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Whose Future Is It? Ethical Family Decision Making About Daughters' Treatment in the Oncofertility Context

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Introduction

In cases of fertility-threatening cancer treatments, the choice whether or not to undergo fertility preservation treatment before cancer treatment begins represents a high-stakes, time-sensitive, emotionally charged, nested decision [1]. The choice is life altering and, although presumably a discrete decision, the fertility preservation decision serves as an outcome of a very recent challenging decision to pursue fertility-threatening cancer treatments. Patients and their family members will experience the dual impact of these linked treatment-related decisions for years to come. For many patients, family members play significant roles in treatment-related decision making. However, if the patient has not reached the age of legal majority, family members play additional roles in the decision-making processes. Multiple issues confound the fertility-focused decision involving female children and adolescents; such complicated and critical family-related medical decisions raise multiple underexplored ethical concerns.

This chapter addresses a range of family factors and related ethical issues that affect decision making when a female child or adolescent is faced with fertility-threatening cancer treatments. Following the presentation of a framework through which to examine the role of children in decision making, several child- and family oriented complications related to both ethics and family communication will be explored. The focus of this chapter is on girls because the current oncofertility options for prepubescent and adolescent girls are more invasive and less predictable than they would be for an adolescent male considering sperm banking to achieve future biological parenthood.

This exploration reflects a family systems' perspective, best captured by Minuchin's [2] claim, "Decontexted individuals do not exist" [2, p. 2]. From this perspective, individual family members are considered as parts of a family system and its interaction patterns; a change affecting one member of the family reverberate through the entire system. Communication is central to understanding these family system patterns and their changes [3] because decisions made by one or more members impact all members to the extent that they are connected. The American Academy of Pediatrics (AAP) states that effective communication "is essential to patient-centered and family-centered care" [4, p. e1441]. In addition, factors related to the family's background and experiences (be they cultural, socioeconomic, or religious) affect the decision making by family members as individuals and as a unit.

Ethical Consent and Children

Traditionally, parents have assumed responsibility for making medical decisions for their children's care, even if that has meant choosing to allow a doctor to decide for them. But, in recent decades, the extent to which children and adolescents should be involved in medical

decision making related to their treatment has emerged as an important issue. The prevailing spirit underlying historical parental control is “that parents are the most motivated and capable people to act in their children’s best interests, that they often have similar interests to their children, and they are more competent to make medical decisions” [5, p. 507]. However, as there has been a transformation in how American society views the role of the adult patient [6], there has been a similar shift in how child involvement in decision making is conceptualized. The prevailing view today seems to be that children should be involved to the extent possible, given their prior experiences, maturity level, and cognitive and emotional capabilities [4, 5, 7]. In practice, this is difficult to implement with confidence, as every child, family, and clinical situation present unique challenges.

Clinical psychologist Mary Ann McCabe (1996) argues that “we need to support minors’ involvement in decision making, particularly for treatment decisions where the clarity of the ‘right choice’ fades, where treatment preferences are based upon the personal values and ‘quality of life’ issues” [5, p. 506]. Therefore, “in medical situations where the ‘correct choice’ is not clear, the adolescent should be invited to have more involvement and his/her own values should be brought to bear on treatment choices” [8, p. 320]. This focus on clinical equipoise (i.e., where there is no evidence for preferring one medical option above another) is in keeping with shared decision making. Although most frequently applied to the adult setting, this approach that advocates for patient involvement in care and an explication of the patient’s personal values and preferences [9–11] is also relevant to children.

The American Academy of Pediatrics has several position papers directly relevant to the issues at hand [4, 7, 12]. Currently, the AAP is clear that “[t]here is a moral and ethical obligation to discuss health and illness with the child patient.” [4, p. e1445]. The Academy further states that older children and adolescents should have “a significant role” when there is no clearly superior option from a medical standpoint. A model of decision making in pediatric oncology recently introduced by Whitney and colleagues takes this further by attempting to delineate under which circumstances a child, parent, or clinician should have decisional authority [13]. Although deciding whether to initiate cancer treatment, and which treatment to support, may require heavy reliance on the professional’s knowledge and perspective, fertility preservation reflects a quality of life decision or personal value approach that the parents and child might address together, assuming a child is able to comprehend the issues.

The Family Rule Approach

In his widely cited article on obtaining ethical consent for medical interventions involving children, Foreman (1999) argues that “informed consent in children should be regarded as shared between children and their families, the balance being determined by implicit, developmentally based negotiations between child and parent – a ‘family rule’ for consent.” [14, p. 491]. Although his writing relies on the British legal tradition, the issues raised provide a valuable grounding for considering the ethical issues within a health and family communication framework. As we address ethical issues, we will consider Foreman’s guidelines and conditions from a communication perspective rather than a legalistic perspective.

