

Postprint

This is a pre-copyedited, author-produced PDF of an article accepted for publication *Journal of Child and Family Studies* following peer review. The definitive publisher-authenticated version [Lewis, P., Mooney-Somers, J., Jordens, C. C., & Kerridge, I. (2014). Parents as Advocates for the Psychosocial Survival of Adolescents and Young Adults with Cancer. *Journal of Child and Family Studies*, 1-10. doi: 10.1007/s10826-013-9896-x; published online: 10 Jan 14] is available online at <http://link.springer.com/article/10.1007/s10826-013-9896-x>

Parents as advocates for the psychosocial survival of adolescents and young adults with cancer

Peter Lewis • Julie Mooney-Somers • Christopher F.C. Jordens • Ian Kerridge, 2014

P. Lewis, Centre for Values, Ethics, and the Law in Medicine, University of Sydney, Camperdown, NSW 2106, Australia, e-mail: peter.lewis@sydney.edu.au

Abstract

Many young people with cancer have a parent or parents who care for them during their hospitalisation and treatment, and remain an important part of their lives after the ‘crisis’ has passed and young people have moved into survivorship. This qualitative study explored the impact of cancer diagnosis, treatment and survival during adolescence and young adulthood on the practice and experiences of parenting. We conducted focus groups with a total of 22 parents of young people diagnosed with various cancers between the ages of 11 and 19 years old. The results indicated that parents advocated for their offspring in different ways at different points of the cancer journey. Parents used their parental knowledge of their offspring to secure a medical diagnosis and treatment, developed medical knowledge to advocate for appropriate treatment within the medical system, and then used parental and medical knowledge to advocate for their offspring’s successful psychosocial survival. In this final point in the journey, parents entered social worlds from which they would normally be absent and some went to great lengths to ensure their offspring were not socially disadvantaged.

Key Words: Adolescent, Young Adult, Parent, Cancer

Introduction

Youth is predominantly described in Western culture as a period of transition that results in rapid change to all aspects of a young person’s life: biological, psychological, and social (Holmbeck, 2002). The primary tasks of adolescence and young adulthood from a perspective of developmental psychology are to achieve autonomy, realise a self-identity, and forge intimate relationships with people outside the birth family (Erikson, 1968). These transitions are typically described as linear and predictable and as taking place within three distinct sub-phases: early adolescence (ages 11-14 years), middle adolescence (ages 15-17 years), and late adolescence (ages 18-20 years) (Kelly and Gibson,

2008). To these, Arnett (2000) has added a phase of emerging adulthood between the ages of 18 and 25 which overlaps with late adolescence. Social development is marked by transition to independence from parents, from one social setting to another, such as from school to work or university, and by changes in social role such as from student to employee (Horowitz and Bromnick, 2007). The onset of a chronic illness like cancer has the potential to disrupt any or all of these transitions at different times (Horowitz and Bromnick, 2007). Every year about 1,800 young Australians are diagnosed with cancer, and more are surviving their illness and treatment – with concomitant adverse and late effects – than ever before (AIHW, 2011). Alterations to physical appearance can disrupt their psychological development and result in anxiety about attracting a sexual partner (Abrams et al., 2007; Evan, Kaufman, Cook, and Zeltzer, 2006). Ongoing experiences of pain or fatigue can limit their capacity to participate in social activities with their friends, potentially leading to social isolation (Gibson, Edwards, Sepion, and Richardson, 2006; Corey, Haase, Azzouz, and Monahan, 2008). Diagnosis and treatment can also interrupt their pursuit of education or employment (Grinyer, 2002; Grinyer 2007). These young people rarely undertake their cancer journey alone and in this paper we explore the impact of their cancer diagnosis, treatment and survival on parents and parenting.

Parents play a particularly central role in the lives of early adolescents and young adults during hospitalisation and treatment for cancer, and remain an important part of their lives after the ‘crisis’ has passed and they have moved into survivorship (Lewis, 2013). We know the moment of cancer diagnosis is experienced by parents as a catastrophe (Young, Dixon-Woods, Findlay, & Heney 2002), a pivotal moment in their lives that results in chaos and alters their perspective on life itself (Bjork, Wiebe, & Hallstrom, 2005; Schweitzer, Griffiths, and Yates, 2011). Parents respond to the crisis of cancer diagnosis in a number of ways. Parents of children modify their parenting style by relaxing discipline, spoiling, or bribing their child, and in adolescence or young adulthood by returning to parenting styles that were appropriate for younger children (Williams, McCarthy, Eyles, and Drew 2013). They take steps to control the chaos prompted by diagnosis and attempt to return to normal or re-establish equilibrium in their lives (Bjork et al., 2005), try to remain positive and optimistic (Bjork et al., 2005; Han, Cho, Kim, and Kim 2009; Schweitzer et al., 2011) and seek support from other parents whose offspring is being treated for cancer (Bjork et al., 2005; Elcigil and Conk, 2010; Enskar, Carlsson, Golsater, Hamrin, and Keuger, 1997). Having a child with cancer can also have significant adverse effects on parents, causing stress, fear, and loneliness (Bjork et al., 2005; Elcigil and Conk, 2010; Quinn, 2005; Schweitzer et al., 2011). Some parents report finding benefit in their experience as it changes their perspective on life, uniting their family and inspiring family members to value family relationships more highly than they had before cancer (Norberg and Green, 2007; Quinn, 2005).

