

## PAPER

# Self-disclosure to peers by young adult cancer survivors

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**Funding information**

Faculty Seed Grant

**Abstract**

**Objective:** Given the potential benefits of self-disclosure, the goal of this study was to learn more about how young adult cancer survivors navigate the process of disclosing their cancer history to peers.

**Methods:** A sample of 122 young adult cancer survivors completed a brief, online survey. Data were collected to assess how and why survivors self-disclose to peers and how peers react.

**Results:** Participants endorsed a number of reasons for disclosing their cancer history to peers (eg, felt it was important for them to know) or choosing not to disclose (eg, to avoid upsetting/burdening them). Participants used a variety of strategies during the disclosure with the most frequently endorsed being humor and providing reassurance. Mediation analyses supported the study hypothesis: The relationship between peer reactions to self-disclosure and the likelihood of future disclosure was mediated by survivors' satisfaction with the self-disclosure experience. Exploratory analyses provided some insight into which disclosure strategies were met with a more positive reaction from peers.

**Conclusions:** The actual and anticipated reactions from peers play a crucial role in shaping young adult cancer survivors' experience of self-disclosure. Clinicians may use these findings to help young survivors optimize their self-disclosure experiences.

**KEYWORDS**

cancer, friends, oncology, peers, self-disclosure, young adult

## 1 | BACKGROUND

Young adult cancer survivors are a vulnerable, underserved population. Although approximately 70 000 young adults are diagnosed with cancer each year in the United States—and thousands more childhood cancer survivors reach young adulthood—research targeting this population is scant.<sup>1</sup> Consequently, little is known about issues that likely impact young survivors, such as entering the dating world as a cancer survivor, building a career after taking time off for cancer treatment, or communicating with other young adults about the cancer experience.<sup>1,2</sup> Regarding the latter, there is a paucity of research on how young adult cancer survivors disclose their cancer status to others. Given the relative rarity of a cancer history among young adults,<sup>3</sup> young survivors may lack role models to guide them through such

self-disclosures. This may compound the difficulty of discussing a cancer history with similarly aged friends or romantic partners who may have had little personal experience with cancer.<sup>1</sup> The goal of this study was to learn more about how young adult cancer survivors navigate the process of disclosing—or choosing not to disclose—their cancer status to peers.

The small body of literature on self-disclosure among young adult cancer survivors indicates that the experience may be fraught, particularly when self-disclosing to friends or romantic partners. A number of young survivors in one interview study reported that they did not disclose their cancer status to friends to avoid differential treatment.<sup>4</sup> Others reported that they used humor when disclosing to peers to diffuse tension.<sup>4</sup> Likewise, young survivors appear to experience ambivalence about self-disclosing to romantic partners. Some feel their

partner has a right to know about their cancer history but worry that self-disclosure will make them appear weak.<sup>5,6</sup> Others are unsure when to make the disclosure: Discussing a cancer history too soon (eg, on a first date) may seem premature, but waiting too long may make their partner feel that they were not being up front.<sup>6,7</sup> Young survivors may be particularly uncomfortable disclosing the emotional aspects of their experience.<sup>5,6</sup> Thus, it appears that young survivors wrestle with how, when, and what to disclose.

Given the scant literature on self-disclosure among young adult cancer survivors, many aspects of the experience remain unclear. For example, why do young survivors choose to self-disclose in some situations but not others, how do they go about making self-disclosures, and what strategies are met with the best response from peers? Models of information disclosure decision making may offer some insight into these issues. Some models suggest that the likelihood of disclosing information depends in part on the anticipated reaction from others.<sup>8,9</sup> Those who anticipate that disclosing a “secret” will be met with distress or an unsupportive reaction are less inclined to make the disclosure.<sup>10</sup> Those anticipating a supportive reaction are more likely to self-disclose,<sup>8</sup> and, some theorists posit, those receiving a positive reaction to self-disclosure may be more likely to disclose again in the future.<sup>11</sup> Thus, young survivors may choose to self-disclose based, in part, on the anticipated and previously experienced reactions from others.

