A Connectedness Primer for Healthcare Providers: Adolescents/Young Adult Cancer Survivors' Perspectives on Behaviors That Foster Connectedness During Cancer Treatment and the Resulting Positive Outcomes

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Purpose: Many healthcare providers (HCPs) struggle to communicate and connect with adolescents and young adults (AYA) with cancer that hinders their ability to adequately assess and address the psychosocial needs of AYA. The purpose of this article is to describe the key behaviors of HCPs AYA perceive as essential to fostering connectedness with them and the outcomes AYA experience from such connectedness.

Methods: The sample for this empirical phenomenological study was nine AYA cancer survivors (aged 20–23 years) who were diagnosed in adolescence. In-person individual interviews were conducted using a broad, data-generating question and analyzed using an adapted Colaizzi's method.

Results: The key behaviors of HCPs AYA perceive as essential to fostering connectedness include (1) exhibiting characteristics of knowing how to connect; (2) being watchful and attentive to AYA needs; (3) displaying a willingness to foster the relationship; (4) using humor; and (5) conveying respect, support, and caring. Outcomes of connectedness for AYA include a sense of being cared about, understood, and respected as unique individuals. In addition, AYA experience a sense of confidence/comfort in expressing themselves to HCPs, anticipation of interacting with HCPs in the future, a sense of gratitude for HCPs, and enhanced well-being.

Conclusion: Findings highlight the specific behaviors HCPs can use to foster connectedness with AYA and the outcomes AYA experience from connectedness. Improving HCPs' ability to connect with AYA and maintain connectedness is essential to identifying and addressing the psychosocial needs of AYA. AYA-HCP connectedness may help reduce the psychosocial distress AYA experience during and after treatment.

Keywords: psychosocial, survivorship, supportive care, quality of life

Introduction

ADOLESCENTS AND YOUNG ADULTS (AYA) with cancer experience higher levels of psychological distress and poor psychosocial outcomes than AYA without cancer.[1–4] It is often a challenge for healthcare providers (HCPs) to identify AYA's unique psychosocial needs and assess factors that increase their distress, which may negatively impact their psychosocial outcomes.[5–7]

To help cancer patients effectively adjust and manage their cancer experience it is essential to establish patient-provider connectedness.[8–10] Connectedness is defined as the degree to which a patient perceives having a close, meaningful, and significant relationship with HCPs; these perceptions are characterized by positive expressions (i.e., empathy, belonging, caring, respect, and trust) that are both received and reciprocated.[11] When HCPs are able to connect to their patient, they better understand the patient's needs and are able to incorporate this information into the patient's care.[12,13] However, in AYA oncology, many HCPs appear to struggle when communicating and connecting with AYA to adequately assess and effectively address their needs.[6,14] Previous research indicates that AYA needs are unmet during treatment[15–17] with HCPs underestimating their level of distress[5] and AYA desiring more empathic and honest communication with HCPs.[6,18,19]

Before HCPs can effectively assess and address the psychosocial needs of AYA and potentially help them better cope and manage the cancer experience, they must first establish connectedness. AYA report that connectedness with HCPs is important for them because it helps them buffer the disconnect they experience during the diagnosis (i.e., being misdiagnosed, misinformed, or not taken seriously).[20] However, there is a knowledge gap in the literature on AYAs'

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perception of how HCPs foster connectedness and outcomes of connectedness. Thus, the purpose of this article is to describe the key behaviors of HCPs AYA perceive as essential to fostering HCPs connectedness and the outcomes AYA experience from such connectedness. Findings reported here are part of a larger phenomenological study that more broadly explored AYA cancer survivors' experiences of connectedness with HCPs, including varying degrees of connectedness, disconnectedness, and unconnectedness experiences.

Methods

Design

The study design was empirical phenomenology, a qualitative research philosophy and research approach.[21,22] Empirical phenomenology is useful to describe commonalities of meaning underlying an experience. The focus of this study was on the commonalities of meaning in experiences of connectedness with HCPs as experienced by AYA with cancer.

