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Health and social care professionals' experiences of supporting parents and their dependent children during, and following, the death of a parent: A qualitative review and thematic synthesis

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Abstract

Background: Children need to be prepared for the death of a parent and supported afterwards. Parents seek support from health and social care professionals to prepare their children. Support is not always forthcoming.

Aim: To systematically identify, analyse and synthesise literature reporting of the experiences of health and social care professionals when supporting parents and children during, and following, the death of a parent.

Design: A systematically constructed qualitative review and thematic synthesis. Registered on Prospero (CRD42017076345).

Data sources: MEDLINE, CINAHL, Embase, PsycINFO, PsycARTICLES and PROSPERO, searched from January 1996 to July 2018 for qualitative studies in English, containing verbatim reporting of health and social care professionals' experiences of supporting parents and children during, and following, the death of a parent. Qualitative data were appraised using a modified Critical Appraisal Skills Programme qualitative appraisal checklist.

Results: The search yielded 15,758 articles. Of which, 15 met the inclusion criteria. A total of 13 included professionals' experiences of supporting parents and children before parental death. Two included experiences of supporting surviving parents and children afterwards. Three analytical themes identified as follows: (1) aspiring to deliver family-focussed care, (2) health and social care professionals' behaviours and emotions and (3) improving connections with parents and children. Connecting empathically with parents and children to prepare and support children entails significant emotional labour. Professionals seek to enhance their confidence to connect.

Conclusion: Professionals struggle to connect empathically with parents and their children to prepare and to support children when a parent is dying and afterwards. Awareness of professionals' needs would enable provision of appropriate support for parents and children.

Keywords

Health personnel, attitude of health personnel, social support, parents, child, hospice and palliative care nursing, terminal care, experience

What is known about the topic?

- If not prepared for the death of a parent, or supported afterwards, children can suffer emotionally.
- Parents struggle to prepare their children for the death of a parent and to support them after a parent has died.
- Parents seek help from health and social care professionals to enable them to prepare and to support their children.

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What this paper adds?

- Although health and social care professionals aspire to deliver family-focussed care to enable parents to prepare and support their children during, and following, the death of a parent, doing so entails significant emotional labour.
- Personal emotions can affect professional behaviours, both enhancing and inhibiting the ability to connect empathically with parents and children.
- Health and social care professionals seek recognition by employers of the importance of their supportive role and help to manage the personal consequences of their emotional labour.

Implications for practice, theory or policy

- Policymakers need to acknowledge the significant role played by health and social care professionals when connecting with parents and with their dependent children during, and following, the death of a parent.
- Health and social care professionals need support to enhance their ability to manage the emotional labour of building empathic connections with parents and with dependent children.
- Changes to workplace culture and the development of supportive interventions would enable health and social care professionals to acknowledge the presence of children in families when a parent has a life-limiting illness and to make the time to connect with parents and children.

Background

Diagnosis with life-limiting illness can be devastating for parents, for their partners and their dependent children.[1] Defined as illness leading to inevitable death,[2] the most prevalent causes of life-limiting illness in people of parenting age in the United Kingdom are cancers, followed by heart disease and stroke.[3] Approximately 23,600 parents with dependent children (defined as children under the age of 18 years)[4] died in the United Kingdom in 2015.[5]

To prevent the pathological consequences of children's grieving, UK policy for end-of-life care includes commitment to early, sustainable health interventions for patients and their families.[6] In Sweden, it is mandatory for nurses to involve children in their dying parent's care.[7–10] However, in the United Kingdom, the National Institute for Health and Care Excellence (NICE) guidelines only generally acknowledge supporting patients' children.[11]

If not prepared for parental death, or supported afterwards, children whose parents die are more likely than their peers to have higher levels of referral to psychiatric outpatient and specialist services and absence from school.[12,13] However, children can be resilient if given age-appropriate information when a parent is dying and if supported to grieve.[14–16]

The extent to which a child is prepared and supported is led primarily by the wishes of their ill parent.[17] They, and their partners, often seek advice from registered health and social care professionals (also referred to as professionals within the results and discussion section of this review) who include nurses, physicians, physiotherapists, psychologists and social workers, about how to prepare and support their children.[1,18,19] Occasionally, health and social care professionals will talk to children independently of their parents.[20–22]

Reviews informing this study report the impact on[23] and support needs of[1,24,25] parents and children when parents are dying and in bereavement. Health and social care professionals are vital to helping parents to prepare and to support their children in the period surrounding the death of a parent. However, they struggle to do so.[8,19–22,26–28] Even when parents ask for the support, it is not always forthcoming.[1,24]

Settings included in the review include hospitals, palliative care hospices and home care. Health and social care professionals' experiences will be influenced by the healthcare systems they work within and associated educational preparation, practice requirements, and professional regulations that operate. The review was undertaken to inform future research exploring issues for health and social care professionals supporting parents in the United Kingdom. Thus, the focus was on Western countries.

Review question

What are the experiences of health and social care professionals when supporting parents and their dependent children when a parent has a diagnosis of life-limiting illness and following the death of a parent?

Design

This systematically conducted qualitative review and thematic synthesis was conducted by following the Enhancing Transparency in Reporting Synthesis of Qualitative Research (ENTREQ) guidelines.[29] The review protocol was registered on PROSPERO, (PROSPERO 2017 CRD42017076345)