The importance of learning more about self-disclosure among young adult cancer survivors is underscored by research demonstrating that self-disclosure impacts quality of life. Survivors who report greater openness about their cancer identity and willingness to self-disclose experience greater life satisfaction, post-traumatic growth, and positive affect.<sup>12</sup> Those who disclose their cancer status to coworkers are less likely to think about quitting their job.<sup>13</sup> Further, there is a body of research indicating that self-disclosure of traumatic experiences improves physical well-being by enhancing immune system functioning.<sup>14,15</sup> Research also indicates that those who refrain from self-disclosure report more negative mood and lower levels of relationship satisfaction, social functioning, and emotional well-being.<sup>16,17</sup> An important caveat, however, is that self-disclosure is not always met with a supportive response; when survivors disclose to friends or partners and do not receive the reaction they hoped for, they may feel frustrated or dismissed.<sup>5</sup> Thus, it behooves researchers to learn more about the factors linked with successful self-disclosure.

This study was designed to shed light on the processes by which young adult cancer survivors self-disclose their cancer history and experiences to peers. Descriptive analyses were conducted to better understand (1) the rationale used when deciding whether to self-disclose to friends, (2) the strategies used and information provided when self-disclosing, and (3) the reactions received to self-disclosures. In addition, the following a priori hypothesis was tested: The relationship between friends' reactions to the survivors' self-disclosure and the likelihood of survivors disclosing to friends in the future would be mediated by survivors' satisfaction with the self-disclosure experience. Finally, exploratory analyses were conducted to determine whether survivors who used certain disclosure strategies (eg, humor) were more likely to receive a favorable response than those who did not.

## 2 | METHODS

Institutional review board approval was obtained prior to initiating the study (IRB#20170030). The study was advertised via social media by a national organization that serves young adult cancer survivors. Those interested clicked on a link posing two questions to confirm eligibility; survivors were asked if they had been diagnosed with any form of cancer other than nonmelanoma skin cancer and if they were currently between age 18 and 45. Participants who met these criteria were presented with an online consent form. Those who indicated their consent proceeded to the online survey, which took approximately 15 minutes to complete. Survivors were offered a \$20 gift card for participating.

### 2.1 | Measures

The measures included in the survey are detailed below.

#### 2.1.1 | Demographics and medical information

Participants were asked to provide standard demographic and cancer-related information (eg, type of cancer).

#### 2.1.2 | Level of cancer self-disclosure

Given the lack of standardized measures assessing cancer self-disclosure, a validated scale used to measure self-disclosure of sexual orientation was adapted for this study. The Nebraska Outness Scale<sup>18</sup> (NOS) contains a five-item self-disclosure subscale asking participants to estimate the percentage of people in different social groups (including friends/acquaintances) who are aware that they are lesbian, gay, or bisexual. This measure also contains a five-item concealment subscale asking participants how frequently they avoid talking about topics related to sexual orientation with members of each of these five groups. A total “outness” score is created by reverse scoring items on the concealment subscale and calculating a mean of all items. The full scale has a reliability of 0.89 and internal consistency<sup>18</sup> from 0.87 to 0.92. The NOS was adapted for this study by replacing the words “your sexual orientation” with “your cancer” or “you were diagnosed with cancer”; internal consistency of the adapted scale was 0.76.

#### 2.1.3 | Reasons for self-disclosing or not disclosing

Participants were given a list of factors that might prompt self-disclosure about their cancer to friends (eg, “It was important for them to know about me”) and asked to indicate any that applied to them. Participants could then type in other factors that had prompted them to self-disclose. Next, participants were then given a list of factors that might inhibit self-disclosure (eg, “It was none of their business”) and asked to indicate any that applied to them. They were then able to type in other reasons they had sometimes chosen not to self-disclose.

