



Mothers' Experiences Post-Childhood Cancer Treatment: A Qualitative Study

Jenny Davies ¹ · Moira O'Connor ¹

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Abstract

Every year in Australia, ~770 children aged under 15 years of age are diagnosed with cancer. Due to the increasing incidence and survival rates of paediatric cancer more families are contending with life post-childhood cancer. Research has demonstrated that mothers of children with cancer experience significant psychological distress. Our study explored the lived experiences of mothers of children diagnosed with cancer after completion of treatment. We recruited participants via notices distributed at a childhood cancer support group and on childhood cancer social media sites. The sample consisted of 14 mothers (aged 35–57 years, $M = 45$) whose children had completed treatment. Children's age at diagnosis ranged from 14 months to 16 years old, 57% ($n = 8$) were male and 42% ($n = 6$) female. Our study employed a qualitative design using a phenomenological approach. Mothers participated in semi-structured face-to-face interviews. Six themes were identified: cast adrift; fear never ends; guilt and loss (containing two sub-themes: siblings: ongoing guilt & lost opportunities; lack of self-care; everything is different (containing three sub-themes: lost connections; reassessment; and peer support); and a way forward. Our findings suggest mothers experience substantial negative effects. They often struggled to manage complex emotions and develop a new way of 'mothering' their children following cancer treatment. Mothers feared relapse and late effects and felt guilt about impact on siblings. These findings contribute to an understanding of mothers' lived experience of childhood cancer, highlighting the need to improve post-treatment services. Findings can be used to formulate improvements in end of treatment.

Keywords Cancer · Childhood · Mothers · Qualitative · Post-treatment · Families

Highlight

- Due to increasing incidence and survival rates of paediatric cancer more families are contending with life post treatment.
- After treatment mothers must adjust to new identities as mothers of children who have been diagnosed with cancer.
- Fear of relapse and late effects makes it difficult for mothers to develop a new narrative for their children and themselves.
- Mothers felt guilt and regret about impact of childhood cancer on siblings and this guilt did not dissipate after EOT.
- There is a need for more practical and psychological support tailored to mothers' individual needs.

In Australia between 2011 and 2015, on average 770 children under the age of 15 were diagnosed with cancer annually (Youlden & Aitken, 2019). Recent improvements in treatment and diagnosis have seen mortality rates in Australia decrease from 40.2 per million children in 1998 to

22.2 per million children in 2015, and in 2015 the five-year survival rate was 85% (Cancer Council Queensland, 2018; Youlden & Aitken, 2019). Additionally, over recent decades the incidence of childhood cancer has increased, rising 34% between 1983 and 2015 (Youlden & Aitken, 2019). The combination of rising incidence and declining mortality means that a growing number of families have had to adjust to life post-treatment and manage the long-term health, social and psychological ramifications of childhood cancer.

Childhood cancer treatment is a challenging experience for parents, and numerous studies demonstrate, that regardless of the course of treatment, they experience significant psychological distress and a lower quality of

✉ Jenny Davies
jenny.davies@postgrad.curtin.edu.au

¹ School of Population Health, Faculty of Health Sciences, Curtin University, GPO Box U1987, Perth 6102 Western Australia, Australia

life (Sultan et al., 2015). For instance, a recent study by Katz et al. (2018) found that 74.3% of caregivers experienced clinical symptoms of depression during treatment and 37.3% of caregivers had symptoms above clinical cut-offs for post-traumatic stress symptoms (PTSS). A childhood cancer diagnosis impacts the entire family and research has also shown that siblings also experience significant difficulties when their brother or sister is diagnosed with childhood cancer (Alderfer and Hodges (2010); Kaplan et al., 2013; Prchal et al. (2012)). Qualitative studies exploring the lived experience of carers during treatment have provided further evidence of the profound impact of childhood cancer. A systematic review by Gibbins et al. (2012) found several common themes including the challenges in dealing with the unpredictability and loss, lowered coping abilities, support needs, impact of gender and cultural differences. These studies help to highlight the ramifications of childhood cancer and demonstrate that mothers experience significant disruption to their well-being during treatment.

Recent research has reported that while levels of psychological distress may decrease after the end of treatment (EOT), for many carers the distress does not cease and carers continue to experience ongoing effects. One such study by Lemos et al. (2019) found that after the completion of treatment parents exhibit symptoms of psychological distress. Analysis of the after-treatment phase has highlighted that late-effects such as secondary cancers, and heart disease is an area of significant concern for parents and Hsiao et al. (2017) reported that 70% of children diagnosed with cancer experience at least one late effect and these often require ongoing treatment and frequent hospital visits.