Medline	7,488
PsycINFO	4,458
CINHAL	3043
Embase	743
PsycARTICLES	26

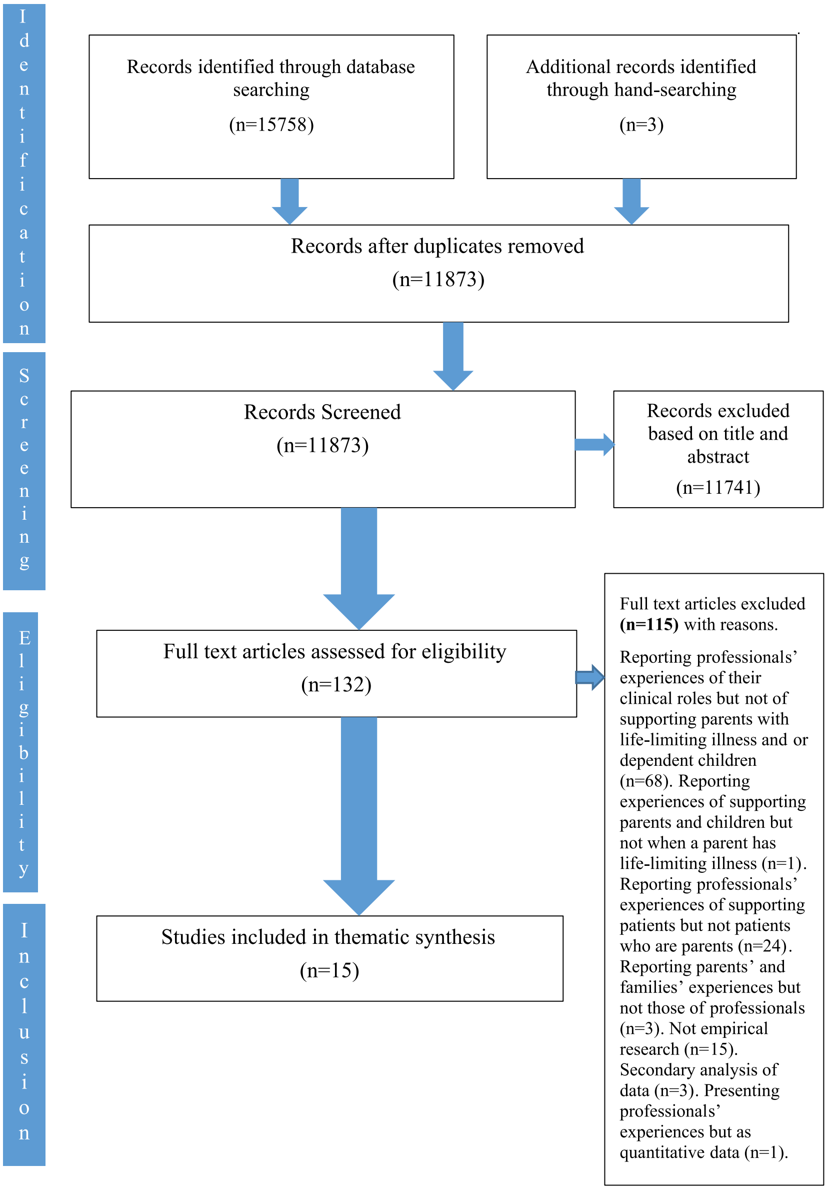

Figure 1. Preferred reporting items for systematic reviews flow diagram. Moher et al.[44]

https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=76345.[30]

As this study is a review of existing published studies, ethics permission was not required.

Qualitative review and thematic synthesis

A systematic database search was conducted to identify qualitative studies that included verbatim reporting by

Table 1. Inclusion and exclusion criteria.

Inclusion	Exclusion
Study design • Primary research articles • Published in peer-reviewed journals • Written in English • Published after January 1990 • Reported on studies, using qualitative research Participants • Reporting the experiences of registered health and social care professionals • Working in healthcare systems using western medicine	• Reporting on trials evaluating interventions aimed at helping health and social care professionals to support parents and/or their dependent children during, and following, the death of a parent • Reporting the experiences of health and social care professionals of supporting parents and/or their dependent children, when a parent has a diagnosis of cancer or another condition that is not life limiting. • Systematic reviews related to the topic

health and social care professionals of their experiences. Thematic synthesis was used as a method to analyse and blend findings from these studies all of which had used various methods of inquiry and analysis.[29,31] In keeping with the three-step method described by Thomas and Harden[32] verbatim quotes were (1) coded line by line to (2) generate descriptive themes which were (3) merged into each other to generate analytical themes providing new interpretations of the experiences of health and social care professionals concerning the topic (Figure 1).

Inclusion and exclusion criteria

Previous systematic reviews relating to the support needs of parents with life-limiting illness and of their dependent children[1,12,23–25] and database thesauri informed the search (Table 1).

Search strategy

A search of the Cochrane CENTRAL Register of Controlled Trials,[33] and PROSPERO[34] identified no reviews in relation to the aims of this review. A comprehensive search strategy was developed, with the help of a specialist librarian, for the MEDLINE database, then adapted and applied to CINAHL, Embase, PsycINFO, PsycARTICLES and ProQuest. The search encompassed papers published in peer-reviewed journals in English from 1990–2018, the period when studies addressing support needs of parents and children during, and following, the death of a parent were mostly published.[1,12,24,35–41]

The search was conducted on 6 June 2017 and updated on 31 July 2018. Search results were uploaded and stored using Clarivate Analytics Endnote version 7.4.[42] Duplications were removed. Reference lists of selected publications were hand searched and considered against eligibility criteria. In addition, all journals containing included studies were hand searched retrospectively from January 2018–July 2018.

A modified Population, Intervention, Comparison and Outcome (PICO) strategy directed the database search.[43]. Search terms staying close to the research question split into three categories: (1) the experiences of health and social care professionals (primary population and observed phenomenon); (2) when supporting parents and or dependent children (secondary population) and (3) from when a parent is diagnosed with life-limiting illness to the period following the death of a parent (outcome/s). Medical subject headings (MeSH) and keywords using truncation (*) within the title, abstract and full text fields were identified for each of the above categories. The main MeSH headings used in the search are included in the abstract. As MEDLINE does not provide a MeSH heading for 'experience', this was searched as a key text word. Search terms were kept broad to capture all relevant literature. Boolean terms 'OR' and 'AND' were used to combine searches both within and between categories (Table 2).

Data extraction and analysis. The electronic database search yielded 15,758 articles. Hand searching of journals which included publications identified by the database search identified three studies. The review included a total of 15 papers (Figure 1). An adapted Critical Appraisal Skills Programme (CASP) checklist for appraisal of qualitative data[45] was used to identify the methodological quality and validity of all studies fitting the eligibility criteria.[46] Critical appraisal comprised the following criteria: whether there was a clear statement of aims for the research, appropriateness of the chosen methodology, explanation given of the research design, relevance of method of data collection, adequacy of sample size in relation to the identified aim of each study, sampling strategy and specificity of the sample, theoretical perspective, rigour of the analytical strategy and clarity of explanation of findings. Furthermore, papers were assessed for researcher reflexivity, ethical considerations, relevance and transferability. The tool was piloted by three members of the team (P.F., A.A. and E.R.) using a subsample of studies. It was then used independently by two members of the team (P.F. and A.A.) to assess all eligible remaining studies.

Studies are sometimes excluded from systematically conducted reviews because of the quality of their reporting.[47,48] All studies containing verbatim reporting by health and social care professionals of their experiences were included

Table 2. Example of main search terms and combinations – linking to the full search strategy (supplementary table 4).

