

A Grounded Theory Investigation into the Psychosexual Unmet Needs of Adolescent and Young Adult Cancer Survivors

Katherine A. Dobinson, BPsych(Hons),¹ Michael A. Hoyt, PhD,² Zac E. Seidler, BPsych(Hons),¹ Amelia L. Beaumont, BA,^{3,4} Stephanie E. Hullmann, PhD,⁵ and Catalina R. Laws, PhD^{1,5}

Purpose: For many adolescents and young adults (AYAs) with cancer, psychosexual well-being is compromised due to the onset of illness at a vulnerable stage of sexual development. To date, prior studies have focused on the psychosexual well-being of older adult survivors, largely ignoring AYAs. Furthermore, the few studies investigating AYA psychosexual well-being have been prematurely quantitative in nature, limited by a lack of in-depth exploration regarding the unique psychosexual experiences of AYA survivors. Qualitative research is required to better identify and understand the unique complexities surrounding psychosexual needs among AYAs with cancer.

Methods: Semi-structured interviews were conducted with 11 AYA cancer survivors (aged 15–45 years at the time of diagnosis). Transcripts were coded using a grounded theory methodology.

Results: Constant comparison data analysis gave rise to the Pathways to Problems model, denoting the pathways to psychosexual unmet needs among AYA survivors. Participants experienced identity conflict, whereby an incongruity occurred between their chronological age and their self-perceived age. The experience of identity conflict, combined with changes to intimate relationships, shifts in priorities, physicians' assumptions, and inadequate support, contributed to the onset of psychosexual unmet needs. Six areas of psychosexual unmet needs were identified: fertility concerns, sexual communication, dealing with side effects, dating and disclosure, relating to other AYAs, and reconciling identity conflict.

Conclusion: The present findings provide evidence for shared and unique psychosexual unmet needs among AYA survivors. Practical implications include the need for validation and incorporation of unique AYA unmet needs into screening tools and care plans, as well as peer support.

Keywords: psychosexual, sexuality, survivorship, qualitative, identity

ASPECTS OF CANCER SURVIVORSHIP are unique for adolescents and young adults (AYAs) because diagnosis coincides with novel developmental milestones, such as forming intimate relationships and developing a healthy body image.¹ Unfortunately, the impact of cancer upon these milestones is often negative,² leading to unique medical and psychosocial needs.

One physical and psychosocial challenge faced by patients with cancer is psychosexual concerns. Psychosexual concerns are the psychological and physical aspects of sexual well-being.³ Theories of sexual health suggest that sexual

well-being is influenced by physical, psychological, cultural, and relational aspects.^{4,5} Physically, patients with cancer experience decreased sexual arousal and satisfaction, influenced by pain, vaginal atrophy, and erectile dysfunction.^{6,7} Cancer-related psychological difficulties, such as low self-esteem and distress, may also negatively impact patients' psychosexual well-being.⁸

Sexual development is an important normative developmental task for AYAs that may be interrupted by cancer treatment.^{8–11} AYA cancer patients may experience physical sexual difficulties, such as sterility, low testosterone, pain,

¹Department of Psychology/Science, The University of Sydney, Sydney, Australia.

²Department of Psychology, Hunter College, City University of New York, New York.

³Department of Media and Communications, The University of Technology, Sydney, Australia.

⁴Project Management, Cancer Council New South Wales, Sydney, Australia.

⁵Department of Psychology, Rush University Medical Center, Chicago, Illinois.

and psychological difficulties related to sexual health, such as poor body image, psychological stress, and fear of rejection.¹² These psychosexual difficulties threaten the normative progression of AYA sexual development.^{8,13} Further, intimate relationship difficulties and body-image concerns have been associated with poorer mental health among male and female AYA survivors.^{14,15} Consequently, it is imperative that investigations of sexual concerns among AYAs address both physical and psychological aspects of sexual health.

Investigations into psychosexual issues have focused on the needs of older adults, resulting in a paucity of information regarding the needs of AYAs. Moreover, psychosexual unmet needs of AYAs may be different from older survivors. Due to the importance of sexuality at this life stage, psychosexual concerns may impede AYA identity formation and health-related quality of life (HRQOL).^{8,10,16}

There is a high prevalence of psychosexual unmet needs among AYA survivors, exceeding that of older adults.¹⁷ Unfortunately, current survivorship care models are not meeting these needs.^{17–19} Greater unmet needs are associated with poorer HRQOL and increased risks of depression and anxiety amongst AYAs.^{18,20,21} AYA psychosexual unmet needs include the desire for information regarding sexuality and intimacy, infertility treatment options, and age-appropriate websites.¹⁷ Investigations to date have been predominantly quantitative in nature.^{17,22} Without foundational qualitative inquiries, quantitative investigations may lack sufficient depth of understanding due to assessing AYA sexuality using pre-existing measures designed for older adults.^{16,23} AYA research requires the development and validation of theoretical models through qualitative investigations prior to quantitative analyses.²⁴

This study aimed to delineate the pathways through which AYA survivor psychosexual unmet needs manifest, and to demonstrate further the types of psychosexual unmet needs experienced by AYAs.

Methods

Ethics approval was granted by the Sydney Local Health District Human Research Ethics Committee.

Participants

The Cancer Council New South Wales defines AYAs as individuals aged between 15 and 45 years at the time of diagnosis (J. Mills, pers. commun., April 2014). Eligibility to participate required fulfilment of the following criteria: (i) AYA cancer survivors aged 15–45 years *at time of diagnosis*; (ii) *currently* aged 18 years and over; and (iii) at least 6 months between the conclusion of primary treatment and participation.

