



Published in final edited form as:

J Adolesc Health. 2013 February ; 52(2): 164–169. doi:10.1016/j.jadohealth.2012.05.011.

Healthy Adolescent Girls' Perceptions of Cancer-Related Infertility Having cancer doesn't change wanting a baby: Healthy adolescent girls' perceptions of cancer-related infertility

Gwendolyn P. Quinn, Ph.D.^{1,2,*}, Devin Murphy, MSW², Hua Wang, MS³, Kelly K. Sawczyn, MD⁴, and Caprice Knapp, Ph.D.³

¹College of Medicine, University of South Florida, Tampa, FL, United States

²Health Outcomes and Behavior, H. Lee Moffitt Cancer Center and Research Institute, Tampa, FL, United States

³Institute for Child Health & Policy, College of Medicine, University of Florida, Gainesville, FL, United States

⁴All Children's Hospital, St. Petersburg, FL

Abstract

Purpose—The goal of this study was to determine healthy adolescents' perceptions of cancer and fertility. A secondary goal of the study was to test items related to the development of a health related quality of life tool with healthy controls to determine if the participants shared a common understanding of the items, response options and confirm face and content validity.

Methodology—Four focus groups of two age groups were held with healthy adolescent females: 12-14 (N=11) and 15-18 (N=14).

Results—Adolescents in both age groups expressed significant concerns regarding potential infertility from cancer treatment, hereditary transmission and the impact it would have on their future. Differences emerged in language preferences among older adolescents who preferred more open-ended statements.

Conclusions—Fertility concerns and desires for future motherhood can be accurately assessed using the 10 statements tested, and clinicians should be made aware of the differences between younger and older adolescents to facilitate effective communication. This research suggests adolescents have predetermined expectations for becoming future parents and their concerns about fertility and childbearing are present prior to becoming a patient.

Keywords

Fertility; Adolescents; Health Related Quality of Life; Perceptions

© 2012 Society for Adolescent Medicine. Published by Elsevier Inc. All rights reserved.

*Corresponding Author: 12902 Magnolia Drive, MRC CANCONT, Tampa FL 33612, 813-745-1359 (office), 813-449-8019 (fax), gwen.quinn@moffitt.org.

Publisher's Disclaimer: This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final citable form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

Introduction

Fertility and reproductive concerns are an emerging topic among adolescents and young adults (AYA) with cancer as well as childhood cancer survivors. Identifying these concerns further highlights the historical lack of knowledge and communication regarding fertility during treatment for cancer in adolescent patients. Oosterhuis et al. identified that approximately 43% of adolescent oncology patients were concerned their treatment may make them infertile (Oosterhuis, Goodwin, Kiernan, Hudson, & Dahl 2008). Female adolescent oncology patients have been shown to frequently think about the future in terms of childbearing and are interested in methods that could preserve fertility during treatment (Burns, Boudreau C, & Panepinto, 2006). However, if concerns about fertility are not communicated by the parent, patient, or not assessed in health-related quality of life instruments (HRQOL), it can be difficult to measure the impact of these concerns over time. Fertility has been a significant factor in longitudinal HRQOL studies often linked with regret, guilt for current or future partner, or fear of never finding a partner (Crawshaw & Sloper 2006).

One instrument was developed for a cancer population. Wenzel's 14-item Reproductive Concerns Scale (RCS) was developed in 2005 to assess a variety of reproductive concerns of adult female cancer survivors. The scale was validated using adult female healthy controls of childbearing age and found to have a high internal consistency among survivors (Cronbach's alpha coefficient=0.91) and healthy controls (Cronbach's alpha coefficient=0.81) (Wenzel et al. 2005).

Healthy controls play a significant role in development of HRQOL instruments in pediatric populations. Existing instruments that measure pediatric HRQOL have infrequently utilized children and adolescents in the process of item development (DeWalt, Rothrock, Yount, Stone, & Group, 2007; Varni, Seid, & Rode 1999). Despite this, multiple studies suggest the use of focus groups as healthy controls has led to more accurate, relevant items, which fully capture the concerns of pediatric patients (Varni, Seid, & Kurtin 2001; Walsh, Irwin, Meier, Varni, & DeWalt 2008). Focus groups of healthy controls significantly contribute to item development in pediatric assessment scales (Walsh et al. 2008) by showing where perspectives are generalizable across groups as well as divergent and unique to patients with the illness. Further, item development is facilitated through homogeneity of the group that can be readily compared (Miller, Palermo, & Grewe 2003; Peterson-Sweeney 2005).