These findings echo the broader literature on parenting a young person with a chronic illness, where parents report recognising and valuing the uniqueness of their offspring (Samson, Tomiac, Dimillo, Lavigne, Miles, Choquette, Chakraborty, and Jacob, 2009) and gaining an appreciation for what is important in life (Kratz, Uding, Trahms, Villareale, and Kieckheffer, 2009). Young people are said to be made vulnerable by illness not only because of their immaturity but illness can threaten what they will, or imagine they will, become in the future. Within this framework, parents are morally, and sometimes legally, responsible for both their child’s current and future well-being – their *futurity* (Jenks, 1996). This responsibility can be enacted in the role of ‘biography guardian’ (Young et al, 2002). Young et al talk of guardians of biography as having a desire for “the child to survive their cancer illness and treatment without significant physical, psychological, or developmental impairment” (Young et al., 2002: 1843). Thus, parents respond to the crisis of illness in their offspring cognisant of both the immediate threats to the young person’s existence and of their hopes and dreams for the future.

Following treatment many young people are neither sick enough to need intensive inpatient medical care nor well enough to be cared for exclusively at home. This liminal state, or “journey within a journey”, is often characterised by parental ambivalence about the health status of their offspring (Shepherd and Woodgate, 2011). Parents experience mixed feelings of excitement and trepidation (Flurry, Ullmann-Bremi, and Spichiger, 2011) that manifest as relief and joy as well as anxiety, helplessness, uncertainty, and loneliness (Wakefield, McLoon, Butow, Lenthen, and Cohn 2011). When the situation stabilises and parents have the opportunity to reflect on their own experience of having an offspring with cancer, some experience a “down time” that can last for months (Norberg and Green, 2007). This whole process and stress of diagnosis and treatment can then be experienced for a second time if a young person relapses or when care is transferred from a paediatric to an adult health care institution (Casillas, Kahn, Doose, Landier, Bhatia, Hernandez, & Zeltzer 2010).

Our knowledge of parents’ individual responses to the diagnosis of cancer, however, does not provide a clear understanding of the *practice* of parenting when their child has been diagnosed with cancer. The limited literature that does exist on how cancer diagnosed in young people shapes the experience and nature of parenting suggests that parents’ experience changes to their normal role within the family either by choice or as a response to the expectations of others. For example, they might be expected by health care professionals to ensure their offspring’s co-operation with treatment (Young et al., 2002). They might advocate for their offspring in a health care system that is unfamiliar to them and in which their role is unclear (Clarke, McCarthy, Downie, Ashley, and Anderson, 2009). Parents sometimes have to master different medical tasks that they find burdensome in order for their offspring to remain out of hospital (Flurry et al., 2011). They are likely to become friends, teachers, and counsellors (Norberg and Green, 2007). Having an offspring with cancer has also been described as *intensifying* the parenting role (Long and Marsland, 2011) because the disease intensifies the offspring’s dependence and vulnerability (Young et al., 2002). We know from the broader literature on parenting and chronic illness, that parents’ established identities can be threatened as roles change and the capacity to engage in valued activities is lost (Hodgkinson and Lester, 2002). Following cancer treatment, parents might find it difficult to let go of parenting practices required by the crisis of cancer treatment. While parents can see how difficult it is for the young person to lose his or her newly won independence, they sometimes find it difficult to hand back freedoms when the young person has recovered (Grinyer, 2009). In short, parents develop a new self-identity and social role in response to the demands of parenting an offspring with cancer (Young et al., 2002).

Unfortunately, research in this area rarely distinguishes between parenting younger children and parenting adolescents or young adults. For example, Flurry et al’s (2011) participants were parents of children aged 2-16 years and Shepherd and Woodgate’s (2011) were parents of children aged 5-15 years; neither highlighted potential differences in parenting young people across diverse developmental stages. Notable exceptions are Grinyer’s (2002, 2003, 2006, 2009) research with parents of young adults over 18 years of age and more recent research by Cassilas et al. (2010) with parents of 15 – 30 year olds. Williams et al (2013) studied parents of young people diagnosed with cancer in childhood and adolescence and divided their findings into three groups; those applying only to parent of children 14 years and younger, those applying only to parents of young people 15 years and older, and those applying to parents of young people diagnosed in all age groups (Williams et al 2013). Our paper builds on this important work to further explore the implications of cancer-related demands on and changes to the experience and practice of parenting at a time when young people are already going through significant transitions associated with adolescence and young adulthood.

Method

This study of parents was a component of a broader research project entitled “Growing Up With Cancer” (GUWC) that examined the impact of cancer illness and treatment on the experience of growing up through adolescence and young adulthood. The project explored this issue from several perspectives – those of young people who had survived cancer, their parents, health care professionals who specialise in the care of young people, and high school students who had no first-hand experience with cancer in young people. Our research with parents sought to explore their experiences of caring for a young person with cancer, with a focus on the impact of cancer on the young person’s developing identity, and how parents described the involvement of adolescents and young adults in decisions about care. We used a qualitative approach as we were interested in understanding social phenomena in natural (rather than experimental) settings, and wanted to give due emphasis to the meanings, experiences, and views of all participants (Pope and Mays, 1995). Our perspective is interpretivist in that we assume the practice of parenting to be an intentional act that has meaning for the parents themselves (Schwandt, 2000).