Recruitment strategies involved emailing invitations to support groups, private oncologists, Cancer Council NSW, and an online cancer registry (Register 4). Initial recruitment involved convenience sampling. Purposive sampling was later employed to substantiate theoretical construction and ensure data reflected diverse perspectives across sex, age, and cancer type.²⁵

Procedure

Following informed consent, participants completed self-report medical background questionnaires. Data were

collected through semi-structured interviews, which were developed and analyzed according to grounded theory.²⁶ Interview guides (see Appendix A) provided questions and prompts that evolved alongside theoretical development. Initial topics of interest informed by the literature included impact of cancer on sexual function, relationships, and sexuality. Interviews, conducted by either K.D. or Z.S., lasted approximately 1 hour. Audio files were transcribed verbatim and imported into NVivo 10.²⁷ Eleven participants (five male) completed an interview (Table 1). Age at diagnosis ranged from 15 to 40 years ($M = 27.82$ years, standard deviation [SD] = 8.45 years), and age at interview ranged from 21 to 43 years ($M = 31.73$ years, SD = 7.48 years). Two participants were contacted for member-checking interviews, at which stage thematic saturation had occurred.²⁸ Saturation of data was agreed upon by three colleagues.

Data analysis

Analysis commenced with open coding whereby words and phrases were assigned a code.²⁹ Initial codes revealed sexual difficulties such as side effects and relationship issues, which were defined and categorized through independent cross-coding by two researchers. Properties and dimensions of categories were further defined via the constant comparative method.²⁹

Axial coding followed open coding of the first five interviews, conducted in accordance with Strauss and Corbin's "paradigm," an organizational scheme that encourages consideration of structure and process.²⁹ Categories were closely defined by their conditions, actions, and consequences, as well as the dynamic relationships between categories.

Selective coding assisted in revealing higher-order themes and constructing theory through an in-depth analysis of thematic interactions. Rigor was ensured through creating memos, verbally debriefing, member-checking, and cross-coding (Table 2).³⁰

Results

Comparative analysis gave rise to the substantive Pathways to Problems model, describing the emergence of psychosexual unmet needs as explained by AYA survivors (Fig. 1). While analysis revealed several psychosexual unmet needs, the model emphasizes the factors contributing to their formation (see Table 3 for frequency of factors).

Pathways to Problems model

Causal conditions of developmental stage and age at diagnosis and illness factors preceded the experience of identity conflict, a phenomenon depicting the tension experienced by AYA survivors in terms of their chronological age competing with their self-perceived age. Identity conflict was influenced by *intervening conditions* (changes to intimate relationship(s), shift in priorities, individual factors), and participants' consequential *actions/interactions* (detaching from the sexual self, social comparisons) in response to such conditions (see Fig. 2 for analytical example). The internal dissonance of identity conflict was often accompanied by external factors that exacerbated the onset of psychosexual unmet needs. Consequently, six categories of psychosexual unmet needs emerged.

TABLE 1. PARTICIPANT CHARACTERISTICS ($N = 11$)

<i>Participant name^a</i>	<i>Age at diagnosis (years)^b</i>	<i>Age at interview (years)</i>	<i>Sex</i>	<i>Cancer type</i>	<i>Treatment(s) received</i>	<i>Relationship status</i>	<i>Years in current relationship^c</i>
Ruth	37	43	Female	Breast	Chemotherapy, radiotherapy, surgery	De facto	8
Lucy	17	21	Female	Acute myeloid leukemia	Chemotherapy, surgery	Single	—
Reece	21	24	Male	Hodgkin lymphoma	Chemotherapy	Partner, not living together	1
Rachel	24	26	Female	Ovarian	Chemotherapy, surgery	Partner, not living together	7.5
Claudia	31	31	Female	Breast	Chemotherapy, radiotherapy, surgery	Married	5
Kaitlin	10, 15	24	Female	Sarcoma (neck, lung)	Chemotherapy, radiotherapy, surgery	Partner, not living together	0.25
Jenny	32	39	Female	Breast	Chemotherapy, surgery	Single (separated)	—
Martin	11, 22	29	Male	Sarcoma (knee, lung)	Chemotherapy, radiotherapy, surgery	De facto	2
Victor	40	40	Male	Testicular	Surgery	Married	16
Tim	31	36	Male	Testicular	Surgery	Single	—
James	30, 36	36	Male	Testicular	Chemotherapy, surgery	Married	11.5

^aPseudonyms are used to protect participants' confidentiality.

^bTwo numbers indicates two separate cancer diagnoses, and participants' respective age at each diagnosis.

^cA dash indicates that the participant was not in an intimate relationship at the time of the interview.

Psychosexual unmet needs

The majority of participants reported experiencing at least one psychosexual unmet need, categorized as fertility concerns, sexual communication (verbal and non-verbal with partners), dealing with side effects, dating and disclosure, relating to other AYAs, and reconciling identity conflict (see Table 4). Needs highlighted AYAs' desire for options regarding fertility preservation, to learn how to discuss their sexual concerns openly with partners, and how to cope with physical side effects. Unmet needs were further identified as requiring assistance re-entering the dating scene, understanding other AYAs are experiencing similar difficulties, and reconciling age-related incongruities. Participants who did not report unmet needs (Martin, 29, and Victor, 40) largely attributed their position to having highly supportive partners.

Some participants made attempts to fulfil unmet needs, including psychological counselling, voicing concerns with partners, investigating fertility preservation options, and attending support groups. However, many participants expressed that additional support was required. Preferences for support included face-to-face (healthcare professionals/other survivors) and online support. Participants emphasized the importance of including partners wherever possible, claiming that "when it comes to ... sexual relationship issues, it's not enough for one person to do the work" (Rachel, 26). AYAs desired support to be offered at different stages throughout the cancer trajectory.

