et al. 2012, 2016; Niswander et al. 2014; Maynard & Lynn 2014, 2016a, 2016b; Friedrichsdorf et al. 2015; Bennett et al. 2016; Bender et al. 2017), seven papers reported parental experiences of receiving EOL care at home (Vickers & Carlisle 2000; Hannan & Gibson 2005; Zelcer et al. 2010; Kars et al. 2011; Weidner et al. 2011; Lovgren et al. 2016; Eskola et al. 2017), and four papers examined staff experiences of providing palliative and EOL care at home (Sentilhes-Monkham et al. 2003; Neilson et al. 2010; Reid 2013a, 2013b). Of those papers reviewing an EOL programme or service, on two occasions the same service was reported in more than one paper - three papers reported audit data evaluating a UK service (Maynard & Lynn 2014, 2016a, 2016b) and three papers reported on specialised pediatric palliative home care provided by the Coordination Centre for Pediatric Palliative Care of the Munich University Children's Hospital in Germany (Vollenbroich et al. 2012, 2016; Bender et al. 2017). Therefore, eight distinct services or programmes were included within this scoping review.

Findings

Key findings are presented under the headings of the three main questions posed at the outset of this review:

1. *What models of care or services provide access to home-based care for families who have identified home as the preferred place of death for their child?*

Eight services providing EOL care to children at home were included in this review (Arland et al. 2013; Bender et al. 2017; Bennett et al. 2016; Dangel et al. 2000; Friedrichsdorf et al. 2015; Maynard & Lynn 2014, 2016a, 2016b; Niswander et al. 2014; Vollenbroich et al. 2012, 2016; Wolff et al. 2010). Most papers provided a limited account of how these services were structured and operate to deliver effective EOL care to children at home. Moreover, whilst EOL care was referred to as a feature within each service, it was often provided in addition to wider palliative care across the illness trajectory. Only two papers, one originating from Germany (Wolff et al. 2010) and the other from the USA (Arland et al. 2013), explicitly stated that the service was designed solely to provide home-based care for children at the EOL.

In terms of study design, three papers evaluated services through retrospective review of case notes to identify specific outcomes including number of hospital admissions or place of death (Arland et al. 2013; Bender et al. 2017; Niswander et al. 2014). The remaining nine papers were retrospective service evaluations, four employing mixed methods (Bennett et al. 2016; Maynard & Lynn 2014, 2016a, 2016b) and five undertaking questionnaire surveys of professionals involved with the service or families accessing the service (Dangel et al. 2000; Friedrichsdorf et al. 2015; Vollenbroich et al. 2012, 2016; Wolff et al. 2010).

Thematic content analysis identified five components of home-based EOL care that were reported consistently across the services. These are presented in table 1 together with key characteristics of each service extracted from the papers.

Table 1. Characteristics and components of services providing home-based EOL care for children with LSCs and their families (n=8).

Service	**Authors (year/s of publication)**	**Location of the Service**	**Life-shortening conditions of the children**	**Staff Delivering the Service**	**Service Components (X=present)**				
					Families have 24 hour access to nursing and/or medical input whilst at home	**Service delivered in partnership and collaboration with various agencies/ disciplines**	**Families have access to a link nurse or care coordinator**	**Staff have specialist knowledge and experience in pediatric palliative care**	**Symptom management advice and planning**
1	Arland et al. (2013)	Based out of the Children's Hospital Colorado, USA; EOL service provides care to a large geographical area that includes the surrounding eight states.	Oncology (brain tumours)	Healthcare providers and nurses from the Primary Brain Tumour Team		X	X	X	X
2	Bender et al. (2017); Vollenbroich et al. 2016); Vollenbroich et al. (2012)	Specialised Pediatric Palliative Home Care (SPPHC), Munich, Germany – provide	Oncology, congenital, neurological, and cardiac conditions	SPPHC team – multi-professional including pediatricians, pediatric nurses, social workers	X	X		X	X