Most of the research supports the conclusion that mothers experience higher rates of psychological distress compared both to the general population and to fathers both during and after EOT (Bruce, 2006; Pai et al., 2007). A study by Ljungman et al. (2015) reported that five years after EOT, 19% of mothers compared to 8% of fathers reported partial PTSD. Mothers generally undertake more caregiving responsibilities, and it is suggested that this could explain mothers' higher rates of psychological distress (Al-Gamal et al., 2019; Clarke, et al., 2009; Wilford et al., 2019). Wakefield et al. (2014) found that mothers experience significant disruption to their employment both during and after their child's cancer treatment, demonstrating that childhood cancer has a wide-reaching impact on mothers' lives.

According to Cox (2016), who examined carers' experiences during treatment, a child's diagnosis of cancer significantly disrupts caregivers' sense of security and requires them to reconceptualise their view of a 'normal' life. Similarly, Young et al. (2002) qualitative study found that during treatment there is a biographical shift as mothers

must take on the role of providing nursing care, understanding the complex world of treatment and taking on responsibilities for helping children cope with painful treatments. This raises questions about how mothers integrate experiences of childhood cancer into their lives and identities beyond the end of treatment, and how it changes their perceptions of themselves as mothers. Societal norms emphasise the importance of the mother-child bond and, from infancy mothers have certain expectations and envision a life trajectory for their children and themselves as mothers (Bury, 1982; Sevön, 2011).

Current studies on childhood cancer often focus on carers and parental dyads or the mother acts as a proxy for the entire family. These studies thus often blend the results in analysis exploring the whole family perceptions which may obscure individual experiences (Patterson et al., 2004). As such, these studies fail to capture the full picture of mothers' lives or gain insight into how experiencing childhood cancer affects mothers' personal narratives and the narratives they carry for their children.

There is a significant body of literature examining parental experiences of childhood cancer during treatment, however, scholars have suggested that there is a need for more qualitative research to examine experiences of childhood cancer post-treatment (Phipps, 2005). The post-treatment phase is often difficult and requires families to process their experiences and develop a new 'normal' (Björk, et al., 2011). Few qualitative studies focus specifically on the mother's experiences post-treatment (Cox, 2016; Wakefield et al., 2011). Qualitative research is valuable in this context as it provides the ability to explore mothers' insights and perceptions of their experiences (Forrester, 2010). An in-depth qualitative examination of the lived experiences of mothers in the post-treatment phase would enable a more thorough understanding of the complex challenges, both practical and emotional, faced by mothers during this time. It is envisioned that this will enable a better understanding of gaps within the system, thus allowing the development of recommendations for better provision of psychosocial support for mothers.

Aim

We aimed to explore mothers' lived experiences after the completion of their child's cancer treatment.

Research questions

1. What is the impact of a children's diagnosis of cancer on mothers' physical and psychological wellbeing?

2. How does the experience of childhood cancer affect mothers' perspectives on their role as mothers', and how do they make meaning from the experience?
3. What is the impact of a child's post-treatment medical issues on mothers' lives?
4. What types of psycho-social support would mothers have found beneficial during and immediately after treatment?

Method

Study design

We adopted a qualitative design using a descriptive phenomenological approach. A phenomenological approach allows an exploration of hidden meanings and enables the development of an in-depth understanding of lived experiences (Forrester, 2010).

Ethical approval

Our study was approved by Curtin University Human Research Ethics Committee (April 2019).

Participants

Convenience sampling was used to recruit mothers whose children had been diagnosed with cancer and had received treatment at a children's hospital in Australia within the previous ten years. Participants' children needed to be off treatment but were eligible for inclusion if receiving treatment for late effects or under monitoring for recurrence. Bereaved parents were not considered for participation.

Procedure

Recruitment occurred between May 6th and June 14th, 2019. We recruited participants via notices placed on childhood oncology Facebook pages. These pages are closed and vetted to ensure that only families whose children have undergone treatment for cancer are approved to join. Flyers were also distributed at childhood oncology support groups. In addition, participants were recruited via snowballing and participants were invited to pass on study information to other families and disease specific support groups. All participants were asked to contact the researcher and we then provided them with detailed study information. Seventeen participants contacted the researcher and initially indicated an interest in participation, however, two subsequently withdrew before the interview explaining that talking about their experiences would be too painful and

another was unavailable due to time constraints. Once mothers agreed to participate, they were contacted to arrange an interview time/location. The final sample consisted of 14 mothers.

Data was collected via semi-structured face-to-face interviews. We used an interview guide as a framework and research questions were based on previous literature and were reviewed by an oncology parent consumer representative. All questions were open-ended which provided participants with the opportunity to give in-depth information on their experiences (Gysels et al., 2008). A consumer representative, who was not part of the study, completed a pilot interview to ensure that questions were easily understood with minor modifications made to the interview guide. An example of an interview question is "Could you describe the emotions and thoughts you experienced at end of your child's treatment?"