1. Health Personnel + [MeSH]
2. Attitude [MeSH]
3. Attitude of Health Personnel [MeSH]
4. Experience * (Text Word}

S1 AND S2 OR S3 AND S4
5 Communicat * [Text Word]
6 Communication Barriers [MeSH]
7 Health Communication [MeSH]
8 Information Dissemination [MeSH]
S5 OR S6 OR S7 OR S8
9 Social Support [MeSH]
10 Support* [Text Word]
S9 OR S10
11 Child of Impaired Parents [MeSH]
12 Child [MeSH]
13 Child* [Text Word]
14 Adolescen* [Text Word]
15 Parents + [MeSH]
16 Parent* [Text Word]
S11 OR S12 OR S13 OR S14 OR S15 OR 16
17 Hospice and Palliative Care Nursing [MeSH]
18 Palliative Medicine [MeSH]
19 Terminal Care [MeSH]
S17 OR S18 OR S19
20 Terminal* ill* [Text Word]
21 Palliative Care [MeSH]
22 Incurable cancer [Text Word]
23 Incurable disease [Text Word]
24 Advance* disease [Text Word]
25 Life-limiting* [Text Word]
26 End of life [Text Word]
27 Dying [Text Word]
28 terminal cancer [Text Word]
S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR 28
29 Death [MeSH] OR
30 bereave* [Text Word]
S29 OR S30
31 = S1 AND S2 OR S3 AND S4
32 = S5 OR S6 OR S7 OR S8
33 = S9 OR S10
34 = S11 OR S12 OR S13 OR S14 OR S15 OR S16
34 = S17 OR S18 OR S19
35 = S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28
36 = S28 OR S30
S31 AND S32 AND S33 AND S34 AND S35 AND S36

MeSH: medical subject headings.

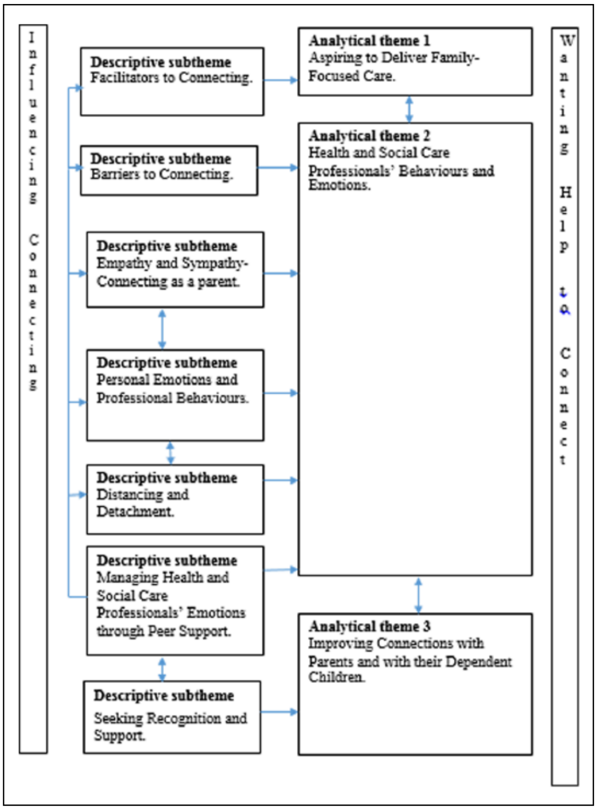

Figure 2. Descriptive subthemes and analytical themes.[44]

in this review. However, less weight was given in the discussion to poorly conducted studies.

Results

Table 3 presents demographic details of participants included in each of the studies. A total of 312 registered health and social care professionals took part in the studies making up this review. The majority were nurses, ($n = 277$). Professions included specialist palliative care nurses,[8–10,19–22,27,49] oncology nurses,[7,21,27,50,51] general nurses,[7,26,52] community nurses,[8,9,19,22,26,49] physicians (doctors)[22,51] ($n = 22$), physical therapists ($n = 6$),[22] psychologists ($n = 2$)[22] and social workers ($n = 5$).[19] Fields of work were inpatient oncology,[7,21,27,28,49,51] haematology,[7,51] neurology,[7,51] oncological gynaecology,[51] palliative care in hospices,[10,19,20,22] in the community,[8,9,19,26,49] for example, in nursing homes[10,22] and in patients' homes.[8,9,10,19,22,26,49] One study does not state the setting.[52] Although not always specified the majority of health and social care professionals were female.[8,9,10,20,22,26–28,49,51,52] Five studies took place in the United Kingdom,[19,20,26,27,50] three in Australia,[21,28,49] four in Sweden,[7–10] one in Canada,[52] one in Italy[22] and one in Denmark.[51] Methods of data collection included focus group interviews,[7,9,21,22,27,28,52] one-to-one unstructured,[10,26,49] semi-structured,[8,19,20,51] in-depth[10,51] and telephone interviews,[21] and participant observation.[51]

Of the 15 included studies, seven explored health and social care professionals' experiences when supporting parents with life-limiting illness, and also experiences of supporting children.[8,9,21,26,27,28,51] In six studies, although the emphasis was on experiences of supporting the dying parent health and social care professionals also discussed experiences of encountering children.[8,9,10,49,50,52] In five studies, they reported experiences of supporting children directly, rather than connecting with children through their parents.[7,8,19,20,22] Although supporting children following the death of a parent was mentioned in two studies,[10,22] only one

Table 3. Summary of studies assessed in this qualitative review.