Also involved in the item development process is confirming face and content validity through qualitative analysis methods. Content validity is the property that determines the comprehensiveness of the measuring instrument, while face validity assesses how participants understand each question in order to complete the questionnaire (Brod, Tesler, & Christensen 2009). Participants provide their responses to generated evidence-based items so that emergent themes can be categorized then later used to revise the instrument (M. Patton 1999; Walsh et al. 2008). Face and content analysis is just one step in the multi-layered process of instrument development (Brod et al. 2009). Focus groups are especially valuable in instrument development because group members naturally validate or reject one another's perspective while appreciating influential individual personal experiences. This process can aid in ensuring that instruments and tools developed for a specific group can accurately capture the perspectives of the target audience (M. Patton 1999). The goals of confirming face and content validity in instrument development are to ensure the words used in the questions establish culturally normative values on a topic; questions are comprehensible, and easy for subjects to answer. Using healthy controls allows for pilot testing and cognitive debriefing of survey instruments by comparing responses of patients to subjects who are not emotionally affected by a cancer diagnosis. This in turn creates an

instrument that is anchored to the intended population based on verbal transactions that stimulate insights (Jobe 2003; M. Patton 1999).

The goal of this study was twofold. We aimed to determine healthy adolescents' perceptions about cancer and infertility. A secondary goal of the study was to test HRQOL items with healthy controls to assess if participants shared a common understanding of the items, response options and to confirm the face and content validity. An adaptation of Wenzel's RCS for adolescents with cancer was created by the research team and used in this study.

Method

The design of the study was based on Jobe's framework (Jobe 2003) for assessing cognitive and social-motivational processes wherein respondents verbalize their thinking around each item and response.

Survey Instrument

The research team collaborated to adapt Wenzel's RCS instrument which was independently developed for use in the 2006 study. The original RCS used Likert scale ratings that ranged between 0-5 for each item. Each item's score is summed for all 10 items, then divided by the total possible (56 points). A higher score indicated a higher reproductive concern. For the adapted version, the research team was guided by the RCS and preliminary literature review which showed a strong desire for information, desire for future parenthood, and desire for control over reproductive rights.

Subjects and recruitment

Approval was obtained from the University of South Florida (USF) Institutional Review Board (IRB) and the University of Florida (UF) IRB. Healthy adolescents were recruited through flyers posted at the Moffitt Cancer Center (MCC) in Tampa, Florida and Shands Hospital in Gainesville, Florida. Eligibility criteria included: 1) female adolescents between the ages of 12- 18 and 2) no prior major illness. Participants were partitioned into two age groups: 12-14 and 15-18.

After participants provided signed assent forms and parental consent was obtained, four 90-minute focus groups were conducted (two with each age group at each site). Participants were compensated with a \$25 gift card at the completion of the focus group.

Respondents in the focus groups were first asked if they knew about a connection between cancer or its treatment and fertility (Figure 1).

The adolescents were told to imagine they had cancer and to consider how they might feel about each of the 10 statements (Table 1), which were then read aloud by the moderator. Respondents were asked to provide feedback on the vocabulary used, if they believed the statement would be relevant to them, if the statement was confusing, and suggestions for additional items that might be relevant yet not captured in this instrument. After the discussion had reached consensus or agreeable differences, the next item was read.

Piloting of Assessment Tool

Focus group participants were separated into the two age groups because age similarity has been noted as a key component in focus group dynamic, even more so than being acquainted with the other members of the group (Hughes & DuMont 1993). Similar studies have shown effective discussion occurs in focus groups with adolescent participants who have a 1-2 year age difference (Hughes & DuMont 1993). Additionally, researchers were concerned the

discussions that may occur about reproductive health and fertility in a group of 16 year-old adolescents may not be appropriate for 12 year olds.

