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Parental terminal cancer and dependent children: a systematic review

Alexandra Wray [1], Julie Seymour,[2] Sarah Greenley,[3] Jason W Boland [4,5]

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[1]Wolfson Palliative Care Research Centre, Hull York Medical School, Univeristy of Hull, Hull, UK
[2]Institiute of Clinical Applied Health Research, Hull York Medical School, Univeristy of Hull, Hull, UK
[3]Institute of Clinical and Applied Health Research, Hull York Medical School, University of Hull, Hull, UK
[4]Wolfson Palliative Care Research Centre, Hull York Medical School, University of Hull, Hull, UK
[5]Palliative Medicine, Care Plus Group and St Andrew's Hospice, NE Lincolnshire, UK

Correspondence to
Alexandra Wray, Wolfson Palliative Care Research Group, Hull York Medical School, Hull, UK; Alexandra.wray@hyms.ac.uk

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ABSTRACT

Background When a parent has terminal cancer, their children are part of that experience. Parents often want to protect their children from their disease and prognosis. Knowledge of dependent children's experience will help ensure they receive appropriate support. To date, there is lack of synthesis of this evidence examining children's perspectives.

Objectives To systematically search and synthesise the qualitative literature exploring the experiences of dependent children when their parent has terminal cancer.

Methods Databases of MEDLINE, Embase, PsycINFO, CINAHL, Assia and the Cochrane library were searched systematically from inception to July 2020 to determine eligible studies. Included studies were appraised for quality and thematically synthesised using Thomas and Harden's thematic synthesis framework.

Results Fourteen studies were included, which interviewed children about their experiences (n=654 children aged 4–18 years at the time of parental death), from six countries. Five descriptive themes were identified, further categorised into two broad themes: (1) finding out about parental cancer and its impact on the family and (2) coping with life with parental cancer, death and beyond.

Conclusion Children want to be involved in their parent's cancer experience and to help support the family. Healthcare professionals are ideally placed to support and encourage parents to include their children. They should reassure parents that children can cope well and that maintaining normality will help, and explain the benefits of honest and open communication and how they can include dependent children from diagnosis and beyond.

What is already known about the topic?

- Parents want to protect their children.
- Parents want support from healthcare professionals to communicate with their children and children want the opportunity to speak to healthcare professionals.

What this paper adds

- This review demonstrates that children are and want to be actively involved in family life when their parent has terminal cancer.
- Children do not want to be protected; they want to be informed to prepare for what is to come.
- Children need parents to provide open and honest communication to allow them to understand what is happening.

Implications for practice, theory or policy

- When a parent has terminal cancer, it is vital that healthcare professionals encourage the parent to include their children and encourage families to have open and honest conversations from diagnosis and beyond.
- Additional research to identify what support children and their families experiencing parental illness and parental death should receive is needed to inform how we can better support families.

INTRODUCTION

Within the UK, it was estimated in 2015 that a child under the age of 18 is bereaved of a parent every 22 minutes. This equates to 41 000 dependent children bereaved each year.[1] A parental death causes radical change for children.[2] The consequences within the family and home will be the most fundamental loss they will experience, which will alter the core of their existence.[2 3]

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When a parental death is anticipated, children can experience increased psychosocial distress and anticipatory grief.[4] Certain coping mechanisms can help, including maintaining routine and normality, maximising social networks, open communication and quality time with their dying parent.[5]

Following a parental death, children are at greater risk of experiencing adverse reactions and behaviours, including increased feelings of aggression, despair, anxiety, depression, social isolation, post-traumatic stress disorder, suicide, disruptive behaviour, and problems with attainment and achievement.[3 6–9] Children need support, nurturance and continuity; their emotions and behaviours are strongly influenced by the surviving parent and other adults reactions.[3]

A parental cancer diagnosis has an impact on the whole family who have to adapt to a life involving cancer which will bring additional needs and struggles.[10 11] Parents and children desire support from healthcare professionals who are often reluctant to provide support due to their fears of insufficient time and expertise[12]; children are often excluded from what is happening in their family.[13]

A few studies have focused solely on the impact of parental cancer on the children of parents with non-terminal cancer or other life-limiting illnesses.[5 14–17] No systematic review has assimilated research on the voice of children of all ages when a parent has terminal cancer.

Listening to the voice of the child and their lived experience is vital to inform clinical practice, shape policies and to develop services and information to support them.[1] Children are experts on their own lives; however, often adult–child power dynamics act as a barrier to their voices being heard, and it is impossible to explore the lived experience of children without including them.[18] Children are in a unique position to provide insight into their own lived experience.[19] Despite this, there is currently limited empirical knowledge about the experience for children, in their words, when a parent has terminal cancer.

The aim of this systematic review was to identify from children's accounts the lived experience of having a parent with terminal cancer; from them learning about the cancer diagnosis, through treatment and following the death of their parent. As a result, the provision of this knowledge will contribute to an important gap in the evidence of how healthcare professionals and parents can support and improve the experience for children when a parent has terminal cancer.

METHODS

The review followed an a priori protocol and is reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2009 guidelines,[20] which is a widely recognised standardised guide which facilitated the development and reporting of this systematic review.

Search strategy and sources

A draft search strategy for Ovid MEDLINE was developed with a university information search specialist (SG) after reviewing existing systematic reviews on related topics to determine potential terms for inclusion and using PubMed PubReminer and Yale MeSH Analyzer. The strategy was devised to be inclusive of all potentially relevant studies, using Medical Subject Heading terms and also text word searches to increase the search sensitivity. The MEDLINE search (box 1) was then adapted for use in other databases with their database-specific indexing.

The search strategy combined three concepts: (1) the population of children, adolescents and young people; (2) parents with terminal cancer or who had died from cancer; and (3) the child's experience.

