

Chapter 8

The Birds and the Bees and the Bank: Talking with Families About Future Fertility Amidst a Cancer Diagnosis

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Introduction

Talking with teens about reproductive health issues can be awkward and uncomfortable. Talking with families about a cancer diagnosis, treatment, and prognosis can be devastating and traumatic. Talking about reproductive health and a cancer diagnosis at the same time, with teens and their parents, confounds these overwhelming emotions.

Why Is There a Communication Gap in Oncofertility?

When parents learn their child has cancer, or when a patient hears the word “cancer,” often nothing else is heard after that point. It is not common for the parents and/or patient to remember much of what was told to them during the initial conversation in which the cancer diagnosis was disclosed. Additionally, the shock and devastation of the diagnosis may put parents and the patient in an emotional state where

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they are incapable of making a decision or choosing a treatment regimen [1, 2]. Often parents look to health-care providers to make important decisions for them or to guide them toward information that will aid in decision-making.

Unfortunately, there are decisions that need to be made around the time of diagnosis and prior to treatment that can impact the future health-related quality of life (HRQOL) for the teen cancer patient. Loss of fertility is an expected consequence of many cancer chemotherapy and radiation treatments. The exact odds of temporary or permanent infertility for teens are unknown and depend on the age of the patient, the cancer type and stage, and the treatment type and duration [3, 4]. Several national organizations, including the American Society of Clinical Oncology [4], the American Society for Reproductive Medicine [5], and the American Academy of Pediatrics [6], advise clinicians to discuss fertility issues with *all* cancer patients of childbearing age and refer interested patients to a reproductive endocrinologist (REI) or infertility specialist prior to their first cancer-related treatment. Discussing fertility and preservation of fertility (e.g., banking of sperm, oocytes, embryos, or gonadal tissue) prior to the first cancer-related treatment provides the best opportunity and the most options for ensuring biological children in the future. However, even among those cancer patients who choose to pursue fertility preservation prior to treatment, having a biological child in the future is never guaranteed.

Several studies of adult survivors of childhood cancer show that fertility is their most prevalent concern, resulting in not only a physical late effect but a psychological late effect [7, 8]. The fertility status of survivors is not well known [3, 9], and some studies indicate that survivors may be unaware they may have impaired fertility because of their cancer treatment [10, 11]. Other research reports that some survivors believed they were permanently sterile and then accidentally became pregnant or impregnated their partner unintentionally [12–14].

Poor communication on the topic of fertility and reproductive health at the time of a cancer diagnosis is understandable for a multitude of reasons. First, the priority for all involved is treating the cancer, and so it is possible that discussions about reproductive health and fertility simply do not occur during this crisis. Second, adolescent patients and family members may “shut down” after receiving a cancer diagnosis and may not absorb subsequent information about treatment options, schedules, and expectations, let alone information on future reproductive capacity. Third, oncology health-care providers may not feel comfortable discussing reproductive health issues with teen cancer patients, especially younger-aged teens and teens whose parents are present in the room with them. Compounding their own personal discomfort, these providers may not have training in communicating about reproductive health with adolescent patients who are still treated in a pediatric setting and may not feel comfortable discussing an issue outside their area of expertise. Fourth, there may not be an institutional infrastructure, system, or process in place to support referrals to a local REI, and in some cases, no such specialist may exist within the oncology health-care system or even the state [15, 16]. Finally, physicians may attempt to discuss reproductive health issues with the patient and/or parents and one or both parties may decline the information, believing it is not important at a time when treating the cancer is their only priority.

There are resources in place to assist health-care providers with communication [myoncofertility.org; fertilehope.org; livestrong.org] and developing a referral system within their health-care institution [17]. Despite these resources, little is known about the best way for oncology health-care providers to provide information to families and patients that facilitates the sharing of information and the decision-making process. While education materials are usually recommended to improve health literacy and patient understanding of a health-care issue, recent studies suggest that in the area of reproductive health, these materials are often not distributed [18–20]. Designing tailored educational materials that match the information needs of the population and the protocols and guidelines of the institution regarding fertility and referrals is especially recommended [21–24].

It is important to note that distributing educational materials alone is usually insufficient to guide parents and patients on the path of informed decision-making about future fertility and options for fertility preservation/banking. The stark reality is that some adolescent patients may not fully understand basic human reproduction or may not have thought about their future parenting goals. Additionally, parents may not have had the opportunity or desire to discuss reproductive health issues or their children's desires for parenthood, particularly with younger children.

What Is Important to Young Cancer Patients and Their Families?

