



Knowledge and perceptions of infertility in female cancer survivors and their parents

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Abstract

Purpose The purpose of this study was to assess knowledge and perceptions of infertility, reproductive concerns, quality of life, and emotional burden of fertility concerns in adolescent female cancer survivors and their parents.

Methods A cross-sectional design was used to investigate reproductive knowledge and concerns among female childhood cancer survivors and their parents. The instruments administered at a single, routine visit were the 13-item knowledge instrument, Adolescent Fertility Values Clarification Tool (VCT), Impact of Event Scale (IES), and Pediatrics Quality of Life Assessment (PedsQL). The knowledge instrument was given to both patients and caregivers, while the PedsQL and VCT were given to only patients and IES only to caregivers.

Results Twenty-six survivors and 23 parents completed evaluations. The mean age of survivors was 16. The mean knowledge instrument score for survivors was 9.5 (± 1.9) and 9.96 (± 1.7) for parents with a maximum possible score of 13. The VCT indicated almost all patients agreed or strongly agreed they would like more information on how their treatment may affect their fertility, with 84.6% identified wanting a baby in the future. The mean survivor PedsQL score was 67.7 (± 15.3). While parental IES scores as whole did not endorse symptoms of PTSD, 30% of our sample did fall within the range for PTSD.

Conclusion Although this population of women has above average knowledge scores, they still demonstrated a desire for more information on reproduction after cancer therapy. While PedsQL scores fell within a normal range, survivors report infertility would cause negative emotions.

Implication for cancer survivors This information can be used refine educational programs within survivorship clinics to improve knowledge of post-treatment reproductive health.

Keywords Fertility · Quality of life · Cancer · Survivorship · AYA · Knowledge

Introduction

Significant improvements have been made in the treatment of childhood cancers, with the 5-year survival rate currently over 80% in the USA [1]. Of the children and adolescents who reach this milestone, 95% are expected to reach 15-year survival [1]. As the population of childhood cancer survivors

continues to grow, more attention is being dedicated to improving quality of life post-treatment. Survival is often accompanied by long-term adverse outcomes from radiation and chemotherapeutic agents that leave many organ systems vulnerable [2]. Addressing these “late effects” of treatment in survivors is essential to provide quality care [3]. As such, fertility and reproductive health have become important topics among adolescent cancer survivors.

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Background

Although many patients do maintain their reproductive potential, infertility is a late-effect of concern, especially for female cancer survivors. Female childhood cancer survivors have a 50% increased risk of clinical infertility compared to their

siblings [4]. Exposure of the ovaries or uterus to radiation or alkylating agents independently increases the risk of infertility in a dose-dependent fashion [5]. In fact, adolescent oncology patients and parents of pediatric cancer patients express concern about fertility-related side effects regardless of the type of treatment received or predicted risk of infertility [6]. In a study of young women with breast cancer, the concern about having children and future family was second only to fears of recurrence and an uncertain future [7].

The American Society for Clinical Oncology (ASCO) recommends physicians discuss risks of infertility with all cancer patients of reproductive age and provide fertility preservation information and/or referrals to reproductive specialists when appropriate [8]. Numerous fertility preservation options are available to address the reproductive needs of survivors, including embryo, oocyte, and ovarian tissue cryopreservation [9]. Yet, discussions about fertility can be challenging for newly diagnosed pediatric cancer patients. The doctor-parent-adolescent triad presents unique communication challenges, particularly with regard to fertility [10]. Physician discomfort from lack of knowledge about fertility preservation, uncertainty about its success or cost, and cultural barriers make discussions less likely [11]. Providers may also view survival as top priority and regard the urgency of treatment too great for the potential delay required for fertility preservation techniques [12]. Furthermore, conversations about fertility and other late effects may not get the same attention or retention by patients and parents in the setting of an emotionally traumatic diagnosis and the overwhelming discussions about prognosis and treatment. Therefore, although there is consensus that physicians should engage in conversations about potential risk of infertility and fertility preservation, this does not necessarily occur.

