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Growing Up With Cancer: Accommodating the Effects of Cancer Into Young People's Social Lives

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Abstract

Adolescence and young adulthood are transitional periods of rapid and dramatic personal change. Few events can cause as unpredictable and challenging alterations to this process as the onset of a serious illness, such as cancer. Although we know much about the physical and psychological consequences of having cancer at this time, we know little about the effect of cancer on young people's relationships. We conducted interviews with 15 women and 12 men aged between 16 and 29 years, who had survived cancer. Our findings demonstrate that the experience of cancer and how it affects relationships is complex. It arrests young people's development by increasing their dependence on parents, giving them life experiences unavailable to peers, and complicating the process of establishing new relationships. However, it also accelerates development by facilitating closer and more mature relationships with parents and giving young people wisdom and insight not shared by peers. Cancer profoundly shapes how young people conduct their relationships. These changes require ongoing accommodation by young people with cancer, their parents, peers, and new acquaintances.

Introduction

Adolescence and young adulthood can be difficult periods of transition for young people. Theories of development suggest a linear, unidirectional progression from a stable state of childhood to a state of adulthood through intermediate, unstable periods of adolescence and young adulthood (Erikson, 1968). However, transitions through adolescence and young adulthood can be accelerated, slowed down, or redirected by significant and unexpected life events including changes in economic and domestic circumstances, the breakdown of relationships, or confounding of a young person's plans for the future (Horowitz & Bromnick, 2007). Few events can cause as unpredictable and challenging alterations to the process of growing up than the onset of a serious illness, such as cancer.

Between 2003 and 2007, 8,783 young Australians aged 15 to 29 years were diagnosed with cancer—an average of 1,756 per annum. As a consequence of advances in treatment, more of those diagnosed with cancer are surviving than ever before. Recent data suggest that of Australians aged 15 to 29 years diagnosed with cancer, 95% can be expected to survive for 1 year post-diagnosis and 87% will be alive at 5 years post-diagnosis (Australian Institute of Health and Welfare, 2011). Survival is only part of the story. The ongoing and late effects of cancer illness and treatment can be physical, psychological, and social. Physical effects include alterations to both bodily appearance and function. Cancer itself can induce weight loss, skin pallor, and short stature (Feinberg, 2007), while treatment may cause a wide range of adverse effects. Chemotherapy can cause infertility, growth failure, and hair loss (Feinberg, 2007). Corticosteroids can result in weight gain, osteoporosis, diabetes, and cataracts (Feinberg, 2007). And surgery can result in surgical scarring, limb amputation, and leave in place physical devices for treatment such as those used for central venous access (Algren & Arnow, 2007; Feinberg, 2007; Heiney, 1989). Young people commonly experience ongoing pain (Carlsson, Annica, & Venke, 2008; Corey, Haase, Azzouz, & Monahan, 2008; Decker, Haase, & Bell, 2007), fatigue (Corey et al., 2008; Erickson et al., 2010; Gibson, Edwards, Sepion, & Richardson, 2006; Ream

et al., 2006), impaired cognitive function, and reduced mobility (Evan & Zeltzer, 2006; Woodgate, 2005).

The psychosocial consequences of these physical effects have been documented for many years (Smith, Ostroff, Tan, & Lesko, 1991). Fatigue, for example, may inhibit young peoples' daily function (Gibson, Edwards, Ream, & Sepion, 2005) including interactions with family and friends (Corey et al., 2008) and result in decreased satisfaction with and difficulty participating in the normal daily activities enjoyed by their peers (Erickson et al., 2010; Gibson et al., 2005).

One of the most profound social consequences of cancer and its treatment is a disruption to the search for independence as young people are thrown back into the care of their parents (Grinyer, 2007). Further complications arise after treatment has finished when young cancer survivors seek to reassert their independence but continue to experience the physical effects of cancer that make them dependent (Hokkanen, Eriksson, Ahonen, & Salanterä, 2004). While young people with cancer generally appreciate receiving special care and attention from parents (Woodgate, 2006), they may also experience an overwhelming sense of guilt for causing their parents to suffer and a desire to repay what they "owe" them (Cantrell & Conte, 2009)—feelings that may conflict with their desire for independence (Yi & Zebrack, 2010).