Few studies have systematically assessed the reproductive concerns and preferences of adolescent and young adult (AYA) cancer patients, and only a handful have focused exclusively on the teen population [25, 26]. Adolescents in particular are an important group to study as they represent approximately the majority of childhood cancer patients [27].

HRQOL assessment tools are commonly used in the adolescent cancer population to measure physical, psychological, social, and cognitive domains that can predict and track outcomes in clinical trials, as well as highlight needs for a variety of health-care services [28]. HRQOL tools can also be used for research and evaluation purposes. Though HRQOL assessments are intended to be completed by the patients themselves, there are settings, particularly in child and adolescent populations, in which patients cannot complete them due to illness, age, cognitive impairments, or extreme fatigue [29]. In these cases, parents may serve as the proxy patient; however, parent reports of their child's HRQOL should be noted as a secondary outcome and not identified as the patient's own words due to the incongruence of many parent-proxy reports [28, 30]. Other studies and practice settings have even used assessment tools with adolescent populations that are designed for and by adults, further limiting the accuracy of the results [31, 32].

Using parents as proxy reporters in HRQOL assessments and discussions about their child's fertility concerns may lead to an ineffective use of resources, as health-care workers attempt to meet the needs of both the parent and adolescent. It was

Table 8.1 Phase 1 ten-item Reproductive Concerns Scale (RCS-Teen) (Adapted from Wenzel assessment^a)

1. One day I would like to have a baby
2. If I cannot have a baby I will be sad _____
3. I feel frustrated that I might not be able to have a baby in the future
4. I feel like I have control over my ability to have a baby in the future
5. I feel like I can talk to my parents about my ability 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 satisfied with the information that my doctor/nurse told me about my future fertility
9. I am worried about having a baby in the future because I might get sick/cancer again
10. I am worried about having a baby in the future because my baby might get sick/cancer

^aQuestions were the same for both age groups

once thought that parents should be the only reporters of their children's HRQOL [33], but now adolescents' unique health perceptions are being recognized as important [30, 34].

Current HRQOL instruments for both adult and adolescent cancer patients lack comprehensive assessments of reproductive concerns. Wenzel developed a stand-alone 14-item Reproductive Concerns Scale (RCS) in 2005 to assess a variety of reproductive concerns of adult female cancer survivors [35]. The RCS was validated using adult female healthy controls with a high internal consistency among survivors (Cronbach's alpha coefficient=0.91) [35]. No parallel measure currently exists for adolescent oncology patients.

In a step toward producing such an instrument for the adolescent oncology population, we conducted a study to pilot test a reproductive concerns scale for female adolescent cancer patients, called RCS-Teen. Since the RCS instrument was developed for adult women with cancer [35], we adapted it for teens through a series of qualitative tests [36, 37], resulting in a 10-item instrument applicable to adolescent females 12–18 years of age (Table 8.1).

Based on the existing literature [12, 30, 38–41], we hypothesized that adolescents would have fewer reproductive concerns than their parents and that adolescents would not view their concerns as drastically and negatively as their parents. This hypothesis was made based on the assumption that adolescents would struggle to actualize the long-term effects of not being able to have biological children. Parents, on the other hand, already have had the life experience of parenthood and thus would be expected to assess reproductive issues differently than their adolescent children. We also hypothesized that congruence between parent and adolescent would vary by age. Specifically, older adolescents would be better able to absorb the information provided to them and may also have a better understanding of basic human reproduction. As a result, older adolescents may tend to share reproductive concerns with their parents, thus producing a higher congruence in their responses to the 10 items on the RCS-Teen as compared with younger adolescents.

Our pilot study of the RCS-Teen instrument had three goals: the first was to assess the congruence between parent and teen responses, the second was to assess the acceptability of the items in terms of capturing accurate thoughts and emotions about reproductive concerns, and the third was to assess the feasibility of administering the instrument in the clinical setting. Participants in the study were adolescents ages 12–18 and their parents. Eligibility criteria included having a cancer diagnosis, on treatment or has undergone treatment within the past 6 months of recruitment, the ability to speak and comprehend questions in English, and willingness to provide assent from adolescents and written consent from parents. The multicenter study included adolescents who received treatment at two pediatric oncology centers: All Children's Hospital in St. Petersburg, Florida; Children's Hospital of Orange County, in Orange County, California; and at a nonprofit pediatric oncology community in Tampa, FL. Interviews were conducted between July 2009 and March 2011. The Institutional Review Boards of the University of South Florida, All Children's Hospital, and Children's Hospital of Orange County approved the study.