Moreover, a gender bias exists in the dissemination of fertility information. Among young adult cancer survivors, women are less likely to receive information about treatment impact on fertility [13]. Women are also more likely to report emotional distress about risk of infertility and more negative experiences with fertility-related patient-provider communication [14].

There has been limited quantitative investigation to date about post-treatment retention of knowledge regarding fertility by parents and patients and how the degree of retention may influence attitudes toward a survivor's reproductive state. It has been shown that comprehension of one's disease and treatment is closely associated with overall quality of life [15]. Therefore, this study team aimed to collect quantitative data about knowledge and perceptions of fertility in the female pediatric cancer survivor population. Among adolescent and young adult cancer survivors, unmet informational need has been associated with an elevated anxiety state [16]. We hypothesized that female childhood cancer survivors with limited knowledge on fertility and its relationship to cancer

treatment would have more reproductive concerns and lower quality of life. Furthermore, parents with lower knowledge scores would report higher parental distress. We hope identifying potential deficits in knowledge about fertility and fertility preservation can facilitate the development of educational interventions, thereby improving access to fertility resources and survivor's attitudes towards fertility. Ultimately, the more comprehensive care will bring about improved long-term outcomes and quality of life in survivors.

Methods

A cross-sectional design was used to investigate reproductive knowledge and concerns among a population of female childhood cancer survivors and their parents at a single academic institution. All investigations were performed during routine follow-up at the institution's late effects clinic for childhood cancer survivors, which sees patients greater than 2 years post-completion of therapy. Participants were required to meet the following inclusion criteria: female, between ages 13–18, at least 2 years post-treatment for primary cancer, no cognitive impairments, and active treating relationship with the institution's Late Effects Clinic. Patients were excluded if they were non-English speaking, medical records were not available for review, or there was documented infertility at the time of the study. Parents or guardians of eligible females were also eligible for participation. All participants provided consent and those younger than age 18 provided assent. Chart review was performed to extract demographic characteristics as well as information regarding the patient's cancer diagnosis and treatment. Patients and parents were not paired for any part of the analysis. Approval was obtained from the Institutional Review Board of Washington University in St. Louis.

Instruments

Knowledge scale Knowledge regarding fertility was evaluated using a 13-item questionnaire previously reported by Balthazar, Fritz, and Mersereau at the University of North Carolina at Chapel Hill [15]. This questionnaire was developed by fertility preservation specialists and was pilot tested among a cohort of women who had required medical treatment for serious illnesses with a potential impact on their future fertility. Patients received 1 point per correct answer, with 13 total points possible if all answers are correct. Both patients and parents completed the knowledge questionnaire.

Adolescent fertility values clarification tool To determine value placed on reproductive potential and the level of reproductive concerns experienced by patients, the Values Clarification Tool (VCT) was used. This survey was adapted from the Reproductive Concerns Scale (RCS) which was originally

developed to measure concerns regarding fertility among female long-term survivors of cancer diagnosed as an adult [17]. The RCS was later modified for adolescent and young adult cancer survivors [18]. The VCT is a 10-item instrument. Nine items were scored using a Likert-scale from 0 to 4 (strongly disagree to strongly agree). One item contained the fill-in-the-blank prompt “If I cannot have a baby, I will be ___.” Patients were instructed to fill in the word that best completed the statement.

Impact of event scale The Impact of Event Scale (IES) was used, with permission of the author, to assess the emotional burden experienced by parents due to their child’s fertility concerns. It is a 15-item scale with responses ranging between 0 and 3, with increasing value corresponding to increasing frequency of experiencing each item. For scoring, the mean score of seven items determined the intrusion subscale and the mean of the other eight determined the avoidance subscale. The two computed means were then summed to give the total score for each participant [19].