At the commencement of the interview, we briefly explained study details, consent forms were completed, and demographic information was collected via a two-page written survey. Interviews were conducted at the university 21% ($n = 3$), participant's home 60% ($n = 8$), and a childhood cancer drop-in-centre 21% ($n = 3$) from May to July 2019. On average, interviews lasted 58 min (range, 38–98 min, $SD = 15$) and all interviews were digitally audio-recorded. After the interview, we provided participants with local support services details. We also provided participants with a \$20 gift card as a thank you. Mothers were advised that they could provide clarification following the interview process including adding any comments. Two mothers contacted the interviewer at a later date to provide additional comments. Participants' ages ranged from 36–57 years ($M = 45$) with 78% ($n = 11$) living in the metropolitan area and 21% ($n = 3$) living in rural or semi-rural regions. There was a range of childhood cancer diagnoses and ages. The age of the child at diagnosis ranged from 14 months to 16 years old and 57% ($n = 8$) were male and 42% ($n = 6$) female. The majority of children, 80%, had completed active treatment less than four years ago (range 8 months to 7 years). Most mothers, 85%, indicated that their children were experiencing late effects including sensory, neuro-cognitive and endocrinology issues. Further demographic details are provided in Table 1.

Analysis

We completed data collection and thematic analysis concurrently. Interviews were transcribed verbatim, all individual identifiers and identifiable locations were removed, and pseudonyms were assigned (Forrester, 2010). Data was analysed inductively, and each transcript was read multiple times by the principal researcher, recurrent themes were identified, and codes applied. Initial themes and codes were

Table 1 Participant Demographics ($N = 14$)

Demographic	<i>N</i>	%
Marital-status		
Married	7	50
Divorced	3	21
De-facto	2	14
Single	1	7
Separated	1	7
Educational level		
Year 10	2	14
Year 12	1	7
TAFE ^a	1	7
University	10	70
Current work status		
Full-time	7	50
Part-time	2	14
Self-employed	1	7
Maternity leave	1	7
Homemaker/carer	3	21
Child's primary diagnosis		
Brain cancer	4	28
Sarcoma	4	28
Haematological	5	35
Other	2	14
Time since EOT		
>5 years	3	21
3–4 years	5	35
2–3 years	4	28
1–2 years	0	0
<12 months	2	14
Length of treatment		
3–4 years	3	28
2–3 years	1	7
1–2 years	2	14
<1 year	8	56
Number of siblings		
0	2	14
1	6	42
2	5	35
3 or more	1	7

^aIn Australia, technical and further education (TAFE) provide a wide range of predominantly vocational courses

then reviewed by the research team and refinement of codes was discussed. Another team member reviewed portions of transcripts and the team discussed findings. If there was disagreement, the discussion continued until consensus was reached. After rich detailed themes emerged it was decided by the team that saturation was achieved, and the decision was made not to recruit further participants. Multiple steps

were taken to ensure rigour including completion of a reflexive diary and an audit trail (Forrester, 2010). To reduce the possibility of identification of participants, care was taken during the analysis and writing not to provide quotes with multiple identifying factors, for example, gender of the child with age and diagnosis, as these details when combined could identify participants. To ensure credibility, brief descriptions of themes were sent to participants. We received positive feedback, and in keeping with previous research, participants commented that taking part in the research was a beneficial experience that provided them with an opportunity to discuss their feelings and experiences (Gysels et al., 2008).

Findings

Six themes were identified. Due to the complexity of emotions related to childhood cancer, there are some overlaps between themes, but all themes outline distinct aspects of mothers' experience of childhood cancer. A thematic map (Fig. 1) was constructed to visually represent the themes.

Cast adrift

This theme describes mothers' reflections regarding feelings at the EOT. Participants recalled looking forward to EOT. However, for many, it was not what they expected shown in one mother's comment "it was a bit of an anti-climax." Several mothers described feeling "abandoned". One mother whose son was three years from EOT described how it was "really tricky...you feel a bit deserted...it was like can we just stay a bit longer? Can we have a bit more chemo?" Their child's medical treatment often required mothers to spend many nights in the hospital, and it had become a familiar "safe" environment. The staff had provided support and the majority of mothers felt a sense of loss at no longer seeing them, seen in the reflection by one mother whose child was two years from EOT "I really missed seeing the nurses and doctors...it felt like we had lost something." Another area of concern was the feeling that they were now solely responsible for their child's health, and they had to incorporate providing medical care into daily 'normal' life as mothers. This was described as "a big weight of responsibility". Mothers expressed concern that they felt scared that they would not be able to adapt to the new demands of caring for their children without the support of health care professionals.

