





REVIEW

How 'significant others' may support parents with decision-making about their child's cancer care: An integrative literature review

Elizabeth C. L. Jestico MSc, PGDipRN (Child), MA (Cantab),
MPhil/PhD Student, Senior Lecturer  | Susan E. Schutz PhD, MSc, RGN, Senior Lecturer  |
Teresa M. D. Finlay PhD, RN, Associate Lecturer  |
Jane V. Appleton PhD, RGN, RHV, BA (Hons), MSc, PGCEA, FiHV,
Professor of Primary, Community Care 

Oxford School of Nursing and Midwifery,
Oxford Brookes University, Oxford, UK

Correspondence

Elizabeth C. L. Jestico, Oxford School of
Nursing and Midwifery, Oxford Brookes
University, Oxford OX3 0FL, UK.
Email: ejestico@brookes.ac.uk

Funding information

This MPhil / PhD study is being financially
supported by Oxford Brookes University.

Abstract

Aim: To synthesise what is known from current international evidence about how parents are supported by significant others when they are faced with making decisions about their child's cancer care.

Background: Parents are faced with making challenging decisions when their child has cancer and may benefit from support. Whilst previous research has comprehensively explored how healthcare professionals can offer support, little attention has been given to how support may be informally provided from a parent's network of significant others.

Method: An integrative literature review was undertaken and reported following the ENTREQ framework. Literature was identified from comprehensive database searching across four relevant databases (CINAHL, PubMed, PsychINFO and British Nursing Database) and hand-searching reference lists of retrieved studies. Studies that met the inclusion criteria were critically appraised and then analysed using the Constant Comparative Analysis method.

Results: Twenty-six articles were included in the review. Two overarching themes were identified. Theme 1—Dimensions of Decision-Making support—included three sub-themes: informational, emotional and instrumental mechanisms of support. Theme 2—Expectations of Decision-Making support—identified that parents' expectations of their own role, and the role of their significant others, affected how decision-making was supported.

Conclusions: Parents may seek and receive support from various significant members of their network, but there is a fine line between supportive and unsupportive behaviours.

Relevance to clinical practice: Each family's unique personal, social and cultural context strongly impacts on their support needs, and nurses and other healthcare professionals should be mindful of how parents may access support from their significant others. Further in-depth research around this area would contribute important knowledge around parents' support needs.

KEYWORDS

cancer, child, decision-making, neoplasms, parents, review literature, social networks

1 | BACKGROUND AND AIM

When parents are told that their child has cancer, they are faced with having to make many challenging decisions about their child's care (Coyne et al., 2014). These decisions may initially include treatment options, central line insertion and fertility preservation, and as time goes on may include nutrition support, location of care and symptom support.

Contemporary debate about healthcare ethics emphasises the importance of a person's right to make autonomous decisions (Beauchamp & Childress, 2019). However, where a child is too young to make an autonomous decision for themselves, this responsibility is usually deferred to the parents on the basis that the parents should make decisions in line with the child's best interests (Griffith & Tegenah, 2017). The rights and responsibilities of parents around decision-making are supported by legal frameworks both internationally, such as the United Nations Convention on the Rights of the Child (1989), and nationally (e.g. in England, this is expressed in the 1989 Children Act).

However, these rights and responsibilities may be accompanied by a sense of burden (Brinchmann et al., 2002). For parents of children with cancer, whose world has been turned upside down by a life-changing diagnosis, this burden has been described as generating stress, doubts and uncertainties (Bandinelli & Goldim, 2017). It is therefore vital that nurses and other healthcare professionals have a good understanding of the support mechanisms that may help or hinder families when they are in these situations.

Existing research has comprehensively explored the role of healthcare professionals supporting parental decision-making in the context of children's cancer care—this includes nurses' and allied healthcare professionals' roles but predominantly focuses on doctors' roles (Coyne et al., 2014; Pyke-Grimm et al., 2006). Providing this support is a fundamental part of healthcare professionals' roles but it is also important to recognise that other people may informally support parents as they make these decisions. Whilst this has been explored within the context of adult care, it cannot be assumed that the same findings would apply to a parent making a decision on behalf of their child (Gagnon & Recklitis, 2003; Lipstein et al., 2012). This review therefore aims to synthesise what is currently known from an international perspective about how parents' significant others may support them with decision-making in this context.

It is worth clarifying the meaning of significant others, as terms and concepts in the literature vary. Thoits (2011) defines significant others as relationships within a 'primary group' consisting of people such as family members and close friends, which is distinct from 'secondary groups' which are larger and may include work colleagues, neighbours and members of social organisations. This combination of primary and secondary groups could be conceptualised

as a broader social network consisting of an inner circle of significant others and an outer circle of looser relationships. However, it is important to acknowledge that these relationships are characterised by their fluidity and people may contextually move between the inner and outer circles. It is also important to recognise that individual perspectives and definitions of the meaning of significant others will vary and allowing people to self-define these relationships should be valued.

2 | METHOD

An integrative literature review was undertaken, aligned with Whittemore and Knafl's (2005) approach. Integrative reviews provide a broad approach to reviewing and synthesising literature, enabling the development of new understanding (Whittemore & Knafl, 2005). In the context of this topic, this approach therefore enabled the inclusion of diverse research methodologies. This was deemed necessary following initial scoping of the literature when it was noted that relevant research included mainly qualitative, but also quantitative and mixed methods approaches. The results are reported here using the framework of Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) (Tong et al., 2012) (Supplementary File 1). Currently, there is not a reporting guideline designed specifically for integrative reviews and so a framework was selected to align with the nature of the literature included within this study. The ENTREQ framework was used because the included studies are mainly qualitative, and the synthesis is presented in a narrative fashion. It was therefore appropriate to adopt this qualitative framework rather than a framework used primarily for quantitative systematic reviews.

2.1 | Identification of literature

Whittemore and Knafl (2005) emphasised the importance of comprehensive searching for relevant literature. The predominant search strategy in this review involved using four computerised databases (The Cumulative Index to Nursing and Allied Health Literature (CINAHL), PubMed, PsycINFO and the British Nursing Database (BND)) using the search terms presented in Table 1. These search terms were initially constructed by the first author but then reviewed by all authors and discussed with university librarians. Subject headings were also explored for each database.

The terms 'caregiver' and 'carer' were used as alternatives to 'parent / guardian / mother / father', and the retrieved studies did use a range of terms. Whilst it is not always the case that a parent will be the main caregiver and make decisions on behalf of the child,

TABLE 1 Search terms

1.	caregiver OR mother* OR father* OR parent* OR guardian* OR carer*
	AND
2.	decision* OR decide* OR consent*
	AND
3.	neoplasm* OR cancer OR oncolog*
	AND
4.	influence* OR support* OR help* OR advice* OR advis*
	AND
5.	child* OR pediatric* OR paediatric* OR adoles* OR youth* OR teen* OR infan*

it was implicit within the context of all included studies in this review that the parents were the child's caregivers and consequently made decisions. After lengthy consideration, it was decided to exclude the concept 'significant others' as this is self-defined by individual families. There was a risk that by including synonyms, the search would become restricted to the researchers' subjective definitions of the concept and therefore miss relevant studies.

In addition to database searching and retrieval, reference lists of retrieved papers were also consulted to search for further relevant studies. Finally, a process of networking with experts in the field took place whereby discussions highlighted other potentially relevant research. In addition to published research, relevant dissertations and theses were retrieved from the database searches.

Inclusion and exclusion criteria were developed and applied (Table 2) in order to ensure that irrelevant studies were excluded. The search was limited to studies published in English. No research was excluded according to the date of publication as there was no clear rationale to do this and it was important to capture all research about this topic. However, the publication date was considered during the critical appraisal process to assess the relevance of the findings, and the studies spanned publication dates between 1996 and 2021. All types of primary research were included. Screening of titles and abstracts according to the criteria reduced the number of papers significantly. The full texts of these remaining papers were then read by the first author to decide whether the inclusion criteria were met.

Figure 1 presents a PRISMA flow chart demonstrating the number of papers identified, included and excluded throughout this process. 26 studies met the inclusion criteria and were included in the analysis of this review.

2.2 | Critical appraisal

The Mixed Methods Appraisal Tool (MMAT) (Hong et al., 2018) was used to appraise all of the research papers as this tool allowed for the appraisal of quantitative, qualitative and mixed method studies. This tool was initially completed by the first author, but for rigour a selection of four studies was read by the other authors who

reviewed the information represented in Table 3. Discussion about the identified limitations drawn from the appraisal tool led to a refinement of the data presented in Table 3. In line with Whittemore and Knaf's (2005) approach, this process did not result in the exclusion of studies; the key limitations identified through this process are indicated in Table 3.

2.3 | Data extraction

Table 3 presents the studies selected for the review with key details about the design and findings of each study.

2.4 | Data analysis

There were two stages of analysis. The first stage (represented in Table 4) involved extracting detail about the types of decisions that parents faced in each study and the source of support (in relation to significant other). It is important to recognise that most studies did not focus on support from significant others, and therefore, the parents had not identified these people as significant to them. It was therefore not possible to further categorise these sources of support into the primary and secondary groups defined by Thoits (2011). It should be noted that Gage's (2013) study specifically explored the role of 'experientially similar others' and drew a distinction between 'significant others' (parents' pre-existing social network of family members and close friends) and 'similar others' which in this context related to a new network of people who were living through a similar experience. It could be argued though that this concept of significant versus similar others was imposed on participants by the researcher rather than defined by participants.

Future research could explore which groups of people parents identify as 'significant' to them within this context. However, in the absence of this, the label of 'significant other' was assigned according to the interpretations of the researchers.

