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Title

Maternal breast cancer and communicating with children: a qualitative exploration of what resources mothers want and what health professionals provide.

Running Title

Resource Communicating BrCa with Children

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Acknowledgments

The Authors would like to thank Dr. Ruth Little for contributions to the manuscript.

Conflict of Interest Statement for all Authors

The Authors declare that they have no competing interests

Funding statements

This study was funded by an Early Career Seed Grant from the Victorian Cancer Agency awarded to the principal investigator, LS (grant number ECSG15013). The funding body had no role in the study design, execution, analysis, interpretation of the data, or the decision to submit results. The funding body has had no role in the writing of this manuscript.

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Article type : Original Article

Title

Maternal breast cancer and communicating with children: a qualitative exploration of what resources mothers want and what health professionals provide.

Abstract

Objective: To explore the communication and resource needs of mothers diagnosed with breast cancer treated with curative intent in communicating with their young children, and to identify gaps in the resources and support provided to these women.

Methods: Data were collected via semi-structured telephone interviews from 13 mothers who were diagnosed with breast cancer while parenting a young child (age 3-12 years), and 10 health professionals in Victoria, Australia. Data were analysed qualitatively using the Framework Method.

Results and Conclusion: Mothers and health professionals prioritised communication with children about the cancer diagnosis; however, health professionals and mothers differed in their views of parents' communication needs both in terms of the nature of the support/information needed and the delivery of this support/information. Mothers wanted easily accessible resources that were both instructive and practical. Mothers also emphasised quality over quantity of support. Health professionals were mostly aware of mothers' needs; however, emphasised less instructive support and information. This study highlights the need for improved coordination and tailoring of psychosocial resources and supports for these parents and families communicating about a cancer diagnosis with their young children.

Key words

Cancer, Parents, Children, Communication, Psycho-Oncology, Resource Guide

Introduction

When a parent is diagnosed with cancer, the whole family is affected (Rolland, 2005). Communicating with children about the diagnosis is reportedly one of the biggest challenges for parents, and concerns about overwhelming children can lead parents to be hesitant or avoid communication (Morris, Martini, & Preen, 2016). Parents report greater reluctance to communicate with younger children in comparison to older children (Bugge, Helseth, & Darbyshire, 2009). They may also underestimate the psychological impact of the diagnosis, as well as their child's information needs and desire for communication about cancer (Morris et al., 2016; Welch, Wadsworth, & Compas, 1996). This is important as the quality of communication between parent and child may also be a contributing factor to the child's coping (Osborn, 2007). Indeed, well-informed children have demonstrated better adjustment to a parental cancer diagnosis (Huizinga, van der Graaf, Visser, Dijkstra, & Hoekstra-Weebers, 2003). While parents may be aware of the importance of communication with their children, they are commonly unsure of how to communicate about diagnosis and treatment, and desire more support from health professionals to achieve this goal (Fearnley & Boland, 2017; Semple & McCance, 2010a).

Research exploring communication with children about a parental cancer diagnosis has focused on the experiences of parents with advanced cancers (Forrest, Plumb, Ziebland, & Stein, 2009; Kennedy & Lloyd-Williams, 2009; Park et al., 2016), parents with adolescent children (Huizinga, Visser, van der Graaf, Hoekstra, & Hoekstra-Weebers, 2005), and on children's experiences and needs (Ellis, Wakefield, Antill, Burns, & Patterson, 2017; Furlong, 2017; Thastum, Johansen, Gubba, Olesen, & Romer, 2008). There has been little research on parents' communication with younger children (Furlong, 2017) or the needs of parents with younger children when the parent is diagnosed with cancer treated with curative intent. There is also a deficit in the literature on the perspectives of the health professionals who provide these resources to parents; information which would help providers better understand gaps in existing services.

The aim of this study was to explore the communication and resource needs of families in which a parent was diagnosed with cancer treated with curative intent while parenting a young child (age 3-12 years). The perspectives of parents and professionals involved in the care of this population were sought, to better identify the lived experiences and needs of parents and to guide the development of content for future communication resources.

Methods

This research was conducted as a component of a larger study to develop a communication resource for parents diagnosed with cancer who have young children (Stafford et al., 2017). The Royal Women's Human Research Ethics Committee provided ethical approval for the study (project approval entitled 'Development and evaluation of a brief psychoeducational intervention to support parents with cancer who have young *children'*).

Sampling and Recruitment

Potential participants were recruited separately from two different populations: (a) parents, and (b) health professionals with experience of providing psychosocial support to adults with cancer.