Cancer may also significantly disrupt a young person's relationships with peers. While they are pleased to have survived their treatment and to have the opportunity to return to "normal," they frequently notice differences between themselves and their peers (Hokkanen et al., 2004), a feeling that they now have less in common or that their peers have "moved on" while they have "stagnated" (Hokkanen et al., 2004). Young cancer survivors might also fear being rejected or stigmatized by their peers, which can inhibit their willingness to tell their friends about their diagnosis (Hilton, Emslie, Hunt, Chapple, & Ziebland, 2009). Such fears are reinforced by the fact that young people with cancer often do experience stigmatization and bullying at school (Glasson, 1995; Lahteenmaki, Huostila, Hinkka, & Salmi, 2002). The experience of cancer is a complex one for many young people; for while they often miss out on the shared experiences of daily life with their peers, they are also exposed to experiences young people do not normally have, such as the possibility of their own death (Cantrell & Conte, 2009). This is especially so for young people who are school students at the time of their diagnosis and treatment (Abrams, Hazen, & Penson, 2007; Evan & Zeltzer, 2006; Whyte & Smith, 1997). While peer support, including a "peer shield" (Abrams et al., 2007; Larouche & Chin-Peuckert, 2006), may help young people with cancer ameliorate the impact of social isolation, cancer survivors frequently use other mechanisms, such as avoidance, withdrawal, and isolation, to avoid conflict or abuse (Grinyer, 2007).

Cancer illness and treatment may also adversely affect young cancer survivor's sexual relationships. Most research in this area has looked at the disruption to sexual function (Heiney, 1989; Katz, 2007; Klopovich & Clancy, 1985; Thompson, 1990; Zebrack, Casillas, Nohr, Adams, & Zeltzer, 2004). Cancer treatment may threaten fertility and require young people to make decisions about fertility preservation—a process that is medically more straightforward for young men than for young women (Beerendonk & Braat, 2005; Katz, 2007; Sweet, Servy, & Karow, 1996). Young people may fear the potentially toxic effects of chemotherapy on their sexual partner's health (Finnegan, 2004; Katz, 2007) and on the health of their unborn children (Hosalkar, Henderson, Weiss, Donthineni, & Lackman, 2004) but may inconsistently use condoms to alleviate these risks (Katz, 2007). Few studies have discussed the effects of cancer on a young person's developing sexual identity and relationships. Those that have, report that in some social settings young people have concerns regarding their ability to attract a sexual partner or to establish and maintain intimate relationships of a romantic nature (Kelly & Gibson, 2008).

Therefore, we now have extensive knowledge of the physical and psychological impact of cancer on young people. We also have an extensive knowledge about how young people cope with their

disease and its ongoing effects. And we have some knowledge about the social consequences for them of cancer illness and treatment. However, we have more to learn about the social processes that young people engage in when they seek to manage the effects of cancer on their relationships with other people. We have more to learn about the nature of the relationships in which they engage that complements our current understandings of their physical experience of growing up with cancer. We have more to learn about the process of renegotiating independence from parents who have been major sources of support during illness and treatment. We have more to learn about how young people manage their peer relationships when they return to their usual social worlds. And we have more to learn about the ways in which young people discuss their cancer illness with new acquaintances and manage the ongoing effects of their cancer illness and treatment on their new relationships. This research, therefore, sought to develop a more nuanced understanding of the impact of cancer illness and treatment on the relationships young people conduct while they engage in the process of growing up.

Methods

Study Design

We employed a qualitative research design. We used a purposive sampling strategy to ensure roughly equal numbers of male and female participants, and representation across a range of diagnostic groups and life experiences. Young people were eligible to participate if they were between 14 and 29 years old and diagnosed with cancer between the ages of 10 and 24 years. Young people were excluded from the study if they were diagnosed with a non-melanoma skin cancer, were diagnosed with cancer less than 8 weeks before the recruitment period, or were intellectually impaired to the extent that they could not complete the requirements of the study.