		palliative home care in south eastern Bavaria (population of about 4.5 million)							
3	Bennett et al. (2016)	Berkshire, England, UK	Oncology, congenitial, metabolic, neurological, and cardiac conditions	Hospice and community children’s nursing team led service with access to medical and wider multi-disciplinary teams	X	X	X	X	X
4	Dangel et al. (2000)	Warsaw, Poland – covers an area with a population of 3 million	Oncology, neurological, metabolic and cardiac conditions	Hospice home care service delivered by six nurses, three physicians, a psychologist, chaplain and two social workers.	X	X		X	X
5	Friedrichsdorf et al. (2015)	Children’s Hospitals and Clinics of Minnesota, USA. Home care pediatric	Oncology	Pediatric palliative care nurses, chaplains, social workers, physicians (oncology) or oncology	X	X			X

		palliative care service available for families who live within 30 miles from one of the two CHC hospital campuses (Minneapolis or St. Paul's)		advanced practice nurse practitioners.					
6	Maynard & Lynn (2014); Maynard & Lynn (2016a and 2016b)	Four counties covering approximately 5125 square miles within one region in England, UK. Rural area with a total population of 690,000 children and young people up to 19 years.	Range of life-limiting and life-shortening conditions	Nurse-led service consisting of clinical nurse specialists (n=5), nurse consultant (n=1), and hosted by a children's hospice service….	X	X		X	X
7	Niswander et al. (2014)	CompassionNet serves families living in Upstate and Western New York, USA	Oncology, genetic, neurological, and cardiac conditions	Pediatric nurses, pediatric nurse practitioners, pediatrician board-certified in hospice and palliative medicine, child life specialists,		X		X	X

				social workers, chaplain, expressive therapists					
8	Wolff et al. (2010)	St. Hedwig’s Hospital, University of Regensburg, Bavaria, Germany covering a geographic area (60,000 square km) with a population of 2 million.	Oncology, cystic fibrosis, neurological, metabolic, endocrine, gastrointestinal and cardiac conditions	Nurses and physicians		X		X	X

Outcomes frequently reported included prevalence of hospital admissions towards the EOL; frequency in which death occurred in the family's preferred setting; and family satisfaction with the service.

A key finding from Arland et al. (2013), following a retrospective review of medical charts, was fewer hospital admissions in those children who received the EOL care service. Bennett et al. (2016) similarly reported a decrease in unnecessary hospital admissions for those children receiving the service.

Six papers reported on the frequency in which death occurred in the family's preferred place (Arland et al. 2013; Bender et al. 2017; Friedrichsdorf et al. 2015; Maynard & Lynn 2016a, 2016b; Niswander et al. 2014). Of these, five reported that those children who accessed the service had an increased likelihood of dying in their preferred place (Bender et al. 2017; Friedrichsdorf et al. 2015; Maynard & Lynn 2016a, 2016b; Niswander et al. 2014). Arland et al. (2013) was the exception and the authors acknowledged a number of methodological limitations in their study that contributing to this.

Service evaluations reported a high level of satisfaction from families who accessed the services. Families provided positive accounts of the care received (Bennett et al. 2016; Dangel et al. 2000; Friedrichsdorf et al. 2015; Maynard & Lynn 2014, 2016a, 2016b; Vollenbroich et al. 2012, 2016; Wolff et al. 2010) and expressed gratitude for being given a choice of where their child was cared for at the EOL (Wolff et al. 2010).

2. *What are families' experiences of receiving care and support when their child died at home?*

Seven papers (Eskola et al. 2017; Hannan & Gibson 2005; Kars et al. 2011; Vickers & Carlisle 2000; Weidner et al. 2011; Zelcer et al. 2010; Lovgren et al. 2016) reported on parents' experiences of receiving EOL care at home. Of these, three (Eskola et al. 2017; Kars et al. 2011; Vickers & Carlisle 2000) focused exclusively care provided at home whilst four papers (Hannan & Gibson 2005; Weidner et al. 2011; Zelcer et al. 2010; Lovgren et al. 2016) compared parents' perspectives and experiences of receiving EOL care at home or in hospital. Perspectives from other family members, including the child or his/her siblings were absent in these papers. Four themes were identified as outlined in table 2.

Table 2. Themes emerging from parents' experiences of receiving EOL care at home and relevant papers communicating these themes.