(a) Parent participants were recruited via convenience sampling through a range of Australian community-based cancer advocacy groups across multiple tumour streams (including breast, blood, skin, bowel, head and neck, and gynaecological). We intended to capture the views of parents who could comment on their prior experiences with the benefit of hindsight. Interested parents were invited to contact the first author (MS), a psychologist experienced in interviewing, who provided information about the nature and purpose of the project. During this initial discussion, the potentially distressing nature of the interview was covered and that if participants became distressed as a result of any aspect of participation in the study, they would be offered appropriate psychological support. Potential participants were also informed that interview data were confidential, stored securely by the researchers, accessible only by the first- (MS) and last-named authors (LS), and would be reported in a de-identified format. Following receipt of participant consent, a convenient time for the telephone interview was arranged. No incentive was offered for participation.

Inclusion criteria for parents were that they were either: (1) a parent previously diagnosed with any cancer treated with curative intent while parenting at least one child between the ages of 3 and 12, no longer receiving active treatment, and currently well, or (2) the co-parent of a parent previously diagnosed with cancer who would have been eligible to participate. A co-parent was defined as any adult with a significant role in parenting the child/children during the parent with cancer's treatment. Co-parents were eligible to participate without the parent with cancer.

Exclusion criteria for parents were that they were receiving active treatment (surgery, chemotherapy, radiotherapy), currently nearing end of life or receiving end-stage palliative treatment. Co-parents were excluded if the parent with cancer was now deceased as this was considered a different parenting experience to the target population. All participants had to be English speaking.

(b) Health professionals were recruited from three tertiary hospitals with large oncology services in Victoria, Australia. Purposeful sampling of health professionals was used to capture perspectives from varied professionals across a number of hospital sites in order to better understand professionals' views and to target professions that were most likely to provide communication resources to parents (nurses, social workers, clinical psychologists and psychiatrists). Health professionals were not the care providers of the parents who participated in the study. Nineteen health professionals were contacted via telephone or/and email and invited to participate. These 19 health professionals were chosen based on the researchers' knowledge of their clinical role and experience with parents with cancer and young children.

Data Collection

Two semi-structured interview guides were developed (see Appendix A), informed by a literature review and discussions with the multidisciplinary steering committee (which included professionals with expertise in oncology, psychology, psychiatry and parenting, and two consumers with experience of parenting a young child when diagnosed with cancer). For parent participants, the guide included questions about their socio-demographic details, children and cancer diagnosis. Health professional participants were asked for socio-demographic and occupational information. The interviews covered content including the impact of the illness and its treatment on the parents, children, and family functioning; acknowledgment of family's needs by health care providers; communication with children about cancer; and communication resource needs. Interview length was not prescribed.

All participants received an email with information about the study goals and likely areas of questioning prior to the interview. None of the interviewees were previously known to the interviewer. All interviews were conducted over the phone and audio-recorded via a teleconference recording platform. Prior to formal commencement of the telephone interview, MS re-confirmed verbal consent and gathered general socio-demographic information from the participant. Participants were advised that they were not required to answer any questions that they did not wish to, that they could pause or terminate the interview if needed, and that if they became distressed during the interview or as a result of participation in the study, they would be offered appropriate support. Participants were also advised that the interviewer would suggest pausing the interview if judged appropriate to do so. Participants were notified when the recording was to commence and voiced their consent on the recording. Interviews were anonymised, transcribed verbatim, checked for accuracy and corrected as appropriate by MS. Transcripts were not returned to participants for comment or correction.

Data Analysis

Data analysis was conducted concurrently with data collection with parent data collected first. Data were qualitatively coded, charted and analysed by two researchers (MS and LS) from a phenomenological (lived experience) paradigm based on the seven stages of the Framework Method (Gale, Heath, Cameron, Rashid, & Redwood, 2013). Recruitment continued for seven weeks (November 2016-December 2016) until no new themes or codes pertaining to the theme of Communication resource needs were identified by MS, who discussed and confirmed this with LS. This criterion was decided a priori, as it directly aligned with the aim of the study to identify communication resource needs.

Emphasis of transcription was on content of the interviews with conventions of dialogue not analysed (e.g., ums, pauses). MS read and re-read all transcripts, re-listening to recordings where helpful for further familiarisation. Data were initially grouped and coded in alignment with the four content areas of the interview guide (the preliminary framework); Impact of illness, Recognition of family needs, Communication with children about cancer, and Communication resource needs. Data within each of these areas were then analysed by LS and MS for meaning and themes, using the NVivo 12 software package to further develop the framework and allow for data driven codes to be identified and included. Codes and patterns were refined and grouped to form two frameworks (one for parents and one for health professionals). These frameworks were then applied to all relevant transcripts. The frameworks continued to be modified until no new themes emerged. During this process, the overlap between health professionals' and parents' frameworks became apparent. Where this overlap was consistent, the analytical frameworks were assessed to be appropriate to combine, and important divergences highlighted. The framework was not considered final until all transcripts had been coded and MS and LS were in agreement. Descriptive statistics were analysed using SPSS Version 23.

