

Providing care to parents dying from cancer with dependent children: Health and social care professionals' experience

Jeffrey R. Hanna^{1*},

Eilís McCaughan²,

Esther R. Beck¹,

&

Cherith J. Semple^{1,3}

* indicates corresponding author

1. School of Nursing, Ulster University, Newtownabbey, UK

2. School of Nursing, Ulster University, Coleraine, UK

3. South Eastern Health and Social Care Trust, Cancer Services Ulster Hospital, Belfast, UK

ABSTRACT

Objective: Parents often feel ill-equipped to prepare their dependent children (<18 years old) for the death of a parent, necessitating support from professionals. The aim of this study is to explore health and social care professionals' (HSCPs) experiences and perceptions of providing supportive care to parents regarding their children, when a parent is dying from cancer.

Methods: Semi-structured qualitative interviews were conducted with 32 HSCPs, including nurses, allied health professionals, social workers and doctors from specialist or generalist roles, across acute or community sectors.

Results: HSCPs' perceptions of the challenges faced by many families when a parent is dying from cancer included: parental uncertainties surrounding if, when and how to tell the children that their parent was dying, the demands of managing everyday life, and preparing the children for the actual death of their parent. Many HSCPs felt ill-equipped to provide care to parents at end of life concerning their children. The results are discussed under two themes: (1) hurdles to overcome when providing psychological support to parents at end of life and (2) support needs of families for the challenging journey ahead.

Conclusions: There appears to be a disparity between HSCPs' awareness of the needs of families when a parent is dying and what is provided in practice. HSCPs can have a supportive role and help equip parents, as they prepare their children for the death of their parent. Appropriate training and guideline provision could promote this important aspect of end of life care into practice.

Keywords: *parental cancer, oncology, health professionals, parental life-limiting illness, psycho-social support, parents, end of life, dying, qualitative research*

1. BACKGROUND

Preparing dependent children (<18 years old, hereafter referred to as children) for the death of a parent is one of the greatest challenges faced by families, when a parent is dying from cancer^{1,2}. This article refers to the term ‘dying’ when the death of a patient is anticipated within the next three months³. Often, parents feel ill-equipped to prepare their children for this end of life (EOL) experience⁴⁻⁶.

Where children are regularly informed of a parent’s declining health at EOL and included in family communication, this enhances family functioning and trust between the child and parents^{4,7,8}. Children prepared for the death of a parent adapt better long-term with improved psychosocial functioning⁹, compared to peers less prepared for the death of a parent^{10,11}. Often, parents feel they are protecting their children by not including them throughout the EOL experience⁶. There is a need to support parents to foster an environment of open and honest communication with the children, when a parent is dying from cancer⁶.

Parents have reported a need for guidance from health and social care professionals (HSCPs), as parents support their children throughout the cancer trajectory¹², especially when the parent's health is declining and death is impending^{6,12,13}. Despite parents’ desire for guidance, the literature highlights this aspect of care is often not addressed as part of routine practice¹³. HSCPs have reported a lack of knowledge and confidence to provide emotional support for parents who are dying regarding their children, as well as highlighting environmental healthcare barriers such as time pressures¹³⁻¹⁵. These studies have predominately focused on oncology nurses¹³, whereas there are a variety of HSCPs who provide important clinical and non-clinical support when a parent is dying from cancer¹⁶. These include specialist (i.e. social workers [SWs], allied health professionals [AHPs], clinical nurse specialists [CNS’]) and generalist (i.e. community and acute care nurses) HSCPs. While international studies demonstrate that 20-78% of patients die in the acute setting,^{17,18} global trends have reported an increase in patients dying in the community,¹⁹ necessitating the need for this research to be inclusive of HSCPs across acute and community sectors.

Exploration of HSCPs’ experience and perceptions of caring for families when a parent is dying from cancer will aid our understanding of how HSCPs working in clinical practice can be

equipped to provide psychological care and support to parents concerning their children, when a parent is dying from cancer.

Aims and objectives

The current study aims to explore HSCPs' experience and perceptions of providing care to parents concerning the children, when a parent is dying from cancer. The objectives of this study are to explore:

1. HSCPs' experiences within routine clinical practice of providing care and support to parents concerning their children, when a parent is dying from cancer,
2. HSCPs' perceptions of the challenges experienced by families when a parent is dying from cancer,
3. HSCPs' perceptions of how parents can be best supported in relation to the children, when a parent is dying from cancer.

2. METHODS

A qualitative design using semi-structured interviews. The study is reported following the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines²⁰.

