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 JOURNAL OF  
**ADOLESCENT  
 HEALTH**


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Review article

## Who Decides? Decision Making and Fertility Preservation in Teens With Cancer: A Review of the Literature

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Article history: Received April 7, 2010; Accepted January 9, 2011

Keywords: Fertility, Decision making, Teens, Cognition, Cancer

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### A B S T R A C T

**Purpose:** The knowledge that cancer treatment may impair fertility in pediatric populations is an emerging aspect of quality of life in this population. However, decision making and use of fertility preservation (FP) among adolescent cancer patients and their families has not been well studied. This review summarizes the available published data on aspects of decision making and FP in adolescent cancer patients.

**Methods:** An electronic search was performed to identify peer-reviewed studies published between 1999 and 2009 using key Medical Subject Heading terms and inclusion criteria. Inclusion criteria limited eligible studies to those that focused on adolescent decision making in cancer treatment or FP, fertility concerns in pediatric oncology, capacity for decision making, and health decision making in pediatrics. Studies that did not meet at least one of these criteria were excluded.

**Results:** A total of 29 articles were reviewed and summarized. Three categories of results were seen: a focus on adolescent decision making in oncology, decision making in chronic illness, and decision making in cancer-related infertility and preservation.

**Conclusion:** Most of the studies showed that adolescents have a strong desire to participate in decisions related to their cancer treatment and many have concerns regarding their future fertility, although barriers often prevented these discussions. More research is needed to explore the role of teenagers and parents in decisions about fertility in relation to cancer treatment.

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Approximately 16 cases per 100,000 people aged 0–19 years are newly diagnosed with cancer in the United States [1]. Fortunately, medical advances have resulted in improved survival and the current average 5-year survival rate for pediatric cancer patients is 78% [2]. Cancer during adolescence presents chal-

lenges regarding treatment and late effects, and as the population grows, the focus has shifted toward assessments and interventions that improve the quality of survivorship. Research on quality of life during survivorship generates options to improve daily living while regaining a sense of normalcy. However, these options also give rise to the dilemma of the adolescent's role in making decisions regarding long-term survivorship issues, such as infertility.

Cancer-related infertility is an important issue because decisions about preserving future fertility will affect the adolescent as an adult survivor, although these decisions may not seem

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relevant during the time of treatment. Although cancer treatments such as chemotherapy, radiation, or surgery are designed to save lives, there are risks of side effects such as infertility. The likelihood of infertility is dependent on age, type of therapy, as well as site, stage, and grade of the cancer [3,4].

Infertility affects the future quality of life of cancer survivors of reproductive age and is a predictor of stress in present and future relationships. Janson et al showed that even a perceived loss of fertility resulted in the reduced likelihood of being married and a higher likelihood of divorce [5]. Some adolescent survivors have revealed that they do not disclose their actual or suspected infertility for fear of rejection [6]. These concerns were recognized in 2006 when the American Society of Clinical Oncology (ASCO) published guidelines suggesting that all newly diagnosed cancer patients of childbearing age should be informed about potential loss of fertility and receive referrals to infertility specialists [7].

Fertility preservation (FP) technologies are available for adolescent cancer patients and in most cases should be pursued before treatment. The established (nonexperimental) option for males is sperm cryopreservation, and for females the established options are ovarian transposition and embryo cryopreservation. There are experimental options available for both males and females including oocyte, testicular, and ovarian tissue cryopreservation [8,9]. In some cases, the physician may decide that an adolescent patient is unable to delay cancer treatment to pursue an FP option [9]. However, the need to consider FP depends on physical and developmental capacity, prognosis, financial circumstances, and religious, cultural, and ethical values.

The values and duties of the relevant parties and the potential conflicts that may arise must be examined. The Ethics Committee of the American Society for Reproductive Medicine extended physicians' fiduciary duty in a 2005 statement noting that, "Physicians should inform cancer patients about options for FP and future reproduction prior to treatment." [3] In this view, they opine that preserving future reproductive choices, and making accommodations so that later autonomous decisions may be made, is in the best interest of the preautonomous minor with cancer. The principle of nonmaleficence limits potential harm to future fertility and reduces the threat of eliminating these later autonomous choices.

Conflicting evidence exists as to whether adolescents possess the capacity to make health-related decisions that they will be satisfied with in the future. Fueling this conflict is the lack of standardized definitions of children, minors, adolescents, and young adults. The National Cancer Institute defines children as persons between the ages of 0 and 14 years, and adolescents between 15 and 19 years [10]. The World Health Organization defines adolescents as individuals between the ages of 10 and 19 years [11] and CDC defines adolescents as those aged between 12 and 19 years [12]. This has implications for cancer registries and national data collection efforts. More recently, the term Adolescent/Young Adult has been suggested for persons between 15 and 39 years of age [13–15].