Participants

We undertook three recruitment strategies simultaneously: 1. We sent invitations to participate in the research to parents of patients who had been treated at two haematology and oncology departments in public hospitals in Sydney. 2. Our project partner, CanTeen (Australia’s largest support group for young people living with cancer), emailed patient members an invitation for their parents. 3. We asked young people who had already participated in our young person-study (Lewis 2013; Lewis et al in press) to pass invitations to their parents. We recruited 22 parents: 16 women and six men. There were six couples and 10 individual parents; no men came as individual parents. Participants were parent to six young women and 10 young men who had been diagnosed with cancer between the ages of 11 and 19 years (median age 16) – the period covering adolescence. At the time of the study, offspring were aged between 16 and 24 years (median aged 20) – a period that straddles adolescence and young adulthood. Offspring had been diagnosed with a variety of cancers and haematological malignancies, and had been treated in haematology or oncology departments of paediatric and adult hospitals, many in both settings. All offspring except one were off treatment at the time of the study, however we have no record of the time elapsed since their treatment finished. Thirteen of the 22 parents were recruited through patient members at CanTeen.

Procedure

Focus groups help people explore and clarify their views around a particular topic in ways that might be more accessible than in a one on one interview. Group discussion can provide an attractive alternative for participants who feel threatened by the prospect of a one-on-one interview and group dynamics can encourage participation by people who feel they have little to contribute to a particular topic (Kitzinger, 1995). For example, in one of our focus groups a father spoke very little but when he did so his contribution was important to the discussion; we feel it unlikely that he would have consented to a one-on-one interview. Focus groups are well suited to the study of sensitive or taboo topics because less inhibited group members can introduce topics to which more inhibited group members have the opportunity to respond. Finally, focus group participation can provide support for people discussing experiences that they have in common but which they feel might deviate from the social or cultural norm (Kitzinger, 1995).

We flagged with participants in the participant information sheet and again at the start of the focus group discussion that talking about the experience of caring for an offspring with a life-threatening

illness can be upsetting. For all but one participant their offspring was in remission, so they were reflecting on a medical challenge that had been resolved, although others challenges continued. We encouraged participants to consider how much they wanted to share and aimed to give them permission to be upset – a normal response to a difficult situation. For some, the study was the first time they had been asked to discuss experiences that had placed them under a great psychological burden. For others, it was the first time they had discussed these experiences with people who had undergone a similar journey. Our impression was that participants found the experience beneficial. None left the focus group early, the groups had a warm and supportive atmosphere, and we witnessed several participants swapping contact information at the end of the group. Ethical approval to conduct the Growing up with Cancer study was granted by the Sydney West Area Health Service (now Western Sydney Local Health District) and Sydney University Human Research Ethics committees.

We aimed to hold three focus groups with between six and eight people in each group. However, as is common with focus groups, some participants failed to attend and others unexpectedly brought their partners. Three focus groups were conducted in Melbourne and Sydney with nine, 11, and two participants (this last group had two mothers who were unknown to each other). Each group was facilitated by two members of the GUWC research team and lasted between 1 hour 50 minutes and 2 hours 15 minutes. We posed a number of broad topics for discussion: the specifics of the cancer journey; managing medical and social decisions; their offspring's growing independence in the context of cancer; changes in the parent-child relationship, and dealing with the long term consequences of cancer. All three groups spent a substantial amount of the discussion talking about their own experiences as parents. Regardless of the number of participants involved, we took the same approach to facilitation. Focus groups were digitally recorded and transcribed for analysis.

Analysis

Two of the authors (PL and JMS) conducted a thematic analysis (Braun and Clarke, 2006) which identified major categories that most contributed to our understandings of the experience of parents. PL and JMS refined individual categories through discussion until they agreed upon the meaning of each category and then examined relationships between categories by discussing how parental experiences in one domain influenced their actions in other domains and vice versa. One major theme emerging from this process – and the focus of this paper – was around the practice of parenting an adolescent or young adult offspring who had been treated for cancer.

Results

Across the cancer journey from diagnosis to survivorship we saw three different sub-themes around the interface of parenting and cancer. First, parents used their existing parental knowledge to advocate for a diagnosis and to secure appropriate treatment for their offspring. Second, they developed medical knowledge in order to advocate for treatment for their offspring. And third, parents used both their parental and medical knowledge in order to advocate for successful psychosocial survival for their offspring. Throughout the results and discussion we use the term 'offspring' to talk about young people who are the children of the parents who participated in our research, but who are developmentally no longer children. Illustrative quotes have been stripped of identifying information and where names are used within a quote, pseudonyms have been employed .

Parenting within the health care system: using parental knowledge to advocate for diagnosis and treatment

The parents in our study had intimate knowledge of their offspring which helped them to recognise that their offspring was unwell. They described using this knowledge, and medical knowledge gained through a family history of a particular disease, to try to prompt or assist general practitioners in a diagnostic process. Participants commonly reported that their attempts were rebuffed or dismissed by health care professionals. Yet they persisted when their offspring's medical condition remained static or worsened, or when health care professionals had failed to diagnose a medical problem or refused to agree that there was a medical issue at all.