Various aspects of EOT seemed to be difficult to manage and for many participants, the post-treatment phase was a difficult time, as explained by a mother whose son was four years from EOT "[It was] the hardest time ... Those first

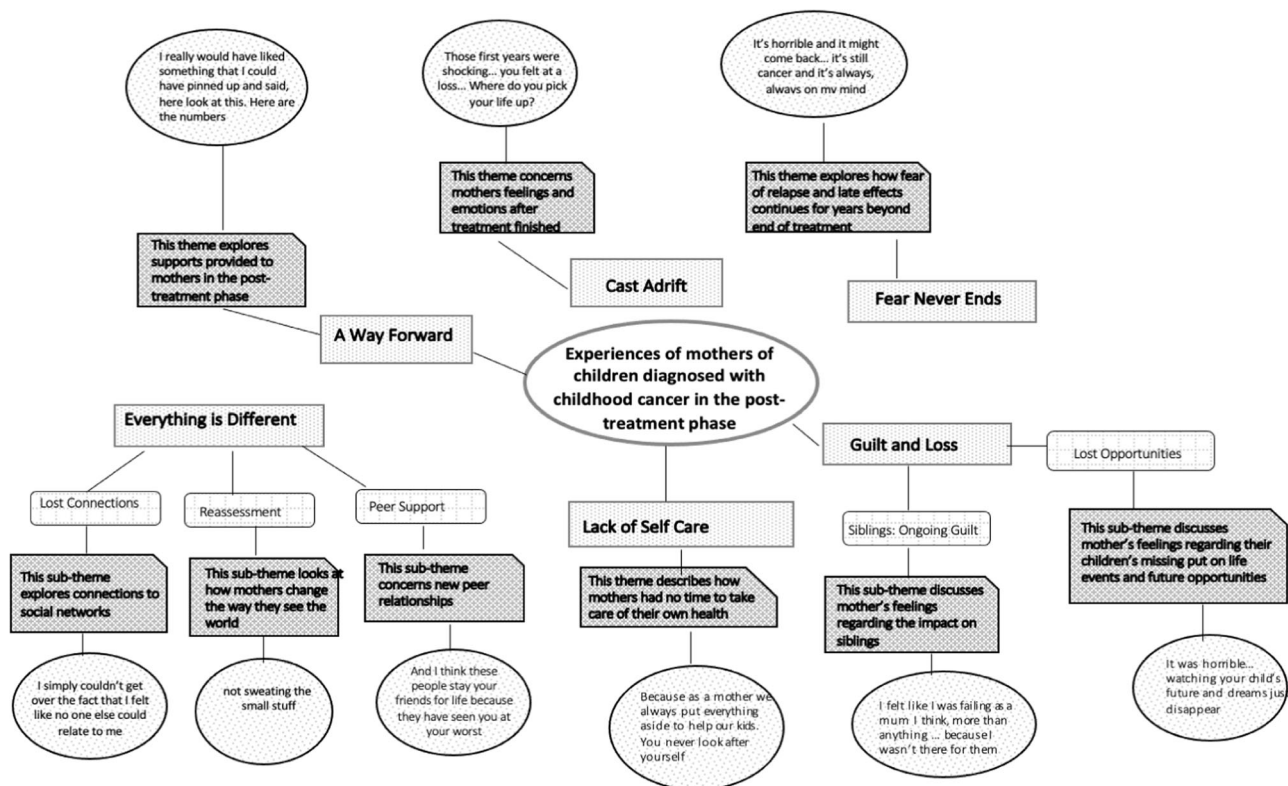


Fig. 1 Thematic map

years were shocking ... you felt so alone ...” Similar thoughts were expressed by another mother “Where do you pick your life up? Suddenly you’re just out there and everybody telling you, oh [child’s] okay now, you’ll be all right now and you’re not.”

At the EOT mothers also related it was a time when they began to process what they had been through. A mother of a child with leukaemia described it as the “five stages of grief...angry...depressed... denial.” During treatment they described being in crisis or “fight or flight mode” and many reflected that years later they still felt the ongoing effects. This is seen in the reflection by one mother “Anxiety is way more intense now than when we were in [treatment]. The further we get on from treatment and the more I feel I should be coping better, yet the worse I feel ... It’s like that bubble has popped and now my body is getting slammed with all the stress ... that just doesn’t seem to get better.” Thus, the post-treatment phase was difficult, as it was a time when mothers had to reconcile their experiences and process their losses and this adjustment continued years beyond EOT.

The fear never ends

The potential for their child’s cancer to relapse was a significant source of anxiety for the majority of participants.

This experience was described by one mother “It’s horrible and it might come back ... My (child) has had cancer and it might come back one day you just don’t know.” This fear of relapse did not subside, and mothers expressed that it continued for years beyond the EOT, for example, one mother whose child was five and half years from EOT:

Even during that five year of check-up, you still don’t feel you can breathe. You don’t want to jinx yourself. You’re just working to the next one...and somebody will use the word cured, and I’m like well we don’t use that word. Because I’m fully aware that there are people out there that might relapse after five years.