In the United States, individuals are considered minors until 18 years of age; however, recent studies have challenged this [16–19]. There is disagreement regarding an adolescent's competency to make healthcare decisions with long-term consequences, although research has shown that adolescents have the ability and desire to participate in their own medical decisions [20–22].

Adolescent brain development contributes to the law for legal age of consent [23]. Normal brain development posits the prefrontal cortex as a necessary region for decision making [24–27]. The amygdala, part of the limbic system and responsible for regulating emotions, grows at a much faster rate than the prefrontal cortex. Some studies of adolescent brain development show that judgment and responsibility do not increase until 19 years of age, thus suggesting that younger adolescents may be less competent decision-makers and are more likely to make decisions on the basis of emotions rather than facts [28].

Theories on the biological capabilities of adolescent decision making have an effect in healthcare [29]. There is research that addresses the components of adolescent decision making regarding cancer treatment, fertility, and reproduction; however, studies combining these topics are limited. This is an important issue considering that the retrospective studies on survivors of childhood cancer suggest a reduced quality of life and increased regret for those who experienced a loss of fertility [30]. Coping skills and interactions within adult relationships can be directly affected by the loss of fertility [5]. The objective of this review is to summarize the available published data on decision-making aspects of FP among adolescent patients suffering oncology and recommend strategies for participation.

## Methods

### Search strategy

An electronic search was performed to identify studies addressing adolescent oncology patients and fertility decision making. Databases searched included Science Direct, Wiley InterScience, PsycINFO, and PubMed. Search criteria included peer-reviewed prospective studies published between 1999 and 2009, in English, and limited to the age categories of 6–12 years and 13–18 years. Medical Subject Heading terms searched were as follows:

*[adolescent AND decision making AND ability OR cognitive development OR culture AND neoplasms OR consent AND cancer AND treatment AND participation OR cancer treatment AND Fertility OR decision making AND reproduction AND chronic disease OR illness OR health AND pediatric].*

Given the inconsistencies in defining adolescents, we chose to focus this article on the definition provided by World Health Organization (ages 10–19 years). It should be noted that some studies included subjects aged <10 years. For example, one article included participants aged 8–17 years. In those cases, we still included these articles in our review. We acknowledge that this may bias our conclusions, but it also reiterates the need for standardization.

### Selection strategy

Limiting the search to the past 10 years ensured that this review summarized the most current published data, especially with the onset of new FP technologies that may influence an adolescent's outlook on decision making. Initially, 226 titles were identified. The retrieved studies were subjected to four inclusion criteria agreed upon by the authors (G.Q. and D.M.) to encompass the interplay between factors related to FP and decision making. Each study was focused on at least one of the following: adolescent decision making in cancer treatment or FP; fertility concerns in pediatric oncology; cognitive development

and capacity for decision making; and health decision making in pediatrics. Review articles ( $n = 56$ ), as well as 141 additional articles that did not meet the inclusion criteria, were excluded. Overall, 29 studies were reviewed. Information on the purpose, method, and results were extracted.

## Results

A total of 29 studies were reviewed by the research team. Factors regarding adolescent decision making and FP in oncology emerged as following: (1) Factors unique to oncology, (2) Simi-