Authors, title, country, year	Aims/objectives	Participants and setting	Methods	Relevant findings	Strengths and limitations
Arber and Odelius.[27] Experiences of oncology and palliative care nurses when supporting parents who have cancer and dependent children. *Cancer Nursing*.	To explore the experience, needs and confidence of nurses working in acute cancer services when supporting parents who have cancer and who have dependent children.	Oncology nurses ($n = 9$) Palliative care nurses ($n = 3$) 11 females, 1 male Working in one acute hospital trust in the south of England.	Focus groups.	Oncology and palliative care nurses take their cues to support children from parents with life-limiting illness.	Good representation of the understandings of oncology and palliative care nurses when supporting parents with cancer and their children. The focus was on supporting mothers with life-limiting illness. Authors recognised the need for further research regarding support for fathers. Findings are transferable to nurses working in acute cancer services but not generalisable as the research was conducted in one National Health Service (NHS) trust in England.
Clipsham et al.[20] Experiences of hospice inpatient nurses in supporting children before the death of a parent. England, UK.	Exploring hospice nurses' experiences of the support needs of children under the age of 18 years whose parents were dying. Exploring the impact on palliative care nurses when providing this support.	Palliative care nurses working in a hospice in the United Kingdom ($n = 10$). All female. 7 months to 33 years of practice. Average 15.9 years of practice.	Semi-structured individual interviews.	The study demonstrates how hospice nurses try to meet the support needs of children whose parents are dying. Provision of support for parents and their children depended on multiple factors including a need for formal training and easy access to resources.	Researcher reflexivity is demonstrated under the heading *Ethical Considerations* p. 453, where the authors considered the potential for responder bias. Findings may be transferable but not generalisable as the study focussed specifically on palliative care nurses and occurred in one hospice in the United Kingdom. Findings are biased towards the views of female nurses.
Davis et al.[28] Communicating with families of patients in an acute hospital with advanced cancer: problems and strategies identified by nurses. Western Australia	To describe nurses' perceptions of communication issues, potential barriers and strategies associated with nurse–family interactions in an acute cancer setting.	Nurses ($n = 60$). All female. Aged 21–30 years and who worked full time. Typical participants had worked in oncology for 3 years and 6 months. Working in two cancer wards in an acute hospital in Western Australia.	Focus groups.	One participant reported that she perceived that younger nurses experienced stress when caring for parents with a life-limiting illness who had young children.	The study is robust in reporting how to strengthen nurses' communication with families of patients with acute cancer. The focus of the study is on communicating with families and not specifically on communicating with families with dependent children. There is only one quote regarding communicating with parents who have dependent children. There is a need for research into the views of male nurses. Lack of rich reporting of professionals 'experiences' when communicating with parents with dependent children means that results are not transferable to settings where health and social care professionals support parents with their dependent children.

Table 3. (Continued)

Authors, title, country, year	Aims/objectives	Participants and setting	Methods	Relevant findings	Strengths and limitations
Dencker et al.[51] A qualitative study of doctors' and nurses' barriers to communicating with seriously ill patients about their dependent children. Denmark.	The study explores doctors' and nurses' experiences of, and attitudes to, perceived challenges and barriers when supporting communication between parents and their dependent children.	Doctors (n = 9), nurses (n = 15). All nurses were female, and one-third of the doctors were male. The average age for doctors and nurses was 46. Average years of experience was 19. Working in three hospital wards –haematology, neurointensive care and oncological gynaecology in Denmark.	Semi-structured in-depth interviews and participant observations.	The study identified structural and emotional barriers to communicating with patients about their dependent children. Not dealing with emotional barriers intensified structural barriers. Findings from the study report that to enable them to identify children of seriously ill patients, health professionals need to be supported by the workplace structure. However, even when workplace structure facilitates health professionals to identify children, their emotional reactions lead to avoidance of connecting with parents about their children.	Strengths include reporting the relationship between structural, organisational and emotional barriers affecting health professionals' ability to identify and to support children of seriously ill patients. The study focuses on organisational and structural processes inhibiting or enhancing the identification of children of sick patients in Denmark. The sample size is small. Results although transferable to similar healthcare settings are not generalisable to other healthcare settings or to other countries, where organisational and structural processes might differ.
Dunne et al.[26] Palliative care for patients with cancer: district nurses' experiences. Northern Ireland.	Exploring district nurses' experiences of providing palliative care for family units.	First-level registered district nurses (n = 25). All female. At least 1-year of experience of working in a district nursing team.	Unstructured tape-recorded interviews.	This study explores district nurses' experiences of caring for the family. Often, district nurses play a crucial role in managing dying patients at home. Researchers state that district nurses have difficulty when dealing with children and adolescents whose parents are dying. One district nurse identified that children could be excluded when caring for their sick parents.	Findings and discussion relate to caring for family members of all ages. There is discussion regarding the difficulties experienced by district nurses when caring for children and adolescents. There is only one participant quote relating to a district nurse's difficulties when caring for children when a parent is dying. There is not enough evidence to enable transferability or generalisability regarding supporting parents and children when a parent is dying.
Fearnley[19] Supporting children when a parent has a life-threatening illness: the role of the community practitioner. The United Kingdom.	To explore children's experiences of living with a parent who is dying.	Healthcare professionals (n = 9). Nurses (n = 4), Social workers (n = 5). Information provided by Fearnley's[53] doctoral thesis. Hospices and palliative care centres.	Semi-structured interviews.	Findings identified the importance of sharing information with children of all ages about their parents' illness. Healthcare professionals are significant in facilitating communication either with parents about their children or with children directly. However, healthcare professionals fear to talk to children about their ill parent, as this might make it harder for the children.	The study reports findings from Fearnley's doctoral research with occasional brief quotes representing the perceptions of healthcare professionals. Using more examples of verbatim quotes from healthcare professionals would have strengthened the discussion. The study does not identify the specific roles of the healthcare professionals. Analysis of findings is unclear. Without the knowledge of the specific roles of the healthcare professionals as reported in this article, it is not possible to transfer or to generalise findings.

(Continued)

Table 3. (Continued)

Authors, title, country, year	Aims/objectives	Participants and setting	Methods	Relevant findings	Strengths and limitations
Golsäter et al.[7] Are children as relatives our responsibility? – how nurses perceive their role in caring for children as relatives of seriously ill patients. Sweden.	To provide a detailed understanding of how nurses perceived their role of caring for children of parents with serious illness.	Registered nurses. (*n* = 19), Working at 1 neurological, 1 haematological and 2 oncological wards.	Focus group interviews.	Nurses were conflicted regarding their supportive role for children when parents are dying. Findings identified that children need to be acknowledged as relatives when visiting their parents. However, despite having a legal responsibility to support children when a parent is dying, findings indicated a lack of conviction that this was a nursing role. There is a need for education to enhance nurses' confidence in their supportive role.	Before taking part in the data analysis researchers who were nurses themselves recognised their bias and discussed this with each other and with academics with no knowledge of the field. Purposive sampling through the head nurse and advertising meant that nurses may have felt obliged to take part in the study, or that those with a particular interest in the topic may have volunteered, adding bias to findings. There was no piloting of focus group questions. Nursing students rather than researchers conducted focus groups. Doing so could have been beneficial, as it reduced researcher bias. However, it could also have been detrimental as student nurses might not have identified sensitivities relating to the topic area. Variation of ward settings for participants strengthens transferability. The focus was on the experiences of Swedish nurses for whom it is mandatory to recognise the support needs of dependent children when parents are dying. It is not possible to generalise to healthcare settings in other countries.
Iranmanesh et al.[10] Swedish nurses' experiences of caring for dying people: a holistic approach. Sweden.	To shed light on nurses' experiences of caring for dying patients at home and in a special unit in the hospital.	Registered nurses (*n* = 8). Female. Ages of hospital nurses were 35–38 years. The age range of home care nurses was 37–56 years. Four working in private homes and 4 in a special unit in the hospital. Nurses working in hospital settings had 7–36 years of experience. Home care nurses had 14–37 years of experience. Mean experience of nurses working in specialist hospital settings was 9 years. Mean experience of home care nurses was 12 years.	In-depth, individual, unstructured audio-taped interviews with a narrative approach.	A participant quote outlines the emotional burden of supporting children following the recent death of a parent. The participant feared breaking down and was glad of the support from the multidisciplinary team. A participant highlights her emotional experience of working with families when parents are dying and where the children were the same age as the nurse's children.	Although participant numbers were small, a hermeneutic phenomenological analysis of reported experiences provided a rich interpretation of findings. Researchers were aware of their own experiences of caring for dying patients and acknowledged and reflected on how these might have influenced the findings. Nurses were recruited to the study by the head nurse. This could have lent bias to the findings. Neither researchers' first language was English. They acknowledged that important findings might be lost in translation. Experiences of working with parents who are dying and with their children are not the primary focus of this study. There are two quotes, identifying the emotional difficulties experienced by nurses when supporting parents who are dying. Overall results may be transferable to nurses working with dying patients in hospitals and at home in Sweden. However, small numbers of quotes related to the experiences of supporting children when parents are dying means that findings cannot be transferred to settings where nurses are required to support parents and dependent children when parents are dying. Results cannot be generalised to wider healthcare settings or to other countries.