Electronic searches were undertaken in databases from their inception to July 2020 using Ovid MEDLINE All (R) (1946 to July 08, 2020), Ovid Embase 1974 to 2020 July 09, OVID PsycINFO 1967 to July Week 1 2020, CINAHL Complete via Ebsco, Assia via Proquest and the Cochrane library (Cochrane Database of Systematic Reviews and Cochrane Central Register of Controlled Trials). Results were downloaded to an EndNote Library and duplicates were removed.

Study inclusion and exclusion

Inclusion and exclusion criteria (table 1) were applied to ensure only studies relevant to the aim of the review were included. This included any studies that spoke to children or young adults about their experience living with or losing a parent to terminal cancer when they were aged 18 or under. There were limited studies that included only participants under the age of 18; therefore, studies were included, providing most participants were aged under 18 at the time of bereavement. No restrictions were applied to the year of publication to enable a comprehensive understanding of the literature.

Data extraction and quality assessment

Data were extracted on the authors, year, country, study aim, research design, sample characteristics, key finding and methodological criticisms using an extraction sheet in Excel, developed by the research team to summarise the included study characteristics and their results. Only data for children up to 18 years were extracted. Papers were appraised for quality by identifying methodological strengths and limitations using the Critical Appraisal Skills Programme (CASP) tool (online supplemental appendix 1), which is the most commonly used tool in qualitative evidence synthesis.[21] The CASP tool systematically considers issues relating to the quality and validity of the studies.[22] Studies were not excluded on the basis of the quality assessment, recognising that studies with lower methodological quality are able to provide credible and transferable data.

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Box 1 Search terms used in MEDLINE

Search category 1: 'children'
1. exp child/ or exp child, preschool/.
2. exp infant/ or exp infant, newborn/.
3. exp INFANT/.
4. Adolescent/.
5. Young Adult/.
6. (child* or adolescen* or teen*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, protocol supplementary concept) word, rare disease supplementary concept) word, unique identifier, synonyms].
7. or/1–6.

Search category 2: 'parental cancer'
1. terminal care/ or exp hospice care/.
2. Terminally Ill/.
3. exp bereavement/ or exp grief/.
4. (bereave* or grief or grieving or death* or dying).ti,ab.
5. or/8–11.
6. exp parents/ or exp fathers/ or exp mothers/ or exp single parent/ or exp surrogate mothers/.
7. (parent* or mother* or father*).ti,ab.
8. 13 or 14.
9. exp parental death/ or exp maternal death/.
10. ((parent* or mother* or father*) adj3 (death* or bereave* or loss or grief or grieving or dying or terminal illness or terminally ill or advanced cancer)).ti,ab.
11. 16 or 17.
12. 12 and 15.
13. 18 or 19.
14. exp NEOPLASMS/.
15. (cancer$ or neoplas$ or tumortumour$ or tumour$ or malignan$ or carcinoma$ or metasta$ or oncolog$ or leukemi$ or leukaemi$ or lymphoma$ or myeloma$ or sarcoma$).mp.
16. 21 or 22.
17. 20 and 23.

Search category 3: 'experience, qualitative studies, needs and psychosocial support'
1. exp "Surveys and Questionnaires"/.
2. exp cohort studies/ or follow-up studies/.
3. exp INTERVIEW/.
4. exp Adaptation, Psychological/.
5. (survey* or interview* or narrative*).ti,ab.
6. Attitude to Death/.
7. Life Change Events/.
8. Needs Assessment/.
9. qualitative research/.
10. needs.ti.
11. unmet needs.ti,ab.
12. psychosocial needs.ti,ab.
13. Self Report/
14. exp Health Personnel/
15. exp social support/ or exp psychosocial support systems/.
16. help-seeking behavior/.
17. "Health Services Needs and Demand".sh.
18. Self-Help Groups/.
19. health services/ or adolescent health services/.
20. exp School Health Services/.
21. Child Health Services/.
22. Professional-Family Relations/.
23. ((bereav* or grief or griev*) adj3 (support or service* or counsel* or group* or programprogramme*)).ti.
24. (need$ adj2 assessment$).ti,ab.
25. ((child* or adolescen* or teen*) adj3 experience*).ti,ab.
26. or/25–49.
27. 7 and 24 and 50.

Data analysis and synthesis

As the 14 eligible studies were qualitative, the thematic synthesis, three-step approach by Thomas and Harden[23] allowed the synthesis of studies by (1) coding of text, (2) developing descriptive themes and (3) generating analytical themes. Findings including participant quotes and author descriptions and interpretations were entered into Microsoft Word; findings were initially coded line by line to create initial codes. Using in vivo coding allowed the findings to remain close to the participants' experiences and is a useful coding technique with child participants, whose experiences are often marginalised; therefore, using their actual words can help us deepen our understanding of their experience.[24] Through discussion, initial codes were grouped into five descriptive themes; together the authors identified two broad analytical themes which allowed the consideration of concepts and processes as compared with the topics produced by descriptive themes: (1) finding out about parental cancer and its impact on the family, and (2) coping with life with parental cancer, death and beyond.

RESULTS

Search results

Database searches yielded a total of 3900 results. After deduplication, 2434 unique remaining studies were independently reviewed by title and abstract by the authorship team (AW, JS and JWB). Full-text articles were retrieved for the 64 articles deemed eligible on the basis of title and abstract. The authorship team then independently assessed the full texts of all potentially relevant studies and identified 14 studies which were relevant, with a total of 654 participants. Disagreement at all stages was resolved by discussion and with recourse to an independent party, if needed. A PRISMA diagram illustrates the screening process and explanations for excluding articles at the full-text stage (figure 1).