Results

Study Participation

A total of 25 parents expressed interest in the project, 22 of whom were eligible for inclusion. Two female parents with cancer whose children were younger than 3 or older than 18 years at the time of the cancer diagnosis and a male co-parent of a parent with cancer who was now deceased were excluded. Among the 22 eligible individuals, five could not be contacted after their initial expressions of interest and two were unavailable for interview. Despite substantial efforts to recruit parents with different cancer diagnoses, all 13 parents with cancer were mothers who had been diagnosed with breast cancer. Two co-parents were recruited; the mother and the husband of one of these women. However, due to the limited data provided by these participants, these interviews were excluded from the analysis.

Once interviews with parents had ceased, health professionals were approached about participating in the study. Among the 19 health professionals to whom invitations were extended, seven failed to respond, one was unwell and one on leave. Ten health professionals consented and participated.

Table 1 provides demographic information for health professionals and mothers who participated and Table 2 provides information about the children of the mothers who participated.

Themes

Themes consistent with the first two areas of exploration in the framework, Impact of illness and Recognition of family needs, were found to replicate existing research on the impact of parental cancer on children and families, and health professionals' recognition of children and family needs when the parent has cancer. We have included descriptions of these themes with illustrative quotes as found in the current study in Appendix B. Since these findings have been well documented elsewhere (Barnes et al., 2000; Fearnley & Boland, 2017; Rashi, Wittman, Tsimicalis, & Loiselle, 2015; Semple & McCance, 2010b; Semple & McCaughan, 2013), we report here on the novel themes in the framework relevant to communication and resource needs: Communication with children about cancer and Communication resource needs.

Communication with children about cancer.

Table 3 includes illustrative quotes for the sub themes Open and honest, *Children's'* developmental needs and protecting children under the theme Communication with children about cancer.

Open and honest.

The majority of mothers and all health professionals noted that open and honest communication about cancer diagnosis and treatment was the most helpful approach to facilitating coping and understanding in children. Clear communication was recognised as the best way to avoid misconceptions as it was likely that children would be aware that something was happening. Mothers reported being unsure about when the 'right time' might be to talk to their children, and they struggled with the amount of information to share. Mothers also expressed being caught in a dilemma of not wanting to exclude or lie to their children, but also, feeling worried about overwhelming them.

Health professionals were mostly aware of these concerns and said that they attempted to either provide reassurance and advice during the consultation or direct parents to resources if time was limited. Mothers and health professionals found conversations with children about death or dying to be particularly challenging, noting that it was important to provide some reassurance, but not too much, in case the prognosis changed.

Children's developmental needs.

Communicating with children using developmentally appropriate language and gauging the appropriate amount of detail were substantial concerns noted by parents and health professionals. This was complicated when there were children of different ages in the family and parents were unsure of how to tailor information according to varying needs of their children.

Mothers and health professionals observed that some topics of conversation were revisited as children matured. Specifically, as children aged, their understanding of illness matured and changed, and the conversation was re-visited through the lens of this new understanding (although the diagnosis may have been years ago and disruptive treatment long since completed).

Protecting children.

Mothers and health professionals commented on parents' worries about their children's reactions to hearing the word 'cancer' and how to best protect children from treatment side-effects that were visually confronting (such as hair loss or scars) or emotional in nature (lack of patience, distress). Some women provided detailed information distinguishing between types of cancer in order to manage their children's fear abour the word 'cancer', particularly when the child had known someone who had died from the disease. Mothers and health professionals agreed that minimising the disruption to routine and encouraging open communication and questions were the best ways to mitigate the impact of treatment and side-effects on children.

Another concern identified by the majority of mothers was protecting their children from inappropriate, inconsiderate and thoughtless comments made by those outside the family in response to news of the cancer diagnosis. To alleviate undue distress, mothers encouraged their children to ask them directly if they heard concerning information or if someone said something distressing to the child, thus identifying the parents as the reliable sources of information. Some parents commented that protecting their children from situations such as this led them to be judicious about disclosing the diagnosis to the school or to adults, and to be selective in the offers of support they accepted. Mothers consistently identified that it was the perceived quality of the support, resources or information offered that was most important to them. If there was potential that the support offered may also be upsetting or disruptive to their children, they were less inclined to accept or value it. Dealing with insensitive comments from others was not identified as a source of concern by health professionals, who consistently encouraged accepting all support available with an emphasis on quantity. Only one health professional acknowledged that managing the support offered can be challenging and they identified this understanding came from a personal experience of illness, rather than an observation of patient's experiences.