Participants

Between March 2018 and August 2019, purposive and convenience sampling identified 32 HSCPs within one Trust in the UK. This method was considered most appropriate to ensure a diverse range of oncology and palliative care HSCPs across acute and community sectors were recruited to the study. Eligible participants were identified from a database and contacted by the fourth author [CJS] via email, and provided them with the participant information sheet, of which seven potential participants declined. Interested and willing professionals confirmed participation with the first author [JRH] who coordinated and facilitated the study.

Data collection

Semi-structured interviews were carried out. A topic guide was developed and piloted, guided by the literature, alongside the research and expert group (Table 1). The expert group consisted of a palliative care SW and CNS, a family support worker and a bereaved parent and child

(aged 14). Members of the expert group were identified from a healthcare Trust, a hospice service, and a family support service in Northern Ireland. The HSCPs within this expert group were recruited because of their vested interest and experience of delivering care to families at EOL. The topic guide was reviewed and iteratively modified as necessary, to enable follow-up with identified categories in subsequent interviews. Interviews were completed when no further categories were identified. Interviews took place within the healthcare setting, face-to-face, audio recorded and lasted between 20 and 50 minutes. The first author [JRH] who had no prior relationship with the HSCPs conducted the interviews.

Data analysis

Audio-recordings were transcribed verbatim and verified by the research team. Braun and Clarke's thematic analysis framework²¹ was used to analyse the data. Initially, the first author [JRH] read and reread the transcripts to gain a sense of each participant's story. Following line by line scrutiny of the transcripts, the first author [JRH] coded the data using NVivo V12. Deployed as an inductive method, codes were developed by marking similar phrases or words in the participants' narratives. The first author collated the codes and identified where some of them merged into themes. To ensure rigour, credibility and trustworthiness, the codes and themes were independently analysed by three co-authors [EMcC, ERB, CJS]. Themes were verified and refined through discussion with all authors.

Ethical considerations

HSCPs received oral and written information about the study and provided written consent. Participants were made aware of the right to withdraw, and a distress protocol procedure was established to protect HSCPs. Data protection procedures were observed and assurances of confidentiality were given. Ethical approvals were obtained from Ulster University Filter Committee and South West - Cornwall and Plymouth Research Ethics Committee [REC:17/SW/0155].

3. RESULTS

A varied sample of generalists (*n*14) and specialists (*n*18) from both the acute (*n*17) or community (*n*15) settings were recruited. HSCPs had at least four years experience working with

cancer patients ($mAvg = 18years$, range: 4-34 years), with five who had formal training on caring for parents who are dying regarding the children. Sample characteristics are reported in Table 2.

Two overarching themes were identified: (1) hurdles to overcome when providing psychological support to parents at EOL and (2) support needs of families for the challenging journey ahead.

Theme 1: Hurdles to overcome when providing psychological support to parents at EOL

HSCPs highlighted the importance of providing supportive care to parents at EOL regarding the children. However, the provision of this care was considered by most HSCPs as ‘outside my remit’. Also, obstacles were perceived as barriers towards providing care to parents at EOL in routine care in relation to the children. These issues are further discussed under two sub-themes: (1) not my role and passing responsibility onto other HSCPs and (2) navigating an emotional obstacle course.

Sub-theme 1.1: Not my role and passing responsibility onto other HSCPs

Most HSCPs described their role as providing physical care such as pain or symptom management, when a parent was dying from cancer. Often, HSCPs working in the acute setting reported clinical interactions as too short and focused on the ill-parent’s treatment needs. As a result, many HSCPs working within the acute setting perceived parental needs at EOL in relation to the children were ‘picked up’ by community teams. Despite this, within the community sector HSCPs often perceived this support was provided in the hospital setting, either at outpatient appointments or during inpatient admissions.

“You know as a nurse you are restricted with time. Its like you come in, change the driver and leave. I would imagine that someone would have spoken to the parents about their kids when they got the bad news” [HSCP 11; community generalist; community care nurse]

Some specialist HSCPs working in outpatient clinics felt parents required time to process distressing information shared with them during their consultation. These HSCPs perceived engagement in conversations regarding the children could be ‘too much’ for parents to handle in the

same appointment, and perceived community care nurses were better placed to care for the needs of parents when mum or dad was dying from cancer. It was suggested by these HSCPs that the community care team would have insight to the particular needs of each family as a result of regular contact with the parents (and children) in the home.

“Appointments here can be very distressing, particularly if it is bad news. But district nurses are rubbing shoulders with everybody who’s coming into the house. They have more time to get to know the family and explore their needs” [HSCP 03; acute specialist; palliative clinical nurse specialist]

It was perceived by most HSCPs that healthcare disciplines such as counsellors and social care professionals, or family support workers at cancer charity organisations were better skilled to support families when a parent is dying from cancer.