Procedures

Following approval from the Institutional Review Board, a purposive sample of AYA cancer survivors was recruited from a childhood cancer survivor clinic in a large pediatric hospital in the Midwest. Redundancy of themes was obtained after enrolling nine participants. Eligibility criteria included (1) diagnosed with and treated for cancer during adolescence (aged 15–21 years); (2) currently aged 18–24 years; and (3) completed treatment ≥ 1 year and ≤ 9 years ago. Four participants were recruited in-person and five were recruited by telephone after receiving a letter describing the study. All AYA provided written informed consent before data collection.

Data were collected by the first author during individual, face-to-face interviews at a time and private location convenient to participants. Interviews were digitally recorded.

Detailed descriptions of the participants' experience were elicited through a broad data-generating question that was provided to participants at least 3 days before the interview.[23] The goal of each interview was to obtain a rich description of the AYA's experience and ensure that the AYA, not the interviewer, determined the details of the experience discussed.[24] Open-ended questions and probes encouraged participants to provide full descriptions of their experience. Interviews lasted between 15 and 99 (mean [M] = 43.2) minutes. For this study, the data-generating question was as follows:

> Please tell me about your experiences of connectedness with healthcare providers. Perhaps you experienced a strong connection with a healthcare provider. Perhaps you perceived yourself as never being connected with a healthcare provider. Or you might have experienced a connection but then became disconnected from your healthcare provider for some reason. Whatever your experiences were, I would like to hear about them. It is sometimes most useful to tell your experiences as a story, starting at the beginning of your contact with healthcare providers. Please describe your experience as fully as you can, including all the circumstances, thoughts, and feelings you can remember.

Data analysis

The audio-recorded interviews were transcribed and analyzed using Haase's adaptation of Colaizzi's method.[21,22,25] The analysis included five steps: (1) listening to each recorded interview several times to gain an understanding of the meaning as a whole, while simultaneously checking interview transcription accuracy; (2) extracting significant phrases and sentences directly pertaining to the phenomena and restating these into more general language (e.g., eliminating personal names/pronouns); (3) formulating meanings for each significant statement and validating meanings through research team discussions until consensus is achieved; (4) identifying themes from formulated meanings and organizing them into a hierarchy of theme clusters and larger theme categories; (5) developing a full narrative description of themes; and (6) distilling the full narrative description into the essential structure of the experience. Throughout the analysis process, data were managed using a combination of Microsoft Word tables and outline features to track iterations of the analysis.

Trustworthiness

We used several strategies to establish trustworthiness and credibility.[26,27] First, the analysis procedures were systematically and consistently applied.[21,25] Second, three research team scientists with expertise in pediatric oncology nursing, communication, phenomenology, and psychology worked through all steps of analysis until consensus was reached. Then, three different team members not involved in the data collection or analysis reviewed the results for trustworthiness and credibility. Third, an audit trail was used to ensure all analysis steps are traceable back to participants' original interview statements.

Results

Sample characteristics

Nine participants (56% female) aged 20–23 years (M = 21.0, standard deviation [SD] = 1.1) and diagnosed between ages 15 and 18 years (M = 16.1, SD = 1.2) were enrolled. Eight were Caucasian and one was African American. Diagnoses included osteosarcoma (n = 3), lymphoma (n = 2), ovarian germ cell (n = 2), and leukemia (n = 2). Treatments lasted 3–38 months (M = 11.1, SD = 10.6). Years post-treatment ranged from 1.5 to 5.5 (M = 3.7, SD = 1.0). Eight participants attended yearly follow-up appointments and one no longer attended.

Findings

Analysis of data resulted in the extraction of over 2900 significant statements categorized into eight main theme categories. Two of the eight main theme categories—those related to the AYA experiences of the behaviors of HCPs used to connect and the resulting outcomes of feeling connecting—are described here, along with illustrative quotes from AYA participants.