Themes	***Papers***
Staying together as a family	Eskola et al. 2017; Hannan & Gibson 2005; Kars et al. 2011; Vickers & Carlisle 2000
Dual roles - parent and caregiver	Eskola et al. 2017; Hannan & Gibson 2005; Kars et al. 2011; Vickers & Carlisle 2000; Weidner et al. 2011; Zelcer et al. 2010
Maintaining control	Eskola et al. 2017; Hannan & Gibson 2005; Vickers & Carlisle 2000; Weidner et al. 2011
Support needed by parents	Eskola et al. 2017; Hannan & Gibson 2005; Weidner et al. 2011; Zelcer et al. 2010

Staying together as a family

Parents described how being at home at the EOL was both their choice and the choice of their child (Hannan & Gibson 2005; Vickers & Carlisle 2000). It was important for parents to have their child at home towards the EOL as it allowed them to be together as a family, and represented a time of normality, as much as could be possible (Eskola et al. 2017; Hannan & Gibson 2005; Kars et al. 2011; Vickers & Carlisle 2000).

Dual role – parent and caregiver

One of the driving factors for parents choosing to have their child die at home was their desire to remain as the primary caregiver for their child up to the very end (Zelcer et al. 2010). The importance of recognising parents as key partners in the wider care team responsible for providing EOL care at home resonates with the pediatric palliative care standards advocated by Together for Short Lives (Together for Short Lives 2012) which maintains families should be central in discussions surrounding their child's care needs. Four papers (Eskola et al. 2017; Vickers & Carlisle 2000; Weidner et al. 2011; Zelcer et al. 2010) described how parents, over time, became increasingly skilled in and adept at administering care, managing symptoms and administering medication to their child. Vickers and Carlisle (2000) reported how parents view this provision of care for their dying child as both their role and responsibility. Zelcer et al. (2010) described how parents' desire to be their child's primary caregiver, thus undertaking all of the clinical and nursing-related activities, sometimes impeded them from being 'just a parent'. Caring for a child at the EOL can lead to challenges in maintaining the fine balance between the role of being the child's parent and being their main care provider (Weidner et al. 2011; Zelcer et al. 2010). However, some parents described this caregiver role as a safety measure to protect themselves emotionally (Kars et al. 2011). Providing EOL care was perceived by some parents as extremely demanding and often resulting in exhaustion (Eskola et al. 2017). Vickers and Carlisle (2000) reported accounts of parents being fearful of 'getting things wrong' and of having sole responsibility for their child's care during out of hours. Inherent difficulties in predicting duration of the EOL phase can result in families unexpectedly delivering care over an extended period, thus leading them towards becoming anxious and working beyond what they are capable of (Hannan & Gibson 2005).

Maintaining control

Control was an important concept represented in the papers (Eskola et al. 2017; Hannan & Gibson 2005; Vickers & Carlisle 2000; Weidner et al. 2011). Parents explained how providing EOL care within their own home helped them to regain some control over their child's care as they were within a safe and familiar setting and surrounded by family and friends (Eskola et al. 2017; Hannan & Gibson 2005; Vickers & Carlisle 2000). Control could be viewed in a variety of ways including the responsibility to make specific decisions related to their child's care (Eskola et al. 2017; Kars et al. 2011), advocating on behalf of their child (Weidner et al. 2011) or having better control over their environment and greater access to privacy when desired (Vickers & Carlisle 2000). Conversely, a lack of control over the course of their child's illness resulted in parents feeling overwhelmed and exhausted (Kars et al. 2011).