Data Analysis

Once all the audiotapes were transcribed, the research team utilized the constant comparative method and grounded theory approach to analyze responses (Turner 1981). The research team first independently then collaboratively reviewed the data and discussed any discrepancies, confirming face validity. Codes were created to categorize responses until saturation was reached and no new codes emerged, and were then aggregated into themes. Similar themes were grouped together (Dye, Schatz, Rosenberg, & Coleman 2000), and the research team identified sub-categories that emerged through several rounds of thematic validation (M. Q. Patton 2002). Hand-coding techniques allowed for appropriate themes to emerge. Themes of the adolescents' perceptions and appropriate revisions to the instrument were discussed until a consensus was reached in order to ensure inter-rater reliability. Content Validity Ratio (CVR) was determined by the research team by independently categorizing items into 'essential,' 'useful,' and 'not necessary.' The CVR is computed as $(N_e - N/2)/(N/2)$, where N_e equals the number of research team members who indicated an item was 'essential.' N equals the total number of team members in the panel. CVR values range +1 to -1, and products closer to +1 show an agreement that the item is essential to content validity (M. Q. Patton 2002). A panel of 5 members requires a minimum CVR of 0.60 to meet a 0.05 significance level, meaning agreement by at least 4 of 5 respondents.

Results

Twenty-five adolescent females participated in the focus groups. Participants were between 12-18 years old (mean + SD = 15.4 ± 2.1). Eleven females participated in the younger age group (12-14), while 14 participated in the older age group (15-18) (Table 2). No additional focus groups were required as there was a clear saturation of data wherein no new responses arose.

Desire for Information

All adolescents in the younger group agreed they would like to have information on fertility risks prior to treatment. Respondents were asked at what point in the timeline of diagnosis and treatment they would want to know about fertility related issues. The majority said they would want to know "right away." The adolescents in the older group focused on the fact that information about fertility was related to "my body" and voiced strong feelings about the doctor telling them first and not their parents. Adolescents from both groups said they would prefer to have a discussion with a physician and a pamphlet at the same time.

Impact of a Hypothetical Cancer Diagnosis on the Desire to Have Children

All of the older adolescents agreed they would like to have baby in the future. Among the younger adolescents there was one participant that said she was not interested in having children. Despite the majority who said they wanted to have a baby, two adolescents said if they had cancer, they may not want to have a child because they were concerned about the baby getting sick or getting cancer. Respondents were asked if it was upsetting to hear the statement about their desire to have children. The majority said it made them think and it concerned them, but it was something important to think and talk about it, whether one had cancer or not.

Respondents suggested the words sad, disappointed, upset, and insecure to describe their feelings if they found out they could not have children in the future because of their cancer treatment. The majority of the older adolescents said they would use the word 'sad' to

describe their feelings, while the younger adolescents said they would be equally 'sad' and 'disappointed.' One may feel disappointed during the time they are grieving over the loss of expectations for the future.

The statement asking about frustration brought mixed responses from all adolescents within both age groups. Some respondents focused on the word 'frustrated' and said it was not strong enough and that perhaps words like 'angry' and 'mad' and feeling 'cheated' were more appropriate. Other adolescents said that before dwelling on the words to describe the potential side effect of infertility, they would instead 'be grateful to be alive, to have a life.' Several of the adolescents mentioned that having a child was a life goal, and the inability to do so would make them feel 'unimportant' or 'helpless.' Adolescents from the younger age group talked about being given a consequence that was not fair because they had not done anything wrong. The majority of the younger adolescents said that the word 'frustrated' would accurately described how they felt if they could not have a baby due to cancer treatment. This contrasts with the majority of the older adolescents, who said that a patient answering these questions should be able to define the feeling for themselves.

Feelings of Blame

Initially the group of older adolescents thought the concept of blame was appropriate but the majority noted that it was the treatment and not the cancer that probably caused the damage. They also noted the treatment most likely was saving their life or allowing them to continue living and that blaming the cancer or the treatment 'didn't have a point.' As the discussion continued, this older group came to consensus that a better word than blame would be 'associate.' Some of the adolescents in the older group said that they would blame themselves or their family if it was a genetically inherited cancer.