Study characteristics

The 14 qualitative studies that met the inclusion criteria were published between 2007 and 2016 in six countries: Sweden (4), UK (4), USA (3), France (1), Australia (1) and Norway (1). All studies collected data directly from children or young adults bereaved

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Table 1 Inclusion and exclusion criteria

	Inclusion	Exclusion
Participants	Children and young adults who were aged 0–18 when their parent died from cancer Children whose parent has terminal cancer	Children whose parent had died from any other cause Children who have died from cancer Parents whose children have died from cancer Children whose siblings have died
Study design	Qualitative studies, questionnaires and surveys if they were qualitative in design, interviews, narrative research studies that describe in the words of children their experience living with or losing a parent to terminal cancer	Quantitative studies that did not give the children's experience Studies that gave the child's experience according to their parent Surveys or questionnaires that did not describe the children's experience Case studies
Interventions	Studies describing children's experience of finding out about a parent's terminal cancer, living with terminal cancer and having a parent who has died from terminal cancer	Studies that evaluated support interventions for children
Setting	No restrictions by setting or country	
Date	No restrictions by date	
Language	English language papers	Non-English language papers

as children; four studies additionally collected data from their parents[25–28]; and one study included additional data from healthcare professionals and school services.[27] There were 654 children included in the studies aged from 4 to 18, when either their parent had terminal cancer or they were bereaved.

Children were interviewed at different stages, from diagnosis to death. Half of the studies interviewed

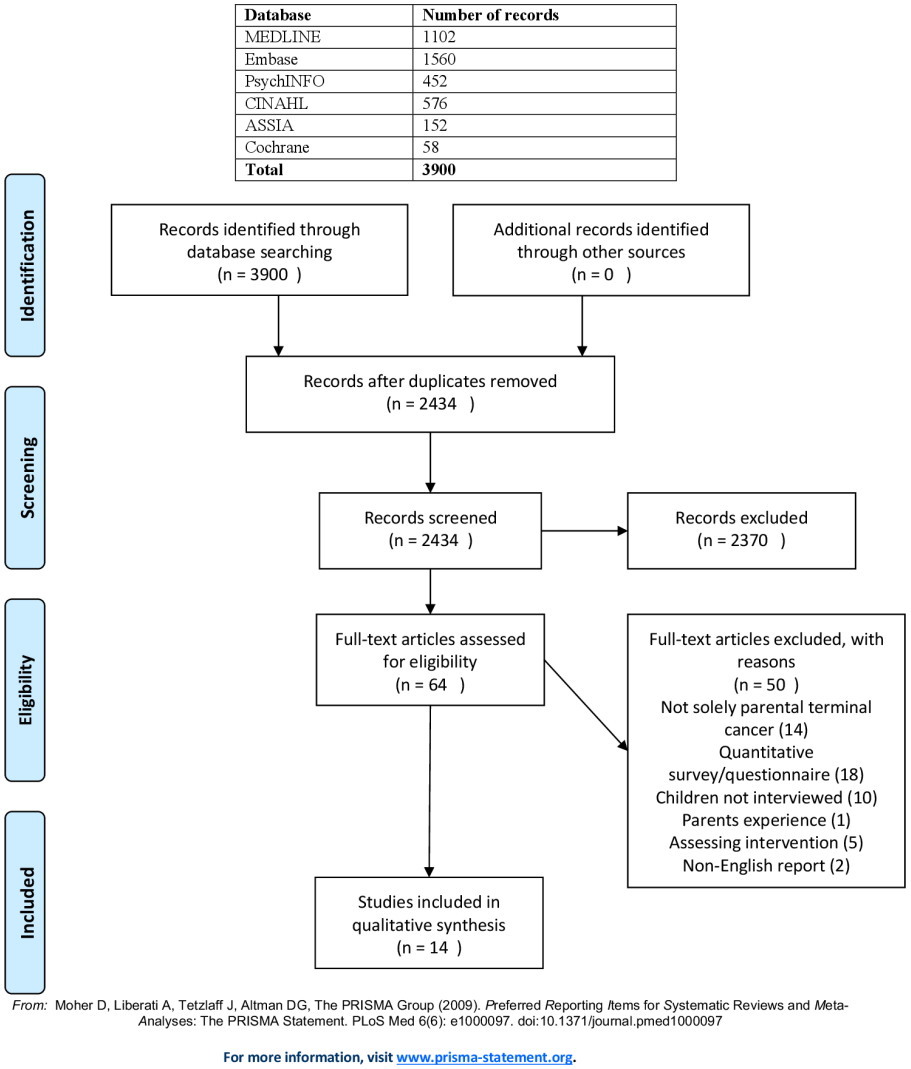

Figure 1 Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

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children at the time their parent was living with cancer[28–34] and the others interviewed children post-bereavement.[27 35–41] Children interviewed postbereavement had varying lengths of time from the actual bereavement until interview. This ranged from 3 months up to 9 years. One study did not specify the length of time since bereavement.[41] Full characteristics of the included studies can be found in table 2.

Synthesis of results

Five descriptive themes emerged from the studies, further categorised into two broad analytical themes: (1) finding out about parental cancer and its impact on the family, and (2) coping with life with parental cancer, death and beyond table 4

Finding out about parental cancer and its impact on the family

Need for open communication and honest information

All the studies in the review suggested children need to be included and to understand their parent's cancer, and they wanted to have an active role to help. Children were informed about their parent's cancer diagnosis at different times, some at the point of diagnosis and others later. A few children sensed something was wrong before they were told. Most children received news from their parents.[29 32 33 35 38 39 41] Children admitted they knew little about cancer.[29 30] Regardless of their parents' prognosis, on hearing their parent had cancer, children had the immediate worry of parental death.[29 38 41]

> Make sure children know how bad it is…there are many times when you understand nothing at all (p.4)[35]

