

## Cancer-Related Disclosure Among Adolescent and Young Adult Cancer Survivors: A Qualitative Study

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**Purpose:** Adolescents and young adults (AYAs) employ self-disclosure in normative social interactions and in promoting identity development. Disclosure is associated with numerous psychological and physical benefits. Little research has examined how AYA cancer survivors diagnosed during adolescence disclose their cancer history.

**Methods:** Using a qualitative design, this study explored cancer-related disclosures among survivors ( $N = 26$ ) 16–24 years old at study ( $M = 19.6$  years), 14–18 years old at diagnosis ( $M = 15.6$  years), and currently at least 6 months post-treatment ( $M = 3.2$  years). Semi-structured interview guides were developed and used. Disclosure-related topics included survivorship communications and others' responses to AYAs' disclosure of their cancer experiences.

**Results:** Grounded theory and thematic content analysis guided analyses, with an inductive data-driven approach. Three themes and eight subthemes emerged: “it depends” decision-making processes (don't ask/don't tell, shared experience, relationship potential), perceptions of others' responses (perceived apprehension, positive responses), and methods of disclosure (verbal, written, behavioral). No thematic differences were found by gender or age, although females reported greater frequency of disclosures.

**Conclusion:** Disclosure emerged as a nuanced and complex process. “It depends” decision-making processes were most frequently endorsed, consistent with developmental complexities of this age group. This reflects social and psychological changes and highlights unique challenges for AYA survivors. This also reflects the importance of peers and social interactions as variables that influence disclosure. In the context of AYA cancer survivorship, understanding ways in which disclosure may bolster or hinder social support can assist survivors, clinicians, and families navigate survivorship. Implications for future research are discussed.

**Keywords:** self-disclosure, disclosure, survivorship, social relationships, cancer communications

CURRENT 5-YEAR SURVIVAL RATES for childhood and adolescent cancer survivors exceed 80%.<sup>1,2</sup> The latest Surveillance, Epidemiology and End Results monograph reports that 2.7 times more individuals are diagnosed with cancer during ages 15 to 30 than before turning 15.<sup>1</sup> Adolescent and young adult (AYA)-aged survivors diagnosed while an AYA are found to have poorer outcomes when compared to younger or older patients.<sup>3,4</sup> AYAs experience a unique set of healthcare challenges and psychosocial needs as they navigate normative development alongside survivorship and potential late effects.<sup>4–10</sup> Cancer diagnosed during the AYA age range impacts AYAs' psychological well-being and relationships, psychosocial adjustment, and coping skills, and can inform values, goals, and worldviews.<sup>9,11</sup> Poorer psychosocial outcomes and fewer positive health beliefs are

found among survivors diagnosed later in adolescence.<sup>12</sup> Sharing the impact or meaning of one's cancer experience may direct or shape AYAs' development post-treatment. The present study explores cancer-related disclosures among AYA-aged survivors diagnosed while an AYA. Self-disclosure—the sharing or communication of one's personal thoughts, feelings, and experiences—is a hallmark of human interactions and an essential dimension of social and intimate relationships.<sup>13–16</sup>

Self-disclosure can promote identity development and impact social interactions through the development of social support and intimacy.<sup>13,15–17</sup> Little research has examined AYA survivors' disclosures of their cancer history. Self-disclosure can take many forms, which include verbal, written, or behavioral (e.g., event or organization participation). It is associated

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with numerous benefits (e.g., self-concept, greater social intimacy and support, empowerment, greater self-awareness) and can affect a variety of variables (e.g., emotional well-being, interpersonal relatedness, behavioral- and health-related outcomes).<sup>13,16,18–21</sup> Expressing negative, stress-related, or traumatic experiences verbally or in writing is associated with physical and psychological benefits.<sup>18,19,22–26</sup>

Social cognitive theory posits that talking with others facilitates processing of an experience if the context is supportive and positive.<sup>27–30</sup> During AYA cancer survivorship, this suggests that limited and unsupportive social environments, or social development negatively hindered by treatment, may significantly reduce opportunities for disclosure and subsequent benefits.<sup>31,32</sup> Talking about cancer and meeting survivors has been identified as a social information need for survivors diagnosed during adolescence and young adulthood, a need currently unmet.<sup>31</sup> Post-illness disclosure can also create opportunities to establish social support or rejection, adding new information about the discloser in a broader social context.<sup>32,33</sup> Disclosure may play a role as AYA survivors incorporate cancer into their sense of self and negotiate a lifestyle that includes visible (e.g., scars) and invisible (e.g., infertility) late effects.