None of the adolescents in the younger group said they would blame the doctor or nurse, however two adolescents in the older group said that they would. The adolescents that felt they would blame the doctor or nurse explained it was easier to blame a person, and that blame should go to a health care professional if they had not clearly explained what the cancer treatment may do to future reproduction. The majority of the adolescents in both groups said that after time had passed they expected they would be resigned to the issue and would have 'grown up' enough to not place blame.

Concerns of Recurrence/Transmission

Half of the older adolescents said they would be worried they could get cancer again, while only a small portion of the younger adolescents said they would be worried. There was a clear consensus that they would be more concerned about transmitting cancer to their baby or creating a baby who was sick in some way from the cancer or treatment they had experienced. This same group of respondents was also concerned about learning if having a baby would increase the risk of or causes the cancer recurrence.

The statement regarding the future child being diagnosed with cancer was the only statement where the majority of respondents said the question itself caused them concern or distress. All adolescents in both groups agreed with this statement and the majority had disclosed this concern prior to the statement being read. They explained that the potential genetic transmission of cancer was something they had not considered and hearing this statement raised many additional questions. The majority of adolescents from both groups noted the word 'baby' added to the emotion they felt about the situation and suggested that options such as "child" or "kid" would minimize the emotional impact.

Some adolescents said that they would not consider childbearing if there were a great risk of recurrence or transmission. Some adolescents in the older group said to replace the word

'worried' with 'scared' and that if they survived cancer they would have an arrangement in place in the event their baby were diagnosed with cancer. Both groups felt this question was not overly distressing however remarked the topic was inherently distressing.

None of the adolescents in the younger group felt they would have control over their fertility however they did say it was an important statement because it would initiate a conversation. In contrast, the majority of older adolescents felt they would have control over their own fertility. The older adolescents explained that after a cancer diagnosis there would be multiple areas in their lives that they would not have control over, and therefore would be actively looking for areas where they could have control, such as having children in the future.

Overall, the 10 item instrument was found by the research team to have face and content validity. Face validity was determined by assessing all feedback and revisions to the overall instrument that was in consensus with all members of the research team. Content validity was confirmed through CVR, in which the resulting ratio was either .60 or +1 for all 10 items for both age groups, with the exception of one item for the younger group which was removed based on a CVR of -1. This suggests the majority of items are essential to capturing the overall intended measurement of adolescents' perceptions of fertility if diagnosed with cancer, and sharing a common understanding of the items. When asked what, if anything, the instrument was missing, the adolescents explained that revising key questions will capture the relevant information the instrument is intending to.

Instrument Revision

Based on feedback from the focus groups, it was determined that two instruments were needed to accurately capture the distinguishable differences between younger and older adolescents (Table 3). These revised instruments will be pilot tested with female oncology patients in the same age ranges and their parents.

Discussion

The adolescents who participated in these focus groups expressed significant concerns regarding fertility information and the impact infertility would have on their future. Both age groups showed similar information needs found in other studies with adolescents with cancer. A 2004 study by Decker et al. reports that adolescents with cancer have high information needs not only at the point of diagnosis but throughout the continuum of care. This is further confirmed by a review of conducting focus groups with healthy children, which suggests participants learn about a health science topic and continue to desire additional information. (Kennedy, Kools, & Krueger 2001). Adolescents' need for information is not unique to adolescents with cancer, but true across all adolescent groups as a fundamental developmental stage whether or not a chronic illness is present. (Decker, Phillips, & Haase, 2004; Kennedy et al. 2001).