Communication resource needs.

Table 4 includes illustrative quotes for the sub themes Tailored, specific and instructive communication information, and delivery of communication information under the theme Communication resource needs.

Tailored, specific and instructive communication information.

Mothers and health professionals identified that information tailored to the type of cancer, treatment, and age of their children was most useful. Mothers preferred prescriptive information regarding the quantity of information to provide to their children and guidance about the exact words and phrases to use (i.e., developmentally appropriate language). Mothers also wanted information from health professionals on how to distinguish developmentally normal behaviour from cancer-related distress in children.

Health professionals perceived parent perspectives, experiences and peer support to be more helpful for parents than information from professionals. In contrast, mothers preferred specific, instructive and factual information from health professionals at the time of diagnosis. They specifically wanted to speak with a professional about communicating with their children. Some mothers described perspectives and experiences of other parents as not balanced, overly negative or positive, and not practically useful.

Delivery of communication information.

Mothers and health professionals observed that parents can be overwhelmed by the volume of written information provided at the time of diagnosis, and that parenting information may be missed or not absorbed when (or if) provided together with multiple other resources. Parents and health professionals identified ease of accessibility of information (e.g., online) as important. Health professionals further commented that when information is not provided in an accessible format, the combined impact of diagnosis, treatment side-effects and parental responsibilities make it unlikely that parents will access the resources at all. Both sets of participants commented on the desirability of a resource that could easily be integrated into family routine (such as a book to read to children at story time); and that would be accessible to culturally and linguistically diverse families. Health professionals noted that they inform parents where to find resources tailored to their circumstances and preference; however, parents stated that they are overwhelmed and unlikely to retain that information if they are not provided with a tangible resource (i.e., something that they can take away with them) at the time of the discussion.

Health professionals noted that barriers to providing resources to parents included limited capacity, competing demands, time constraints (e.g., limited time to provide patients with information during consultations, and no time to follow up patients due to high volume of cases), and referrals not being made to psychosocial services by treating medical staff who are at the frontline of care and on whom referrals to supportive care services depend. Several health professionals identified a need for improved communication about, and the collation of, existing resources for parents. Many health professionals noted that the quality of referrals for parents was limited by inadequacies in their own knowledge.

Discussion

This study explored the communication and support needs of mothers diagnosed with breast cancer treated with curative intent, who were parenting a young child. Parent and health professional perspectives were sought, to provide a more comprehensive overview of parents' needs and to identify gaps in the content and delivery of existing communication resources for parents. Many of the findings are consistent with previous literature: mothers prioritize communication with their children about a maternal cancer diagnosis, find balancing information challenging (Barnes et al., 2000; Barnes et al., 2002; Turner et al., 2007), but need and seek professional guidance to accomplish this successfully (Fearnley & Boland, 2017).

Of interest were novel findings around communication resource needs and delivery, particularly how mothers' preferences for information about communication differed from those perceived as most useful by health professionals. This suggests that health professionals may be able to provide more helpful support to parents at the time of diagnosis than the information and support that is currently prioritised. Consistent with previous research on parents diagnosed with advanced cancer (Turner et al., 2007), mothers reported that they wanted to discuss the what and how of communicating with their children and to be provided with this practical guidance at the time of consultation. Interestingly health professionals provided resources with an emphasis on other parents' stories, and referrals to support groups and psychologists. This suggests that when it comes to parenting with cancer, health professionals defer to parents with lived experience. However, women in the current study reported that at the time of diagnosis, emotional support and parent stories were not as important as practical tools for communicating with their children. Previous research has highlighted that although peer support is helpful for women in reducing feelings of isolation, it is less helpful in providing assistance with communication with their children (Turner et al., 2007). While parents who have survived a cancer diagnosis can identify common challenges, they may not be able to tailor guidance to another child or family and their experience does not necessarily render them experts in parent guidance. This suggests that health professionals treating these women could be more effective by providing psycho-educational parenting guidance to mothers at that time of consultation. Psychological support services could therefore be offered at a later time, or in an ongoing way so that these parents can accept this support when they have the capacity. For health professionals, this finding may reflect a lack of confidence in providing more detailed information to parents when asked about the specifics of communicating with children, which has been found previously in nursing staff (Turner et al., 2007). Alternatively, as suggested by the health professionals in this sample, this could also reflect a lack of awareness of existing resources that may meet the parents' specific communication needs. This implies that health professionals could be more comprehensively educated about managing these conversations, how to communicate with children about cancer (Semple, McCaughan, & Smith, 2017) and which resources are available for these parents.