Theme Category 1. "They knew how I worked best": Behaviors of HCPs that foster connectedness

Theme Category 1 describes behaviors (i.e., actions and interactions) of HCPs that AYA identify as imperative to move beyond the beginning stages of connectedness. There are five theme clusters. Table 1 provides a list of specific behaviors of HCPs that foster connectedness.

TABLE 1. THEME CATEGORY 1: CONNECTEDNESS STRATEGIES

Theme Cluster 1.1. Connectedness characteristics	Caring Calm Honest Friendly Endearing Thoughtful Competent	Understanding Approachable Available Continuity Attractive Young in Age
Theme Cluster 1.2. Displaying a willingness to foster a relationship	Spending quality time with AYA Expressing a desire to get to know AYA on a personal level Treating AYA more like a friend than a patient	
Theme Cluster 1.3. Being watchful for and attentive to AYA needs	Preventing and quickly managing treatment-related side effects/symptom distress Gatekeeper role	
Theme Cluster 1.4. Humor to foster connectedness	Using humor to ease awkwardness Responding to AYA silly request for humor Making AYA laugh Using humor to promote positive health behaviors Knowing appropriate times to use and *not* use humor	

Theme Cluster 1.5. Conveying respect, support, and caring	Conveying respect
	   Treating AYA more than just another cancer patient
	   Respecting AYA's space
	   Providing enough information for AYA to know what to expect
	   Handling embarrassing situations delicately
	   Inquiring about AYA needs, opinions, and desire
	   Communicating in an age-appropriate manner
	Conveying support and caring
	   Supporting AYA need to keep up with the outside world
	     (e.g., school, sports, and friends)
	   Supporting AYA's autonomy and independence
	   Helping AYA work through difficult situations
	   Caring above and beyond (i.e., celebrating birthday, special
	     occasions, and treatment milestones)	

AYA, adolescents and young adults.

Theme Cluster 1.1. "Connectedness worthy": Exhibiting characteristics indicating the HCP knows how to connect. Participants describe specific HCPs who instinctively know how to connect by being themselves. Such HCPs seem to naturally exhibit characteristics or qualities that foster a desire to connect with them. HCPs characteristics that facilitate connectedness include being caring, calm, honest, friendly, endearing, thoughtful, competent, understanding, and unexpectedly approachable (i.e., down to earth, unpretentious). "Some doctors have this kind of 'I know everything' [attitude] and are not personable. But she [oncologist] was very…down to earth…she was pretty cool." Other HCPs connectedness characteristics include being available (i.e., consistently seeing HCPs enough to establish a connection), physical attractiveness, and being close in age.

Theme Cluster 1.2. "Tell me a little about yourself": Displaying a willingness to foster the relationship. HCPs willingness to foster a relationship with AYA facilitates connectedness. Behaviors of HCPs that show their willingness to extend the relationship include (1) spending quality time with AYA: "hanging out," "watching TV," or "coming into the room to just talk when they had some down time"; (2) expressing a desire to get to know AYA on a personal level. "We [AYA and nurse] would just talk about food, basketball, just everything. She was so nice…she reminded me a lot of my mom, like caring but not overly caring. We just talked about what I wanted to talk about as opposed to 'how do you feel' constantly, 'how do you feel being sick'"; (3) treating AYA more like a friend than a patient: "Some of the other ones [nurses] that I really enjoyed, it wasn't a nurse-patient relationship, it was like, 'Hey, guess what I did today!'"; and (4) self-disclosing personal information about themselves to AYA (e.g., HCPs acknowledging having a similar interests with AYA, like TV shows or sport activities).

Theme Cluster 1.3. "Always on top of it": Being watchful for and attentive to AYA needs. Participants describe HCPs recognizing and responding to their need for help to prevent or quickly manage treatment-related side effects/symptom distress. "I loved her [nurse] so much because she…cared. Every time I was going to get sick she was right on it." Another connectedness strategy includes HCPS taking a gatekeeper role. "She [the nurse] didn't have to get to know my friends. But it helped a lot…I could tell her, 'I really can't hang out right now'…She would tell them…It was just easier for her to tell them."