**Table 1**  
Adolescent decision-making in oncology ( $n = 10$ )

Study	Purpose	Method	Sample	Results
Decker et al., 2004 [40]	This study describes how adolescents with cancer rate the importance of specific cancer-related information, analyzes gender and age group differences, and compares two different adolescents with cancer groups	Questionnaire	$n = 201$ ; aged: 11–21	Adolescents with cancer rated the need for information as high. There were no significant differences by age, but females had significantly higher total scores for both groups and for many item means in the newly diagnosed group. Qualitative analysis of the additional write-in items generated four themes: treatment/side effects, uncertainty, social issues, and personal/emotional issues
Geller et al., 2003 [38]	To better understand the process by which families at increased risk of disease would decide to enroll their children in genetic susceptibility research	Face-to-face, audio-taped, semi-structured interviews	$n = 74$ ; parents and children: 10–17	In general, the older/more mature the child, the less risky the research and the more open the communication style, the greater the likelihood that decisions would be made jointly. Most children wanted some parental input, but still thought the final decision should be theirs.
Hokkanen et al., 2004 [35]	To understand what adolescents with cancer think about their life situation, the support they receive, and the information they receive about their illness	Focus groups (3)	$n = 60$ ; aged 13–18 Three focus groups, $n = 20$ participants each	Adolescents made very little, if any, conscious effort to plan ahead for the future. As for the adolescents' chances to take part in making decisions about their care and life, the analysis yielded six categories: joint decision-making, inadequate chances for decision-making, independent decision-making, illusion of decision-making, reluctant to make decisions, and excluded from decision-making.
Hui, 2008 [33]	This paper reports two cases in Hong Kong involving two native Chinese adolescent cancer patients (APs) who were denied their rights to consent to necessary treatments refused by their parents, resulting in harm	Observational	$n = 2$ ; aged: 15–17	Specifically for adolescent cancer patients, we suggest that parental authority and family integrity should be re-interpreted in terms of parental responsibility and the enhancement of children's interests, respectively.
Miller, 2009 [34]	To present a case study on parent refusal of treatment for their child if it is deemed as the court to be in the child's best interest	Secondary data analysis	$n = 1$ ; aged: 13	Judge ordered that family cannot refuse chemotherapy for their 13-year-old son and mother was arrested for evading police.
Palmer et al., 2007 [31]	This study reports the outcomes of a focus group conducted to explore issues of unmet physical, psychological, and social needs of adolescents with cancer	Focus group	$n = 6$ ; mean age: 17	The participants identified a number of concerns relating to three broad categories: information provision, treatment processes, and survivorship. This indicates gaps in current cancer services provided to adolescents.
Pousset et al., 2009 [36]	To investigate the attitudes of adolescent cancer survivors toward end-of-life decisions with life shortening effects, including decisions for non-treatment, alleviation of pain, euthanasia, and how illness influences these decisions	Questionnaire	$n = 83$ ; aged: 11–18	In terminal situations, 70%–90% found requests for non-treatment acceptable, 84% requests for APS, and 57%–64% requests for euthanasia. frequently cited reasons for holding back physicians from administering a lethal drug to a child were the child not being well informed about his or her condition (92%) and the parents' opinion not being asked (92%). Cancer survivors were more accepting toward requests for non-treatment decisions and alleviation of pain and symptoms in terminal situations.
Stegenga and Ward-Smith, 2008 [39]	Few research studies have obtained data directly from the adolescent with cancer regarding decision-making. The purpose of this pilot, or exploratory, study was to determine whether the research question is appropriate and whether participants between 13 and 15 years of age were capable of providing rigorous data	Semi-structured interviews	$n = 3$ ; aged: 13–15	The results suggest that treatment decision-making was not a concern for these patients and that they were capable and appropriate study participants. Infusing information and education into the health care plan from time of diagnosis may allow the adolescent to become knowledgeable about the disease process. This may enable him or her to participate in health care treatment decisions, when appropriate.
Tyc et al., 2001 [37]	To examine sociodemographic and health perception variables as predictors of health-protective behaviors in pediatric cancer survivors	Cross sectional survey	$n = 46$ ; aged: 10–18	Results indicated that the practice of health-protective behaviors was best predicted by patient's age and SES; younger adolescents and patients from higher SES more frequently engaged in healthy behaviors. Survivors perceived themselves to be vulnerable to health problems.
Zwaanswijk et al., 2007 [32]	To investigate the communication preferences of childhood cancer patients, parents, and survivors of childhood cancer	Cross sectional survey	$n = 36$ ; aged: 8–17	They agreed on the importance of interpersonal and informational aspects of communication, such as honesty, support, and the need to be fully informed. Participants generally preferred a collaborative role in medical decision-making. Patients differed in their satisfaction with their parents' role as managers of the communication.

larities between adolescents with cancer and other chronic illnesses, and (3) Factors specific to FP. The available published data were organized into these three categories.

#### *Adolescent decision making in oncology*

In all, 10 articles focused on participation in oncology decisions (Table 1). A 2007 qualitative study showed that six oncology patients aged 14–21 years unanimously wished to participate in their healthcare decisions; however, they did not feel included in this process. The majority felt their healthcare providers did not provide any or adequate information about their treatment or side effects [31].

In a study of 25 cancer patients and survivors aged 8–17 years participating in online focus groups, the majority expressed a strong desire to have information on their disease and statistics on survival; however, results varied on desire for their parent's involvement in making decisions [32]. Thus, adolescent patients wish to be well-informed regardless of whether they are the primary decision maker.

Further, factors such as religious beliefs may have significant ethical impacts on the adolescents, such as the two cases of native Chinese cancer patients aged 15 and 17 years. Despite the adolescents' desire to engage in standard care, their parents refused treatment because of their cultural beliefs. Both situations resulted in negative health consequences [33]. The turbulence of a cancer diagnosis can overshadow an adolescent's independent desires. In some situations, a court may override decisions made in agreement by parents and the minor [34]. This was seen in the recent case of Daniel Hauser in May, 2009. Daniel was a 13-year-old leukemia patient, and his parents desired alternative treatments that were in accordance with their religious beliefs in lieu of chemotherapy. Minnesota courts overruled the family's authority and Daniel was treated with modern medicine [34].