The pediatric quality of life inventory In order to assess the quality of life of study participants, the Pediatric Quality of Life Inventory™ Cancer Module (PedsQL) was used. The Cancer Module was designed to measure dimensions of quality of life specific to children with cancer [20]. The PedsQL includes eight subscales, each consisting of several questions with responses ranging between 0 and 4. All items are reversed scored and linearly transformed to a 0–100 scale. The total score is the mean score of all the items. Higher scores indicate better quality of life.

Analysis

All data analysis was performed using IBM SPSS Statistics 23. Descriptive statistics were used to evaluate clinical and sociodemographic characteristics of patients and parents and distribution of scores of the outcome variables. Pearson correlation coefficients were used to determine potential associations between knowledge scores and other outcome variables. Two-tailed independent *t* test was used to evaluate difference in knowledge scores between patients and parents. The statistical significance was set to an alpha level of 0.05.

Results

A total of 26 female pediatric cancer survivors and 23 parents completed the study questionnaire. Selected characteristics of both cohorts are shown in Tables 1 and 2. The median age of the survivors was 16 (range, 13–18) years old. Most had a primary diagnosis of leukemia or lymphoma (69%), and

Table 1 Selected characteristics of survivors (*n* = 25–26)

Variable	<i>n</i> (%) or median (range)
Age at time of survey (years)	16 (13–18)
Age at diagnosis (years)	5.25 (0.68–15.86)
0–5	13 (50)
6–10	8 (30.7)
11–15	4 (15.4)
16–18	1 (3.8)
Primary diagnosis	
Brain tumor	1 (3.8)
Leukemia/lymphoma	18 (69.2)
Sarcomas	2 (7.7)
Non-sarcomatous solid tumor	5 (19.2)
Type of treatment	
Chemotherapy	25 (100.0)
Radiation	10 (40.0)
Surgery	7 (28.0)
Bone marrow transplant	1 (4.0)
Length of therapy (months)	21.5 (2–36)
Health insurance	
Private	17 (65.4)
Public	9 (34.6)
Education level	
Grade 6–8	5 (19.2)
Grade 9–12	17 (65.4)
High school graduate	1 (3.8)
Some college	3 (11.5)
Type of education	
Public	25 (96.2)
Private	1 (3.8)
Exposure to fertility information	
Physician counseling	9 (36.0)
Parents	11 (44.0)
Own research	4 (16.0)
Peers/friends	1 (4.0)
	Mean (± SD)
Knowledge score	9.5 (± 2.0)
Pediatric Quality of Life Score	67.7 (± 15.3)

received chemotherapy (100%). Only 40% were treated with radiation. In regard to health insurance coverage, 65% received private health insurance, while 34% were on Medicaid. Most were in high school at the time of the study (65%) and in public schools (96%). The routes of exposure to fertility information selected the most by survivors were from parents (44%) and physician counseling (36%). Of the parents, most were white (87%) and mothers of participating survivors (87%). In regard to parental education, 39% of parents were college graduates, and 26% were high school graduates. The highest reported resource for exposure to fertility

Table 2 Selected characteristics of parents ($n = 20$ – 23)

Variable	n (%)
Race	
White	20 (87.0)
Black	1 (4.3)
Other	2 (8.7)
Education level	
College graduate	9 (39.1)
Some college	5 (21.7)
High school grad	6 (26.1)
Some high school	3 (13.0)
Relationship to patient	
Mother	20 (87.0)
Father	2 (8.7)
Grandmother	1 (4.3)
Religion	
Protestant	7 (30.4)
Catholic	5 (21.7)
Jewish	0 (0.0)
Muslim	0 (0.0)
Other	7 (30.4)
No practicing religion	4 (17.4)
Exposure to fertility information	
Physician counseling	7 (30.4)
My own research	11 (47.8)
Peers/friends	5 (21.7)
	Mean (\pm SD)
Impact of Event Scale	
Total score	20.7 (\pm 16.6)
Intrusion subscale	11.8 (\pm 9.4)
Avoidance subscale	8.9 (\pm 8.4)
Knowledge score	9.96 (\pm 1.71)

information by parents was through their own research (48%), with physician counseling (30%) and peers/friends (22%) less common.

