



# Telling the Story of Childhood Cancer—The Experience of Families After Treatment

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## Abstract

**Background:** The Discovery Interview methodology was introduced to Oncology Services Group in 2012 as a service improvement strategy and was evaluated positively by staff and families. It enabled clinical staff to hear the deidentified families' stories, understand their experience, and implement process and practice enhancements. **Objective:** This study collected family stories following treatment for childhood cancer at the tertiary center in Queensland, with the goal of raising awareness and improving family experience. **Method:** Twenty-five families were interviewed via an interview spine which covered the major stages of cancer treatment and themes were extracted. **Results:** Major themes were psychological support needs, adapting to the new normal, and rebuilding relationships. After treatment, the parent had time to reflect on their experience and lost the reassurance of regularly attending the tertiary hospital. There was ongoing anxiety regarding relapse. Parents reported various coping strategies and some wanted to maintain contact with other oncology families. Families strived to get back to a level of normality such as attending school and experienced some challenges in relationships with family and friends. **Conclusion:** Families needed support and reassurance from their local health professionals to navigate the ongoing challenges following treatment.

## Keywords

cancer, patient perspectives/narratives, long-term care, caregiving, clinician–patient relationship

## Introduction

Despite advances in treatment, cancer remains the leading cause of death of 0- to 14-year olds in Australia. Many caregivers report feeling overwhelmed by the complex treatment regimes and supportive care needs of their child with cancer (1). Research has shown significant impacts on health-related quality of life for caregivers, including physical and psychological health, and emotional and social functioning (2). Cancer treatment can be a stressful event for the whole family, and regional families may have the extra burden of the family being split-up to enable 1 parent to accompany the child to the tertiary center.

In Queensland, approximately 170 children are diagnosed with cancer each year, and more than half reside over 100 km from the tertiary center at the Queensland Children's Hospital (QCH; formerly Royal Children's Hospital [RCH]) in Brisbane. Queensland covers more than 1.85 million square kilometers and to address the geographical challenges for families, care is provided through a model which includes

10 regional hospital shared care units throughout the state with trained and supported clinical staff.

To enable consumer-driven service improvement, it is important to understand the experiences of families and work together to design services to fulfill family needs. This study recorded the stories of the families, including challenges following the intensive phase of treatment. It discusses suggestions made by parents regarding how they could be better supported by their local health providers, including general practitioners (GPs).

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## Methods

Discovery Interviews were a patient-centered methodology developed in the National Health Service (NHS) in the United Kingdom in 2000 as a tool for service improvement and patient involvement and enabled the collection of detailed experiences of families with the content driven by the interviewees (3–6). It has been used in several different services, and evaluation of this methodology within the QCH showed benefits in exploring the families' needs and improving their experience (7).

Generally, the approach used a one-to-one, face-to-face open interview technique that enabled the collection of detailed experiences of participants with some prompting based on key stages of the experience of the service (a spine) (8).

The spine was:

- Thinking something was wrong
  - Seeing someone in the health system
  - Having tests to find out what was wrong
  - Being told what was wrong
  - Receiving treatment
  - Living with your condition
  - Being followed up
  - Learning to cope with the future

Following the Queensland Health Human Research Ethics Committee approval (HREC/10/QHC/51), 5 oncology staff members were extensively trained and practiced in undertaking Discovery Interviews with an experienced interviewer originally trained by the NHS staff in person.

An invitation letter was sent from the corporate health department to the carers of all patients who were admitted to the RCH with a diagnosis related to cancer management and treatment during 2010. After replying and expressing an interest to be involved, interviews were collected from these consenting carers. In addition, consenting members of the Queensland Paediatric Palliative Care, Haematology and Oncology Network (QPPHON) Patient, Family and Carer Network, which commenced in October 2013, and a number of interested parents in the inpatient ward at QCH in 2015 were also interviewed. Interviewees were excluded if they were less than 18 years of age or had a cognitive impairment, intellectual disability, or a serious mental illness.

The interviews took place in the hospital in a quiet location or in the family's home. The interviewee was taken through an information sheet and consent form, which was signed, and instructions were given about how to revoke an interview from the pool. Interviews lasted anywhere between 30 minutes and 2 hours, as guided by the interviewee and were audiorecorded. Interviews were transcribed, deidentified (patient, family, and clinicians), and condensed to enable them to be read back to clinical teams.

The interviewers recorded 17 Discovery Interviews between March 2012 and May 2014 at RCH, then a further

**Table 1.** Characteristics of the Parents and Patients Involved in the Study.

Characteristic	Category	Number
Parents	Male	5
	Female	20
Residential remoteness	Major city	11
	Inner regional	9
	Outer regional	5
Patient's diagnosis	Solid tumor	14
	Leukemia/lymphoma	10
	Nonmalignant hematology	1
Patient age-group at interview	0-4	4
	5-9	9
	10-14	9
	15-19	3

8 interviews after the move to QCH between March and November 2015.

