Healthcare Staff Experience of Providing End-of-Life Care to Children: A Mixed Method Review

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Abstract

Background: Staff who provide end-of-life care to children not only have to deal with their own sense of loss, but also that of bereaved families. There is a dearth of knowledge on how they cope with these challenges.

Aim: The aim of this review is to explore the experiences of health care professionals who provide end-of-life care to children in order to inform the development of interventions to support them, thereby improving the quality of paediatric care for both children and their families.

Data sources: Searches included CINAHL, MEDLINE, Web of Science, EMBASE, PsychINFO, and The Cochrane Library in June 2015, with no date restrictions. Additional literature was uncovered from searching reference lists of relevant studies, along with contacting experts in the field of paediatric palliative care.

Design: This was a systematic mixed studies review. Study selection, appraisal and data extraction were conducted by two independent researchers. Integrative thematic analysis was used to synthesise the data.

Results: The 16 qualitative, six quantitative, and eight mixed-method studies identified included healthcare professionals in a range of settings. Key themes identified rewards and challenges of providing end-of-life care to children, the impact on staff's personal and professional lives, coping strategies, and key approaches to help support staff in their role.

Conclusions: Education focusing on the unique challenges of providing end-of-life care to children and the importance of self-care, along with timely multidisciplinary debriefing are key strategies for improving healthcare staffs' experiences, and as such the quality of care they provide.

What is already known about the topic?

- One of the leading causes of death among children is chronic conditions requiring end-of-life care
- The death of a young patient has a huge impact on the professional and personal lives of the healthcare professionals involved in their care
- There is a dearth of knowledge on how healthcare professionals cope with the challenges of paediatric palliative care

What this paper adds?

- This review identified staff rewards as well as challenges when providing end-of-life care to children

- A wide range of healthcare staff feared grieving in public

- Finding meaning, closure, and practicing self-care were important strategies for helping staff cope with the death of a young patient

Implications for practice, theory or policy

- This review highlights the need for healthcare organisations to support and care for staff who provide end-of-life care to children, through the provision of ongoing paediatric palliative care education and timely multidisciplinary debriefing

- Effective models of multidisciplinary working and co-ordination of services are important for mitigating the stress experienced by healthcare professionals when providing end-of-life care to children

- The experiences of doctors and support staff providing end-of-life care to children are areas requiring further research, along with experiences encountered within the hospice setting

Introduction

The death of a child is considered unthinkable in Western culture, with the general belief that children will always outlive their parents.[1] However, over 3,000 babies younger than one, and over 2,000 children and young people aged between one and 19 died in the United Kingdom during 2012. One of the leading causes of death were chronic conditions.[2] On a global scale, 160,000 cancer diagnoses were made in children under the age of 15, and caused 90,000 deaths every year.[3] However,

although palliative care and hospice services are well established in adult medicine, paediatric palliative care is a comparatively young discipline.[4]

Although advances have been made in recent years to broaden palliative care to children, the research base and training for paediatric palliative care still falls short in comparison to adult palliative care.[5] Paediatric care is unique because of the need to have parents/guardians involved in caring procedures and decision making, while also taking due cognisance of the child's right to have their views and wishes respected according to their level of development and independence.[6] Paediatric palliative care is defined as 'the active total care of the child's body, mind and spirit'[7]. In common with all forms of palliative care, it focuses on improving 'the quality of life of patients and their families facing … life-threatening illness'.[7]

When a child dies, the effect on the family is overwhelming.[8] Likewise, for those healthcare professionals who provide end-of-life care to children, the death of a young patient has a huge impact on their professional and personal lives.[9-11] Mental health risks in relation to professionals who work in stressful situations has been recognised for quite some time.[12] Professionals who provide palliative care are at high risk for a number of reasons. Prolonged exposure to death may intensify unresolved losses and produce grief responses or underlying depression, which can have a negative impact on personal relationships with friends, partners and family members.[13]

The extant literature reinforces the proposition that supporting health care professionals in the palliative setting improves patient care.[14,15] However, while national and international policy and guidance acknowledge the key role of children's nursing services for providing palliative care, there is little recognition of the impact such care has on the nurses and other healthcare professionals involved.[16] The main aim of this review was to systematically explore the experiences of health care professionals who provide end-of-life care to children, the impact this has on health care professionals, and how they cope, in order to draw recommendations for interventions to support them, thereby improving the quality of paediatric care for both children and their families.

Main research questions

- What are the experiences of healthcare professionals who provide end-of-life care to children?

- How do these experiences impact on the professional and personal lives of healthcare professionals?

- How do healthcare professionals cope with the impact/challenges of providing end-of-life care to children?

- On the basis of the answers to the above questions, what interventions have the potential to support healthcare professionals who provide end-of-life care to children?

Methods

This was a systematic mixed studies review[17] following an integrated design[18] to combine and synthesise quantitative, qualitative and mixed method study's findings. Qualitative research is often portrayed as useful for elucidating new understanding of a phenomenon, while quantitative approaches are often depicted as more useful for elucidating what works. However, combining the two approaches increases the potential for identifying unexpected outcomes (Bryman, 2006).[19] We chose to include quantitative and mixed-method research as we were looking not only at staff experience but also the impact of those experiences, in order to provide a more comprehensive understanding of health care professionals experience. The review recommendations outlined in the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) statement were followed for this review.[20]

Identification of relevant literature

Six electronic databases, including CINAHL, MEDLINE, Web of Science, EMBASE, PsychINFO, and The Cochrane Library were searched in June 2015, with no date restrictions outside those of the databases. Searches used mesh terms when applicable and free text words, modified as appropriate for all databases. To ensure rigour, an information scientist in Queen's University Belfast helped develop the search strategy. References were managed using Refworks. Additional literature was uncovered from searching reference lists of relevant studies retrieved from electronic searches, along with contacting experts in the field of paediatric palliative care. Table 1 presents the search method for Medline.