The second stage of analysis involved using the Constant Comparative Analysis method as recommended by Whittemore and Knaf (2005). Each study was read multiple times by the first author. Direct quotations of relevant extracts from all studies were recorded, and initial notes were made about codes and themes. This was an inductive and iterative process. As each study was read, ideas about themes evolved and notes about previous studies were reviewed and added to. Once all the studies had been read several times, the notes from each study were compared with each other. The research team met monthly throughout this project where findings of the studies were extensively discussed. These discussions led to the construction of the two main themes, and feedback from the team on the first author's early draft writing, refined the labelling of themes and identification of sub-themes. The other authors supported this process by reading four of the studies confirming that they had been appropriately represented within the analysis. All studies were analysed in a narrative, qualitative way regardless of

TABLE 2 Inclusion and exclusion criteria

Inclusion	Exclusion	Rationale	Number of studies excluded (at full text level of screening)
Population involved in making decisions			
Parents of children with cancer	Children / adolescents / young adults with cancer	The focus of the study is on parents' support needs for decision-making, not children's support needs for decision-making.	10
	Parents of adolescents / young adults with cancer	In this study, the focus is on parents of children, as opposed to adolescents or young adults. The relationship and responsibility for decision-making between parent and child changes as the child becomes older, and the focus of this project is on a child who has limited capacity to make their own decisions. Therefore, if the research focused exclusively on parents of adolescents / young adults with cancer, it was excluded. However, a significant amount of the research did not differentiate between the ages of children, so in some cases literature was included that covered a broader age range.	0
	Adult patients with cancer who have children	Several of the retrieved studies related to adults with cancer who were parents, and the impact of this on their children, as opposed to the child having cancer.	10
	Parents of children with other conditions	The focus of this review is specific to children with cancer, and only these studies could be included.	32
Context of Decision-Making			
Any decision that parents make about their child's cancer care, when their child has a cancer diagnosis	Decisions related to cancer screening	The focus of this project is on parents whose child has cancer and the decisions related to their care.	18
	Decisions related to cancer prevention (e.g. HPV vaccination)		
Source of Support or Influence			
Support from self-identified 'significant other' or social network member (even if this is not the primary focus of the study)	No reference to who the significant others are	A few research studies referred to an unidentified person or group of people, as being involved in the decision-making process. These papers were excluded as one of the aims of this review is to understand how relationships may affect experiences of support. It is therefore necessary to identify the type of relationship between parent and 'significant other'.	4
	Support from healthcare professionals	The focus of this review is on the support from the parents' significant others. It is possible that parents will identify the child's team of healthcare professionals as an emerging part of their network. However, the healthcare professional's role in supporting the parents' decisions is complex as their primary role is to advocate for, and promote the best interests of the child, rather than the parents. Healthcare professionals do play a significant role in supporting decision-making; however, the abundance of existing research about the healthcare professional's role in supporting decision-making and the complexity of this role places this source of support beyond the remit of this review.	19

TABLE 2 (Continued)

Inclusion	Exclusion	Rationale	Number of studies excluded (at full text level of screening)
	No reference to decision-making being supported	When the full texts were screened, it became apparent that a significant number of studies focused on parental decision-making processes, and there was no focus on the parents receiving support from others with this process.	55
Type of Literature			
Primary research including all types of methodology (quantitative, qualitative and mixed methods)	Secondary research (literature reviews) Opinion-based literature	The intention was to exclude literature reviews; however, no relevant literature reviews were retrieved in the search. One non-research paper was relevant to this review (Massimo et al., 2004). However, the opinions expressed in this paper did not add any original insight to the findings of this review.	4
Total excluded at full text level of screening			152

the study's methodological approach. The decision to do this was made because, as identified above, most studies did not focus specifically on support from significant others. This prevented meaningful, relevant conclusions being drawn from the quantitative data, and so, qualitative supporting data were extracted from the quantitative and mixed methods studies.

Computer software was not used for the analysis of this review.

3 | FINDINGS

Two overall themes were identified: 'Dimensions of Decision-Making Support' and 'Expectations of Decision-Making Support'. The first theme (Dimensions of Decision-Making Support) included three sub-themes—informational support, emotional support and instrumental support. The second theme (Expectations of Decision-Making Support) included two sub-themes—parental expectations of their role and parental expectations of the role of significant others.

3.1 | Dimensions of decision-making support

Parents experienced support, and a lack of support, in three key dimensions—informational, emotional and instrumental. These three dimensions were labelled according to House and Kahn's (1985) functions of support in order to explore whether, and how, the mechanisms of social support could be aligned to decision-making support.

3.1.1 | Informational support

Managing information

Parents received informational support in two distinct ways. The most direct way was when other people provided them with information or researched information on their behalf. This helped

parents to gather and manage the information that they felt that they needed to make their decision.

Some parents used their significant others to gather and assimilate information simply so that they could gain sufficient knowledge to make an informed decision (Holm et al., 2003; Kilcarslan-Toruner & Akgun-Citak, 2013; Levi et al., 2000; Yeh et al., 1999). Often, this information came from other parents of children with cancer. In addition, Holm et al. (2003) found that some parents would seek this support specifically from family members and friends who had medical expertise, and Levi et al. (2000) noted that one family asked friends to conduct research, which supported their decision-making process.

Some authors were able to provide a more nuanced understanding of how information gathering could help parents. Gage (2013), Gage-Bouchard (2017) and Robertson et al. (2019) found that parents spoke about using their network to 'translate' specialist knowledge to aid their understanding. Again, the source of this support varied. Like Holm et al. (2003), Gage-Bouchard (2017) found that parents would seek informational support from particular people within their network who had specialist expertise. For example, one mother identified that there were two registered nurses within the family who were able to translate specialist medical information into more understandable language. These findings suggest that this type of support aided parents' understanding, which helped them to communicate more easily with clinicians. This may have subsequently eased the process of making decisions, but this is not explicit.

Gage (2013) found that other parents of children with cancer carried out this translation of specialist knowledge. This was particularly noticeable when families with more experience supported the families with a new diagnosis to understand the hospital structure, cancer treatment and medical jargon. Parents reported that this information felt more accessible and easier to understand which allowed them to use this information to consider alternative options. Interestingly, the parents in Gage's study expressed that they placed more credibility on the information that came from other parents than the information from healthcare professionals. The parents in Robertson et al.'s (2019) study acknowledged that the information

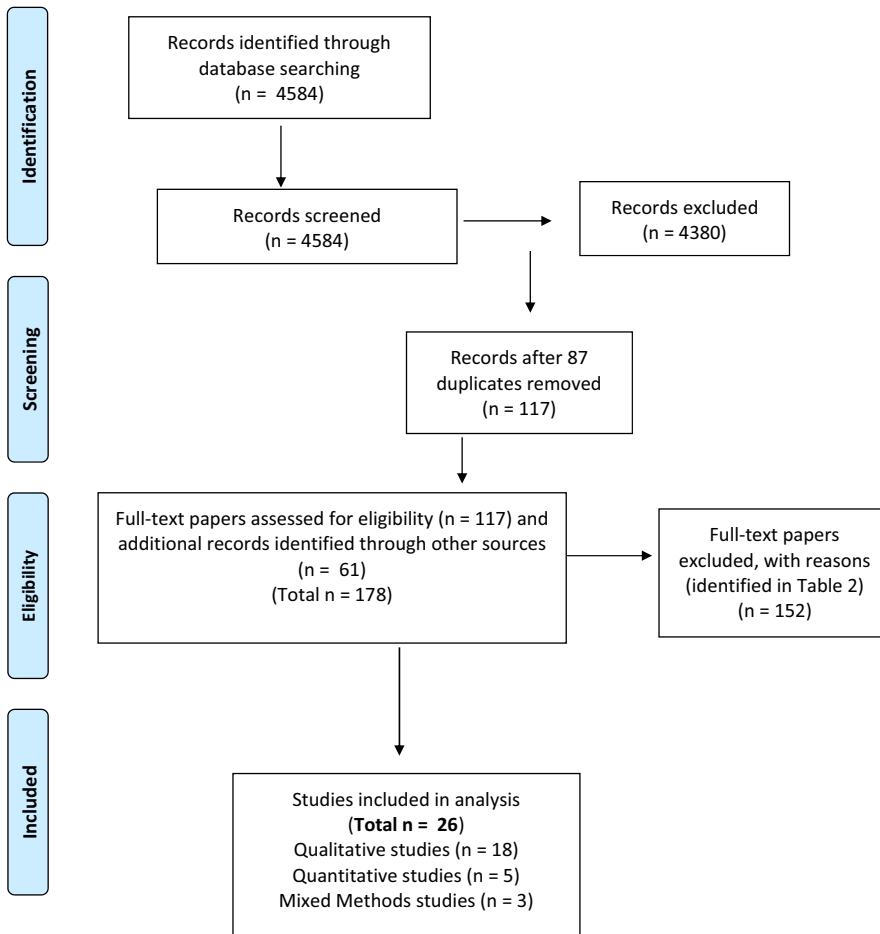


FIGURE 1 Flow diagram of screening process (adapted from PRISMA) flow diagram (Moher et al., 2009)

given by healthcare professionals could feel overwhelming, but that seeking further information from their significant others made it feel more understandable. This translation of information helped parents to compile a list of questions for their treating team, which enabled them to clarify information.

Whilst the studies reviewed highlighted that parents asked their network of significant others to seek information on their behalf, a contrast is presented by Stewart et al. (2012). In this study, whilst a few parents sought information from their network, the majority deliberately did not seek this and only wanted input from medical professionals. This demonstrates that different parents, in varying contexts, may have a range of perspectives about what is helpful and supportive.

Learning from people's stories and experiences

Informational support extended beyond this direct method of information provision, and parents learnt from other people's experiences and stories. This became a way for them to absorb less formal, experiential information but that had the potential to strongly influence their decisions.