Females often see children as part of their future (American Academy of Child and Adolescent Psychiatry 2006; de Morneffe 2007; Kuther 2003; Ogle, Glasier, & Riley 2008) therefore, it is not surprising that almost all adolescents desired motherhood. The majority of younger adolescents agreed with the 4th and 5th statements indicating they would feel 'sad,' 'disappointed,' and 'frustrated,' however the older adolescents explained they would have multiple emotions and the instrument would be more appropriate if it allowed the patient to define her own feelings. Adolescents in these age ranges have been shown to better predict future behavior when given multiple, rather than dichotomous, options (Purewal & van Den Akker 2007). Feelings of sadness and frustration among these adolescents parallels studies done with adults who have expressed these same emotions (Carter et al. 2005; Dozier 1991;

van Balen & Trimbos-Kemper 1995) as well as other studies with adolescent cancer patients who face fertility impairment (M. A. Crawshaw & Sloper 2006).

Older adolescents tend to search for areas of control in their lives (Luskse & Vacc 1999), and the desire for control and externalizing blame is a normative developmental stage for older adolescents (Partridge et al. 2004). It seems that because the younger adolescents felt they did not have control over their fertility, there was subsequently no one to blame.

Adolescents have been shown to understand emotional and social impacts of cancer and other chronic illnesses for peers (Vangelisti 1992). Both groups believe that acceptance emerges as a normal developmental pattern, even though much literature reports on cancer survivors' internal and external blame for their infertility (Elkind 1998; Ogle et al. 2008; Wenzel et al. 2005).

Many adult survivors have indicated a fear of recurrence as a psychological late effect of cancer (Bauer-Wu & Farran 2005; Gray & Rodrigue 2001; Self 2007), however very limited studies exist about pediatric cancer patients' fear of recurrence (Boman & Bodegård 1995). The responses to the fear of transmitting cancer to offspring were similar between both age groups, and also in line with studies of adult cancer patients and childhood cancer survivors (Surbone & Petrek 1997). Limited studies have explored adolescent cancer patients' views regarding fear of transmission to offspring, however Chambas found that the majority of cancer patients aged 12- 19 were concerned about transmission and the health outcome of their future children (Chambas 1991).

Processing a cancer diagnosis seems to take precedence over concerns about fertility for the older group. Crawshaw et al. described similar results in a study with adolescent cancer survivors and their views of fertility discussions occurring during the time of diagnosis. These investigators suggest it is appropriate to raise issues of fertility alongside a diagnosis with females between 11-20 years old with the precaution of having support systems in place, and re-visiting the conversation later (M. Crawshaw, Glaser, Hale, & Sloper 2009).

This study has several notable limitations. The small sample size and geographic commonality between participants limits generalizability. Likewise, the demographic characteristics of the girls may not be representative of the general population, although this is an inherent limitation of focus groups in general along with social desirability bias and groupthink. All of these could have impacted these results; however, participants did express diverging views.

Conclusions

Healthy adolescent females parallel the reproductive concerns of adolescents with cancer in the same age ranges. This study highlights the fertility concerns among healthy adolescents and strengthens the argument for using the adapted 10-item scale; however the differences in younger and older adolescents should be taken into account. The validation of this tool with a healthy population increases its potential value for girls diagnosed with cancer. This scale can be useful in clinical practice settings to determine the values female adolescents with cancer hold on fertility, and how this life-altering event has impacted these values. Future research using this tool with a larger, more representative group is needed. Understanding the importance of reproductive concerns of healthy adolescents confirms the need for interventions and developmentally appropriate tools to prevent negative quality of life late effects during survivorship among those diagnosed with cancer.