Some children described the initial stages following learning about the diagnosis to be the time point when they needed the most information.[30] They wanted information about their parent's medical examinations, treatments, prognosis and what caused the illness.[29 30 35] Children admitted they did not ask questions for fear of upsetting their parents, and many did not know how to initiate such conversations.[30 31 33 39] Healthcare professionals were perceived as a valuable source of information regarding cancer, and many children would have welcomed an opportunity to speak with them; despite this, few children had that opportunity.[30 35 38]

> It's really hard to talk to dad about cancer but yeah, I usually don't talk to dad about it. Well when I do talk to him about it, it's a little hard for me to get the courage to ask him (p.856)[33]

If children were not given the information they needed, they would look elsewhere, such as friends, books, the internet and media. Some children reported this to be a negative and scary experience.[29 30] Children wanted honest information, no matter how upsetting that could be.[26 35] Children understood their parents were trying to protect them, but they wanted to be informed so they could prepare for what was to come.[28 30 33 35 38] One study found that children spoke more with their mother regardless of which parent was ill.[30]

> It was the only thing you thought about, but yet we were not talking about, everyone just went around and was…very tense (p.700)[38]

Changes and extra roles

For children, their parents' cancer became part of normal everyday life. Maintaining normality and integrating cancer into everyday life helped children deal with and protect themselves from what they described as the uncertainty of living with cancer.[29 32 33]

> It's just been such a long time since we found out now…I'm kind of used to it. It's just another part of life really (p.217)[29]

Some children had never seen their parent unwell before[29]; for many, cancer did not affect them until their parent began treatments and they saw the visible signs of cancer, which were dominated by their parent's fatigue. They were acutely aware of other side effects, including physical and emotional symptoms.[29 31–33] Children saw their parent's vulnerability, weakness, inability to cope and deterioration both in body and personality from the disease and its treatments; the side effects of cancer affected the family, disrupted their lives, and limited availability of both parents, leading to strained relationships and time constraints. Cancer was a threat to family roles and relationships.[29 31–33 38]

> If I wanted to go over and see friends, but my mom wasn't feeling well, I had to stay here with her (p1061)[32]

Many children spoke of their changing roles and taking on extra responsibilities at home, assisting with practical roles such as housekeeping, running errands, picking up and caring for siblings and direct care giving.[28 29 31–33] A few children were aware of the financial implications of cancer and sought paid work.[34]

> I was kind of the second parent, the second mom… so taking care of everyone and just making sure the house is running ok (p.1065)[32]

For some children it was a real struggle taking on extra responsibilities; despite this, many children spoke of feeling useful; by actively contributing to supporting their parent, they had a purpose and it made them feel less helpless.[29 31 39] Following the death of their parent, a few children described continuing with the extra roles alongside dealing with the emotions of losing their parent; this they found to be a struggle. They wanted their surviving parent to take control again.[39]

> I needed a parent to take control of my life again, so I could re-find my organisation and not have to

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Table 2 Characteristics of included studies

Author and country	Aims/objectives	Participants	Methods	Key findings of the experience of children and young adults and what they want
Alvariza *et al*[35] Sweden	To explore bereaved young adults' advice to healthcare professionals on how to support teenagers who are losing a parent to cancer	Young adults (n=481) Bereaved age 13–16, surveyed 6–9 years later Recruited using death register	Descriptive/interpretative design using qualitative content analysis Single open-ended question within larger survey 'What advice would you give to healthcare professionals working in cancer care with patients who have teenaged children?' Interviewed 6 to 9 years post bereavement	► To be seen and acknowledged. ► To understand and prepare for illness, treatment and impending death. ► To spend time with ill parent. ► To receive support tailored to the individual needs.
Finch *et al*[29] UK	How do young people find out about their parent's cancer diagnosis? What is their experience, how do they perceive and make sense of it and the impacts on their daily life and relationships?	Children (n=7) aged 14–18 Recruited in a cancer centre using poster advertisements seeking parental permission	Interpretative phenomenological approach and analysis Interviewed once Semistructured interviews Interviewed 4–11 months postdiagnosis	► First hearing about parents' diagnosis. ► Vulnerability of self and others. ► Communications within the family, feeling supported in experience. ► Experience and support of school and hospital.
Flahault *et al*[36] France	Understanding grief in children who have lost a parent to cancer and how they give meaning to the experience	Children (n=14) aged 7–11 Recruited from support group within cancer centre	Non-directive single interview with interpretative phenomenological analysis Interviewed 1–2 years postbereavement	► Grief is an announcement that is hard to believe, followed by a ceremony that makes it real—being told a parent has died. ► Grief means change—changes that emphasise the loss and emptiness. ► What has to stay the same—many ongoing routines stay the same. ► Grieving is missing someone—feeling of emptiness. ► Grieving is experiencing various deep feelings. ► Growing up. ► Staying little—fear of growing up.
Karlsson *et al*[38] Sweden	To describe young adults' own perspectives on the experience of having a parent with cancer when the young adult was an adolescent	Adults (n=6) aged 20–26, bereaved of a parent at age 15–18 (n=4) and one bereaved at age 20 but living with cancer from age 16 Recruited through a university	Qualitative design using interviews in the form of narratives, single interview Content analysis focusing on interpretation of texts Interviewed 2–5 years postbereavement	► No one understands. ► Lack of tools to understand. ► Grief and anger. ► Belief in the future. ► Comfort and relief. ► The importance of support.
Kennedy and Lloyd-Williams[30] UK	To explore children's information needs when a parent is diagnosed with advanced cancer	Families interviewed, children (n=11), aged above 8–18 Ill parent (n-10), well parent (n=7) Recruited via cancer centre, hospices, GP practices and gynaecological oncology team or media	Topic-based semistructured interview schedule with parents and children, interviewed once, data analysed using principles of constructionist grounded theory Interviewed between 2 and 28 months following diagnosis of advanced cancer	► The need and type of information. ► Sources of information. ► Communication with parents. ► Communication with others.
Kennedy and Lloyd-Williams[31] UK	Aim to explore how children cope when a parent has advanced cancer and to identify areas where there may be barriers to children accessing support to enable them to cope	Families interviewed, children (n=11), aged 8–18 Ill parent (n=10), well parent (n=7) Recruited via cancer centre, hospices, GP practices and gynaecological oncology team or media	Topic-based semistructured interview schedule with parents and children, interviewed once, data analysed using principles of constructionist grounded theory Interviewed when parents had advanced cancer, no further details	► Response to diagnosis. ► Mechanisms of coping. ► Life changes. ► Positive aspects.