In many of the studies, this support stemmed from other families of children with cancer (Alam & Kumar, 2019; Cohen et al., 2017; Gage, 2013; Huang et al., 2008; H-Yazdi & Meadows, 2021; Mostert et al., 2014; Renner & McGill, 2016; Sitaresmi et al., 2010; Yeh et al., 1999). However, this was not exclusively the case and some parents

also sought information from family and friends who had related experience (H-Yazdi & Meadows, 2021; Jong et al., 2020; Sitaresmi et al., 2010).

Whilst this type of experiential informational support was acknowledged in several studies, some did not explore this aspect in sufficient depth to provide understanding of how learning from others' experiences supported parents' decision-making, nor were they explicit that this actually impacted on decision-making (Alam & Kumar, 2019; Cohen et al., 2017; Huang et al., 2008).

However, more detail about this process was given by H-Yazdi and Meadows (2021) who found that parents focused on the importance of learning from real-life stories. In this study, parents whose children had received proton-beam therapy felt it important to listen to the experiences (often through virtual contact) of other families whose child had received the same treatment. The participants explained that these sources of information were preferable to information sheets, medical reports and expertise from doctors, which they felt to be removed from reality. This sense of credibility in learning from others' real-life experiences is echoed by Yeh et al. (1999) and aligns to Gage's (2013) findings that direct information provided from other parents held greater credibility than that received from healthcare professionals.

Gage (2013:48) found that, by observing and listening to each other, parents appraised their own experiences with reference to the experiences of other families and referred to this as a process of

'social comparison'. These stories and observations influenced their attitudes towards their own child's care. Although it was not explicit that this informed their decision-making, parents did feel that this empowered them to advocate for their child, which suggests that this social comparison process could be helpful.

A number of studies focused on factors affecting parents' decisions about treatment continuation versus abandonment, and here, the negative impact of the social comparison process had direct consequences on parents' decision-making (Mostert et al., 2014; Renner & McGill, 2016; Sitaesmi et al., 2010; Yeh et al., 1999). The studies by Sitaesmi et al. (2010) and Renner and McGill (2016) expressed parents' fear of cancer treatment as they heard the stories and watched other families' experiences. Yeh et al. (1999) articulated that watching the negative experiences of other families influenced parents' decisions to abandon treatment, as they watched other children suffer treatment side effects or die despite treatment. This is echoed by Mostert et al. (2014) who noted that parents hearing and seeing what was happening to other parents of children with cancer significantly influenced their decision-making. These findings demonstrate that by observing the experiences of others, misinformation was being circulated ('surgery spreads cancer'; 'cancer is not curable') which influenced parents' decisions to abandon treatment. This was particularly evident in research from Taiwan, Indonesia, Kenya and Ghana and not noted in research findings from Australia, or European and North American countries.

The potential negative impact of learning from others' experiences was found by O'Neil (1996) to be a reason why parents deliberately avoided this type of informational support. Parents expressed that they did not seek support from other parents of children with cancer, as it was too frightening to observe other families travelling their own journeys of relapsed cancer. This is in contrast to many other studies cited in this review where parents did look to other families for support (Alam & Kumar, 2019; Cohen et al., 2017; Eder et al., 2007; Gage, 2013; Holm et al., 2003; Huang et al., 2008; H-Yazdi & Meadows, 2021; Kilicarslan-Toruner & Akgun-Citak, 2013; Levi et al., 2000; Mostert et al., 2014; Renner & McGill, 2016; Robertson et al., 2019; Sitaesmi et al., 2010; Yeh et al., 1999).

This is perhaps due to the focus of O'Neil's study which is on children with relapsed cancer (who are likely to have a poorer prognosis), whereas the majority of other studies focused on decision-making through the child's first diagnosis.

3.1.2 | Emotional support

Emotional support was perhaps less tangible than informational support, but it was nevertheless viewed by parents as important, and similarly, it came from different parts of parents' networks. Hamama-Raz et al. (2012:30) described parents need for 'emotional containment' in order to be able to make decisions. O'Neil (1996) found that parents felt that having an emotionally supportive network gave them the time and space to make decisions.

Often emotional support stemmed from parents' relatives and friends. Papadatou et al. (1996:229) framed this as 'being present', although it is not explicit that this emotional presence led to mothers feeling supported specifically with decision-making. This sense of parents feeling a 'supportive presence' from their significant others was also found by Stewart et al. (2012:424) and whilst it is suggested that this did support treatment decision-making, it is acknowledged that this was only discussed by very few parents in the study.

The manifestation of emotional support was more actively demonstrated in other studies. The parents in O'Neil's (1996) study looked to their wider community for emotional reassurance. A similar sentiment is expressed by Gage (2013), who found that parents needed people to understand how they felt. The parents interviewed in this study did not feel that they could get this sense of understanding from their pre-existing network of family and friends and so they turned to other parents of children with cancer. Whilst this extract of Gage's (2013) study does not link explicitly to decision-making, Gage did suggest that this emotional support reduced parental stress, which may then have helped them feel better placed to make decisions. The parents in Eder et al.'s (2007:854) study also looked to other parents of children with cancer as they felt that these people were at a similar 'emotional level', and similarly, Huang et al. (2008:2744) described this emotional support from other parents as a contribution to parents' strength and 'courage to carry on'.

However, there appeared to be a risk that parents seeking this emotional understanding and reassurance could inadvertently put themselves in the position of feeling judged for their decision-making. This had the potential to be emotionally unsupportive and damaging. This concern was particularly noted by the parents in O'Neil's (1996) small phenomenological study who felt that some members of the community had negatively judged their decision, which parents had found difficult to manage.

3.1.3 | Instrumental support

Instrumental support was offered to parents in two distinct ways, practical and financial support.

Practical support

Several studies discussed practical support being offered to parents (Huang et al., 2008; Mostert et al., 2014; O'Neil, 1996; Papadatou et al., 1996; Stewart et al., 2012). This took the form of cooking (O'Neil, 1996; Papadatou et al., 1996), shopping (Papadatou et al., 1996) and providing childcare for parents' other children (Mostert et al., 2014; O'Neil, 1996). None of these authors explicitly stated that this practical support affected parents' decision-making. However, there is an implicit thread in O'Neil's (1996) work that suggests that the support gave the parents the time and space to consider the decisions they were making. Similarly, Papadatou et al. (1996) suggested that having this practical support provided by family and friends, reassured mothers that they could choose for their child to die at home rather than in the hospital, as the support would

TABLE 3 Data extraction

Author, year and country	Aim of study	Research Design And Method
Alam and Kumar (2019) India	To investigate the impact of an extensive financial, social support and group counselling programme on treatment refusal and abandonment from 1995 to 2017 in North India.	Quantitative: Retrospective cohort study with three phases of support interventions. Data collected from the cancer registry. Children who abandoned / refused treatment were identified, and their parents were asked to complete a questionnaire about the reasons for abandonment.
Blakeley et al. (2000) Canada	To evaluate whether parents were satisfied with the education and support provided to them in relation to making decisions about their child's central venous access device (CVAD).	Quantitative: 83 item questionnaire survey.
Cohen et al. (2017) Australia	To compare views among parents, patients and healthcare workers on the positive and negative aspects of enteral tube feeding (ETF), the ways in which information was provided, and how the decision-making process was conducted.	Qualitative: Semi-structured interviews. Data analysed using content analysis.
Eder et al. (2007) USA	To report suggestions that parents made about improving the informed consent process.	Qualitative: Interviews and focus groups. Parents were interviewed twice (at the time of informed consent and again 6 – 8 months later. Focus groups including all parents who had participated in the interviews. Finally, a parent advisory group on informed consent (PAGIC) was convened. Data analysed using an approach based on grounded theory.
Gage (2013) USA	To examine how network ties among parents of paediatric cancer patients shape parents' perceptions of the healthcare experience.	Mixed Methods: In-depth Interviews and standardised survey questionnaire. Thematic analysis was conducted.
Gage-Bouchard (2017) USA	To explore how social support helps people to navigate the healthcare system.	Qualitative: In-depth interviews were undertaken, and observations of clinical interactions between oncologist and the parents were conducted. The parents who were interviewed were not the same parents who were observed.
Hamama-Raz et al. (2012) Israel	To investigate the coping experience of parents of a child with retinoblastoma.	Qualitative: Phenomenological Interviews. Content analysis was undertaken.
Holm et al. (2003) USA	To explore parents' descriptions of their participation in medical care for their children with cancer.	Qualitative: Focus groups. Content analysis was undertaken.

