Journal of Pediatric Oncology Nursing
2017, Vol. 34(4) 295–308

DOI: 10.1177/1043454217697669
journals.sagepub.com/home/jpo
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"A Tribe Apart": Sexuality and Cancer in Adolescence

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Abstract

This qualitative study employed hermeneutic phenomenology and narrative inquiry to examine the topic of sexuality and adolescents with cancer from the perspectives of survivors who had experienced cancer as adolescents. This investigation examined the potentially sensitive, disquieting, and often taboo issue of sexuality in the interest of optimizing wellness in young people, and, ultimately, in the health of adults. Understanding the adolescent body as a sensitive, sexual, and developing self can enrich our understanding of adolescent cancer and promote best health care and practices, examining ways that we might mitigate the long-term effects of arrested or delayed development of sexual identity. In this article, we discuss phase 1 of the study, which used hermeneutics as the method of inquiry. Findings included a general experience of adolescents having a sense of "losing themselves" while at the same time finding themselves in a new light. Other findings include the connection between sexuality, self, and identity; the unique "tribe" of adolescents with cancer; the necessity for sexuality to take a backseat to cancer; the changing mirror images from self and others; sexuality and fertility; and, ultimately, that sexuality is a relational experience.

Keywords

adolescents and young adults (AYA), hermeneutic research, sexuality, adolescents

> They (adolescents) are labeled and classified like so many phyla in the animal kingdom, by how they look and how they act. Theories abound on how to manage them, fix them, and improve them, as if they were products off an assembly line: just tinker with the education system, manipulate the drug messages, impose citywide curfews, make more rules, write contracts, build more detention centers, and be tough. Maybe if we just tell adolescents to say no, no, no to everything we disapprove of, maybe they will be okay. But the piecemeal attempts to mend, motivate or rescue them obscure the larger reality: *We don't know them.*
>
> —Hersch (1999, pp. 13-14, *A Tribe Apart*)

Adolescence is a time of immense change, development, and adjustment. When cancer is factored onto this experience, it is possible that developmental issues typically experienced in adolescence become eclipsed or refracted by the disease experience. Adolescents are in many ways, as Hersch (1999) suggested, "a tribe apart" (pp. 13-14), and adolescents experiencing cancer are yet another tribe within the tribe.

The ways that young people's sexuality and self-image are affected by cancer and treatment remain largely overlooked in clinical research and practice (Tindle, Denver, & Lilley, 2009). Sexuality is the experience of oneself as a sexual being and the behaviors that arise from sexual identity and experience. Complications with the development of sexual identity and healthy sexuality have lifelong and serious ramifications such as relationship difficulties, fewer meaningful sexual relationships, and sexual and social delays or deficits (Bancroft, 2002; Dietz & Mulrooney, 2011; Eccles et al., 1993; Hyde & DeLamater, 2008; LeVay & Valente, 2003; Sameroff, Lewis, & Miller, 2000; Stinson et al., 2015; Tindle et al., 2009). During adolescence, a large portion of self-esteem is derived from the active crafting of sexual identity. For adolescents with cancer, treatment regimens may compromise physical appearance, self-esteem, body image, and emerging sexuality (Bancroft, 2002; Bolte & Zebrack,

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2008; Dietz & Mulrooney, 2011; Eccles et al., 1993; Epelman, 2013; Hyde & DeLamater, 2008; Jervaeus, Nilsson, Eriksson, & Wettergre, 2015; Kelly, 2013; LeVay & Valente, 2003; Sameroff et al., 2000; Stinson et al., 2015; Tindle et al., 2009). Establishing a positive sexual identity is further complicated by missed or delayed opportunities to develop interpersonal relationships, explore a sexually maturing body, and developing body image differently from peers without cancer.

In this study, we investigated sexuality of survivors who had experienced cancer as an adolescent. Using hermeneutic phenomenology and narrative inquiry as research methods, we interviewed 10 participants and analyzed data in the hermeneutic tradition for phase 1 and, in phase 2, we used narrative inquiry as our method of inquiry. In this article, we report on phase 1, the hermeneutic phase of our study. Our research question for the study was the following: How might we understand the complexity of issues of sexuality, sexual development, knowledge, expression, and identity in a population of young adult survivors who experienced cancer as adolescents?

Literature Review

Adolescence is the pivotal transitional period between puberty and adulthood encompassing ages from 10 to 24 years (Sharpe, 2003). The word adolescent is figuratively described as "to be nourished, to grow up" (Online Etymology Dictionary, n.d.), a kind of metamorphosis that involves biological, social, and psychological change. With this in mind, tasks of adolescence include differentiating self from parents, developing comfort with one's own body, and building new and meaningful relationships with others of the same and other sex. The fulfilling of age-specific developmental tasks in childhood and adolescence is of great importance to adjustment to adult life (Sameroff et al., 2000).

Sexuality in Adolescence

During this often-turbulent time, puberty occurs and sexual maturation begins. Sexuality is the complex interrelationship that emerges between biological sex (whether one is male, female, or intersex), physical and physiological mechanisms of the sexed body, sexual identity (understanding oneself as a sexual being), desire (the experience of an external sexual object), sexual orientation (the preference for sexual object, such as same or other sex), and the capacity for sexual expression (acting on desire and orientation) (Hyde & DeLamater, 2008; LeVay & Valente, 2003). The elements that make up human sexuality are not fixed, but in flux, and take on different forms in concert with the many other features of self and social world (Hyde & DeLamater, 2008; LeVay & Valente, 2003; Weeks, 2007).

There is much that remains to be understood about interactions between biological, cultural, and psychosocial features of sexuality. This complex and often confounding time of development influences physical appearance, self-esteem, self-identity, body image, sexual needs, desires, values, and social expectations and experiences (Evan, Kaufman, Cook, & Zeltzer, 2006; Sharpe, 2003). The World Health Organization defines sexual health as a state of physical, emotional, mental, and social well-being related to sexuality. As such, its development requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having enjoyable, pleasurable, and safe sexual experiences (Evan et al., 2006). Self-awareness and body awareness are central components in the emergence of sexuality, sexual health knowledge, and a healthy sense of self-in-world.