Causal conditions

Developmental stage and age at diagnosis. Psychosexual concerns differed depending on participants' developmental stage and age at diagnosis. For young survivors, such as Lucy, being diagnosed at 17 years of age drastically disturbed her independence. Lucy explained being "on the brink of freedom" having just passed her driver's license test 1 week prior to diagnosis. However, this sense of freedom quickly deteriorated, as cancer compromised Lucy's ability to achieve financial and social autonomy.

For Rachel, a cancer diagnosis at 24 years of age led to a loss of psychological as well as physical and sexual autonomy. Rachel (now 26 years old) described how an inability to complete standard daily activities, such as walking and eating, triggered intimacy issues. For Rachel, the physically inhibiting nature of cancer meant "the prospect of being intimate was pretty much ... gone."

Illness factors. Participants with cancer in a sexual organ, accompanied by lengthy, invasive treatments, more frequently reported having psychosexual unmet needs than those with less-invasive cancers did. Testicular cancer survivors emphasized how cancer in a sexual organ "adjusted" their masculinity, describing the removal of their testicle(s) as a "hidden secret" (Tim, 36 years old), which often led to feelings of emasculation and self-consciousness.

Vaginal dryness and a decreased sex drive were reported by many female participants as the most problematic physical

TABLE 2. IMPLEMENTATION OF QUALITATIVE STANDARDS OF RIGOR

<i>Standard of rigor</i>	<i>Strategies implemented in current study</i>
Creditability	<ol style="list-style-type: none"> 1. Personal views regarding psychosexual issues among AYA survivors were documented in post-interview reflection statements 2. Memos were used throughout the analytic process as an additional source of reflexivity, and awareness of the researcher's personal interpretations of the data 3. Weekly debriefings occurred between authors whereby the primary researcher discussed her reactions to interviews 4. Participants were the primary informants of the inquiry process through the use of <i>in vivo</i> codes 5. Member-checking interviews enhanced the trustworthiness and shaped theoretical adjustments
Fittingness/ transferability	<ol style="list-style-type: none"> 1. Defining demographic characteristics and medical background information allowed by a clear delineation of the sample 2. The level of theory generated was acknowledged: the grounded theory emerging from the data is a substantive theory—true for the particular situational context from which it was generated 3. A review of the related literature revealed similar aspects of the phenomenon (psychosexual unmet needs) to those evident in the categories and themes in the current study
Auditability/ dependability	<ol style="list-style-type: none"> 1. Interviews were audio-recorded and listened to by the researcher <i>prior</i> to transcription 2. Transcripts were firstly compared with recordings to ensure accuracy 3. Transcripts were read multiple times to ensure a precise documented account of participants' experiences and accuracy 4. Cross-coding of interviews was completed by the primary researcher and two other colleagues, yielding a high level of consistency among the emerging themes, with only minor coding disparities 5. The decision trail involved in recruitment was identified. First, convenience sampling was used to recruit any participants who met the eligibility criteria. After the first five interviews, purposive sampling was adopted to ensure the data reflected a broad range of experiences

AYA, adolescent and young adult.

side effects, describing that “without enough lubrication” it was too painful “to actually have intercourse” (Claudia, 31 years old).

Difficulties associated with the aforementioned *causal conditions* contributed to the emergence of identity conflict alongside *intervening conditions* and *actions/interactions*.

Intervening conditions

For participants in relationships, the cancer experience often triggered changes to intimate relationships due to declines in intimacy and sexual activity. AYAs attributed these declines as a defining characteristic of older couples, describing these issues as “older adults problems” (Rachel, 26 years old).

Participants explained a shift in priorities, whereby less emphasis was placed upon prioritizing appearance, sex, and intimacy throughout the cancer journey. Lowering the importance of sexual well-being was common, with survivors expressing that this contributed to psychosexual needs remaining unmet.

Individual factors, such as a decrease in self-esteem and “feeling down” further facilitated the onset of identity conflict. Hair loss, weight loss, fatigue, and facing one's own mortality contributed to this decrease in self-esteem, as survivors began to focus on negative aspects of their illness.

Actions/interactions

Participants' actions/interactions added to the impact of causal and intervening conditions upon the formation of identity conflict. Many AYAs responded to their diagnosis by detaching from the sexual self. Statements such as “you're a sick person, not a sexy person” highlighted the process of partial detachment from sexual identity. Kaitlin, who was diagnosed at 15 years of age, felt that she has missed out on common sexual experiences throughout her adolescence. She described that feeling “quite childlike” led to a disengagement from her sexual self, rather than experiencing sexual milestones typical for AYAs.

Survivors engaged in social comparisons, viewing themselves as different from their peers. These comparisons influenced identity conflict in causing survivors to feel younger or older than their chronological age. For Jenny (39 years old), social comparisons made her feel older, confessing feeling “different to [her] friends” and that “these events happen to older people.” The dynamic process through which individuals experienced these changes lead to the identity conflict phenomenon.

Identity conflict

AYAs revealed an identity conflict depicting the tension between their chronological age competing with their self-perceived age, experienced as either regression to childhood or early maturation.