“I encouraged them [parents] to use the voluntary sector because they seem to be the right sort of people that can help” [HSCP 08; acute specialist; oncology physiotherapist]

Many of these HSCPs stated these disciplines would have the expertise to care for the needs of parents and their children at EOL. Some specialist HSCPs reported experiences of signposting parents to a family support service, if a parent suggested concern surrounding the impending death could have on the children. However, it was not clear if the support services were availed of or helpful for families, as HSCPs usually reported no follow up with parents in relation to accessing these services. Alongside this, many HSCPs were unaware what the family support service actually offered.

Sub-theme 1.2: Navigating an emotional obstacle course

Most of these HSCPs were parents who had dependent children and stated how they often ‘put themselves in a patient’s shoes’, transferring how distressing the EOL experience is likely to be for parents. As a result, HSCPs talked about how emotionally challenging engagement in conversations with parents concerning their children could be and steered away from it.

“Here was this thirty year old woman sitting in front of me who was probably in the last few weeks of life, and I was thinking about her little people at home. But I didn’t talk about the kiddies then. I didn’t want to upset her anymore, or myself at that time. I did tell her if she needed anything to get in touch” [HSCP 02; acute specialist; palliative clinical nurse specialist]

Furthermore, some suggested a display of their emotion could appear unprofessional and they had to ‘keep it together’ to continue on to the next patient. Others suggested they felt unable to offload the emotional impact of providing care to parents at EOL, as they did not have access to clinical supervision and lacked support within clinical teams.

“Emotionally I find patients with young teens more challenging because I find it hard to separate myself from the situation. I suppose I’m aware that’s something that could make me emotional and I’m not there to cry. I’ve a job to get on with.” [HSCP 13; community specialist; speech and language therapist]

HSCPs stated they had a lack of confidence and, or rapport with parents they had just met to pursue in conversations regarding the children. Alongside this, HSCPs often reported a lack of knowledge on how best to provide parents with age-appropriate support for the children according to their developmental understanding. Also, HSCPs were concerned that discussing with parents how best to support their children may appear as interfering.

“I wouldn’t want to say do this and do that and then the child reacting bad to it. They [parent] would be coming back here saying why did that silly woman tell me to do that” [HSCP 07; acute specialist; acute clinical nurse specialist]

Some HSCPs reported there were a lack of opportunities to get the parent (either) alone to discuss what the children had been told and how to support them. On many occasions both the clinical area and home lacked privacy. For example, in the hospital only a curtain separating patients or in the family home whilst changing a syringe driver there were always people around.

HSCPs perceived it would be inappropriate and insensitive to engage in emotive conversations with parents regarding the children when privacy was lacking or in the presence of others.

“It would have been insensitive for me to ask the parent if the kids knew that she was going to die, and them [children] sitting in the next room. What if they didn’t know and heard me”
[HSCP 20; community generalist; community care nurse]

Theme 2: Support needs of families for the challenging journey ahead

There was an awareness by some HSCPs of the need to empower parents to support the children, pre-bereavement. These HSCPs described how beneficial it would be if parents *‘actively walked with the children’* through the EOL experience, involving them in decisions and care being provided. This could reduce the possibility of later adverse outcomes for the child’s grief, such as guilt, mistrust and anger. These HSCPs reported experiences of responding to and caring for the needs of parents, when mum or dad was dying from cancer. Rather than the location of delivery of care (acute or community) or discipline of the HSCP, factors such as previous clinical and personal exposure to cancer and death appeared to impact on the level of supportive care provided.

“I’ve been in the profession for over thirty years now, and over that time I’ve picked up some tips on what seemed to of worked well for some of these families. That exposure has shaped my confidence and practice” [HSCP 17; acute specialist; oncology clinical nurse specialist]

HSCPs highlighted perceptions of the challenges experienced by many families, and some reported how HSCPs could care for parents concerning their children in routine practice when mum or dad is dying from cancer. These are discussed under three sub-themes: (1) to tell or not to tell, that mum or dad is dying, (2) ongoing and changing needs and (3) preparing for the actual death.

Sub-theme 2.1: To tell or not to tell, that mum or dad is dying

HSCPs reported that some parents thought it was best to tell the children mum or dad was dying, providing reasons such as the children would know *‘something’s wrong’*. Other parents were described as less forthcoming to disclose the reality of the situation with the children. These

parents were perceived by HSCPs as protecting their children from pain and upset. Also, HSCPs talked about how some ill-parents were *'living and coping relatively well'* despite dying from cancer. Consequently, these parents were perceived as *'trying to keep things normal'* within the family with the hope that death was not so imminent, thus postponing sharing the reality of the situation with the children until there was an evident and rapid physical decline in the parent's condition. Other parents were described as focused on hope that the cancer could be cured, to which HSCPs viewed as parents denial surrounding the reality of the poor prognosis.

