

Coping Styles of Female Adolescent Cancer Patients with Potential Fertility Loss

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Purpose: The purpose of this qualitative study was to assess the coping styles of female adolescent cancer patients regarding potential loss of fertility. Expectations and desires for the future, coping styles in typical adolescence, and coping styles when faced with potential loss of fertility due to cancer treatment are discussed.

Methods: Female adolescents diagnosed with cancer aged 12–18 years at study ($N=14$) were administered a 10-item values clarification tool to pilot test the readability and relevance of the items on reproductive concerns, followed by a cognitive debriefing interview asking participants how they would respond to each item. These qualitative responses were assessed for coping style type using the constant comparative approach.

Results: All adolescent participants reported having a strong desire for biological children in the future. Reactions to questions regarding the loss of fertility fell into two categories of coping styles: emotion-focused coping or problem-focused (engagement) coping. Within emotion-focused coping, there were three distinct styles: externalizing attribution style, internalizing attribution style, and repressive adaptation. Problem-focused coping adolescents displayed optimism.

Conclusion: Successful interventions aimed at promoting adaptive coping styles should seek to uncover adolescents' values about future parenthood and reproduction. Development of an age-appropriate assessment to stimulate dialogue regarding fertility and initiate an adolescent's cognitive processing of potential fertility loss is warranted.

Keywords: coping, fertility, reproduction, survivorship

RATES OF SURVIVORSHIP among adolescents diagnosed with cancer continue to rise. Between 1992 and 2004, more than 5000 adolescents aged 10–19 were diagnosed with cancer in the United States.¹ Current trends suggest pediatric cancer patients from infancy through adolescence have an 80% rate of survival.² Cancer treatments are often associated with decreased fertility. Specifically, sustained infertility exists in 50–95% of adult cancer survivors.^{3–7} The American Society for Clinical Oncology⁸ and the American Academy of Pediatrics⁹ both recommend oncologists discuss potential loss of fertility with patients and refer interested patients to a reproductive endocrinologist or fertility specialist to consider preservation options prior to treatment. Currently, preservation methods for females include established methods such as embryo and oocyte cryopreservation and shielding the ovaries from radiation, as well as experimental methods such as ovarian tissue cryopreservation.¹⁰

Concerns about potential infertility may not be solicited by parents or healthcare providers during treatment discussions for a variety of reasons. Previous studies suggest parents and healthcare providers do not see fertility as a priority,^{11,12} do not have adequate knowledge or referral sources available,^{11–13} or feel uncomfortable discussing sexuality with adolescents.^{11–15} Research also suggests that most adult survivors of childhood cancer are not aware of their fertility status.¹⁶

Though survivorship studies have highlighted fertility loss as a significant quality of life indicator,¹⁷ the coping strategies adolescent cancer patients use to manage potential fertility loss are understudied. While there are several conceptualizations of coping, two are most common. The first—emotion-focused coping—focuses on managing emotions such as anxiety, anger, or sadness evoked by a stressor.¹⁸ The second—problem-focused (engagement) coping—focuses on the engagement or disengagement with the stressor or emotions related to the

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stressor.¹⁹ Emotion-focused coping follows the principles of attribution theory by crediting emotions to forces within or outside of a person's control, thus justifying or rationalizing their response.²⁰ This form of coping is often associated with emotional instability, reduced empathy, and impulsivity.^{21,22} On the other hand, problem-focused (engagement) coping can be divided into primary control coping, with a focus on changing the stressor or one's reaction to it, and secondary control coping, which focuses on attempts to adapt to the stressor or to adapt one's own reactions to the stressor.¹⁹ Problem-focused (engagement) coping has been associated with decreased levels of anxiety and depression in many populations, including pediatric oncology patients.²³

Most adolescents are capable of formulating problem-focused (engagement) coping mechanisms such as information seeking, accepting support from others, and internal reflection to predict long-term consequences.²⁴ Maladaptive disengagement (emotion-focused) coping mechanisms such as withdrawal and avoidant or escape coping are less common,¹⁹ demonstrating the resilience and fortitude of most adolescents.

Adolescents with cancer typically develop coping skills for both their illness and for dealing with traditional developmental milestones. As such, AYAs with cancer may have astute adaptive coping skills, which are correlated with higher rates of adjustment.²⁵⁻²⁷ Adult survivors of childhood cancer who never discussed fertility concerns with their healthcare provider, or declined to utilize fertility preservation options, have exhibited significant regret during survivorship.^{28,29} Only one known study has evaluated adolescent cancer survivors' coping styles in relation to a potential loss of fertility. Adolescents who did not know their fertility status maintained hope they would be able to have children in the future, and exhibited more adaptive coping styles than those who were told they were irreversibly sterile.⁷

Given the importance of the topic and the scant research in this area, the current study's purpose was to investigate the coping strategies used by female adolescents diagnosed with cancer and facing potential fertility loss due to cancer treatment. As part of a larger study designed to elicit feedback from adolescent-parent dyads on a reproductive values clarification tool,³⁰ coping patterns emerged from patient interviews regarding fertility concerns. With increased understanding of the strategies used to cope with potential cancer-related infertility in this population, providers may be more equipped to address patient concerns and improve provider-patient dialogue.