Conflict may arise over an adolescent's competency to make decisions during a time of crisis, such as in the case of a cancer diagnosis. Some studies indicate that adolescent cancer patients have struggled to plan appropriately for the future. Hokkanen et al reported that of 20 adolescents aged 13–18 years attending a cancer adjustment camp, the majority made little if any attempt to plan for the future [35]. If an adolescent treated for cancer does show difficulties in long-term planning, parents may be less likely to allow autonomous decision-making. Desires for autonomous decision making were assessed in a 2009 study of cancer survivors aged 11–18 years along with survivors' views on whether a physician should adhere to an adolescent's desire for legal euthanasia. It was concluded that the patient's own experience with illness affected decision making and planning when considering end-of-life care; therefore, not all adolescent oncology patients are ill-equipped for long-term planning. More than half of cancer-surviving adolescents felt that their decision for legal euthanasia should be respected by the physician, although they identified safeguards that should be in place. Such safeguards include that the adolescent should be well-informed about their prognosis and process of euthanasia, parents must be consulted, and the adolescent cannot make this decision if he or she shows symptoms of depression. In all, 50% of adolescent survivors felt that their decision for euthanasia should still be respected even if the parents do not agree [36].

An adolescent's desire for joint decision making cannot always be predicted, although some studies have assessed this. Tyc

et al found that among 46 adolescent cancer survivors aged 10–18 years, decisions for health-protective or less risky health behaviors were more predictable in younger subjects [37]. Comparatively, Geller et al report that among adolescents aged 10–17 years, with a family history of cancer, the largest predictors of joint decision making to enroll in clinical trials were age and the adolescent-parent relationship. Most adolescents emphasized that the final decision should be their own [38]. This shows that an adolescent's desire to participate in healthcare decisions may not always be predictable and preferences should be inquired directly.

Not all adolescent oncology patients desire autonomous or participatory decision-making. Stegenga and Ward-Smith found from three individual interviews with adolescents aged between 13 and 15 years diagnosed with cancer, that each felt that decisions were best left to the healthcare team. Despite this, all three agreed on the need to be kept informed during the initial 6 months of treatment [39]. This is supported by a 2004 study, in which most of the 72 adolescents with cancer rated their desire for information as high, stressing the need to include adolescents in initial and ongoing discussions related to treatment [40].

#### *Adolescent decision making with chronic illnesses*

Oncology is not the only area where adolescent decision making is controversial. Adolescents with chronic illnesses may also be faced with healthcare decisions. There are inconsistencies in the previously published data regarding their decision-making capabilities, desires, and satisfaction with participation during a time of illness, and how this is generalizable between adolescents with chronic illnesses and those with cancer. Nine articles were reviewed on this topic (Table 2).

Like many adolescents with cancer, chronically ill adolescents have also shown a desire to participate in decision making. A total of 96% of 25 chronically ill adolescents aged 13–21 years desired to participate in treatment decision making, and 80% believed their doctors would adhere to their decisions [41]. In two studies that interviewed a combination of pediatricians, parents, and adolescents with chronic conditions, the child was most often found not to have an equal part in decision making, despite a desire to do so [42,43]. In a study conducted by Garth et al, most of the patients with cerebral palsy, aged 8–12 years ( $n = 10$ ), desired to participate in treatment decision-making; however, they were not included as equal partners with parents and physicians [43]. Broome and Richards assessed decision making among 34 individuals aged 8–22 years with chronic illnesses. Their results indicate a desire to be involved in their own medical decisions and the ability to communicate their decisions articulately. The majority expressed that they had "faith" in their parents to adhere to their decisions [21].

Parents may allow participatory decision making at their discretion. Runeson et al conducted an observational study of 24 in-patients, aged 5 months to 18 years, for 135 total hours. There was a distinction between participatory decision making among older patients aged 11–18 years ( $n = 5$ ) versus younger patients aged 5 months to 10 years ( $n = 19$ ). Nine times in the younger age group parents either refused their child's decisions or did not consult with them at all, versus only once in the older age group. Of the 21 situations classified as poor communication between parents and patients, the lowest level of participation for both groups was in the treatment decision-making process [44]. Parents also have discretionary authority to involve their child in the