Theme Cluster 1.4. "Did you hear the one about…?": Humor to foster connectedness. Participants describe humor as a valuable means to connect because humor eases any awkwardness in relating to HCPs. Participants describe HCPs ability to use humor as both beneficial and enjoyable.

Humorous behaviors that foster connectedness include responding to silly requests such as singing, making AYA laugh, and using humor to promote positive health behaviors. ''She [patient care assistant] would come in at 9:00 o'clock and say, 'It's 9:00 o'clock. I've made this many beds, and…What have you done today?' I would be lying there like 'ah, um', [and she would say] 'I want you to get up and walk around'. Or 'you need to eat something right now…' and that worked so well for me.'' Humor works best when HCPs use it at the appropriate times and, more importantly, knew when not to use humor. ''They'd come in, and tease me…when I'd be awake. They'd kind of know when to do it…when I'd be having a bad day they'd just…leave me alone.''

Theme Cluster 1.5. "Knowing who I am": Conveying respect, support, and caring. HCPs who convey respect for AYAs' personhood are more likely to connect with AYA. Conveying respect is (1) treating AYA more than just another cancer patient; (2) acknowledging and respecting AYAs' space; (3) providing enough information so AYA know what to expect; (4) handling embarrassing situations delicately; and (5) taking time to inquire about AYAs' needs, opinions, and desires. In addition, communicating in an age-appropriate manner that respects AYAs' autonomy is important: ''[The doctor] would…say 'if it is okay with you we were thinking about doing…we just wanted to make sure it was okay with you before we scheduled you for surgery'. That was cool because I am not the type of person that likes somebody to come in and say this is what we are doing…But he…knew how I was, so he asked me that way knowing that I would be like, 'oh, okay'.''

Participants feel their personhood is respected when HCPs act in supportive and caring ways, including (1) supporting their need to keep up with outside world; (2) supporting their autonomy and independence; and (3) helping them work through difficult situations. HCPs also convey caring by going above and beyond participants' expectations. ''I had my seventeenth birthday in the hospital and…my parents…forgot…so this one nurse…[had] a cake brought up to my room…we had a mini little party…I just thought that was really cool because I know she was so busy and she thought about giving me a cake.''

Theme Category 2. Characteristics and outcomes of connectedness: When connectedness is solidified

When HCPs exhibit specific behaviors to connect, described under Theme Category 1, participants describes the feelings they felt when they felt connected to HCPs. Theme Category 2 includes four theme clusters that describe the immediate outcomes of connectedness with HCPs. See Table 2 for a list of specific outcomes of connectedness.

Theme Cluster 2.1. "They valued what I had to say": Sense of being cared about, known, respected, and valued. When HCPs display behaviors of connectedness, participants experience a sense of being known, cared about, understood, respected, and valued as unique individuals. ''The way [surgeon] made sure every incision…was hidden. He [said] 'I know you might want to wear a bikini or swimsuit…So he wasn't like, 'this is how it's going to be'…he knew that I was a kid and that I was concerned about that kind of stuff. So he was very cool…I was appreciative.''

Sense of intimacy, security, and trust. Connectedness also fosters a sense of intimacy, security, and trust. ''He held