Regression to childhood. Kaitlin, diagnosed at 15 years of age, described how cancer “interrupted ... [teenage] sexual development,” leaving her to “revert to childhood.” Fostered by an abnormally close relationship with her parents, and a cancer-driven inability to interact frequently with peers, Kaitlin's sense of autonomy was compromised:

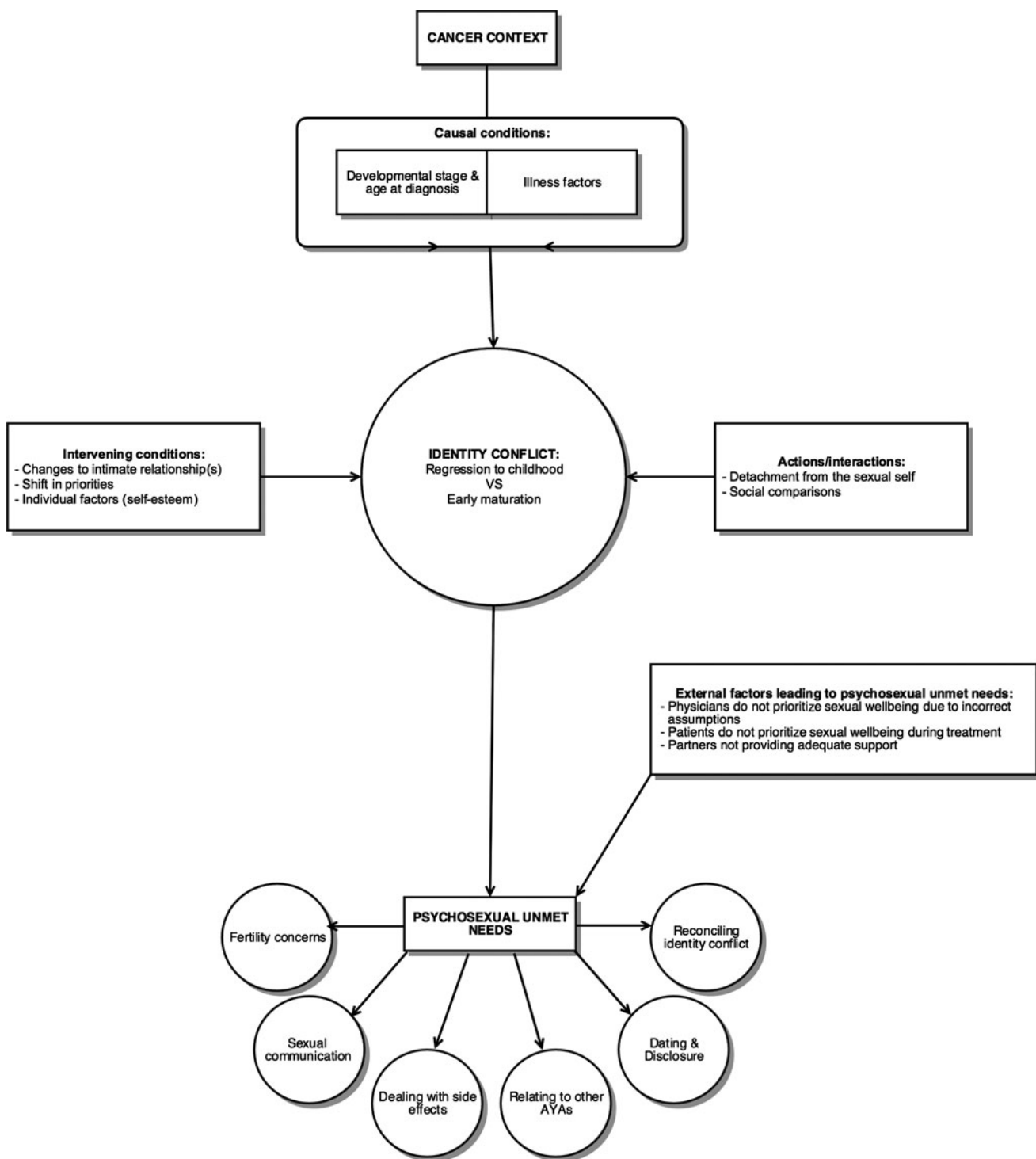


FIG. 1. Pathways to Problems: a visual model depicting the emergence of psychosocial unmet needs among adolescent and young adult (AYA) cancer survivors. *Note:* Circular figures symbolize phenomena or outcomes, whereas rectangular figures symbolize factors that influence these outcomes. Arrows indicate direction of relationship between phenomena and respective factors influencing these phenomena.

I never really had boyfriends through high school ... at the time when you're supposed to be ... creating your own independence ... I was spending all of my time with my parents and ... almost reverted to childhood ... sex was probably the last thing on my mind. (Kaitlin, now 24 years old)

Younger participants often clung to childlike behaviors, such as becoming easily “emotionally attached” and “needy,” rather than experiencing the sexual milestones typical for AYAs.

Early maturation. Considering one's own mortality often enhanced a sense of feeling older, or early maturation, as AYAs

TABLE 3. FREQUENCY OF SUBCATEGORIES AS EXPRESSED IN BY PARTICIPANTS

Category	Subcategory	Frequency
Intervening conditions	Changes to intimate relationship(s)	7
	Shift in priorities	5
	Individual factors (self-esteem)	4
Actions/interactions	Detachment from the sexual self	6
	Social comparisons	8
External factors leading to psychosexual unmet needs	Physicians do not prioritize sexual wellbeing due to incorrect assumptions	7
	Patients do not prioritize sexual wellbeing during treatment	4
	Partners not providing adequate support	2

reported that death is “not something that [young] people ... think about” (Rachel, 26 years old). A shift in priorities occurred, whereby less emphasis was placed upon prioritizing physical appearance and sexual activity. Faced with challenges common among older adults, such as a diminished sex life, many survivors reported that they identified “more with a 40-year-old than an adolescent” (Rachel). Participants felt “more pressure” from society to be sexually active, and to be “going out ... partying ... drinking and having sex” (Rachel). However, physical impairments prevented them from doing so. Consequently, AYAs’ lived experiences were incongruent with societal expectations of young people, which exacerbated the notion of early maturation.

External factors leading to psychosexual unmet needs

In addition to experiencing an internal identity conflict, several external factors facilitated the onset of psychosexual unmet needs.