Support needed by parents

A number of papers highlighted the services, resources and support required to deliver quality care. In Eskola et al. (2017), parents of 47 children who received EOL care at home between the years 2011 and 2012 participated in an interview to explore their experiences and perceived care needs. Of these, only 35% were supported within their homes by a specialist palliative care team. Those families living at a considerable distance from the hospital where specialist palliative care teams were based, were less likely to access care in the community which highlights inequity in service provision. Parents expressed a requirement for both practical help with domestic and household tasks and a range of psychosocial and support needs. The theme of parents having access to sufficient resources whilst caring for their child at home surfaced frequently. Where professional support was absent, parents relied heavily on help from their network of family and friends (Eskola et al. 2017; Weidner et al. 2011; Zelcer et al. 2010). The evidence also suggests that a lack of community-based palliative care services is a barrier to achieving a home death for their child (Zelcer et al. 2010). Hannan and Gibson (2005) reported a similar requirement for community-based care but went further to suggest that the availability of care 24 hours a day was important to families who described themselves as being dependent on access to 24-hour care to enable their child to remain at home. Moreover, this care should be provided by specialist staff who have expertise in children's palliative care. Families were aware of the challenges and pressures placed on local nursing teams to provide such services and parents were sometimes reluctant to use the service for 'fear of overstretching the staff and losing the service' (Hannan & Gibson 2005, p.288).

3. *What are professionals' experiences of delivering children's EOL care in the home?*

Four papers (Neilson et al. 2010; Reid 2013a, 2013b; Sentilhes-Monkham et al. 2003) explored professionals' experiences of delivering EOL care to children in a home setting with four themes identified as outlined in table 3.

Table 3. Themes emerging from professionals' experiences of delivering children's EOL care at home and relevant papers communicating these themes.

Themes	Papers
Emotional impact	Neilson et al. 2010; Reid 2013a, 2013b
Becoming 'part of the family'	Neilson et al. 2010; Reid 2013a, 2013b
Specialist knowledge, skills and experience	Neilson et al. 2010; Reid 2013a, 2013b, Sentilhes-Monkham et al. 2003
Challenges in ensuring availability of a 24-hour service	Neilson et al. 2010; Reid 2013a, 2013b, Sentilhes-Monkham et al. 2003

Emotional impact

The impact caring for children at the EOL has on professionals was clearly documented in the literature. Three papers (Neilson et al. 2010; Reid 2013a, 2013b) described the emotional impact working in this specialised field can have from the perspective of those delivering care. One paper described community nurses struggle with providing emotional support to families at the expense of looking after their own emotional needs (Reid 2013a). Neilson et al. (2010) highlighted the emotional toll of providing out of hours home care to families whose child was dying from cancer and the importance of protecting their emotional health and well-being.

Becoming 'part of the family'

A further impact on those delivering EOL care at home was a blurring of professional boundaries believed to arise as a result of being in the child's home for extended periods and providing such sensitive and personal care (Neilson et al. 2010; Reid 2013a, 2013b). One paper described how community nurses felt like they were becoming 'part of the family' as they worked closely with and developed trusting relationships with families (Reid 2013a). The impact of close relationships with families was communicated in another paper which described how it frequently led to nurses working above and beyond their remit to support families, particularly if there was limited availability or access to out of hours care provision (Reid 2013a).

Specialist knowledge, skills and experience

The specialist knowledge, skills and experience required by professionals to deliver EOL care at home was reported in four papers (Neilson et al. 2010; Reid 2013a, 2013b, Sentilhes-Monkham et al. 2003). Sentilhes-Monkham et al. (2003) suggested the relative infrequency in which staff care for children at an EOL stage could pose challenges in developing expertise in EOL care. Nurses discussed some of the challenges in developing and maintaining their knowledge and skills, especially when they are faced with very complex and rare symptoms (Neilson et al. 2010; Reid 2013a, 2013b). This can result in low confidence amongst staff and highlights the importance of continual learning and reflection on their practice (Neilson et al. 2010).

Challenges in ensuring availability of a 24-hour service

Professionals' accounts of the difficulties in sustaining a 24-hour service for families choosing EOL care at home was consistently reported (Neilson et al. 2010; Reid 2013a, 2013b, Sentilhes-Monkham et al. 2003). Neilson et al. (2010) highlighted how senior nurses providing an out of hours EOL care service, often in addition to their usual working day and case load, was described as 'draining' and not sustainable in the long term. Similarly, Reid (2013a) described how the absence of formalised services to provide 24 hour EOL care at home resulted in community nurses providing out of hours care to families on a voluntary and goodwill basis, an approach also recognised as unsustainable.