As an important aspect of AYA social development and its potential benefits, cancer-related disclosure warrants closer examination. To date, there are no published studies examining cancer-related disclosures among this cohort. Few validated measures on self-disclosure exist for general or cancer populations of any age that cater to qualitative methodology. This study examined cancer-related disclosure among AYA-aged survivors diagnosed during adolescence and young

adulthood. Aims were: (1) to identify and describe themes of cancer-related disclosure and (2) to describe related subthemes and explore possible gender and age differences.

## Methods

### Participants

Potentially eligible participants seen at Memorial Sloan Kettering Cancer Center (MSKCC) and who lived within one hour of MSKCC were randomly selected. Eligibility included: 15–25 years old at participation, 14–21 years old at diagnosis, completed cancer treatment at least 6 months prior, and ability to interview in-person. Recruitment letters were sent to 90 survivors and/or parents. From recruitment, 28% ( $n = 25$ ) were unable/unwilling to travel (e.g., scheduling conflicts, at college), 28% ( $n = 25$ ) were lost to follow-up, nine refused, and five were ineligible. Consent and/or assent (for participants under age 18) was obtained from 27 participants (29%), a response rate of 70%.

### Interviews

As part of a larger study, 26 semi-structured individual interviews (90 minutes in length) were conducted between March and June 2009 by a trained research assistant. Semi-structured interview guides containing topics and probes were developed based on themes derived from literature and clinical practice (JSF). Probes were generated, pilot-tested, and refined with five non-participant AYA survivors. See Table 1 for relevant disclosure-related probes. Participants were compensated \$40.

TABLE 1. DESCRIPTION OF CODES AND INTERVIEW PROBES

Code	Description	Interview probes
Survivorship communications: <i>Deciding who to tell</i>	Comments describing how participants decide to whom they will or will not disclose that they have been diagnosed with cancer after treatment. This is different than disclosure at the time of diagnosis because the participant often has more choice and control over to who they disclose their cancer history.	(1) How do you decide who you are going to tell and/or not tell about being a survivor? (2) When you meet people for the first time do you tell them you are a survivor? How? What do you say? (3) Do you tell people who you date about your cancer?
Survivorship communications: <i>Disclosure attitudes and experience</i>	A narrative that describes how a participant discloses their cancer story or experience to others. This may include: (1) Orientation, thoughts, feelings. (2) How others respond or react. (3) Various forms of disclosure (e.g., writing essays, Facebook posts). (4) Explanation that something about themselves or what is important in life was learned from the disclosure process. (5) Responses to others during disclosure (e.g., reassuring others they are okay). (6) Avoiding using the word cancer.	(1) Do your friends know that you are a cancer survivor? How do they react when you tell them? How does that make you feel? (2) Do you tell your teachers or your co-workers? How do they act toward you afterwards?
Others' response to disclosure of cancer diagnosis, treatment, and/or survivorship	Others publicly recognize the participant's cancer experience at any point during their cancer experience, diagnosis/treatment, or in the survivorship phase.	(1) Do your teachers treat you differently since learning about your cancer? How? How does it make you feel?

Data analysis

Interviews were audio-recorded, transcribed, and imported into ATLAS.ti as part of the larger study.<sup>34</sup> Grounded theory and thematic content analysis guided analyses with an inductive data-driven approach. This included multiple stages of intensive reading and interpretation of transcripts to identify recurring thematic patterns across the entire data set.<sup>34-37</sup>