Sexuality in Adolescent Cancer Patients

During adolescence, a large portion of self-esteem is derived from the active crafting of sexual identity (Eccles et al., 1993; Gavaghan & Roach, 1987). Cancer treatment regimens may compromise organ function and cognitive or motor activity as well as significantly affect individual physical appearance, self-esteem, body image, and emerging sexuality (Abrams, Hazen, & Penson, 2007; Stinson et al., 2015; Weeks, 2007). Different sources for sexual health knowledge, missed or delayed opportunities to develop interpersonal relationships, and navigating body image differently from peers without cancer can further complicate establishing a positive sexual self for adolescents with cancer (Carpentier & Mullins, 2008; Epelman, 2013; Evan et al., 2006; Jervaeus et al., 2015; Stinson et al., 2015). When an adolescent with cancer spends large amounts of time in a hospital setting or at home, sexual knowledge may be transmitted and acquired very differently, or not at all.

What emerges in this experience of being an adolescent that is overlapped by a cancer experience might be thought of as a "marginal" sexuality (Raoul, Canam, Henderson, & Paterson, 2007). In adolescent cancer care, the emphasis on recovery of the physical body can eclipse other developmental concerns that have long-term significance for the adolescent. Thinking about sexuality in adolescents with cancer is difficult because, in some regards, it remains a social taboo to discuss young people in sexual terms. Furthermore, cancer itself, as well as treatment for cancer, can lead to an interruption in the formation of a sexual self; in fact, cancer has been equated as being a master of "identity theft" (Fiedler, 2011). A treatment that sustains life can also alter how that life

may be lived, meaning that adolescent sexuality in the context of cancer care may not fit with conventional stories of sexual maturation (Raoul et al., 2007). For the individual, these differences become concerns about identity and the crafting of sexual maturation. Young people with cancer are not yet fully sexually mature; their illness trajectory often threatens sexual maturation and sexual identity and, worse perhaps, few talk about it (Bolte & Zebrack, 2008).

Psychosocial care is one way to help young people address sexuality issues. Though valued in principle, psychosocial care often continues to be viewed as adjunct to the primacy of medical intervention (Carpentier & Mullins, 2008). However, the development of sexual identity is foundational to the rest of the adolescent's life. An investment in understanding ways of supporting adolescents with cancer is therefore preventive; it is an investment in the future wellness of the adult as a healthy, contributing, and fully functioning member of society. As sexuality emerges into the adolescent body, it is interrupted by cancer, and expressions of sexuality can be put on hold. Clinicians (as well as patients and family) can take a "disease first" perspective, which may make discussions and research about sexuality in this population seem gratuitous (Carpentier & Mullins, 2008). We know, however, that survivors of childhood cancer have fewer meaningful sexual relationships than their peers who have not experienced cancer (Dietz & Mulrooney, 2011), and that they experience delayed physical, psychological, and social development in their sexuality (Stam, Grootenhuis, & Last, 2005). As we have argued, the development of a healthy sexual identity is complicit in long-term mental health and social development and, because cancer interrupts this development, it is incumbent on health care providers to better understand the sexuality needs and experiences of this group.

Gaps in the Literature and the Significance of This Study

Studies on biological effects of cancer such as fertility (Carpentier & Fortenberry, 2010; Stinson et al., 2015; Zebrack & Isaacson, 2012); high-risk sexual behaviors or anxiety about sexuality (Sklar et al., 2006); body image (Larouche & Chin-Peuckert, 2006; Shroff-Pendley, Dahlquist, & Dreyer, 1997; Stinson et al., 2015); peer relationships (Roberts, Turney, & Knowles, 1998; Stinson et al., 2015; Tindle et al., 2009; Zebrack & Isaacson, 2012); and broader developmental issues (Jervaeus et al., 2015; Kelly, 2013; van Dijk et al., 2008; Zebrack, Foley, Wittman, & Leonard, 2010; Zebrack et al., 2002) have all contributed useful findings about particular aspects of adolescents with cancer that directly or indirectly support our knowledge of sexuality in this population. The overall picture, however, is partial and fragmented.

Issues of adolescence are sometimes addressed retrospectively after long periods of time, for example, inquiring into marital relationships in adulthood among people who had cancer in adolescence (Zebrack & Chesler, 2001), or examining variables among adolescents who previously had cancer in childhood (Zebrack et al., 2010). These various and valuable perspectives circle around the actual experiences of adolescents or young adults who experienced cancer in recent years. This limitation in the existing research is borne out in another way by studies that have focused on caregivers, and possible barriers or resistance to raising questions of sexuality with adolescents who have cancer (Bolte & Zebrack, 2008; De Vries, Bresters, Engberts, Wit, & van Leuwen, 2009; Kelly, 2013; Stinson et al., 2015; Zebrack & Walsh-Burke, 2004). These studies have recognized the importance of finding ways to bring issues around sexuality into the care of adolescents with cancer, and one study described a pilot intervention to do so (Canada, Schover, & Li, 2007). Stinson et al. (2015) completed the most comprehensive study to date on adolescents with cancer and issues of sexuality, relationships, and fertility concerns. Interestingly, in a review of the literature about psychosocial interventions for adolescent cancer patients (Seitz, Besier, & Goldbeck, 2009), only a few studies (Canada et al., 2007; Epelman, 2013; Jervaeus et al., 2015; Kelly, 2013; Stinson et al., 2015) addressed sexuality directly. This study adds to the scant body of literature in this area from an interpretive perspective and research approach.

Research Method and Design

This research received ethical approval by the Conjoint Health Research Ethics Board at the University of Calgary (REB13-1218). The research adhered to the principles of the "Tri-Council Policy Statement: Ethical conduct for Research Involving Humans" and to the Alberta "Health Information Act." Since all participants were older than 18 years, parental consent was not required.