Table 1. Medline search strategy

1	health personnel/ or allied health personnel/ or medical staff/ or nurses/ or nursing staff/ or personnel, hospital/ or physicians/ or volunteers/

2	child.mp. or Child/ or Pediatrics
3	terminal care/ or hospice care/ or Palliative Care/ or degenerative illness.mp.
4	experienc*.mp. or perspective.mp. or "Attitude of Health Personnel"/ or Attitude/ or Attitude to Death/ or attitude.mp.
5	Stress.mp. or coping behaviour.mp. or Anxiety/ or depression/ or stress, psychological/ or Burnout, Professional/ or compassion fatigue.mp.
6	1 and 2 and 3 and 4 and 5

Study criteria were established prior to searching the literature and were guided by the aims of the review. Peer-reviewed primary research studies, in English, using quantitative, qualitative or mixed method approaches were included. In order to make the review applicable to a broad, multiprofessional audience, we included different professional groups with differing levels of experience. This decision was also based on the increasing recognition of the value and need for multidisciplinary teams when delivering paediatric palliative care, rather than any one professional group in isolation.[21] Studies were included if they considered the experience of health care professionals (specialist or non-specialist), including clinical, administrative and support staff, in any setting that delivered end-of-life care to children. Studies that included both patient and professional perspectives were only included if professionals' views were presented independently. Studies were included if the findings clearly focused on staff experiences of providing end-of-life care to children. We excluded studies that did not provide any relevant findings on staff experience, such as staffs' perceptions of quality end-of-life care, and end-of-life care educational programmes. Figure 1 describes the process of identifying and selecting studies as suggested by Moher et al.[20] Searching electronic databases yielded a total of 1061 articles, with a further 25 articles identified from hand searching references. After removal of duplicates, this left a total of 964 articles. Title

and abstracts were screened using the eligibility criteria to ensure only those studies

meeting the aim of the review were included. This left 55 studies which were

assessed in full. Of these, 25 were rejected for not meeting the eligibility criteria,

leaving a total of 30 studies included in the review.

Figure 1. PRISMA flow diagram
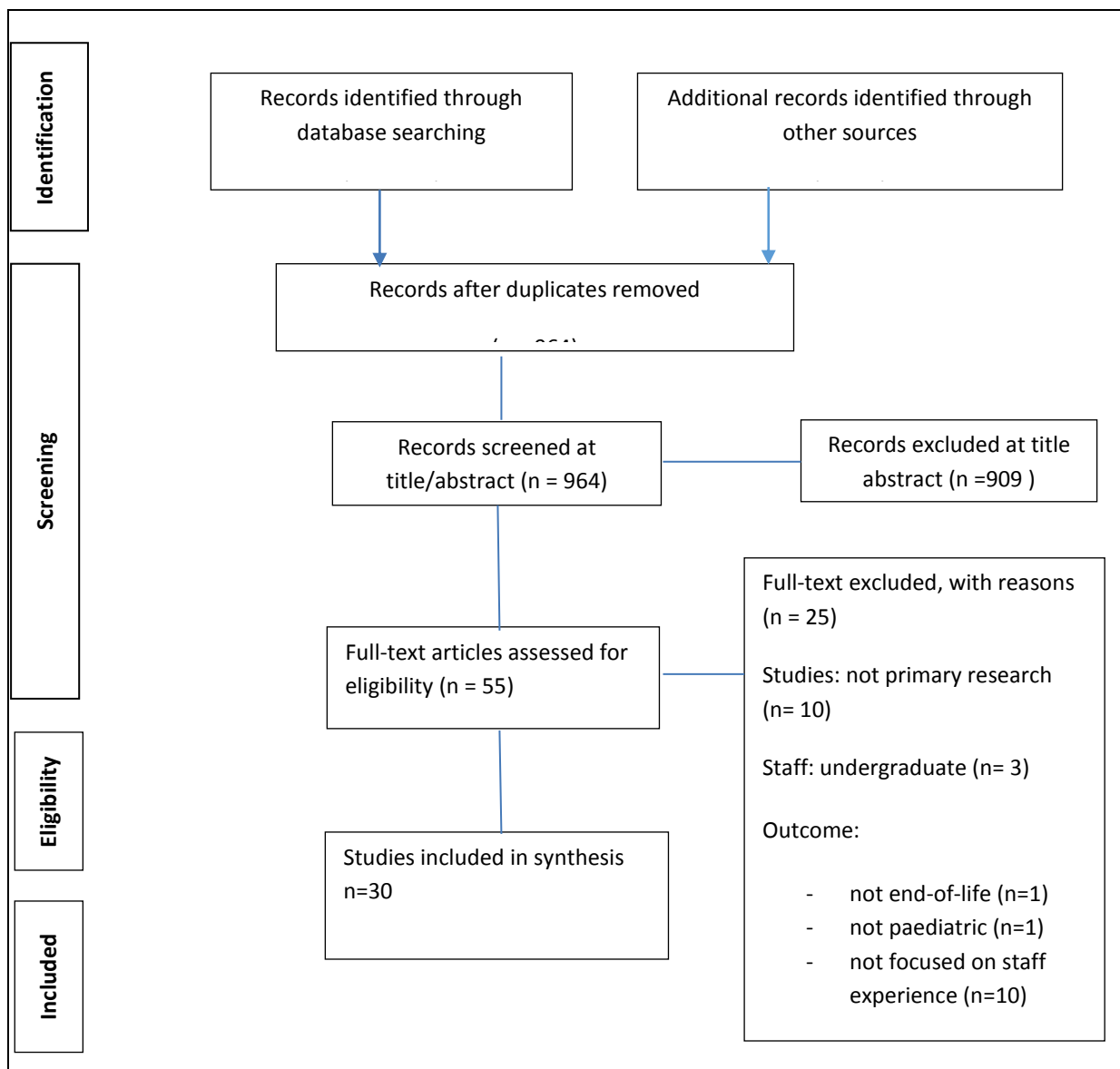
Appraisal and data extraction.

Each individual study was assessed for quality by two review authors using the Mixed Method Appraisal Tool (MMAT);[22] a universally utilised, validated tool for mixed-method systematic reviews.[23] Methodological quality was assessed using the relevant criterion for each method of investigation. Each included study was assigned a score based on the number of criterion met, along with a brief rationale for lower scores (see Table 2).

We used a previously piloted data extraction form to extract data on study aims, setting, participants, method and relevant findings. All stages of study selection, appraisal and data extraction were conducted by two independent researchers. Any discrepancies were discussed among the research team until consensus was achieved.

Data synthesis.

Data were analysed and synthesised using a systematic mixed studies review and integrative design.[18,24] This approach enabled the grouping of data into findings focused on the same phenomenon rather than according to method.[18] Descriptive thematic analysis was used to synthesise and analyse extracted data, following the stages set out by Whittemore and Knafl[24] which included data reduction, data display, data comparison, conclusion and verification. Data reduction involved the extraction of data into a data extraction form, and data display involved summarising data in relation to staffs' perspectives (Table 2).