The Discovery Interview methodology was not designed to provide a representative sample but to discover insights into the family's experience that cannot be gained in other approaches. Even one interview was a rich resource for the service team to develop service improvements.

The interviews were analyzed through an inductive thematic approach (8). This methodology ensures the voice and experience of individual participants are retained but allowed for the exploration of collective themes. The person doing the analysis listened to the full interview to gain the greatest understanding of the parent's story, and the transcript was read several times. Themes that arose were recorded and grouped in a spreadsheet table, along with the interview extract to which they refer.

Themes were allowed to rise through the coding process, rather than being predetermined, consistent with the Discovery Interview approach (6). Interviews were deidentified and condensed and relayed to the clinical teams for their insight and discussion about service and practice improvements (7).

This article focused on 2 questions—what was the ongoing impact on families of the child's cancer episode after the intensive phase of treatment had been completed, and what support would help improve that experience? All names have been changed in the quotes provided.

## Results

The characteristics of the parents involved in the study are shown in Table 1 and a summary of themes found in the analysis of the interviews in Table 2.

### *Psychological Support*

Eight parents reported an impact of cancer treatment on their child including an ongoing fear of medical procedures,

**Table 2.** Number of Parents Who Talked About Experiences Related to the Themes of the Discovery Interviews, of a Total of 25 Interviews.

Theme	Subtheme	Number of Parents
Psychological support	Child	8
	Caregivers	11
	Coping strategies	5
	Ongoing anxiety	8
	Local health providers	3
The new normal	Back to normality	8
	Schooling	6
Rebuilding relationships	Family unit	8
	Other family/friends	7

temporary regression in development, reduction in social skills, and physical limitations.

Jane regressed to very much a child—I think it was just too overwhelming for her.

Six of the parents described how well their child had coped and matured through the learning experience, and how it had influenced their career choices to help others, and improved their communication with their parents. One teenager had developed some short-term goals which she found motivating during treatment.

She had experiences that none of her peers have had. She is able to deal with situations at school that other children probably wouldn't. She doesn't get sucked into all the social thing, where people fall out with each other.

She's been a tower of strength to go through it all. At one stage we were home between chemos, and she'd say I don't feel like going back for chemo. But she'd hop in the car and away we'd come.

She's coping really well with all her treatments and the follow-ups. I don't think I could be as strong as her, everything she's been through.

Children and parents had to deal with the deaths of some of their friends at the hospital:

We've lost some kids lately, and one was her best friend. We went to the funeral but we both lost it, so now we just do things with her on the day of the funeral, take her out and do fun things, come home, release a balloon.

Eleven parents mentioned the impact of finishing treatment and coming to terms with their experience. One parent gave the contrast of being on treatment, where they were very task orientated and focused on their child, to after treatment when their child was doing well and they had time to

reflect. Several mentioned losing the safety net of being at the hospital frequently and getting that reassurance.

When she started maintenance it all hit me and I completely lost it. I had a complete breakdown because we weren't going up there every week.

When we hit maintenance it was like yeah great, we can try and get a bit of a life back and relax a little. But I didn't realise how much of a shock it was going to be because all of a sudden we weren't going up there every week, and I wasn't getting the reassurances from my doctor.

Then I had time to think and the more I thought, the more depressed I got and the more it hit me, and it just completely bowled me over and I couldn't cope with the little things.

It would be helpful to give parents a bit of a warning going in to maintenance, because I've spoken to some other mums after it hit me and they said, Yeah same thing happened to me.

Parents described returning to the hospital as a bad dream or having a wave of unease as they drove down. However, this was offset when they arrived at the hospital by seeing familiar and friendly families and staffs.

Parents developed coping strategies including writing a book about the experience, seeing a psychologist for assistance, being prescribed antidepressants, and talking to their social worker. Others coped through fighting on, the attitude of finding something everyday to be grateful for, making everyday count, and being glad for the time they had with their child.

People would say you're doing great and I could get out of bed and brush my hair and leave the house and that was a choice I made to get up and fight for him and my family.

Two parents called for a role at the hospital that dealt with the emotional needs of families. Two others were keen to maintain contact with other oncology families for support, referring to a level of honesty and understanding not felt from other people.

A couple of parents had seen their local GP to get some assistance, although one said it was difficult to explain what stopped her from sleeping and caused anxiety.

As a mother, living with a child that's had cancer, I know my life has changed forever, and I'm still learning to life with that. I went to my GP and we agreed I need a little help right now, in the form of low dose anti-depressants and some psychologist appointments to give me skills to process what's happened and cope with the future. I can't operate at this high level, with adrenalin and fear any more.