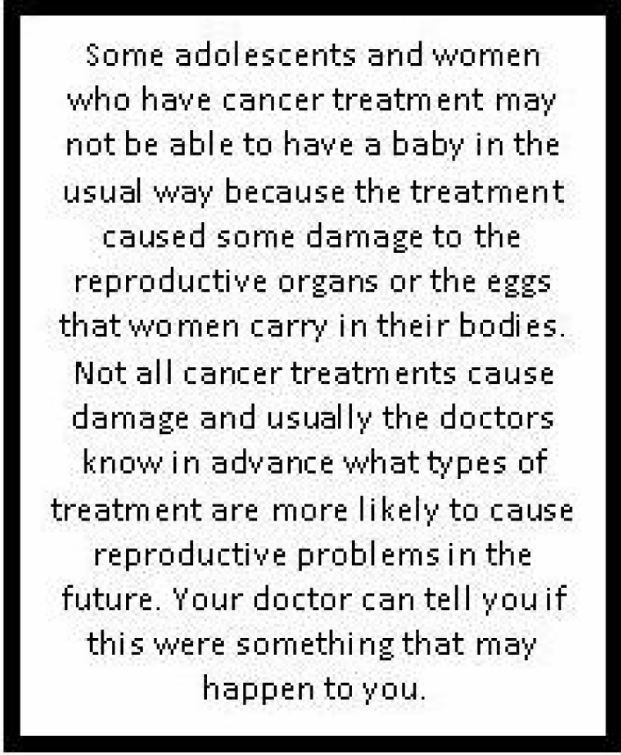
Acknowledgments

This work was supported by a grant from the Oncofertility Consortium at Northwestern University. All authors listed have contributed significantly to the work.

References

- American Academy of Child and Adolescent Psychiatry. [Accessed March 11, 2011] The Child with a Longterm Illness. Fast Facts for Families. 2006. from [http://www.aacap.org/galleries/FactsForFamilies/19_the_child_with_a_long_term_illness .pdf](http://www.aacap.org/galleries/FactsForFamilies/19_the_child_with_a_long_term_illness.pdf)
- Bauer-Wu S, Farran CJ. Meaning in Life and Psycho-Spiritual Functioning. *Journal of Holistic Nursing*. 2005; 23(2):172–190. doi: 10.1177/0898010105275927. [PubMed: 15883465]
- Boman K, Bodegård G. Psychological long-term coping with experience of disease and treatment in childhood cancer survivors. *Acta Pædiatrica*. 1995; 84(12):1395–1402. doi: 10.1111/j.1651-2227.1995.tb13576.x.
- Brod M, Tesler L, Christensen T. Qualitative research and content validity: developing best practices based on science and experience. *Quality of Life Research*. 2009; 18(9):1263–1278. [PubMed: 19784865]
- Burns KC, Boudreau C, Panepinto JA. Attitudes Regarding Fertility Preservation in Female Adolescent Cancer Patients. *Journal of Pediatric Hematology & Oncology*. 2006; 28(6):350–354.
- Carter J, Rowland K, Chi D, Brown C, Abu-Rustum N, Castiel M, Barakat R. Gynecologic cancer treatment and the impact of cancer-related infertility. *Gynecologic Oncology*. 2005; 97(1):90–95. [PubMed: 15790443]
- Chambas K. Sexual Concerns of Adolescents With Cancer. *Journal of Pediatric Oncology Nursing*. 1991; 8(4):165–172. doi: 10.1177/104345429100800404. [PubMed: 1930809]
- Crawshaw M, Glaser A, Hale J, Sloper P. Male and female experiences of having fertility matters raised alongside a cancer diagnosis during the teenage and young adult years. *European Journal of Cancer Care*. 2009; 18(4):381–390. doi: 10.1111/j.1365-2354.2008.01003.x. [PubMed: 19594609]
- Crawshaw, MA.; Sloper, P. A Qualitative Study of the Experiences of Teenagers and Young Adults when Faced with Possible or Actual Fertility Impairment Following Cancer Treatment. University of York; York: 2006.
- de Morneffe, D. *Maternal desire: On children, love, and the inner life*. Little Brown Book Group; New York: 2007.
- Decker C, Phillips CR, Haase JE. Information Needs of Adolescents With Cancer. *Journal of Pediatric Oncology Nursing*. 2004; 21(6):327–334. doi: 10.1177/1043454204269606. [PubMed: 15475469]
- DeWalt DA, Rothrock N, Yount S, Stone AA, Group, o. b. o. t. P. C. Evaluation of Item Candidates: The PROMIS Qualitative Item Review. *Medical Care*. 2007; 45(5):S12–S21. 10.1097/1001.mlr.0000254567.0000279743.e0000254562. [PubMed: 17443114]
- Dozier M. Functional Measurement Assessment of Young Children’s Ability to Predict Future Behavior. *Child Development*. 1991; 62(5):1091–1099. doi: 10.1111/j.1467-8624.1991.tb01591.x. [PubMed: 1756657]
- Dye JF, Schatz IM, Rosenberg BA, Coleman ST. Constant comparison method: A kaleidoscope of data. *The Qualitative Report*. 2000; 4(1/2):1–9.
- Elkind, D. *All Grown Up and No Place to Go*. Perseus Books; Reading, MA: 1998.
- Gray CC, Rodrigue JR. Brief Report: Perceptions of Young Adolescents About a Hypothetical New Peer With Cancer: An Analog Study. *Journal of Pediatric Psychology*. 2001; 26(4):247–252. doi: 10.1093/jpepsy/26.4.247. [PubMed: 11329484]
- Hughes D, DuMont K. Using focus groups to facilitate culturally anchored research. *American Journal of Community Psychology*. 1993; 21(6):775–806. doi: 10.1007/bf00942247.
- Jobe JB. Cognitive psychology and self-reports: Models and methods. *Quality of Life Research*. 2003; 12(3):219–227. doi: 10.1023/a:1023279029852. [PubMed: 12769134]
- Kennedy C, Kools S, Krueger R. Methodological Considerations in Children’s Focus Groups. *Nursing Research*. 2001; 50(3):184–187. [PubMed: 11393641]