### 2.1.4 | Type of information disclosed

Participants were asked to indicate all of the types of cancer-related information they have disclosed to friends including cancer diagnosis, cancer treatment, treatment effects, and emotional aspects of the cancer experience.

### 2.1.5 | Strategies used for self-disclosure

Participants were asked to indicate the strategies they used when self-disclosing to friends from a list of possible strategies (eg, used humor to keep things light). Participants also had the opportunity to type in other strategies.

### 2.1.6 | Postdisclosure experiences

Participants were asked to rate how well their friends had generally reacted to their self-disclosures on a scale from 0 (very badly [eg, got upset, did not seem interested]) to 10 (very well [eg, listened, were supportive]). Participants also rated how satisfied they were with the experience of self-disclosing to friends on a scale from 0 (not at all satisfied) to 10 (very satisfied). Finally, participants rated their likelihood of self-disclosure to friends in the future on a scale from 0 (not at all likely) to 10 (very likely). For each of these items, participants were also given the opportunity to indicate if the item was simply not applicable (eg, because they had not disclosed their cancer status to any friends).

## 2.2 | Data analysis

Data analyses were performed using SPSS version 24.0.0.0 (for Windows). Descriptive analyses were used to assess the factors that young survivors weigh when deciding whether to self-disclose, strategies used during self-disclosures, and experiences of self-disclosing. Regression and bootstrapping were used to test the key study hypothesis. *T* tests were used for exploratory analyses.

## 3 | RESULTS

Of the 199 people who indicated consent and launched the online survey, 137 provided data. Of these, 15 participants only responded to a few items on the survey. These “dropout” participants did not differ significantly from the remaining 122 participants (who responded to most/all items) with respect to any demographic characteristic (eg, age, gender, marital status, and race; *P* values = 0.09 to 0.97). Analyses were conducted on data from the 122 participants who completed most or all of the survey.

The demographic characteristics of the sample are detailed in Table 1. Participants ranged in age from 19 to 45 years (mean = 31.9 years, standard deviation [SD] = 6.2). A majority identified as female (80.3%), White (89.3%), non-Hispanic (85.2%), and highly educated. Participants had been diagnosed with 28 different forms of cancer with the most prevalent being breast cancer (26.2%), Hodgkin's lymphoma (13.1%), and thyroid cancer (7.4%). Participants

**TABLE 1** Demographic characteristics (N = 122)

	n	P
Gender		
Female	98	80.3
Male	24	19.7
Ethnicity		
Non-Hispanic	104	85.2
Hispanic	18	14.8
Race <sup>a</sup>		
White	109	89.3
More than one race	7	5.7
Asian	4	3.3
Marital status		
Married	52	42.6
Single	44	36.1
Living with partner	17	13.9
Divorced	8	6.6
Separated	1	0.8
Education		
Bachelors' degree	45	36.9
Graduate school degree	38	31.1
Some college	16	13.1
Associates degree	15	12.3
High school diploma	5	4.1
Vocational or trade school	3	2.5
Employment status		
Employed full-time	62	50.8
Unemployed	18	14.8
Employed part-time	16	13.1
Homemaker	11	9.0
Student	10	8.2
Medical leave	4	3.3
Retired	1	0.8
Annual household income <sup>a</sup>		
\$70 000 and above	56	45.9
\$50 000-\$69 999	25	20.5
\$30 000-\$49 999	18	14.8
\$10 000-\$29 999	14	11.5
<\$10 000	8	6.6

<sup>a</sup>Two participants did not respond to the item on race and one participant to the item on income.

were diagnosed at a mean age of 27.4 years (SD = 6.2)—a mean of approximately 4.8 years prior to participation in the study. A majority were treated with some form of surgery (72.1%), and/or chemotherapy (72.1%) with smaller percentages receiving radiation (36.9%), hormone therapy (19.7%), or bone marrow transplant (6.6%).