I actually asked our GP – 'cause my dad and my sister had brain tumours – my mother-in-law said, "Mention the family history. Jog his memory." And he said, "It couldn't be a brain tumour 'cause she's not throwing up." But she was nauseous every morning and that's part of the condition. (FG2)

...we saw the GP quite a few times in that fortnight; the first times were only a fortnight apart. And the GP sort of went to the point of saying that I probably needed the time out and a holiday. My son was fine. But I just didn't believe her. So I took him to an emergency department. [I] made him take his shirt off for the doctor and said, "... you tell me if that's all right." Because to me it was like pieces of a jigsaw puzzle. When you've got that many little minor complaints, you should be seeing a picture. (FG1)

Parents attributed the success of their attempts to secure a diagnosis for their child to their persistence:

So I rang the local doctor again. Demanded to see a particular doctor. Took her back around. He then did a – and went "I'm going to do an ultrasound now and a CT scan". Now we were in [the children's hospital] by that night. (FG2)

Consistent with what is known about the experience of parenting in a crisis (Young et al 2002), parents in this study described a strong commitment to securing optimal care for their sick offspring. They often constructed this as a moral obligation. For example, "you've got a long road, and you just have to do it, don't you" (FG1).

Securing a diagnosis of cancer for their offspring marked a threshold from being a parent of a young person who was unwell to being the parent of a young person with cancer; but it did not mark the end of a need for parental persistence. Parents of one young person described how they responded when, because of their offspring's age at diagnosis, neither the local paediatric nor adult hospital would accept them for treatment:

P1: I obviously went ballistic at the doctor.

P2: Yep.

- P1: I said, “You know, you want me to ring Channel Nine right now?” because it was about that – the similar time that they had a miscarriage in [a local adult hospital where a woman delivered her stillborn baby in a hospital bathroom] so I said, you know, and so the wheels got in motion and we ended up at [a children’s hospital]
- P2: That’s not normally how we act. But we realised because of - - -
- P1: I got angry.
- P2: - - - because of the diagnosis they told us he had only seven to ten days to live. So we knew if it required us to throw a tantrum, and stamp our feet, then that’s exactly what we were ready to do. (FG1)

Another parent described consciously using her personal resources and social networks to secure a timely diagnosis and optimal treatment:

I did a lot of homework. I did a lot of running around, a lot of phone calls and I pulled every string that I knew. And I’ve done that all the way through. And I’d suggest that to everybody. You ring everybody you know. You ring your local – you ring your local member of parliament. You ring every fricking person that you know who might know someone, et cetera, et cetera. (FG2)

Engagement with the health care team continued over a period of months or years. During this period, parents were very aware of having special and privileged knowledge of their offspring that health care professionals did not have, and could not develop. This was, in part, because of the longevity of their relationship and their consistent presence with the young person. As one mother said, “you are her constant”(FG1). Importantly, they saw this knowledge as giving them unique insights into their offspring’s situation. A sense of parental duty also gave them the ‘right’ to intervene in their offspring’s medical care and to scrutinise the health care professional looking after their offspring.

- P1: One of the things I did notice as much as the medical staff have so much knowledge, they didn’t see her day in day out. And they don’t know - - -
- P2: No.
- P1: - - -what their highs look like, and what their lows look like.
- P2: Yeah.
- P1: So I think that was the one thing - - -
- P2: You pick up on them.
- P1: - - - I think a friend has now got a daughter who’s just been diagnosed at 16 with leukaemia. And I just said to her, “You are her constant.”
- P2: Don’t ever be afraid to say, “No, I’m sorry, you’ve just done that to her. Why are you doing it again?” (FG1)

One parent described how she had asserted this privileged knowledge in an effort to draw attention to her child's psychological health during cancer:

... and [health care professional] thought that he was fine. And I'm saying, but he's not fine, because he was in this denial thing. Even though he's saying, "Yep, let's get on with it," it was like it was for another person he was saying it for. (FG3)

These perceived rights were sometimes contested, in a context where the 'child' being treated was in fact a young person with developing independence and perceived by health care professionals to have autonomy around decision making:

... the nurse of diabetes comes in and says, "Oh could you go away I need to talk with Adam?" I said, "No. Adam is 18 but we are his parents." We supported him all the way through. We were there all the time with him. ... I said, "Outside now." "No, he's ..." I said, "Out now." And I took her outside and I gave her a piece of my mind. (FG2)

Parenting within the health care system: developing medical knowledge to advocate for treatment

Parents described occasions where their 'parental' knowledge about their offspring was not sufficient, and they sought to augment it with 'medical' knowledge of their offspring's disease, its treatment, and prognosis:

P1: I was on the computer at two in the morning.

P2: And you think of something; I'm going to look that up? (FG3)

The development of specialised 'medical' knowledge included becoming an expert in their offspring's disease and its treatment. It also included developing the capacity to navigate– and if necessary, circumvent – the health care system:

P1: Everybody was gorgeous, except for one nurse who everybody couldn't stand. Patricia. But – you would – everybody has a story about Patricia. But - - -

P2: You've just got to know how to work around her.

P1: Oh, you just tell her to piss off.