Table 2. Summary of included studies

Author, Year, Country	Aims	Participants	Setting	Method	Summary of relevant findings	Appraisal scores
Bartholdson et al [6] 2015 Sweden	To describe healthcare professionals' experience of ethical issues and ways to deal with these when caring for children with cancer	Healthcare professionals. Physicians: 15 Nurses: 34 Nurse aides: 38 Total: 87	Paediatric oncology unit and inpatient units for children with chronic diseases and for neurological diseases of a children's hospital	Qualitative using study-specific questionnaires	Staff found the following issues challenging: infringing on children's autonomy regarding painful procedures, deciding on treatment levels, withholding the truth from children when treatment futile	Researcher reflexivity not addressed QUAL 5/6
Beckstrand et al [25] 2010 USA	To determine paediatric intensive care unit nurses' perceptions of sizes, frequencies, and magnitudes of selected obstacles and helpful behaviors in providing end-of-life care to children	Paediatric intensive care unit nurses. Total: 474	Paediatric intensive care units	Quantitative descriptive survey using The National Survey of Paediatric Nurses' Perceptions of End-of-Life Care questionnaire	Language barriers and parental discomfort with withdrawing mechanical ventilation were the highest rated obstacles in providing end-of-life care to children.	Response rate was low QUAN DES 5/6
Bergstraesser et al [26] 2013 Switzerland	To describe the perceptions and needs of paediatric health care professionals taking care of children with palliative care needs and to	Health care professionals. Physicians: 30 Nurses: 24 Therapists including psychologists, social workers, and physiotherapists:	Children's hospitals	Qualitative using interviews	Key themes included communication with parents and the child, the process of decision making, their need for support and supervision, the role of paediatric palliative care teams, and the opportunity to receive support following the death of a child	Researcher reflexivity and context not addressed QUAL 4/6

	develop a concept for the first Center of Competence for Paediatric Palliative Care in Switzerland	22

Total: 76 | | | | |
| Bloomer et al [27]
2014
Australia | To determine the prevalence of death anxiety in Paediatric or neonatal intensive care nurses and identify associated demographic factors | Paediatric or neonatal intensive care nurses:

Neonatal intensive care: 141
Paediatric intensive care units: 134

Total: 275 | Two metropolitan tertiary hospitals | Quantitative cross-sectional survey using a 14-item modified Templer Death Anxiety Scale | Death anxiety decreased with increasing age, and was lower for those with postgraduate education. The only modifiable factor was education and the authors concluded that further investigation into its potential as a protective factor is required | QUAN DES 6/6 |
| Clarke and Quin [28]
2007
Ireland | To present findings of professional carers' experience of providing paediatric palliative care to children with life-limiting conditions | Professional carers

Paediatricians:35
Clinical nurse managers: 28
Clinical nurse specialists: 70
Medical social workers: 17
Palliative care teams/groups: 25

Total: 174 | Hospitals caring for children with palliative care needs and community-based agencies | Qualitative focus groups using open-ended questions | Three key themes emerged including clarity of definition and complexity of engagement in relation to the primary diagnosis; anticipating and recognising the imminence of death; and parental acceptance | Researcher reflexivity and context not addressed

QUAL 4/6 |
| Contro et al [29]
2004
USA | To develop a paediatric palliative care program based | Staff members.

Attending physicians: 110 | Children's hospital | Mixed-method cross-sectional survey using a likert-scale and one open-ended question | Staff members reported feeling inexperienced in communicating with patients and families about end-of-life issues, transition to palliative care, and do | Methods lacked methodological transparency |

	on a needs assessment of hospital staff and family members regarding improving paediatric palliative care	Residents: 48 Nurses: 191 Social workers: 17 Psychosocial support staff members: 21 Ancillary support staff members: 42 Other: 17 Total: 446			not resuscitate status. Staff also reported feeling inexperienced in symptom and pain management and described occasions when pain could have been better managed. 54 per cent of staff reported that adequate support was not provided for those who treat dying children and stated their desire for more support. Those who described their most difficult experiences caring for a dying child referenced personal pain and inadequate support most frequently	MIXED 6/13
Cook et al [30] 2012 USA	To describe and understand behaviour and coping strategies used by paediatric nurses caring for dying children	Nurses: 22 Staff nurses: 17 Nurse practitioners: 5 Total: 44	Inpatient acute care cardiology unit at a children's academic tertiary-care centre	Qualitative focus groups using semi-structured questions	Key themes included difficulties around professional boundaries, memories as both comforting and distressing, disconnecting in relation to distancing one's self, and labelling in relation to using words or phrases to describe a nursing experience to protect others	QUAL 6/6
Fanos [31] 2007 USA	To identify paediatricians' early experiences with illness and death during their childhood and adolescent years, and identify coping strategies to manage the stress of caring for children who are seriously ill	Paediatric oncologists: 30	24 were in university and community hospital settings, 6 no longer worked as a paediatric subspecialist, 2 were general paediatricians in private practice, 2 were general paediatricians in community hospitals, 1 worked for a	Mixed method study. Semi-structured interviews with topic guide and anxiety and depression scales to explore the relationship between anxiety/depression and gender, marital status, having children or not, and still practicing paediatric oncology or not	Key themes included diagnosis/relapse with the majority finding relapse difficult as it signalled the terminal phase; stress on family life; repetitive dreams in relation to anxieties over illness and death; existential beliefs in relation to feeling angry at the unfairness of life; support from their patient in relation to reassuring the practitioner; maintaining distance and a 'strong' façade in relation to hiding their emotions from colleagues and distancing themselves from patients in order to protect themselves; and the importance of training in communicating about death and dying	No rationale for mixed method design. Scales used had no clear relevance to aim of study. Quantitative methods lacked methodological transparency MIXED 7/13

		pharmaceutical company, and 1 was worked at a blood bank				
Feudtner et al[32] 2007 USA	To test the hypothesis that individual nurses' level of hope is associated with greater self-reported comfort and competence in providing palliative care	Paediatric nurses working in a wide variety of clinical units throughout the hospital Total: 410	Large tertiary care children's hospital in Philadelphia	Web-based quantitative cross-sectional survey using questions adapted from published studies or written for this study regarding nurses' knowledge, attitudes, practices, and experiences regarding various aspects of palliative care.	Nurses reported feeling most competent in relation to pain management, and less competent in relation to talking about dying with children and families. Higher numbers of years in nursing practice, and more hours of palliative care education, were individually associated with higher levels of comfort working with dying children and their families, and a higher total palliative care competency score. The most significant finding was the large association between hours of palliative care education and personal comfort providing palliative care, reduced difficulty talking about dying or death, and self-reported competence	Sample not representative and low response rate QUAN DES 4/6
Furingsten et al[33] 2015 Sweden	To describe healthcare workers' experiences of caring for dying children	Nurses: 4 Registered nurses: 2 Paediatric nurse assistants: 2 Total: 8	Acute paediatric ward	Qualitative phenomenological approach using in-depth interviews	Being there for the child and family was reported as important but also the importance of boundaries. Self-knowledge was important in terms of recognising one's own needs, strengths and limitations. Staff also reported feelings of injustice over the death of a child and the importance of support from others when struggling with emotional pain and injustice	Context and researcher reflexivity not addressed QUAL 4/6
Kain [34] 2013 Australia	To explore the grief reactions of neonatal nurses caring for dying babies	Neonatal nurses with at least 2 years clinical experience in the neonatal intensive care environment	Tertiary level hospitals	Qualitative focus groups using semi-structured interview guides	Key themes included the need for the loss to be acknowledged by their peers and management, difficulties maintaining professional boundaries, and the need for debriefing sessions after difficult cases along with training in effective grief management skills and coping mechanisms	Context and researcher reflexivity not addressed QUAL 4/6