Another interesting finding was that protecting children from insensitive comments from those outside the immediate family was a major concern for mothers in the current sample; however, this was not identified by health professionals. This finding is significant, because some mothers identified this as the reason for limiting disclosure of the diagnosis to other adults or the school, which may in turn have limited the support received by these families. Parents could benefit from guidance about anticipating, managing and responding to insensitive comments directed at their children or themselves. Wanting to protect younger children has been reported previously (Barnes et al., 2002; Turner et al., 2007); however, this was quite prominent in the current sample and also affected whether the mother accepted support. Mothers consistently identified that quality of support was very important to them and dictated whether support was accepted. Although support may be available, this does not necessarily mean the parent perceives it as helpful. Health professionals may be able to more accurately assess the level of support that a parent or family has by exploring parental perceptions of the quality of available support. Health professionals need to be aware that parents may be reluctant to take up offers of support perceived to be unhelpful.

Strengths and limitations

This study explored perspectives of health professionals and mothers. This allowed for identification of discrepancies and gaps in the resource and support needs of these women. Our findings highlight the needs of these breast cancer survivors in terms of communicating with their children and provide direction for meeting these needs. Despite substantial efforts to recruit parents with different types of cancer, including repeated and prolonged advertisement of the study via various community-based cancer advocacy organizations with national reach, only women with breast cancer responded to calls for recruitment. This partially reflects the demographics of cancers that occur in adults of child bearing age and the high prevalence of breast cancer (Melaku et al., 2018). The generalizability of the current study was limited by the participation of mothers with experience of breast cancer only, and no co-parent or father data. Further, although a retrospective sample was appropriate for current purposes and allowed for the recognition of children's evolving understanding with developmental maturity, time elapsed between cancer diagnosis and interview ranged from 0 to 28 years. This may mean that mothers' recollection of communication with their children may be inaccurate; details may have been forgotten, or changed over time. Future research might focus on populations with more recent diagnoses, on parents diagnosed with different cancers and on perspectives of fathers and co-parents. As mothers diagnosed with cancer have been shown to have higher anxiety than fathers (Ernst et al., 2013), future research could explore if similar themes are found with fathers diagnosed with cancer while parenting young children. All health professional participants were also female. This reflects the gendered (feminine) nature of the helping professions that were included in this study (Australian Bureau of Statistics, 2018). National data show that 89% of nurses (Department of Health, 2017), 80% of psychologists (Psychology Board of Australia, 2018) and 79% of social workers (Government of South Australia, 2013) are female. It is possible that views of male health professionals would have differed. It should also be noted that interviews ceased once no new themes or codes pertaining to Communication and resource needs were identified. While this was appropriate to meet the aim of the current study, it is possible that with additional interviews, new codes relating to other themes not considered central to our study may have emerged.

Conclusion

This research highlights that currently, the delivery and timing of information, resources and support around communicating with children to families in which a mother has a curable breast cancer diagnosis is not ideal and may, in fact, overwhelm these families. Although health professionals recognized the vulnerabilities of mothers affected by parental cancer and prioritise support for these families, this support does not align with what mothers report they need. Heath professionals could support this population more effectively by prioritising prescriptive communication resources and exploring the perception of quality of support as well as quantity. Health professionals wanted to do more to meet the needs of mothers; however, they were constrained by large caseloads and cognisant of their own limited awareness of available resources. Moreover, the findings underscore the importance of coordinating and tailoring psychosocial resources and supports specific to the needs of individual parents and families and exploring parental perceptions of the quality of supports.

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Tables

Table 1.

Demographic information for health professionals and mothers with breast cancer.