After addressing the binds inherent in children’s assent and parental consent, Foreman distinguishes between consenting to an *event* (e.g., an action, such as a procedure) and consenting to a *rule* (e.g., agreement to follow a set of prescriptions and prohibitions that regulate conduct) before arguing that “the most important rule children consent to is that of their family” (p. 493). He makes the case that children *implicitly* consent to a family rule thereby agreeing to “follow a set of prescriptions and prohibitions that regulate one’s general

conduct” (p. 492) and claims that this family rule must promote the welfare of the child and must not be viewed as an all-or-nothing arrangement because developmental factors require ongoing renegotiation of the rule’s application until the child reaches adulthood.

In an attempt to provide guidelines for medical practitioners, Foreman proposes a five-step process for ensuring the child has enough information needed to give rational consent (See Table 33.1). In addition, he identifies five conditions that medical practitioners may encounter as they attempt to balance respect for the autonomy of the child as well as respect for the variable (diffuse) nature of a child’s right to consent (See Table 33.2). Issues such as age, maturity, and a child’s cognitive or emotional state influence a child’s decision-making capacity. Medical decision making for a child ideally includes active family communication among the involved parties. Foreman’s conditions are based primarily on whether or not the child can provide consent and whether or not the child consents to the family rule.

In the first of Foreman’s five conditions, there is the option for joint parent/child decisions and necessitates full medical explanation to both parties. This situation supports open and detailed discussion between a child and parents as they move toward a joint decision. When the child cannot provide fully informed consent, medical practitioners must give a full explanation to the parents and limited information to the child. Importantly, Foreman asserts that *just giving the information to the parent does not ensure the child receives sufficient information*. Therefore, this position implies that parents and a child may hold conversations, but that the burden is on the medical professional to ensure that certain information is conveyed to the child at his or her level of understanding about the future implications. In some instances, this may be at odds with the AAP’s position paper on communication with children and families [4]. This document states that the parents and the pediatricians should discuss how to involve the child in decision making. Regardless of which model is followed, the clinician must ensure that the child has an understanding commensurate with his or her capacity. That is, one could argue for ethical decision making if the parents inform the child or if the clinician does the informing, as long as the provider is satisfied that the transfer of knowledge was both adequate and adequately understood.

The remaining situations are more problematic. In the third situation, a child is capable of giving informed consent, but does not consent to the family rule. If the child truly can consent, then the child’s desire must be respected [4, 14, 15]. As adolescence is a time of questioning and increasing intellectual and emotional independence, such a scenario is easily contemplated. For example, this might involve a 16-year-old with strong religious beliefs different from her parents. In such cases, family communication is likely to be painful, complicated, and even fractious. In some situations, it may be preferable for the healthcare provider to consider overriding the parents’ wishes. This could detrimentally affect the parent/healthcare provider relationship. In these situations, the healthcare provider has an obligation to become the child’s advocate [7].

A situation may arise in which the child cannot give informed consent and does not consent to the family rule. Examples include a child misjudging his or her capabilities, believing that expressing individuality trumps a rational approach, or continuing a pattern of rebellious disagreement while expecting to be overruled. This is challenging for two main reasons. First, even adults do not make decisions entirely rationally. It is not reasonable to expect a child to decide based on rational thought when an adult in the same situation would not be expected to act rationally. Ladd and Forman argue that adolescents make choices according to values that they hold precisely because they are developmentally appropriate (and would not necessarily be so in adulthood) [15]. Second, it may be difficult to distinguish the child who can consent but who disagrees with the family rule from a child who cannot consent and disagrees with the family rule.

In each case, the child dismisses parental authority. Superseding the child's wants is difficult, but may be more ethically defensible if he or she is not capable of consent. These situations, in which the child and parents disagree, frequently involve dissension, anger, and complications. Despite these complications, each scenario, at its core, has an assumption that the parents are behaving with the child's best interests at heart. In such cases, a member of the healthcare team may aid the family in identifying the objectives of the parents, child, and healthcare provider [16]. Through such discussion, a resolution may be reached.

Foreman describes a fifth case, in which unethical parents make what Foreman refers to as an "irrational" decision regarding their child's treatment, i.e., offering consent that ignores or recklessly disregards a child's benefit. Essentially, this circumstance disconfirms the child, rendering him or her nonexistent. Rather than using the family rule approach, the American Academy of Pediatrics recommends that "the cultural and family values, roles, and structure that have always governed the [child-parent] relationship should be treated with due respect" [4, p. e1445]. This statement is sufficiently vague so that its value in reducing child/parent conflict and promoting decision making is weakened. However, the position that the healthcare provider has an obligation to act in the child's best interest can be useful in situations in which there are cultural or role conflicts.