In separate interviews, female adolescent cancer patients and their parents were read each of the 10 items on the RCS-Teen and then asked to both answer the item and describe how they felt about the statement itself. This process, called cognitive debriefing, is a key component to ensuring that the adaptations were age- and cognitively appropriate [42, 43]. Parents were asked to also predict their child's response to each item [44, 45], and both parent and child completed a demographic form that captured information such as age, race, ethnicity, religion, diagnosis, treatment, and health status.

In total, 14 parent–teen pairs were interviewed ($n=28$). In all but one case, the mother was the parent who participated in the study. Overall, incongruence was found among all the parent–child responses. Sixty-four percent (9/14) of parents provided incorrect predictions of their daughter's responses on five or more of the statements. This incongruence was not impacted by age, disproving our original hypothesis. Our hypothesis about the level of concern was also disproved; in fact, overall the teens had more reproductive concerns than their parents.

Due to the small sample size, more sophisticated quantitative analyses were not conducted; however, there were clear associations between some items and demographic characteristics of the patients. First, 63% of adolescents who were dissatisfied with the information they received (item 1) were diagnosed with leukemia. Second, all adolescents who were not on treatment at the time of interview indicated they had talked to their parents about fertility (item 2). Third, half of the adolescents who said they would blame their cancer (item 6) were Caucasian. Lastly, all adolescents who said they had “very good health” and 57% of adolescents who reported having “good health” on the demographic form were worried about having a child and getting cancer again (item 8).

We assessed the overall frequencies of the responses by demographic characteristics. The analysis showed that, with regard to acceptability of the items in capturing appropriate emotions and adolescent oncology patients' thoughts on reproductive health, only four of the original 10 items were retained in their original form. Three items were revised and three were added as new items. Two items in particular

solicited the highest rates of disagreement among teens: the item that assessed frustration if they were not able to have a baby in the future and the item that examined the likelihood of patients blaming their doctor if their fertility was impaired were regarded as not relevant to the healthy controls. Additionally, the original ordering of the items incited strong emotions and tears among teens and parents during the earlier interviews. It was determined that the items needed to be reordered for graduated sensitivity, with the most emotionally charged items, such as items 4–7, presented in the middle of the assessment (Table 8.2).

To further validate the responses to the items, we conducted two focus groups with unaffected (healthy) teen girls in the same age group as the cancer patients. The goal was to utilize the responses of adolescents in the healthy focus groups to test if language, comprehension, and overall thoughts on the reproductive concerns items were valid and consistent across the two groups as well as divergent and unique to cancer patient group [46]. In instrument/item development, the use of focus groups serving as healthy controls has been noted to lead to more accurate, relevant items that fully capture the concerns of pediatric patients as well as the use of language and terms that are relevant to the age group [47, 48].

We asked the healthy girls who participated in the focus groups to imagine they had a serious illness that may affect their ability to have children in the future, and we conducted cognitive debriefing with these girls as well. A total of 25 girls between the ages of 12 and 18 years (mean \pm standard deviation [SD] = 15.4 \pm 2.1) participated, and the results mirrored that of the group of girls we interviewed who had a cancer diagnosis. The same two items that were problematic in the healthy population were also an issue in the teen cancer group (items 5 and 7). Adolescents in both age groups expressed significant concerns regarding potential infertility from cancer treatment and the impact it would have on their future. Older teens preferred to respond to open-ended statements, such as filling in the blank to item 4, “If I cannot have a baby in the future I will feel ____.” This response was similar in the cancer population. Parallels in language preferences such as replacing the word “frustrated” with “disappointed” were seen between the healthy controls and cancer groups; these adjectives for feelings have also been preferred in adult populations [26, 49, 50]. Table 8.2 provides a schematic of the changes that were made to the original to produce the final items on the RCS-Teen instrument.

The most important finding of our pilot study was that the RCS-Teen as an HRQOL assessment is not an appropriate instrument to administer in a clinical setting. Field notes from the social worker who conducted all the interviews and focus groups with the parents and teens, as well as with the healthy control group, noted that the content of the items and the topic of reproductive concerns were highly emotional issues. The instrument raised multiple questions from the cancer patients and their parents and in some cases incited tearful responses. Further, from a quantitative perspective, it was difficult to place an assessment on the final score and establish a benchmark to indicate what does and does not qualify as a reproductive “concern.” Wenzel’s original RCS used a Likert scale for ratings, with a 0–5 range of response categories [35]. An overall score was then calculated by summing all responses from the participant and dividing by the total possible score of 56. In this way, a higher score, especially when compared to a control group, indicated a higher