P3: You've just got to scare her. (FG1)

New medical knowledge and the experience of negotiating the health care system allowed parents to see themselves in a different light – as experts rather than novices:

...you recognise the newbies, the faces of the shock, the wide eyes, that look that people have when you've got a child that's newly diagnosed. We became very quickly familiar with it. (FG1)

We were in a chemo room and there'd be another person there who'd started six months before you and you'd start talking to them and they'd tell you. And then people would talk to you and you were the old hand at it. (FG2)

Perhaps unsurprisingly, parents' medical knowledge – or expertise – was often not recognised by health care professionals. Parents described feeling frustrated when their proffered medical knowledge was not taken and acted on. They were aware that they ran the risk of being seen as a 'pushy parent':

... remember sleeping next to him in his room and he was up and down getting more and more delirious so I'd ring the hospital, "Look this is the situation. I need to bring him in." "Oh, no, no we haven't got any room, haven't got any room. Just monitor him. He's fine." Anyway at three in the morning it just got out of control. I rushed him in ... (FG2)

And I've done so much research for this guy [consultant oncologist]. And looked at the trials he gave the current website address for trials. And I looked into it, and I came back to him with 70-odd pages of stuff. He oversees every [jurisdiction], and no, nup, nup, nup. And one of them – this was February last year. One of them in October last year, he said, "I might use this," and I said, "I showed you that in February and you said no." And that's the trial drug he's on now from Europe that they could've started earlier. So now he won't talk to me because, I'm not an intimidating person by any stretch; because Jack and I are very similar that we are quiet. (FG3)

Parenting beyond the health care system: using parental and medical knowledge to advocate for successful psychosocial survivorship

In interactions with the health care system and with health professionals parents drew on parental knowledge and newly gained medical knowledge about their offspring's cancer illness and treatment. After treatment had finished, parenting moved back to the domestic sphere. Here, however, their parental knowledge was augmented with knowledge about cancer illness, its treatment, and its ongoing effects. Parenting was no longer simply a function of their relationship with their offspring but had become a relationship with their offspring as a survivor of cancer. This meant that while they were dealing with ordinary behaviours of young adults, their responses were unavoidably shaped by the experience of cancer. These new insights were often deployed in practical ways to influence their offspring's treatment within the hospital and to oversee their recovery at home:

We've never put any restrictions, apart from when he was sort of having his low immunity time between chemos, and I was wrapping him in cotton wool and telling him that his friends couldn't come over because young kids are always - well not kids - 18, 19 are always coughing and spreading a bug to someone. So I sort of kept them away then, and apart from that it was – "if you want to go out and do anything you just go and do it". (FG3)

But the degree to which they regarded their offspring as a 'child' who had experienced cancer was a source of considerable introspection and anxiety. In describing both their private worries and negotiating with their offspring around what they *should* do, parents tried to balance their knowledge of what the young person had been through and their offspring's desire to live a life they almost lost:

... we get John through cancer and he wants to jump out of a plane with a parachute. I couldn't watch. I just couldn't watch. I thought, after all that now you're going to jump out of a plane. But that's the kind of thing that he wants to do now. (FG2)

And the only other thing I'd like to say was it's very, very hard for him and for us mainly because we're the pains-in-the-arse because we fuss and worry so much about everything. ... "Are you sure?" "But you went out til four o'clock last night." "You shouldn't go out with your friends tonight for a coffee." ... "Why don't you stay at home tonight?" "Nuh". And he wants to live life much more than he did before. (FG1)

One parent reflected explicitly on the challenges parents encountered in negotiating a balance between being 'suitably concerned' and being hyper-vigilant:

But that's what we try to avoid and we are very careful and again the other thing – do we keep him in cotton wool, do we not keep him in cotton wool, do we let him go – all of that sort of stuff. (FG1)

In many ways the advocacy role that parents adopted to secure a diagnosis and to ensure optimal treatment continued in the domestic and social worlds – but changed focus. Here, parental advocacy was orientated to optimising their offspring's opportunities to participate fully in various activities and have the same opportunities as their peers. One parent described the various rites of passage their daughter had participated in and how they had facilitated access to another: *Schoolies* (an Australian rite of passage where graduating high school students travel away from their families to spend a week together to ritually celebrate the end of their school years.).

But she got to do her formal, her valedictory dinner and she got put on a trial drug four days before Schoolies was due. And so Barry and I went to Schoolies. Don't go to Schoolies. I found it hard but there was probably only 10 minutes away from where she was. So because [the medical team] had said 'no, she can't go'. And I said, 'Well if

we go can she go? And [the specialist] said 'yes'. ... And we were needed. ... We had to go and get her a couple of times and do a bit of TLC along the way. (FG1)

Other parents described advocacy oriented to education:

... Juliana got a scholarship to [another country] for four years and it was very hard to let her go 'cause she had absolutely no sense in looking after herself for her medical life. She couldn't even go to the GP and tell the GP that she needed her medication. So I hopped on an aeroplane and went to visit her to basically to sort out with the university about how to handle someone who's coming off treatment. And they were absolutely marvellous. And with the Head of [School] I talked to her about Juliana's reluctance to follow up with the blood test appointments and she said, "Fine, just send me the information via email. I'll get on to Juliana. I'll make sure that she walks the walk." So it's been an excellent system. But I – I had to get on an aeroplane and sort it out. (FG2)

Discussion

When children have cancer their parents are both their principal decisions makers and carers, while parents of adults with cancer are more likely to be consigned to the roles of observers and supporters. The participants in our study were parent to a young person diagnosed with cancer between the ages of 11 and 19, and had years of experience parenting during treatment and survivorship. They parented during a time we would expect their offspring to become increasingly independent and move away from the care and shelter of their parents; a time when their very role as parents is in flux (Grinyer, 2002). Our aim was to study parenting when cancer occurs during this developmental stage.