"They were hopeful that the treatment was going to work. Their approach was to shield the children. I guess they didn't want to upset them" [HSCP 22; community specialist; palliative care educationalist]

Some HSCPs reported experiences where both parents had different ideas on how best to support the children. One example was where one parent (either) felt the children should be informed mum or dad was dying, and the other believed it was protecting the children from upset by not telling them. HSCPs perceived this to result in heightened levels of tension, worry and anger between the two parents. These HSCPs suggested it could be helpful if HSCPs encouraged both the ill and well-parent to tell the children that mum or dad was dying, as soon as possible, *'as they may know something is wrong and think it is their fault if not informed'*.

"The daddy was quite dismissive of approaching the subject with the children. She [well-parent] felt like she couldn't go against him [ill-parent]. It was eating away at her" [HSCP 15; community generalist; community care nurse]

HSCPs stated that many parents were unsure how best to tell the children that mum or dad was going to die from cancer. HSCPs often suggested parents should have a *'natural conversation'* with the children, for example at the dinner table, and ask the children open questions to gauge understanding such as *'do you know what is going on?'* or *'are you worried about Mum or Dad?'* HSCPs perceived it was good practice to encourage parents to avoid vague language with young children, such as *'Mummy is poorly'*. Rather, provide the children with small chunks of information such as, *'the doctors have tried their best to help Mummy, but she isn't going to get better'*,

with regular updates surrounding the parent's treatment and declining health. It was reported some parents were concerned if the children would ask difficult questions such as '*when are you going to die?*'. A suggested response was '*we don't know exactly when, but we will take one day at a time*'.

Sub-theme 2.2: Ongoing and changing needs

HSCPs perceived some parents were 'family-managing' the dying period with the children, and had relatively clear plans to navigate the parental role throughout the EOL experience. It was reported these parents appeared to be openly communicating with their children about the reality of the parent's declining health. Other parents were suggested to have reached out themselves to cancer charity organisations for support in relation to preparing the children for the actual death of the parent, or engagement in pre-bereavement activities such as writing letters for the child's future or 'memory boxes'.

However, HSCPs did describe how the unfolding EOL experience was demanding for many well and ill-parents. Often, well-parents were perceived as juggling different roles when mum or dad was dying, such as taking a lead in parenting, caring for the partner and responsibility (sometimes sole) for being the primary earner. It was suggested by HSCPs that increased parental responsibilities or managing the home was '*alien*' to some well-parents, as this was not the typical role the mum or dad played in the family before the poor prognosis. HSCPs perceived some well-parents were overwhelmed in managing day to day parenting tasks when mum or dad was dying.

"The chap had his work cut out for him. He was coming up and seeing his wife and on top of that running round looking after two boys and managing the farm. He seemed exhausted"
[HSCP 09; acute generalist; acute care nurse]

It was reported some ill-parents appeared to struggle to do everyday parenting activities as a result of declining health, to include taking the children to school or cooking meals for the family. Some community care nurses and AHPs outlined examples of helping the ill-parent to practically carry out the parenting role at EOL, such as sourcing volunteers to help with grocery shopping or

driving to appointments, and obtaining physical aids so the parent could attend the child's sports day.

“She went off her feet but was adamant about getting to the daughter's sport's day. So we were able to facilitate getting a wheelchair and taxi with wheelchair access, so she could be part of that” [HSCP 16; community generalist; community care nurse]

Also, HSCPs reported how some well-parents were unable to maintain usual employment hours, as a result of balancing different parenting and caregiving roles when mum or dad was dying. HSCPs described some of these parents as having money worries to 'getting by', as a result of a reduced household income. It was perceived helpful to families when the HSCP informed parents of the sources of financial benefits the family were entitled to.

“He [ill-parent] started a new treatment which made him quite sick and spent a good few weeks as an inpatient. She [well-parent] stopped work at this stage to be with him, but the money was getting tight” [HSCP 17; acute specialist; oncology clinical nurse specialist]

Sub-theme 2.3: Preparing for the actual death

HSCPs perceived parents were often uncertain how to navigate the active dying stage with the children. This included sharing the news that mum or dad was moving to a hospice, or may not return home from hospital, or was coming home from hospital to die. Also, parents were often perceived anxious if the children could be present when mum or dad was actively dying. In situations where the dying parent was perceived not to be in 'distress', some HSCPs reported providing advice to parents on offering the children the choice to be present when their mum or dad was actively dying, as being present could help the child's understanding of how the parent died.