Research Method

In phase 1 of this study, which is the phase we discuss in this article, we employed a sophisticated method of research well documented under the umbrella of phenomenological studies: hermeneutics. Hermeneutic inquiry is described as the philosophy, practice, and theory of interpretation and understanding in human contexts (Moules, McCaffrey, Field, & Laing, 2015). As a research method, it attends to the particulars of experiences to arrive at deeper understandings of how people experience the angst, fortitude, and capacity to learn to live alongside

life events (Gadamer, 1960/1989; Koch, 1996; Moules, 2002; Moules et al., 2015; Smits, 1997). Unlike some qualitative methods, hermeneutics is focused on understanding in the context of someone's life; it does not result in thematic reduction, semantic codes, constructs, or theories; nor is it focused on explanation. Hermeneutics is an act of sensemaking and therefore understanding (Moules et al., 2015).

Recruitment of Participants and Data Collection

Ten survivors of adolescent cancer were recruited and interviewed for this study. The age range for the participants at the time of diagnosis was between 12 and 20 years; at the time of interview, ages ranged from 19 to 26 years. Seven of the participants were female, and 3 were male. Diagnoses included brain tumors (n = 2), Hodgkin's lymphoma (n = 2), acute myelocytic leukemia (n = 2), acute lymphoblastic leukemia (n = 1), sarcomas (n = 2), and aplastic anemia (n = 1). It is noted that aplastic anemia is not a cancer but the participant did receive a bone marrow transplant and had similar issues as the other participants; therefore, ethical approval was granted to include this interview. Participants self-selected in response to advertising through the Kids Cancer Care Foundation of Alberta (KCC) on their website, through the teen leadership group of the Foundation, and also through word of mouth, sometimes referred to as a snowballing technique, within the community of cancer patients and survivors connected through KCC. All participants were off initial treatment, although some were having treatment for side effects; all participants who volunteered were interviewed. Other demographic details around length and kind of treatment, socioeconomic status, and specific other factors were not collected and cannot be reported because our intent was not to create a typology of experience.

In hermeneutics, researchers aim for a richness of data through exemplars of experience, otherwise known as purposive sampling (Koch, 1996; Morse & Field, 1995; Moules, 2002; Moules et al., 2015; Sandelowski, 1995). The number of participants required for interpretive inquiry is difficult to predict prior to the beginning of the study, but typically 6 to 15 participants provide sufficient data for analysis (Moules et al., 2015). Each participant was interviewed once. The interviews lasted 1 to 1.5 hours and were open ended, conducted in person by an experienced member of the research team, and audiotaped for transcription (Kvale & Brinkmann, 2009). An interview guide was not used; however, a few questions were asked of each participant such as "How did you learn about sexuality?" Interviews in hermeneutic studies take on a more conversational tone. They are purposeful but not scripted, and involve deep listening and responsiveness, engaging the participants in a discussion of the topic under investigation.

Hermeneutics attends closely to a topic or phenomenon that is informed by participants' experiences. As such, "the participants in the study are not the topic but are chosen to bring their knowledge about, and to, the topic and expand our understanding of the phenomenon" (Moules et al., 2015, p. 123). Participants are therefore not individually described or identified as connected to the quotes as the intent is not to represent them as individuals or conserve their stories; the intent is to shed light on the phenomenon under study.

Data Analysis and Interpretation

Analysis in hermeneutics is synonymous with interpretation, which occurs in the complex dialectic of research interviews with participants and interpretive memos written by researchers based on the transcripts of the interviews (Moules et al., 2015). The dialectical movement between transcripts and memos yielded new understandings for this study. We did not use qualitative research software for interpretive purposes (recognizing it can be used effectively for data organization or coding if coding is employed) because interpretation is not based on repetition of themes but rather on particular expansion of data that furthers understanding of the topic. Software data analysis used for interpretation of data is unable to recognize the particular and the hermeneutic interpretation of the valuing of the individual "case" (Moules, Jardine, McCaffrey, & Brown, 2013). We arrive at interpretations through a careful reading of the data, looking for instances that resonate and offer portals to understanding the topic. In the vernacular, we look for statements that "have grab," in that they catch our attention, shed light on the phenomenon, and invite reflection and consideration. These statements and instances are then developed into fulsome interpretations, with supporting data as well as any other supporting literature, which leads us to an examination of the implications of these interpretations in understanding the phenomenon under investigation.

The interview transcripts were interpreted by 3 of the authors (the hermeneutic researchers). A dynamic and evolving interaction between the whole and parts of data characterizes analytic and interpretive movement towards understanding that opens up new possibilities (Moules et al., 2015). Because the interpretation lies with the researchers, the method does not involve what is known as "member checking." In other words, it does not need to be validated by the participants but rather the researcher "thinks with the data" (Steeves, 2000, p. 98), making it possible to fulfil the "obligation of the researcher to go

beyond his or her data, but not in the sense of reaching conclusions unrelated to the data or unjustified by the data" (Steeves, 2000, p. 97). Put another way, the truthfulness of hermeneutic research does not rely on the nod of agreement from informants, but rather on its capacity to open up and extend the landscape of understanding. The rigor, integrity, trustworthiness, and credibility of the interpretations are put to the test by the communal discussion of the research team and consultation with others in the field to read the interpretations looking for resonance, concurrence, and recognition of the relevance of them (Moules et al., 2015).

From Data to Interpretations

In this section, we present the findings of phase 1 of the study, written as interpretive accounts. In hermeneutics, the interpretations are expanded into a discussion, rather than having the discussion as a separate section. Our interpretations weave the voices of participants with the interpretive reach of hermeneutics. Interpretations extend from and return to participants' experiences in a way that acknowledges, reveals, and extends how we might understand the topic. Participant quotes are presented verbatim and appear either in quotation marks or indented. Ellipses indicate that a part of what was spoken was not included as it was not relevant to the interpretation; line breaks indicate a different participant.