		Total: 24				
Kaplan [35] 2000 USA	To understand the emotional reactions of nurses who work with dying children	Haematology/oncology nurses: 14 Intensive care unit nurse caring for children with various medical conditions: 1 Total: 15	Inpatient hospitals, outpatient clinics, private practice offices, and hospice organisations	Qualitative using structured interviews	When caregivers recognise the need to grieve and express their feelings while acknowledging that this is a natural, normal, and appropriate manner in which to respond to the death of a child, they then become better able to take care of themselves, and thus their patients	Context and researcher reflexivity not addressed QUAL 4/6
Kaunonen et al[36] 2000 Finland	To describe how staff members experience the death of a child and how they support the grieving family	Staff including midwifes, nurses, orderlies and physicians Total: 69	Prenatal ward, paediatric ward, maternity ward, maternity outpatient ward, and delivery ward of a university hospital	Mixed method study using questionnaires with both structured and open-ended questions	Staff reported feelings of grief, injustice; limited resources and sometimes relief. Approximately half felt they were well able to support grieving families, with education in supporting the grieving family increasing their ability to support them. The majority of staff expected support from their colleagues after the death of a child and need support themselves in order to support the grieving family	No rationale for mixed method design. Questionnaire no clear origin and no reference to validity/standardisation. MIXED 8/13
Klassen et al [37] 2012 Canada	To describe the key work-related demands and rewards in relation to working closely with parents from the perspective of health care providers	Health care professionals. Doctors: 13 Nurses: 9 Social workers: 5 Child life specialists: 6 Total: 27	Paediatric oncology centres	Qualitative using semi-structured interviews	Health care professionals found the establishment of close or long-term relationships with parents rewarding, although they found it challenging to work with complex families; demanding, rude or angry parents; parents with differing views about treatment and palliative care; and having to communicate bad news	Researcher reflexivity not addressed QUAL 5/6
Korzeniewska-Eksterowicz et	To evaluate job satisfaction	Health professionals	Home hospice service in Poland	Quantitative descriptive study using a	The mean level of job satisfaction was rated as good. The highest level of job satisfaction	Questionnaire not validated or

al [38] 2010 Poland	among health professionals of home hospice	including paediatricians, nurses, social workers, physiotherapist and psychologist Total: 12		questionnaire designed specifically for the study and divided into six domains; evaluation of self-abilities, evaluation of job responsibility, relationships with the team, relationships with patients and their families, work organisation and social conditions, and general work evaluation	was for relationships with patients and their families. The lowest level of satisfaction was for relationships with the team and the general work evaluation. The authors concluded that improving job satisfaction may contribute to improving the quality of home palliative care	standardised QUAN DES 5/6
MacConnell et al [39] 2012 Canada	To describe the experiences of nurses who provided bereavement follow-up with families after the death of a child or a pregnancy loss	Registered nurses: 8	Tertiary maternal child health centre caring for a paediatric population from 0-16 years with a broad spectrum of illnesses, and women with both normal and high risk pregnancies	Feminist poststructuralism	Highlights the importance of relationships, self-care and closure, professional boundaries, and the invisible nature of bereavement follow-up and institutional support	QUAL 6/6
Macpherson [40] 2008 USA	To examine peer-supported storytelling for grieving paediatric oncology nurses	Registered nurses: 6	Tertiary care paediatric hospital inpatient oncology unit	Mixed method single-group descriptive repeated measures design using questionnaires	Nurses reported receiving and providing support during sessions; sessions had an impact on their meaning-making; and of particular help was the explicit session focus on making sense of and identifying benefit in their experience	Context and researcher reflexivity not addressed. Sample not representative and low response rate. MIXED 9/13
Maytum et al[41]	To identify the	Experienced	A variety of	Qualitative descriptive	Findings indicated that compassion fatigue	QUAL 6/6

2004 USA	triggers and coping strategies that nurses who work with children with chronic conditions use to manage compassion fatigue and prevent burnout.	nurses who work with children with chronic conditions. Care coordinators: 7 Case managers: 4 Staff nurses:6 Clinic nurse::1 Manager: 1 Nurse practitioner: 1 Total: 20	health care settings, including inpatient tertiary care, outpatient care, community health, home care, and hospice care.	study using an interview guide consisting of 11 open-ended questions relating to compassion fatigue and burnout	is commonly and episodically experienced by nurses working with children with chronic conditions and their families. Participants reported that insight and experience helped them develop short- and long-term coping strategies to minimize and manage compassion fatigue episodes and prevent burnout.	
McCloskey et al[11] 2010 Northern Ireland	To explore the experience of occupational stress in nurses providing children's palliative care	Children's palliative care nurses. Nine hospice nurses, seven community children's nurses, two hospital nurse specialists working in the children's hospital Total: 18	Children's hospice, community and children's hospital	Qualitative using focus groups	Four key themes included work demands in relation to the emotional load, ethical conflicts, constraints to the delivery of good care, limited resources, the pressures associated with administration, and for community children's nurses the stress associated with living and working in the same community; lack of opportunity to develop relationships in the context of late referrals; managerial support and ambiguity in defining the role of community children's nurses. The key consequences of stress reported included compromised family relationships, sleep disturbance, irritability, and having to take sick leave	Researcher reflexivity not addressed QUAL 5/6
Meadors et al[42] 2008 USA	To describe the scope of compassion fatigue in health care providers	Health care providers. Nurses: 115 Child life specialists: 14	Children's hospital	Quantitative pre-post test using questionnaires	Those in the low-stress group exhibited higher positive behaviors such as meditation, massages, regular exercise, setting limits at work, and rituals for dealing with a loss.	QUAN DES 6/6