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Table 2 Continued

Author and country	Aims/objectives	Participants	Methods	Key findings of the experience of children and young adults and what they want
MacPherson and Emeleus[27 37] UK	To identify the psychosocial needs of children facing the death and subsequent bereavement of a parent from cancer	Children (n=13), aged 4–16 Bereaved 6 months–3 years prior to the study Recruited from a children and family counselling and support service	Qualitative design, single semistructured face-to-face interviews and focus group, thematic analysis, interviewed 6 months–3 years postbereavement	► Generic needs—education, need for people who understand, the need for consistent relationships. ► Individual contextual needs—contact with dying parent and preparation for death, ways to hold memories that are meaningful and private, normality and continuity, life to carry on as normal, empathy, making connections with someone who understands, quick response to request for support, differing needs, variable and flexible responses, some understanding of death.
Patterson and Rangganadhan[39] Australia	To identify and better understand the needs of the adolescents and young adults who have lost a parent to cancer and to ascertain the extent to which these needs have been met	Children and young adults (n=62) aged 12–23; the majority were bereaved aged 12–17 (n=50) with some bereaved age 18–21 (n=11) Recruited from organisation for young people living with cancer	Open-ended questionnaire Thematic analysis 38 participants interviewed less than 2 years postbereavement, 24 participants interviewed more than 2 years postbereavement	► Support and understanding. ► Help coping with feelings. ► To talk to people who have had a similar experience. ► Information. ► To have a break and have fun. ► Space and time to grieve. ► Help with household responsibilities.
Phillips[32] USA	To gain an understanding of the experiences of adolescents, in their own words, to gather pilot data about the needs of this population that will be valuable in developing interventions for adolescents facing parental cancer	Children (n=10) aged 14–17, age at diagnosis 3–16 years, recruited from psychosocial support group	A hermeneutic phenomenological approach using in-depth semistructured interviews to enquire about adolescents' experiences Interviewed once after terminal cancer diagnosis Phenomenological analysis.	► Life interrupted—perceptions about cancer, struggling with changes, limits what they can do, voices of fear, juggling life and cancer. ► Being there—being a 'good kid' and caring for family. ► Managing emotions—distraction, talking helps, thinking positively, social support. ► Positives prevail—personal growth, increased appreciation, enhanced relationships, changed views of life
Phillips and Lewis[33] USA	To provide the adolescent's perspective on the impact of their parent's advanced cancer on their lives	Children (7) from 6 families aged 11–15, parents approached first	Qualitative single-occasion, semi-structured elicitation interviews. Inductive content analysis used to code data. Interviewed after terminal cancer diagnosis, no further information	► Feeling the weight on your shoulders. ► Cancer changes ► Confronting or getting away from cancer ► Talking about it ► Cancer can be positive
Sheehan and Draucker[28] USA	To develop an explanatory model that explains interaction patterns between parents with advanced cancer and their adolescent children and to identify strategies to prepare children for their lives after a parent dies	Parents (n=9) with cancer and their spouses/partners (n=7) and their adolescent children (n=10), aged 12–18 Recruited from a hospice, parents gave permission first.	Grounded theory methods and analysis alongside an iterative analytical process Semistructured interviews Interviewed after terminal cancer diagnosis, no further information	► Not having enough time together. ► Making the most of the time left together. ► Coming to know time together is limited. ► Spending more time together. ► Extending time together. ► Giving up time together to end suffering.
Sveen *et al*[40] Sweden	To explore how teenagers reason about a parent's recent death and about their life without that parent	Children (n=10) aged 14–19 who were aged 14–17 at the time of bereavement Recruited from palliative care units, surviving parent approached first	Descriptive and interpretative design using qualitative content analysis, interviewed twice as free-ranging conversations Interviewed 3–12 months postbereavement	► Death was the worst thing that could happen, but still it was a relief for the ill parent and teenager. ► Talk or silence. ► The surviving parent's impact on everyday life.

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Table 2 Continued

Author and country	Aims/objectives	Participants	Methods	Key findings of the experience of children and young adults and what they want
Tillquist *et al*[41] Sweden	To describe female teenagers' experiences of losing a parent to cancer using blogs written by them	Blogs (n=5) written by girls aged from 13 to 19.	Personal blogs were analysed with a qualitative design using descriptive study and content analysis Blogs reviewed postbereavement	▲ Sadness—pain, hopelessness, regret, guilt ▲ Fear—unawareness, anxiety, escape, shock ▲ Anger—hate, frustration, annoyance, injustice ▲ Comfort—relief, confidence, control, pride
Torp *et al*[34] Norway	To investigate the financial effects of cancer in families when a parent has cancer, to identify financial hardship risk factors and to describe children's experience regarding the impact of cancer on their socioeconomic situation	Cancer parents (n=386) living with their children completed a questionnaire. Children (n=10) aged 7–18 interviewed Children recruited from the cancer society, parents contacted initially.	Mixed methods research approach for both quantitative and qualitative data Quantitative survey among parents with cancer Children given qualitative in-depth and open-ended interviews using a thematic interview guide Single interview Analytical process unclear	▲ Financial and material consequences. ▲ Social consequences. ▲ The healthcare services. 29% of parents reported financial hardships with 14% minimising expenditures on goods and activities for the children because of costs attributed to cancer

GP, general practitioner.