Participants	Key findings in relation to this literature review	Study limitations
<p>Children recorded on the cancer registry from 1995 to 2017 ($n = 1041$)</p> <p>Parents of children with acute lymphoblastic leukaemia aged less than 18 years who completed the questionnaire relating to reasons for treatment abandonment ($n = 196$)</p>	Engagement with parent support groups appeared to influence parents' decision to continue treatment for their child.	<ul style="list-style-type: none"> • Longitudinal nature of the study makes it impossible to eliminate other factors that may not be directly linked to the interventions. • Limited depth around the reported findings (possibly due to journal word limit) so not possible to unpick what element of the intervention impacted on decisions.
<p>Parents of children with cancer who had a central venous access device inserted ($n = 44$, return rate of 88%).</p> <p>86% of respondents were mothers.</p>	Some parents reported that their decision was made jointly with another family member.	<ul style="list-style-type: none"> • Questionnaire was not formally validated although it had been piloted. • Authors acknowledges that generalisability is problematic.
<p>Two groups of participants: (i) children with cancer aged less than 18 years ($n = 10$) or their parent if the child was aged less than 12 years ($n = 20$: 18 mothers, 2 fathers); (ii) healthcare professionals ($n = 18$)</p>	Parents seek information from other families on ward. They watch other families' experiences, and this seems to influence their decision.	<ul style="list-style-type: none"> • Single site study. • Authors acknowledge that recall bias may be problematic.
<p>Parents of children with leukaemia (across 6 hospitals).</p> <p>Initial interview ($n = 132$); follow-up interview ($n = 110$); focus groups ($n = 72$); PAGIC meeting ($n = 9$)</p>	Parents suggested that they wanted to talk to their family and friends, and also other parents of children with cancer, before making a decision, they also suggested that allowing another person to attend the consultation with them would be helpful.	
<p>Parents of children with cancer ($n = 76$: 49 mothers, 27 fathers)</p>	Other parents of children with cancer support parents and this may affect decision-making.	<ul style="list-style-type: none"> • Concept of 'similar' versus 'significant' others are imposed by the researcher on participants rather than self-defined.
<p>Two groups of participants were interviewed: (i) parents of children with cancer ($n = 80$: 51 mothers, 29 fathers) and (ii) paediatric oncologists ($n = 8$). Observations of clinical interactions between families and physicians ($n = 73$)</p>	Social networks can offer informational support which may inform decision-making. The provision of practical support from social networks allows parents to be more present at the hospital and therefore more involved in decision-making.	<ul style="list-style-type: none"> • Unclear why the decision was made to interview a different group of parents to those being observed.
<p>Parents of children with retinoblastoma ($n = 12$ sets of parents, although one interviewee had been widowed and so was interviewed alone)</p>	Other parents of children with retinoblastoma are considered a source of emotional support, and this links to the parents feeling that they can make decisions.	<ul style="list-style-type: none"> • Some of the participants had received their child's diagnosis 12 years previously which may have been considered too long a period of time for the participants to reflect back on their experiences.
<p>Parents of children who had completed cancer treatment at least one year prior to the focus group ($n = 45$: 26 mothers, 19 fathers)</p>	Parents sought informational support from other parents of children with cancer, and from family members and friends with medical expertise. This informed their decision.	<ul style="list-style-type: none"> • Data collected between 1990 and 1998 and therefore may not be representative of people's experiences today. • Authors acknowledge that the data drawn upon for this study are used to answer a question that was not the original focus of the research project. Further questioning and exploration in relation to this topic may have elicited different responses. • Possible recall bias as participants were reflecting on events that happened up to nine years previously.

TABLE 3 (Continued)

Author, year and country	Aim of study	Research Design And Method
Huang et al. (2008) Taiwan	To explore family experiences in terms of family resources and how these assist a single-parent caring for a child with cancer.	Qualitative: Phenomenological interviews. Transcripts were analysed based on Colaizzi's (1978) principles of phenomenology.
H-Yazdi and Meadows (2021) UK	To explore how parents of children treated with proton beam therapy (PBT) view the treatment and the sources of information surrounding the treatment.	Qualitative: Interviews. Transcripts were analysed thematically.
Israëls et al. (2008) Malawi	To gain insight into the guardians' perspective on cancer treatment, especially concerning factors which could influence abandonment of treatment.	Qualitative: Interviews and focus groups. A sequence of semi-structured interviews were undertaken at various points during the child's treatment trajectory. Focus groups were also held. Analysis was influenced by a grounded theory approach.
Jong et al. (2020) Sweden / Netherlands	To develop an evidence-based decision aid for parents of children with cancer and to help guide them in the use of complementary and alternative medicine (CAM) for cancer care.	Mixed Methods: 23-item, validated questionnaire survey; and focus group (analysed using a directive content analysis). The survey and focus group were the first phase of the development of the decision aid (there were 4 phases in total) and is relevant to this review as it related to how people made decisions.
Kelly and Ganong (2011) USA	To explore how parents who no longer live together make treatment decisions for their children with cancer.	Qualitative: Grounded theory interviews. Analysis followed the grounded theory process.
Kilicarslan-Toruner and Akgun-Citak (2013) Turkey	To explore the information-seeking behaviours, perceptions and decision-making experiences of parents of children with cancer.	Qualitative: Interviews. Inductive content analysis was undertaken.
Levi et al. (2000) USA	To learn about and to describe retrospective perceptions of parents of the circumstances of their child's cancer diagnosis and of the informed consent process.	Qualitative: Focus groups. Cross-case analysis was used.
Liang (2002) Taiwan	To discover the cultural care practices of caregivers when promoting the health and well-being of children with cancer.	Qualitative: Ethnonursing interviews. Analysis underpinned by principles of ethnonursing.
McKenna et al. (2010) UK	To identify parental perceptions of both their own involvement and that of others in the decision to enrol their child on to a specific cancer treatment protocol, and their satisfaction with this decision.	Quantitative: Questionnaires and Interviews. Parents completed two validated questionnaires within an interview context with four additional questions also asked at the interview. Data analysed using the Statistical Package for the Social Sciences.

Participants	Key findings in relation to this literature review	Study limitations
Single parents of children aged less than 18 years receiving treatment for cancer ($n = 9$: 5 mothers, 4 fathers).	Single parents may receive emotional, informational and practical support from relatives and friends, and also seek information from other parents of children with cancer. However, parents feel that the decision must be made alone.	<ul style="list-style-type: none"> The authors identify that the results may not be representative as a limitation of their study; this is misaligned with the concept of phenomenology as the purpose of this research is not to present people's experiences as representative of others.
Parents of children who had been treated with proton beam therapy ($n = 27$: 19 mothers, 8 fathers)	Parents seek information from family, friends and from other families of children who have undergone PBT.	<ul style="list-style-type: none"> Authors acknowledge that a limitation is that parents were recruited to this study via online support groups which may have meant that the participants were more engaged with online support than other families may have been.
Guardians of children with Burkitt lymphoma or Wilms tumour ($n = 32$: 31 mothers, 1 father)	Some guardians asked their relatives for advice about decision-making.	<ul style="list-style-type: none"> Lack of detail reported about the methods and analysis. No quotes are used to illustrate themes. Authors acknowledge that one of the interviewers was a physician on the ward where the child was being cared for and that this may introduce bias.
Parents of children with cancer (survey $n = 70$: 93% mothers; focus group $n = 7$)	Some parents sought informational support from family and friends.	<ul style="list-style-type: none"> Unclear whether the survey findings influenced the design of focus groups.
Custodial ($n = 7$: 6 custodial mothers, 1 custodial father); non-residential ($n = 5$: 1 mother, 4 fathers); and step-parents ($n = 3$: 1 stepmother, 2 stepfathers) who had previously made a major treatment decision for their child with cancer (total $n = 15$)	The responsibility around the decision-making in diverse family structures is complex. Step-parents offered significant emotional support and often informational support. However, the parent also needed space to make decisions. Different types of decisions required different types of support.	<ul style="list-style-type: none"> Single site study.
Parents of children with cancer ($n = 15$: 13 mothers, 2 fathers)	Parents are supported with finding information from friends, and from other parents of children with cancer.	<ul style="list-style-type: none"> Authors acknowledge that the findings are not intended to be generalisable. Authors suggest that the study could have been strengthened by interviewing the other parent in the family.
Parents of children with cancer who had been eligible for a clinical trial research protocol ($n = 22$: 16 mothers, 6 fathers)	Some parents sought emotional and informational support from family, friends, and other parents of children with cancer. This helped them to make decisions.	<ul style="list-style-type: none"> Although described as a qualitative study, the data analysis is treated in a quantitative way. Authors suggest that it is not possible to generalise as the sample size is small, but this is not in line with a qualitative perspective.
Two groups of participants: (i) caregivers of children with cancer ($n = 34$: 23 mothers, 8 fathers, 1 grandmother, 2 aunts) and (ii) nurses ($n = 6$).	Extended family members significantly influenced parents' decision-making about treatment. Parents worried that they might offend their family and healthcare professionals if they rejected their advice.	<ul style="list-style-type: none"> Single site study.
Parents of children with cancer ($n = 66$)	Some parents sought advice from relatives. When other people were involved with making a decision, they reported more difficulties with the decision-making process; however, parents reported that they felt more satisfied with their decision if they had received the right amount of support.	<ul style="list-style-type: none"> Nature of the methodology prevents depth in the exploration of parents' experiences. Limited potential to establish cause versus effect, for example whether parents find it more difficult to make a decision when relatives are involved because of that involvement, or whether this is because they asked for support because it was a difficult decision to make. This is acknowledged by the authors.

(Continues)

TABLE 3 (Continued)

Author, year and country	Aim of study	Research Design And Method
Mostert et al. (2014) Kenya	To explore parents' experiences with hospital retention policies and the impact of attitudes of family and friends on parents' decisions about continuing cancer treatment for their child.	Quantitative: Questionnaire via interview. Most questions framed on two-point, three-point or four-point rating scale. There was one open-ended question. The responses were statistically analysed.
O'Neil (1996) USA	To explore the experiences of parents as they made decisions when their child had a recurrence of cancer.	Qualitative: Phenomenological interviews (<i>Doctoral Thesis</i>). Analysis underpinned by the philosophy of Heidegger.
Papadatou et al. (1996) Greece	To investigate the experiences of Greek mothers who cared for a child dying of cancer at home or in the hospital, and to highlight some of their major needs during the terminal period.	Mixed Methods: Three methods of data collection were used: semi-structured interviews, patient medical records and a validated questionnaire—the Grief Experience Inventory.
Renner and McGill (2016) Ghana	To explore factors influencing parental decision-making for children with cancer with regard to health seeking and retention in treatment.	Qualitative: Interviews and focus groups. Thematic content analysis was undertaken.
Robertson et al. (2019) Australia	To explore parents' and adolescents' views and perceptions of making medical decisions in paediatric oncology.	Qualitative: Semi-structured interviews. Demographic data statistically analysed. Interview data thematically analysed.
Sitairesmi et al. (2010) Indonesia	To analyse parents' reasons for treatment abandonment and to ascertain the consequences of children who abandoned treatment.	Quantitative: Semi-structured questionnaires / interviews and observations of social / home circumstances were made. Statistical analysis applied.
Stewart et al. (2012) USA	To describe the process of parents making major treatment decisions for their children with cancer.	Qualitative: Grounded theory interviews. The interview guide was revised throughout the study in line with the constant comparative analytic technique of grounded theory.
Woodgate and Yanofsky (2010) Canada	To understand Canadian parents' participation in decisions about childhood cancer trials.	Qualitative: Interviews. Constant comparative method was used to analyse the data.
Yeh et al. (1999) Taiwan	To document the determinants of parental decisions to 'drop out' from cancer treatment for their child.	Qualitative: Interviews. Content analysis was undertaken.

be in place. It should be noted though that in both cases, these inferences came from the authors' interpretations rather than the direct words of the parents.