Administrative officers working in the hematology and oncology departments of 2 hospitals located in Western Sydney mailed 480 letters of invitation—and follow-up letters—to eligible young people; this produced 10 participants. An email invitation to members of CanTeen (Australia's largest support organization for young people with cancer) and an article in the member magazine, *Link*, produced 17 participants. The study was approved by the Sydney West Area Health Service (now Western Sydney Local Health District) and University of Sydney Human Research Ethics Committees. All participants provided informed consent and signed written statements to this effect. Parents of all participants younger than 18 years also provided informed consent and written statements to that effect.

Data Collection

The first author conducted 48 interviews with 27 participants in offices at the University of Sydney, participant family homes, and via telephone. Interviews lasted between 40 and 120 minutes, were digitally recorded, and transcribed in full. Interviews were semi structured and conversational in style. Participants engaged in 1 (n = 27), 2 (n = 17), or 3 (n = 4) interviews. During the course of the first interview, participants provided a description of their life before their cancer diagnosis, including their living arrangements, school, and extra curricula activities, and the impact of having cancer on their psychological, emotional, and social lives. Participants were then invited to work with an artist to create a self-portrait of their experience of growing up with cancer. The second and third interviews were opportunities to discuss the experience of creating a self-portrait and to ask follow-up or clarifying questions about topics discussed during the first interview.

Data Analysis

Analysis of interview data focused on the experiences of growing up with cancer. We conducted a thematic analysis (Braun & Clarke, 2006), guided by the theoretical perspective of Symbolic

Interactionism (Blumer, 1969). Preliminary analysis occurred contemporaneously with data collection. PL, in collaboration with the co-authors, categorized the data on the basis of what he had identified as being salient factors in the process of growing up. This process resulted in a large number of individual categories (80) that were collapsed into 15 major themes. Five of these major categories make up the 3 findings presented in this article: Family, Independence, and Self-sufficiency; Friendships, Gaining and Losing Friends; and Sexually Intimate Relationships. Analysis was supported by NVivo Version 8.

Findings

Interviews were conducted with 15 women and 12 men aged 16 to 29 years. All had been diagnosed with cancer between the ages of 10 and 22 years. Diagnostic groups included leukaemia (n = 10), Hodgkin's lymphoma (n = 5), sarcoma (n = 5), testicular tumour (n = 2), brain tumour (n = 2), and ovarian tumour, medulloblastoma, bowel cancer (n = 1 each). The time that had elapsed between diagnosis and interview varied from 12 months to 14 years. Most participants lived in large urban centres, with 6 living in regional and remote areas.

Our findings reveal how the impact of cancer manifests in young people's relationships with parents, peers, and new acquaintances. We have therefore organized our findings into 3 categories. First, we report on relationships between participants and their parents; second, between participants and their peers; and third, between participants and new acquaintances. Importantly, changes to relationships varied across different phases of adolescence and young adulthood; early adolescence (10-13 years old), mid-adolescence (14-17 years old), and late adolescence/young adulthood (18 years and older). Within each relationship category we explore the shift in relational priorities of young people in early, middle, and late adolescence/young adulthood.

Relationships With Parents

A diagnosis of cancer in young people usually means being hospitalized for treatment, at least in the short term. During their period of treatment, participants in this study described experiencing a sense of physical limitation and adverse effects of treatment. Parents responded to their child's temporary disability by remaining with them in hospital and assisting them to perform the usual activities of daily living. The close proximity of parents had the potential to alter relationships between participants and their parents. Their changed relationship had implications for the negotiation or renegotiation of the young person's independence as they recovered from their illness and treatment.

Participants diagnosed in early adolescence often experienced accelerated development in their relationships with their parents because of the concentrated time they spent together during hospitalization discussing weighty topics of life and death. Indeed, their experience more closely resembled a relationship between 2 adult friends than between a child and parent. Some participants subsequently developed a deeper understanding of their parents as individuals than they had before their diagnosis.