“Her husband was dying and she was just looking at me for answers or for something to help along in her thoughts. She didn't know what to do about her son” [HSCP 01; acute specialist; palliative social worker]

It was suggested that some parents themselves were unaware of what the death process would look like physiologically, as they had never seen a death before. As a result, these families were perceived as unsure how best to prepare the children for the actual death of a parent. One acute care nurse suggested it could be helpful if HSCPs informed parents of the process of what may happen during the active dying phase such as colour changing, excess secretions, and lack of consciousness, so the well-parent is equipped to prepare the children when mum or dad is actively dying.

4. DISCUSSION

Findings highlighted HSCPs' experience and perceptions of the challenges and complexities encountered by many families when a parent is dying from cancer. Challenges reported included parents' uncertainty to tell or not to tell the children that mum or dad is going to die, challenges surrounding juggling of parental responsibilities when a parent is dying, and preparing the children for the actual death. However, many HSCPs reported a lack of confidence and felt ill-equipped to provide care to parents regarding their children when mum or dad was dying from cancer. These perceptions have been echoed in studies with oncology nurses by Arber and Odelius²², Dencker et al.²³ and Turner et al.²⁴. However many HSCPs in this study, whether in the acute or community setting, felt it was not their role to provide advice and guidance to parents at EOL regarding their children.

Providing psychological care to parents in relation to their children when a parent is dying from cancer was highlighted as a highly emotional activity for HSCPs. It is possible HSCPs in this study did not feel comfortable engaging in these emotive conversations at EOL for a fear of causing parents²⁵ or themselves^{26,27} further distress. In addition, HSCPs are unsure if it is their role, and if so, how and when is it appropriate to open up conversations with parents who are dying regarding their children, as parents often need time to process this distressing information²⁸. Multiple other factors and complex family dynamics can influence and inhibit the provision of advice to parents about what to tell their children when mum or dad is dying with cancer from HSCPs, such as knowledge of a child's developmental stage and/or learning needs²⁴, background family factors relating to divorce or separation²⁹, and their previous or vicarious experiences. Other possible explanations as to why this aspect of care is often lacking in clinical practice includes: a desire to

avoid an emotional attachment with a dying patient³⁰, HSCPs' focus of providing physical rather than psychological care³¹, and shifting responsibility of the role to other HSCPs³².

Engaging in conversations with parents at EOL concerning their children appear to be difficult for HSCPs to have¹³. Alongside this, obstacles may act as barriers towards the provision of supportive care to parents at EOL concerning their children. For example, some parents may not feel emotionally ready to tell their children mum or dad is going to die, some parents may feel they have 'more time' and do not feel the need to prepare their children for an uncertain future, and some parents may be adamant that protecting their children is not to tell them the reality of the situation^{6,13}. There is a need for parents to understand that some necessary preparation is helpful and protective for their children surrounding the inevitable death of their mum or dad^{9,33}. HSCPs are ideally placed between acute and community sectors and 'outside' the emotional tension in the family to encourage this forward planning, and navigate parents through the dying period when there are heightened family needs⁶. There is a requirement for training to equip HSCPs with the knowledge and confidence to provide these challenging aspects of care, and to know when it may be appropriate and where to refer parents onto specialist services.

Clinical implications

To help facilitate adjustment for their child's future, parents should be encouraged to prepare children for their parent's death as early as possible, as the ill-parent's health could deteriorate quickly and the parents may be less able to support the children at that time. Therefore, HSCPs should equip parents by encouraging and supporting them to consider and plan how best to tell their children that mum or dad is going to die from cancer, when the parent is presented with the poor prognosis. Preparing and supporting the children earlier may reduce the stress and demands often experienced by the well-parent when the ill-parent is actively dying. Encouraging open communication alongside a child's sense of inclusion within the family are factors that can mitigate adverse effects into adult life^{6,9,34}. It may be helpful if HSCPs equipped parents with age-appropriate language as they prepare to tell their children that mum or dad is going to die (see section 'to tell or not to tell, that mum or dad is dying' for detail), and when the ill-parent is actively dying (see section preparing for the actual death for detail).

It would also be pertinent for HSCPs who are caring for parents at EOL to identify, and help them with ongoing needs at EOL such as obtaining practical support and, or financial support. Guidelines and training may promote HSCPs' awareness of their pivotal role, and to increase their confidence to provide supportive care to parents concerning their children, when mum or dad is dying from cancer^{13,35}. Provision of this training could be incorporated as a dedicated component within Advanced Communication Skills Programmes³⁶, equipping HSCPs with the necessary language to support parents to have age-appropriate conversations with children when their parent is going to die, and preparing parents for difficult questions.