Financial support

Financial support was significant for many of the parents in the studies—particularly in research from African and Asian countries (Huang et al., 2008; Israëls et al., 2008; Mostert et al., 2014; O'Neil, 1996; Renner & McGill, 2016; Sitaresmi et al., 2010). This financial support was useful for different reasons. A parent in

O'Neil's USA (1996) study talked about how a friend had started fundraising on the family's behalf; this was specifically because the family were struggling to cover the cost of travelling to and from the hospital so regularly. For the families in Mostert et al.'s (2014) and Renner and McGill's (2016) studies, this financial support was provided by the parents' relatives, friends and wider communities, and was extremely significant as it enabled the families to pay for the medical bills and drugs that their child needed. The focus of both of these African studies was around treatment retention versus abandonment, and as one of the factors for

Participants	Key findings in relation to this literature review	Study limitations
Parents of children with cancer who had abandoned cancer treatment (<i>n</i> = 46)	In many cases, extended family and other members of the community advised parents to abandon conventional treatment. Other parents of children with cancer also influenced the parents' decisions.	<ul style="list-style-type: none"> • An open question in the interview is alluded to but there is no reported analysis of responses.
Parents of children with relapsed cancer (<i>n</i> = 6 family units)	Support from family and friends was helpful if it was non-judgemental, emotionally reassuring and provided practical / financial help. However, sometimes the help offered was misdirected and detrimental.	
Mothers of children who had died of cancer (<i>n</i> = 15)	The findings suggest that having practical and emotional support available from extended family influenced the mother's decision to care for her child at home.	<ul style="list-style-type: none"> • Small sample size for a mixed methods study and therefore statistical analysis is limited. • Emphasis in the paper is therefore on qualitative analysis. • No identification of how the information from medical records was integrated into the analysis.
Parents of children with cancer (interviews <i>n</i> = 12, focus groups <i>n</i> = 7. Of this total of 19 participants, 13 were mothers and 6 were fathers)	Parents sought information from relatives, friends and other members of the community. Some parents made decisions to use native / herbal medicine because of influence of these people. Financial support from these groups also influenced their decision-making.	<ul style="list-style-type: none"> • Authors suggest that a limitation is that the findings are not representative of the general population, but this is misaligned with a qualitative perspective.
Two groups of participants: (i) parents of children with cancer (<i>n</i> = 25: 23 mothers, 2 fathers); (ii) adolescents with cancer (<i>n</i> = 5)	Parents sought informational support from online parent forums and from other families on ward.	<ul style="list-style-type: none"> • Authors acknowledge that only one site was accessed and there was limited diversity of participants.
Families of children with acute lymphoblastic leukaemia (<i>n</i> = 37)	Other people in their community, and other families of children with cancer, influenced the parents' decisions. Financial support from other people was also a factor that influenced their decisions.	<ul style="list-style-type: none"> • No information reported about how the questions were developed or piloted.
Parents of children with cancer (<i>n</i> = 15: 9 mothers, 6 fathers)	Findings suggest that parents do not want involvement of their social network when they make major treatment decisions.	<ul style="list-style-type: none"> • Authors acknowledge that there was a lack of cultural diversity within their group of participants.
Parents of children with cancer (<i>n</i> = 31: 20 mothers, 11 fathers)	This suggests that advice from 'expert' family / friends is supportive.	<ul style="list-style-type: none"> • Authors acknowledge the retrospective nature of the study but also that the opportunity to reflect on decision-making is a strength. • There is a lack of diversity represented in the group of participants.
Parents of children with cancer who had dropped out of cancer treatment (<i>n</i> = 19: 14 mothers, 5 fathers)	Decision to abandon treatment significantly influenced by other parents of children with cancer. Some parents also influenced by religious beliefs.	<ul style="list-style-type: none"> • Authors suggest that the study is limited by its small sample and that the sample is not representative; however, neither of these limitations are in line with a qualitative perspective.

abandonment was linked to financial pressure, this support likely contributed to the parents' decision to continue cancer treatment for their child.

An opposing perspective was shared by Israëls et al. (2008) and Sitaresmi et al. (2010). The parents in both of these studies acknowledged that they consulted with people on whom they were financially dependent (such as their relatives). These people had a strong influence on the decision-making process, and in Sitaresmi et al.'s (2010) study, parents' financial dependency on others influenced their decision to abandon treatment.

Another aspect of financial support related to parents' employment. Sitaresmi et al. (2010) found in their Indonesian study that 54% of fathers lost their job because of having to accompany their child to hospital. Huang et al. (2008) discussed how, in Taiwan, the combination of financial assistance and practical support that relatives provided allowed the parent to leave their child temporarily so that they could keep their job. However, it is not clear if, or how, that affected making decisions. However, Gage-Bouchard (2017) reported that parents felt excluded from healthcare decisions because they were working and therefore not at the hospital with their

child. The parents in this American study felt that if they could have received sufficient financial support to be able to take leave from work, they would then have been able to be more involved with making decisions.

3.2 | Expectations of decision-making support

Parents' experiences of support were influenced by their expectations of their own role (sub-theme 3.2.1) and other people's roles (sub-theme 3.2.2) in decision-making. Their expectations and roles were affected by their relationships with other people, and these relationships could have both a positive and negative impact on parents' feelings of being supported.

3.2.1 | Parental expectations of their role

The parents in several studies strongly believed that as an advocate for their child, it was their responsibility to make decisions about their child's care, and nobody else's (Huang et al., 2008; Kelly & Ganong, 2011; O'Neil, 1996; Papadatou et al., 1996). For the parents in Kelly and Ganong's (2011) study, this responsibility was an extension of their parental role, and similarly, Papadatou et al. (1996) expressed that this responsibility was enmeshed with the culture of Greek family functioning, where parents take an active and protective role in decision-making. Further explanation about this responsibility was highlighted by a parent interviewed by Kelly and Ganong (2011) who explained that taking full responsibility to make the decision avoided the risk of blaming others if the outcome was negative, suggesting that this process would protect both the significant others and also protect the parents from this feeling. Interestingly Huang et al. (2008) uncovered a different perspective. They found that parents would rely only on themselves, suggesting a lack of trust in others. It should be noted that the focus of Huang et al.'s (2008) study was on parental experiences in single-parent families, and Kelly and Ganong (2011) focused on single-parent and re-partnered family structures, so perhaps this sense of responsibility lying solely with the parent stemmed from a history of potentially complex relationships. Indeed, Kelly and Ganong (2011) acknowledged the difficulty of making decisions in families with pre-existing conflict as some parents felt very mistrustful.

However, this sense of responsibility and self-expectation that their role, as a parent, was to make difficult decisions about their child's care could come to feel burdensome. This was particularly the case for single-parent families (Kelly & Ganong, 2011) where a mother talked about feeling alone, and struggled with not being able to share this decision-making burden with anybody else. Parents in Woodgate and Yanofsky's (2010:14) study also talked about the immense difficulty of trying to meet the expectations of being a 'good parent' by making the 'right' decision for their child. This burden and emotionally charged context could lead parents to lose confidence in their ability to make decisions (Stewart et al., 2012) and thus their

confidence in performing their role as the child's advocate. This could then lead, in some cases, to parents looking to their significant others to play a role in supporting the decision-making process.

3.2.2 | Parental expectations of the role of significant others

Parents had varied expectations of the role that significant others should play when decisions needed to be made. For the parents who felt strongly that nobody else should be involved in decision-making (as acknowledged above by Huang et al., 2008; Kelly & Ganong, 2011; O'Neil, 1996; Papadatou et al., 1996), the expectation was that other people should give them the time and space to make this decision. Whilst parents acknowledged that other people may provide support during this time (such as the informational, emotional or instrumental dimensions of support explored in Theme 1), they were not expected to take a role in actually making, or influencing, the decision. Kelly and Ganong (2011:355) described this process in terms of step-parents being expected to 'step back'. However, in other cases, parents needed their significant others to become more involved with directly supporting decision-making.

In these situations, when parents turned to others to discuss the decision that they were facing, they needed to talk through their thoughts and essentially needed significant others to listen and to act as a sounding board (Blakeley et al., 2000; Eder et al., 2007; Huang et al., 2008). A parent in O'Neil's study (1996: 210) described this as 'being able to hear your own voice'. In some cases, this role of being a sounding board evolved to significant others providing advice to parents (Israëls et al., 2008; Kelly & Ganong, 2011; McKenna et al., 2010; Woodgate & Yanofsky, 2010). Parents acknowledged that it could be helpful to hear other people's perspectives about the decision that they were making (Eder et al., 2007). Woodgate and Yanofsky (2010) found that parents would seek out key family members or friends who had specific knowledge, and that they would ask these people for advice. This is consistent with the informational dimension of support where it was also acknowledged that parents would seek information from members of their network who had specific knowledge. However, Woodgate and Yanofsky (2010) suggested that by specifically asking for advice from these people, parents could cope better with the stress and guilt that they were experiencing about making decisions. This was though, dependent on relationships, as Stewart et al. (2012) noted that some parents limited the involvement of their social network in decision-making because of pre-existing conflict. Interestingly, McKenna et al. (2010) found that where parents sought advice from other people (such as family members) they reported that their decision was more difficult to make. However, the authors acknowledged that it cannot be assumed that this meant that seeking advice made the decision-making harder, as it is also possible that parents who were already finding the process difficult sought the advice.