TABLE 2. THEME CATEGORY 2: CHARACTERISTICS AND OUTCOMES OF CONNECTEDNESS

Theme Cluster 2.1. Sense of being cared about, known, respected, and valued. Sense of intimacy, security, and trust.	Sense of being cared about Sense of being known Sense of being respected Sense of being valued	Sense of intimacy Sense of security Sense of trust
Theme Cluster 2.2. A comfortable haven in the midst of chaos	Sense of comfort among all of the turmoil related to the diagnosis and treatment Sense of comfort in communicating within the AYA-HCP relationship Sense of comfort in expressing oneself Buffers some of the discomfort AY endure during treatment	
Theme Cluster 2.3. When healthcare providers and adolescents connect so well–outcomes of connectedness	Blown away by HCPs who go the extra mile Strong desire to connect with HCPs Looking forward to future interacts with HCPs Sense of admiration for who HCPs are as a person Sense of joy and pleasure interacting with HCPs Increasing sense of confidence in self Increasing sense of empowerment Enhancing well-being	
Theme Cluster 2.4. Sense of gratitude	Overwhelming sense of gratitude Deep sense of gratitude for being treated as a unique person Highly appreciative Sense of gratitude for existential growth through their connectedness with HCPs Empathic understanding for HCPs Overflowing sense of connectedness (expands to perceived sense with the majority of HCPs and the environment) Grateful for the cancer journey finally coming to an end	

HCP, healthcare provider.

my hand [while I] counted back from 100 ... I was confident...he would do a good job—whether he did or not I have no idea. But for that split second...I felt confident that he would...take care of me.'' Recognizing the extent of the oncologist's trust is also common: ''...when I was feeling sorry for myself, I had my head under the blanket..., [the doctor] comes in and he's trying to tell us what is going on...My mom [says to me] take that blanket off of your head and listen...[he] said, 'she's listening'. I was listening. He knew. He knew that I had my mind set, I was feeling sorry for myself right then, but I was still listening.''

Theme Cluster 2.2. "We could just sit and talk": A comfortable haven in the midst of chaos. Participants describe experiences of connectedness with HCPs as having a comfortable haven in the midst of chaos. In other words, among all the turmoil related to the diagnosis and treatment, connectedness is a pleasant surprise that facilitates a sense of comfort. Participants gain a sense of comfort in communicating within the AYA-HCPs relationship when connected. Connectedness makes it easier to talk about uncomfortable subjects after having the opportunity to first sit down and talk to HCPs like a friend: ''We could just talk, sit and talk...then we would move on to the side conversation, 'when was your last period'.''

Another component of connectedness is a sense of comfort in expressing themselves, their concerns and frustrations to HCPs. ''I was able to talk with [my doctor], which was something I found I couldn't do with some of the other doctors. Some [doctors] just don't tend to have the greatest bedside manner, so they are kind of harder to talk to...especially for somebody my age...I would tell her things I wouldn't tell the other doctors.''

Connectedness with HCPs also buffers some of the discomfort participants endure in the hospital. They feel connectedness alleviates the tension of having to deal with HCPs they feel unconnected with and connectedness facilitates tolerance for having to endure things that might otherwise be considered intolerably intrusive.: ''He [doctor] would bring all the other doctors in with him, and put me on display—basically that is what it felt like, and he would always kid me about it. He's like, 'I'm going to start charging admission for all these kids coming in here to take a look at you'...I had certain things he said he wanted them to see.''

Theme Cluster 2.3. "Blown away": When HCPs and AYA connect so well–outcomes of connectedness. Participants describe being ''blown away'' by HCPs who go the extra mile to connect. They feel an overwhelming desire to connect with these HCPs and look forward to other opportunities to interact with them. They admire such HCPs as individuals and experience a sense of joy and pleasure when interacting with HCPs who connect so well. In addition, connecting with HCPs increases participants' own sense of confidence, empowerment, and well-being. ''They all really care...and understand...[Your] prognosis depends on that...If you don't feel okay...you're not going to be okay...your emotions play on you mentally and all of that plays into your physical well-being. So, [connectedness] helps a lot. When you know that other people are caring for you and care about you and really are focusing on 'what can I do to help this person'...it's really cool.''

Theme Cluster 2.4. "A dream-come-true": Sense of gratitude. When HCPs' behaviors facilitate connectedness, participants are pleasantly surprised and experience an overwhelming sense of gratitude. Although participants never directly used the word ''gratitude,'' their tone and words convey a strong sense of gratitude they feel toward HCPs who establish a meaningful connection with them. They are grateful for HCPs treating them as a unique human being, their existential growth, and the long journey finally coming to an end. These three aspects are hereafter described.