Table 2 details the reasons participants endorsed for disclosing or not disclosing their cancer status to friends. The most frequently endorsed reasons for self-disclosure were that participants felt it was important for their friends to know about them or thought their friends would respond well and be supportive. Several participants wrote in additional reasons for self-disclosing their cancer history to others (ie, not necessarily just friends or peers). The most frequently offered reasons included providing help and support to other cancer

**TABLE 2** Percentage of participants endorsing each reason for disclosing or not disclosing to friends, using each disclosure strategy and disclosing each type of information

	N	P
Reason to disclose		
It was important for them to know about me	97	79.5
I thought they would respond well and be supportive	83	68.0
We were talking about a related topic (eg, my health)	63	51.6
I needed their help with something cancer-related (eg, ride to doctor, time off work)	43	35.2
N/A—I have not told [any friends] about my cancer	1	0.8
Reasons to not disclose		
To avoid upsetting or burdening them	57	46.7
So they wouldn't see or treat me differently	49	40.2
N/A—I told [all my friends] about my cancer	38	31.1
They wouldn't have responded well or been supportive	30	24.6
So they wouldn't distance themselves	28	23.0
It was none of their business	17	13.9
Disclosure strategies		
Used humor to keep things light	85	69.7
Reassured them that I am ok (or will be ok)	82	67.2
Did not tell them some of the scarier information	53	43.4
Waited until a time I thought they could handle it	40	32.8
Only provided the information they asked for	27	22.1
Information disclosed		
Cancer diagnosis	117	95.9
Cancer treatment	102	83.6
Treatment effects (including long-term such as physical disability, infertility, fatigue)	84	68.9
Emotional aspects of cancer experience	80	65.6

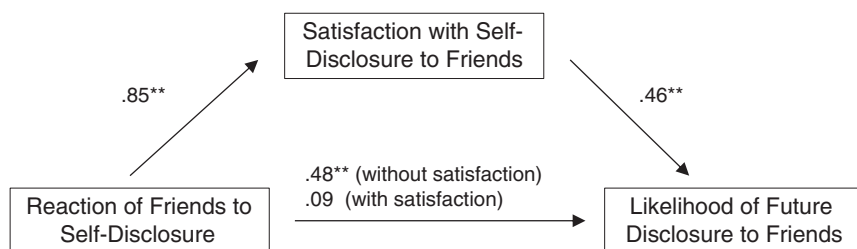
patients or their loved ones ( $n = 21$ ), advocacy or fundraising ( $n = 10$ ), explaining physical disability, scars or altered appearance ( $n = 9$ ), and combating stereotypes/increasing awareness of cancer ( $n = 8$ ). The most frequently endorsed reasons for choosing not to self-disclose

cancer status to friends were to avoid upsetting or burdening them and so that their friends would not see or treat them differently. Participants also supplied several other reasons for not disclosing their cancer history to others with the most prevalent being tired of explaining or talking about it ( $n = 8$ ), wanting to avoid others' pity or differential treatment ( $n = 7$ ), feeling uncomfortable talking about it ( $n = 6$ ), and fearing workplace discrimination ( $n = 6$ ).

Participants reported using a variety of strategies during self-disclosures (see Table 2). The most commonly endorsed were using humor and providing reassurance. In the open-response item, participants mentioned additional strategies; the most frequently reported were using email or social media (eg, blogs and Facebook) for self-disclosure ( $n = 13$ ) and "coming right out with it" ( $n = 3$ ). When asked what type of information they typically disclosed to their friends (Table 2), participants most often reported disclosing their cancer diagnosis and treatment.

Level of outness to friends ranged from 10% to 100% (mean = 70.9, SD = 22.8) with total outness scores averaging 58.6 (SD = 16.2). The experience of self-disclosing to friends reflected a range in valence. Participants' mean rating of how well friends reacted was 7.2 (SD = 2.4) on a 0-to-10 scale. Mean satisfaction with the experience of disclosing to friends was 7.0 (SD = 2.6) on 0-to-10 scale. The mean likelihood of disclosing to friends in the future was 7.4 (SD = 2.6) on a 0-to-10 scale. These data were used to test the hypothesis that a survivor's satisfaction with the self-disclosure experience would mediate the relationship between their friends' reactions and the likelihood of disclosing to friends in the future.