Table 3. (Continued)

Authors, title, country, year	Aims/objectives	Participants and setting	Methods	Relevant findings	Strengths and limitations
Karidar et al.[8] A gap between the intention of the Swedish law and interactions between nurses and children of patients in the field of palliative oncology – the perspective of nurses. Sweden.	To explore nurses' perspectives on what happens in meetings and interactions with nurses and children of parents in receipt of palliative care.	Nurses ($n = 9$). Three working in palliative care inpatients and 6 working in advanced medical home care. At least 2 years of experience of working in specialist palliative care.	Semi-structured interviews.	Nurses reported experiences of connecting with children of parents with a life-limiting illness. Contact with children was dependent on the wishes of the ill parent. Nurses in Sweden are required to support children when a parent has a life-limiting illness. However, nurses reported that when caring for parents, they did not always see the children. The organisational structure such as limited time and lack of resources acted as barriers to their ability to interact with children about their parents. Nurses found teenagers to be particularly challenging to support.	There is good reporting of nurses' perceived difficulties when trying to make connections with children about what is happening with their ill parents. The study is biased towards the experiences of nurses in Sweden. Authors acknowledge that identifying nurses through their managers makes the selection of participants problematic. The authors identify that the sampling process and small sample numbers could have biased nurses' reporting of their experiences. It is possible to transfer findings regarding Swedish nurses' experiences of supporting children of parents with a life-limiting illness to other settings. However, because the focus is on compliance with Swedish law, findings relating to organisational processes that support, or inhibit, connecting are not generalisable to nurses working in other countries.
Kaup et al.[9] Care for dying patients at midlife. Sweden.	To highlight nurses' experiences and coping strategies when caring for patients in midlife who receive palliative care.	Nurses ($n = 14$). Female. Aged between 42–60 years. Working in 3 specialist palliative home care teams. Experience of working in advanced palliative home care ranged between 1–25 years.	Focus groups.	Findings are presented in the context of Swedish law where nurses have a mandate to treat children like adult relatives and to inform and support them when a parent is dying. Nurses identified that they experienced stress when there was concern about the well-being of children within a family. Nurses felt responsible for the well-being of teenagers, perceiving this responsibility as an emotional burden.	Sampling was dense with 11 participants all from the same team. There was no evidence of member checking. Authors identify how their preconceptions of children and particularly teenagers being challenging to work with might affect the trustworthiness of the study. Direct evidence in the form of verbatim reporting by participants related to supporting adolescents is limited. The verbatim description was modified because several focus group participants spoke at the same time, and because of the translation process. Trustworthiness and credibility are therefore limited. Findings may be transferable to nurses working in specialist home care teams in Sweden; however, because of sparse evidence, transferability related to supporting children of parents with a life-limiting illness is questionable.

(Continued)

Table 3. (Continued)

Authors, title, country, year	Aims/objectives	Participants and setting	Methods	Relevant findings	Strengths and limitations
Punziano et al.[22] Health professionals' experiences of supporting teenagers who have lost a parent. Italy.	To understand palliative care professionals' experiences of providing supportive care for teenage children of patients in palliative care.	Registered healthcare professionals. Nurses (*n* = 39), Doctors (*n* = 13), Physical therapists (*n* = 6), Psychologists (*n* = 2), 42 females and 20 males. Total numbers of participants included two social health operators who are not registered healthcare professionals.	Focus groups.	Healthcare professionals who demonstrated empathy with teenagers reported their own emotional difficulties when doing so. Eight themes highlighted professionals' perceptions of the difficulties experienced by teenagers during, and following, the death of a parent. Themes demonstrated how teenagers are present surrounding the loss of a parent and how loss can instigate change. They identified difficulties experienced by professionals when '… *Being present in the loss*'. p. 420, and how they need to be competent and supported when helping teenagers with their loss. Themes describe professionals' perceptions of supporting teenagers and what is needed by teenagers surrounding the loss of a parent. Recommendations include the development of valid tools to aid health professionals to support teenagers whose parents are dying and when they have died.	Representing a range of healthcare professionals. Rich reporting of findings as represented in themes and subthemes supported by verbatim quotes. Findings are transferable to palliative care settings where healthcare professionals are supporting teenagers. This study focuses on the experiences of healthcare professionals in Italy. There is a small number of participants from each profession. Findings are not generalisable to other healthcare settings.
Quinn[50] Exploring nurses' experiences of supporting a cancer patient in their search for meaning. England, UK.	Exploring nurses' experiences of supporting patients in their search for meaning, while living with cancer.	Nurses (*n* = 11). Working in a medical oncology unit and bone marrow transplant unit as part of a central teaching hospital in England.	Audio-taped interviews.	One verbatim quote in the study where a nurse described her experience of being a mother and how she used this to provide insight into the needs of parents who are dying. The above links to an assertion in the narrative that not all nursing care is taught, but learned from the lived experiences of nurses.	Using a phenomenological approach supplies a rich representation of findings. There is no member checking, therefore the credibility of findings might be in question. Not all findings are represented or thoroughly discussed because of the word count for the article. Supporting parents with life-limiting illness and dependent children is not the primary focus of the study. Only one quote links to demonstrating a nurse's ability to empathise with a parent who is a patient because the nurse is a parent herself. Findings are not transferable to healthcare settings where nurses are required to connect with parents and children because of limited evidence related to supporting them. The study contains small numbers of participants and occurs in one cancer centre in England. Therefore, findings cannot be generalised.