		Nurse practitioners: 8 Social workers: 2 Nurse managers: 2 Secretaries: 9 Other: 33 (chaplain, care partner etc.) 2 had missing data Total: 185				
Neilson et al [43] 2011 UK	To explore the experiences of primary care practitioners following their involvement in the palliative care of a child with cancer at home	Primary care professionals. GPs: 10 Community nurses: 37 Total: 47	Community setting	Qualitative using in-depth interviews	One key finding was the emotional toll on GPs providing palliative care. Visual changes to the child caused distress and carrying the families sadness during the working day was reported in interviews	QUAL 6/6
Papadatou et al [9] 2001 Greece and Hong Kong	To explore the subjective experiences of oncology and critical care nurses who provide care to dying children	16 oncology nurses and 23 critical care nurses in Greek sample, and 12 Paediatric nurses and 12 paediatric critical care or neonatal critical care nurses in Hong Kong sample Total: 63	General hospitals in Greece and Hong Kong	Mixed method using semi structured interviews and quantitative analysis comparing nurses experience in oncology versus critical care units and Greek versus Chinese cultures.	Most nurses experience a sense of helplessness and difficulties in communicating with the child and parents during the terminal phase. A large majority acknowledged that the impending or actual death of a patient elicits a grieving process. However, despite this suffering, nurses reported significant rewards from caring for chronically and acutely ill children, and the majority are satisfied with their jobs despite the shortage of personnel and cooperation problems with physicians	Researcher reflexivity not addressed. Low response rate and can't tell if considered limitations of integrating mixed data. MIXED 10/13
Papadatou et al [44] 2002 Greece	To explore and compare the grief responses and experiences of	Oncologists: 14 Paediatric oncology nurses: 16	Paediatric oncology units within a paediatric	Mixed methods using semi-structured interviews	Professionals do grieve over the death of a child. Both doctors and nurses experienced stress, feelings of helplessness and grief when providing end-of-life care to children.	Researcher reflexivity not addressed and can't tell if

	Greek physicians and nurses who provide care to children dying from cancer	Total: 30	hospital		However, they did experience significant satisfaction from providing a dignified death. Both groups of professionals experienced fluctuation between experiencing and avoiding grief. Differences between groups related to how they expressed this grief. For physicians grief was a more private process, and support from colleagues was rarely sought. For nurses grief was a more social process with support from colleagues. Physicians grieved over loss of their unmet professional goals whereas nurses grieved over the loss of special relationships with the children and families.	considered limitations of integrating mixed data. MIXED 11/13
Pearson [45] 2013 UK	To understand children's cancer nurses experiences of providing palliative care in the acute hospital setting	Children's cancer nurses Total: 7	Acute hospital setting	Qualitative using semi-structured in-depth interviews	Five key themes included ''lack of a plan'', ''managing the symptoms'', 'family'', and ''experience''. The findings of this suggest nurses need specific palliative care education not only at pre-registration level but also continuing professional development	QUAL 6/6
Plante et al [21] 2011 Canada	To assess emotional reactions, coping strategies ad perceived needs of paediatric health care professionals	Health care professionals. Nurses: 46 Paediatric physicians: 22 Paediatric residents: 11 Respiratory therapists: 13 Other: 9 Total: 101	General hospital	Quantitative cross-sectional study using questionnaires	The level of grief experienced by health care professionals after a memorable death were intense. Respiratory therapists showed the highest level of grief and younger staff experienced higher levels of grief than older staff. In terms of coping strategies, 70% spoke with colleagues after the death of a child, 48% with their family and friends. 37% felt this social support was the most helpful.	QUAN DES 6/6

Price et al [46] 2013 UK	To investigate health and social care professionals' perspectives on developing services for children with life limiting conditions at the end-of-life using issues identified by bereaved parents as priorities	Health and social care professionals with over 2 years experience of working in diverse aspects of children's palliative care Total: 35	A regional children's cancer unit and a children's hospice in the UK	Qualitative focus groups using nominal group technique	Six key issues included truth telling in relation to the complexities of communicating with children, including siblings, about death; symptom management; communication with, and relationships between families and professionals; emotional impact; and the withdrawal of feeding or treatment and sibling support	QUAL 6/6
Quinn et al [47] 2011 Ireland	To obtain a picture of the current nursing service to determine if the needs of children requiring care at home owing to life-limiting illness are being met	Community palliative care clinical nurse specialists who had experience in caring for children with palliative care needs during the previous 2 years of the study Total: 7	One community health region in Ireland	Qualitative focus group using an interview schedule piloted on senior palliative care nurses who had cared for children with palliative care needs	Key themes included difficulties accessing the patient due to parental anticipatory grief, prognostic uncertainty, and a general lack of awareness of the philosophy of paediatric palliative care; the complexities of the role in terms of physical, psychological and spiritual components; the pressures of caring in relation to ability, feelings and organisational issues; and personal and professional support strategies	QUAL 6/6
Reid [48] 2013 UK	To highlight challenges perceived by rural adult community nurses delivering palliative care to a child or young person and their	District nurses and four adult community palliative care clinical nurse specialists Total: 6	Rural community settings in Scotland	Qualitative phenomenological using semi-structured interviews	Key challenges included feeling underprepared to deal with the emotional impact of a child's death, inadequate discharge planning which resulted in late introductions to the families, the challenge of maintaining professional boundaries when closely involved with families and challenges of providing skilled and sensitive	Researcher reflexivity not addressed. QUAL 5/6

	families at home				communication, and the challenge of scarce resources in rural areas	
Swinney et al[5] 2007 USA	To examine the effect of involvement in end-of-life paediatric care on support staff	Support staff involving Patient Care Service Aids, Outpatient Clinic Representatives, Financial Consultants, Unit Assistants, Volunteers, Patient Liaison, Office Support Technician, Receptionists, and Child Life Assistants Total: 65	Department of hematology/oncology at Children's Hospital Los Angeles	Cross-sectional mixed-method survey developed from a prior study evaluating beliefs, workplace experiences, and attitudes of health care staff at the Children's Hospital Los Angeles	Findings suggested that support staff develop numerous, substantial, direct interactions with dying children and their families. They also suggested that these experiences had caused some adverse outcomes in their lives in relation to depression, irritability, family arguments, job performance, sex life and concern over substance abuse. A large majority felt that they did not have sufficient knowledge or training in palliative care. The authors concluded that support staff play a key role in the palliative care team and as such research and resources should be directed to educating, training, and supporting them	While this study claims to be mixed method, no qualitative element is described MIXED 6/13
Woolley et al[12] 1989 UK	To examine the degree of stress experienced by staff caring for children and their families, which factors staff found stressful, which helped them manage difficult circumstances, and degree of, and factors associated with job satisfaction	Hospice staff. Qualified nurses: 12 Teaching, physiotherapy or social work qualifications: 5 No formal qualification: 6 GP: 1 Total: 24	Hospice setting	Mixed method study using interviews and Goldberg's general health questionnaire	Overall job satisfaction was high. The main sources of stress included feelings of helplessness when unable to relieve perceived needs or distress, dealing with negative responses from families, and conflicts among staff. The most important moderating factors included informal staff support, homelike atmosphere of the hospice, and the variety of professional and personal skills among staff.	Context and researcher reflexivity not addressed. Analysis and triangulation of qualitative data not discussed. MIXED 9/13

Data comparison involved coding and condensing data relating to staff experience, impact of, and how they cope with providing end-of-life care to children, which were grouped according to patterns and themes. Data were also evaluated for contrasting outcomes or views within groups of data. The conclusion and verification stage involved identifying themes and sub-themes which were then described according to their relationships. Experiences were verified throughout the analysis stage by crosschecking primary sources in order to enhance credibility and reliability of the review findings.