The fear was often grounded in the experience of knowing children on the ward who had relapsed or died. One mother described this “I know so many mothers whose children have died ... kids I’ve grown to love who have gained their angel wings [died] ... and I know it could be my kid next.” Fear was exacerbated by the frequent scanning/monitoring which another mother noted was “a constant reminder that it could come back.” Three participants completed EOT but were never told that their children were in complete remission due to remaining tumours or shadows on scans. For these mothers, feelings of fear after EOT were more pronounced. The lack of an ‘all-clear’ resulted in a

constant state of vigilance as one mother described “I felt there was just a time bomb ... and I was just sitting and waiting for something to happen.”

The majority of mothers also expressed fear regarding future late effects including secondary cancers. One mother expressed “I think you are always aware in the back of your mind that [child] might not have a long life.” Similar sentiments were reflected by another mother “You’re like, yes, [child] might look fine ... but there’s a lot of other things that might come in the future ... what damage radiation did to [child’s] brain ... you don’t know where we are going to end up.” The fear of long-term impact was a common factor that all mothers experience to varying degrees.

Guilt and loss

This theme explores mothers’ feelings of guilt regarding the impact on siblings and the losses their children experienced.

Sub-theme: siblings: ongoing guilt

Mothers expressed feelings of regret about the impact on siblings. The majority of mothers with more than one child reflected on the guilt that they were unable to care for siblings while taking care of the child with cancer as seen in the comment “so [sibling] did miss lots of contact ... I feel really guilty incredibly guilty.” One mother who was ten months from EOT described how she felt she had “missed out” on parenting the siblings. When discussing being away from the siblings, one mother stated “I felt like I was failing as a mum ... I know I did because I wasn’t there for them. Even when I was there, I wasn’t there, I was too busy thinking about [child with cancer] and worrying about [child with cancer].” The time spent away from siblings was often considerable with one mother commenting “within the first 12 months, at one point, I added it up, and [child] was inpatient for over 270 nights within a year ... That was a huge source of guilt.” Emotions often came to the forefront after treatment, as families tried to develop new routines. Several mothers described how siblings felt that mothers had a closer bond with the child diagnosed with cancer. One mother remembered one of her children saying, “[child with cancer] is the golden child” another recounted a sibling saying, “I think you love [child with cancer] a little bit more than me.” The impact on siblings was an issue of deep concern to mothers and seems to have left many of them feeling profound regret and guilt years later.

Sub-theme: lost opportunities

A child’s diagnosis of cancer left many mothers feeling a sense of sadness regarding the life they had envisioned for

their children and themselves. One mother reflected “I felt like I was going through a grieving period where you have anger and all those feelings because I was grieving for the loss of the future ... that I had in my head.” Concerns also focused on the future and the potential impact on their child’s long-term fertility. These were fears and concerns were expressed by one mother whose young child had had three years of chemotherapy “I think we worried about where [child with cancer] is going in life in the sense of development, physical development ... will [child with cancer] be able to have kids one day ... how will it affect [child]?”

Mothers frequently highlighted the impact of cancer on schooling and physical fitness. One mother whose child was two and half years from EOT described how her son was worried about school and reflected that “it’s heartbreaking.” Several mothers of teenagers indicated regret that their children who enjoyed sports or who had aspired to professional sports were no longer able to function at pre-cancer levels. One mother, whose child had wanted to enter a sports-related profession, commented “it was horrible watching your child’s future and dreams just disappear.” Often the treatments children received caused them to become neutropenic preventing them from attending school and social events such as parties and this further contributed to mothers’ feelings of loss for their children. As seen in one mothers’ reflection “those things that are normal parts of childhood that they can never get back ... they are gone forever.” Mothers expressed guilt and distress that they as mothers had not been able to protect their children from these losses and had failed their children with many mentioning the ‘mum guilt’ that they still carried with them.

Lack of self-care

Having a child with cancer affected every facet of the mothers’ wellbeing, both physically and mentally. All mothers reflected that during treatment they had no time for eating well and fast food often became the norm. One mother recalled, “I normally eat very healthy ... but you cannot when you’re in the hospital for weeks.” Mothers generally reported negative dietary changes and expressed that there was no time for exercise during treatment. When discussing health, one mother explained “Because as a parent we always put everything aside to help our kids ... You never look after yourself and it never stops.” The detrimental effect on health and sleep continued beyond treatment:

I worry a lot, so I don’t sleep well. I’m not really interested in eating well. I think everyone expects it to be only during ... but I don’t think it is. Last year [3 years post-treatment] was the worst year.