Three parents raised concerns about seeking support from local health providers.

Where do you go in the community when you finish, because no GP wants a problem like that. They think you're being over-protective of your child for simple things.

Anxiety for the future was mentioned by 9 parents. “Scanxiety” was a term commonly used by parents in the interviews. When their child was due for a magnetic resonance imaging, or similar test, they reported being emotional and anxious. In addition, when their child was lethargic or sick, the parent became fearful of relapse and the side effects of treatment.

We were up in emergency as she had a virus, they kept using the word relapse. You don’t say that to me, you don’t use that word ever.

### *The New Normal*

One of the aims for families following the upheaval of treatment was to get back to a level of normality for the family. Parents talked about the difficulty in balancing what they saw as the 2 lives of hospital and their community. Financially, families sometimes struggled to get back on an even keel.

From the outside we look like we’re normal but we’re not, we try to pretend how normal things are because my son needs that.

All we’re doing is trying to get back to some level of routine, so we can build some consistency, then work on her development.

An important part of getting back to normal was the child returning to school.

The best part about her being back at school is just being back into a partial normal life for her, being around her friends, and doing all the things at school.

Two parents with younger children, although missing out on some content, thought their children were not impacted too greatly in missing school, as their education had been supported by their usual teachers providing work, the RCH/QCH school teachers and extra education through iPads. One parent was dissatisfied with the support from their regular school for teachers providing work.

If it’s so important for them to be educated when they’re well, what’s so different about that when they’re sick? The kids think, I must be going to die because no-one cares anymore.

Some older patients had continued with school through distance education during treatment, although 1 parent found treatment too overwhelming to add home schooling to their duties. On returning to school, another child decided to enroll in less complex subjects and work toward a tertiary entrance score to reduce the pressure on themselves.

One parent described the difficulty of fitting back into school:

He was starting school with no hair and was a bit swollen from the steroids, he looked different. Some days I’d go and pick him

up and he was hiding, so that broke my heart. Academically he hasn’t suffered at all, but behaviourally, getting him there and getting him confident, has been a real challenge.

### *Rebuilding Relationships*

The interviews showed that cancer treatment had an impact on the whole family unit. It was sometimes difficult for the child to reconnect with their friends after being away for sometime and they were on a different level socially.

It was hard maintaining contact with her friends—you lose social skills when isolated and not been able to socialise. It took a while to hook into new friendships at school as some had moved on. Her friends matured socially, she matured from a life perspective.

One parent described how the child had become closer to their mother who stayed with them in hospital, and families had to actively work on the relationship with the other parent.

The relationship between the spouses/partners also required time and effort. One parent reported hiding some of their feelings from their spouse, another cited a lack of understanding, while another said their partner was their great leveler.

I’m hoping in the future time, when we get back to some kind of a new normal, that we can rekindle that relationship with my spouse; to try and get back what we’ve missed out on together.

Siblings were sometimes resentful of the attention that the patient was getting, including special gifts such as iPads, even jealous that they had to eat all their tea and their siblings did not.

We have encouraged his brother to be open and ask questions and he’d ask is Jack dying? I said well initially yes, but now the doctors are making him better and we talk about Jack’s sick blood, and how it’s getting better.

I worry about the impact of me just sort of disappearing and being emotionally a bit distant probably. I was not around very much. She’s a pretty tricky sort of kid. I don’t know if that’s just her or it’s because of what has happened and whether I’m going to carry this guilt around for the rest of my life.

My other son, now he’s older, he didn’t want me to go this time. But he couldn’t come as we had to fly. He rang yesterday asking if his brother was still sick. I said I don’t know, we haven’t had the tests yet. He said “You ring me and let me know if he’s sick cause I want you to come home.” So that’s upsetting.

We got a little bit of support talking to his siblings about it, but there were some tricky times that weren’t covered in the book. His older brother John was really resentful of the attention and all the stuff his brother got. And why he had to eat all his tea and his brother didn’t. I’d just say to him that his brother had all these horrible things going on at the moment, so for him to get a few extra nice things is not unfair, and I’m sure he’ll share them

with you. And we'll do something special ourselves. So every now and then my husband dealt with the hospital and I'd spend some time with John.

Parents who involved the siblings as much as possible in the treatment and related decisions, and deliberately spent time with the other siblings when they could, reported that this helped. Siblings were also helped through the work of Camp Quality and CanTeen, and the Siblings Day at the hospital was also commended.

Several parents talked about challenges to relationships with wider family and friends. The family may have isolated themselves to prevent infection or felt that there was a lack of understanding of what they had been through and a wearing down of goodwill of others over the years of treatment. Two parents protected their friends and family from the realities of cancer treatment.