Methods

Participants

Participants were female adolescents ranging in age from 12 to 18 years at the time of the study, and were recruited from two pediatric cancer centers. Participants and their parents ($N=28$) were informed about the values clarification study by their oncologist. Those interested allowed the physician to give their contact information to the study coordinator. Of note, the values clarification measure used in this study was adapted from a validated adult reproductive concerns scale. The statements were therefore pre-generated.³¹ Study inclusion criteria included: (1) a cancer diagnosis, (2) previous or current cancer treatment that may impact fertility (as determined by treating physician), (3) aged 12-18 years at diag-

nosis and at time of study, and (4) able to speak and comprehend English. Adolescents provided assent, and parents provided written consent for themselves and their daughter to take part in the study. This was a multicenter study that included adolescents who received treatment at one of two pediatric oncology centers, and was approved by both Institutional Review Boards. Ninety-three percent of the adolescents/parents gave permission to be contacted. One dyad declined to participate due to a recent recurrence. After learning more about the study from the coordinator, 14 adolescent-parent dyads were scheduled to meet with the interviewer prior to the patient's usual outpatient clinic visit. One adolescent was in-patient at the time, and the interview was conducted at bedside. Four families agreed to participate but did not show up for their scheduled interview and did not respond to follow-up calls. Our original goal was to interview 10 adolescents (five at each site). However, we had not yet reached saturation, so we recruited an additional four pairs. After these four interviews, we did not discover new information and concluded saturation had been reached.

Prior to the interview, participants were given a demographic form to complete, asking their race/ethnicity, age at study, insurance type, religion, diagnosis, and treatment type. Each adolescent was also asked to rate their own health as excellent, very good, good, fair, or poor. Demographics are shown in Table 1. The mean age of participants was 15.44 years (standard deviation ± 1.7). The majority were White, non-Hispanic, and privately insured. The majority had a diagnosis of hematologic malignancy (79%). Ninety-three percent self-reported their health as "good" or better.

Procedures

The analysis of coping styles was conducted as part of a larger study. Parents were interviewed separately from

TABLE 1. ADOLESCENT PARTICIPANT DEMOGRAPHIC INFORMATION ($N=14$)

	<i>n</i> (%)
<i>Race/ethnicity</i>	
White	10 (72%)
Hispanic/Latino	2 (14%)
Other	2 (14%)
<i>Age at diagnosis (years)</i>	
Mean \pm SD	15.44 \pm 1.7
Range	12-18
<i>Insurance</i>	
Private	11 (79%)
Public	3 (21%)
<i>Diagnosis</i>	
Hematologic malignancy	11 (79%)
Solid tumor	3 (21%)
<i>Treatment type (multiple responses possible)</i>	
Chemotherapy	14 (100%)
Radiation	9 (67%)
Surgery	1 (7%)
<i>Participant self-reported health</i>	
Excellent or very good	5 (36%)
Good	8 (57%)
Fair	1 (7%)

SD, standard deviation.

TABLE 2. VALUES CLARIFICATION TOOL ADAPTED FROM REPRODUCTIVE CONCERNS SCALE³¹

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1. I would like more information about how my cancer treatment could affect my ability to have children.
 2. I feel like I can talk to my parents about my ability to have a baby in the future.
 3. One day I would like to have a baby.
 4. If I cannot have a baby I will be _____.
 5. I feel frustrated that I might not be able to have a baby in the future.
 6. If I cannot have a baby I would blame my illness/cancer.
 7. If I cannot have a baby I would blame my doctor.
 8. I am worried about having a baby in the future because I might get sick/cancer again.
 9. I am worried about having a baby in the future because my baby might get sick/cancer.
 10. I feel like I have control over my ability to have a baby in the future.
-

their daughters. The purpose of the parental interview was to examine the congruence between parents' and daughters' responses to a values clarification tool. The results of that portion of the study, in which the majority of parents inaccurately predicted how their daughter would respond to each item, are reported elsewhere.³⁰ The coordinator read aloud each statement from the 10-item values clarification tool (Table 2). Adolescent participants were first asked to provide feedback on the comprehension, language, and relevance of each item in the values clarification tool. They were then asked to discuss their own responses to each item.

All interviews were audiotaped and transcribed verbatim. Each interview lasted approximately 30 to 40 minutes. Participants were given \$25 at the completion of the interview as compensation for their time.