The mean knowledge score for survivors was 9.5 (\pm 1.9), out of a maximum possible score of 13. This did not differ significantly from the mean knowledge score for parents of 9.96 \pm 1.7 (t (47) = -0.86 ; $p = 0.394$). Table 3 lists the knowledge scale questions and the percentage of patients and parents answering each item correctly. Notably, knowledge gaps primarily existed in questions addressing differences in fertility treatments. About half of patients and parents were aware that different fertility preservation options had varying success rates in achieving pregnancy (58 and 55% respectively) and that these treatment options could change following their cancer treatment (58 and 59% respectively). A low percentage were aware of the difference in success of egg freezing compared to embryo freezing, with 36% of survivors and 55% of

parents answering correctly. Only 54% of survivors and 59% of parents thought that IVF with embryo freezing was an established treatment for patients without cancer. In addition, more survivors believed chemotherapy increased the risk of birth defects in future children (50% of survivors compared to 23% of parents).

Results of the Adolescent Fertility Values Clarification Tool are shown in Fig. 1. Notably, almost all patients wanted information about the effect of cancer treatment on their fertility (96% either agree/strongly agree). Similarly, most reported wanting a baby in the future (85% agree/strongly agree) and felt frustrated about the risk of infertility (69% agree/strongly agree). Half of the survivors stated that they would feel upset, sad, or depressed if they could not have a baby. Six (23%) survivors reported more negative feelings such as being devastated, mortified, or depressed. A significant portion of patients endorsed worry about their future baby getting sick or having cancer (60% agree/strongly agree). Unfortunately, only a minority (27%) of patients felt like they had control over their ability to have a baby in the future.

The mean survivor PedsQL score was 67.7 (\pm 15.3). This was not found to be statistically significantly correlated with the patient knowledge score ($r = -0.005$; $p = 0.98$).

Parent IES mean subscale scores for intrusion and avoidance were 11.83 (\pm 9.4) and 8.9 (\pm 8.4) respectively. Mean total score for parents was 20.7 (\pm 16.6). There was no statistically significant correlation between parent knowledge scale scores and IES scores ($r = -0.05$; $p = 0.82$).

Discussion

Female pediatric cancer survivors and their parents were given four survey tools to assess knowledge and attitudes towards the survivor's fertility. In the knowledge scale, this cohort of patients and parents demonstrated higher scores than previously reported. Balthazar et al. (2011) found the mean knowledge score for their pilot group of adult women to be 5.9 (\pm 2.7), much lower than mean scores in this study of 9.6 (\pm 1.9) for patients and 9.96 (\pm 1.7) for parents. This discrepancy in knowledge may be, in part, attributed to differences in the time of survey administration. In the pilot study by Balthazar et al. (2011), the survey was distributed after cancer diagnosis during consultation with a reproductive endocrinologist, but prior to initiation of therapy. In comparison, in this study, the survey was given at least 2 years post-completion of therapy. In that time, all survivors had been integrated into a survivorship program that provides care to childhood cancer survivors off therapy. During this regular long-term follow-up, the attention shifts from cancer treatment and surveillance to late effect education and wellness promotion. Other discrepancies in survey results occur on a number of questions that specifically pertain to cancer and fertility. Within the study population of

Table 3 Knowledge scale items and percent correct in survivors and parents

	% correct	
	Survivors (n = 25)	Parents (n = 23)
All cancer treatment results in infertility	100.0	100.0
A patient must be married or have a partner to receive fertility preservation treatment	92.0	100.0
All fertility preservation treatments have a similar chance of achieving pregnancy	57.7	54.5
Insurance never covers fertility preservation treatments	84.6	85.7
My fertility preservation treatment options will be the same following my cancer treatment	57.7	59.1
What is the percentage of women who freeze their embryos who will become pregnant in the future?	69.2	56.5
Women who have fertility preservation treatment have an increased risk for recurrence of their cancer in the future	76.9	91.3
Egg freezing has the same chances of future pregnancy as embryo freezing	36.0	54.5
A woman who freezes her eggs will have them available in the future whenever she is ready to use them	80.8	82.6
Frozen eggs are guaranteed to result in pregnancy in the future	96.2	95.7
Frozen embryos are guaranteed to result in pregnancy in the future	88.5	95.7
IVF with embryo freezing is an established treatment used in patients without a cancer diagnosis	53.8	59.1
Chemotherapy increases the risk that my future children will have birth defects	50.0	77.3