"When I was in the hospital and had to talk to my mum and she just talks to me more about how she feels about my stepdad and coming from [her country] to Australia and how hard life is in [her country] . . . so I could get a better perspective of that. So, it really changed the way that I saw my parents. (Mahalya, 22; diagnosed at 13, relapsed at 18)"

Some participants who were diagnosed in early or mid-adolescence said that the close relationship they developed with their parents during their period of illness and treatment continued post-

treatment. Malcolm, for example, described how his mother had become a “best friend,” a person with whom he shared his secrets:

"Now I tell my mum about every single aspect of my life. . . . I tell all my bits of my social life, I tell my friends' secrets to my mum, we share absolutely everything now. (Malcolm, 17; diagnosed at 15)"

Participants diagnosed in late adolescence or young adulthood who had moved out of the family home and begun to live independently before they were diagnosed returned to live at their family home after they were diagnosed. This was more than just a physical relocation—it also symbolized resuming a particular “place” within the family. Some participants described how they moved back into their childhood bedrooms or were required to share a bedroom with younger siblings and became positioned (again) as children. This move had adverse consequences for participants, such as loss of independence, as Mel makes clear:

"Moving home was probably one of the hardest things to do [because you lose] all your independence. Even simple things like I love cooking and going to not cooking, or cooking for a whole family, which is harder and . . . now I'm back in my childhood room. (Mel, 20; diagnosed at 19)"

Attempts to regain independence from their parents were complicated when participants experienced ongoing physical effects of treatment, such as impaired cognition, that prolonged their dependence on their parents. A life crisis, such as an unexpected pregnancy, could also throw older cancer survivors back into the care of their parents for a second time. There was also some ambivalence around the desire to regain independence as participants did not want to jeopardize the deep bond they developed with their parents through the cancer experience:

"I've become [my parents'] daughter again. I very much play the daughter role. So . . . I need to cut the apron strings again, I think. But they're all very much my emotional support, my mum is anyway. (Alice, 29; diagnosed at 22, relapsed at 23)"

Relationships With Peers

During middle adolescence, peer relationships normally increase in importance for young people. This was no different for the participants in our study. When treatment allowed, participants in this study began to re-enter their usual social worlds of school, university, sporting, and social clubs and to reconnect with their peers. Their social worlds are governed by institutional rules and social norms. But when they did return to their usual social worlds, they generally did so intermittently—a consequence of the need to balance the ongoing demands of illness and treatment and, somewhat reluctantly, accommodating the impacts of their altered physical appearance and changed outlook on life. Participants of all ages experienced difficulty fitting back in with their peer group. To some extent, all faced challenges arising from the fact that they violated norms of attendance, achievement, and appearance—the consequences of such violations differed depending on the participant's social setting and phase of life.

Participants returning to secondary school often described some degree of social alienation or isolation because part-time attendance, due to fatigue and the need to attend medical appointments, was not a “normal” pattern of attendance.

"One of the kids said, "Oh Talia is not in our class anymore, you know, she's gone." Pretty much just bluntly said that I wasn't part of the class because I hadn't been there for ages and it wasn't fair that I could just pop in and out how I liked. (Talia, 16; diagnosed at 14)"

While absent from their usual social worlds because of illness and treatment, all participants experienced a shift in priorities. For some, the importance of education changed and this affected their efforts to achieve. Those who came to attach less importance to their education said that they did not try as hard as they had prior to their diagnosis and were indifferent to their level of achievement:

"Everybody pretty much does have a new perspective in life after going through something like [cancer] . . . going through a near death experience, you think, "Shit, I really only do have one life, . . . I should enjoy it and I should get out there." . . . I'm enjoying life a hell of a lot more than I was and I've learnt that school isn't everything in life. (Talia, 16; diagnosed at 14)"

Others, in contrast, came to attach more importance to their education—trying harder at school and in some instances achieving results at a higher level than they had before their cancer diagnosis. Their peers reportedly noticed this:

"I think for the first few years [after my crisis] I felt that my education performance was just a lot more important to me and I worked a lot harder paying attention in class. . . . All my friends asked me if I was taking brain steroids because no one could believe that I had changed so much. (Mahalya, 22; diagnosed at 13, relapsed at 18)"

Those who returned to school spoke of being given "special treatment" at exam time by teachers who sought to maximize the participant's level of achievement. Special treatment was noticed by school peers and participants described being picked on as a result. This marked participants as being different to their peers which caused problems for participants:

"Some of the insensitive things they would say, obviously not on purpose; like for example the School Certificate, I received provisions for the exam, which weren't really much, just a glass of water and a separate room, which really probably disadvantaged me more than anything. But the thing is that people, some of them, were saying, "Oh, I should shave my head to get that!" And I'm thinking it's a bit insensitive, as in it's not just that I'm bald it's a lot more that I'm going through. (Rudi, 21; diagnosed at 14)"

Some participants were also marked as different in a way that their peers recognized as valuable to them. This enabled participants to occupy a "special" place within the peer group—that of advisor or counsellor.