The literature reviewed demonstrated that there was a fine line between significant others offering supportive advice to parents,

and this being perceived by parents as interference. The step-parents interviewed by Kelly and Ganong (2011:357) referred to this as needing to 'tread lightly', as whilst they could offer opinions it was important that they recognised that it was not their place to make the decision. The crossing of the boundary from support to interference was particularly noted in Liang's study from Taiwan (2002:213) where parents sometimes felt pressurised to listen to suggestions from elder family members, citing an example of a parent who said 'I have to listen to my mother-in-law's suggestions to give my child herbs sometimes'. A similar story from Ghana was cited by Renner and McGill (2016) where the child's grandmother would not allow the parents to make the decision to access hospital treatment, and instead insisted that the child should be treated with native medicine. Yeh et al. (1999), who similarly conducted their research in Taiwan, also found that in a small number of cases (3 out of 19), the decision to abandon treatment was made by the grandparents, rather than the parents. In all three of these studies, it was unclear how this involvement of grandparents in the decision-making process affected the parents' experiences. However, O'Neil (1996) found that interference from others felt to parents like an assault on their advocacy for their child, suggesting that the arguably self-appointed role of others was in direct conflict with the role identity of the parents.

4 | DISCUSSION

The analysis process led to the development of two themes. Wider reading around the topic area identified that the three sub-themes in Dimensions of Decision-Making Support (informational, emotional and instrumental) aligned to the social support framework identified by House and Kahn (1985). Gage (2013) applied this framework to support within the children's cancer context, and so, it was of interest to explore whether these categories would also apply to social support specifically with decision-making. The findings of this literature review suggest that, to an extent, this is the case. However, within the context of decision-making, there seemed to be another aspect that was also important which was not captured within these three categories. This broadly related to people's expectations of support, and in particular to their roles and responsibilities of decision-making, and whether or not it was considered helpful for significant others to offer advice or opinions about the decisions that were being made.

It is clear throughout the themes and sub-themes that the behaviours of significant others could be perceived as supporting parental decision-making. However, there appeared to be a fine line, and in some situations, these behaviours could be perceived as unsupportive. This suggests that parents' support needs vary, which is unsurprising as every family's experience is situated in a different personal, social and cultural context (United Nations Convention on the Rights of the Child, 1989).

Of all the support dimensions, informational support was portrayed with most prevalence in the review and with a wide

geographical representation. This resonates with wider legal perspectives about decision-making, as receiving sufficient information is critical when making informed decisions (Griffith & Tegnah, 2017). Within the context of children's cancer care, Mack et al. (2006) suggested that most parents want as much information as possible. However, this review demonstrates that the type, and source, of information preferences varies. Whilst the majority of parents in Stewart et al.'s (2012) study valued information from healthcare professionals above other sources, the parents in many of the other studies identified in 3.1.1 sought information from their significant others, whether this be in the form of formal information management, or informally learning from other people's stories and experiences. It is of significance that some parents placed higher credibility on these sources of information, than from their healthcare professionals. The fine line between supportive and unsupportive behaviours is apparent in this theme, which is particularly noted in studies from Taiwan (Yeh et al.'s 1999) and Kenya (Mostert et al.'s 2014) where parents abandoned treatment for their child as a result of watching others' experiences, and misinformation circulating within networks.

The variation in parents' support needs is similarly evident in both the dimensions of emotional and instrumental support. An example of the way that social and cultural contexts may influence this variation is highlighted within the financial aspect of instrumental support. Several studies discussed financial influences on decision-making. Some found that financial support from significant others either enabled treatment to be continued (where members of the community could enable families to pay for the medical bills and drugs, or enable parents to take time away from work). Others found that financial dependency on a significant other led to parents deciding to abandon treatment. It is interesting that the countries represented in this sub-theme were Taiwan (Huang et al., 2008); Malawi (Israëls et al., 2008); Indonesia (Sitaresmi et al., 2010); Kenya (Mostert et al., 2014); Ghana (Renner & McGill, 2016); and United States (Gage-Bouchard, 2017; O'Neil, 1996). With this diversity of national representation, comes diversity of healthcare funding and employment protection, and perhaps, this goes some way to explaining the variation within this aspect of decision-making support.

Again, there was a fine line between emotionally supportive behaviours and harmful behaviours (particularly parents feeling like they were being judged). However, the extent to which these behaviours directly affected parents' decision-making is unclear. There was also a lack of depth about how or why this behaviour was supportive or unsupportive. This presents an opportunity though to draw the two themes together, as perhaps the effects of the support dimensions are influenced by the individual's perspective of their role as a parent, and their existing relationship dynamics.

The role of the parent of a child with cancer has been discussed by Gagnon and Recklitis (2003), Pyke-Grimm et al. (2006), and Hinds et al. (2009) among others. In particular, Hinds et al. (2009), who framed this role as parents needing to be a 'good parent', highlighted that many parents felt that their role was to advocate for their child. Gagnon and Recklitis (2003) expressed this as a natural extension

of the parental role during times of health, when parents are used to functioning as proxy decision-makers for their child. However, Pyke-Grimm et al. (2006) found that the parent's role as decision-maker became increasingly difficult in the period following diagnosis as often the parents were in a state of shock and felt pressured into making a rapid decision. These sentiments are echoed within this review. However, whilst the parents in Pyke-Grimm et al.'s (2006) study turned to healthcare professionals for support, the parents represented in this review sometimes turned to their significant others for support and advice.

Interestingly, literature around supporting surrogate or proxy decision-making in adult healthcare shares similar findings. Iverson et al. (2014) note that seeking support from the decision-maker's extended network could boost confidence in their role and act as a buffer to the burden of decision-making. Batteux et al. (2017) suggest that seeking advice from others can cast a different perspective. Other people in a network are arguably in a position where they can provide more *objective* advice than the decision-maker, but more *subjective* advice than a healthcare professional.

Whilst there are difficulties with comparing the role of surrogate decision-making on behalf of an adult family member, and the role of a parent making decisions on behalf of their child (Lipstein et al., 2012), this concept of confidence and need for advice from the right person is significant. It is notable within the review that the parents in O'Neil's (1996) study seemed to turn to others less often than in some other studies. This was a small study and not intended to be generalisable. This may though relate to the focus of O'Neil's study, relapsed cancer, where the parents had more experience of, and thus increased confidence in, their role as decision-maker. Similarly, by the time that a child has been diagnosed with relapsed cancer, it is likely that the parents will have built up strong and trusting relationships with the healthcare professionals, and are likely to place more credibility in support from their medical team at this stage as they trust that they can provide both objective and subjective advice. Arguably, a parents' confidence in their role, and their dependent relationships on others, may evolve over time—this would warrant further exploration.

The findings of this review suggest that relationships influenced the role that parents felt others should take, and again, this sense of a fine line is evident between advice and interference. These relationships may have extended and influenced more than the expectations and balance of roles in decision-making, and influenced the perceived supportive influence of the three dimensions. Again, this suggests that the unique family contextual position is significant. In addition to the variation in social dynamics among each family's social network, Barbarin and Chesler (1984) note that a child's cancer diagnosis can have a significant impact on these dynamics, and thus, relationships and networks evolve over time, further impacting on roles and dimensions of support.

Jackson et al. (2008) define decisional support as anything that helps people to gather information and clarify their values. Whilst the findings of this literature review support the importance of informational support, it also demonstrates that supporting

decision-making extends beyond Jackson et al.'s definition and is placed within a complex personal, social and cultural context. In addition to informational support, emotional and instrumental support can also play a role in parental decision-making, and expectations of support are strongly influenced by people's perceptions of decision-making roles and relationships with significant others.

4.1 | Implications for research

Whilst this review has synthesised current research across a number of countries, many questions are left unanswered due to the lack of focus on this specific topic. This review adopted a broad approach around the identification of significant others, but further research should allow parents to self-identify their networks. It would be interesting to explore whether parents identified other parents of children with cancer to be a member of their significant other network. Thoits (2011) and Gage (2013) delineate between 'significant others' and 'similar others' and exploration around whether parents would themselves separate these groups would also be worthwhile. Further exploration around support needs for different decisions is warranted. Coyne et al. (2014) found that parents drew a distinction between 'major' and 'minor' decisions. It would be of interest to explore whether significant others had a different supportive role to play within the context of these different decisions. Other factors that affect decision-making support would also warrant further exploration such as demographic and clinical characteristics, and the extent to which the support from significant others actually influences the final decisions that parents make. Finally, greater understanding about what it feels like to be a parent being supported by their significant others with decision-making would facilitate development of important knowledge around this topic.

4.2 | Strengths and limitations

There are several general limitations acknowledged within this review. The publication dates of the retrieved studies spanned a significant time (from 1996 to 2021). It is important to be mindful of this, as social and cultural practices may have evolved during this time and it cannot be assumed that findings would still be the same today. Similarly, the research reviewed was representative of a variety of countries, and cultural transferability cannot be assumed. That said, this breadth of social and cultural practices has brought greater depth to the findings and could be perceived as a strength rather than a limitation of the review. Whilst some authors acknowledged the lack of cultural diversity as a limitation to their study (Cohen et al., 2017; Kilicarslan-Toruner & Akgun-Citak, 2013; Renner & McGill, 2016; Robertson et al., 2019; Stewart et al., 2012; Woodgate & Yanofsky, 2010), the ability to synthesise studies from a range of countries and cultures in this review has afforded a much greater diversity than would be possible in a single study.