Table 3. (Continued)

Authors, title, country, year	Aims/objectives	Participants and setting	Methods	Relevant findings	Strengths and limitations
Stajduhar et al.[52] What makes grief difficult? Perspectives from bereaved family caregivers and healthcare providers of advanced cancer patients. Canada.	This study aimed to explore the perspectives of bereaved family caregivers of what made their grief difficult. This study also reported the experiences of health professionals when parents were dying.	Registered nurses (n = 11). 1 male, 13 females. Age range 46–57 years.	Focus groups.	One nurse reported her emotions when instructed by the well parent to withhold information from a child about a parent's impending death.	There is a rich interpretation of findings and reporting within the text is supported by verbatim quotes. The focus of the study was on the experiences of family caregivers and not directly on those of healthcare professionals. Only one verbatim quote relates to this qualitative review. The quote demonstrates a nurse's sympathy for a mother who was asking the nurse to support her to tell her 5-year-old son the truth about his father's death. Authors state that readers should treat findings cautiously, as they are part of a more extensive unpublished study. This study was a secondary study analysing answers to a focus group question which was part of a bigger mixed method yet to be published study. The focus of this study is on the coping experiences of family caregivers when a relative reaches the end of life. The one verbatim quote relates to a specific incident. Findings are not transferable to professionals supporting parents and dependent children when a parent has a life-limiting illness. The healthcare setting is not known. Findings cannot be generalised.
Turner et al.[21] Oncology nurses' perceptions of their supportive care for parents with advanced cancer: challenges and educational needs. Australia.	To assess the perceptions of oncology nurses about their role in the supportive care of parents with advanced cancer. To explore potential challenges and to understand their educational needs.	Oncology nurses (n = 29). Twenty-four from 3 large metropolitan cancer services. Five rurally based.	Focus groups with 24 nurses. Individual telephone interviews with five nurses.	The emotional burden of their supportive role was a challenge for nurses. In addition, participants identified that healthcare systems were not structured to meet the needs of parents with advanced cancer and those of their children. Nurses highlighted the need to look after themselves emotionally. To enhance their confidence, they wanted access to role models, demonstrating how to support parents and children, access to information about the impact of parental cancer on children, information on child development and on how to communicate with children of all ages.	There is a good use of verbatim quotes to identify nurses' challenges when providing psychosocial support for parents and their children. The anonymity of participants is preserved by not collecting demographic data. Recruiting participants through a regional newsletter reduces bias. There is no acknowledgement of limitations. Findings from this study are not transferable to nurses in other oncology settings.
Wilkes and Beale[49] Palliative care at home: stress for nurses in urban and rural New South Wales, Australia. Australia.	To compare the stress experienced by urban and rural community nurses working with palliative care clients in the home.	Urban and rural community nurses (n = 11). Female. Seven urban nurses and 5 rural nurses.	Unstructured audio-taped interviews.	The introduction contains a participant quote which identifies an urban nurse's experience of supporting a mother who has a life-limiting illness and her teenage son. The quote identifies the nurse's needs to talk to others and to feel supported in her experience. Dynamics concerning patients' families impacted nurses' experiences of stress. Nurses wanted opportunities to debrief and emotional and educational support.	Reporting of verbatim quotes supports in-depth analysis of data. The focus of the study is on the stresses experienced by palliative care community nurses working in rural and urban areas. There is one verbatim quote identifying nurses' experiences of supporting parents with life-limiting illness and their children. Findings are not transferable to nurses who support parents and children when a parent is at the end of life. Results are specific to a small number of nurses working in urban and rural Australia and cannot be generalised.

focussed specifically on health and social care professionals' experiences of supporting children when their parent was dying, and following parental death.[22]

Summary of findings

Aspiring to deliver family-focussed care

Within this review, health and social care professionals aspired to deliver family-focussed care, connecting with parents to assist them in preparing their children for the death of a parent and supporting them afterwards. However, there were facilitators and barriers to doing so.

Facilitators to connecting. Developing early rapport, from the point of parental diagnosis, was perceived to be key to facilitating supportive connections with parents and with children:[19–22,27,51]

> When they come in you tell them the diagnosis you then obviously ask about what the family situation is at home, what else they have got going on so recognizing that straight away you know, I am a mum as well. (FG-5, p. 3)[27]

There was a reported need to be sensitive to parental wishes to establish affinity and trust with parents, gaining permission to approach and to talk to their children.[7,8,20–22,27,52] Identifying with parents, as parents themselves, and because of their own life experiences, helped professionals to develop empathic rapport, to support parents and children:[20–22,27]

> You can feel their pain, but I think your empathy there is so strong because you have been there and done that.[21] (p. 153)

Building empathic rapport allowed professionals to support parents to talk about their children,[27] encouraging them to let the child visit the hospice[7,20] and by involving children in parents' care.[7,20,21,27] Connecting directly with children was aided by creating a child friendly environment[7,20] and by seeking training on engagement and communication with children of different ages.[19–22,27] Although not all professionals were parents[28,51] for some putting themselves into the ill parent's shoes helped them to recognise what parents needed.[20,27]

Barriers to connecting. Multiple perceived barriers inhibited professionals from connecting with parents to help them to support their children. Led by the wishes of the ill parent, professionals feared *making it worse* for the children and opening *a can of worms* (p. 24)[19], and causing distress and conflict in the family by *saying the wrong thing*[21] (p. 152).[19–21]

Perceiving themselves to be lacking relevant skills, such as age-appropriate communication and counselling, prevented some from engaging with parents[21,27,51] and from engaging directly with children.[19,20,22,28] Instead parents and children were referred to other members of the team including a chaplain,[20] psychologists,[22] specialist palliative care nurses, social workers[19,20] and to immediate colleagues.[10]

Despite there being a mandate in Sweden for nurses to inform children about their parents' impending death, some did not see this as their professional responsibility.[7,8] Also, professionals working in oncology[7,21,28,51] and those in palliative care[8,20] highlighted that they had no time to sit and talk with parents or with children.