	Health Professionals (N=10) **n (%)**	**Mothers (N=13)** **n (%)**
Gender		
Female	10 (100%)	13 (100%)
Country of birth		
Australia	6 (60%)	11 (84.6%)
United Kingdom	1 (10%)	2 (15.4%)
Greece	1 (10%)	
Malaysia	1 (10%)	
Thailand	1 (10%)	
Relationship status		
Married/cohabitating	6 (60%)	10 (76.9%)
Single	4 (40%)	1 (7.7%)
Separated/divorced		2 (15.4%)
Working status		
Full time	5 (50%)	4 (30.8%)
Part-time	5 (50%)	8 (61.5%)
Retired		1 (7.7%)
Profession		
Social worker	4 (40%)	
Psychologist	2 (20%)	
Breast care nurse	4 (40%)	
Education		
Some secondary school		2 (15.4%)
Completed Secondary schooling		2 (15.4%)
Tertiary education	10 (100%)	8 (61.5%)
Trade/TAFE[†]/Certificate		1 (7.7%)
Recruitment location		
Breast Cancer Network Australia[‡]		12 (92.3%)

Counterpart [§]		1 (7.7%)
Peter MacCallum Cancer Centre[¶]	5 (50%)	
The Royal Melbourne Hospital[¶]	4 (40%)	
The Royal Women's Hospital[¶]	1 (10%)	
Treatment		
Chemotherapy		9 (69.2%)
Mastectomy		8 (61.5%)
Radiotherapy		7 (53.8%)
Lumpectomy		7 (53.8%)
Hormone therapy		6 (46.2%)
Axillary clearance		4 (30.8%)

Table 1 continued.

	Health Professionals (N=10) **M (SD), range**	**Mothers (N=13)** **M (SD), range**
Age (years)	44.2 (4.19), 38-52	52.54 (7.39), 39-64
Years since cancer diagnosis		9.13 (9.41), 1988-2016
Years worked in oncology	13.8 (6.88), 3.5-23	
Interview length (minutes)	19.35 (5.54), 11.38-31.06	28.24 (7.69), 19.00-42.00

[†] Technical and Further Education (TAFE) institutions provide vocational training

[‡] Breast Cancer Network Australia is a not-for-profit organisation that supports Australians affected by breast cancer

[§] Counterpart is a not-for-profit organisation that supports Australians affected by gynaecological or breast cancer, previously named BreaCan.

[¶] Tertiary hospital in Victoria, Australia

Table 2.

Descriptive information about children of mothers represented in current study.

Number of children in family	**n (%)**
1	4 (30.8%)
2	6 (46.2%)
3	3 (23.1%)
Number of children in the family between the ages 3 and 12 at time of diagnosis	
1	7 (53.8%)
2	5 (38.5%)
3	1 (7.69%)
Ages of all children in the family at time of diagnosis (years)	
0-2	3 (12.0%)
3-6[†]	14 (56%)
7-12[†]	6 (25%)
13-14	2 (8.0%)
	M (SD), range
Age of oldest child at time of diagnosis	7.93(4.56), 3-16
Age of youngest child at time of diagnosis	4.07(1.91), 1-8

[†] Age range of children of interest in current sample n=20.

Table 3.

Illustrative quotes for the sub themes Open and honest, Children's' developmental needs and Protecting children under the theme Communication with children about cancer.

	Communication with children about cancer	
	Mothers	**Health professionals**
Open and honest	**"**being very open with them about what was happening…The day I was formally diagnosed we told them, and that was good because when she would ask, when did you know you had cancer? I could say the day we told you…I had a concern of knowing how much to tell them. Wanting to give them information but not freak them out… We felt we told them everything I wanted to." (P5, 45yrs, two children aged 4 and 7) " Mummy, are you going to die? And that's a really hard question to answer when it's your children asking you that… So the challenge was to keep it simple enough and give them enough information that they felt like they knew what was happening without overloading them and them feeling swamped." (P6, 44yrs, three children aged 4, 6 and 8)	"Being as open and honest with kids is important because they know a lot more than... About what's going on than you think they do. And they imagine things that are worse than reality in some respects." (HP1, 42yrs, social worker) "firstly, is whether they understand the diagnosis at all or whether they've even been told about it in able to have a full understanding of the diagnosis. I think it's something that parents struggle with in terms of how much information, when to do it and how to do it. It's not just whether they should or not." (HP7, 52yrs, social worker)