To introduce this section, we summarize the general findings in this study. A broad finding that arose in phase 1 was a very interesting juxtaposition: adolescents experienced cancer as something that robbed them of themselves or at least temporarily led them to experience a sense of "losing themselves" while, at the same time, cancer also helped them find themselves, and create new narratives of themselves as developing adults, some of which includes their sexuality. Other specific findings include the connection between sexuality, self, and identity; the unique "tribe" of adolescents with cancer and their ways to find themselves inside and outside of boxes; the ways that developing sexuality necessarily takes a backseat to cancer; how the cancer experience not only marked them in terms of self-esteem and body image but also marked them with a different maturity than their peers without cancer; how they experienced a poor relationship with their own changing mirror images but also felt their cancer was mirrored in the negative gaze of others; how the cancer experience was attributed to being responsible for who they are today; how cancer and treatments left them with concerns about lingering side effects related to sexuality and fertility; and how sexuality is fundamentally a relational experience—the participants were less concerned about sexuality than they were about forming good and loving relationships now and in the future. We will speak to each of these interpretations with examples from our data.

Sexuality and Self: Necessity and Identity

Sexuality was memorably defined by one participant who, like some of our participants, was a high-functioning athlete prior to diagnosis: "It's honestly accepting who you are and being comfortable in your skin as a person." In some very direct, philosophical ways, the participants adhered to a claim that sexuality in its various forms was normal. Though individually found and expressed, it was a mode of finding or reclaiming one's self, of feeling normal again and, in some cases, it was a part of the healing process.

> Sexuality is loving your body, you know, and that's why there's a connection between mutilation, self-harm, all those things, um, but yeah that's fundamentally, yes that is what I am saying, that sex is a way to heal your body and your relationship to yourself . . . sexuality is a great way to heal your relationship with your mutilated body . . . it has the potential to heal and it has the potential to harm. Sexuality can be a very, you know, tumultuous idea and concept and act. Especially if you go about it in the wrong way, you know? Um, and what that means for you and what that means for someone else could be different things, and it's impossible to judge. It's impossible to say this will help you, this will harm you.

For one participant, this sense of healing extended to sexuality (as expressed through sex) was like the basic necessities of life:

> I think sex is synonymous with food and water, um, in terms of what we need. I mean, yes and no—you can go your whole life and not have sex and survive. Um, but as like, the sort of Buddhist, religious, you know, spiritual side, I think the soul is something that needs to be fed, and I think sex is a huge part of that. I mean our bodies are designed to quote–unquote "evolve," whatever, to receive pleasure…So cancer was hell, it was a horrible experience . . . I think sex and spirituality are very tied, and I think that being sexually healthy and having a very positive and open view of sex is overall beneficial just because it gives you so much. . . . It's a very intimate way of getting to know people and yourself and I think that's a key part of humanity, and this idea of connection and being with people, but sex feeds your soul.

The sense of healthy sexuality is more than feeding the soul. A sense of a healthy, sexual self is a relational conduit that allows for connection between self and other:

> All I wanted was to get healthy enough so I could wean off enough of the medication so I could get back to feeling like me and honestly, I wanted to feel fit because I wanted to be

> an athlete again. I wanted to feel fit because I wanted my self-image back and I wanted to go back to a normal sexual relationship. You know?
>
> Though I wasn't as strong or as good of an athlete as I was, I did feel good about my self-image and when I looked in the mirror I was like, "OK, I see me again." That freed me up for sex.

"Strange Cases" of Adolescent Sexuality

Although the participants in this study spoke about sexuality in ways that did not surprise us, they also spoke about sexuality in relation to cancer in ways that started to reveal tensions, contradictions, and complexities in their experiences. In this interpretation, we explore some of the strangeness that arises from these experiences. These "strange cases" of adolescent sexuality show how the stark experiences of adolescent cancer are lived alongside many of the ordinary concerns and worries of adolescents. We are not suggesting that these young people themselves are strange cases, but rather that they are experiencing a strange case. We are reminded that the interpretive endeavor seeks to make the familiar strange, as it also makes the strange familiar. In this way, our understanding of experiences, such as those of adolescents with cancer, may be interrupted, challenged, shown differently, and extended. Strange is not a label, but rather a call to attention to the differences and varieties of experiences. It is not until we open the "case" that we can notice its contents are not what we expected, or arranged in the order we predicted.

We asked all participants about how they learned about sexuality, and most said through the Internet. It was here too that they learned about different orientations and opened up the possibility that not everyone has to fit into normative boxes.

> The Internet. School didn't teach us about the things that are important like the different number of sexualities that there are, and you look in the media and stuff and you see heterosexual, homosexual, bisexual . . . but they don't talk about people who might have different thoughts like asexual, pansexual . . . and all of the different varieties. I tried to do research on my own to figure it out. . . . There's not just one box. People don't always fit into those boxes and sometimes it can vary from day to day. . . . I think that really we should be able to discuss it with our pediatricians and everything and if we feel these feelings before puberty or whatever. I think just bringing it up would help a lot.

The idea of fitting into boxes was particularly interesting, given that some participants resisted being boxed into particular identities or behaviors, while other participants experienced doubt when they felt they were pushed out of a box to which they wanted to belong. Another participant said,

> Well for one, my sexuality I define as, homosexual, I guess. I think that cancer played a huge role in the development of my sexuality . . . there are certain factors that influence you throughout your life. So, that's womb-included, and then certain social experiences such as relationships developed with friends, or, possibilities, the relationships you form with strangers, certain major developmental delays or events, and cancer plays into that role for me, because cancer happened at puberty and delayed puberty. Cancer affected me in the sense of my sexuality because I was in a vulnerable position, being taken care of by attractive women nurses . . . at the peak of my sexual development, or the beginning of it, and that it sort of laid the groundwork to this predisposed stuff that I was talking about earlier about being born being gay. I think that cancer shaped my predisposal to being gay, does that make sense? Nurses form more of a relationship than doctors, I remember distinctly thinking like, being attracted to a nurse and thinking "oh my God, I'm gay."