Connecting was perceived as being harder for young and newly qualified professionals[28] and for those without children.[51] Conversely, having children of the same age as those of their patients made it harder for some to connect with parents about their children:[21,27,51]

> I entered the room and those … um … two boys looked like my own boys. They were the same age as them. And then it just hit me – bang! There was only one thing I could do and that was to leave the room again. I simply could not do it. Tears just poured down my cheeks. (D4:1, p. 2165)[51]

Parental death was reported to be veiled in a *shroud of secrecy*[21] (p. 153) and talking about it was seen as taboo. Ill parents[7,8,19–22,27] and the wider family[21] were reported to block discussions about how to prepare the children. Parents were perceived to be coping by not sharing concerns about the children, choosing instead, to keep support within the family.[20,27]

By not asking for help, parents were seen to be protecting their children.[19,22] Some parents were reported to be in denial about their illness, making it hard for professionals to talk to them about their children.[8,21,52]

Stage of parental illness was reported to affect professionals' ability to talk to parents about how to prepare their children.[20,22] Parents were perceived to be either too ill to raise the subject with them,[21] or not ill enough.[20]

It was hard for professionals to talk to children about death, as children were not always visible.[19–22,27] In the words of a palliative home care nurse in Sweden, children of all ages were passing through the 'entire system … and being overlooked' (p. 26).[8] Length of parental stay in a unit determined whether children were seen by professionals, for example, if parents were visiting as outpatients, then children were less likely to be present.[19,27] Moreover, children did not always visit parents in a hospital acute cancer care unit,[7] in the hospice,[20] and were not always present when professionals visited the ill parent at home.[8,19,22]

Teenagers were especially hard to support, deliberately excluding themselves when the nurse visited; choosing to get support from their peers and the Internet.[8,19] Even when visible, teenagers were especially hard to engage with.[8,9,19,22,26,27]

Health and social care professionals' behaviours and emotions

This theme illustrates the connection between professional behaviours and personal emotions. There are four descriptive subthemes: (1) empathy and sympathy-connecting as a parent, (2) personal emotions and professional behaviours, (3) distancing and detachment and (4) managing health and social care professionals' emotions through peer support.

Empathy and sympathy-connecting as a parent. Professionals who were parents empathised with patients by putting themselves in the ill parents' shoes.[20,27,51] Empathic connecting helped them to build rapport and facilitated discussions about the children[20,21,27]

For some, life experiences such as being parents themselves[8,19–22,27,50,51] or being the same age as dying parents,[49] helped them to be aware of their reactions to their patients' difficulties.

Experiences such as childhood bereavement[21] or remembering when they were seriously ill[20] made it harder for professionals to connect with parents. Empathising with parents and children thinking about their own children[20–22,27,52] while thinking of the possibility of dying and leaving them behind[51] led professionals to experience heightened subjective awareness of their patients' plight and that of the children.[20–22,27,50,51] However, heightened sympathetic concern for patients and their children was given as a reason not to connect with them:[19,21,51]

> … but I don't think I would want to be the one that said to the six-year old 'your mummy's going to die' (P8, p. 456)[20]

Sympathising with children led to strong emotions where professionals wanted to protect and feared to upsetting them.[19–22] For example, one palliative care nurse did not want to … *force the children* …[8] (p. 26) to hear about their parents' illness.

Personal emotions and professional behaviours. Over-identification with patients blurred boundaries, where professionals crossed over from experiencing helpful empathy, to subjective sympathy, where heightened personal emotions inhibited their abilities to provide support.[8,20–22,27,28,51,52] 'You could spend your whole day in tears with people, couldn't you?' (P8, p. 457).[20] One oncology nurse described the emotional burden of connecting empathically with parents as … *feeling their [the ill parents'] pain* …[21](p. 152) and another, as being … *immersed in suffering*.[21] (p. 4). Heightened emotions were particularly prevalent for those who were involved in supporting teenagers.[8,9,21,22,26,27,49] However, dealing with dependent children of any age was described by a district nurse as being … *heart-rending* … (p. 377).[26] Dealing with stressful emotions, was harder for those who worked in isolation without the support of the multidisciplinary team.[21,28]

Distancing and detachment. By … *not daring to face these children* … (p. 36)[7] professionals distanced themselves from supporting them.[7–10,21,26–28,51] *You just have to switch off* … and *You do have to keep yourself a bit detached* (p. 152).[21] Experiencing painful emotions fuelled a sense of helplessness and uncertainty in professionals about how they should act.[19,20,27,51]

Managing health and social care professionals' emotions through peer support. To help to manage their emotions, professionals sought reassurance from peers that they were … *doing the right thing* (p. 154).[21] They welcomed the opportunity to reflect on, and to share with the multidisciplinary team,[7,20,27] their experiences of, the … *hurt really that happened* … (p. 458).[20] They sought feedback from the wider team to deal with the stress and intense emotions engendered by their supportive role.[7,8,10,20–22,27] Some reported that they would value debriefing, counselling support and role modelling by experienced others such as psychologists and specialist nurses.[19,21,49]

Improving connections with parents and with their children

The focus of this analytical theme was on professionals' perceptions of what they needed to help to improve their ability to connect empathically with parents and children. Thematic synthesis identified one descriptive subtheme.

Seeking recognition and support. Professionals sought affirmation from employers of their supportive role with parents and recognition of their responsibility towards dependent children.[7,8,20,21,27] To prevent children from being overlooked when a parent was dying, health and social care professionals wanted improvements in organisational policy.[8,20,22] In addition, nurses identified the need to 'flag up' inpatient records, the presence of children in the family, from when a parent is admitted to hospital[51] or the hospice.[20] Those working in haematology, neurointensive care, gynaecological cancer,[51] oncology,[21,27] palliative care[19,20] and in primary care[19,26] wanted training to enhance communication with parents and with children of different ages and to understand children's developmental stages concerning and support needs.[8,19,21,22]

What this study adds

The three analytical themes demonstrated that developing empathic rapport with parents and with their children was key to professionals' ability to deliver family-focussed care. Conceptualised by Baillie,[54] empathy in the context of healthcare involves health professionals connecting with the experiences of their patients to facilitate supportive rapport and an effective working alliance.[55–57] However, this involves complex relational interactions between health and social care professionals, patients and the healthcare environment.[58]

Connecting with parents and children to provide family-focussed care in the context of this review demanded significant emotional work for professionals.[19–22,26,27,49,51,52] This construct was first defined by Hochschild[59,60] in 1983 to be how employees' emotions, values, and how they work, are shaped and managed by the ethos of their employing organisation. Developed in a nursing context by Smith,[61,62] emotional labour describes the ethos of how nurses' workplaces influence the quality of patient care. For example, if not supported by employers and by colleagues to manage and recognise their emotions, nurses were in danger of losing their ability to empathise and act compassionately.