In their attempt to extend the Patient Self-Determination Act [17] to address involving adolescents in medical decision making, McCabe and colleagues (1996) frame their position based on the many situations in which adolescents have autonomous involvement in medical decisions [8]. They claim that, because in many states adolescents have autonomous involvement in medical decisions such as testing and treatment for sexually transmitted diseases and reproductive care, the views of adolescents should be solicited in other medical circumstances to protect his or her best interests. The authors propose that adolescents' capacity for decision making should be evaluated according to the legal requirements for informed consent and suggest that this assessment is most effective when performed by a healthcare provider who has an established relationship with the adolescent as well as with the parents. The latter suggestion, although important, is problematic in cases of fertility preservation decisions immediately following a cancer diagnosis; the healthcare providers are likely to be relative strangers to the family members.

When considering childhood cancer treatments, complications may emerge as decisions about cancer treatments and fertility treatments are addressed sequentially. Even in circumstances when cancer treatment decisions might be made openly and clearly by healthcare providers, parents, and (sometimes) a child, the addition of a treatment-related fertility threat may significantly alter the decision-making processes. Applying the family rule to the fertility preservation decision may elicit a joint agreement among the parents and the child, depicted in Foreman's first two conditions described above (child consents within the family rule and child either can or cannot provide fully informed consent so family moves to joint decision). Alternatively, one of the other three conditions will elicit interpersonal struggles as parents, children, and healthcare providers attempt to move forward. Family interaction practices, ranging from highly open to very closed communication, would impact the child's ability to provide consent within Foreman's ethical framework. In families characterized by closed communication, a child's consent may appear to be consenting within the family rule, but her lack of awareness of certain key information undermines that perception. In certain cases, this may reflect Foreman's fifth condition – parents offer consent that does not consider the child.

Other factors may contribute to limiting the decision-making capacity of family members or patients. An extension of Foreman's fifth circumstance (disregarding the child) may occur when healthcare providers provide neither parent nor child with information about the

fertility threat inherent in the necessary cancer treatments – therefore, professionals ignore the family and the child’s benefit. In their study of discussion of fertility issues before treating young cancer patients, Anderson and colleagues (2008) found that oncologists reported discussing the effect of treatment on fertility with 63% of patients, of whom 61% were viewed to be at high or medium risk of fertility problems [18]. Discussions were held more commonly with boys than girls, a finding that raises issues of gendered conversation practices that provide more information to males than females. In addition, the pressure for decision(s) comes at a time when parents may be both cognitively and emotionally overwhelmed, creating what is perceived as the major obstacle to informed consent related to pediatric cancer clinical trials [19] and, by extension, the fertility preservation decision.

Family Communication and Ethical Decision Making: Issues and Complications

Having reviewed some of the general issues and complications involving medical consent when children face life-threatening cancer, a number of more specific factors related to family communication and decision making will be addressed. These include: (1) parental disagreement (2) complicated family forms, (3) assumptions inherent in biomedical language, (4) discussions at time of treatment, (5) discussions of sexuality, (6) discussions long after treatment, (7) keeping the topic a secret, (8) a child’s rights to options, (9) parental/familial rights to options, and (10) decision based on current child vs. the forecasted adult child. All of these issues are compounded by the very short timeframe in which this decision must be made.

Parental Disagreement

In two-parent legally constructed families, problems may arise if parents disagree, leaving the child aligned with one against the other. Child–parent disagreement remains a key area of concern, yet little is known about disagreements *between parents* when serious medical outcomes are at stake. The AAP’s previously discussed stance on respecting the family structure can provide some guidance. Although the parents may disagree, if the “family rule” for a particular family is that one parent has decisional authority in most cases, it may be a way to resolve conflicts within the existing family structure. However, an adolescent should be respected for the “emerging adult” that he or she may become (p. 1447).

Few discussions of parental consent assume parental disagreement, although Foreman (1999) suggests that when caretakers disagree the healthcare provider has two responsibilities: (1) to do everything to bring the parents to agreement and (2) to recognize if agreement is impossible within the necessary time frame. The latter situation necessitates that healthcare providers must “support the child *against* the disagreement between the parents” (p. 494) and have the responsibility to side with the parent who appears to act in the child’s best interest. Although this advice seems straightforward, criteria for this decision are not indicated. Many of these specialists are encountering a family for the first time, and many clinicians do not fully understand their options to provide the best care. Therefore, when it comes to fertility preservation, there is no clear indication of what would be in the child’s best interest based on prior contact with the child or family. In their study of clinicians’ knowledge of informed consent, Fisher-Jeffes et al. [20] described a fictitious scenario to healthcare professionals in which married parents disagree about chemotherapy for a 5-year-old leukemia patient. Only 65% of the pediatricians and 36% of other health practitioners knew that they could obtain consent solely from the mother who supported the treatment. The rules concerning consent may be even more complicated in situations in which the child is eligible for a clinical trial, as some protocols may require both parents to agree before entering [21]. Given that the majority of pediatric cancer patients receive some

form of treatment through participation in a clinical trial [22], it is understandable that there is much confusion on the part of healthcare providers.