Interview excerpt:

when you don't feel very good about yourself (causal condition/context – cancer context) and you're down on how you look and your self-esteem (intervening condition – low self-esteem) ...and when you're a sick person you're a sick person, you're not a sexy person (action – detaching from feeling sexy). You're not...you stop thinking of yourself in that frame of mind and I think, well I can't speak for other people, but I think that you don't even worry about it... You know, you almost become ...In a weird way, you're so self-conscious that you become egoless, and I know that's really contradictory but, you sort of get to a point where you're like “I don't even care. I don't even identify any part of myself as being sexy, so, I'm not even going to try (action – detachment from feeling sexy). At the end of the day all I care about is being alive.” So, you stop looking in the mirror, you don't care how you look. (consequence – disengage from youthful identity)

FIG. 2. Axial coding example. *Note:* Axial coding analysis example depicting dynamic relationships between causal conditions, intervening conditions, actions/interactions, and consequences leading to identity conflict and psychosexual unmet needs. Bold writing indicates analysis by the researcher; italicized writing indicates interview content of AYA participant.

Physicians do not prioritize sexual well-being due to incorrect assumptions. AYAs did not believe physicians prioritized “making sure [the patient has] a healthy sex life” (Rachel, 26 years old). Physicians’ misassumptions that AYAs were not developmentally ready to consider sex and fertility contributed to these unmet needs. For Ruth, being in a same-sex relationship and hearing her oncologist say, “You’re not having kids, are you?” exacerbated her psychosexual unmet needs.

Patients do not prioritize sexual well-being during treatment. Being young and “unexperienced” meant that many survivors lacked the “confidence to raise it [sexual concerns] out of the blue with [their] doctor” (Rachel, 26 years old). Many participants expressed the desire for information regarding psychosexual concerns, irrespective of how they prioritized these needs at early stages of treatment:

...even if it [receiving psychosexual information] was earlier on...to have it in my arsenal later on would have been good. (Rachel)

Partners not providing adequate support. Unsupportive, withdrawn partners were highly conducive to the onset of survivors’ unmet needs. Jenny (39 years old) described how her “unkind and [physically and verbally] abusive” ex-husband prevented her from seeking help, feeling that she “couldn’t speak up about anything ... whether sexual or in any way.” Thankfully, only one participant experienced this extreme level of non-supportive behavior from their partner. However, other partners did not provide adequate emotional support or opportunities for communication. Thus, survivors’ needs remained unmet. Paradoxically, highly supportive partners protected survivors from several unmet needs by speaking openly and supportively regarding their partner’s sexual concerns.

Discussion

The model provides an explanation of the pathways leading to psychosexual unmet needs among AYA cancer survivors. AYA testimonies identified the experience of identity conflict and psychosexual unmet needs as outcomes

TABLE 4. PSYCHOSEXUAL UNMET NEEDS OF AYA SURVIVORS

<i>Psychosexual unmet need</i>	<i>Explanation</i>	<i>Illustrative quotes</i>
Fertility concerns	Participants experienced unmet fertility concerns, such as the need for age-appropriate information. Survivors also expressed the need to learn how to cope psychologically with infertility.	Q: What actual information did you actually get regarding fertility and sexual side effects? Ruth: Zero Claudia: ...with the fertility, being a young age with sort of a... I guess we didn't realize we would have to go at it so quickly. Lucy: I'm not really one of those women who really wanted to have children anyway, so ... I'm concerned for like future partners who would value that more than I ... what if it causes conflict in the future for future relationships?
Sexual communication	AYAs reported concerns regarding how to communicate sexual issues to their partner(s). Learning how to assert oneself sexually was a common unmet need. Participants also expressed the need for assistance regarding raising sexual concerns with their partner(s) without judgment. Fear of judgment was expressed as a barrier to open sexual communication.	Lucy: Learning how to be a little bit more ... assertive maybe? Knowing how to actually ... educating the future partner on the sexual function, or like menopause. Because when you think about it we don't really learn a lot about it. Claudia: I don't want to mention everything [sexual side effects] 'cause I don't want to be seen as a complainer.
Dealing with side effects	The need to receive quality information regarding how to cope with side effects, particularly those of a sexual nature, emerged as a psychosexual unmet need. Common sexual side effects that participants experienced difficulty with included vaginal dryness, premature menopause, hair loss, and fatigue.	Kaitlin: No one ever mentioned to you that you might not find yourself attractive, or you might have a warped sense of body image, or anything like that. All you really know is sort of medical side effects.
Dating and disclosure	Re-entering the dating scene was not an easy task for many participants. Factors influencing whether participants chose to disclose their cancer history to new sexual partners included trust, and their predicted reaction of the new love interest.	Q: Yeah, you don't want it to be something like the elephant in the room or something like that. Kaitlin: Yeah, or for them to feel like ... to look at me like I should be pitied.
Relating to other AYAs	Participants expressed the desire to relate to other AYA survivors about their sexual problems. Having the opportunity to discuss the social isolation of treatment, sexual side effects, and the impact of cancer upon relationships was a desire that remained unfulfilled for many participants.	Reece: I don't have a lot of people in my life now who really know what chemo does to you, who really know what that cancer experience does to you ... and that's hard ... I'm sure that if I had somebody to talk to about the sex and the tiredness when I was going through it, they'd just be like "man, it's okay." And that's all you need to hear from somebody else who actually knows what you're going through.
Reconciling identity conflict	Experiencing identity conflict frequently resulted in a desire to resolve the friction between actual and self-perceived age. Information regarding normative sexual milestones was something that participants did not receive, despite a strong desire to receive such information from health professionals.	Kaitlin: ...having someone talk to you about puberty and experiences and then how chemotherapy impacts on that is a good thing because I really reverted and I was allowed to, I was let to revert. My parents let me revert, my oncologist let me revert, and to have someone focusing on the development milestones that you probably should be achieving even though you have this horrible thing happen to you, could be or I think is a good thing. At least to occasionally remind you that you are in fact a 15-year-old and these things will become important to you.

evolving from internal and external factors, such as individual self-esteem, changes to intimate relationships, and level of support from physicians. Participants described a sense of conflict between how old they were and how old they felt, leading to the construction of identity conflict as a core component of the Pathways to Problems model. The notion of identity conflict appears to shape psychosexual needs of AYA survivors, specifying that survivorship care requirements may be similar to those of older adults, or unique to AYAs depending on the individual's self-perceived age.