There are only a few studies that focus on the experience of parenting an adolescent or young adult with cancer. They have generally focussed on the individual experience of parents including the physical, psychological, and social impacts on them such as the changes they experience to their parenting role (Bjork et al., 2005; Elcigil and Conk, 2010; Quinn, 2005; Schweitzer et al., 2011), the intensification of the parenting role (Long and Marsland, 2011), or their changes in parenting style (Williams et al 2013). By contrast, we focused on the *practice* of parenting and our results reveal that parental advocacy is a central and persistent feature across the cancer journey.

Early in the illness trajectory parental advocacy was oriented to survival as they sought to have their offspring's ill-health recognised by general practitioners and a diagnosis secured. Parental knowledge of their offspring's usual health status was important and they were certain that the current state of health was both different and, potentially, in crisis. Parental knowledge was also deployed when parents advocated for optimal treatment; they asserted their privileged knowledge compared to the health care professionals treating their offspring – "you are her constant" (FG1). Parents augmented their knowledge with information about their offspring's disease, its treatment, and prognosis. This new medical knowledge was used to navigate the health care system and secure better treatment and care. Parents also used this knowledge to influence their offspring's behaviour and optimise recovery from cancer. Parents' knowledge was not always welcome and parents described feeling that health care professionals dismissed both their parental knowledge of their offspring and their new medical knowledge of their offspring's disease. Yet parents attributed securing a diagnosis and optimal

treatment to their own persistence. We know from work with parents of young people with a chronic illness that interactions with health care professionals can be distressing when they fail to result in satisfactory delivery of care (Kratz, et al., 2009).

Parenting during an offspring's health crisis can be complicated by a parent's relative powerlessness in the medical context where decisions and actions need to be warranted by expert knowledge. The practice of modern medicine has potentially adverse consequences when practitioners over-extend their scientific and cultural authority (Tomes, 2007). The extent of this process of 'medicalisation' (Illich, 1976) has been limited by a number of factors including increasing recognition of the *expert patient* – a person who is regarded by health care professionals as an expert in his or her own medical diagnosis and treatment (Williams and Calnan, 1996). However, current medical practice is now dominated by the principles of evidence based medicine; personal experience regarded as poor evidence in the evidentiary hierarchy of evidence based medicine (Kerridge, Lowe, and Stewart 2013). 'Medicalisation' persists when practitioners of evidence based medicine fail to recognise or legitimate the expertise or knowledge of lay individuals (Tomes, 2007), as was clearly the experience of many parents in our study. On the one hand, parents claimed expert knowledge of their offspring based upon 'constant experience'. On the other hand, they 'up-skilled' with an aim to reduce the knowledge asymmetry that gave clinicians a stronger warrant than lay people in the medical context. Parents seemed to be augmenting their power and status so as to act more effectively as advocates for their offspring.

Parents consistently characterised themselves as advocates – a role that did not change when their focus moved away from the health care system and back to the domestic sphere. Again parents drew on parental knowledge and medical knowledge as they advocated for their offspring's successful re-entry to regular life. Yet some of the practices of parenting described by participants in this study do not resemble a return to regular life or to normal relationships. Indeed, many closely resemble an intrusion by parents into social settings, such as Schoolies, from which they would normally be absent. One way of interpreting this is to construe parents as being overly-protective (Quinn, 2005; Wakefield et al., 2011). Construing parents as overly-protective tends to demonise them and is an overly simplistic explanation for their ongoing high levels of participation in the lives of their offspring.

A less stigmatising way of framing our results is to accept that parents continue to respond to their offspring's vulnerability - which persists after the acute threat to their life and health has passed and their treatment has finished (Abrams et al., 2007; Corey et al., 2008; Gibson et al., 2006). Young cancer survivors can experience delayed social development because of the ongoing, adverse physical and psychological effects of cancer (Abrams et al., 2007; Whyte and Smith, 1997). Parents have a desire for their offspring to "survive their cancer illness and treatment without significant physical, psychological, or developmental impairment" (Young et al., 2002). In this way, we see parents in our study entering social settings from which they would normally be absent in order to extend their advocacy to their offspring's successful psychosocial survival.

Securing care for their offspring when parental care reaches its limits is to be expected (Young et al., 2002). Parents have a responsibility in our society to protect and advocate for their children (Kratz et al., 2009) and in health care contexts they may be required to behave in ways that would otherwise be unacceptable in order to secure optimal care for their offspring, for example, by repeatedly challenging a doctors' capacity to diagnose an illness, demanding to see a particular doctor, or by threatening to escalate the situation. The role of parent brings these responsibilities in our society regardless of the age of the offspring or the disease with which he or she is diagnosed (Kratz et al., 2009). We do not know if parents continued advocacy and actions caused tension in the relationships between parents in our study and their offspring. Certainly findings from previous studies have suggested that this might be

the case (Grinyer, 2009). Grinyer's (2002) work demonstrates that relationships between parents and their adolescent and young adult offspring are in a constant state of renegotiation under normal circumstances and that young people often return to the family home and the care of their parents when they are diagnosed with cancer and debilitated by treatment. The task of gaining independence is known to be complicated and non-linear in trajectory and can be disrupted by a host of unpredictable and unforeseeable challenges including the onset of a severe and/or chronic illness (Horowitz and Bromnick, 2007; Wyn and White, 1997).