> worry about the little things- food, washing, getting to work etc…I am too young to be independent (p.261).[39]

Coping with life with parental cancer, death and beyond

Once children are aware of their parent's cancer and life has adapted, they need to find ways of coping.

Dealing with emotions during parental cancer and death

Children spoke of feelings of loneliness throughout their parent's illness and in their experience.[33 38] When children found out about the cancer diagnosis, they were shocked, had a sense of grief, loss and hopelessness. Some spoke of beginning the grieving phase immediately.[29 38] They were anxious and uncertain, with a complete lack of control over what the future would be for them, their parent and the rest of the family.[31 33 41] Some worried what would happen after their parent had died; they feared the separation, knowing their parent was irreplaceable.[29] Some had sorrows for future losses, knowing the milestones their parent would not see.[28] Many children admitted keeping these fears private to protect their parent from further upset.[29 31] Children in a few studies had fears and worries that they themselves, their siblings or other family members could die. Some children worried they would get cancer themselves.[30 32 33 38 39] Girls in one study wondered if they would be tested for cancer and what that involved.[31]

> Sometimes I'll just feel alone, like I'm the only one dealing with this and it's like having the weight of the world on my shoulders (p.854).[33]

Hearing that their parent was dying was painful and distressing; their world was collapsing; they felt sad, upset, heartbroken and stuck between hope and despair.[27 31 41] Some children could not understand why their parent had not improved after treatment and felt guilty for their inability to understand.[27 29 31 38] When a parent died, not all children had the chance to say goodbye.[27] Those that did, despite the pain, were left with precious and valued memories.[27 41] Being present at the time of death was described as distressing. Despite feeling sorrow and helpless watching the parent suffer, some children wanted to be present; it made them realise there was no chance of recovery. Other children found it too distressing to be in the same room as their parent at this time.[27 40] Following the death of the parent, some children spoke of relief that their parent was no longer suffering.[40 41] Others described death as incomprehensible with feelings of shock, ignorance and anxiety.[41] Grief made children angry; they were angry their parent had not recovered, that friends did not understand, and they had an intense hatred of the cancer.[36 38 40 41]

> My mum said I wasn't allowed to go into hospital. There wasn't much to see. I would get bored and um my dad was really tired…I was really upset because

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> I only got to see him twice in hospital. I never saw him again that was the last time. (p.593)[27]

Support and coping

Many children cited friends as a vital network of support as well as their other existing social networks of family, school and church. Despite this, some children found friends were not always readily available to offer support and some were not able to offer the desired support.[27 29 30 32 33 38–40]

> Friends always know what to say to make you feel better (p.219)[29]

Some children had access to peers who had been through similar situations.[32] This appeared to offer the most beneficial support. Having someone to talk to who understood was helpful and important, helping the children ease their burden by sharing concerns, grief and worries.[30 38] Children felt less alone if they had someone they felt they could relate to, empathise with and share experiences.[27 29 39]

> I needed to talk to other people whose parents had passed away…it helped me to cope better and talk about my feelings because they knew what I was going through (p.260)[39]

The few children who spoke to healthcare professionals found this beneficial.[41] Children in one study suggested that healthcare professionals could help by providing information about available support and encouraging the children to spend time with their dying parent, give them permission to laugh and have fun together, and make suggestions on how to do this when the parent is having a bad day.[35]

Though children used various coping strategies, they all expressed the need to maintain normality as a method of coping.[29 33 36] Sometimes children coped by talking about cancer and confronting it head on, while at other times they wanted to block cancer from their heads and not think about it. Similarly, when spending time with their parent, sometimes they wanted to be close and maximise their time together, while at other times they needed space and would withdraw from their parent and the family home.[27 28 31–33 38 39] Distraction was a coping method used by many children and achieved by going to school, seeing friends, physical activities, doing something fun and playing games.[27 28 32–34 38–40] Adopting a positive attitude helped many children. Some learnt this from their parents' way of coping; others could foster a positive attitude from hearing uplifting stories from friends or the media.[31 32]

> Just like when I think of him it upsets me a little bit and I just want to try and do something to take my mind off it, well just, I just phone my mates up, ask them to come over, to do something or, I just go out, just try to do things with my mates really, keeps my mind off it (p889)[31 42]

Maintaining bonds and finding the positives of terminal cancer

Following the death of their parent, some children found it helped to create new bonds to recall their presence and remember them as a healthy parent before they had cancer.[29 38 40] They maintained memories and bonds to remain close to the parent using a variety of methods including memory boxes, books, pictures, clothing, perfumes, letters, text messages, talking to them and memories of shared experiences.[28 36 38 41]

> We can think about her, talk to her and even know what she would reply (p.486)[36]

Many children believed having a parent with cancer had positive aspects for them.[29 31–33 41] Although the experience had been difficult, many children believed they fared well.[38] The experience had positive outcomes in helping transform and shape their characters, giving them an appreciation of life and others.[30 32] Taking on extra roles and responsibilities was described in a positive way. Children felt they had grown up, developed independence, learnt to care for others and be prepared for adult life without relying on others.[30 32 33 36]

> …it helps you kind of grow up more and appreciate everything you have and appreciate life, and kind of changes the way you look at things and makes like some of the smaller things more exciting for you (p.1067)[32]

DISCUSSION

This review has synthesised the experience of bereaved and prebereaved children internationally, showing similarities in experience regardless of the country of origin. Findings are reflective of nuclear families and do not explore the additional profound and challenging experiences of blended or lone parent families, who account for an increasing number of families in Western society.[43]