TABLE 4 Types of decision and sources of support

Author and year	Type of decision	Source of support (significant other)
Alam and Kumar (2019)	Treatment abandonment	Other parents of children with cancer
Blakeley et al. (2000)	Choice of central venous access device	Family member
Cohen et al. (2017)	Nutrition (enteral tube feeding)	Other parents of children with cancer
Eder et al. (2007)	Enrolment in research trial	Family / friends / other parents of children with cancer
Gage (2013)	Not specified - any decision relating to child's cancer care	Other parents of children with cancer
Gage-Bouchard (2017)	Not specified but focus is on 'navigating the healthcare system'	Not specified but refers to 'personal networks' and suggests that this includes relatives and friends. There is specific reference to members of networks who are healthcare professionals
Hamama-Raz et al. (2012)	Surgical treatment (removal of eye as treatment for retinoblastoma)	Other parents of children with cancer
Holm et al. (2003)	General decisions about cancer care	Family / friends with medical expertise and other parents of children with cancer
Huang et al. (2008)	Various decisions; the focus of this research is not on decision-making but there is discussion about general decisions, place of care, education, and other lifestyle choices, all of which relate to the child's cancer care in a broad context	Family / friends and other parents of children with cancer
H-Yazdi and Meadows (2021)	Proton Beam therapy	Family / friends with specialist expertise; other parents of children with cancer and online support groups
Israëls et al. (2008)	Treatment adherence / abandonment	Relatives, mainly grandparents
Jong et al. (2020)	Complementary and alternative medicine	Family / friends
Kelly and Ganong (2011)	Major treatment decisions and daily decisions	Step-parents
Kilicarslan-Toruner and Akgun-Citak (2013)	General decisions and information, for example mouth care, diet, and bigger treatment decisions	Relatives / friends / other parents of children with cancer
Levi et al. (2000)	Treatment / research decisions	Friends / family / other parents of children with cancer
Liang (2002)	General care decisions including diet, alternative medicines (e.g. Chinese medicine / herbal medicine)	Friends / community (elders) / religious community / grandparents / other parents of children with cancer
McKenna et al. (2010)	General treatment decisions	Grandparents and other relatives / family members
Mostert et al. (2014)	Treatment abandonment	Grandparents and other relatives / friends / community / religious community / other parents of children with cancer
O'Neil (1996)	Relapse treatment decisions	Family / friends / neighbours / religious communities / employer / NOT other parents of children with cancer
Papadatou et al. (1996)	Place of death of child with cancer	Relatives / grandparents / other parents of children with cancer / religious community
Renner and McGill (2016)	General treatment decisions	Friends / relatives / religious communities / herbalists / other parents of children with cancer / grandparents
Robertson et al. (2019)	General but emphasis on treatment decisions, also acknowledges minor decisions.	Online parent forums / other parents of children with cancer
Sitairesmi et al. (2010)	Treatment abandonment	Relatives / people on whom they are financially dependent / religious communities / other families of children with cancer
Stewart et al. (2012)	Major treatment decisions	Family / friends / religious figure
Woodgate and Yanofsky (2010)	Research trial enrolment	Family / friends with expertise
Yeh et al. (1999)	Treatment abandonment	Grandparents / parents of other children with cancer / religious communities and figures

A further consideration relates to the study participants. Kilicarslan-Toruner and Akgun-Citak (2013); Robertson et al. (2019); and H-Yazdi and Meadows (2021) acknowledged that a limitation of their studies was that fathers were underrepresented in their samples. Indeed, exploring the participant demographics highlighted that many studies within this review recruited a majority of respondents who were mothers. Robertson et al. (2019) noted that it is common to recruit mainly mothers in psycho-oncology research. It is therefore important to take into account that the prevailing voices in the findings of this review were from mothers, rather than fathers, of children with cancer.

There is potential bias in this review as only papers in the English language were included. Whilst significant efforts were made to retrieve all relevant studies, it is acknowledged that no search strategy is perfect and further networking and snowballing may have yielded further studies.

5 | CONCLUSION

Making decisions about a child's cancer care can be challenging for parents. Whilst attention has previously been given to how health-care professionals can support parents, little focus has been given to how parents' significant others can offer support. This integrative literature review has synthesised what is currently known about how parents are supported by their significant others when they are faced with these decisions.

Current international research suggests that significant others can support parents in three dimensions: informational, emotional and instrumental support. However, parents' perspectives of their own and others' roles in decision-making also influences how support may be provided and received. Sources of social support range from parents' family members and friends to other parents of children with cancer, and there is a fine line between supportive and unsupportive behaviours. The uniqueness of each family's personal, social and cultural context strongly impacts on their support needs, and healthcare professionals should be mindful of how parents may access support from their significant others in order to enhance provision of family-centred care.

6 | RELEVANCE TO CLINICAL PRACTICE

Whilst this review demonstrated that parents' decision-making support needs varied, it is evident that some parents did turn to their significant others for support. It is important that nurses and other healthcare professionals are aware of this and consider how decision-making may be influenced. Various strategies to support this are discussed in the literature such as sharing information booklets with families' social networks (Mostert et al., 2014), engaging local communities in educational programmes (Sitaresmi et al., 2010) and inviting other people to consultations (Eder et al., 2007; Massimo et al., 2004). The appropriateness of these strategies will

depend on families' individual contexts but should be considered in order to enhance provision of family-centred care.

ACKNOWLEDGEMENT

None.

CONFLICT OF INTEREST

None.

ORCID

Elizabeth C. L. Jestico  <https://orcid.org/0000-0002-4119-2614>

Susan E. Schutz  <https://orcid.org/0000-0002-1441-0495>

Teresa M. D. Finlay  <https://orcid.org/0000-0003-2538-8366>

Jane V. Appleton  <https://orcid.org/0000-0002-1903-3975>

REFERENCES

- Alam, A., & Kumar, A. (2019). Impact of financial support and focussed group counselling on treatment abandonment in children with acute lymphoblastic leukaemia. Experience over 22 years from North India. *Psycho-Oncology*, 28(2), 372–378. <https://doi.org/10.1002/pon.4951>
- Bandinelli, L., & Goldim, J. R. (2017). Evaluation of parents decision-making in oncologic pediatric treatment. *Psicologia Em Estudo*, 21(4), 603–615. <https://doi.org/10.4025/psicoestud.v21i4.31716>
- Barbarin, O. A., & Chesler, M. A. (1984). Coping as interpersonal strategy: Families with childhood cancer. *Family Systems Medicine*, 2(3), 279–289. <https://doi.org/10.1037/h0091662>
- Batteux, E., Ferguson, E., & Tunney, R. J. (2017). Risk preferences in surrogate decision making. *Experimental Psychology*, 64(4), 290–297. <https://doi.org/10.1027/1618-3169/a000371>
- Beauchamp, T. L., & Childress, J. F. (2019). *Principles of biomedical ethics*, 8th ed. Oxford University Press.
- Blakeley, J. A., Ribeiro, V., & Crocker, J. (2000). Parent satisfaction with education, support, and decision-making regarding their children's central venous access devices. *Canadian Oncology Nursing Journal*, 10(1), 8–13. <https://doi.org/10.5737/1181912x101810>
- Brinchmann, B. S., Forder, R., & Nortvedt, P. (2002). What matters to parents? A qualitative study of parents' experiences with life-and-death decisions concerning their premature infants. *Nursing Ethics*, 9(4), 388–404. <https://doi.org/10.1191/0969733002ne523oa>
- Children Act (1989). c. 41. <https://www.legislation.gov.uk/ukpga/1989/41/contents>
- Cohen, J., Wakefield, C. E., Tapsell, L. C., Walton, K., & Cohn, R. J. (2017). Parent, patient and health professional perspectives regarding enteral nutrition in paediatric oncology. *Nutrition and Dietetics*, 74(5), 476–487. <https://doi.org/10.1111/1747-0080.12336>
- Coyne, I., Amory, A., Kiernan, G., & Gibson, F. (2014). Children's participation in shared decision-making: Children, adolescents, parents and healthcare professionals' perspectives and experiences. *European Journal of Oncology Nursing*, 18(3), 273–280. <https://doi.org/10.1016/j.ejon.2014.01.006>
- Eder, M. L., Yamokoski, A. D., Wittmann, P. W., & Kodish, E. D. (2007). Improving informed consent: Suggestions from parents of children with leukemia. *Pediatrics*, 119(4), e849–e859. <https://doi.org/10.1542/peds.2006-2208>
- Gage, E. A. (2013). Social networks of experientially similar others: Formation, activation, and consequences of network ties on the health care experience. *Social Science and Medicine*, 95, 43–51. <https://doi.org/10.1016/j.socscimed.2012.09.001>
- Gage-Bouchard, E. A. (2017). Social support, flexible resources, and health care navigation. *Social Science and Medicine*, 190, 111–118. <https://doi.org/10.1016/j.socscimed.2017.08.015>