Similar to older adults, developmental stage and age at diagnosis and illness factors are precursors to sexual problems among AYAs.^{24,31–33} However, identity conflict appears unique to AYAs due to its interruption of normative development, whereas for older adults, the onset of illness occurs at a time where a stable self-identity has been established.³ Recent research has identified the AYA paradox, a construct highlighting how the AYA cancer experience may obstruct normative developmental tasks.³⁴ However, identity conflict extrapolates further on this construct, specifying the bidirectional nature as either regression to childhood or early maturation.

Unmet needs of fertility concerns, sexual communication, dealing with side effects, and dating and disclosure identified by AYAs have also been reported in older adult literature.^{5,35–37} The model suggests that illness factors and external factors, such as amount of support received, may explain these shared unmet needs in both AYA and older adult survivors. Thus, it is important that support tailored to psychosexual needs be provided to AYAs, regardless of their chronological age.

Psychosexual unmet needs unique to AYAs included relating to other AYAs and reconciling identity conflict. AYAs explained that cancer altered their identity in a way that was not conducive to young adulthood. While previous investigations have also identified the need to relate to other AYAs, the current study extends this psychosocial concern to psychosexual unmet needs.⁹ AYA survivorship care should prioritize connecting survivors with peers experiencing similar psychosexual problems. Considering research that indicates AYAs may be more likely to seek online support, it is suggested that the internet would be a useful medium for AYAs to communicate in an anonymous environment that allows for control over levels of disclosure.^{38–40}

The unmet need to reconcile identity conflict implies that survivorship care should acknowledge the importance of self-perceived age when considering psychosexual concerns, not just chronological age. Needs-based care that considers a broad spectrum of sexual difficulties should be presented in a developmentally appropriate manner to ensure AYAs receive best-practice care.

Results suggest that older, more developmentally advanced AYAs may share similar psychosexual concerns to older adults. Consequently, older AYAs may benefit from pre-existing psychosexual interventions designed for older adult survivors. However, the prevalence of unique psychosexual unmet needs reported by younger AYAs implies that these individuals require interventions addressing their *unique* needs. Validating and incorporating AYA-specific psychosexual concerns in screening tools and survivorship care plans would be the first step toward improving AYA survivors' sexual well-being.

Participants identified misassumptions held by physicians, namely that younger AYAs are not concerned with sexual issues and that same-sex patients may not require fertility

information. Consistent with the results, previous research has recognized that while physicians may consider sexuality and fertility as important to *survivors*, they do not prioritize fertility for AYA *patients*.⁹ Physicians should ensure that they do not prevent necessary screening of psychosexual unmet needs among AYAs due to misassumptions.

The findings assist in identifying AYA survivors most at risk of developing unmet needs. The Pathways to Problems model suggests that a younger age at diagnosis, an advanced stage cancer, an intensive treatment regimen, and a lack of support increase the likelihood of psychosexual unmet needs emerging.

The study may be limited by interviewer effects, as well as difficulties with recruitment that prevented the researcher from consistently engaging in purposive sampling. However, sample size was sufficient for theoretical saturation. Thus, effects from the aforementioned limitations are considered minimal.

Strengths include the establishment of a novel theoretical framework delineating the manifestation of AYA survivors' psychosexual unmet needs. The sample included a balance of males and females, as well as a broad spectrum of AYA ages. Utilizing an extensive range of strategies to ensure rigor enhanced the study's quality.

Future research could explore multiple sexual orientations, and consider partner testimonies. It is recommended that theoretical constructs identified in the model may be adopted as variables for future quantitative investigations. Finally, future studies should adopt longitudinal designs, investigating whether time since treatment impacts upon likelihood to disclose sexual information.⁴¹ The current theoretical framework should stimulate future investigations that aim to ensure more positive psychosexual experiences for AYAs during life after cancer.

Acknowledgments

To the inspiring young people who participated in this study, thank you for your generosity in sharing your personal and intimate experiences. Your kindness and bravery have been the driving forces for this project, and I truly hope the finished product resonates with you. I would also like to thank Associate Professor Paul Rhodes for his assistance with qualitative analysis for this project. This research was supported by Cancer Council NSW and The University of Sydney.

Author Disclosure Statement

No competing financial interests exist.

References

1. Zebrack BJ. Psychological, social, and behavioural issues for young adults with cancer. *Cancer*. 2011;117(10 Suppl): 2289–94.
2. Bellizzi KM, Smith A, Schmidt S, et al. Positive and negative psychosocial impact of being diagnosed with cancer as an adolescent or young adult. *Cancer*. 2012;118(20):5155–62.
3. Rowland JH. Developmental stage and adaptation: adult model. In: *Handbook of psychooncology*. Holland JC, Rowland JH (Eds); New York: Oxford University Press; 1989; pp. 25–43.
4. Strong B, DeVault C. *Human sexuality*. Mountain View, CA: Mayfield Publishing Company; 1994.
5. Bober SL, Varela VS. Sexuality in adult cancer survivors: challenges and intervention. *J Clin Oncol*. 2012;30(30): 3712–19.