Children's developmental needs	"With three children, I think for me and having them at different age groups, is... was challenging, but in saying that, sitting them all down and, you know, being all included and all together was really important." (P11, 50yrs, three children aged 6, 14 and 16) "What you talked to a 5-year-old about. Then, at 7, there's [a] different understanding and you would actually have to revisit it when the occasion arose. So it's not something that, you know, you've gone and you've dealt with and that's the end of it." (P9, 35yrs, one child aged 5).	"I think maybe more specific age related [information]… maybe more specific age related or a document on communication or how to have some of those difficult conversations… more targeted for the specific [ages]." (HP9, 42, clinical psychologist) "I think talking with kids … it's an on-going process for parents and so requires on-going kind of thought and vigilance and effort, at times which can be very challenging for parents" (HP10, 43yrs, clinical psychologist)
Protecting children	"you don't want the bloody disaster people … Who come with their terrible stories or their advice that is not helpful and not needed and not even requested. So you got to keep those people out because they going to be a bloody disaster and you end up spending all your energy trying to put out the fires there." (P13, 40yrs, one child aged 3) " 'Your mum's really unwell, is your mum okay?"…So, asking for information from the kids, I think, was inappropriate. And also telling the kids to be good because, you know, everything's so bad. It is a common thing that people think they're being helpful." (P10, 46yrs, two children, 1 and 3)	"Children find it difficult, the disruption of routine. They find it difficult… find it frightening to see their mothers without hair… its mostly about their routine being disrupted." (HP5, 29yrs, breast care nurse) "I guess in some families, the parents have large families who are great support. So it's not an issue of doing the treatment and having, you know, grandparents look after the kids or, you know, having brothers and sisters look after the kids. But some parents don't have anything." (HP7, 52yrs, social worker)

Ellipsis signifies omitted text. Square brackets denote explanatory text. Ages of women and children listed at the time of diagnosis. Ages of health professionals listed at time of interview. P= Parent. HP=Health professional

Table 4.

Illustrative quotes for the sub themes Tailored, specific and instructive communication information, and Delivery of communication information under the theme Communication resource needs.

	Communication resource needs	
	Mothers	**Health professionals**
Tailored, specific and instructive communication information	"I mean really like concrete statements. Like not vague statements, [how to] talk to them in an open way. Actual examples of what open communication is, like this is what you can say. I think that is actually very useful. The breakdown by age in terms of what children can process and understand." (P3, 44yrs, one child aged 8) "This sounds terrible but just to keep hearing women's stories – I just wasn't interested in that. I wanted some really good facts and advice, not this you know, all women standing together. It's lovely but I just wasn't in the frame of mind to really be interested in that to be honest." (P11, 50yrs, three children aged 6, 14 and 16)	"And it's something that parents always come to me about, is that do you think we should tell them? You know, how should we tell them? When should we tell them?" (HP7, 52yrs, social worker) "I think [a resource should have]… parents… telling a little bit of their own stories. You know, from beginning to the end or little snippets of different things to offer families a sense of … hope and clarity of how they …might proceed through what they're facing and come out the other end ideally." (HP9, 42, clinical psychologist)

Delivery of communication information	"Then they gave me supplementary information and there was certainly a pamphlet in there, you know, talking to your kids about cancer. But you start to read it and you just think, I can't... It's information overload." (P6, 44yrs, three children aged 4, 6 and 8) "I think now it would be great to have a book to be able to read to the kids … I think that would be a nice… otherwise… a lot of people spend a lot of time on their i-Pads or their phones when they're going for check-ups, …that's accessible, you know, that people can… either go to your website or, you know, have a reference of where they have to go to get it. I find that with all the brochures, like there's a zillion brochures that you get, and you, sort of, have a quick look at them and then you put it aside." (P8, 36yrs, two children, 3 and 8)	"We actually just don't have the capacity to follow any particular patient, you know, all the way through. Because we're just such a busy service unfortunately. So like you know, a general question is how are you doing and how is the family coping would be as much as I would sort of really get a chance to ask." (HP6, 44years, Breast care nurse) "But it's almost like just to know what's available it would be great to have one resource where they could just click on a link and there's links to the appropriate things that they can do to help themselves." (HP3, 42yrs, breast care nurse)

Ellipsis signifies omitted text. Square brackets denote explanatory text. Ages of women and children listed at the time of diagnosis. Ages of health professionals listed at time of interview. P= Parent. HP=Health professional

Appendix

Appendix A.

Semi-structured interview guides including sociodemographic questions for parents and health professionals.

Parents	Health professionals

Socio-demographic information	• What is your gender? • What is your age? • Is English your first language? • In which country were you born? • What is your relationship status? • What is your current employment status? • How far did you go in school? • How many children do you have? • What are the current ages of these children? • What was the cancer diagnosis? • What year was the cancer diagnosed? • What treatment was given? • How long has it been since treatment ended?	• What is your gender? • What is your age? • Is English your first language? • In which country were you born? • What is your relationship status? • What is your current employment status? • How far did you go in schooling? • What is your profession? • How many years have you worked in oncology?
Interview questions		
Impact of illness	• What was the impact of your diagnosis on your children? • Were there aspects of your treatment or illness that were more difficult for your family? • Which elements of family life were affected? • What were the challenges for you in your role as parent? • What was it like for you to manage your illness (or your partner's illness) and raise your family? • What was the worst part of your experience?	• What impact do you think a diagnosis has on patients' families and children? • Are there aspects of treatment or illness that you believe are more difficult for patients' families to manage? • What do you see as the key challenges for patients in their roles as parents?