- Gagnon, E. M., & Recklitis, C. J. (2003). Parents' decision-making preferences in pediatric oncology: The relationship to health care involvement and complementary therapy use. *Psycho-Oncology*, 12(5), 442–452. <https://doi.org/10.1002/pon.655>
- Griffith, R., & Tengnah, C. (2017). *Law and professional issues in nursing*, 4th ed. Sage Publications.
- Hamama-Raz, Y., Rot, I., & Buchbinder, E. (2012). The coping experience of parents of a child with retinoblastoma-malignant eye cancer. *Journal of Psychosocial Oncology*, 30(1), 21–40. <https://doi.org/10.1080/07347332.2011.633977>
- Hinds, P. S., Oakes, L. L., Hicks, J., Powell, B., Srivastava, D. K., Spunt, S. L., Harper, J. A., Baker, J. N., West, N. K., & Furman, W. L. (2009). "Trying to be a good parent" as defined by interviews with parents who made phase I, terminal care, and resuscitation decisions for their children. *Journal of Clinical Oncology*, 27, 5979–5985. <https://doi.org/10.1200/JCO.2008.20.0204>
- Holm, K. E., Patterson, J. M., & Gurney, J. G. (2003). Parental involvement and family-centered care in the diagnostic and treatment phases of childhood cancer: Results from a qualitative study. *Journal of Pediatric Oncology Nursing*, 20(6), 301–313. <https://doi.org/10.1177/1043454203254984>
- Hong, Q. N., Pluye, P., Fabregues, S., Bartlett, G., Boardman, F., Cargo, M., Dagenais, P., Gagnon, M.-P., Griffiths, F., Nicolau, B., O' Cathain, A., Rousseau, M.-C., & Vedel, I. (2018). *Mixed Methods Appraisal Tool (MMAT), Version 2018*. McGill, 1–11. <http://mixedmethodsappraisaltoolpublic.pbworks.com/>
- House, J. S., & Kahn, R. L. (1985). Measures and concepts of social support. In S. Cohen, & S. L. Syme (Eds.), *Social support and health* (pp. 83–108). Academic Press.
- Huang, I. C., Mu, P. F., & Chiou, T. J. (2008). Parental experience of family resources in single-parent families having a child with cancer. *Journal of Clinical Nursing*, 17(20), 2741–2749. <https://doi.org/10.1111/j.1365-2702.2008.02447.x>
- H-Yazdi, N., & Meadows, R. (2021). Child proton beam therapy: A qualitative study of parental views on treatment and information sources. *Radiography*, 27(1), 101–107. <https://doi.org/10.1016/j.radi.2020.06.016>
- Israëls, T., Chirambo, C., Caron, H., de Kraker, J., Molyneux, E., & Reis, R. (2008). The guardians' perspective on paediatric cancer treatment in Malawi and factors affecting adherence. *Pediatric Blood and Cancer*, 51(5), 639–642. <https://doi.org/10.1002/pbc.21703>
- Iverson, E., Celious, A., Kennedy, C. R., Shehane, E., Eastman, A., Warren, V., & Freeman, B. D. (2014). Factors affecting stress experienced by surrogate decision makers for critically ill patients: implications for nursing practice. *Intensive & Critical Care Nursing*, 30(2), 77–85. <https://doi.org/10.1016/j.iccn.2013.08.008>
- Jackson, C., Cheater, F. M., & Reid, I. (2008). A systematic review of decision support needs of parents making child health decisions. *Health Expectations*, 11(3), 232–251. <https://doi.org/10.1111/j.1369-7625.2008.00496.x>
- Jong, M. C., Boers, I., van Wietmarschen, H., Busch, M., Naafs, M., Kaspers, G. J. L., & Tissing, W. J. E. (2020). Development of an evidence-based decision aid on complementary and alternative medicine (CAM) and pain for parents of children with cancer. *Supportive Care in Cancer*, 28(5), 2415–2429. <https://doi.org/10.1007/s00520-019-05058-8>
- Kelly, K. P., & Ganong, L. (2011). Moving to place: Childhood cancer treatment decision making in single-parent and repartnered family structures. *Qualitative Health Research*, 21(3), 349–364. <https://doi.org/10.1177/1049732310385823>
- Kilicarslan-Toruner, E., & Akgun-Citak, E. (2013). Information-seeking behaviours and decision-making process of parents of children with cancer. *European Journal of Oncology Nursing*, 17(2), 176–183. <https://doi.org/10.1016/j.ejon.2012.03.001>
- Levi, R. B., Marsick, R., Drotar, D., & Kodish, E. (2000). Diagnosis, disclosure, and informed consent: Learning from parents of children with cancer. *Journal of Pediatric Hematology/Oncology Issue*, 22(1), 3–12. <https://doi.org/10.1097/00043426-200001000-00002>
- Liang, H.-F. (2002). Understanding culture care practices of caregivers of children with cancer in Taiwan. *Journal of Pediatric Oncology Nursing*, 19(6), 205–217. <https://doi.org/10.1177/104345420201900605>
- Lipstein, E. A., Brinkman, W. B., & Britto, M. T. (2012). What is known about parents' treatment decisions? A narrative review of pediatric decision making. *Medical Decision Making*, 32(2), 246–258. <https://doi.org/10.1177/0272989X11421528>
- Mack, J. W., Wolfe, J., Grier, H. E., Cleary, P. D., & Weeks, J. C. (2006). Communication about prognosis between parents and physicians of children with cancer: Parent preferences and the impact of prognostic information. *Journal of Clinical Oncology*, 24(33), 5265–5270. <https://doi.org/10.1200/JCO.2006.06.5326>
- Massimo, L. M., Wiley, T. J., & Casari, E. F. (2004). From informed consent to shared consent: a developing process in paediatric oncology. *The Lancet Oncology*, 5, 384–387. [https://doi.org/10.1016/S1470-2045\(04\)01496-2](https://doi.org/10.1016/S1470-2045(04)01496-2)
- McKenna, K., Collier, J., Hewitt, M., & Blake, H. (2010). Parental involvement in paediatric cancer treatment decisions. *European Journal of Cancer Care*, 19(5), 621–630. <https://doi.org/10.1111/j.1365-2354.2009.01116.x>
- Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., & PRISMA Group (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *Journal of Clinical Epidemiology*, 62(10), 1006–1012. <https://doi.org/10.1016/j.jclinepi.2009.06.005>
- Mostert, S., Njugna, F., Langat, S. C., Slot, A. J. M., Skiles, J., Sitaresmi, M. N., van de Ven, P. M., Musimbi, J., Vreeman, R. C., & Kaspers, G. J. L. (2014). Two overlooked contributors to abandonment of childhood cancer treatment in Kenya: Parents' social network and experiences with hospital retention policies. *Psycho-Oncology*, 23(6), 700–707. <https://doi.org/10.1002/pon.3571>
- O'Neil, J. A. (1996). *Naming the silences: A hermeneutic phenomenology of the dimensions of parental decision making in pediatric oncology*. Ph.D. thesis, Faculty of the Graduate School of The University of Maryland at Baltimore.
- Papadatou, D., Yfantopoulos, J., & Kosmidis, H. V. (1996). Death of a child at home or in hospital: Experiences of greek mothers. *Death Studies*, 20(3), 215–235. <https://doi.org/10.1080/07481189608252778>
- Pyke-Grimm, K. A., Stewart, J. L., Kelly, K. P., & Degner, L. F. (2006). Parents of children with cancer: Factors influencing their treatment decision making roles. *Journal of Pediatric Nursing*, 21(5), 350–361. <https://doi.org/10.1016/j.pedn.2006.02.005>
- Renner, L. A., & McGill, D. (2016). Exploring factors influencing health-seeking decisions and retention in childhood cancer treatment programmes: Perspectives of parents in Ghana. *Ghana Medical Journal*, 50(3), 149–156. <https://doi.org/10.4314/gmj.v50i3.6>
- Robertson, E. G., Wakefield, C. E., Shaw, J., Darlington, A., McGill, B. C., Cohn, R. J., & Fardell, J. E. (2019). Decision-making in childhood cancer: parents' and adolescents' views and perceptions. *Supportive Care in Cancer*, 27(11), 4331–4340. <https://doi.org/10.1007/s00520-019-04728-x>
- Sitaresmi, M. N., Mostert, S., Schook, R. M., Sutaryo, & Veerman, A. J. P. (2010). Treatment refusal and abandonment in childhood acute lymphoblastic leukemia in Indonesia: An analysis of causes and consequences. *Psycho-Oncology*, 19(4), 361–367. <https://doi.org/10.1002/pon.1578>
- Stewart, J. L., Pyke-Grimm, K. A., & Kelly, K. P. (2012). Making the right decision for my child with cancer: The parental imperative. *Cancer Nursing*, 35(6), 419–428. <https://doi.org/10.1097/NCC.0b013e3182431071>

- Thoits, P. A. (2011). Mechanisms linking social ties and support to physical and mental health. *Journal of Health and Social Behavior*, 52(2), 145–161. <https://doi.org/10.1177/0022146510395592>
- Tong, A., Flemming, K., McInnes, E., Oliver, S., & Craig, J. (2012). Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. *BMC Medical Research Methodology*, 12, 181. <https://doi.org/10.1186/1471-2288-12-181>
- United Nations Convention on the Rights of the Child (1989). <https://www.unicef.org/child-rights-convention/convention-text>
- Whittemore, R., & Knafl, K. (2005). The integrative review: Updated methodology. *Journal of Advanced Nursing*, 52(5), 546–553. <https://doi.org/10.1111/j.1365-2648.2005.03621.x>
- Woodgate, R. L., & Yanofsky, R. A. (2010). Parents' experiences in decision making with childhood cancer clinical trials. *Cancer Nursing*, 33(1), 11–18. <https://doi.org/10.1097/NCC.0b013e3181b43389>
- Yeh, C.-H., Lin, C. F., Tsai, J.-L., Lai, Y.-M., & Ku, H.-C. (1999). Determinants of parental decisions on drop out' from cancer treatment for childhood cancer patients. *Journal of Advanced Nursing*, 30(1), 193–199.

SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

How to cite this article: Jestico, E. C. L., Schutz, S. E., Finlay, T. M. D., & Appleton, J. V. (2022). How 'significant others' may support parents with decision-making about their child's cancer care: An integrative literature review. *Journal of Clinical Nursing*, 00, 1–20. <https://doi.org/10.1111/jocn.16220>