6. Falk SJ, Dizon DS. Sexual dysfunction in women with cancer. *Fertil Steril*. 2013;100(4):916–12.
7. Schover LR. Sexuality and fertility after cancer. *Hematology Am Soc Hematol Educ Program*. 2005;2005(1):523–7.
8. Hughes MK. Sexuality and the cancer survivor: a silent coexistence. *Cancer Nurs*. 2000;23(6):477–82.
9. Zebrack B, Bleyer A, Albritton K, et al. Assessing the health care needs of young adult cancer patients and survivors. *Cancer*. 2006;107(12):2915–923.
10. Bolte S, Zebrack B. Sexual issues in special populations: adolescents and young adults. *Semin Oncol Nurs*. 2008;24(2):115–19.
11. Zebrack B, Isaacson S. Psychosocial care of adolescent and young adult patients with cancer and survivors. *J Clin Oncol*. 2012;30(11):1221–6.
12. Vadaparampil ST, Hutchins NM, Quinn GP. Reproductive health in the adolescent and young adult cancer patient: an innovative training program for oncology nurses. *J Cancer Educ*. 2013;28(1):197–208.
13. Canada AL, Schover LR, Li Y. Pilot intervention to enhance psychosexual development in adolescents and young adults with cancer. *Pediatr Blood Cancer*. 2007;49(6):824–8.
14. Tuinman MA, Hoekstra HJ, Fleer J, et al. Self-esteem, social support, and mental health in survivors of testicular cancer: a comparison based on relationship status. *Urol Oncol*. 2006;24(4):279–86.
15. Fobair P, Stewart SL, Chang S, et al. Body image and sexual problems in young women with breast cancer. *Psychooncology*. 2006;15(7):579–94.
16. Nightingale CL, Quinn GP, Shenkman EA, et al. Health-related quality of life of young adult survivors of childhood cancer: a review of qualitative studies. *J Adolesc Young Adult Oncol*. 2011;1(3):124–32.
17. Zebrack B. Information and service needs for young adult cancer survivors. *Support Care Cancer*. 2009;17(4):349–57.
18. Dyson GJ, Thompson K, Palmer S, et al. The relationship between unmet needs and distress amongst young people with cancer. *Support Care Cancer*. 2012;20(1):75–85.
19. Feuz C. Are current care models meeting the psychosocial needs of adolescent and young adult cancer survivors? A literature review. *J Med Radiat Sci*. 2014;45(2):119–30.
20. Smith AW, Bellizzi KM, Keegan TH, et al. Health-related quality of life of adolescent and young adult patients with cancer in the United States: the adolescent and young adult health outcomes and patient experience study. *J Clin Oncol*. 2013;31(17):2136–48.
21. Smith AW, Parson HM, Kent EE, et al. Unmet support service needs and health-related quality of life among adolescents and young adults with cancer: the AYA HOPE study. *Front Oncol*. 2013;3:1–11.
22. Hall AE, Boyes AW, Bowman J, et al. Young adult cancer survivors' psychosocial well-being: a cross-sectional study assessing quality of life, unmet needs, and health behaviours. *Support Care Cancer*. 2012;20(6):1333–41.
23. Kelly D. Developing age appropriate psychosexual support for adolescent cancer survivors: a discussion paper. *Sex Med*. 2013;10(1):133–8.
24. Juraskova I, Butow P, Robertson R, et al. Post-treatment sexual adjustment following cervical and endometrial cancer: a qualitative insight. *Psychooncology*. 2003;12(3):267–79.
25. Suri H. Purposeful sampling in qualitative research synthesis. *Qual Res J*. 2011;11(2):63–75.
26. Corbin J, Strauss A. *Basics of qualitative research*. 3rd ed. Thousand Oaks, CA: Sage; 2008.
27. NVivo Qualitative Analysis Software (Version 10). QSR International Pty Ltd; 2012.
28. Strauss A, Corbin JM. *Basics of qualitative research: grounded theory procedures and techniques*. Thousand Oaks, CA: Sage; 1990.
29. Strauss A, Corbin J. *Basics of qualitative research: techniques and procedures for developing grounded theory*. Thousand Oaks, CA: Sage; 1998.
30. Chiovitti RF, Piran N. Rigour and grounded theory research. *J Adv Nurs*. 2003;44(4):427–35.
31. O'Brien R, Rose P, Campbell C, et al. "I wish I'd told them": a qualitative study examining the unmet psychosexual needs of prostate cancer patients during follow-up after treatment. *Patient Edu Couns*. 2011;84(2):200–7.
32. Thewes B, Butow P, Girgis A, Pendlebury S. The psychosocial needs of breast cancer survivors: a qualitative study of the shared and unique needs of younger versus older survivors. *Psychooncology*. 2004;13(3):177–89.
33. Pauwels EE, Charlier C, De Bourdeaudhuij I, et al. Care needs after primary breast cancer treatment. Survivors' associated sociodemographic and medical characteristics. *Psychooncology*. 2013;22(1):125–32.
34. Kent EE, Parry C, Montoya MJ, et al. "You're too young for this": adolescent and young adults' perspective on cancer survivorship. *J Psychosoc Oncol*. 2012;30(2):260–79.
35. Derogatis LR, Kourlesis SM. An approach to evaluation of sexual problems in the cancer patient. *CA Cancer J Clin*. 2008;31(1):46–50.
36. Hill EK, Sandbo S, Adramsohn E, et al. Assessing gynecologic and breast cancer survivors' sexual health care needs. *Cancer*. 2010;117(12):2643–51.
37. Flynn KE, Reese JB, Jeffery DD, et al. Patient experiences with communication about sex during and after treatment for cancer. *Psychooncology*. 2012;21(6):594–601.
38. Treadgold CL, Kuperberg A. Been there, done that, wrote the blog: the challenges of supporting adolescents and young adults with cancer. *J Clin Oncol*. 2010;28(32):4842–9.
39. Palmer S, Patterson P, Thompson K. A national approach to improving adolescent and young adult (AYA) oncology psychosocial care: the development of AYA-specific psychosocial assessment and care tools. *Palliat Support Care*. 2014;12(3):183–8.
40. Nicholas J, Oliver K, Lee K, O'Brien M. Help-seeking behavior and the internet: an investigation among Australian adolescents. *Aust e-J Adv Mental Health*. 2004;3(1):16–23.
41. Barnett ME, Shuk EM, Conway FP, Ford JS. Cancer-related disclosure among adolescent and young adult cancer survivors: a qualitative study. *J Adolesc Young Adult Oncol*. 2014;3(3):123–9.