As part of the larger study, qualitative data analysis was conducted by four trained coders who independently read a selection of interviews to identify high-level domain areas given the aims of the larger study. During preliminary open coding, coders independently referenced domain areas to select salient quotations and create descriptive codes that represented meaning of the content, generating a foundational codebook.<sup>37</sup> Interviews were then independently coded and code consensus reached. Coders resolved coding differences, merged similar codes, simplified code names/definitions, and ensured mutually-distinct and inclusive coding (inter-rater reliability >80%). Thematic salience was assessed through analyst triangulation (multiple analysts reaching similar conclusions during independent analysis) and evaluating the degree thematic findings repeated and recurred across participants overall, by gender, and by current age.<sup>38-41</sup> Rigorous analysis and iterative consensus work provided opportunities for generating themes systematically, an effective method of attaining outcome confidence.<sup>42,43</sup>

For the current analysis, four of the 88 overall codes were identified based on broad relevance to cancer-related disclosures, therefore capturing a range of applicable quotes from all the coded narrative content. These codes included survivorship communications (i.e., deciding whom to tell, disclosure attitudes, disclosure experiences) and others' responses to disclosures (Table 1). Identified themes were compared by gender and age group (ages 15-19 and 20-25).

Results

Participants (N=26) were predominantly female (61.5%), Caucasian (65.4%), 16-24 years old at participation (M=19.6 years; standard deviation [SD]=2.8), and diagnosed while 14-18 years old (M=15.6 years; SD=1.3). Half of participants were within 2-5 years post-treatment (M=3.2 years). The most common cancer diagnoses were lymphoma (30.8%), sarcoma (19.2%), and leukemia (11.5%); 65.4% of participants received multi-modal treatment. The majority of participants were currently in school (84.6%) and employed (61.5%) either full- or part-time (Table 2).

Overall, 141 disclosure quotes were identified that described varying decision processes, perceptions of others' responses, and methods of disclosure. All participants reported at least one instance of cancer-related disclosure. Three themes and eight subthemes emerged (Table 3): "it depends" decision-making processes (don't ask/don't tell, shared experience, relationship potential), perceptions of others' responses (perceived apprehension, positive responses), and methods of disclosure (verbal, written, behavioral). Themes were not mutually exclusive.

No significant thematic differences emerged by gender. Females, however, identified more instances in which they disclosed, and provided greater detail and depth of individual experiences and decisions to disclose. Consistent with the participants' gender distribution (61.5% female), 63.8% of

TABLE 2. DEMOGRAPHIC AND MEDICAL CHARACTERISTICS (N=26)

Variable	n	%	M	SD	Range
Gender					
Female	16	61.5			
Male	10	38.5			
Age at diagnosis (years)			15.6	1.3	14-18
Age at study (years)	26		19.6	2.8	16-24
15-19	15	57.7			
20-24	11	42.3			
Ethnicity					
White	17	65.4			
Hispanic	2	7.7			
African American	5	19.2			
Asian/Pacific Islander	2	7.7			
Marital status					
Single	26	100.0			
Married or equivalent	0	0			
Highest education level completed <sup>a</sup>					
Partial high school	7	26.9			
Partial college	12	46.2			
Completed college	1	3.8			
Not indicated/Unsure	6	23.1			
Currently a student	22	84.6			
Currently employed	16	61.5			
Time since treatment ended (years)					
<2	8	30.8			
2-5	13	50.0			
>5	5	19.2			
Cancer diagnosis					
Leukemias	3	11.5			
Lymphomas	8	30.8			
Neuroblastoma	2	7.7			
Other <sup>b</sup>	6	23.1			
Sarcomas	5	19.2			
Thyroid	2	7.7			
Type of treatment					
Chemotherapy	18	68.2			
Radiation	11	42.3			
Surgery	17	65.4			
Multi-modal treatment	17	65.4			

<sup>a</sup>As per self-report.

<sup>b</sup>"Other" includes: craniopharyngioma, germ cell cancer, gestational trophoblastic disease, melanoma, pancreatic cancer, and teratoma tumor.

SD, standard deviation.

the 141 disclosure quotes were reported by females. No significant differences were found between age groups.

Decision-making processes: it depends

Participants' decisions regarding if, when, and with whom to disclose involved three thematic processes that were influenced by social interactions and an "it depends" thought process. This highlights the internal decision-making process and social nature of disclosure and was the most commonly cited theme, described by 57.7% of participants.