Balthazar et al. (2011), only 17% of women answered the question “Women who have fertility preservation treatment have an increased risk for recurrence of their cancer” in contrast with 77% of adolescents and 91% of parents that were able to answer correctly. Also, on the question “chemotherapy increases the risk that my future children will have birth defects”, only 14% of the women in the Balthazar et al. (2011) group answered correctly as compared to 50% of survivors and 77% of parents in our study. One can assume from these differences that education on cancer diagnosis and impact of treatment on fertility may affect a patient’s knowledge of fertility preservation, since that is the most significant difference between the original study group and our population.

This requires further investigation as the study populations had many differences. Of note, our patient population was young, but the parents were of a comparable age to the Balthazar et al. (2011) group.

The Adolescent Fertility Values Clarification Tool indicated that almost all patients agreed or strongly agreed that they would like more information on how their treatment may affect their ability to have children. Despite their overall above average knowledge scores, the desire for more information is consistent with previously reported literature [21, 22]. The evaluation of reproductive potential and interventions to assist those with impaired fertility are complicated and evolving. While patients reported low levels of perceived control of their

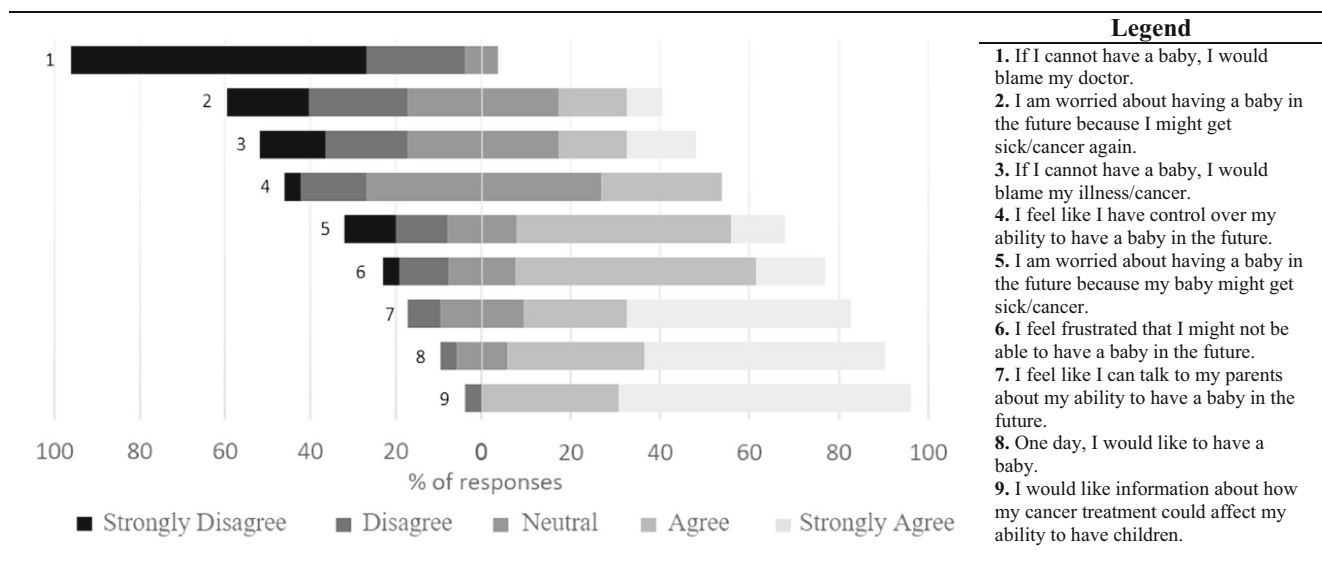


Fig. 1 Adolescent Fertility Values Clarification Tool results

fertility, it is likely that the desire for knowledge is related to their lack of perceived control. Also, consistent with previous literature, most of the patients would like to have children in the future and report negative feelings if they would be unable to have a baby [23]. It is important for those providing survivorship care to acknowledge that many negative emotions are associated with the threat to fertility in this young population of cancer survivors. This negative impact could significantly influence other health-related issues, having a significant impact on the overall state of the patient. Providers can then anticipate that psychological support services should be available, even to young patients, if it is determined the patient has compromised reproductive potential. Despite the patient-reported negative emotions associated with the inability to have a child, quality of life scores were within normal range, consistent with previously published data for adolescents with cancer. Quality of life among this group of adolescent survivors is not correlated with knowledge scores, indicating that perhaps the threat of potential fertility issues and the knowledge relating to those issues minimally contribute to the overall quality of life of female adolescent cancer survivors.