Address correspondence to:
Katherine A. Dobinson, BPsych (Hons)
The University of Sydney
Sydney 2006
New South Wales
Australia

Email: kdob8206@uni.sydney.edu.au

(Appendix follows →)

Appendix A: Interview Guide

Disclaimer: The questions in the interview guide were subject to change in each interview, as participants' responses influenced the direction of future questions asked by the facilitator. As the analysis progressed, some additional questions were added to fill gaps and clarify the emergent theory. Additional questions added to the original interview guide are presented below as underlined text. Please note that this was a guide, not a stringent script.

Psychosexual Unmet Needs Among Adolescent and Young Adult Cancer Survivors

Interview Guide

OPENING SCRIPT (to build rapport):

Hello Mr./Ms. _____, this is [facilitator's name] calling from the *Addressing Intimacy Amongst Cancer Survivors* study. Thank you for responding to my call. How are you doing today?

I'll be asking you a series of questions about how you have been feeling physically and emotionally in terms of issues regarding sex, intimacy, and your body. The whole interview should take around 60 minutes. Your answers to these questions will help us understand what intimate and/or sexual needs, if any, are not currently being addressed for you. This information will assist in improving supportive care efforts in the future.

As you know, interviews for the study will be recorded and may be listened to by a study investigator. The recording will be labeled by a number so the investigator listening to the recorded interview will not be able to identify you by name. The recording will be stored on a password-protected computer, and is therefore private. Once I turn on the recorder, I will not say your name from that point forward. Do you have any questions? All right, if you're ready, I will begin the recording now. [*Record Audio Label Code, then begin the interview*].

The purpose of this interview is to learn more about your experiences surrounding intimacy and sexual function during and after cancer treatment. We are interested in learning from your experience so we can better address the needs of other young adult cancer survivors. These questions are an opportunity for us to learn from you. So we really want to hear about your personal experiences whether or not you think they are typical. In order to learn the most, I'm going to be asking a lot of follow-up questions to get at the details of your experience. If at any time you don't want to delve further into a particular question, or you don't feel like expanding more, please let me know and we can move on. Most importantly, if you wish to withdraw at any time during the interview that is completely fine just let me know. Of course, at the end of the interview if you have anything additional you'd like to share, please feel comfortable doing so. Ok, do you have any questions? [IF NO, OR AFTER QUESTIONS ARE ANSWERED] So now, let's begin.

INTERVIEW QUESTIONS

- I understand you were diagnosed with _____ cancer. What was it like for you receiving this diagnosis?

Physical Side Effects

- What if any changes in your sexual functioning have you experienced since you completed your cancer treatment?
- How prepared were you to experience these changes?
- How have you coped with these changes?

If coping well, no unmet needs:

- What helped you get through this experience and cope so well? PROBE: personal traits, attitude, access to quality support

If no physical changes to sexual functioning:

- Has the way you feel psychologically influenced your sex life or how you feel about yourself sexually?
- How, if at all, has having cancer influenced your body image?
PROBE: Self-conscious? Embarrassed? Confident?

Relationships (if currently single)

- You mentioned that you are currently not in an intimate relationship. However, at the time of diagnosis, or during your treatment, have you been in an intimate relationship?
- To what extent, if any, did having cancer influence this relationship?
PROBE: Was this positive, or negative, and what were the factors that influenced this?
- How has your cancer treatment influenced dating and the way you meet new people (casual or otherwise)?
- How would you define the term "intimacy"?

Relationships (if currently in an intimate relationship)

- What impact, if any, has cancer had on your relationship?
- How do you communicate with your partner about sex, or sexual concerns? PROBE: What, if anything, would you like to change about this?
- How has your partner impacted upon your cancer experience?

Youth and Cancer

- How would you describe yourself developmentally now (during survivorship)?
- How would you describe yourself developmentally when you were diagnosed?
- What were some of the factors that influenced your sexual identity at this time?
- How has your age impacted upon your cancer experience?
- Do you consider yourself as a young adult?
PROBE: Why/Why not?
- How did your cancer experience influence how old you perceived your age to be?
- What impact, if any, has this had on your sexual identity?

Support

- What support have you received to manage sexual changes (physical or psychological) after cancer?
- How would you prefer to receive this support as a young adult (e.g., telephone, in person, web-based)?

Unmet Needs

- Of all the sexual issues discussed today, which is most important for you, and why?
- Are there any specific sexual needs you have that have not been met?
- How have your sexual needs been influenced by your age at diagnosis?

- Among the psychosocial concerns we've discussed, which ones do you think providers should be sure to address, specifically for AYAs?

OK, that was my last question for now. Is there anything else that you would like to talk about that hasn't yet been discussed?

CLOSING SCRIPT: *[Stop recording device]* All right Mr./Ms. ____, that's it, we've completed the interview! Thank you very much for taking the time to speak with me about this topic. Did you have any questions about what we've talked about? Okay.