For some, stepping outside the box also allowed them to acknowledge not having sexual feelings or preferences:

> Personally, I've never felt any distinct sexual stuff…because I'm not really attracted to males or females either way . . . don't know if that could possibly be because of my experiences or if it's just who I am. I'm just a good example of a strange case. I guess I can understand the aesthetic attraction, attractiveness, male or female, but I never felt the urge to date, to have sex, or anything like that.

Learning about sexuality and experiencing it are two different things, but there is a connection in how one first learns and from where one learns, to how one enters into the experience of it. In some ways, the young people in the study are, as the above participant expressed, having experiences of feeling like "strange cases." Their experiences are at odds with the norm, and they learned about their sexuality in unconventional ways. While the participants talked about being inside and outside of "the box," we would offer that these boxes are, themselves, strange cases. A case contains that which we put in it, but a full case is also more than the sum of its parts.

Cases expand and contract depending on what we put in and what we take out. Always though, the case must be in balance. It must be the correct weight and the correct dimensions. The addition of cancer to one's case necessitates the removal of sexuality if one expects the case to meet the correct weight. Strange cases are different. They expand and contract in unexpected and unpredictable ways. As our participants moved between their "boxes," we imagine them filling strange cases of sexuality, cases that both weighed participants down with wondering about their direction, as well as provided the necessary

elements for them to travel toward their own developing sense of a sexual self.

The participants in this study were very open in talking about this process, and how it had and was unfolding for them. During some of our interviews in our conversations about learning and fitting into normative boxes of societal expectations, we noticed how participants both resisted being put into a sexuality-related box, yet also experienced concern when their experiences and cancer treatment precluded them from being able to claim their place within it. In the context of these discussions, participants were quick to remind us that, as important as sexuality is, many of them left it out of their case: It was not their primary concern while they were in the middle of treatment for cancer.

Sexuality Taking a Backseat to Cancer

For many, if not most of the participants, sexuality was secondary to the desire to live and to be cured of cancer. In this sense, sexuality then took a backseat to more immediate life and death concerns.

> Before I went through chemo and everything, it never really occurred to me that there were more than one or two sexualities. That I could have died, everything major going on just made me realize that things like that don't really matter even though people make it seem like it does.

Another participant said,

> I think referring to Maslow's Hierarchy of Needs pyramid, I don't even know if sexuality is on there, nor do I really agree with the entire theory as a whole, but if you were to use that sort of model and put sexuality on there, you know, fighting for your life and for cancer is going to take hold and pushes everything else to the side. So, it becomes less of a priority I would say.

Another participant drew our attention to the very immediate concerns of many young people with cancer:

> Dating was a thought but kind of in the back of my mind. I was in grade 9 or grade 10 for that matter, I was more concerned about dying, you know? Back then I had an oncologist and a couple of surgeons trying to save my leg . . . keep me alive . . . with how urgent things were, I just don't think it was much of a focus, my sexuality. Or my sex life and the fact that I was gonna be reproductive in the future. You know, I could end up on testosterone replacement therapy in the future. I just don't think it was an area of concern.

What some said were not their concerns at that time came later, which fits with the literature around future adjustment, but the concerns in the moment were to live. Sexuality was not even in their peripheral vision during this time. It suggests to us that young people may need professionals to be attentive to these issues, even allow sexuality to sit in the backseat and help the young person have a conversation about sexuality in a way that does not distract the driving or become overwhelming.

Being Marked, Being Neutral: Self-esteem and Body Image

Cancer leaves a mark on everyone concerned. In this study, we heard of these physical markings, and they were often spoken about as a reflection that is offered back by a mirror, a reflection that does not match how the adolescents remembered or saw themselves in their own minds. The markings too were emotional and psychological, as body image often equated to self-esteem and, in many cases, these translated into a lack of confidence in their physical bodies that resulted in a lack of confidence in their sexual image and sense of attractiveness. One person offered this reflection: "I was more comfortable in expressing myself sexually before the diagnosis . . . now I feel as though I've lost a lot of my ability to express myself sexually." Mirrors that were once friends became foes as the adolescents attempted to "see" themselves again, hoping to recognize and find themselves in the mirror and being met by someone they did not know; nor did they like who they saw.

What Mirrors Reflect and What Mirrors Construct: "All the Girls Had Curly Hair and I Had a Hat." Mirrors serve a particular purpose. A mirror offers a reflection, an opportunity for self-admiration, personal scrutiny, and they offer reassurance that what lies on our outside matches our vision and expectation for ourselves. Strangely, mirrors also contain surprises and challenges. Standing in front of a mirror can become a site of the unexpected when our sense of who and how we are does not match what we see. Mirrors also hold memories; they are more than a simple reflection. They remind us of what they once reflected. Even as people age, we often carry the image of ourselves as younger than we are. Perhaps we also remember our concerns with blemishes, nose size, and dull hair. The mirror is harsher for adolescents with cancer than for the "average adolescent." Adolescents with cancer can literally "lose" the self they knew, and the mirror confirms this loss. As much as the mirror offers the adolescent with cancer a reflection, it also represents a fundamental interruption to sense of self. For some participants, what they saw did not reconcile with what they knew, believed, and felt about themselves. A mirror's reflection potentially negates memories of who they were. What some saw made it difficult to even find facets that confirmed they were looking at themselves.

> It's almost like looking in a mirror and not recognizing who you're looking at.

Several of the participants were competitive, high-level athletes prior to the onset and diagnosis of cancer. Before cancer, they defined themselves as athletes and their bodies reflected this. With treatment came weight gain, weight and muscle loss, hair growth, and hair loss. When they described their precancerous bodies, it was with confidence and pride.