**Table 2**  
Adolescent decision-making with chronic illnesses (n = 10)

Study	Purpose	Method	Sample	Results
Beresford and Sloper, 2003 [47]	To explore the experiences of chronically ill adolescents in communicating with health professionals, including the identification of factors which hinder or facilitate their use of health professionals as an information source	Individual interviews and focus groups	n = 63; aged: 11–16	Factors affecting the openness and effectiveness of communication included: duration and frequency of contact; gender; perceived attitudes towards adolescents; the communication skills of the adolescent and health professional; and the presence of parents and medical students/trainee doctors.
Broome and Richards, 2003 [21]	To describe how relationships with adults influenced pediatric patients' involvement in clinical research	Semi-structured interviews	n = 34; aged: 8–22	Were shown to articulate their ability and right to make decisions about involvement in research, along with their parent(s).
Coyne, 2009 [42]	To explore the views of children, parents, and nurses to determine desired engagement in decision-making within a healthcare setting	In-person interviews, questionnaires and observation	n = 11; children and adolescents aged 9–15 n = 10 parents n = 12 nurses	Adolescents expressed the need to be consulted so that they could understand their illness, be involved in their care, and prepare themselves for procedures. However, children's views were underused and had varying experiences of being consulted about their care and treatment.
Garth et al., 2009 [43]	To explore the interaction between physicians, parents, and pediatric patients when the child is a participant in decision-making	Semi-structured interviews	n = 33 9 pediatricians, 14 parents, and 10 children aged: 8–12 with cerebral palsy	The child was not perceived to be an "equal" or "regular" partner as there were reports of variability in the involvement between children, as well as variability in the progressive involvement of each child.
Knopf et al., 2008 [46]	To describe the decision-making preferences of adolescents with chronic illnesses and their parents, and the extent to which they agree	Survey	n = 82; adolescents mean age: 15 years, 62 parents	Nearly equal percentages of adolescents (37%) and parents (36%) preferred shared decision-making. Overall, the largest proportion of adolescents (46%) and parents (53%) preferred passive decision-making compared with active or shared decision-making. Across five response choices, 33% of pairs agreed. physicians need to inquire directly about patient and parent preferences
Lyon et al., 2004 [41]	To explore whether differences exist between chronically ill and healthy adolescents with regard to their attitudes about end-of-life issues	Survey	n = 25; adolescents with chronic illness, 25 healthy adolescents aged: 13–21	Ninety-six percent of chronically ill and 88% of healthy teenagers want to share decision-making if they are very ill; 76% prefer to discuss their wishes earlier in the course of a life-threatening illness. Half of all adolescents believed that they would be allowed to change their minds once they had made a decision. Eighty percent of chronically ill and 68% of healthy teenagers believed that their doctor would respect their wishes, while many were uncertain.
Runeson et al., 2002 [44]	The aim of this study was (1) to identify everyday situations in medical and nursing care that illustrate children's participation in decision-making; (2) to identify various levels of participation, actual and optimal; and (3) to compare actual and optimal participation. A further aim was: (4) to describe the way in which children, parents and staff interact during the decision-making process	Observation	n = 24; aged: 5 to 18 months	Children and adolescents are not always allowed to participate in decision-making to the extent that is considered optimal. This showed that parents do not always support their children in difficult situations and that health care staff often inform children about what is going to happen without presenting alternatives or asking for their views. It is of great importance that children are looked upon as potentially autonomous individuals and that staff members realize that one of their core duties is to facilitate children's participation in decision-making concerning their health care.
Young et al., 2003 [48]	To examine young people's and parents' accounts of communication about cancer in childhood	Semi-structured interviews	n = 32; aged: 8–17	The patients identified elements of their parents' role that both facilitated and constrained their communication, and while they welcomed their parents' involvement, some expressed unease with the constraining aspects of their parents' role.
Varma et al., 2008 [45]	To know how children and parents make decisions regarding pediatric research	Survey	n = 117; children aged: 7–14	In the research group, 90.5% of pediatric respondents believed they should be involved in making research enrollment decisions, whereas only 61.5% of the adult respondents believed children should be involved in making these decisions.

decision to enroll in clinical trials. Of 81 chronically ill minors aged 7–14 years, 90% believed they should be involved in making research enrollment decisions, contrasted with 62% of parent respondents who believed children should be involved [45].

Despite much of the available published data indicating an adolescent's preference for shared decision making, Knopf et

al found that only 36% of 82 adolescents with chronic illnesses preferred shared decision making, whereas 17% preferred sole decision-making authority. The highest rating at 46% was actually passive decision making, which is further evidence that parents and physicians need to inquire directly about the adolescent's preference [46].

Quality decision making stems from open communication, yet many barriers exist. In a 2003 study of 63 adolescents aged 11–16 years with a chronic condition, adolescents identified communication barriers with physicians as: frequency of contact, gender, physician's perceptions of adolescents, and the presence of parents and medical students [47]. The unease of parent's presence in the examining room was corroborated by another study with 13 families, including patients aged 8–17 years. Many adolescents were happy with their parents' involvement, but some identified their parent as restrictive [48]. The presence of a parent or a physician may cause the adolescent to feel they have limited decision-making authority. Even if adolescents do communicate their concerns, they are likely to feel discouraged if these concerns are overlooked. Coyne found that most of the children and adolescents treated for chronic conditions ( $n = 11$ ) explained that despite wanting physicians to consult them about treatment decisions, many expressed feeling "ignored" [42].

#### *Adolescent decision making and fertility concerns*

The public is becoming increasingly aware of the effects of cancer treatments on fertility. Despite this, little is known about what information is and what should be provided to adolescent patients. Can adolescent cancer patients make decisions about consenting or refusing FP procedures that they will not regret in adulthood? Long-term studies of pediatric cancer survivors and their satisfaction with FP decisions made in childhood are rare. Nine articles on the concerns of fertility-related decision-making within pediatric oncology were reviewed (Table 3).