Analysis

Data analyses were based on the constant comparative method and the grounded theory approach.^{32,33} Transcript data were first organized into inductive categories, and then each research team member independently appraised emergent themes. Final consensus on categories, codes, and themes were discussed among the research team and an inter-coder reliability rate of 95% was established after two rounds of coding.

Results

Two distinct themes emerged regarding the adolescents' responses to items about the potential loss of fertility. These two themes were congruent with two categories of coping styles: problem-focused (engagement) coping and emotion-focused coping. In response to the item "One day I would like to have a baby," all adolescents reported having a strong desire for biological children in the future. However, none of the adolescents or parents was aware of the adolescents' actual fertility status. Adolescents were not asked directly if they knew their fertility status, only if a healthcare professional had discussed with them the possibility of fertility loss due to treatment. Two adolescents disclosed that their

physician told them their fertility would be compromised due to the required treatment, but their actual fertility status was unknown. Self-perceived health did not influence coping styles.

Problem-focused (engagement) coping

Seventy-one percent ($n=10/14$) exhibited problem-focused (engagement) coping. They took an active role in adapting their emotional response to the stressor—loss of fertility. The predominant theme that emerged was optimism balanced with their reproductive concerns and loss of reproductive capacity.

Optimism. Adolescents who exhibited problem-focused (engagement) coping tended to be hopeful about the ability to be a parent in the future if they found themselves sterile or with impaired fertility. In response to the item "If I cannot have a baby I would blame my illness/cancer," respondents were hopeful about alternatives as well as reluctant to place blame on anyone or the cancer experience:

I don't think I would blame anything on what's happened so...you get dealt certain hands...it's just life.

I just thought of it [ability to have children] more optimistically like I'm pretty sure that I'm gonna be fine through all of this because I trust the doctors and everything and they're gonna do their best.

I'd like to know more to like try and prevent [fertility loss] so that I can do more. I'd wanna know about the effects of treatment to know what's going on inside of me.

Emotion-focused coping

Sixty-four percent ($n=9/14$) of adolescents exhibited emotion-focused coping to manage the feelings they were experiencing related to the potential loss of fertility. These participants attempted to escape the feelings and minimize distress associated with the potential loss of fertility. Three themes emerged related to emotion-focused coping: (1) externalizing attribution style, (2) internalizing attribution style, and (3) repressive adaptation.

External explanatory attribution style. In response to the question "I feel like I have control over my ability to have a baby in the future," adolescents tended to attribute their circumstances to outside forces, highlighting their perceived lack of control over their fertility:

No, I don't [feel in control]; I feel like at any moment, I can just come in for scans and they tell me that I'm done like I'm no longer a woman so I feel like just someone out there is...like I'm a puppet like someone's controlling me so, I don't know.

I blamed it [cancer] toward the end of my treatment; I didn't really think about anything; I just wanted to get back in volleyball at the beginning of my treatment but I really thought about it at the end; I don't know why but at the end, it hit me and then I got upset and angry and, like, overwhelmed.

Internal explanatory attribution style. A few adolescents exhibited maladaptive coping styles by assuming responsibility if their fertility was impaired. In response to the questions "If I cannot have a baby I would blame my illness/

cancer” and “If I cannot have a baby I would blame my doctor,” some adolescents displayed a coping style of blaming themselves:

Being a teenage girl, I'd probably end up redirecting it to something wrong with me too. I'd probably end up being frustrated with myself.

I've always thought about being a mom and having babies. If I couldn't, I think I would blame myself just 'cause I think I did something to, like, get this; I did something to deserve this.

Repressive and avoidant adaptation. In response to the item “I would like more information about how my cancer treatment could affect my ability to have children,” there was a trend for adolescents to minimize the distress of actualizing a loss of fertility by preventing their emotions from reaching the conscious level, thereby avoiding disturbing cognitions:

I kinda wish I was told before maybe, but it wouldn't change anything; I'd totally choose the treatment over being able to have kids but... 'cause ya could always adopt but I don't know; it's fine; I wish I found out before, but it's fine.

In response to the item “I am worried about having a baby in the future because I might get sick/cancer again,” several adolescents verbally said, “No, I'm not worried...no,” while at the same time were visibly tearful. There was also incongruence in the statements made by adolescents with this coping style. For example, when asked to provide feedback to the statement “If I cannot have a baby I will be _____,” two adolescents responded:

Well, when I first heard that I may or may not be able to have a baby I cried with Mom in the doctor's office 'cause I felt sad.

I want to be able to hold my child in my hands, to see it grow up and go to college.

But when these same adolescents were asked to respond to the item “One day I would like to have a baby,” they responded:

No, I won't care if I can't have children.

Adolescents also depersonalized some of their own feelings by responding to several of the items about adolescent cancer patients in general:

Teenagers always need someone to blame; they never think of themselves to blame.