My best friend knows my life out here but they don't understand the life in hospital, unless you've been in there and slept the nights, it's difficult to explain. I've guarded and protected a lot of friends and some family from some of the realities in there.

Why do people keep telling us to get over it, you can't get over this. You do move on and try not to think about it, but you do get worried when it's time for blood tests and to see doctors.

The community has no idea, and there's very, very few people out here that would have half a clue about how the family feel, what they carry around in their heart, how lonely they are.

Parents spoke about the lack of awareness in the community about the need to prevent infections in oncology patients, the length of the treatment, and some of the resulting behavioral difficulties that may arise in the child. Parents felt the local community had no idea about how their family felt and this resulted in further isolation.

Society's not well educated with regard to the prevention of secondary infections and without that their chances of survival is slim. So many families end up segregated—I don't have a good relationship with most of my family because of it and issues that evolved from it.

## Discussion

The psychological impact of a childhood cancer diagnosis for the child and family is well-documented. Survivors score lower in psychological assessments (9), tend toward anxiety and depression (10,11), behavioral issues (11,12), and have post-traumatic stress symptoms (13,14). Siblings also show emotional, behavioral, and social difficulties (15,16) and can have changed relationships within their family (17).

Quality of life and post-traumatic stress scores may only normalize after 1 to 3 years after end of treatment (11,13,14,18). Longer recovery times are related to the length of treatment, poor prognosis, greater psychological distress in the parents, and less social support (10,11,12,19). Follow-up should include psychological monitoring of the whole family,

including psychosocial screening, education check-in, and availability of counseling (11,20,21).

This study suggests that proactive interventions from a psychologist and support through relevant charities should continue after treatment. Parents asked for education regarding coping at end of treatment, and QCH now provides an "End of Treatment Parent Day" and a booklet entitled "Life back in the Community," which have been very well received by those who access them. Online support is also being developed. Interventions should be based on the developmental and cognitive stage of the child and the status of the family (22,23).

The parents in this study pursued personal coping strategies such as writing, developing a positive attitude, and seeking out support from health professionals and other oncology families. Other studies have found yoga programs and general physical activity had benefits (24,25).

The parents interviewed discussed the need to return to normality, such as the child returning to school. However, some reported behavioral issues and difficulties reconnecting with friends who may have moved on during their child's treatment. Child and adolescent survivors returning to school may have academic or social issues (26–28). As a result of their experience, some children relate better to older children or teachers than their peers (26). To prevent this, children need peer socialization during treatment (26) and support for reintegration into school (28).

Social isolation may impact on a child cancer survivor for various periods of time, and this should be monitored (29). Parents reported in this study that cancer treatment impacted relationships between the parents, between members of the family, and with extended family and friends. This may reduce the opportunities of support and socialization through their usual networks, especially when there may be a lack of understanding of what the families have been through. Several parents asked for ongoing coordinated connections to other oncology families.

Childhood cancer survivors have been shown to have ongoing life issues, such as academic attainment, obtaining a job and life and health insurance, and lower rates of marriage and parenthood (30). They can have more uncertainty, reliance on their parents, and need for assistance than their peers (31). This is exacerbated by the economic burden of cancer treatment (32).

Physical issues may also prevent a child from "returning to normality." Physical well-being (33) and motor functioning (12) of survivors have been found to be affected for all ages. Our End of Treatment Parent Day provided a panel of allied health professionals including a dietician, physiotherapist, and psychologist to provide advice to parents on issues they were facing.

To enable consistent and ongoing care, especially for over half our families from regional and rural areas, support must be available from local health providers. This support can improve a family's readiness to return home after

treatment (34) and result in better mental health quality of life scores (18).

General practitioners can support long-term follow-up if they receive adequate guidelines, information, and communication from specialists (35). In Queensland, QCH is developing connections to upskill referring GPs to support families after treatment along with health professionals at the regional shared care unit.

### Limitations

This study reports on families' experiences based on the narrative from parents. Significant correlation has been shown between parent-reported and child self-reported quality of life scales, and parents are able to accurately convey their child's experience (36). However, future studies could collect Discovery Interviews from older children to determine any additional support that could be provided to them.

### Conclusion

The interviews provided a unique opportunity to bring forth the voice of the families regarding their needs. When families return home from cancer treatment, they need support to adjust to changed circumstances with their family and friends, rebuild the relationships with other siblings and their spouses/partners, get back to a level of normality, and cope with the continuing anxiety that the cancer could return. They need to be diligently monitored and reassured by their local health professionals. Targeted interventions guided by these narratives could provide much needed support and be applicable for any family with a child with a long-term condition.

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