Table 8.2 Map of item restructure

Original item and order	Debriefing comments	Final item and order
		Values clarification tool
1. One day I would like to have (my daughter to have) a baby	Keep, but should not be first question Add additional question about having a “partner or family” in the future—this comes first in their mind and provides a context for the “baby”	1. In the future I would like to have a family (new item)
2. If I (my daughter) cannot have a baby, I will be sad	Replace sad with disappointed Or leave blank for respondent to define	2. In the future, I would like to have (my daughter to have) a biological baby (prior item 1)
3. I feel frustrated that I might not (my daughter) be able to have a baby in the future	Remove because it is asking the question again as above. Or rephrase Q2 to include a series of adjectives (sad, frustrated, and disappointed) for respondent to choose or define	3. If I (my daughter) cannot have a baby, I will be frustrated (prior item 2)
4. I feel I have control over my (daughter’s) fertility in the future	Remove—not relevant to mother or daughter	4. I would like to learn more from my doctor/nurse about future fertility (new item)
5. I feel I can talk to my parents (daughter) about fertility	Keep—use guide to explain only 2 in 14 groups had agreement between mother and teen. It is not unusual for discordance. Also 10 out of 14 preferred to talk to MD or other HCP and not parent	5. I feel I can talk to my parents (daughter) about fertility (former item 5)
6. If I cannot have a baby (daughter) I would blame the cancer	Delete question—most teens said if they blamed at all, they would blame the cancer treatment not the cancer. Most teens did not like to use the word blame and that was the same for most parents	6. I am satisfied with the information that my doctor/nurse told me about my (daughter) future fertility (expansion of former item 8)
7. If I (daughter) cannot have a baby I would blame my doctor or nurse	Delete question—no one agreed and the question incites anger	7. I am worried about (daughter) getting cancer again in the future (former item 9)
8. I am satisfied with the information that my doctor/nurse told me about my (daughter’s) future fertility	Keep as is	8. I’m worried about having a baby (daughter) in the future because I might get sick or get cancer (former item 9)
9. I am worried about having a baby in the future because I might get sick or get cancer again	Keep. As with Q 1, the first worry is about any recurrence, the second thought is about recurrence in relation to a child. Also response depends on where child is in process, if they are pre- or mid treatment, the worry may not have surfaced yet. Add additional question prior—Have you worried about getting cancer again?	9. I am worried about having a baby (daughter) in the future because my baby might get sick or get cancer (former item 9)
10. I am worried about having a baby (daughter) in the future because my baby might get sick or get cancer	Keep. Girls suggested scared may be a better word or remove “get cancer” and leave “get sick.” Girls and moms suggest the question is upsetting because they have never thought about it, however it appears it can serve as education to explain risk	10. I feel confident I have learned as much as I can about my (daughter’s) future fertility (new item)

reproductive concern. Within the teen population in our pilot study, we found that every item on the RCS-Teen instrument produced some level of concern, and more often than not, teens had difficulty “rating” this concern. Teens tended to provide a dichotomous response (yes/no), but not rate the strength of the response or the value of one emotion or concern over the other. Collecting data from a larger sample and comparing the results to a known group may allow for a benchmark to be established in this population; currently, no benchmark exists. Thus, the results from our pilot study indicated that while the RCS-Teen instrument had positive value, it would not be useful in the way we had originally intended.

How Can We Improve Communication About Oncofertility?

A systematic review by Trevena et al. on communicating with patients about evidence suggests that communication tools that are interactive increase patient understanding [51]. Improved understanding is further increased by values clarification exercises, particularly if the evidence to be assessed requires individual decision-making. A values clarification exercise or values clarification tool (VCT) is often used in environments in which a common shared vision or purpose is required, the goal of which may be to develop the common vision, define roles, or develop long-range plans. Similarly, a values clarification exercise can aid patients and family members to define values and beliefs, especially those that influence behavior. This clarification can lead to decisions that are reflective of beliefs and goals, rather than hypothetical situations or spontaneous thoughts, which are often elicited in stressful or fearful situations [52–55]. Dismantling barriers to decision-making and identifying gaps between what a patient believes or values and the behaviors that are actually exhibited are a key component of resolving decisional conflict [56]. While not a decision aid, a values clarification tool is a precursor or priming tool for future decision-making.

