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Original article

## Intimacy, Substance Use, and Communication Needs During Cancer Therapy: A Report From the “Resilience in Adolescents and Young Adults” Study



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 A B S T R A C T

**Purpose:** The prevalence of intimacy and substance use among adolescents and young adults during cancer therapy has not been well described.

**Methods:** The “Resilience in Adolescents and Young Adults with Cancer” study was a prospective, multicenter, mixed-methods cohort study. English-speaking patients 14–25 years old with newly diagnosed cancer were invited to complete a comprehensive survey at the time of enrollment (T1) and 3–6 months later (T2). Intimate relationships and health behaviors were assessed with questions adapted from the Guidelines for Adolescent Preventative Services assessment. Descriptive statistics characterized the prevalence of sexual and substance-related behaviors at each time point.

**Results:** Of 42 eligible and enrolled participants, 35 (83%) and 25 (59%) completed T1 and T2 surveys, respectively. Their mean age was 17.6 years (standard deviation 2.3), 57% were male, and the most common diagnoses were sarcoma and acute leukemia. Over a third of participants reported dating at each time point; 26% were sexually active at T1, and 32% at T2. Of those endorsing sexual activity, fewer than half reported consistent birth control or condom use and 4 reported their first sexual intercourse during our observation. In addition, 46% (T1) and 44% (T2) reported alcohol use and 23% (T1) and 26% (T2) reported illicit drug use. Despite these activities, fewer than 10% endorsed a worry or need to discuss these behaviors with oncology providers.

**Conclusions:** Intimacy and substance use among adolescents and young adults are common during cancer therapy. Clinical and research implications include the identification of optimal communication and patient-centered supports.

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**IMPLICATIONS AND CONTRIBUTION**

Sexual intimacy and substance use are common among adolescents and young adults with cancer. Medical and psychosocial clinicians should normalize and inquire about these behaviors in order to better meet patient needs, even if such needs are not verbally endorsed.

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The long-term impact of cancer among adolescents and early young adults (AYAs, ages 14–25 years) has been well described. This group of patients has not experienced the same improvements in survival as have younger pediatric and older adults with cancer [1]. Likewise, because it may disrupt normal developmental processes of identity development, a diagnosis of cancer during this age is associated with negative psychosocial outcomes including poor mental health, impaired quality of life, social isolation, and diminished educational/vocational attainment [2–7].

Evidence suggests that certain health behaviors and outcomes among long-term survivors of AYA cancer play particular roles in their overall well-being. For example, childhood cancer survivors diagnosed between 11 and 20 years of age have impaired sexual function and diminished libido compared to those diagnosed earlier in childhood; qualitative data suggest this disrupted sexual development translates to unmet psychosocial and communication needs which, in turn, negatively impact overall AYA quality of life both during cancer therapy and survivorship [8–11]. A recent systematic review described similar patterns of tobacco use among long-term AYA survivors compared to their peers, while data from childhood cancer survivors suggest alcohol and tobacco use are more prevalent in this group compared to sibling or population controls [12,13]. These findings are concerning because substance use, itself, is a leading cause of morbidity and mortality in this age group [14,15]. Furthermore, AYA survivors are at risk for long-term late medical effects such as secondary malignancy and impaired cardiovascular health, both of which may be exacerbated by poor health behaviors [16–18].

Comparatively less is known about AYA health behaviors during cancer therapy. In a cohort of 42 patients (ages 12–19 years) who were receiving chemotherapy, a single cross-sectional survey suggested participants consumed alcohol and had sexual intercourse less than their peers [19]. Those who did engage in sexual activities, however, tended to have more partners and use protection less consistently. To our knowledge, no studies have described longitudinal patterns of health behaviors during cancer therapy. We aimed to prospectively quantify patient-reported intimate and health behaviors plus other communication needs. Such knowledge may not only inform clinical counseling and intervention development but may also provide critical insight into the existing health disparities experienced by AYAs with cancer.

## Materials and Methods

### Participants

“Resilience in Adolescents and Young Adults with Cancer” was a prospective, longitudinal, mixed-methods study conducted at two large pediatric cancer centers (Seattle Children’s Hospital and Dana-Farber Cancer Institute/Boston Children’s Hospital) designed to evaluate patient-reported stress, coping, and resilience. It was approved by the Institutional Review Boards at both sites. Consecutive AYAs (ages 14–25 years) diagnosed with cancer between December 2012 and November 2013 (Seattle Children’s Hospital) or February 2014 and January 2015 (Dana-Farber Cancer Institute/Boston Children’s Hospital) were screened for the following eligibility criteria: English-speaking, able to complete written surveys, and diagnosed with non-central nervous system cancer requiring chemotherapy treatment between 14 and 60 days prior to enrollment. This age range was selected in keeping with National Cancer Institute

definitions of “AYA” and the range of ages treated at the two institutions. Study staff then queried participants’ primary medical providers to request permission to approach. At the time of enrollment, all participants provided written assent (<18 years old) or consent (≥18 years old); parents of participants <18 years old also provided written informed consent.

### Patient-reported outcomes assessment

All participants were invited to complete a patient-reported outcome (PRO) survey (the “Resilience in Pediatric Cancer Assessment,” RPCA) within 1 week following enrollment (T1) and 3–6 months later (T2). These time points were selected in order to capture perceptions early in the cancer experience as well as after a period of adjustment. As an incentive for participation, participants received \$50 for each interview and \$25 for each survey. Participants with refractory or relapsed disease during the course of the study were subsequently removed from the study in order to minimize heterogeneity of experiences.

The RPCA survey includes age-appropriate validated instruments to measure PROs including resilience, hope, psychological distress, quality of life, benefit finding, and sexual and substance-related health behaviors [20,21]. This analysis describes secondary objectives to evaluate the latter, which are queried using adapted questions from the Guidelines for Adolescent Preventative Services risk assessment and request responses based on the past 2 weeks [22]. Items include statements such as, “I am currently sexually active,” or “I have used drugs (marijuana, cocaine, speed, crack, etc.)” and response options are based on a Likert scale (“not at all”/“a little bit”/“somewhat”/“quite a bit”/“very much”). No objective measure of participant substance use (e.g., prescribed opioid consumption) was collected. In addition, participants are provided an opportunity to report other health care communication needs with a stem stating, “Many adolescents and young adults have worries and/or needs their providers may not ask about. Which of the following would you like to talk about more with your providers? (check all that apply).” Response options include mood changes, bullying, suicide, body image concerns, sex, and substance use stems. Finally, additional RPCA items capture demographic and medical variables. The full survey completion time is approximately 30 minutes.

All participants were offered the option of completing the RPCA online or via paper-and-pencil at each time point and received electronic reminders for incomplete surveys 7 and 10 days later. Surveys were collected for up to 3 months following each due date before being considered lost to follow-up (e.g., T1 surveys were collected up to 3 months post enrollment, and T2 surveys were collected up to 9 months after T1). Nonresponse after this window of time was considered to be a passive refusal to participate, and participants were subsequently removed from surveillance.

### Semistructured interviews

In addition to PRO surveys, participants enrolled on the study were invited to participate in 1:1 semistructured interviews at the same time points until qualitative data reached saturation at T1 (n = 18) [23,24]. The interview guide was designed to focus on patient perceptions of stress, coping, and resilience during cancer not necessarily intimacy or substance use [23]. As part of the guide, whenever participants commented on dating or sexuality, these concepts were purposefully probed with questions such as,

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