> I was strong. I was fit. I looked good. That gave me a lot of confidence. My self-image was high because of my perception of my body. And it's the first thing people see. They see your body; they don't see who you are. . . . My self-image was high in regards to my sexuality. I was really comfortable with it. And excited about that kind of thing because I was happy with how I looked.

Another participant said,

> Because I had defined myself as an athlete. And being really proud in having a body and being really confident in the fact that I was a really strong, fit woman. And I don't have that anymore.

This definition of self changed after cancer for all the participants, and not just the athletes. For one participant, (s) he felt like a "neutral being," being neither masculine or feminine and lacking confidence as a result. A nonathletic participant extended this idea of neutrality and told us:

> I was sick at the time that we sort of go through first communion at my church, and all the girls had beautiful curly hair and I had a hat. I don't feel as beautiful as these girls, not as beautiful, oh what else . . . maybe not as girly? Like, that together with the hair loss, um, kind of made me this kind of neutral thing, like not a boy but this not-really-a-girl either.

Another participant said,

> There were definitely times when I, you know, felt like I was not as much of a guy or a man I guess . . . like needing help just to get upstairs and needing help to get out of bed. I didn't feel tough for many years after.

These insights stand alongside accounts of adolescence in which cancer does not feature. Adolescents express concerns for their appearance as well as benchmark and compare that appearance to others. There is also, however, a stark contrast because adolescence is not a neutral time; it is a time of excitement, emotion, power, bias, and conviction. Being "not really this or that" betrays a need to understand one's relationship to the boxes that are both craved and resisted, it seems. For some participants, this sense of how one fits was more directly connected to sexuality.

> I'm a lot more conscious of my body . . . a lot more body awareness. Body image is a big part of my sexuality. I could almost say sexuality is the way in which I express my body image. . . . If I feel comfortable in the way my body looks, I feel much more comfortable as a sexual being. There's stretch marks on my abdomen, muscle tone that just left from the steroids. And I'm just a different person which is really disturbing for me.

One participant described not seeing himself in the mirror anymore. Instead, he found his identity in other ways, such as through his work in his new profession. Also, as discussed later, he described the maturation that came with the experience. He said, "I think I matured a lot; I'm not into clubs and parties like others my age." This, though, has made it hard for him to meet someone with the same level of maturity. He felt that reclaiming his fitness, rather than establishing a sexual relationship, would help increase his confidence.

These comments lead us to the speculation that there is something about being proud of the body that survives/ensures a different kind of trial than what happens in athletic pursuits. If pride is located in looks rather than actual endurance for athletes, then there seems to be an implication for practice here, too—work that helps young people regain some confidence and pride in a robust and healthy body.

However, in a world of culturally accepted norms and consumer-driven images of the perfect body, mirrors are rarely friends to most of us. To adolescents experiencing cancer, they can become vicious foes that serve as visual reminders of what (and who) has been lost in the experience.

Others as Mirrors. Participants in this study also found mirrors in other people's behaviors as they reflected back to the adolescent what they believed others saw in them. Even when this reflection was not tangible, overt, or even intended, it was imagined, anticipated, and interpreted as a judgment and a rejection.

> If someone just saw you walking down the street, they would judge you based on how they see you.

> I felt very, very unaccepted by everyone, you know. By having cancer, I was no longer acceptable, I was no longer the teenager that everyone wanted me to be, I was no longer successful, I was no longer athletic; I was merely boiled down to a "cancer kid."

> It's now like I'm scared of being naked in front of people.

The participants powerfully evoke the fear that lies in the reflections they see through interactions with other people:

> I was scared to death of losing my leg. When I relapsed, and had my lung surgeries, yeah, I was kinda thinking, "Yeah, this relapse sucks but what's more terrible is I'm gonna have two more scars on my back; it's gonna add to all the scars I have all over my body already. What if people see them? What will they think? What will I say?"

Sometimes, nothing is said,

> I don't remember having too many discussions on how she [girlfriend] saw me. Like, of course a 15-year-old couple don't have too many in-depth conversations about feelings. I definitely know that she saw me being sick and I know that she saw that I wasn't what I used to be and that I wasn't this buff guy anymore. But I don't think she saw me as less of a person. Maybe she didn't even see me less attractive but being in her shoes, being a 15- or 16-year-old girl, I wouldn't blame her for finding me less attractive. When you're going through chemo, you're not attractive. You're quite ugly.

Much of what we have discussed to this point reflects the capacity of cancer to commit "identity theft," to rob adolescents of a sense of themselves as someone they once knew. Cancer also robbed them of the freedom from scrutiny, be that self or other scrutiny. Losses of self, self-esteem, self-image, and confidence were clear in the interviews, but there was also an element of cancer as the catalyst to a different life experience: a growth and maturity that they attributed to having endured a cancer experience.

Cancer as Formative. The participants were able to make a shift in the interviews to finding the positive effects that their cancer experiences may have had on them. A part of this reflection is perhaps an intrinsic, human inclination to try to make sense of experience and make meaning out of it. For some, this was located in how cancer was part of how they crafted their identities:

> I think cancer makes me more attractive as to who I am as a person, um, because it truly shaped me into the person I've become and I'm proud of the person I've become and I really think cancer was a portal to the, you know, quote-unquote "world of enlightenment" but not necessarily enlightenment, but I see and I can empathize with people to a greater level. This is my own theory of my own self, um, by having that experience that really, you know, pushed me as an individual. Um, so I think that cancer for me can make a great person, or an okay person, but one that sort of can have the potential of being attractive.

For another participant, it was something more akin to resilience:

> Increasing confidence, and self-esteem and body image, and um, hmm, I don't know if it's directly related to the cancer treatment but yeah, but even going through, like, weight gain, weight loss, and the hair and everything, um, I think maybe I've become stronger because of that? Because I've had to cope to deal with, like, issues like that? So I've had to kind of like grow a backbone and learn to be a strong person kind of thing.