Impact on fertility and FP options has often been neglected during discussions of an adolescent's cancer treatment. Oosterhuis et al reported that less than 30% of parents of pediatric oncology patients aged >14 years were satisfied with the amount of fertility information disclosed by their child's health-care professional ( $n = 134$ ). Less than 11% recalled being given information regarding FP options, more than 50% wanted to discuss FP with their oncologist or a specialist, and more than 60% of adolescents wanted educational material. Approximately 50% of parents incorrectly affirmed that all cancer therapies cause damage to reproduction [49], indicating the need for education.

Absent or ambiguous FP discussions with adolescents may preclude them from being involved in decision making. Edge et al examined survey responses from 45 male cancer patients and survivors aged 12–21 years who had fertility discussions documented in their hospital notes. In all, 74% of males did not have any documentation. Among the remaining 26% with documentation, respondents indicated that they had a higher concern for future fertility during the time of the interview, despite the fact that most of them had been off therapy for about 2 years. Barriers that had an impact on the decision-making process to sperm bank included anxiety related to the cancer diagnosis, embarrassment, and feeling "emotionally drained." When asked what changes could be made to benefit future patients, subjects recommended having more detailed FP discussions as many felt they had an inadequate understanding of how FP procedures were performed [50].

Not all studies have indicated low rates of FP discussions. Burns et al found that of 50 female adolescent cancer patients and their parents, fertility was discussed in 49% and 69% of cases, respectively. Adolescents were separated into groups of 10–14 and 15–21 years, and only 25% of the younger group indicated

they had fertility discussions but were found just as likely as the older group to have fertility concerns. Most patients in both groups reported that they frequently think about having children in the future. Moreover, 94% said they were aware of the concept of infertility, but despite this less than 20% of parents and 30% of adolescents indicated they would delay treatment to undergo FP methods [51]. The authors argue in support of adolescents' competency to make FP decisions and the discussion of FP options.

Survivorship studies document the concern and struggles with having children post-treatment; however, adolescents' concern over future fertility at the time of diagnosis is not well-documented. Only one qualitative study examined survivors aged 16–30 years and their concern with possible infertility ( $n = 38$ ). In all, 16 participants were between the ages of 13 and 21 years; however, age did not prove significant within the results. At the time they were diagnosed, the majority reported having a strong desire to know as soon as possible how their fertility would be affected. No participant had used FP options. The majority who were aware of their impaired fertility status were concerned about "finding a partner willing to enter a potentially childless relationship." The majority were pleased with their parents' involvement in the decision making process; however, a small number of males preferred to make the decision to sperm bank on their own [30]. This conflicts with another study of male adolescent oncology patients (aged: 15–19 years), in which parents were reported to have significant influence on sperm banking, with 80% making joint decisions with their sons. Similar to the previous study, almost half of patients said they preferred to have initial discussions without their parent present.

At times, the pediatric oncologist may be a barrier to FP discussions. In a qualitative study of 21 males aged 16–26 years who had either completed or were still in active treatment for cancer, the majority indicated a high concern about future fertility; however, felt the presence of many barriers to initiating these conversations. Individual interviews yielded concerns, such as needing the oncologist to present sperm banking as a choice and having a desire for counseling that was not offered. Some males described their own unease discussing fertility concerns with the oncologist as the main barrier [53]. Schover et al assessed the likelihood of oncologists recommending sperm banking with male patients and found that 37% felt parental consent should be required for a teenager to sperm bank, and only 9% said they would initiate the conversation with the teenager alone [54]. Gender may also influence the prevalence of fertility related discussions. A recent study of pediatric oncologists showed physicians perceived girls to be more open to discussing fertility than boys; however, girls showed more characteristics of distress than boys [55]. Anderson et al found that in a sample of 1,030 boys and girls in the United Kingdom, aged 1–22 years, who were suffering from cancer, only 1% of postpubertal girls were referred to an FP clinic. Comparatively, 83% of postpubertal boys were referred for sperm cryopreservation; however, this decreased to 39% for prepubertal boys [56].

## **Discussion**

This review summarizes many issues related to adolescent decision making regarding FP. Both ASCO and the American Academy of Pediatrics (AAP) provide guidelines recommending oncologists discuss the effects of cancer treatments on fertility with patients, regardless of age. These guidelines are strong