To protect HSCPs against professional and emotional burnout and enhance the provision of family-centred cancer care, it would be pertinent that HSCPs are equipped and trained to deliver this aspect of care. This includes regular routine clinical supervision sessions for opportunities to discuss professional challenges of caring for parents in relation to the children when a parent is dying from cancer. Also, evaluation of healthcare structures and services could inform the development of interventions to target constraints such as high workloads, time pressures and lack of privacy. This could enhance HSCPs' provision of helping parents to support the children pre-bereavement, which could facilitate better coping for children in the future^{9,34}.

Study limitations

Despite a varied sample of acute, community, specialist and generalist HSCPs, findings are limited to HSCPs working within one Trust in the UK. Findings are representative of healthcare Trusts in Northern Ireland which do not have a dedicated family support worker. It is possible the presence of a family support worker in other healthcare settings may have an impact on HSCPs' provision of supportive care to parents at EOL concerning their children. It is possible HSCPs current role of caring for parents in other settings may vary, such as ethnically diverse cultures. While the findings may be applicable to other life-limiting conditions, the study focused on HSCPs' experience and perceptions of caring for parents dying from cancer.

5. CONCLUSION

Through the lens of HSCPs, this study provided insight to the complexity of some of the challenges faced by many families when a parent is dying from cancer. HSCPs can have an important role to equip parents in routine care, to support their children when a mum or dad is dying from cancer. However, there appears to be a disparity between HSCPs awareness of the needs of parents at EOL concerning their children, and the provision of supportive care in routine practice. There is a need for HSCPs to recognise their pivotal role in providing support to parents concerning their children when a parent is dying from cancer, and empower and equip HSCPs in the provision of caring for the needs of this population. Policy guidelines should also be developed to incorporate this aspect of care into routine clinical practice.

ACKNOWLEDGEMENTS

We would like to express our warm and sincere thanks to the 32 health and social care professionals who volunteered time, and consented to participate in this research. We also extend our gratitude to Dr. Geraldine Horigan for her assistance in obtaining ethical approvals for this research, and to Mr. Roger Theis for his transcription assistance. Finally, we extend our thanks to Prof. Kader Parahoo and Dr. Brenda O'Neill at the Institute of Nursing and Health Research, Ulster University, for insightful and helpful comments on a previous draft of this manuscript.

CONFLICT OF INTEREST

The authors declare that they have no conflict of interest.

DATA

AVAILABILITY

STATEMENT

The data that supports the findings of this study are available at the Ulster University Repository and available on request from the first author. The data are not publicly available due to privacy and ethical restrictions. The study passed ethical committee review [REC:17/SW/0155].

FUNDING

This work was funded by the UK Department for the Economy (DfE), awarded to the lead author [Jeffrey R. Hanna] to undertake this research as part of his PhD.

REFERENCES

- [1] Park EM, Deal AM, Check DK, Hanson LC, Reeder-Hayes KE, Mayer DK, Yopp JM, Song MK, Muriel AC, Rosenstein DL. Parenting concerns, quality of life, and psychological distress in patients with advanced cancer. *Psycho-Oncology*. 2016 Aug;25(8):942-8. <https://doi.org/10.1002/pon.3935>
- [2] Kopchak Sheehan D, Burke Draucker C, Christ GH, Murray Mayo M, Heim K, Parish S. Telling adolescents a parent is dying. *Journal of palliative medicine*. 2014 May 1;17(5):512-20. <https://doi.org/10.1089/jpm.2013.0344>
- [3] Hui D, Nooruddin Z, Didwaniya N, Dev R, De La Cruz M, Kim SH, Kwon JH, Hutchins R, Liem C, Bruera E. Concepts and definitions for “actively dying,” “end of life,” “terminally ill,” “terminal care,” and “transition of care”: a systematic review. *Journal of pain and symptom management*. 2014 Jan 1;47(1):77-89. <https://doi.org/10.1016/j.jpainsymman.2013.02.021>
- [4] Dalton L, Rapa E, Ziebland S, Rochat T, Kelly B, Hanington L, Bland R, Yousafzai A, Stein A, Betancourt T, Bluebond-Langner M. Communication with children and adolescents about the diagnosis of a life-threatening condition in their parent. *The Lancet*. 2019 Mar 16;393(10176):1164-76. [https://doi.org/10.1016/S0140-6736\(18\)33202-1](https://doi.org/10.1016/S0140-6736(18)33202-1)
- [5] Golsäter M, Enskär K, Knutsson S. Parents’ perceptions of how nurses care for children as relatives of an ill patient-Experiences from an oncological outpatient department. *European Journal of Oncology Nursing*. 2019 Apr 1;39:35-40. <https://doi.org/10.1016/j.ejon.2019.01.004>
- [6] Hanna JR, McCaughan E, Semple CJ. Challenges and support needs of parents and children when a parent is at end of life: A systematic review. *Palliative medicine*. 2019 Sep;33(8):1017-44. <https://doi.org/10.1177/0269216319857622>
- [7] Moore CW, Rauch PK. Communicating with children when a parent is dying. *Oxford Textbook of Communication in Oncology and Palliative Care*. 2017 Feb 24:344.