Other participants spoke of how cancer contributed to a sense of maturity, either through gaining a different sense of awareness or through learning new ways to engage with people and the world. They said:

> Different level of maturity that came with the diagnosis . . . because when you go through treatment, you are brought to that edge. You see your mortality all of a sudden. And I started to realize that I don't know how long my life is gonna be anymore. People do not make it. People do die. People have to figure out their values: What are those hedges in your life that you want to keep constant…to be honest, if I hadn't gone through what I did, I don't know if I would have found those values as quickly . . . and in finding my values, I found sexuality.

> My passion for people, and making a difference in this world. I wouldn't have found that if I hadn't gone through cancer.

> I've learned to reflect. I've learnt to realize that the past is in the past, because, yes, it happened, but it doesn't define you now, because right now is the present and you have to look forward to the future. And to carry the lessons, but not the burdens with you.

The Leftovers of Cancer: Lingering Concerns

Previous studies on this population tangentially connected to sexuality have often focused on issues of fertility. Most of the participants admitted to having lingering worries of side effects, including fertility, that may affect their futures.

> I did wonder about the side effects of chemotherapy drugs I received and if that had any, um, impacts on you know, my ovaries and my fertility at all and if I'd be able to have children . . . I think fertility is such a huge part of being a woman, and just like being able to have a baby, and it's definitely something I would, you know, I would like to have some children in the future, so, um, I don't know, if it turns out that my fertility is somehow, you know, I'm not able to have children, then I think it would make me feel kind of less of a woman, so, um, just not being able to…provide or give myself totally or something like that?

> We [family] didn't think about it at the time, but it was like freezing my eggs, or extracting from a woman and freezing it for the future but we didn't, but I was in such dire straits that, like, I had a 25% chance of survival, so my dad kind of made the decision to go ahead and start the treatment and we'll worry about that later, so, um, so we didn't do that. So now, once the treatment that I had, um, I don't know if I can have children.

For both the females and males in this study, the biggest issue when considering side effects was the concern about not being able to have children. They said,

> I wish I would have known about the option to freeze my eggs.

> I would say like a possible clinical effect that one of the chemotherapies could have had on me and . . . causing like the hypogonadism and causing low testosterone in the future. And that's something that I do from time to time worry about. . . . I don't see any effects right now, it's not like I've got an anxiety about it, really, but it's something . . . I wonder, like, back to like the whole manliness thing, and stuff.

Side effect worries did linger, but they were not the thing that took primacy in the concerns of the participants in this study. At the heart of all the conversations about sexuality, fertility, body image, change, and growth, lay the core concern about relationships.

Relationships as the "Bone Marrow" of This Experience

Sexuality is not just about having sex. One's sense as a confident sexual being is also relationally based. Sexuality is a component of relational transactions and, in some instances, as we have reported above, sexuality extends to sex and reproduction. For most participants, the issues were not just about learning to be sexual but learning how to be in a relationship.

> I worry that I would be accepted by someone, and have that part of me accepted. I haven't been in any long- term relationship, so I think that's something that maybe comes later on, and is not something that, you know, first thing "hello, I had cancer" and "By the way I might not be able to have children" or something like that? I'm kinda afraid of how I'd be viewed by someone else.

This participant talked of being very affected by not being able to learn alongside and talk about sexual topics with peers:

> My friends were moving on and I had nobody to really talk to about sexual stuff, and having a boyfriend, and you know, what to expect, um, and that was hard. You know, because I did want a boyfriend, and I didn't know how to approach, you know—because in talking to friends, you kind of learn, you know, the . . . I guess skills, of how to meet somebody.

Another participant powerfully evoked the longing for love, lived with an awareness that it may never be experienced:

> I wanted there to be love . . . if I was gonna have sex with someone, I wanted it to be more . . . there's a lot of emotion attached to our sexuality. I was very much hoping to find people to love me . . . looking for a long-term partnership. I realized life is really short and I wanted to share my life with someone. You see your mortality all of a sudden and I started to realize that I don't know how long my life is gonna be anymore. People do not make it. People do die. I looked for love and affirmation that someone else saw who I wanted to be.

Discussion Summary and Implications for Practice

Amid the waiting and wanting to become who they want to be, cancer makes many demands on young people. The participants in this study reminded us that sexuality is only part of that picture. Despite its partial lens, sexuality was a way that adolescents focused on and thought about their own mortality. They experienced an awareness of mortality and other concerns not typically faced in this way during this developmental stage. Sexuality was one way for these young people to explore what was needed for them to be loved, desired, and affirmed. In this very human search for relationships, issues of attractiveness, scars, history, maturity, self-confidence, and self-esteem arose as companions and provocateurs in the search. One might argue that all of us, in the search for relational connections, are accompanied by these concerns, but we have noticed in this study that adolescents who have had cancer experience them as louder, and yet sometimes silenced, companions along the complex landscape of treatment and hope for a cure.

We asked the participants what advice they might offer other adolescents undergoing this experience, and what advice they would offer healthcare professionals. Our implications for healthcare professionals are embedded in the words of the participants who had experience cancer as adolescents. Hermeneutic research does not presume to speak for the other. Instead, we believe the implications or utility of this research lie in a careful engagement with the expertise of participants. It is then up to those working with adolescents to listen to their words and arrive at implications for how they practice with this population in pediatric oncology.

> Tell kids "you're not gonna stay that person. It will get better. Carry the lessons, not the burdens with you. Who you

> are looking at in the mirror, that will pass. And that won't always be you . . .That person you are looking at in the mirror will become who you want it to be if you work on the things that you know will make the difference."

Participants suggested some online resources such as "frequently asked questions" or anything that would make sex less of a taboo. They suggested that social media is the best way to reach adolescents and the more sex is talked about the less of a taboo it becomes.