Based on our pilot study findings, we believe the best use of the RCS-Teen HRQOL instrument is as a VCT, administered to adolescent teens and parents under the guidance of a social worker, nurse, psychologist, or child-life specialist (Fig. 8.1). VCTs have specific advantages over HRQOL assessments. HRQOL instruments measure the responder’s perceptions by utilizing a norm-based scoring method, such as comparing the respondent’s scores of fatigue or pain to the average person in order to determine the “normalcy” of the patient’s issues. It would not be in the adolescent oncology patients’ best interest to score their concerns about fertility against the general population because adolescent oncology patients have unique concerns that the general population does not, and there is currently no data on healthy adolescents’ concerns about fertility and reproduction to be used for comparison.

VCTs have a dual purpose in benefiting both the adolescent and administrator, whether that person is a researcher, social worker, or psychologist. The open-ended statements of the VCT encourage the patient/parent and administrator to begin a dialogue so that the patient/parent may *process* the idea of having children first and

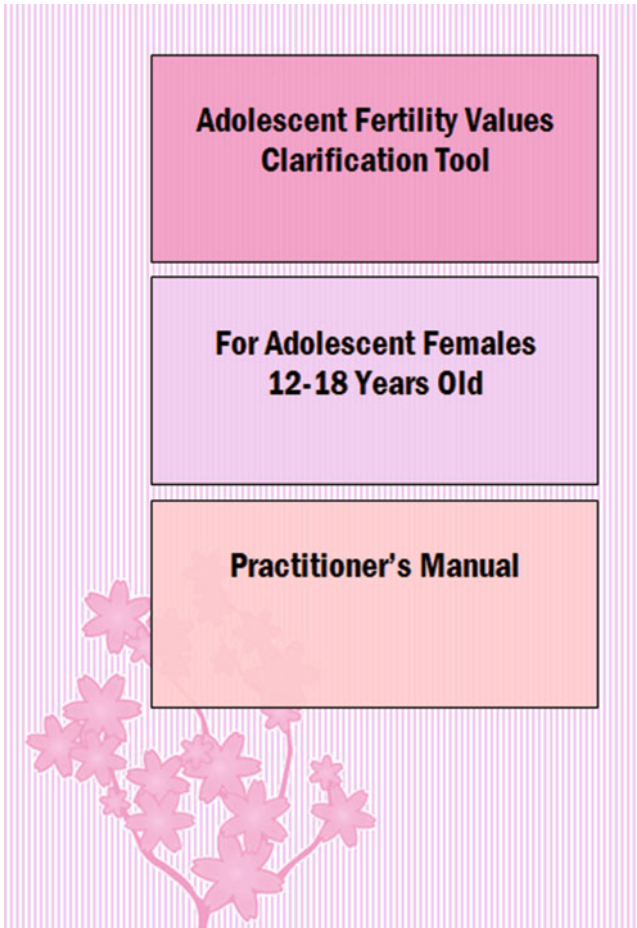


Fig. 8.1 Adolescent Fertility Values Clarification Tool

then consider their feelings about possibly not being able to have children in the future. This allows the administrator to accurately assess the patient's concerns and develop approaches to educate the patient on her risk as well as risk-reducing options. Our experience with the RCS-Teen showed that a teen's initial reaction to the first few statements was not consistent with their reaction to later statements. For example, with item 3, "I would like to have a baby one day," the majority of the teens said "I guess so" or "Maybe, it's not a big deal." However, by the time the interviewer read the items talking about blame, their responses became less ambiguous, and as they began to process the idea of first wanting children and then thinking about not being able to have them, their responses were emotional and led to more concrete statements such as "I've wanted to be a mother my whole life" or "I might not be able to find a husband if I can't have kids." This delay in providing

clear statements may be due to many factors, including difficulty thinking about the future, fear of having “one more thing wrong” that needs to be addressed, disinterest in the topic, or the inability to immediately process the idea that goals for the future, which may be 10 or 20 years ahead and may be impacted by decisions they make at the present time. The order of the items in the RCS-Teen is also important to minimize distress and reduce risk of psychological harm to the teen. Coping strategies, resiliency, and familial support may not be known at the time of test administration. Allowing patients to process the concepts of infertility, their own values, and their own desire for control through a safe and private discussion can empower the adolescent to take an active role in achieving future goals related to biological children. More information on communication between providers and patients is presented in Chaps. 11 and 13 of this book.

Conclusions

Adolescents, whether diagnosed with cancer or healthy, have clear expectations for biological parenthood in the future. However, barriers to discussions and lack of comprehensive assessment tools too often prevent these expectations from being realized, expressed, or taken seriously. Discussions regarding adolescents’ values and goals for parenting in the future should be encouraged with patients and their parents prior to beginning cancer treatment. The VCT can be a particularly useful tool in the clinical setting to begin this dialogue.

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