After treatment, most mothers reported experiencing a range of negative effects including problems sleeping, “self-medication” with alcohol, and a state of anxiety which one mother observed sometimes manifested itself as “full-blown anxiety attacks ...” The physical impacts of treatment did not cease at EOT, and many mothers reported feeling exhausted and not prioritising taking care of themselves.

Everything is different

This theme captures mothers’ reflections on the emotional and social changes they experienced as a result of their child being diagnosed with cancer.

Sub-theme: lost connections

Lack of community awareness of the ramifications of a child’s cancer diagnosis, left many mothers feeling disconnected from their community, as highlighted in this quote by a mother who was just over two years from EOT “I simply couldn’t get over the fact that I felt like no one else could relate to me.” Mothers often felt that people had little understanding making it hard to relate to other mothers. This is seen in the reflection “I suppose the general person would not have a clue and would just wish I would shut up.” As a result, many mothers felt that it was easier not to talk about their experiences. One mother explained, “everyone’s worried about saying the right thing or doing the right thing.” So instead, as observed it was easier to “put your face on ... Pretend, wear your mask and just fake it.” A point of irritation for several mothers revolved around comments received from others that it was time to “move on” or “just get over it”. This sense that no one understood left many mothers struggling to regain connections with their old life or connections to other ‘normal’ mothers.

Sub-theme: re-assessment

This theme reflects how most mothers felt that they had changed as people and had re-assessed how they perceived the world. A phrase used by many participants was “not sweating the small stuff” and developing a focus on the present with a realisation “that you could never look too far ahead into the future, so, therefore, you have to make the most of what was in front of you right now.” For many mothers this change in perspective was influenced by the trauma and death experienced in the ward, one mother observed “witnessing someone else’s grief” was profoundly distressing and continued to impact how mothers saw the world. The majority of mothers also observed that their experiences of childhood cancer also made them aware of the good in the world highlighting the support they received, as described by one mother whose child was

10 months from EOT “community support was amazing ... there are nice people in the world.”

Against the backdrop of a traumatic experience, mothers re-assessed their view of the world, and this was often framed as a pragmatic coping mechanism, as by one mother “You must draw positives otherwise it will weigh you down.” Mothers were very reluctant, however, to characterise these changes as personal gains as seen in one mother’s emphatic comment “I truly believe ... there is no lesson in the world we need to learn from our kids suffering.”

Sub-theme: peer support

Participants reported that the experience of childhood cancer profoundly changed their social networks and there was a common feeling that other mothers of children with cancer were the only people who truly “got it”. When discussing these friendships, it was observed by a mother whose child had received treatment for Acute Lymphoblastic Leukemia (ALL) and had thus spent long periods on the oncology ward “I think these people stay your friends for life, because they have seen you at your worst.” When reflecting on involvement in the parent-run local support group, participants highlighted it was a source of support post-treatment, as it was the only environment in which they could freely express themselves. Social media-based support groups also performed a vital function, providing a “safe space ... a common bond” as described by several mothers who reflected it was a source of “really useful information.” Thus, peer support networks appeared to have played an invaluable role in providing support.

A way forward

This theme examines the support provided to mothers’ post-treatment and suggestions for improvement. Mothers generally reported that at the EOT they were given little information on future health needs, how to manage late effects or psychosocial support. One mother whose child was three years from EOT commented she would have liked “some kind of de-briefing of what to do now.” Some mothers observed that there is a “get on with it yourself approach.” Even when late effects were significant, including sensory loss, mothers reported that they were not provided with support service referrals or psychosocial assessment. This lack of information exacerbated fears and left mothers feeling unprepared to manage the future. Many participants described a situation where they felt unable to contact the hospital for advice describing how they felt “like I was a pest” when querying any aspects of their child’s care post-treatment. When asked what support they would have liked at EOT, most mothers indicated that they would have

liked “more information and support.” Many of the suggestions were specific and focused on having clear guidelines. As seen in the comment by a mother of a child with sarcoma:

I really would have liked something that I could have pinned up and said, here, look at this. Here are the numbers...even a...flowchart with this is what you go to your GP for now. This is what you call the ward for ...

Mothers reported that after treatment there were many challenges such as “money issues and loss of employment” and there was no support to manage these aspects. All mothers with more than one child also expressed disappointment and, on some occasions, anger that there was little understanding or resources available to support siblings. Mothers had mixed opinions regarding their need for psychological support at the EOT. Some indicated a need for support with one indicating that for her “the major thing ... was the psychological aspect.” A few indicated that they just wanted to “get on with it” but all felt that it should have been available. The majority of mothers commented that this care needed to be provided by psychologists/counselors with knowledge of cancer as talking to people who did not “get it” was not beneficial. Finally, mothers also expressed that they felt a more formalised process for connecting with other mums would be helpful:

So, I would have really liked a place that I could have gone to weekly ... and letting out ... everything that I want to talk about that I haven't been able to talk about ... and would be nice for someone to facilitate it ...