It's a possibility that a person will blame their doctor and you could, like, comfort them or help them realize that it's not really their fault because, I mean, you didn't really give yourself cancer; I mean, it wasn't really like your choice to have it.

Anyone going through the process should be able to know what's going on in their body.

Discussion

This study highlights the variety of coping styles female adolescents employ to manage feelings associated with potential fertility loss due to cancer treatment. The majority of adolescents utilized adaptive techniques to minimize distress associated with multiple layers of loss along the cancer con-

tinuum. However, several adolescents avoided distressing cognitions about possible infertility through tactics aimed at soothing emerging feelings of grief. The repressive adaptation technique was clearly exhibited among adolescents who described feelings of grief associated with fertility loss, and then immediately withdrew their complaint to pacify these feelings. Wishful thinking, externalizing, and other emotion-focused coping styles are traditionally viewed as maladaptive when compared to information-seeking and other active coping styles.³⁴ However, there is still widespread debate in the literature. Emotion-focused coping styles should not be labeled as inherently maladaptive, as emotion-focused coping styles aim to reduce negative emotional responses such as guilt and shame associated with stressors—in this case, infertility. This may be a viable coping mechanism when the source of stress is outside the person's control. Indeed, self-serving biases promoting external attributions of adverse events are thought to be psychologically protective. Further, recent evidence examining emotional approach coping, which centers on active processing and expression of emotion, may serve an adaptive value under certain circumstances (e.g., infertility, sexual assault, or breast cancer).³⁵

The optimism and actions portrayed by the majority of adolescents supports existing literature regarding the remarkable resilience of this population. Adolescent cancer patients continuously show strong correlations between optimism and high health-related quality of life, with reported lower levels of pain and increased psychological functioning compared to adolescents who report reduced optimism.³⁶

Not all adolescents in this study exhibited adaptive coping mechanisms. According to attribution theory, people often ascribe causality to events and attributions in an effort to make sense of their world. Misfortunes or unwanted emotions may be attributed to causes outside of their control (externalizing behavior), whereas positive events or emotions may be attributed to personal characteristics (internalizing behavior).^{37,38} It is likely that adaptive coping entails flexibility in attributions and coping behavior depends on the adversity faced. Some adolescents exhibited an internal explanatory style by attributing their potential loss of fertility to something they did or deserved. In this study, the adolescents who blamed themselves for a potential loss of fertility may be perceived as also having a high internal locus of control, although locus of control was not measured in the study. By attributing their potential loss of fertility to something in their control or a punishment for past wrongdoings, these adolescents are at high risk for developing extreme sadness, anticipatory guilt over the inability to have a biological child with a future partner, and worry—all emotions that are consistent with internalizing behavioral outcomes seen in physically healthy adolescent populations.³⁹ These adolescents could be at risk for mental health issues should they assume responsibility for something they most likely could not control.⁴⁰

Similarly, adolescents who exhibited externalizing explanatory attributions are also at risk for poor mental health outcomes. Fully externalizing the sources behind their potential fertility loss creates a pattern of blame and often helpless behavior, which can prohibit relief seeking in controllable adverse situations.⁴¹ This is dangerous for adolescents with and without cancer, who will consistently be faced with developmental challenges and questions as they transition to adulthood. Externalizing attributions can decrease

motivation to find solutions or alternatives, as the adolescent may attribute her loss of fertility to something beyond her control, and because coping mechanisms developed in adolescence continue to be employed throughout the lifespan, this style of emotion-focused coping creates a high vulnerability to depression and decreased motivation or performance.⁴² However, clinical investigations in this area are relatively new and limited in number. Further research is needed to identify the mechanisms underlying the effects of emotional approach coping, as well as potential moderators of these effects (e.g., the nature of the stressor, cognitive appraisals of the stressor, or interpersonal context) before concluding emotional approach orientations should be incorporated into interventions aimed at increasing psychological adaptation to adverse events through constructive coping behavior, such as employing problem-focused coping strategies.

The results of this study should be examined within some limitations. Although male adolescent cancer patients' reproductive concerns are also important, this study focused only on females, and these results may not be relevant to adolescent males. This study included only girls either in or recently out of treatment. Therefore, results may apply only to similar groups. Additionally, this was a qualitative study with a small group of female adolescents in two states within the United States, and thus results are not generalizable, as with most qualitative research.

Conclusion

Female adolescent cancer patients in this study exhibited maladaptive and adaptive coping styles to manage concerns about potential loss of fertility due to their treatment. Successful interventions aimed at promoting adaptive coping styles should seek to uncover adolescents' values about future parenthood and reproduction. Development of an age-appropriate assessment to stimulate a dialogue regarding fertility and initiate adolescents' cognitive and emotional processing of potential fertility loss is warranted. Overall, this study highlighted the importance of understanding adolescent girls' coping styles in relation to their potential loss of fertility due to cancer treatments.

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