> I would say it's an issue that's not really explored or thought about in different contexts, and it's usually sort of shamed and pushed to the side, especially in medicine. I generally think that it's very rarely examined and it needs to be paid attention to because it's such an important aspect of humanity and it's something that we don't talk about enough.

> In my ideal world, I would, you know, host clinics or workshops, or when going in to talk to teens being like "how is your sexuality? What's going on there for you, do you have any questions, anything concerning you?" You know, and I mean it's those—I would love to have had just direct question and answer, um, you know, like sex is fine, you shouldn't be ashamed of it. I mean you're at the age now, or whatever, or maybe it's not developing, I mean there are people that are asexual. It would have to be done with a very open and accepting mind, and to judge would completely thwart the entire process. If someone came into me, or if I came into, you know, a doctor's office and I was with a nurse or something and they were homophobic, how harming would that be?

This participant was clear that, while this kind of support could be very helpful, it could also go wrong if it was offered with an intent that was not exploratory, supportive, or that conveyed judgment of difference. Those who had received some input on sexuality also had suggestions:

> It was pretty mediocre [information on sexuality] I don't know if times are changing or not, but like, um, I didn't often talk about the emotional or sexual part of the cancer with anyone in the health care side of things. So, yeah, I definitely, I think more resources would have been helpful. Or even just, like, them, like, directly saying "you know you can talk to us about your feelings around this," or "are you worried about any of these things?"

> Even having that other person to talk to about my feelings, cause then later on, you know, your mother isn't always enough [laughs], growing up . . . so having that someone to listen to you, and maybe, like, normalize it too, say, like, people like, go through this, it's okay . . . maybe offer advice if they have any, but for me I think it's huge just to listen.

> Definitely talking about, like, fertility, um . . . also, I guess about future relationships and how . . . I don't know, like, how to grow more confident in myself, or being able to trust people about sharing that information with them.

> I don't remember a ton of conversations surrounding the fact of how I looked and how much weight I had lost and stuff like that…but I remember having a rough night one time in the hospital and talking to the nurse about it. And there's quite a few nurses in the hospital that I came quite close with. I remember going through Facebook pictures one night before chemotherapy, it was chemotherapy the next day or something. My nurse came in to check on something, and I was in tears because I was looking at pictures of what I looked like before the diagnosis. And I just kept saying, "I was so strong, I was so healthy." I don't remember what exactly her reply was but it was some sort of uplifting comment or "You'll get better or you'll be like that again," something along those lines.

Opening the Conversation

It became apparent that simply opening the conversation about sexuality with an adolescent in treatment can be seen as an intervention. The participants felt that if someone asked them, even if they did not want to talk about it then and there, they would know that this was a person they could go to if questions arose or if they wanted to talk. For some participants, the conversation could be opened by offering readings about sexuality issues. For others, conversations with a trusted other, usually a nurse, were the most helpful sources of support:

> I was definitely someone visual, so I like to have, you know, like a sheet or a like a pamphlet, or anything with something written down on it, and that gets my attention right away . . . I think just kind of, like, some of the nurses were really good at, um, you know, like, sitting down next to you and talking to you about stuff. I think, kind of, there would be that trust, um, with the nurse and being—you can end up feel really comfortable talking about that stuff . . . I think nurses would be a big part of it, and if they can build up your trust and start to talk to you about stuff, maybe even personal stuff of their own, then you feel like you can talk to them about, um, anything.

Importantly, one participant reminded us that, in the midst of treatment, we must not forget the less obvious or more complex dimensions of the person:

> . . . looking into that kind of stuff, asking those questions, because I think a big thing that they forget in a children's hospital dealing with young kids, is, it's teenagers and their sexual function.

This last quote returns us to adolescents as a "tribe apart" (Hersch, 1999). Adolescents are not big children; they are unique in all aspects, including in the cancer

experience. They need to be addressed differently, talked to differently, consulted differently, and questioned differently. The conversations that some adolescents need require the opening of strange cases, they require health professionals to act as mirrors, and they need support as they work out where they can, want to, and do "fit."

In the course of this study, we are reminded that interpretation "offers a plausible and prudent response to something, but it does not offer a final answer" (Moules et al., 2015, p. 135). This study is thus neither an ending nor a conclusive assertion of what adolescents experiencing cancer need. In many ways, qualitative research and hermeneutic research, in particular, is akin to bench science. It discovers. It seeks understanding of experience through direct inquiry from those "in the know." We discover the information, come to understand the topic, and then it is taken to those in practice to use the information as they see fit to change practice. The wise, mature, experienced voices of these participants have a lot to teach us.

Summary

Adolescence is a time of development, exploration, differentiation, and setting the stage for the adults they envision becoming. During this developmental phase, adolescents are attempting to navigate their own developing sexuality and sexual identity while learning to develop relationships with others. When the complexity of all of these developmental tasks is scaffolded by the diagnosis of cancer, the tasks can often be interrupted or, at the very least, moved to the side, while bigger issues of living and curing cancer take center stage. However, once these young people move past the focus on, and treatment of, the disease, the developmental issues await to be addressed. As stated, we know that complications with the development of sexual identity and healthy sexuality have lifelong and serious ramifications such as relationship difficulties, fewer meaningful sexual relationships, and sexual and social delays or deficits (Bancroft, 2002; Dietz & Mulrooney, 2011; Eccles et al., 1993; Hyde & DeLamater, 2008; LeVay & Valente, 2003; Sameroff et al., 2000; Tindle et al., 2009). However, we do not believe this has to be the case for the majority of adolescents who are survivors of cancer. Listening to their voices and concerns beyond this study, but in everyday practice in pediatric oncology, *is* a portal to the conversation waiting to happen.

Acknowledgments

The authors wish to thank Alex's Lemonade Stand Foundation for their financial support for this study and the Kids Cancer Care Foundation of Alberta for their assistance in recruitment and access to participants. Thanks especially to the participants who so openly shared of their experiences around this sensitive and important topic.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This study was financially supported by Alex's Lemonade Stand Foundation.

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