This review found that children have little knowledge of what a cancer diagnosis means and what that entails. Children can struggle to communicate with their parents; they may suppress their own emotions and may not ask questions for fear of upsetting or burdening their parents.[30 31 33 39] When children learnt about their parent's cancer diagnosis, regardless of the prognosis, they immediately associated cancer with death.[29 38 41] These findings highlight children's lack of knowledge about the disease and are consistent with previous findings.[44] Children also worried about parental death when their parent had a non-terminal cancer diagnosis.[44] The review has highlighted the likelihood that parents attempt to protect their children by keeping them in the dark, meaning they do not always receive open and honest information and communication. This can result in children having unanswered questions; they may try to find information elsewhere or fill the gaps and make up information that can be

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an even worse experience than the reality.[3] Lack of communication, information and involvement could account for children's reports of feeling lonely in their situation, despite being surrounded by others. If children are fully informed and open communication continues throughout, they will be better supported and able to adapt and cope.[3 29 30 35 39 45 46] Furthermore, if families can ensure children are given adequate information at diagnosis with open and honest communication within the family, this may allow children to feel they can ask their parents questions and share their worries, fostering an open-communication approach within the family, allowing them to better adapt to their loss.[46] In previous research, both parents and children have reported open communication as a supportive coping mechanism when a parent is at the end of life.[47] Healthcare professionals have been identified as being well placed and perceived as able to offer support to both parents and their children, to encourage open and honest communications starting at diagnosis.[12 30 35 38] Despite this, these studies have highlighted that this is not common practice. Many children have a desire to speak to a healthcare professional yet rarely have the opportunity to do so.[12]

This review found that some children do not know how they should react following a parental death and looked to their parents to be shown.[25 36] The suppression of their emotions could be something learnt from their parents who are also suppressing their own emotions to protect their children. Children learn that they need to be strong for others, which is reinforced by adults who praise emotional strength and hiding emotions as good behaviour. As a result, these children who are already enormously affected by the death of their parent do not have permission to display emotions, and some lose their childhood because they have had to grow up too quickly.[25 29 32 33 36 38] Children in one study wanted their parents to show their own feelings about the disease rather than protect them.[38] The physical and emotional support received from the surviving parent will help shape the way the child adjusts to the death; however, surviving parents themselves can be depressed, resulting in lack of awareness of the needs of the child.[3] Children generally were not aware of financial concerns and parents shielded them from this information.[34] Only one study discussed the financial situation following a cancer diagnosis, with some children attempting to help by finding paid work.[34] It may be the case that financial worries may not become a concern until they are seen and felt by children after a parent's death. There may be a loss of income or if that parent had insurance, the family could have a financial gain; both happen after death and often are unacknowledged as having an effect on children.[48]

In line with the family systems theory, the behaviours and functioning within a family are interdependent; a change in one family member's functioning will lead to changes in the functioning of others.[43] Children, however, are not simply reactive but show agency as family members. This was seen when children took on extra household roles to help their parents; they could see the changes and disruption in the family caused by the disease, and they had a desire to help and be more involved with the family.[29 31–33 49] Children's desire to be more involved and using their agency to develop coping strategies have also been found with children who are facing the death of a parent to a life-limiting illness,[17] highlighting a tension between children's need for agency and their parents' need to protect them from the illness.[17] James and Friedman[50] warn of the role some children adopt or is expected of them, to take care of everyone else. Surviving parents are also grieving, which can affect the parent and child roles, with children adopting the parent role, comforting and supporting the surviving parent which means their own needs can be forgotten or disregarded[3 51]; this is seen to continue throughout the parent's disease and even after death.[3 29 34 52]

Despite cancer disrupting the entire life of the family, included studies found that families try to reduce disruption by maintaining normalcy; children generally adapt well; and cancer will become part of their normal life. They appear to have adequate support from their existing social networks with friends cited as good providers of support for all children.[27 29 30 32 33 35 38 39] For both parents and children, maintaining a normal life helps them to minimise the impact and disruption of the disease.[53] These findings support previous findings from parents and children when a parent is at the end of life, and despite the challenge, maintaining normality, routine and maximising social networks are all useful coping mechanisms to help children manage their stress and anxiety.[47] In order to cope with family disruption specifically following the death of a parent, children require support, nurturance and continuity.[3] The relationship with the surviving parent is crucial,[3] with some families becoming closer[36 40] and others developing tension.[33] The model of family bereavement and mourning describes four organisational tasks for families, including shared acknowledgement of the reality of the death, shared experience of the loss, reorganisation of the family system, and reinvestment in other relationships and life pursuits.[46] These tasks have been identified within these studies and will help families to adapt to their loss, allow their unique experiences of grief and strengthen the family as a functional unit.[46] The review has shown that some families will require specific support to help them navigate the organisational tasks, have open communication within the family, share their grief and ensure all of the family are involved.[46] Families are resilient with the capacity to overcome a parental death, allowing positive adaption, which strengthens the family.[54] Findings in the present review support previous findings which described the key elements for supporting bereaved

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children to be continuity, instrumental social support and communication.[55] Support from those with a shared experience of bereavement was identified as most helpful. For children who were unable to talk to their surviving parents, it would very useful to be able to share what they were going through with someone who understood and also helped you feel less alone in your experience.[27 29 32 38 39]

Children in several studies found continuing bonds with their deceased parent helpful.[28 29 36 38 40 41] Bereavement is not a process that fully resolves; you do not need to sever bonds with the deceased; and it is healthy to continue those bonds.[56] These studies have shown how children constructed and retained bonds with the deceased parent which helped them cope, which over time, as the child grows older and the intensity of the grief lessens, will change.[56] Memories are precious gifts that children can keep once death has robbed them of the present and future with their parent.[56]

An important issue emerging from this review is how children spontaneously described positive experiences from having a parent with terminal cancer. A possible explanation for this experience is post-traumatic growth, meaning, despite traumatic events, individuals can perceive benefits including changes in self-perception, interpersonal relationships and their philosophy of life.[57] These findings are consistent with previous findings which found a considerable number of adults who had a parent with cancer during their childhood spontaneously reported post-traumatic growth when describing their experience.[58]

Strengths and limitations

This is the first systematic review that synthesises the experience for children, in their own words, when a parent has terminal cancer. The review allows us to realise the importance of including the voice of the child when undertaking research while acknowledging that, currently, we do not hear the voice of all children having this experience.