It depends: If you don't ask, I don't tell. Participants described that if others did not ask, they did not bring cancer up either spontaneously or self-initiated. While not prompted

TABLE 3. THEMES AND EXEMPLAR QUOTES

<i>Theme</i>	<i>Subtheme</i>	<i>Exemplar quotes</i>
Decision-making processes: it depends	It depends: If you don't ask, I don't tell	I don't really [decide]. Whenever someone asks I tell them ... anyone can know if they just ask. (17-year-old male, thyroid cancer) It's not something I go around telling everybody on a day-to-day basis. To me it's in the past. It's something I've moved on from. If it somehow comes up, through other things, then I'll explain it. (19-year-old male, leukemia)
	It depends: If we have a shared experience	If it's a serious situation, I will tell people. At my job, a customer's daughter was in the hospital, so I felt I had to tell her. I like knowing I could be there for somebody in their time of need. (24-year-old female, osteosarcoma)
	It depends: On our relationship potential	If someone is going to be close to me, or people that do care or are going to care about me, they should know things like that. (17-year-old male, melanoma) If I'm going to be close with this person or I'm going to spend a lot of time with them, I think they should know. (16-year-old female, osteogenic sarcoma)
Perceptions of others' responses	Perceived apprehension	I don't want a sympathy party. (24-year-old female, osteosarcoma survivor) I don't want to say I'm a cancer survivor; it'll depress everyone. (19-year-old male, leukemia)
	Positive responses	My friends hear me talk about it. I could talk about it with them. But I talk about it with them for a reason, because they don't look at me like, "Oh, you poor thing." (24-year-old female, osteosarcoma) It brings me joy and positive feelings when I share my experience. It's comforting to repeat my story. (18-year-old male, Hodgkin lymphoma)
Method of disclosure	Verbal	It's such a big part of my life, and had such an impact on me that I do like talking about it. I'm very flattered when people ask me about it or want to talk to me about it. (19-year-old female, pancreatic cancer)
	Written	It felt really good to let everything out [after reading my English essay] ... I was really surprised when people reacted in a positive and supportive way and didn't act weird. (18-year-old female, Hodgkin lymphoma) In my [psychology] essay the goal is to explain how life is not life <i>after</i> cancer; it's more like life <i>with</i> cancer. Just because the disease isn't there you're still living the cancer lifestyle to some extent. (21-year-old male, Ewing sarcoma) I wanted to get the message out to people, but I don't want sympathy. So I wrote it down. It felt really good to just let everything out. (18-year-old female, non-Hodgkin lymphoma)
	Behavioral	I've been more willing to volunteer and get other people involved. It's time to do it back for everyone else. I got to keep going. I met new people that way and I don't really talk to people about what happened but at those points I really wanted people to understand. (17-year-old male, Hodgkin lymphoma)

during the interview to discuss initial disclosures further, participants described initial disclosure as passive (only if others asked), but that they were subsequently open to talking. This suggests that unless prompted, cancer experience was not brought up in conversation. Others stated they were open to disclosing their cancer, but felt it was unnecessary to personally initiate or bring up. One participant described actively telling her boyfriend when they began dating, but stated she would not bring it up again unless he did: "I let him know in the beginning of the relationship, 'I'm a previous cancer patient ... If you need to know more than that just ask. I'll tell you.'"

Within this subtheme, 34.6% of participants described that scars prompted peers to ask cancer-related questions. Physical scars were also a way for survivors to purposefully avoid

disclosing cancer. When asked about scars, some replied with sarcasm ("I was in a gang fight") or vague explanations without mentioning the word "cancer" ("I had surgery").

It depends: If we have a shared experience. Disclosure was described as motivated by a situation or relationship in which others had a shared or similar experience. For instance, they disclosed if concerned about someone's health, or to provide education increasing cancer or health awareness. In these situations, a sense of shared understanding and camaraderie was expressed.

It depends: On our relationship potential. Quality and depth of a survivor's relationship or relationship potential



with the recipient of disclosure, either currently or anticipated, was salient. It was important for significant relationships to know about their cancer, or if they anticipated a close friendship (roommate) or someone they would interact with often (teammate). While interview probes explored disclosures to specific people (e.g., “Do you tell teachers or co-workers?”), the relationship potential was more salient than differences between the role or position of the recipient: “... if I feel like I’m close with a teacher, then I tell them.” Others assumed teachers knew either from their parents disclosing or from prior school absences, foreclosing their disclosure to them: “I don’t tell. I think [teachers] just know.”