- Kuther T. Medical decision-making and minors: issues of consent and assent. *Adolescence*. 2003; 38:343–357. [PubMed: 14560886]
- Luskse MP, Vacc NA. Grief, Depression, and Coping in Women Undergoing Infertility Treatment. *Obstetrics & Gynecology*. 1999; 93(2):245–251. [PubMed: 9932564]
- Miller V, Palermo TM, Grewe SD. Quality of life in pediatric epilepsy: demographic and disease-related predictors and comparison with healthy controls. *Epilepsy & Behavior*. 2003; 4(1):36–42. [PubMed: 12609226]
- Ogle S, Glasier A, Riley SC. Communication between parents and their children about sexual health. *Contraception*. 2008; 77(4):283–288. [PubMed: 18342652]
- Oosterhuis BE, Goodwin T, Kiernan M, Hudson MM, Dahl GV. Concerns about infertility risks among pediatric oncology patients and their parents. *Pediatric Blood & Cancer*. 2008; 50(1):85–89. doi: 10.1002/pbc.21261. [PubMed: 17514741]
- Partridge AH, Gelber S, Peppercorn J, Sampson E, Knudsen K, Laufer M, Winer EP. Web-Based Survey of Fertility Issues in Young Women With Breast Cancer. *Journal of Clinical Oncology*. 2004; 22(20):4174–4183. doi: 10.1200/jco.2004.01.159. [PubMed: 15483028]
- Patton M. Enhancing the quality and credibility of qualitative analysis. *Health Services Research*. 1999; 34(5):1189–1208. [PubMed: 10591279]
- Patton, MQ. *Qualitative research and evaluation methods*. Sage Publications, Inc; 2002.
- Peterson-Sweeney K. The use of focus groups in pediatric and adolescent research. *Journal of Pediatric Health Care*. 2005; 19(2):104–110. [PubMed: 15750555]
- Purewal S, van Den Akker O. The socio-cultural and biological meaning of parenthood. *Journal of Psychosomatic Obstetrics & Gynecology*. 2007; 28(2):79–86. doi: 10.1080/01674820701409918. [PubMed: 17538815]
- Self, MC. *Surviving with Scars: The Long-Term Psychosocial Consequences of Teenage Cancer*. Blackwell Science Ltd; 2007.
- Surbone A, Petrek JA. Childbearing issues in breast carcinoma survivors. *Cancer*. 1997; 79(7):1271–1278. doi: 10.1002/(sici)1097-0142(19970401)79:7<1271::aid-cnrc1>3.0.co;2-k. [PubMed: 9083146]
- Turner BA. Some practical aspects of qualitative data analysis: One way of organising the cognitive processes associated with the generation of grounded theory. *Quality and Quantity*. 1981; 15(3): 225–247. doi: 10.1007/bf00164639.
- van Balen F, Trimbos-Kemper TCM. Involuntarily Childless Couples: Their Desire to have Children and Their Motives. *Journal of Psychosomatic Obstetrics & Gynecology*. 1995; 16(3):137–144. doi: 10.3109/01674829509024462. [PubMed: 8528380]
- Vangelisti AL. Older Adolescents' Perceptions of Communication Problems with Their Parents. *Journal of Adolescent Research*. 1992; 7(3):382–402. doi: 10.1177/074355489273007.
- Varni JW, Seid M, Kurtin PS. PedsQL(TM) 4.0: Reliability and Validity of the Pediatric Quality of Life Inventory(TM) Version 4.0 Generic Core Scales in Healthy and Patient Populations. *Medical Care*. 2001; 39(8):800–812. [PubMed: 11468499]
- Varni JW, Seid M, Rode CA. The PedsQL(TM): Measurement Model for the Pediatric Quality of Life Inventory. *Medical Care*. 1999; 37(2):126–139. [PubMed: 10024117]
- Walsh T, Irwin D, Meier A, Varni J, DeWalt D. The use of focus groups in the development of the PROMIS pediatrics item bank. *Quality of Life Research*. 2008; 17(5):725–735. doi: 10.1007/s11136-008-9338-1. [PubMed: 18427951]
- Wenzel L, Dogan-Ates A, Habbal R, Berkowitz R, Goldstein DP, Bernstein M, Cella D. Defining and Measuring Reproductive Concerns of Female Cancer Survivors. *Journal of the National Cancer Institute*. 2005; 2005(34):94–98. doi: 10.1093/jncimonographs/lgi017. [PubMed: 15784834]