Therefore, there appears to have been significant gaps in the provision of services and information which increased uncertainty and stress for mothers.

Discussion

We aimed to explore mothers' lived experiences after the completion of their child's treatment for cancer. Mothers described the wide-ranging negative impacts on their life in a variety of domains. While there was some variation in experiences, there was a prevailing sense of fear, isolation and apprehension for the future. Consistent with previous research psychological distress did not cease at EOT and mothers expressed that it was a challenging and anxious time (Lemos et al., 2019; Ljungman et al., 2015; McKenzie & Curle, 2011; Wakefield, et al., 2011). Leaving the hospital at EOT was a difficult experience for many mothers.

When talking about the hospital, mothers used terms such as “family” and “safety”. This aligns with research by Wilford et al. (2019) who found that, for parents, leaving the hospital was a jarring experience. For mothers in our study, the contrast between the security felt in the hospital, and the feelings of abandonment at EOT left mothers feeling vulnerable. In addition, the shift in roles of being part of a team focused on curing their child to being now solely responsible for their child's post-treatment care made the adjustment to post-treatment challenging. Mothers appeared to find it difficult to adapt to this shift back to normal life and their ability to develop a new ‘normal’ way of mothering their child after the intensity of treatment.

Our study builds upon previous research by McKenzie and Curle (2011) who found that there was a fear of relapse in the first twelve months after the end of treatment. For mothers the fear of relapse and secondary cancers appears to infiltrate many aspects of mothers' lives, making it difficult to develop a new ‘normal’ and altering their identity and view of their roles in their family and society. Research has shown that, compared to age-matched counterparts, children who have been diagnosed with cancer are five times more likely to be diagnosed with a secondary primary cancer (Youlden & Aitken, 2019). The reality of the threat of secondary cancers was apparent to the mothers in our study and it was a threat that many mothers felt affected their functioning. Living with an ongoing threat from relapse and secondary cancer contributed to difficulties in forming connections with others who do not understand their fear; thus, contributing to mothers' feelings of isolation. Our results differed from the findings of Wilford et al. (2019) who found that fear of relapse declined over time. We found that mothers did not report that the fear of relapse declined to any great degree and the knowledge of children who had relapsed or developed a secondary cancer contributed to mothers' ongoing fear which lasted well beyond the first year after EOT.

An important finding of our study relates to the regret felt by mothers regarding the impact on siblings. Research has shown that childhood cancer has negative impacts on siblings including substantial changes to family routines with mothers spending time in hospital with the child with cancer (Alderfer and Hodges, 2010; Houtzager et al., 2004; Prchal et al., 2012; Sloper, 2000). Our research shows that whilst they understood that these significant absences were part of caring for a child with cancer, this did not assuage their guilt. Mothers expressed feelings of guilt that caring for the child with cancer meant they had to overlook the siblings' needs. Our finding is reflective of the prevailing cultural norms regarding ‘good mothering’ and the expectation that mothers care for all their children equally (Sevón, 2011). These expectations of motherhood, and the realities of caring for a child with cancer,

fundamentally challenged mothers' perception of themselves as 'good mothers'. This finding confers a more thorough understanding of the complexities of childhood cancer within modern societal structures and demonstrates that mothers' experiences are framed within societal expectations and norms. It is also important to note that this guilt and regret did not dissipate once treatment was completed, and the family reunited but continued to affect mothers' psychological well-being and their identity as a mother.

Prior research has found there are significant detrimental health impacts on mothers during treatment (Al-Gamal et al., 2019). Young et al. (2002) highlights that the social discourse surrounding motherhood argues that mothers must comfort their children and place their child's needs above their own. This sense of maternal self-sacrifice seemed to be a 'natural' and inevitable decision for the mothers and their needs were given a lower priority during treatment. For many mothers, neglecting their own needs became an entrenched pattern that continued after EOT. This differs from results by Björk et al. (2011) who found that mothers expressed that after treatment they felt it was time to focus on their care. The findings of our research expand our understanding, showing that a lack of self-care, including disturbed sleep patterns, continues to affect mothers' years after EOT and is a long-term ramification of childhood cancer.

Another major long-term ramification was the change to mothers' sense of identity and security. This is in line with Bury's (1982) theory of biographical disruption which posits that a diagnosis of chronic illness changes people's perceptions of their life trajectory. Our study suggests that biographical disruption also affects mothers of children with cancer and that the disruption continues beyond treatment as mothers process the loss of their previous life. Once the crisis of treatment was over, mothers had to process their grief and accept the realisation that their lives had been irrevocably changed. Their roles as mothers and the future they had envisioned for themselves, and their children, were changed dramatically and after treatment, they had to accept these changes.