Results

Characteristics of included studies

Thirty papers were included with publication dates ranging from 1989 to 2015. Studies were predominantly qualitative (n=18),[6,11,26,28,30,31-35,37,39,41,43,45-48] with a smaller number of quantitative (n=6)[21,25,27,32,38,42] and mixed-method studies (n=8).[5,9,12,29,31,37,40,44] Five quantitative studies were cross-sectional, and one used a pre-post survey design. The majority of studies were conducted in the USA (10)[5,25,29-32,35,40-42] with the remaining 21 studies carried out in the United Kingdom (6),[11,12,43,45,47,48] Canada (3),[21,37,39] Australia (2),[27,34] Poland (1),[38] Greece (1),[44] Greece and Hong Kong (1),[9] Sweden (2),[6,33] Ireland (2),[28,47] Finland (1),[36] and Switzerland (1).[26] The majority of studies considered nursing staff only (15),[9,11,25,27,30,32-35,39-41,45,47,48] while others considered a wide range of health care providers collectively such as nurses, physicians, social workers, physiotherapists, psychologists and support staff (13),[6,12,26,28,29,36-38,42-44,46] one included physicians only,[31] and one support staff only.[5] The majority of studies were conducted in a

hospital setting (22).[5,6,9,21,25-37,39,40,42,44,45] The remaining studies were conducted

across a range of settings such as hospital, hospice and community (3),[11,23,41]

community only (4)[38,43,47,48] or hospice only (1).[12] A summary of the aims, sample,

setting, design and relevant findings from included studies are presented in Table 2.

Review findings

The first theme 'Staff experiences' highlighted the key experiences and challenges

faced by a range of healthcare staff in a range of healthcare settings.

Staff experiences

    Rewards. Despite the stress experienced, staff reported a number of rewards.

The deep relationships that staff developed with children and their families were

viewed as a major source of both personal and professional satisfaction,[38,37,40,11,23,48]

and 'made the pain worth it'.[40] Staff also reported feeling enriched from their

work,[30,48] and felt they gained a new perspective on life in relation to what was most

important and meaningful.[35] However, some sources of job satisfaction differed

between doctors and nurses. For doctors, this related to controlling pain and

providing efficient medical care to alleviate a child's suffering, whereas for nurses

psychosocial care and support for both dying children and their families was as

important as providing physical care to the child.[21]

    Professional boundaries. The difficulty of maintaining professional boundaries

was intricately linked to the length and intensity of relationships developed when

providing end-of-life care to children. Staff defined this challenge as 'walking the

professional and personal line between family members and staff'.[30] This challenge

appeared to be more pertinent to nurses, perhaps due to their more involved role with children and families. Nurses were acutely aware of the risk of becoming excessively or inappropriately involved with children and their families, and reported being viewed as a friend,[46] or pseudo-member of the family[48] rather than a professional care giver. Although nurses reported being taught the importance of professional boundaries in relation to not becoming overly 'personal' with patients, they felt it was difficult to follow these professional policies and feared being seen as unprofessional.[39] Many nurses felt the need for professional boundaries contradicted the fostering of a therapeutic relationship[34] and viewed it as a barrier to providing care and empathy to children and their families.[30] However, some nurses felt it was important to avoid over involvement in order to cope and be able to take care of the other children in their care.[34]

Work environment. The work environment had a significant impact on staff providing end-of-life care to children. For example, workload and inadequate co-ordination and communication between services presented additional challenges. Demanding caseloads, often due to staff shortages [9,26,41,44] meant staff did not have time to grieve or recover from experiencing a child's death before they had to continue taking care of other children under their care, causing frustration and discontent[29,33,35] Not having time to meet a child's needs beyond their clinical care[11] in relation to interacting with the child, or taking time to just be with parents[41] caused additional stress as staff felt this prevented optimal care.[11] Further frustrations and feelings of guilt were reported in relation to not being able to provide follow-up bereavement support to families.[29,39,9,21,47]

The hospital setting offered unique challenges for staff in relation to the culture of cure. Doctors struggled most when a child relapsed as this signalled the terminal

phase.[31] Doctors highlighted the perception among newly qualified doctors that they 'can cure everybody', and their sense of disbelief when they realised they couldn't.[31]

Length and depth of experience. There appeared to be differences between healthcare professionals who dealt with end-of-life care on a more regular basis than those who were less familiar with this aspect of care. One study in a children's hospital found that more experienced nurses and who had a higher level of palliative care education were more comfortable providing end-of-life care to children and their families.[32] In contrast, nurses in community settings with less experience and education in relation to providing end-of-life care to children struggled with this role on both an emotional and professional level.[47,48]

Challenges specific to community healthcare professionals included discharge planning, which they felt did not exist, was ill-planned, or happened too late, and as a consequence prevented the development of trust between staff and families.[48] Furthermore, the vast number of agencies involved with the child's care resulted in confusion surrounding roles, boundaries and responsibilities.[48] Additional challenges included living and working in the same community which meant they were seen as a nurse at all times,[11,48] and restricted support, with colleagues often living long distances away.[48] The wide geographical area that had to be covered by small community teams also meant nurses felt unable to provide the level of support they would have liked to.[48]

The hospice setting appeared to provide the most optimal work environment, with staff referring to its homelike qualities, lack of a rigid hierarchy and red tape, and time to spend with families so they could respond to individual children's needs.[12] Although communication between colleagues was evaluated as good by hospice

staff in one study,[38] communication difficulties between colleagues, management and multi-disciplinary teams were referred to as a major source of stress in other studies within the hospital, community and hospice setting.[9,6,12,38,44] This often led to lower job satisfaction,[38] and discontinuity of care.[25] The current system also presented challenges for hospice staff who felt referrals happened too late, mostly due to inadequate cross-sector understanding of availability and content of hospice care, and ineffective multi-disciplinary working.[46] Those working in the voluntary sector were frustrated by the lack of government funding to assist them in providing services to children at the end of life and their families.[28]

Most challenging experiences. There were a number of experiences that appeared to be especially challenging when providing end-of-life care to children.