No studies included in this review directly identify the concepts of emotional work[59,60] or labour.[61,62] However, Smith's[61,62] findings are borne out by health and social care professionals in this review, who because of perceived lack of emotional support from employers, detached from connecting with parents and children, protecting themselves from experiencing significant emotional distress. To manage the pain of over-identifying with parents and children, professionals developed distancing behaviours such as focusing on the physical care of the patient and avoidance of talking to the parents about their children.[19–21,27,28,51]

First identified in relation to the work of health professionals in 1960, professional distancing was conceptualised by Menzies[63] as a form of emotional protection. Menzies's work resonates with that of Söderberg et al.[64] who reported that when asked to participate in ethically conflicting and difficult care enrolled nurses working in intensive care in Sweden experienced feelings of inadequacy, isolation and powerlessness. These feelings led them to experience emotional desolation and resultant distancing behaviours.

Distancing as part of self-protection is not the whole picture. Harking back to Menzies's[63] their Rankin's[65] ethnography reported an emotional disconnect by nurses when patient care is organised around the technical care of the patient and around institutional policies, rather than being family-focussed.

Within this review, professionals' management of emotions was partly dependent on their perceptions of their professional roles and of their perceptions of the ethos of their employing organisations.[7–10,19,51] In keeping with Rankin,[65] some professionals within this review perceived the focus of their role to be on the technical care of their patients, rather than on the emotional welfare of patients' families.[8,20,21,51] These findings concur with those of Bridges et al.[66] who, building on Menzies's work,[63] concluded that the extent to which an institution embraces patient-centred care enhances or inhibits nurses' capacity to connect with patients to support them.

Bridges et al.[66] contended that to truly connect with their patients, nurses must 'be present', bringing aspects of their authentic selves to the nurse/patient relationship. However, Hochschild[59,60] suggests that for employees to be effective, employing organisations require them to replicate the work they are trained to do and to suppress their authentic selves. For professionals within this review, the level of recognition of the importance of their supportive, family-focussed role, and the extent to which they could bring their authentic selves to enable effective connecting with parents and children, depended partly on organisational culture.[7–10,19–22,26–28,49,51]

Involving their authentic selves in supporting parents and children caused professionals to experience personal and professional conflict.[7,8,19,21,22,26,51,52] For example, aspiring to provide family-focussed care, they sought help from employers to enable them to manage their personal emotions and recognition of the significance of their supportive role.[7,8,19–22,26–28,51] If not supported by their organisations, professionals sought to self-manage sometimes conflicting emotions and roles.[20,21,27] It is possible that some managed their emotions by adopting task-orientated persona.[7,8,28,51]

Strengths and limitations

This review is the first to synthesise findings from studies reported on in peer-reviewed papers about the experiences of health and social care professionals when supporting parents and children during, and following, the death of a parent in Western healthcare systems. Variations in methodology, method, treatment stage, the setting of care, roles of professionals, their employing organisations and quality and relevance of included papers impacted on findings of the synthesis. Conclusions drawn are guided and limited by the research conducted to date. Although some findings are transferable concerning work setting and professional roles, the variety of methods used, demography and diverse geographical settings mean that it is not possible to generalise findings from this review.

The 15 included studies were limited to the experiences of registered health and social care professionals. The review did not take into account the views of parents, dependent children, and non-registered healthcare assistants. As social health operators do not have registration in Italy, their experiences could not be included.[22] The review is of studies using qualitative methods and as such quantitative studies addressing the research question were not included.

Not having their primary focus on professionals' experiences of supporting parents and children meant that some included studies are not transferable to settings where the focus is on supporting parents and children surrounding the death of a parent. Nevertheless, because these studies contained verbatim quotes of relevance to this review, they were included.[9,10,26,28,49,50,52]

Although covering experiences of health and social care professionals in five countries and across three continents, papers within this review focussed on delivery of care in Western healthcare systems only. There is a need for further research into the experiences of health and social care professionals in developing nations.

Implications for current practice

Children were not always visible within the healthcare system.[8,19–22,27] Even when policies and procedures enabling the recognition of children were in place[20,51] and when the importance of involving children when parents are dying was nationally acknowledged by legislation,[7–10] children's support needs were reported to be overlooked.

The ability to connect empathically with parents and with children was blocked by professionals' heightened emotional distress.[8,19,20–22,51] To enhance their confidence to connect with parents and children, managers, employing organisations and national policymakers need to acknowledge the importance of this supportive role. In addition, to enable professionals to fulfil this role, there need to be adequate resources in place. Furthermore, there is a need for healthcare organisations to promote a learning culture in relation to supporting employees to manage their emotions, facilitating connecting with parents and with children surrounding the death of a parent.

Future research

This review highlights professionals' need to develop and maintain emotional resilience to connect with parents and with children surrounding the death of a parent. Only one paper included in this review focuses on experiences when supporting dependent children after a parent has died.[22]

No empirically tested interventions focusing on supporting professionals to connect with surviving parents and children following the death of a parent have yet been identified. There are evidence-based interventions focusing on enhancing professionals' knowledge of how to communicate with parents and children when parents are dying.[67,68] These support palliative care professionals in acute oncology settings and require face-to-face attendance at study workshops.[68,69] There is therefore, a need to develop alternative interventions for a broader professional population, focusing on supporting professionals to connect with parents and children both pre- and post-parental death and which can be delivered flexibly in a time and resource-limited environment. There is a need to conduct participative research with professionals, surviving parents and with dependent children to investigate what is needed to support professionals in their emotional labour. Findings could be used to design, pilot-test and evaluate an intervention to support professionals to establish empathic connections with parents and with children.

Conclusion

Synthesis of health and social care professionals' experiences indicates that despite multiple barriers to doing so, they aspire to connect with parents and with children to prepare and support the children surrounding the death of a parent. To improve outcomes for parents and children, there is a need to transform distancing behaviours and professional detachment into improved confidence to connect with parents about their children, throughout this emotionally demanding life event.

Importantly, health and social care professionals need support from employing organisations to recognise the presence of children in families from when a parent is diagnosed with a life–limiting illness, to after a parent has died. However, this is not enough. To deliver family-focussed care health and social care professionals seek support to manage their personal emotions. Raising international, national and local organisational awareness of the importance of their supportive role surrounding parental death may contribute to the development of policy and to the development of interventions to help health and social care professionals to enhance their confidence to connect with parents and with children.

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