Treated as a unique human being. Participants describe a deep sense of gratitude for being treated as a unique human being by HCPs. They express being highly appreciative of HCPs who take the time to get to know them, go out of their way to provide care above and beyond their expectations, know how to address their emotional needs, and acknowledge and respect their personhood. ''It was cool that he did that because he knew I'm 18 [and] I don't have to do what you are saying...I can sign myself out and leave...But it was cool that he worded it like that even though he was going to do it anyways...Most surgeons won't do that.''

Existential growth. Participants also describe gratitude for having the opportunity to grow in meaningful ways through their experience of connectedness with HCPs. Participants gain insight into who they are as a person from being a cancer patient. In addition, connectedness with HCPs enriches the cancer experience. Gratitude toward HCPs also contributes to gaining an empathic understanding of HCPs. Participants are less angry and demanding of HCPs with whom they feel connected to, even when legitimate needs are not addressed promptly: ''She [the nurse practitioner] runs around like a chicken with her head cut off because she has all of this stuff to do... if I call her [for a prescription] ...she's like 'okay, I'll get right on that'... you might get your prescription in a week or you might not get it at all. That's annoying but you can't be mad at her...because she has all of this stuff she has to do, so you really can't be mad at her for forgetting.''

Participants also describe that their connectedness and gratitude overflows to others. For example, when participants express gratitude toward HCPs they feel connected to it expands to multiple HCPs involved their care. Consequences of having an overflowing connectedness and gratitude include a realization that the environment is not as bad as originally perceived, being reluctant to label the majority of HCPs as uncaring, and taking an active part in achieving their health outcomes.

Discussion

This study revealed the specific behaviors of HCPs to connect with AYA and the outcomes of connectedness. These findings fill a knowledge gap on the behaviors of HCPs perceived by AYA as most beneficial with regards to HCPs identifying AYAs' needs and treatment distress.

One key finding AYA describe as essential in fostering connectedness is HCPs treating them like a friend. This finding is in contrast to reports that describe setting professional boundaries, which are often strict and instruct HCPs to not extend the relationship beyond their professional role.[28,29] AYA in this study use the term ''friend'' to describe the nature

of the communication and relationship that fosters connectedness. A "friend-like" approach to AYA is considered as highly beneficial—rather than unprofessional. In addition, a "friend-like" approach is the key to communicating on the same level as AYA and decreasing their perception of a hierarchical/dominant relationship of HCPs and AYA.[18] Simple strategies that can be used by HCPs include (1) sharing commonalities they have with AYA (i.e., similar interests in sports, movies, and other activities), and (2) asking AYA about their life outside of the hospital.

It is also important to note that several of the behaviors and strategies AYA describe do not require an extensive time commitment. Many behaviors can be easily incorporated into HCPs everyday interactions with AYA. More importantly, the meaningful information that HCPs obtain from AYA using these behaviors will help HCPs deepen the AYA-HCPs connectedness foundation and produce a comfortable environment in which AYA can express their needs and concerns. Furthermore, the outcomes AYA experience from their sense of connectedness with HCPs outweighs any additional time commitment it may take to foster connectedness.

Formal training of HCPs on how to foster and maintain connectedness is generally not provided and may significantly contribute to the difficulty they have in meeting the psychosocial needs of AYA. Findings from this study provide evidence for a need for formal training and can help HCPs tailor their communication. In addition, systematic approaches to help HCPs better assess AYA psychosocial needs and distress is needed. One approach we are developing is a resilience profile that is based on the well-tested Resilience in Illness Model (RIM) for AYA.[30,31] The resilience profile is a psychosocial assessment that summarizes the protective and illness-related risk factors that enhance or hinder resilience in AYA. A series of reliable, valid measures are used to assess the RIM factors and then the scores from the RIM measures are used to generate the resilience profile, which summarizes and interrupts their scores. The resilience profile is then used by a HCP to help facilitate the conversation with the AYA regarding his/her strengths and areas that may need attention. The resilience profile may be useful as a psychosocial workup for HCPs to use as a standardized way to validate or alter initial clinical impressions, systematically identify the AYA needs, and foster AYA-HCP connectedness.