End-of-life decision making. Both hospice and hospital staff reported end-of-life decision making and symptom management as extremely stressful.[6,11,46] Deciding when end-of-life was near was referred to as an 'invisible point in time when transition from curative to end-of-life treatment occurs'.[6] This was exacerbated by parental distress in relation to withdrawing treatment.[11,33,37,45,46] Nurses reported experiencing extreme moral distress and anxiety when families insisted on continuing interventions that they recognised were not in the best interests of the child.[11,45,46]

Keeping silent. An additional stressor related to parents' efforts to shield their child from the truth about their impending death. This raised ethical concerns in relation to withholding information from children about their condition, thereby limiting the opportunities they had to give their views on care matters.[6] Staff reported

experiencing guilt 'just that feeling that I knew more than I had told them. It hurt knowing more about the child's condition than could be revealed'.[33]

Communication with families. A range of staff, including doctors, nurses, social workers, psychologists, and physiotherapists all reported feeing anxious when talking with parents about death or using the word 'dying'.[26] Both doctors and nurses reported feeling at a loss for words,[9,44,45] and as a consequence often avoided talking to parents.[9] Children's cancer nurses working in an acute hospital setting rated communication with parents as the highest perceived obstacle when providing end-of-life care to children.[45]

Impact on personal/professional life. Staffs' experience of providing end-of-life care to children impacted on both their personal and professional lives.

Grief. The majority of studies showed that staff grieved over the death of a young patient, with findings from one study showing doctors exhibited higher levels of grief than nurses, and younger staff exhibited higher levels overall. Grief manifested in many similar ways across staff and settings, from depression,[5,9] sadness,[9,21,35,36,41,44,46] anger,[21,31,35,44,46] emptiness/loneliness,[35] irritability,[5,11] decreased sex life,[5] loss of appetite,[21] sleep disturbance,[11,12,21] anxiety,[12,21] guilt,[9,21,44] withdrawal,[9,12,21,44] and having to take time off work.[11] Staff also reported difficulties forgetting the child,[36] being plagued by painful memories,[29] and recurring thoughts about the child's dying conditions and death.[9,44]

There were however differences between doctors and nurses in *how* they experienced grief. Although two studies of doctors and nurses working in paediatric oncology showed they both fluctuated between experiencing and avoiding grief,[9,44] doctors reported more avoidance behaviour, such as avoiding going into the child's

room when end-of-life was near, and not talking about their grief.[44] Findings suggested that for doctors, grief over losing a young patient was a lonely experience, whereas for nurses it was a more social experience in terms of seeking support from their peers.[44]

Disenfranchised grief. All staff, including doctors, nurses, social workers, psychologists, and support staff in the hospital setting referred to their fears of grieving in public.[9,29,31,33-36,39,41,44] Both doctors and nurses had anxieties around loss of their professional reputation[31,39] and ability to support families if they revealed their feelings and grief.[36] In the absence of any formalised support, staff felt they could not openly express their emotions and reported hiding in the bathroom to cry,[35] or crying on the way home by themselves.[29] While some nurses felt they were not supposed to grieve,[41] others felt it was important to express their emotions in order for parents to feel more comfortable expressing theirs.[33] However, the majority of staff felt they were required to put their grief to the side and return to work instantly, and had therefore no place to share their experiences.[29] Staff not only hid their grief in the workplace, but also in their personal lives. Nurses reported feeling guilty about telling friends or family depressing stories[40] and felt they had to be careful about sharing details of their work with others.[39] Nurses spoke of the consequences of revealing their grief at home in relation to family members feeling uncomfortable and withdrawing from them.[34] Doctors also reported feeling drained when they got home and as a consequence shut down or avoided contact with their own children and family members.[31]

Coping strategies. Staff reported a number of coping strategies which appeared to help them deal with the challenges of providing end-of-life care to children.

Finding meaning, finding closure. The importance of finding meaning and making sense of a child's death was widely cited.[9,21,33,39,40,44] For doctors, the death of a child acquired meaning when they had exhausted all possibilities and felt they had contributed to a good death in relation to control of physical symptoms.[44] Nurses were able to find meaning in their involvement with the dying child's comfort and support,[44] along with supporting families.[39]

Finding closure was also a recurrent theme in the literature, and appeared to aid the healing process for nurses in particular.[34,35,40-42,45] Attending the child's funeral helped bring a sense of closure to the special relationships built up with families,[9,34,39,40] and nurses reported difficulty adjusting when unable to attend[41,42] as they had no chance to say goodbye.[33,39]

Self-care. A number of positive behaviours were mentioned as important for self-care, such as maintaining a sense of humour,[12,21,35,41,42,45] regular exercise,[31,39,41,42] meditation,[41,42] time away from work/setting limits at work,[41,42] healthy eating habits, massage,[42] yoga,[39] and seeking emotional support.[46]

Distancing. Doctors and nurses reported distancing themselves from patients as a way of protecting themselves from becoming too involved,[31,42] and for more experienced nurses to prevent burnout.[30]

Recommendations for practice. A number of factors appeared to be important in terms of supporting staff when providing end-of-life care to children.

Education. All staff felt they lacked experience when communicating with both children and their families about end-of-life issues; this could lead to feelings of stress and inadequacy.[29,36] Education was the highest associated variable for

improving confidence among nurses to provide end-of-life care in a children's hospital,[32] and the only modifiable factor for reducing death anxiety among paediatric nurses.[27]

Debriefing. Debriefing was seen as important by most staff in relation to dealing with emotions,[45,47] bringing closure,[26,33] and sharing experiences.[26] However, timing appeared to be crucial, as if too late could actually be detrimental 'I may have found a 'good place' for that and all of a sudden, I'm back to the beginning'.[34] While those working in the hospice setting were provided with formal debriefing, those in the hospital setting received more ad hoc support and felt this was detrimental to their emotional well-being and professional ability to provide quality care.[46]

Peer support. Peer support was mentioned often as a major source of comfort.[9,12,21,28,30,33,34,36,39,42,44] A wide range of staff experienced a great sense of relief from being able to discuss a child's death with colleagues who understood what they were going through.[30,34,40] Sharing their experience made it more bearable[33] and provided an emotional outlet.[9,44] However, doctors rarely sought support from colleagues.[9,44]

Organisational support. There appeared to be great variation in the level of organisational support for staff. While staff in the hospice setting reported twice weekly staff group meetings with a visiting consultant psychiatrist[12] staff in the hospital setting reported inadequate or no emotional, psychological or social support[21,29,35,39] which left them feeling stressed and alone.[29] Health and social care professionals emphasised the need for comprehensive occupational support to help them provide effective care, manage intense relationships with families, and for their own emotional well-being.[46] A wide range of staff also highlighted the importance of

having time out to reboot emotionally,[21,28] with a time frame of 15-30 minutes frequently mentioned.[21]

Common themes across hospital, hospice and community settings. There were a number of common themes across the different care settings explored in this review. Staff across settings viewed the close relationships built up with children and their families as providing major personal and professional rewards.[11,23, 37,38,40,48] End-of-life decisions and symptom management were also cited as the most common challenges in both the hospice and hospital setting.[6,11,46] Staff in all settings also experienced grief in similar ways after losing a child they had cared for.[9,21,35,44] In terms of recommendations, staff across all settings emphasised the need for ongoing palliative care education,[21,26,29,36,38,41,46] especially in relation to communicating with families about end-of-life issues. [9,44,45]