Some adolescents and women who have cancer treatment may not be able to have a baby in the usual way because the treatment caused some damage to the reproductive organs or the eggs that women carry in their bodies. Not all cancer treatments cause damage and usually the doctors know in advance what types of treatment are more likely to cause reproductive problems in the future. Your doctor can tell you if this were something that may happen to you.

Fig 1.
Definition of Fertility

Table 1

10-Item Reproductive Concerns Assessment

1. I would like 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

Table 2

Demographics

	12-14 Years (n=11)	15-18 Years (n=14)
Race/Ethnicity		
White	18% (2/11)	85% (12/14)
Asian	63% (7/11)	1% (1/14)
Black	1% (1/11)	0
Hispanic	1% (1/11)	1% (1/11)
Mean Age	13	16.8

Table 3

Revisions Based on Feedback

Item	Revision: 12-14 Year Olds	Revision: 15-18 Year Olds
I would like information about how my cancer treatment can affect my ability to have children	I would like information about specific factors that might affect my ability to have children.	I prefer to learn about how my cancer treatment can affect my ability to have children by --
I feel like I can talk to my parents about my ability to have a baby in the future.	I feel like I can talk to someone about my ability to have a baby in the future.	I feel like I can talk to someone about my ability to have a biological baby in the future.
I would like to have a baby.	I've thought about having children in the future.	I've thought about having biological children in the future.
If I cannot have a baby I would be --.	If I cannot have a baby I will feel disappointed.	If I cannot have a biological baby I will feel--.
I feel frustrated that I might not be able to have a baby in the future if I were diagnosed with cancer.	No Change	Remove Question
If I cannot have a baby one day in the future I would blame my cancer.	If I cannot have a baby one day in the future I would have feelings of blame.	If I cannot have a biological baby one day in the future I would relate it to having cancer.
If I cannot have a baby, I would blame my doctor or nurse.	If I cannot have a baby I would be angry at the doctor if I wasn't told beforehand.	If I cannot have a biological baby one day in the future I would look for someone to blame.
I'm worried about having a baby in the future because I might get sick or get cancer again.	I am worried about getting cancer again, and how that would affect me if I'm a parent.	I'm worried about having a biological baby in the future because I might get cancer again.
I'm worried about having a baby in the future because my baby might get sick or get cancer.	I've thought about my future baby getting cancer.	I've thought about my future biological baby getting cancer.
I feel like I have control over my ability to have a baby in the future.	I feel like there are things I can do now to help me be able to have a baby in the future.	I would be interested in knowing about things I can do now to help me be able to have a biological baby in the future.