Lastly, the aim of this study was to describe adolescents' experiences of connectedness with HCP during the time they were diagnosed and treated for cancer, so eligibility criterion adolescents diagnosed and treated for cancer between 15 and 21 years of age. Our inclusion criteria rationale was that adolescents 15–18 years are developmentally different than adolescents <15 years. AYA 15 years and older are who are less dependent on family and have more autonomy (e.g., completed freshman year of High School, learning to drive, etc.) and are likely to be more engaged in treatment decisions than those >15 years. The age range of 18–24 years is circumstantial to the time these participants were diagnosed and treated for cancer—all had to be at least 6 months from the end of treatment.

Study strengths and limitations

This study has strengths and limitations. First, this is the first study to examine the experiences of connectedness with HCPs from the perspective of AYA. Second, the sample has a good representation of gender and the most common cancer types seen in the AYA population; however, the lower representation of race is a limitation of this study. Although the sample size is small, the identified theme categories met the redundancy criterion, required for phenomenological studies to achieve transferability.[32] Lastly, participants in this study were actively engaged in long-term cancer follow-up and felt on some level connected with their HCPs. AYAs who are not participating in long-term follow-up may have different experiences of connectedness, including being disconnected or unconnected. Despite these shortcomings, this study makes an important contribution to the literature in regards to how HCPs connect with AYA and outcomes of connectedness for AYA.

Conclusion

HCPs have difficulty identifying and addressing the psychosocial needs of AYA. Fostering the ability of HCPs to connect with AYA and maintain connectedness is essential in resolving this problem. This article highlights specific behaviors of HCPs used to foster connectedness with AYA. Connectedness breaks down the communication barrier between AYA and HCPs. When AYA feel connected, they feel comfortable and are empowered to discuss their needs with HCPs.

Acknowledgements

Author Disclosure Statement

No competing financial interests exist.

References

1. Phillips-Salimi CR, Andrykowski MA. Physical and mental health status of female adolescent/young adult survivors of breast and gynecological cancer: a national, population-based, case-control study. Support Care Cancer. 2013;21(6):1597–604.
2. Tai E, Buchanan N, Townsend J, et al. Health status of adolescent and young adult cancer survivors. Cancer. 2012;118(19):4884–91.
3. Kazak AE, Derosa BW, Schwartz LA, et al. Psychological outcomes and health beliefs in adolescent and young adult survivors of childhood cancer and controls. J Clin Oncol. 2010;28(12):2002–2007.
4. Seitz DC, Besier T, Debatin KM, et al. Posttraumatic stress, depression and anxiety among adult long-term survivors of cancer in adolescence. Eur J Cancer. 2010;46(9):1596–606.
5. Hedstrom M, Kreuger A, Ljungman G, et al. Accuracy of assessment of distress, anxiety, and depression by physicians and nurses in adolescents recently diagnosed with cancer. Pediatr Blood Cancer. 2006;46(7):773–9.
6. Siembida EJ, Bellizzi KM. The doctor-patient relationship in the adolescent cancer setting: a developmentally focused

literature review. J Adolesc Young Adult Oncol. 2015;4(3):108–117.

7. Zebrack B, Mathews-Bradshaw B, Siegel S. Quality cancer care for adolescents and young adults: a position statement. J Clin Oncol. 2010;28(32):4862–7.

8. Fox SF, Chelse C. Living with chronic illness: a phenomenological study of the health effects of the patient–provider relationship. J Am Assoc Nurse Pract. 2008;20(2):109–117.

9. Bakker DA, Fitch MI, Gray R, et al. Patient-health care provider communication during chemotherapy treatment: the perspectives of women with breast cancer. Patient Educ Couns. 2001;43(1):61–71.