Discussion

Epidemiological data on place of death indicate that hospital remains the most common setting in which children with LSCs die (Pousset et al. 2010; Gomes et al. 2012; Hakanson et al. 2017). This is particularly the case for those less than one year of age and for children with LSCs other than cancer. However, epidemiological data for place of death is not necessarily representative of preferred location of death. Moreover, a limitation of existing place of death data is the fact that it does not account for or explain whether families were given a choice on care settings at the EOL or what palliative care services were available to support death and dying across various settings. Whilst epidemiological data may indicate the proportion of deaths occurring in hospital are higher than in hospices or home, there is growing evidence that families would choose for their child to die at home when offered a choice (Beringer & Heckford 2014; Kassam et al. 2014; Lovgren et al. 2016).

Effective services need to be in place to deliver EOL care in a child's home. Most of the papers included in this review consisted of retrospective service evaluations, providing minimal detail of what each service entailed or how they are delivered in practice, thus making it difficult to inform future service development. There were, however, a number of features which surfaced consistently across the papers and may be of value when planning future models of community based EOL care for children. These involved the inclusion of a link or liaison professional assigned to families with a key role in coordinating care, access to 24 hour care which includes specialist palliative care nurses and additional medical support when required and the importance of partnership working and integrated services. Twenty-four hour access to care is a key component to consider when developing community-based EOL care services as evidence from families synthesised in this review suggests having access to specialist palliative care input from nursing and/or medical staff is essential in allowing them to remain at home towards the EOL. Families rely on the security of knowing that should they require guidance or input on their child's care needs from either the nursing or medical team, at any time of day or night, they have a way of accessing this. However, professionals identify ensuring the provision of 24 hour care to families at home as a challenge to community-based EOL care services (Neilson et al. 2010; Reid 2013a, 2013b, Sentilhes-Monkham et al. 2003). Further robust research that evaluates services from both families' and professionals' perspectives and includes detail on how the service operates to deliver EOL care would be of merit. Additionally, further debate on innovative approaches for addressing the challenges associated with ensuring 24 hour access to care at home for families is a priority.

Those papers exploring the family perspective and experience of home-based EOL care communicate important messages for service development and the enhancement of future care. A central tenet of home-based EOL care must be the provision of specialist psychosocial and emotional support to parents and the wider family. Fraser et al. (2015) reviewed literature surrounding parents' experiences of their child's death. Whilst the papers included in their review focused on death within hospital as opposed to home, the main finding that parents need to continue to remain in the role of a 'parent' to their child during the final stages of life and the psychosocial support that must be in place to enable parents to do this also resonated strongly within this review. The emotional impact that delivering EOL care to children has on professionals was clearly communicated and emphasises the requirement to have appropriate support mechanisms for staff in place.

Limitations of the review

Recognised scoping review methodology was used to map the available evidence on home-based EOL care for children (Arksey & O'Malley 2005; Levac et al. 2010). There were challenges related to terminology with a lack of consistency in defining 'EOL care' and many papers not separating EOL care provision from wider palliative care provided to children at home. Moreover, whilst efforts were made to extract key aspects and components of each service from the papers, if the component was not explicitly mentioned, it could not be extracted and documented within this review. The authors, therefore, cannot be certain that the service did or did not include individual components. For example, the two papers describing services designed solely to provide home-based care for children at the EOL (Arland et al. 2013; Wolff et al. 2010) did not report that families had access 24 hours a day to advice from nurses or medical staff whilst at home. Arland et al. (2013) referred to 'home visits' by medical and nursing personnel but did not provide detail on the frequency or refer to this aspect of the service being available at any time of day or night. This is likely a result of the wide geographical area in which families receiving this service reside.

Our search strategy prioritised sensitivity over specificity and identified a breadth of evidence on children receiving EOL care and dying at home. Whilst we cannot guarantee that papers haven't been missed, we believe a comprehensive approach to locating empirical evidence in this area was undertaken. In accordance with scoping review methodology and given the wide variety of study designs, a quality appraisal of the evidence was not undertaken (Arksey & O'Malley 2005; Levac et al. 2010). It is important to note, however, that the research evidence included in this review was largely descriptive and non-experimental. Many papers were based on retrospective reviews and evaluations.