"I guess with my cancer I feel like it gave me a lot of wisdom, in terms of dealing with problems and it gave me a lot of insight. And in that way I find that because I've had that experience I'm able to relate to other people's problems a lot better. So I found that since then, I've naturally fallen into the role of guidance counsellor. So, yeah I guess and people notice that I have that wisdom and that grounding from that, and so they'll naturally come to me for advice and so because I have a lot of people that look up to me and look to me as the support. . . . I feel like I have that responsibility on me. (Dilshara, 18; diagnosed at 11)"

In contrast to cancer survivors who returned to secondary school, the participants in our study who attended university did not report any special academic consideration except to be granted an extension to the time allowed for their overall degree. Returning to social worlds with flexible norms of attendance such as university or a favourite night club appeared to present few challenges to participants in late adolescence or young adulthood. The reasons for this are unclear but are likely to include that at university individuals are more anonymous, there is a greater emphasis on self-direction, and the greater diversity of people attending could also multiply the variety of issues that affect individual academic performance.

One of the major barriers to reintegration across all social contexts resulted from changes to their appearance. Cancer illness and treatment altered participants' appearance and frequently resulted in heightened levels of attention from their peers. Some attention was stigmatizing, for example, when their appearance was ridiculed or they were rejected because of how they looked. But attention could also be lionizing, for example, when acquaintances acted in an overly friendly manner. Either way, heightened levels of attention marked participants out as different to their peers, and made it difficult for them to fit back in. Norms of appearance were especially salient in night club settings. One participant described returning to her local night club with a marked physical change—baldness:

"I got a few lesbian comments here and there like, "Are you a lesbian?" or whatever. "No I have cancer." But apart from that I had strangers just walk up to me and be like good on you for being out and having a drink and you look awesome . . . they'd be "you're a real hero dancing and all that kind of stuff and you have cancer." Self-esteem wise it helped heaps. (Jo, 21; diagnosed at 18, relapsed at 20)"

Meeting New Acquaintances and Forming New Relationships

Young people with cancer face the prospect of making new acquaintances and establishing new relationships while managing the ongoing effects of their cancer experience. Many participants described how the "marks" created by cancer affected the creation and maintenance of social relationships. For some, their cancer experience was inscribed on their body making them easily identifiable and limiting any possibility for managing disclosure of their cancer history. Others who did not have obvious markers, or whose markers had faded as time passed, had to make decisions about their process of disclosure.

This process of disclosure held both benefits and risks for participants. The primary benefit of disclosing the details of one's cancer diagnosis was that, as is the case with any personal information shared in the context of establishing a relationship, it reinforced the sense of trust and intimacy. It also provided greater possibilities for support and understanding. The principal risk of disclosure was that young people did not know how the other person would respond to them and whether they would reject or stigmatize them. They discussed ways of managing these risks by controlling the method and timing of their disclosure.

Avoiding Disclosure

Some participants chose to avoid disclosing their cancer experience to new acquaintances in certain circumstances. For example, they withheld information about their cancer from people they did not know well, who asked intrusive questions about their health at inappropriate times, or who never earned the participant's trust sufficiently to warrant disclosure:

Sometimes I get in an awkward situation, like I have a [new] friend at Uni, and she was following me around, I had to go to the chemist to buy some medicine and she's like, "Why do you take that medicine for? What's that medicine about?" Asking me too many questions about my medicine, [laugh] and I just went, "Oh, I'll tell you next week," and she forgot, so I didn't get to tell her. So I think if people really want to know they'll ask me, so . . . Like she forgot about it so maybe, she doesn't really want to know, so I'm not going to tell her. I'm not going to repeat myself because it's very private and very personal to me. Like it's the big thing for me. (Mahalya, 22; diagnosed at 13, relapsed at 18)