10. Epstein RM, Duberstein PR, Fenton JJ, et al. Effect of a patient-centered communication intervention on oncologist-patient communication, quality of life, and health care utilization in advanced Cancer: the VOICE randomized clinical trial. JAMA Oncol. 2017;3(1):92–100.

11. Phillips-Salimi CR, Haase JE, Kooken WK. Connectedness in the context of patient-provider relationships: a concept analysis. J Adv Nurs. 2012;68(1):230–45.

12. Atlas SJ, Grant RW, Ferris TG, et al. Patient-physician connectedness and quality of primary care. Ann Intern Med. 2009;150(5):325–35.

13. Mallinger JB, Griggs JJ, Shields CG. Patient-centered care and breast cancer survivors' satisfaction with information. Patient Educ Couns. 2005;57(3):342–9.

14. Nass SJ, Beaupin LK, Demark-Wahnefried W, et al. Identifying and addressing the needs of adolescents and young adults with cancer: summary of an Institute of Medicine workshop. Oncologist. 2015;20(2):186–95.

15. Keegan TH, Lichtensztajn DY, Kato I, et al. Unmet adolescent and young adult cancer survivors information and service needs: a population-based cancer registry study. J Cancer Surviv. 2012;6(3):239–50.

16. Smith AW, Parsons 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;3:75.

17. Zebrack B, Kent EE, Keegan TH, et al. "Cancer sucks," and other ponderings by adolescent and young adult cancer survivors. J Psychosoc Oncol. 2014;32(1):1–15.

18. Bahrami M, Namnabati M, Mokarian F, et al. Information-sharing challenges between adolescents with cancer, their parents and health care providers: a qualitative study. Support Care Cancer. 2017;25(5):1587–96.

19. Tsangaris E, Johnson J, Taylor R, et al. Identifying the supportive care needs of adolescent and young adult survivors of cancer: a qualitative analysis and systematic literature review. Support Care Cancer. 2014;22(4):947–59.

20. Phillips CR, Haase, Broome ME, et al. Connecting with healthcare providers at diagnosis: adolescent/young adult cancer survivors' perspectives. Int J Qual Stud Health Well-being. 2017;12(1):1325699.

21. Colaizzi PF. Psychological research as the phenomenologist views it. In: Valle R, King M (Eds). Existential-phenomenological alternatives for psychology. New York: Oxford University Press; 1978; pp. 48–71.

22. Husserl H. Crisis of European sciences and transcendental phenomenology. Chicago: Northwestern University Press; 1970.

23. Cresswell JW. Qualitative inquiry and research design: choosing among five traditions. Thousand Oaks: Sage; 1998.

24. Giorgi A. The phenomenological movement and research in the human sciences. Nurs Sci Q. 2005;18(1):75–82.

25. Haase JE. Components of courage in chronically ill adolescents: a phenomenological study. ANS Adv Nurs Sci. 1987;9(2):64–80.

26. Guba EG, Lincoln YS. Effective evaluation: improving the usefulness of evaluation results through responsive and naturalistic approaches. San Francisco: Jossey-Bass; 1981.

27. Sandelowski M. The problem of rigor in qualitative research. ANS Adv Nurs Sci. 1986;8(3):27–37.

28. Gabbard GO, Nadelson C. Professional boundaries in the physician-patient relationship. JAMA. 1995;273(18):1445–9.

29. Griffith R, Tengnah C. Maintaining professional boundaries: keep your distance. BJCN. 2013;18(1):43–6.

30. Haase JE, Kintner EK, Monahan PO, Robb SL. The resilience in illness model, part 1: exploratory evaluation in adolescents and young adults with cancer. Cancer Nurs. 2014;37(3):E1–12.

31. Haase JE, Kintner EK, Robb SL, et al. The resilience in illness model part 2: confirmatory evaluation in adolescents and young adults with cancer. Cancer Nurs. 2016;40(6):454–463.

32. Sandelowski M. Sample size in qualitative research. Res Nurs Health. 1995;18(2):179–83.

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