This hypothesis was evaluated using regression and bootstrapping.<sup>19,20</sup> As illustrated in Figure 1, standardized regression coefficients indicated a significant relationship between friends' reactions and satisfaction with self-disclosure to friends (0.84) as well as between satisfaction with self-disclosure to friends and likelihood of future disclosure to friends (0.46). The significance of the indirect effect—ie, the effect of friends' reactions on likelihood of future disclosure via the hypothesized mediator of satisfaction with disclosure

**FIGURE 1** Mediation model in which satisfaction with self-disclosure to friends mediates the relationship between friends' reactions and likelihood of future disclosure**TABLE 3** *T* tests comparing friends' reactions to self-disclosure among participants using or not using each disclosure strategy

Self-Disclosure Strategy	Mean (SD) Rating of Reactions from Friends to Disclosure		<i>t</i>	<i>P</i> Value
	Those Using Strategy	Those not Using Strategy		
Provided reassurance that I would be okay	7.5 (2.3)	6.6 (2.5)	2.0	0.04
Waited until I thought friends could handle it	7.1 (2.6)	7.2(2.3)	0.33	0.74
Used humor to keep things light	6.9 (2.5)	7.7 (2.0)	1.68	0.09
Did not tell some of the scarier info	6.5 (2.7)	7.8 (2.0)	2.94	0.004
Only provided info asked for	5.7 (2.6)	7.6 (2.2)	3.98	0.000

—was tested using bootstrapping procedures. The bootstrapped indirect effect (computed for each of 5000 samples) was 0.39; this was statistically significant using a 95% confidence interval (0.13–0.63).

Exploratory *t*-test analyses were conducted to determine whether participants who used certain disclosure strategies (eg, humor) received more favorable reactions than those who did not (see Table 3). Findings indicate that those providing reassurance during their cancer disclosures rated their friends as responding more positively than those who did not. By contrast, those who reported using the strategies of withholding scarier information or only providing the information specifically requested rated their friends as having a significantly less positive reaction to their self-disclosure than those who did not. A trend in this direction was also seen for those who reported using humor during self-disclosures.

## 4 | CONCLUSIONS

The aim of this study was to develop a better understanding of how young adult cancer survivors navigate the process of disclosing their cancer history to peers. Findings suggest that young survivors make decisions about whether to self-disclose based, in part, on the anticipated response and emotional reaction of others. A frequently endorsed reason for self-disclosure was that participants thought their friends would respond well and be supportive. Similarly, the most frequently endorsed reason for not disclosing to friends was to avoid upsetting or burdening them. These findings are consistent with a number of disclosure decision-making models stipulating that self-disclosure decisions are based on anticipated reactions from others.<sup>8–10</sup> Participants also appear to be aware that, due to the stigma of a cancer diagnosis, self-disclosure may result in less favorable treatment from others. Around 40% indicated that they sometimes do not disclose their cancer status to friends to avoid being treated differently. Relatedly, participants voiced the concern that self-disclosure may lead to discrimination—for example, in the workplace—as a reason not to self-disclose.

Survivors appear to navigate the process of self-disclosure based not only on anticipated reactions but also on the actual reactions received from peers during prior self-disclosures. Results from mediation analyses indicate that survivors who received more positive responses from friends to previous self-disclosures felt more satisfied with the experience and were more likely to self-disclose in the future. This is consistent with research finding that reluctance to self-disclose is correlated with having previously experienced unsupportive social interactions.<sup>16</sup>