We recognise the potential for population bias. Similar to Bluebond-Langner et al. (2013), this scoping review revealed a high proportion of papers focusing on home-based EOL care for children with a cancer diagnosis. It is widely reported that children with cancer, with the exception of haematological cancers, have a greater likelihood of dying at home (Bluebond-Langner et al. 2013; Gao et al. 2016; Klopfenstein et al. 2001; Surkan et al. 2006). This could be contributed to the trajectory of some cancers being more predictable in comparison to other LSCs and thus home care programmes being better suited to manage this diagnosis. Moreover, oncology services, including outreach and community services, are better established than those services available for children with other LSCs. Considering this, a greater representation of children with cancer in the literature may over-estimate prevalence of EOL care and death in the home setting and not be comparable to the wider population of children with LSCs.

A key consideration is the limited generalisability of evidence surrounding home-based EOL care for children. The models of care and services included within this review were not described in sufficient depth or detail to allow for meaningful comparisons. Moreover, comparing services between countries which differ significantly in factors such as geography, culture and beliefs surrounding death and palliative care, and health care systems generally, must be approached with caution. For example, the two UK home-based EOL care services included in this review are based in England and therefore may not reflect the provision of EOL care in the other countries making up the UK (Bennett et al. 2016; Maynard & Lynn 2014, 2016a, 2016b) or indeed further afield. It is also important to consider the socio-economic factors which can impact on families' access to home-based palliative care services. Despite this, a number of key features of the services included in this review were comparable regardless of the setting or country in which they were based.

Irrespective of these limitations, this scoping review provides a valuable contribution to the evidence base concerning EOL care in children and provides the basis for future research and service development in this field.

Implications for practice and research

Our mapping and synthesis of the current evidence offers a contribution to policy, practice and future research in the hope that home can be better facilitated as a place of care and support for children and their families at the EOL. Key components of effective home-based end of life care services were highlighted and there is merit in practice providers considering this evidence in the design and delivery of future end of life care.

Further research would be of value to gain a true reflection of children's EOL care in the home setting, particularly research that embraces the unique perspective of children, including the child nearing end of life and his/her siblings. Moreover, research to ensure services are developed to meet unique needs of underrepresented populations and inclusive of culture, religion and spirituality should be a priority.

Conclusion

The evidence clearly affirms a requirement for families to have choice regarding where their child is cared for at EOL and through death. Home is one of the settings which should be offered. In order for this to happen, services must be in place to deliver specialist care and support and these services should be accessible 24/7 as required. There is a lack of evidence on models of care providing children's EOL care at home to inform best practice. However, the evidence available does suggest that access to nursing and medical care 24/7, staff with specialist knowledge and experience in pediatric palliative care, effective symptom management and partnership working with a range of disciplines and services are key elements of any home-based EOL care service.

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Appendix 1. Search strategy used for MEDLINE electronic database.

#	Query	Results
1	(MH "Palliative Care")	49,491
2	(MH "Hospice and Palliative Care Nursing")	430
3	(MH "Terminal Care")	25,875
4	(MH "Terminally Ill") or dying or ("life N3 limiting" or "life N3 threatening")	37,119
5	TI end N3 life OR AB end N3 life	21,797
6	TI "place of death" OR AB "place of death"	1,034
7	S1 OR S2 OR S3 OR S4 OR S5 OR S6	106,122
8	(MH "Home Care Services")	31,614
9	(MH "Home Health Nursing")	214
10	(MH "Home Nursing")	8,391
11	(MH "Home Care Agencies")	1,307
12	(MH "Community Health Nursing")	19,193
13	(MH "Community Health Services")	30,134
14	(MH "After-Hours Care")	1,612
15	(MH "Continuity of Patient Care")	17,661
16	S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15	100,421
17	(MH "Pediatrics") OR (MH "Pediatric Nursing")	62,864
18	(MH "Child")	1,584,569
19	(MH "Infant+") or neonat*	1,205,137
20	(MH "Adolescent")	1,893,071
21	S17 OR S18 OR S19 OR S20	3,377,671
22	S7 AND S16	4,365
23	S21 AND S22	553
24	S21 AND S22 Limiters - Date of Publication: 20000101-20181231	355