#### *Perceptions of others’ responses*

Participants described their experienced responses (perceived responses) after disclosure, which impacted if and how they disclosed. A difference was found in the perceived responses from younger versus older recipients of disclosure. In general, older recipients (e.g., parents of friends, teachers) were more understanding, less surprised, and more willing to discuss cancer in greater depth than younger recipients (e.g., classmates, same-age peers). Younger recipients responded with greater surprise, bewilderment, or immaturity. Overall, recipients’ age emerged as a more salient theme than their role (e.g., teacher, classmate) in the disclosure interaction. One survivor felt younger people reacted with surprise because they did not know any cancer survivors or understand what treatment entails. He also felt that peers are often surprised by his age, “... some [peers] have the image or assumption that cancer is an old person thing.” Another survivor described:

People my age don’t understand. They’re in their own world. They’re like, “I’m a teenager, I wanna have fun. I don’t care about all this big stuff.” And adults say, “You had a tumor and surgery—that’s big. That’s great that you overcame that, you’re so strong.” I feel adults think about and understand it more.

A recipient’s age difference from the survivor also impacted their comfort to disclose: “I don’t know if it was because I wanted to avoid talking about it or because I was embarrassed. If it was an adult asking, I would’ve been able to talk to them. If it was a girl my age, she wouldn’t get it.”

**Perceived apprehension.** AYAs described not wanting to be viewed or treated differently after disclosure. One survivor felt her disclosure elicited a negative response, decreasing her disclosures: ““Oh, that’s the cancer girl;’ I didn’t want them to think like that.” Additionally they did not want others to feel badly, to “depress or upset” others, or to “bring everybody down.”

**Positive responses.** Disclosure was also described as positive: “It brings me joy and positive feelings when I share my experience.” Without perceived apprehension or negative reactions, disclosure was described as more helpful, positive, comforting, and frequent.

#### *Method of disclosure*

Three methods of disclosure were described: verbal, written, and behavioral.

**Verbal.** Verbal disclosure, reported by 65.4%, involved speaking about cancer regardless of disclosure frequency, quality, depth, or attitude. In addition to talking to family and friends, four participants gave cancer-related speeches to schools or organizations (i.e., Make-A-Wish, Relay for Life), or were interviewed (i.e., local news). One participant felt good when others formally asked about her cancer, providing her more opportunity to talk about it.

Within this subtheme, no participants endorsed or expressed interest in disclosure through counseling. One participant felt counselors’ aims were different from his and did not appreciate a past counselor’s efforts to get him to put cancer behind him: “I don’t want closure on the subject. I don’t want it to be an experience I forget about.”

While every participant endorsed at least one instance of cancer-related disclosure, 11.5% reported infrequent and undesired verbal disclosure. One reason for this was feeling “not worthy” because their “easy treatment” did not significantly threaten or disrupt their life, especially compared to those with more intensive treatments. Additionally, others felt talking about cancer was not relevant to their current life: “I don’t think [others] need to know [about my cancer] to judge me as a person.”

**Written.** Some (30.8%) participants described sharing their cancer through writing (e.g., college essay, school assignment). This writing also created positive reactions from others, and provided an outlet to express and share their experience. After one female read her essay in class, she described that “it felt really good to let everything out.” Writing provided a way to express and clarify their meaning and relationship to cancer without experiencing others’. No participants reported writing about cancer on blogs or online forums.

**Behavioral.** Behavioral disclosure—participating in activities or events indicative of cancer—was endorsed by 23.1% of participants. This overlapped with verbal disclosure, and included joining survivorship groups ( $n=3$ ; e.g., Leukemia & Lymphoma Society, LIVESTRONG), survivorship activities ( $n=3$ ; e.g., Relay for Life), or being the recipient of a survivorship award ( $n=3$ ; e.g., Make-A-Wish trips). Activities provided opportunities to incorporate cancer into survivorship: “I’ve been more willing to volunteer ... I don’t really talk to people about what happened, but [while volunteering] I wanted people to understand [my cancer experience].”