Managing Timing and Method of Disclosure

In each of the age cohorts in this study, disclosure tended to be a consciously and carefully managed process. Those diagnosed in mid-adolescence described disclosing their cancer history to new acquaintances in the company of friends. Some also used humour in their disclosure to new acquaintances. Bill, whose leg had been surgically amputated to treat his osteosarcoma and wears a prosthetic leg, disclosed his cancer history in this way:

We even tricked one of [my new] friends. I went to another room and then made a loud noise and I went down on the ground and then everyone was in on it except for this one guy and he came in and said, "What happened," and I had twisted my leg around so it looked like [laughs] cause I was wearing really long pants so he couldn't tell and I was just screaming my head off and he almost cried [laughs]. (Bill, 18; diagnosed at 16)

In contrast, participants diagnosed in older adolescence and young adulthood disclosed their cancer history to new acquaintances one-on-one. The risk was no different for older participants than it was for younger participants, but the potential benefits of sharing were to deepen intimacy with a new acquaintance. For example, Mahalya chose to tell her new boyfriend about her cancer experience while they were out on a date:

I thought, I really like this guy, and I want to be honest with him, and I think it's a—I feel like it's a big ask for me to have somebody that close in my life and for them not to know, or, sorry, no, to have them know that. . . . I think I might've told him on our first or second date. . . . I just wanted to be really upfront. I just told him that I had cancer. . . . When I saw him, I said, "Do you want to know why I saw—to see my doctor today?" and he said, "Yeah," so I told him. (Mahalya, 22; diagnosed at 13, relapsed at 18)

Losing Control of Disclosure

Participants lost control of the timing and content of their disclosure when other people made the disclosure on their behalf. This was distressing for different reasons. For example, Alexis objected to her father disclosing her cancer experience because she thought he told the story in a boring way.

Well dad normally tells people [laughs]. What do you think of that? Well it's okay like the first time you hear it, because like when I meet someone and he's there he goes oh this is my daughter Alexis and then he starts telling the whole story of the diagnosis and I'm like oh come on, I've already heard this story so many times. (Alexis, 16; diagnosed at 14)

In contrast, Mahalya objected to both the timing and content of a friend's disclosure of her cancer experience because she felt her friend breached her trust:

I had a really good friend and she used to tell everyone. I was so shocked that all these people had, that never, that don't know anything about me know such private information. It's really private and for, it's actually offensive to do that. "You have no right to be telling stuff like that to people," and just because you think it's so inspirational. (Mahalya, 22; diagnosed at 13, relapsed at 18)

Establishing and Developing New Relationships

For older adolescents and young adults in romantic relationships, the ongoing effects of cancer had to be accommodated into the daily routines of their relationship. For example, ongoing medical surveillance and monitoring caused participants anxiety, which manifested as social withdrawal or

short-temperedness. These responses were potentially destructive to new romantic relationships and participants learnt to communicate their feelings to limit possible adverse effects:

I'm trying to learn to communicate more; I haven't been the best communicator so trying to be really open and actually just saying, "I have an appointment, I'm getting quite scared. Sorry if I take it out on you." I have to sort of express that. (Linda, 22; diagnosed at 21)

Others reported that their partners reciprocated their efforts to communicate effectively:

When I do go for blood tests I do talk to him and a little bit about it but just tell him that I'm scared of what's going to happen and he always just says, "We'll deal with it if it happens. When it happens." . . . But I know, he's told me it scares him to think about it as well. He's told me that. (Erin, 24; diagnosed at 10)

For some young people who commenced romantic relationships after treatment had finished, sharing concerns around fertility were a major preoccupation. Interestingly, both actual and assumed infertility required participants to negotiate ways of accommodating cancer into their new romantic relationships. For example, Mick and his wife were contemplating dealing with the demands of in vitro fertilization (IVF):

I can still actually have children of my own in that sense. So, yeah, in the next few years we'll look at having children but we've just gone through that working out the whole fertility clinic and IVF process. (Mick, 29; diagnosed at 14)

Other participants found themselves to be fertile when they had been told by their treating medical teams that they were infertile. These young women and their partners had to manage an unexpected pregnancy. For example, Sharni's boyfriend participated in making decisions about the birth of their child when Sharni became pregnant when she was 18 years old:

And so that's when my mum and (boyfriend) decided that it would be safer if I had the caesarean because I was off on the drugs. I wasn't really able to make the right decision and I, like I said, "What's going to be better?" and they both said, "Probably the caesarean." (Sharni 20; diagnosed at 15)

Discussion

Our findings indicate that cancer illness and treatment profoundly changes relationships between young people, their parents, and peers and influences the way that young people establish and develop relationships with new acquaintances. While the impact that cancer has on relationships changes according to the relationships that are most salient at different stages of adolescence and young adulthood, in all situations and in all relationships the experience of cancer is important because it marks them as "different" both in terms of how they were before diagnosis and by comparison with others—including their peers and new acquaintances.

Participants in our study spoke of their cancer experiences as a complex phenomenon—being positive and negative, as one of gain and loss, and of conferring benefit and disadvantage. In many ways these descriptions were consistent both with theoretical perspectives of human development that emphasize linearity and predictability (Arnett, 2000; Erikson, 1968) and with empirical data regarding the experience of cancer in adolescence and young adulthood. Findings reported in previous studies—challenges to independence; the disruption of the "normal" developmental trajectory from childhood to adulthood (Grinyer, 2007; Hokkanen et al., 2004); the impact on academic achievement; the experience of social disadvantage, bullying, and stigmatization (Hilton et al., 2009; Lahteenmaki et al., 2002); and the impact of infertility (Katz, 2007) as a result of cancer

treatment—were echoed by our participants. And remind us that the experience of cancer can be profound and negative (Mattsson, Ringner, Ljungman, & Von Essen, 2007). But the experience of cancer may also be a positive one—providing a new appreciation of life, enriching relationships with parents and friends, and providing a purpose, meaning, and direction in life as a consequence of one’s confrontation with death (Abrams et al., 2007; Mattsson et al., 2007).

Our participants’ experiences of growing up with cancer also seemed aligned with “late-modern” conceptions of nonlinear or cyclical transition through adolescence and young adulthood (Horowitz & Bromnick, 2007; Wyn & White, 1997). Their relationships and states were dynamic; they moved “back and forth” between social settings, between independence from parents and dependence, between social integration and isolation. Young adults described challenges in (re)establishing independence from parents because they had to negotiate with their parents to regain the independence they had once held. Participants in early or middle adolescence experienced greater challenges transitioning back to their usual social worlds. Their removal from, and partial or incomplete return to, school marked them as noticeably different—a difference that could be the focus of attention, support, contestation, or alienation. Transition, therefore, was not simply delayed but completely transformed.

The experience of cancer also appeared to have a paradoxical effect on development—accelerating and arresting it at the same time. Participants in early and middle adolescence experienced accelerated development when relationships with parents became more like those between 2 adult friends than those between a child and parent. They also experienced accelerated development when they acquired greater wisdom and insight into life’s problems and into their inevitable mortality than their peers. But at the same time, participants experienced arrested development when their physical capacity was reduced by illness and treatment and when they fell behind their peers in their academic progress through school and university.

In the stories recounted by young people in this study, it is clear that these dynamic transitions need to be accommodated into relationships between young cancer survivors, their parents, peers, and new acquaintances. And this is not a simple thing because in relationships, accommodation requires reciprocity—a process of give and take. We saw this in new romantic relationships when young couples negotiated what they expect of each other in terms of commitment to ongoing health care and, later in a relationship, when they decide whether and how to have children.

Concluding Remarks

Cancer has an enormous impact on young people—transforming forever who they are. It is also immensely disruptive—challenging many aspects of young people’s lives and relationships. But it is a mistake to see it simply as a “focal,” specific disruption to linear, progressive transitions from childhood to adulthood. For cancer is a complex social, relational, interpersonal, and continuing influence on people’s lives and so it creates both difference and the necessity for accommodation. And this is a dynamic process that requires reciprocity, flexibility, and adaptability not only in the survivors of cancer but in the relationships that they have and that they make. Because the challenges associated with cancer illness, treatment, and survival may take months or years to overcome and may be lifelong, young people who survive cancer and their parents, peers, and new romantic partners must collaborate and negotiate how they will accommodate the ongoing effects of cancer into their daily lives.

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