[8] Runcan PL, Constantineanu C, Ielics B, Popa D. The role of communication in the parent-child interaction. *Procedia-Social and Behavioral Sciences*. 2012 Jan 1;46:904-8. <https://doi.org/10.1016/j.sbspro.2012.05.221>

[9] Ellis J, Dowrick C, Lloyd-Williams M. The long-term impact of early parental death: lessons from a narrative study. *Journal of the Royal Society of Medicine*. 2013 Feb;106(2):57-67. <https://doi.org/10.1177/0141076812472623>

[10] Appel CW, Johansen C, Christensen J, Frederiksen K, Hjalgrim H, Dalton SO, Dencker A, Dige J, Bøge P, Dyregrov A, Mikkelsen OA. Risk of use of antidepressants among children and young adults exposed to the death of a parent. *Epidemiology*. 2016 Jul 1;27(4):578-85. <https://doi.org/10.1097/EDE.0000000000000481>

[11] Gray LB, Weller RA, Fristad M, Weller EB. Depression in children and adolescents two months after the death of a parent. *Journal of affective disorders*. 2011 Dec 1;135(1-3):277-83. <https://doi.org/10.1016/j.jad.2011.08.009>

[12] Fearnley R, Boland JW. Communication and support from health-care professionals to families, with dependent children, following the diagnosis of parental life-limiting illness: A systematic review. *Palliative medicine*. 2017 Mar;31(3):212-22. <https://doi.org/10.1177/0269216316655736>

[13] Franklin P, Arber A, Reed L, Ream E. 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. *Palliative medicine*. 2019 Jan;33(1):49-65. <https://doi.org/10.1177/0269216318803494>

[14] Dencker A, Kristiansen M, Rix BA, Bøge P, Tjørnhøj-Thomsen T. Contextualisation of patient-centred care: A comparative qualitative study of healthcare professionals' approaches to communicating with seriously ill patients about their dependent children. *European journal of cancer care*. 2018 Jan;27(1):e12792. <https://doi.org/10.1111/ecc.12792>

- [15] Fearnley R, Boland JW. Parental Life-Limiting Illness: What Do We Tell the Children?. In *Healthcare* 2019 Mar (Vol. 7, No. 1, p. 47). Multidisciplinary Digital Publishing Institute. <https://doi.org/10.3390/healthcare7010047>
- [16] Alsop A. Collaborative working in end-of-life care: developing a guide for health and social care professionals. *International journal of palliative nursing*. 2010 Mar;16(3):120-5. <https://doi.org/10.12968/ijpn.2010.16.3.47323>
- [17] Bekelman JE, Halpern SD, Blankart CR, Bynum JP, Cohen J, Fowler R, et al. Comparison of site of death, health care utilization, and hospital expenditures for patients dying with cancer in 7 developed countries. *JAMA*. 2016;315(3):272–83. <https://doi:10.1001/jama.2015.18603>
- [18] Broad JB, Gott M, Kim H, Boyd M, Chen H, Connolly MJ. Where do people die? An international comparison of the percentage of deaths occurring in hospital and residential aged care settings in 45 populations, using published and available statistics. *Int J Public Health*. 2013;58(2):257–67. <http://dx.doi.org/10.1007/s00038-012-0415-4>.
- [19] Etkind SN, Bone AE, Gomes B, Lovell N, Evans CJ, Higginson IJ, Murtagh FE. How many people will need palliative care in 2040? Past trends, future projections and implications for services. *BMC medicine*. 2017 Dec;15(1):102. <https://doi.org/10.1186/s12916-017-0860-2>
- [20] Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International journal for quality in health care*. 2007 Dec 1;19(6):349-57. <https://doi.org/10.1093/intqhc/mzm042>
- [21] Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative research in psychology*. 2006 Jan 1;3(2):77-101.