**Table 3**  
Adolescent decision-making in fertility (n = 9)

Study	Purpose	Method	Sample	Results
Anderson et al., 2008 [56]	To assess UK practice relating to information provision about the effects of cancer treatment on fertility and options for fertility preservation	Survey	n = 1,030; aged: 1–22	The majority (83%) of postpubertal boys assessed as high/medium risk of infertility were referred for semen cryopreservation. This rate fell to 39% of those in early puberty. Only 1% (n = 4) of girls were referred to an assisted conception unit.
Burns et al., 2006 [51]	To determine whether female adolescents with a diagnosis of cancer and their parents were interested in trying to preserve fertility	Cross sectional survey	n = 50 In all, 39 parent/adolescent pairs, three parent-only responses, and eight adolescent-only responses aged 10–21	Adolescents and parents had thought about the future and were interested in research treatments to help preserve fertility, but not willing to postpone cancer therapy. Achieving a state of good health was most important to the adolescent group.
Chapple et al., 2007 [53]	To explore fertility concerns for adolescent males treated for cancer and identify communication barriers of these issues	Narrative interviews	n = 21; aged: 16–21	Communication about sperm storage was sometimes difficult and embarrassing. Patients wanted the opportunity to bank their sperm but decisions were often rushed. Some indicated a desire for counseling as they were unprepared to undergo the process of sperm banking. Uncertainty about fertility status caused worries for the future.
Crawshaw and Sloper, 2006 [30]	To assess the experiences of adolescents and young adults faced with possible infertility following cancer treatment	In-depth interviews	n = 38; aged: 13–21	All desired to have fertility information before treatment.
Edge et al., 2006 [50]	To identify the barriers to successful sperm banking in a group of adolescent and young adult patients	Questionnaires	n = 55; aged: 13–21	Those who had been unsuccessful were younger and described higher levels of anxiety at diagnosis and greater difficulty in talking about fertility. They also described less understanding of sperm banking at the time of diagnosis. Younger patients may be helped by the provision of high quality information and more open discussion of the technique.
Ginsberg et al., 2008 [52]	To evaluate the feasibility of offering newly diagnosed patients the opportunity to sperm bank and to determine the decision-making processes of patients and their parents who considered sperm banking	Survey	n = 68; aged: 12–24	Parent and patient made the decision together to bank 80% of the time. All sons who attempted to bank and their parents felt they had made the right decision, including those who attempted but failed.
Oosterhuis et al., 2008 [49]	To ascertain concerns about infertility risks among pediatric oncology patients and their parents	Survey	n = 97; aged: 14–25	Only 29.9% of parents were satisfied with the amount of information received on fertility.
Schover et al., 2002 [54]	To survey oncologists in three different practice settings to determine their knowledge, attitudes, and practices regarding referring patients to bank sperm before cancer treatment	Postal survey	n = 718; physicians regarding post-pubertal teen boys	52% of physicians thought any teen producing sperm should be eligible to bank and 86% believed males under age 18 should be able to bank. Parental consent is required before offering sperm banking to a teen patient (37% agree) or to allow a teen to view erotic materials in the collection room (61% agree). Seventy-eight percent believed that both parents and teen should be in the room when sperm banking is discussed, 11% would start with the parents only, and 9% preferred to talk to the teen alone.
Vadaparampil et al., 2008 [55]	To examine factors that may influence the discussion with pediatric oncologists, pediatric cancer patients, and their families	In-depth interviews	n = 24; pediatric oncologists who treat patients aged 0–21, mean age 9	Physicians perceived girls were more open to discussing issues of fertility than boys due to embarrassment; however, girls showed more characteristics of distress than boys regarding the potential for infertility.

statements; however, they are not laws. Barriers surrounding these discussions may overshadow the guidelines [55–58].

Research on an adolescent's desires for the parent to manage solely the communication with healthcare providers is inconclusive [40,59]. Ellis and Leventhal showed that 63% of adolescent oncology patients wanted to make their own decisions about palliative therapy. However, 39% of patients and 16% of their parents viewed that decisions about curative therapies were not the role of the pediatric patient [60]. In all, 58 parents of children with cancer aged <13 years were surveyed for their preferences in participation in their children's treatment. Most preferred a

collaborative role, whereas the second most common preference was passivity [61]. In 2004, The Children's Voices Project from the Commission for Health Improvement in the United Kingdom was compiled from 59 reports of children and adolescents admitted to hospitals. Most of the children and adolescents had treatment options explained to them using language they did not understand, were not provided any information, and were not included in the decision making process [62].

Teenagers may be selective about whom they wish to discuss fertility concerns with. In a 1999 study, female teenagers more frequently discussed the physical aspects of puberty with their

mothers, discussed refraining from sexual activity with their fathers, and discussed sexual intercourse with their friends [63]. Apprehension in discussing FP may be relevant if the child has not previously discussed sexuality with their parents. Further, because FP for males is less medically invasive and expensive than for females, gender can also influence the frequency of these discussions [7]. These barriers are likely to affect the adolescents' involvement in decision-making.

Scientific advances have made FP options available in cases previously not possible. Empirical data highlight the need for advocacy regarding the complexities of infertility-related discussions and referrals between providers and patients. Adolescents who are provided with developmentally appropriate language may be more equipped for long-term decision making. Children as young as 11 years have been found to understand their own illness in parallel to their parents' level of understanding [64,65]. Decision making capacity of adolescents has been widely researched in neuroscience and behavioral contexts, but there is no agreement about whether adolescents can make sound, long-term decisions. Behavioral research has argued that although the brain has not completely developed, when provided with comprehensive information, adolescents can understand the ramifications of decisions [39,66,67]. Much of the research in this review indicates that adolescents prefer participatory decision-making concerning cancer treatment; however, these preferences are often not discussed. There is a clear lack of research on adolescents' decision-making preferences regarding FP options.