Recognition of family needs	• To what extent were your needs as a parent recognized or discussed during your cancer treatment? • What advice, resources and input were you given? • Did you make use of these? Were they helpful? • Was any advice particularly unhelpful?	• Do you routinely discuss patient's needs as parents in the face of cancer treatment? Is this something you are asked about? • What advice, resources and input do you provide to parents? • Do you provide this to all parents?

Appendix A Continued.

Communication with children	• How did you talk to your children about cancer? • What were the challenges involved in doing this? • What would have made it easier? • Are there things you would change about how you handled things?	• Do you give advice, resources or input to parents specifically about communicating with their children? • What do you provide?
Suggestions for a new communication resource	• What and who really helped you to parent in the face of cancer? • What would you advise others to do in your situation? • Given your experience, what do you think should be included in resource designed for parents with cancer and young children? • How would this resource look?	• What do you see as the most important resource for parents? What do they need? What do they find helpful? What do they find unhelpful? • Is there anything missing from the resources you provide that you think needs to be put in place for parents? What are the barriers to providing parents with what they need? • What do you think should be included in a resource designed for parents with cancer and young children? • How would this resource look?

Note: Semi structured interview questions listed above, prompts and follow-up questions asked when necessary

Appendix B

Two themes, Impact on families and Experiences of support and support needs with sub themes found in the current study that replicate existing findings.

Theme/Subtheme

Impact on families/ Impact is variable

Parents and health professionals identified multiple factors that moderated the impact of cancer diagnosis and treatment on the family. Open communications and the ability to maintain a child's routine, or adjust to a new routine, were considered central to minimising the effect on children. Other factors that were helpful in reducing the effect on families included intrinsic qualities of the family members (optimistic personality, high levels of parental confidence and pragmatism); and offers of instrumental support from multiple sources in the support network. Factors associated with a more pronounced impact on the family included prolonged treatments, severe and debilitating side effects, poor parental emotional wellbeing, and limited support network or offers of practical support. Health professionals noted that the side-effects of treatment were potential obstacles to parents' ability to access additional support resources, e.g., fatigue impacting ability to attend appointments with a psychologist.

Impact on families/ Reduced availability

Both health professionals and parents identified that parents with cancer have reduced physical and emotional availability for their children and families during treatment and that partners or co-parents usually have to fulfil the roles and responsibilities of the unwell parent. Parents and health professionals also noted that the partner, co-parent or support person was emotionally affected. Areas of family life reported to be most affected were family routine, the facilitation of extracurricular activities and play, making nutritious meals, physical interaction with children, child transportation, and patience for communication with children. Parents reported feeling distressed at the effect of their diminished patience on communication with their children.

Experiences of support and support needs/ Recognition from health professionals

Most parents reported lack of acknowledgement of family needs by health professionals; however, this was variable. All health professionals reported a willingness and desire to talk with, support and consider the needs of parents and their families but also pointed out several barriers to achieving this including limited capacity, competing demands, time constraints (e.g., limited time to provide patients information during consultation, and no time to follow up patients due to high volume of cases), and referrals not being made to psycho-social services.

Appendix B continued.

Experiences of support and support needs /Quality of support is key

Health professionals and parents both identified the support network as a factor affecting parent and family coping. While both health professionals and parents commented on quantity of support, parents noted that the quality of offers of support were just as important. Support was considered most helpful when given freely (rather than begrudgingly), consistently, without implied emotional burden or expectation of reciprocation, and from multiple sources. Both health professionals and parents reported a lack of resources, support or information for the carers and support network around the parent with cancer (e.g., co-parents, grandparents, school). Parents and health professionals frequently described the school community as a potentially high-quality source of support.

Experiences of support and support needs/ Practical support is needed

The strongest support need identified by both parents and health professionals was in the domain of instrumental support such as childcare, cooking of meals, and transport for children, and housework (e.g., cleaning, laundry). Parents and health professionals agreed that the reduced physical availability of the unwell parent meant that practical daily tasks were often not performed, and that when assistance was available, the family fared better.

Health professionals further highlighted financial support as a major area of need and that their own lack of knowledge and awareness of existing resources across all areas of support was a major barrier to linking parents with appropriate resources. Health professionals noted that, in general, there was a need for improved communication about, and collation of, existing resources.