## **Discussion**

Understanding cancer-related disclosure among this unique AYA cohort may help survivors navigate current and future relationships and developmental milestones, especially given the impact of a cancer diagnosis during adolescence.<sup>10</sup> While each participant reported some cancer-related disclosure, it emerged as a nuanced and complex process involving three major themes and eight subthemes.

Disclosure of a concealed identity such as cancer can create opportunities to accumulate social support or rejection. Among adult survivors, this has been found to add new information about one’s self-concept in a broader social context, impacting interpersonal experiences and worldviews.<sup>33</sup> Among non-cancer groups, disclosures are reported to allow

personal expression that builds interpersonal intimacy, results not found salient in this study.<sup>14,44</sup>

The most endorsed theme regarding the decision-making processes of disclosure reflects the dynamic social changes and challenges presented by a cancer diagnosis during adolescence and young adulthood. These processes demonstrate the significance of peers (disclosing only when asked), a range of possible interactions and reactions (positive, apprehensive), and contextual factors (relationship potential, disclosure method) as variables impacting cancer-related disclosure. This suggests maturity in deciding when and with whom to disclose. It also involves survivors' ability to acknowledge both the complexity of their cancer and the process of integrating it into their survivorship, identity, and relationships.

Cancer-related disclosure was often initiated by another person, a meaningful relationship, or a social circumstance rather than by personal initiation, motivation, or need. The process of disclosing cancer involved multiple aspects of a situation or interaction. For instance, the disclosure thought process was active, while often the act of disclosure was more passive (e.g., "only if someone else asks" or "it depends how serious the relationships is"). AYAs may seek permission to disclose through others' actions or reactions. These interactions may lessen insecurities about initiating disclosure, create a form of beneficial trauma exposure, and have psychosocial benefits.<sup>24,26,29,30</sup> AYAs described reactions that felt inhibiting or encouraging of disclosure, such as older recipients being more comfortable discussing their cancer. Prior qualitative work has similarly found older-aged recipients to be more open and engaged with cancer-related disclosures.<sup>44</sup>

Study strengths include a robust qualitative sample size, comprehensive interviews, multiple coders, and a stringent coding process. Including participants ranging in age from adolescence into adulthood was a strength. Potential limitations include the reliance on retrospective reporting, as direct observation was not feasible or practical. While participation itself is a form of cancer-related disclosure, it does not necessarily indicate participants were frequent disclosers. Since in-person attendance was required, geographic and scheduling constraints may not be representative of rural or greater New York areas.

It is possible that AYAs' comfort and willingness to disclose, as well as their patterns of disclosure, may be influenced by the length of time post-treatment. While cursory analyses on this covariate did not appear significant in the present study, future research should examine time since treatment in greater depth. Future research should also examine relationships between cancer-related disclosure and positive outcomes (e.g., social support and post-traumatic growth), and consider subtle and significant negative sequelae of AYAs' disclosure.

## Conclusion

In our study of AYA survivors diagnosed with cancer during adolescence and young adulthood, cancer-related disclosure was nuanced and involved a complex process balancing the decision to tell, perceiving others' responses, and disclosure methods. The disclosure process and act was interactive and may influence social relationships and intimacy, which are important developmental aspects of adoles-

cence and young adulthood. Similar beneficial psychosocial results have been found among AYA-aged childhood cancer survivors and among AYAs' initial disclosure of their diagnosis during adolescence and young adulthood.<sup>44,45</sup> Disclosures to older people were perceived as more understanding and comfortable than those to younger audiences. No thematic differences emerged by gender. Among disclosure interactions without negative apprehension toward the survivor, cancer disclosure was helpful, positive, and more frequent, supporting social cognitive theory. Creating a social environment among families and professionals that acknowledges and is empathic toward cancer-related disclosures may allow AYA survivors to explore and understand their experience. Clinicians can model disclosure and help survivors understand anticipated and perceived responses to disclosure. This may also provide opportunities for survivors to understand how cancer impacts their identity, relationships, and survivorship.

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## Author Disclosure Statement

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