While parental IES scores as whole do not endorse symptoms of PTSD or problematic feelings of intrusion or avoidance related to their child's fertility, 30% of our sample did score within the range for PTSD. It has been reported that 29.5% of mothers and 11.5% of fathers have met the criteria for a diagnosis of PTSD at some after their child's cancer diagnosis [24]. Landolt et al. (2003) found that the incidence rate of PTSD in parents of patients with cancer was much higher than even adults with a cancer diagnosis. A significant association between PTSS symptoms and physical late effects has been found in cancer survivors and their parents [25]. While survivorship care is often focused on the patient, this finding highlights the importance of including the survivor's family or people close in their support system. Survivors of childhood cancer are at risk for a multitude of chronic health issues [3, 26]. While this study is focused on fertility, it is unknown what other potential health risks would cause emotional or distressing symptoms in family members of cancer survivors. Interestingly, knowledge scores were not associated with avoidance, intrusion, or total IES scores. Therefore, regardless of a family's knowledge of potential adverse health outcomes, the level of distress should be evaluated independently in order to detect those that would benefit from additional counseling or support services.

Limitations

Study data was obtained from a single institution, more specifically, a single long-term follow-up program and small, homogeneous sample. Long-term follow-up clinics for survivors of childhood cancer exist throughout the country, each

with unique support services available and varying structures depending on the institution. It cannot be assumed that each long-term follow-up program provides education regarding treatment-related risks to fertility in a similar manner or that survivorship care includes thorough information and counseling regarding potential risk to reproductive potential. Therefore, knowledge scores in particular may vary per institution. Our sample was small, and the majority of patients were treated for leukemia. A more heterogeneous sample would have been beneficial, since other childhood cancers often require more gonadal toxic treatment and may have influenced the emotional impact and knowledge scores [5]. In addition, our small sample size did not allow for univariate or multivariate modeling to be performed to provide a deeper appreciation of the impact treatment and sociodemographic characteristics have on fertility knowledge and quality of life.

Conclusion

Our findings reinforce that long-term follow-up with an oncology team well-versed in late effects of cancer treatment, in particular effects on fertility, is an integral part of survivorship. Our population of adolescents demonstrated average fertility knowledge scores higher than previously found in adult women prior to their cancer treatment, likely reflecting the knowledge gained by engagement in specialized survivorship care. However, deficiencies in knowledge, particularly about types of fertility preservation options, were still present and serve as a target for future educational intervention. Survivors are concerned about the risk of unsuccessful childbearing. Providers need to recognize the significant emotional impact even the potential of infertility can have on adolescent female cancer survivors and their families and provide comprehensive education and support services.

Compliance with ethical standards

Ethical approval “All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.”

Informed consent “Informed consent/assent was obtained from all individual participants included in the study.”

Conflict of interest The authors declare that they have no conflict of interest.

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