Our exploration of the impact of cancer diagnosis, treatment and survival during adolescence and young adulthood on the practice and experience of parenting adds to a small body of existing literature. Still absent in this work are explorations of how social and economic dimensions of family life (ethnicity, class, family structure) at the time of diagnosis shape the experience of parenting during adolescent and young adult illness. This is clearly an important area for future research. The age of young people at the time of their diagnosis has the potential to impact upon their experience of cancer illness and treatment – for example, we know that this is a decisive factor in whether they are admitted to paediatric or adult health care services and that the setting of care can shape dramatically the model of care that they and their parents encounter. We also know that young people's cancer experience affects their experience of growing up and is shaped by their developmental phase (Lewis, 2013). Our findings introduce some much needed nuance into the research on what is broadly called 'childhood cancer', by differentiating between children and young people. However, further detailed work – ideally using qualitative methods – is needed to examine how different developmental stages within adolescence and young adulthood shape parenting during cancer as well as for parents of those living with other chronic illnesses.

Conclusion

We employed focus groups to explore parents' experiences of caring for a young person growing up with cancer. It was clear that many of the parents in this study had had little prior opportunity to talk about their experiences as parents and of parenting. Research that focuses on the experiences of young people with cancer should attend to the 'voices' of others engaged in their care so as to avoid constructing them simply as a supporting cast of dramatis personae in the story about the devastating impact of cancer on a young person's life. If we are to broaden and deepen our understanding of the impact of cancer illness and treatment then we need to expand our field of study to include those people with whom the central characters in the cancer story – the young people themselves – interact most intimately. We have shown that some parents will go to extraordinary lengths to ensure that their offspring have access to the socially sanctioned experiences of growing up; experiences they assume their offspring's peers have had and the absence of which might lead to social dislocation. Paradoxically, parents sometimes advocated for their offspring by entering social settings from which they would more usually be absent, such as university. The long term consequence of this for young people moving into and beyond young adulthood is a question for future research.

Acknowledgments

We are grateful to all the parents who participated in the study. We thank staff at CanTeen and the two hospitals for assistance with recruitment, and special thanks to Pandora Patterson and Fiona E.J. McDonald for facilitating the Melbourne focus group. This research was supported under Australian Research Council's *Linkage Projects* funding scheme (project number LP0883632), with CanTeen as the

Linkage partner. We acknowledge the members of the Growing Up with Cancer project: Ian Kerridge, Christopher F.C. Jordens, Julie Mooney-Somers, and Peter Lewis (University of Sydney), Kris Smith (University of Newcastle), David Bennett (The Children's Hospital at Westmead), Pandora Patterson and Fiona E.J.McDonald (CanTeen) and Susan Cornish.

References

- Australian Institute of Health and Welfare (2011). *Cancer in adolescents and young adults in Australia*. Cancer series no. 62. Cat. no. CAN 59. Canberra: AIHW
- Abrams, A.N., Hazen, E.P., & Penson, R.T. (2007). Psychosocial issues in adolescents with cancer. *Cancer Treatment Review*, 33, 622-630.
- Arnett, J.J. (2000). Emerging adulthood: A theory of development from the late teens through the twenties. *American Psychologist*, 55, 469-480.
- Bjork, M., Wiebe, T. & Hallstrom, I. (2005). Striving to survive: families lived experiences when a child is diagnosed with cancer. *Journal of Pediatric Oncology Nursing*, 22, 265 - 275.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77-101.
- Casillas, J., Kahn, K. L., Doose, M., Landier, W., Bhatia, S., Hernandez, J., & Zeltzer, L. K. (2010). Transitioning childhood cancer survivors to adult-centered healthcare: insights from parents, adolescent, and young adult survivors. *Psycho-Oncology*, 19, 982-990.
- Clarke, N., McCarthy, M., Downie, P., Ashley, D., & Anderson, V. (2009). Gender differences in the psychosocial experience of parents of children with cancer: a review of the literature. *Psycho-Oncology*, 18, 907-915.
- Corey, A., Haase, J., Azzouz, F., & Monahan, P. (2008). Social Support and Symptom Distress in Adolescents/Young Adults With Cancer. *Journal of Pediatric Oncology Nursing*, 25, 275-284.
- Elcigil, A., & Conk, Z. . (2010). Determining the burden of mothers of children who have cancer. *DEUHYO ED*,3, 174 - 181.
- Enskar, K., Carlsson, M., Golsater, M., Hamrin, E., & Keuger, A. (1997). Parental report of changes and challenges that result from parenting a child with cancer. *Journal of Pediatric Oncology Nursing*,14, 156-163.
- Erikson, E. (1968). *Identity, Youth, and Crisis*. New York: W.W. Norton and Co.
- Evan, E.E., Kaufman, M. Cook, A.B., & Zeltzer, L.K. (2006). Sexual Health and Self-Esteem in Adolescents and Young Adults with Cancer. *Cancer*, 107, S1672-1679.
- Flurry, M., Ullmann-Bremi, A., & Spichiger, E. (2011). Experiences of parents with caring for their child after a cancer diagnosis. *Journal of Pediatric Oncology Nursing*, 28, 143-153.
- Gibson, F., Edwards, J., Sepion, B., & Richardson, A. (2006). Cancer-related fatigue in children and young people: Survey of healthcare professionals' knowledge and attitudes. *European Journal of Oncology Nursing*, 10, 311-316.
- Grinyer, A. (2002). *Cancer in Young Adults: Through parents' eyes*. Buckingham: Open University Press.