Despite a comprehensive search strategy, all included studies were conducted in Western populations; despite similar findings among these countries, they might not be representative of all countries. Findings specifically relate to the experience for children when a parent has terminal cancer and so may not represent the wider population and deaths by other causes.

Despite including the experience of children of all ages, the majority of studies included only adolescents, meaning findings could be over-representative of that group. Studies including younger children did not separate response by age, so it was impossible to narrow down finding according to age. Age is a significant factor in how a child adapts to a parental death; children and young adults will have differing support needs.[3] Many children in the studies were recruited through support services, with parents giving initial consent. This means many children would have been excluded from recruitment; therefore, findings are not representative of the experience for all children who lose a parent to cancer.

Implications for clinical practice

Healthcare professionals, parents and existing support networks can support and influence the experience for children when a parent has terminal cancer. Healthcare professionals can enquire as to what support networks families have and how they are coping, signposting them to additional support if required.

Despite often being kept in the dark about their parent's disease, children do not want to be protected; they desire open and honest communication to allow them to prepare for what is to come and to actively support their family. If children do not have information, they will seek this elsewhere. The experience of doing this can be negative and very frightening; they will often seek information alone and may not find trusted sources.[29] This could be prevented by healthcare professionals, who are the experts about the parent's disease, treatments and prognosis. They could support and advise parents to deliver this information to their children. They can also make them aware of parental influence and how parents can help by encouraging open and honest communication and being open with their own emotions from diagnosis and throughout their illness.

Future research

This review found some children direct questions at their mother regardless of which parent is ill, although from a study over 10 years old[30]; this needs further exploration if this has changed in recent years. Future research needs to explore the experience of children according to their age and which parent is dying. The studies within this review looked at different stages of the parent's terminal cancer, as experienced by their children, with findings derived by single interviews with children. Longitudinal research is required to follow children from the point of their parents' diagnosis to death and beyond, to identify the long-term impact of losing a parent to parental cancer and identify what support these children require and how best it can be delivered. Further research is needed to investigate the financial implications of cancer on the family. Research needs to look at the experiences of blended and lone parent families. Research needs to develop innovative ways to access the hard-to-reach children in order to hear the voice of all children. More research is needed to better understand how children and families are supported and by whom, and the types of available bereavement support. Further research should explore the relationship and support between a child and a surviving parent following a parental death.

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CONCLUSION

This systematic review has shown the importance of including children in this field of research. Only they can tell us what their lived experience is to inform what parents, healthcare professionals and others can do to support them. The review has identified that children are and want to be an active part of their family when a parent has terminal cancer; they want to be informed of what is happening and be able to offer their own help and support to their parent and the rest of the family. They do not want to be protected; rather they want open and honest communication to enable them to prepare for what is to come. Their parents have a crucial role in ensuring they enable and facilitate open and honest communication to ensure children understand what is happening.

This review shows that parents with terminal cancer may need guidance on how their illness and communication within the family could positively or negatively affect their children. Parents need to be encouraged to have open and honest conversations with their children and allow them to have an active role in this experience by providing them the chance to be involved and contribute to supporting the family. This research confirms healthcare professionals are in an important position to be able to offer this guidance.

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ORCID iDs
Alexandra Wray http://orcid.org/0000-0003-1743-0288
Jason W Boland http://orcid.org/0000-0001-5272-3057

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Appendix 1. Critical appraisal of included studies using CASP tool.[14]

Study	Clear statement of aims	Qualitative methodology appropriate	Research design appropriate to address the aims of the research?	Recruitment strategy appropriate to address research aim(s)	Data collected in a way that addressed research issue	Relationship between researcher and participants adequately considered	Ethical considerations taken into consideration	Data analysis sufficiently rigorous?	Clear statement of findings	Is the research valuable
Alvariza et al.[23]	Yes	Yes	No	Yes	Yes	No	Yes	No	Yes	Highlights the role HCPs can have in supporting children.
Finch et al.[16]	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Highlights challenges and support needs at diagnosis.
Flahault et al.[24]	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Describes the experience of losing a parent to cancer.
Karlsson et al.[27]	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Describes the experience of living with a parent with cancer.
Kennedy et al.[17]	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Highlights importance of open and honest communication.
Kennedy et al.[18]	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Describes how children cope throughout the cancer journey.
MacPherson et al.[25, 26]	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Highlights children's needs when facing the death of a parent.
Patterson et al.[28]	Yes	Yes	No	Yes	Yes	No	Yes	Yes	Yes	Identifies the needs of parentally bereaved adolescents and if needs have been met.
Philips.[19]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Describes the experience of adolescents when a parent has advanced cancer.
Phillips et al.[20]	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Describes the impact of parental cancer on the lives of their adolescent children.

Sheehan et al.[21]	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Explores interaction between adolescent children and their parents with advanced cancer.
Sveen et al.[29]	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Explores teenagers reasoning following recent parental death to cancer.
Tillquist et al.[30]	Yes	Yes	Yes	Yes	Yes	No	Yes	No	Yes	Provides in teenager's words the experience of losing a parent to cancer.
Torp et al.[40]	Yes	Yes	Yes	Yes	Yes	No	Yes	No	No	Describes financial and social effects of a parental cancer diagnosis for children.