Mothers in our study feared for their child's future and the losses they might experience because of cancer treatment. Existing research into late effects has often focused on specific cancers such as brain cancer and findings indicate that mothers experience significant distress and loss due to the long-term health impacts (Woodgate et al., 2016). Our research elaborates on these findings to demonstrate that this sense of loss relating to late effects is also experienced by mothers of children with a range of cancer diagnoses. Due to the toxic nature of cancer treatments, the EOT does not herald the end of ill health, and there remains a lifelong potential for adverse effects, including secondary

cancers (Hsiao et al., 2017). This seems to prevent mothers from being able to develop a new narrative for their children and themselves.

Living life with fear and loss required many mothers to develop new perspectives, with a focus on living in the present. This change in perspective has been noted in other studies, such as Ljungman et al. (2016), who observed that mothers often gained a sense of focus and joy in appreciating simple things. Mothers in our research, however, framed this change in perspective against the losses they and their children had suffered and viewed it as a survival mechanism that left them with an ongoing sense of uncertainty.

Mothers often reported a sense of disconnection from their old life, plans and social networks, exacerbated by the perception by others that mothers would return to their former lives and identity. The mothers we interviewed reflected that new relationships formed with other parents of children diagnosed with cancer, and peer support groups, helped compensate for lost relationships. This mirrors research by Ljungman et al. (2016) and Björk et al. (2011) that friendships developed between parents of children with cancer were valued highly. Wakefield et al. (2012) found little support for face-to-face support groups. However, in our study mothers expressed keen interest in peer support groups. In addition, mothers also expressed strong appreciation for online methods, as opposed to other methods of support. The current finding may be a consequence of the fact that participants were recruited through social media but are also reflective of changing dynamics in the use of social media and suggests there is a need to change how information is delivered to suit this new environment.

In our study, mothers recounted that there was limited practical or psychological support to manage the complex issues at the EOT. Consistent with most of the research examining the post-treatment phase, our study found that families were provided with limited information or psychological support (McKenzie & Curle, 2011; Wakefield et al., 2012; Woodgate et al., 2016). The failure to provide what is often straightforward assistance, such as contact details of support services, highlights the need for more support after completion of their child's cancer treatment. The majority of mothers wanted psychological services which were tailored to the childhood cancer experience and delivered by experienced professionals who understood the changes that had occurred to their family and their roles. It was also noted by the mothers that the health system did not provide psychological support for the siblings. Mothers felt regret and guilt about the impact on siblings and emphasised that during the post-treatment phase siblings often needed ongoing care to help adjust to the changes in their lives.

Limitations and future research

Our study included only one participant from a culturally and linguistically diverse (CALD) background, additionally, 70% of the mothers in our study had a university degree, which does not reflect the 31% of Australian adults with a Bachelors' Degree or above (ABS, 2018). However, our study contained a diverse sample in relation to age, marital status, geographical location, and work status, capturing a broad range of perspectives. Another potential limitation of our study is that self-selection bias may have meant that only those with a particular type of experience may have volunteered to participate. An extension of this research would be to examine the individual experiences of childhood cancer in other family members for example fathers, siblings, and grandparents. The findings of our research also emphasise the critical role of healthcare providers and further work needs to be completed to examine the viewpoint of health professionals and gather their perspectives on caring for children and families with cancer.

Conclusion and implications

We conclude that there is a need for support tailored to mothers' specific needs. Individuals experience events according to societal norms and expectations related to gender and roles, and there is a need to understand how each group experience childhood cancer to be able to develop appropriate support. Our study also has implications for informing improvements during treatment as it highlights that some of the detrimental impacts experienced at the EOT are a direct consequence of the lack of support services experienced during treatment.

Our findings indicate that having a child with cancer leads to a shift in mothers' self-identity as they have to adjust their self-concept to form new identities as mothers of children who have been diagnosed with cancer. Much of the process of accepting this new identity appears to occur beyond EOT. Our study highlights the common experiences of all mothers irrespective of diagnosis, including highlighting the inadequacy of current support services post-treatment. Our recommendations include introducing a comprehensive EOT discharge process with written guidelines for ongoing care, and psychological assessment and screening for the whole family including child, parents and siblings. Psychological services also need to be provided as required and tailored to mothers' individual needs. In addition, there needs to be an integration of peer support, and clearer guidelines regarding future monitoring and treatment of late effects. Medical staff should be educated on the complexity of emotions felt by mothers during post-treatment to allow them to deliver appropriate care and support tailored to mothers' individual needs. Notably, we

have shown that negative impacts of childhood cancer extend years beyond EOT, and thus support services must be ongoing to mitigate long-term negative ramifications.

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