- Grinyer, A. (2003). Young adults with cancer: parents' interactions with health care professionals. *European Journal of Cancer Care*, 13, 88-95.
- Grinyer, A. (2006). Caring for a young adult with cancer: the impact on mothers' health. *Health & Social Care in the Community*, 14, 311-318.
- Grinyer, A. (2007) *Young People Living With Cancer*. Maidenhead, England: Open University Press
- Grinyer, A. (2009). Contrasting parental perspectives with those of teenagers and young adults with cancer: Comparing the findings from two qualitative studies. *European Journal of Oncology Nursing*, 13, 200-206.
- Han, H.-R., Cho, E.J., Kim, D., & Kim, J. (2009). The report of coping strategies and psychosocial adjustment in Korean mothers of children with cancer. *Psycho-Oncology*, 18, 956-964.
- Hodgkins, R., & Lester, M. (2002). Stresses and coping strategies of mothers living with a child with cystic fibrosis: Implications for nursing professionals. *Journal of Advanced Nursing*, 39, 377-383.
- Holmbeck, G. (2002). A developmental perspective on adolescent health and illness: An introduction to the special issues. *Journal of Pediatric Psychology*, 27, 409-415.
- Horowitz, A. D., & Bromnick, R. D. (2007). "Contestable Adulthood": Variability and disparity in markers for negotiating the transition to adulthood. *Youth and Society*, 39, 209-231.
- Illich, I. (1976). *Limits to Medicine: Medical Nemesis: The expropriation of health*. London: Penguin.
- Jenks, C. (1996). The post modern child. In J. Brannen & T. O'Brien (Ed.) *Children in Families: Research and policy* (pp. 13-25). London: Farmer Press.
- Kelly, D., & Gibson, F. (2008). *Cancer Care for Adolescents and Young Adults*. Blackwell: Oxford.
- Kerridge, I., Lowe, M., & Stewart, C. (2013). *Ethics and Law for Health Professionals*. Sydney: The Federation Press.
- Kitzinger, J. (1995). Introducing focus groups. *BMJ*, 311, 299-302.
- Kratz, L., Uding, M., Trahms, C., Villareale, N., & Kieckheffer, E. (2009). Managing childhood chronic illness: Parents perspectives and implications for parent-provider relationships. *Family, Systems, and Health*, 27, 303-313.
- Lewis, P. (2013). *Growing up with Cancer: A qualitative study of the impact of cancer illness and treatment on the experience of growing up*. Unpublished doctoral dissertation, University of Sydney, Sydney.
- Lewis, P. (In Press) Growing up with cancer: Accommodating the effects of cancer into young people's social lives. *Journal of Pediatric Oncology Nursing*
- Long, S., & Marsland, A. (2011). Family adjustment to childhood cancer: a systematic review. *Clinical Child and Family Psychology Review*, 14, 57 - 88.
- Norberg, A., & Green, A. (2007). Stressors in the daily life of parents after a child's successful cancer treatment *Journal of Psychosocial Oncology*, 25, 113 - 122.
- Pope, C., & Mays, M. (1995). Qualitative Research: Reaching the parts other methods cannot reach: an introduction to qualitative methods in health services research. *British Medical Journal*, 311, 42-45.

- Quinn, S. (2005). The long-term psychosocial effects of cancer diagnosis and treatment on children and their families. *Social Work in Health Care*, 39, 129-149.
- Samson, A., Tomiak, E., Dimillo, J., Lavigne, R., Miles, S., Choquette, M., Chakraborty, P., & Jacob, P. (2009). The lived experience of hope among parents of a child with Duchenne muscular dystrophy: perceiving the human being beyond the illness. *Chronic Illness*, 5, 103-114.
- Schwandt, T. A. (2000). Three Epistemological Stances for Qualitative Inquiry: Interpretivism, Hermeneutics, and Social Constructionism. In N. K. Denzin & Y. Lincoln (Eds.), *Handbook of Qualitative Research* (second ed., pp. 189-211). Thousand Oaks: Sage.
- Schweitzer, R., Griffiths, M., & Yates, P. (2011). Parental experience of childhood cancer using interpretive phenomenological analysis. *Psychology and Health*, 27, 704 - 720.
- Shepherd, E. J. W., & Woodgate, R. L. (2011). A journey within a journey: The lived experience of parents who do not live near their child's tertiary cancer centre. *Journal of Pediatric Oncology Nursing*, 28, 231 - 243.
- Tomes, N. (2007). Patient empowerment and the dilemmas of late-modern medicalisation. *Lancet*, 369, 698-700.
- Wakefield, C., McLoon, J., Butow, P., Lenthen, K., & Cohn, R. (2011). Parental adjustment to the completion of their child's cancer treatment. *Pediatric Blood Cancer*, 56, 524-531.
- Williams, L.K., McCarthy, M.C. Eyles, D.J., and Drew, S. (2013) Parenting a child with cancer: Perceptions of adolescents and parents of adolescents and younger children following completion of childhood cancer treatment. *Journal of Family Studies*, 19, 80-89.
- Whyte, F., & Smith, L. (1997). A literature review of adolescence and cancer. *European Journal of Cancer*, 6, 137-146
- Williams, S., & Calnan, M. (1996). The 'limits' of medicalisation?: Modern medicine and the lay populace in late modernity. *Sociology of Science and Medicine*, 42, 1609-1620.
- Wyn, J., & White, R. (1997). *Rethinking Youth*. Sydney: Allen and Unwin.
- Young, B., Dixon-Woods, M., Findlay, M., & Heney, D. (2002). Parenting in a crisis: conceptualising mothers of children with cancer. *Social Science & Medicine*, 55, 1835 - 1847.