Discussion

The findings from this review contribute to the understanding of the unique experiences of a wide range of healthcare staff who provide end-of-life care to children. Most studies focused on nurses which is not surprising given that nursing makes up the largest segment of healthcare providers.[41] However, a large proportion considered a wide range of healthcare staff which is important considering that many different professionals, including doctors, social workers, psychologists, and support staff all play important roles in providing end-of-life care to children.[29]

Results indicated that staff' experience a number of rewards when providing end-of-life care to children that lead to increased job satisfaction. However, the work

environment had a negative impact on staffs' level of job satisfaction, mostly in relation to inadequate multidisciplinary working and inadequate co-ordination between the many services involved in a child's care. Staff also reported frustrations at resource barriers to providing emotional and spiritual care to children and their families, such as time to interact with the child, be with the parent, or providing follow-up bereavement care. Considering that job satisfaction amongst palliative care providers seems to be one of the key factors for improving the efficacy and quality of end-of-life care,[10,28,38,] it is imperative that those at policy and organisational level address the wider and immediate work conditions that cause staff distress.

As reflected in the literature, findings suggested that more difficulties arise in the hospital setting where the key focus is on short-term or acute cure.[33,50] Doctors struggled to make end-of-life decisions, and both doctors and nurses felt unprepared to have end-of-life discussions with parents. Nurses also experienced moral distress over parents' or other team members refusal to withdraw interventions that were not in the child's best interests, and having to withhold the truth about their condition from the child; ultimately compromising the quality of care delivered.[29] Continuity of care was also an area of contention, with staff feeling frustrated at the lack of provision for follow-up bereavement care.

Some major challenges, such as witnessing children's' suffering and death, communication with children and their families, and inadequate support have been well documented in the literature.[9,41] However, the findings from this review also highlighted the challenges of maintaining professional boundaries in an area of healthcare that requires intense, often long term staff involvement.[42]

Impact

Findings are supported by the wider literature showing that, while healthcare staff experience a diverse range of grief responses when a child under their care dies,[9,35,51,52] as professionals they are not expected to display these emotions.[53] As a consequence, they do not have the chance to mourn openly or receive sufficient support .[54] Findings suggest staff may distance themselves as a protective measure, unintentionally compromising the quality of care provided to children and their families.[55] Doka[54] refers to this experience as disenfranchised grief, where healthcare staff cannot openly mourn, or receive social support because their loss is not acknowledged, even though findings from this review demonstrate that relationships developed with dying children and their families are intense and meaningful.

Coping strategies

In common with previous literature, findings suggested that support from professional colleagues is the most common strategy used for helping them cope when providing end-of-life care to children,[51] often in the form of debriefing sessions which provided a safe place to share experiences with others who understood.[52,56] However, as suggested by previous studies, debriefing may not be beneficial for all staff,[57,58] and in some cases may actually prolong their grief if sessions happen too late after the death of a child. Findings from one hospice and one hospital setting provided models of good organisational support in the form of regular meetings with professionals who were adequately trained to support paediatric staff.

Recommendations for practice

Understanding staff experience of providing end-of-life care to children is essential for the development of support services, which based on the findings of this review should include: organisational support for ongoing education on paediatric palliative care, communication with children and their parents around death and dying, and how to manage professional boundaries without compromising patient care. Communication between healthcare providers and patients is inherently difficult irrespective of the clinical setting, but even more so when providing care to children.[25] However, as effective communication is so vital to connecting with the family, any lack of communication is likely to hamper care. The language used can hinder families understanding of the care being suggested. Beckstrand et al (p. 551)[25] emphasised that the terminology used needs to be revised from terms such as 'withdrawing or withholding to allowing death to naturally occur'.

Debriefing sessions should be timely, and delivered by professionals trained in children's end-of-life care so they understand what their colleagues are going through. As doctors displayed the highest levels of grief, they should be encouraged to attend debriefing sessions to help break the culture of silent suffering that appears to permeate medicine. Staff with less experience also require additional support and education to increase their levels of comfort and competence when providing end-of-life care to children and their families.

As documented in the literature, staff attendance at funerals was shown to be beneficial,[59,60] especially in relation to finding closure. As has been suggested by the findings of this review and the wider literature, staff should be facilitated to attend

funerals as part of their working hours, or paid to attend if during their off-duty time[15,62] so they can continue to offer effective and compassionate care to the other children under their care.[35]

At policy level, steps need to be taken to streamline services within paediatric palliative care, and to raise awareness of hospice services so that referrals are timely. This would help clarify community staffs' roles and facilitate the development of trusting relationships with families, which is a cornerstone of quality end-of-life care.[63]

Limitations

This mixed method review confirms the lack of robust quantitative and qualitative studies relating to staffs' experience of providing end-of-life care to children. As such, it is not possible to draw definitive conclusions. However, this review does highlight the gaps and limitations within the current knowledge base.

A strength of this review relates to the transferability of findings as included studies were conducted in many different countries, with a diverse range of healthcare staff in a diverse range of healthcare settings, yet showed more similarities than differences in relation to the impact of providing end of life care to children and the most important strategies to help support them.

Conclusions

Overall findings highlight the need for healthcare organisations to support and care for staff who provide end-of-life care to children, in the same way they expect their staff to support and care for their young patients. Ongoing education focusing on the

unique challenges of providing end-of-life care to children and the importance of self-care, along with timely multidisciplinary debriefing are key strategies for improving healthcare staffs' experiences, and as such the quality of care they provide.

Future directions for research

As only one study focused on the experience of doctors individually, further research is required to increase the opportunity for greater acknowledgement and recognition that 'emotional experiences do exist within the medical model of care' (Kaplan p. 201).[35] Furthermore, this review revealed the paucity of studies considering the individual experiences of support staff, or individual experiences of staff within the hospice setting. Further research should explore these neglected professional groups and settings so that *all* staff who provide end-of-life care to children can be supported to do so. Research exploring the effectiveness of interventions for mitigating healthcare staffs' stress and grief experiences should also be a priority. In terms of reducing stress caused by the work environment, future research on effective models of multidisciplinary working within paediatric palliative care is required, along with how to improve co-ordination of services. Finally, a systematic review exploring key recommendations in relation to the most effective educational strategies and the most effective supportive strategies for staff providing end-of-life care to children is required.

Contributions

TM: developed the protocol for the review, identified and screened articles for inclusion, data extraction, data analysis and synthesis, and drafted the article. DS identified and screened articles for inclusion, data extraction, data analysis and synthesis, and critically revised the article. SP supervised the review, developed the protocol, data extraction, and critically revised the article. All authors approved the final version.

Declaration of conflicting interests

The authors declare that there is no conflict of interest.

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