Findings from the exploratory analyses may help to explain why some self-disclosures were better received than others; these analyses suggest that participants using (or not using) certain self-disclosure strategies received more favorable reactions. Those who withheld the more upsetting information or only provided the information specifically requested rated the reactions they received from friends as less positive. It is possible that when participants used these strategies, their friends suspected they were not getting the whole story and, consequently, became more distressed. Another possibility is that participants were more likely to use these strategies if they had a less

favorable prognosis; consequently, their friends reacted poorly out of an abundance of concern. Exploratory analyses also suggest a trend for a less favorable reaction from friends when humor was used during self-disclosure. It could be that young survivors are not using humor effectively or, again, were more likely to use humor to lighten the mood when the situation was particularly serious. By contrast, survivors who used the strategy of providing reassurance that they would be okay reported more positive responses. This suggests that any intervention designed to help young survivors optimize their self-disclosure experience should include a focus on this strategy.

The importance of a survivor's willingness to self-disclose should not be underestimated as research has shown that self-disclosure impacts quality of life outcomes. Pennebaker and colleagues have published extensively on the health-promoting aspects of disclosing to others.<sup>14,15</sup> Likewise, research with cancer survivors indicates that holding back from self-disclosure is associated with negative mood and lower levels of relationship satisfaction, social functioning, and emotional well-being.<sup>16,17</sup> This research suggests the utility and potential benefits of developing interventions that can help young adult cancer survivors optimize their experience of self-disclosure to peers and others.

### 4.1 | Clinical implications

Findings from this study have some clear clinical implications for young adult cancer survivors. Given the known physical and psychosocial benefits associated with self-disclosure, clinicians who work with young survivors should provide guidance in optimizing their self-disclosure experiences. For example, findings suggest that young survivors be encouraged to convey an atmosphere of openness, reassure peers that the survivor will be okay, and not inject humor at inappropriate times. Those helping survivors prepare to self-disclose should also communicate, however, that survivors may have good reasons not to self-disclose to certain people or in certain situations. Young survivors should trust their instincts in this regard. This study suggests that when survivors are able to execute successful self-disclosure experiences, it promotes greater willingness to self-disclose again in the future. This sort of positive feed-forward cycle will likely increase the potential for young survivors to reap the benefits associated with self-disclosure.

### 4.2 | Study limitations and future research

This study had certain limitations. It is possible that the sample was not representative of the young adult cancer survivor population as a whole. Demographic data indicate that the sample was predominantly White, female, and well-educated, which may have shaped results. A sample with more young male survivors or greater diversity with respect to race or socioeconomic status (SES) might have identified different reasons or strategies for making self-disclosures. The sample was, however, reasonably diverse with respect to marital status, cancer diagnosis, and ethnicity (ie, nearly 15% identified as Hispanic, which is close to the percentage of the US population identifying as Hispanic). Likewise, there was no indication that those



who dropped out of the study after completing the initial items differed demographically from study completers. It is possible, however, that those ( $n = 62$ ) individuals who launched the survey but did not complete it were distinct in some way. The lack of information on these individuals precludes any conclusions. Another key study limitation is that participants were asked to report on their experience of disclosure to peers (including peer reactions and satisfaction with disclosure) in aggregate; given this, it is unclear whether participant ratings were based on one or two salient experiences or a true integration of all of their experiences. Likewise, this approach may have impacted findings from the exploratory analyses as it is possible that participants used different disclosure strategies (or combinations of strategies) with different peers.

Future research should extend the findings reported here. Researchers might explore the impact of current age and age at diagnosis on the self-disclosure experience. For example, young adult survivors may navigate the self-disclosure experience differently depending on whether they were diagnosed during childhood or more recently. Likewise, current age may influence which type of disclosure strategies are likely to be well received by peers. In addition, it would be useful to examine whether the type of information disclosed impacts peer reactions and, subsequently, survivors' experience of the disclosure.

## ACKNOWLEDGEMENT

This project was supported by a Faculty Seed Grant.

## CONFLICTS OF INTEREST

There are no financial or other conflicts of interest.

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**How to cite this article:** Rabin C. Self-disclosure to peers by young adult cancer survivors. *Psycho-Oncology*. 2019;28: 181-186. <https://doi.org/10.1002/pon.4930>