It is important to understand factors that may contribute to a parent's healthcare decisions on behalf of the child. Parents of terminally ill adolescents base many decisions on their past experiences with death and interpretation of their child's suffering [68]. Parents may be reluctant to include their child in decision making, fearing he/she lacks the emotional strength to consider a variety of outcomes. Parents may also assume that their child does not want to participate because of the overwhelming nature of a cancer diagnosis. If only parents are approached to consider treatment options, they may assume the role as primary decision maker instead of including the adolescent [69–71].

Most teenagers rely on their parents to interpret and process information regarding serious health issues. Similarly, a parent's attitude toward FP options can affect the adolescent's view and perhaps the outcome. A 2002 study examined how the order of delivering information regarding risks and benefits can influence decisions. Participants hearing the risks after the benefits were twice as likely to refuse consent as compared with those who heard the benefits after the risks [72]. An adolescent's decision may actually be a reflection of what the parent understands. Adolescents' decisions tend to reflect the values and morals of their parents and the healthcare system in which they are receiving care [73]. Thus, with regard to FP, if issues of infertility and cancer treatment have not been previously discussed, the teenager may have little context to base a decision, or may understand their options as their parent understands them.

Evidence regarding adolescent decision making in oncology suggests that FP is a suitable conversation for teenagers. The previously published data show that adolescents with cancer have three main desires about fertility: for information on the potential impact to fertility by cancer treatment, for information on FP options, and to participate in making decisions. Clearly such desires mirror those of adults diagnosed with cancer. Despite the adolescents' desire for information on fertility, young

adult survivors of pediatric cancer have reported they were unsure about their fertility status and struggled to recall discussions on the impact that treatment has on fertility [6].

Ethical questions may arise during the decision-making process regarding whether there are conflicting views among the child and the parent(s), child and provider, parents and provider, or between two parents. When autonomy is lacking, and parents do not know what children would want for themselves, who will serve the best interest of the child and the potential offspring? Case law states that, "The child is not the mere creature of the state; those who nurture him and direct his destiny have the right, coupled with the high duty, to recognize and prepare him for additional obligations" [74]. Tension may exist between a parent, who has a constitutional liberty to raise children as he or she sees fit [75], and case law that affirms a child's right to bear children [76]. At the state level, the doctrine of *parens patriae* is invoked in cases when the state must intercede guardianship over minors if the parent is found negligent or incompetent [77]. Conversely, some states have adopted the *mature minors doctrine*, in which an adolescent may independently provide consent for medical treatment on the basis of age and maturity, subjectively determined by the court system [78].

Concerns may continue about what to do with harvested eggs, tissue, or sperm if they are not used [79]. These considerations should be attended to at the time of selection of FP, weighed with the expressed desires of the patient, using a participatory decision-making process [80].

This review synthesized the most current published data to better understand factors that affect the decision-making process regarding FP among adolescent oncology patients. We acknowledge several limitations. The 10-year age range limited the search results to a few eligible studies, and some studies used small sample sizes [31,33,34,39]. Additionally, many studies varied widely on the ages that defined adolescence; therefore, it was left to subjective judgment on inclusion and this may bias our conclusions.

## Conclusions

A variety of previously published data exist discussing decision making, quality of life, and fertility among adolescents both with and without cancer. However, the quantity of empirical research is limited. This topic spans issues on health, sexuality, planning for the future, and decision making in times of crisis. Existing literature shows evidence that adolescents prefer to discuss their cancer treatment's possible impact on fertility; however, further research is needed to explore how to determine personalized approaches for these patients. Additional FP areas of research include the impact of socioeconomic status and cost, decision-making strategies, satisfaction as adults with the decisions made as an adolescent, and reasons for not wanting information on FP. Appropriate timing for fertility-related discussions is also an area of research that has been neglected.

Research is recommended to explore participatory decision making regarding fertility by means of an assessment tool. Developing an assessment tool for use by healthcare professionals would be beneficial by evaluating the adolescents' a) current health literacy, b) understanding of sexual reproduction, c) concern for future fertility, d) decision-making competencies, and e) desire for physician/parental/legal guardian involvement. The tool will be best served by pairing assessment items with AAP/ASCO guidelines. Determining how much an adolescent cancer

patient knows, and is concerned with fertility, will help tailor discussions and language to fit the patient's needs.

## Acknowledgment

This research was supported by the Oncofertility Consortium, funded by the National Institutes of Health through the NIH Roadmap for Medical Research, grant UL1DE19587 and UL1DE019587.

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