[22] Arber A, Odelius A. Experiences of oncology and palliative care nurses when supporting parents who have cancer and dependent children. *Cancer nursing*. 2018 May 1;41(3):248-54. [https://doi: 10.1097/NCC.0000000000000491](https://doi.org/10.1097/NCC.0000000000000491)

[23] Dencker A, Rix BA, Bøge P, Tjørnhøj-Thomsen T. A qualitative study of doctors' and nurses' barriers to communicating with seriously ill patients about their dependent children. *Psycho-oncology*. 2017 Dec;26(12):2162-7. <https://doi.org/10.1002/pon.4440>

[24]. Turner J, Clavarino A, Yates P, Hargraves M, Connors V, Hausmann S. Development of a resource for parents with advanced cancer: what do parents want?. *Palliative & supportive care*. 2007 Jun;5(2):135-45. <https://doi.org/10.1017/S1478951507070204>

[25] Brighton LJ, Bristowe K. Communication in palliative care: talking about the end of life, before the end of life. *Postgraduate medical journal*. 2016 Aug 1;92(1090):466-70. <http://dx.doi.org/10.1136/postgradmedj-2015-133368>

[26] Van Mol MM, Kompanje EJ, Benoit DD, Bakker J, Nijkamp MD. The prevalence of compassion fatigue and burnout among healthcare professionals in intensive care units: a systematic review. *PloS one*. 2015 Aug 31;10(8):e0136955. <https://doi.org/10.1371/journal.pone.0136955>

[27] Whitebird RR, Asche SE, Thompson GL, Rossom R, Heinrich R. Stress, burnout, compassion fatigue, and mental health in hospice workers in Minnesota. *Journal of palliative medicine*. 2013 Dec 1;16(12):1534-9. <https://doi.org/10.1089/jpm.2013.0202>

[28] Sprinks J. Nurses lack confidence in providing end of life care: staff need more training, and time, to hold difficult conversations with patients. *Nursing older people*. 2011 Mar 1;23(2):6-8.

- [29] Bugge KE, Helseth S, Darbyshire P. Parents' experiences of a Family Support Program when a parent has incurable cancer. *Journal of clinical nursing*. 2009 Dec;18(24):3480-8. <https://doi.org/10.1111/j.1365-2702.2009.02871.x>
- [30] Martins Pereira S, Fonseca AM, Carvalho A.S. Burnout in palliative care: A systematic review. *Nursing Ethics*. 2011 May;18(3):317-26. <https://doi.org/10.1177/0969733011398092>
- [31] Towers R, Berry L. Providing psychological support for patients with cancer. *Nursing Standard (through 2013)*. 2007 Nov 28;22(12):50.
- [32] Clipsham L, Islam Z, Faull C. Experiences of hospice inpatient nurses in supporting children before the death of a parent. *International journal of palliative nursing*. 2015 Sep 2;21(9):453-9. <https://doi.org/10.12968/ijpn.2015.21.9.453>
- [33] Kennedy VL, Lloyd-Williams M. How children cope when a parent has advanced cancer. *Psycho-Oncology*. 2009 Aug;18(8):886-92. <https://doi.org/10.1002/pon.1455>
- [34] Niemelä M, Paananen R, Hakko H, Merikukka M, Gissler M, Räsänen S. Mental disorder diagnoses of offspring affected by parental cancer before early adulthood: the 1987 Finnish Birth Cohort study. *Psycho-oncology*. 2016 Dec;25(12):1477-84. <https://doi.org/10.1002/pon.4088>
- [35] NICE. *Improving supportive and palliative care for adults with cancer*. London: Nice, 2004.
- [36] Moore PM, Rivera S, Bravo-Soto GA, Olivares C, Lawrie TA. Communication skills training for healthcare professionals working with people who have cancer. *Cochrane Database of Systematic Reviews*. 2018(7). <https://doi.org/10.1002/14651858.CD003751.pub4>

Table 1: Semi-structured topic guide used to guide the conduct of the study

Initial topic guide based on the literature, research aims and objectives and expert group.

1. Explore HSCPs' perceptions of the challenges experienced by families when a parent is dying from cancer
2. Explore HSCPs' experiences of caring for parents when a parent is dying regarding the children.
3. Establish if providing care and support for parents who are dying regarding the children is part of routine practice.
4. How best could a HSCP help parents in routine care regarding the children when a parent is dying from cancer.

Sample of additional topics following identification of initial categories.

5. Parental readiness in telling the children mum or dad is dying.
6. The role of the generalist vs specialist and acute vs community HSCPs.
7. Supportive clinical environments and emotional offloading.

Table 2: Characteristics of the 32 HSCPs recruited in the study

Variables	HSCPs (n32)
Acute specialists	
Palliative social worker	2
Palliative clinical nurse specialist	2
Palliative care consultant	3
Acute clinical nurse specialist	1
Oncology physiotherapist	1
Oncology clinical nurse specialist	3
Community specialists	
Community clinical nurse specialist	1
Oncology physiotherapist	1
Speech and language therapist	1
Occupational therapist	1
Palliative care educationalist	2
Acute generalists	
Acute care nurse	3
Chemotherapy nurse	2
Community generalists	
Community care nurse	9