Beyond the immediate decision of what to do regarding the child's treatment, this issue gives rise to the following concerns: what are the long-term outcomes of the healthcare provider colluding with one parent against another on the adult marriage or partnership? On the parent-child relationship? On the future relationship with the healthcare provider? The professional's decision to follow one parent's decision against the other's, even if considered necessary, opens the possibility of irrevocably altering the marital and family dynamic, as this might become a relational turning point and an event referenced in any future disagreements.

Complicated Family Forms

Surprisingly, the medical ethics consent literature seldom addresses the variety of family structures; rather, it tends to assume a two-parent biological family, only one of many minority family forms in the United States today. Contemporary families shatter any traditional understanding of "family," reflecting an "increasing diversity of self-conceptions as evidenced through structural and cultural variations, which challenges society to abandon traditional nucleocentric biases, cultural and traditional gender assumptions" [23, p. 5].

Currently, no majority family form exists in the United States. Even the twoparent biological family represents slightly less than half of US families. If one majority form were to emerge, it is likely to be the stepfamily. Stepfamilies, married and cohabiting, provide parenting for more than 4.4 million children [24]; these may include second and third stepparents from one parent's third or fourth marriages. More than a quarter of children live in single parent households, usually headed by mothers [25]. Currently, 2.5% of children younger than 18 are adopted [24], and, in a small but growing number of cases, children are raised in households headed by same-sex partners and foster parents. In lesbian-headed households, the children may be biologically related to one parent, and different children may have different biological mothers. For male or female same-sex couples, there may be legal barriers to both parents having legal authority over decision making, even in intact relationships [26].

One pressing issue involves understanding which family members play a significant role in making fertility preservation decisions or communicatively influencing healthcare decisions. This reality provokes several questions. For example, what happens when a biological father, who has played a very minor role in his daughter's life, attempts to override the decision of a former spouse and custodial stepfather, who together raised the 12-year-old child since age 2 and know her dreams for her future? What moral authority belongs to the man who raised the child as his daughter?

The variety of family forms raises questions with ethical implications such as: what right does the long-term cohabiting stepfather have to influence the decision making? Because of the tremendous increase in "open" adoptions, what rights might an involved birth mother play in the decision? A related sperm donor? Custodial grandparents? Further, where legal guidance exists, it is difficult for healthcare providers to know all the regulations.

A Child's Right to Options

By and large, society thinks of an individual as having a right to reproduce, although this pro-natalist view is more pronounced in some societies than in others. In general, "[t]he right to procreate is inherently regarded as a moral 'negative right', which is to say that others have a duty to not interfere with this right unless there is sufficient and weighty moral ground to do so" [27, p. 167]. However, this position does not go as far as to say that others

should “guarantee the right regardless of cost,” making it a positive right. But by having decisions about fertility preservation in one’s hands, parents may feel that not acting on options open to them is immoral. That is, for one’s own children, fertility may be seen as a positive right that they have the burden of trying to preserve. Preliminary data from interviews with parents whose very young daughters have had cancer indicate that may be a concern [28]. Parents speak of wanting to “preserve” the child’s opportunity for a “normal” life – not that she *must* have children but that they want all doors open to her – “just like anyone else.” These parents are reluctant to allow a female child to lose options for motherhood. Parents may feel responsible for any secondary effects of the cancer treatment, such as infertility, because they approved the treatment that caused these effects. Some bioethicists speak of a child’s “right to an open future” [29], i.e., that a parent should keep options open to children until they develop the maturity to decide for themselves. Although certain experiences can remove or add potential options for children, what obligation does a parent have to maintain a child’s right to procreate?

Parental/Familial Rights to Options

In addition to the child’s rights to options, under what conditions might family members’ preferences hold weight in decision making? John Hardwig (1990) argues for the rights of family members in medical decision making based on the assumption that a family is an interdependent relational system [30]. He asserts that, “The requirements of justice and the needs of other patients (meaning family system members) must temper the claims of autonomous patients” (p. 5). Hardwig believes that in the many cases, when important interests of family members are dramatically affected by the patient’s treatment, “medical decisions often should be made with those interests in mind” (p. 5). He suggests that in certain situations, the interests of family members ought to override those of the patient, arguing that, “To be part of a family is to be morally required to make decisions on the basis of thinking about what is best for all concerned, not simply what is best for yourself.” (p. 6) He states, “It could be argued that, in certain cases ... it is irresponsible and wrong to exclude or fail to consider the interest of those who are close.”

This position could raise questions related to interests of preserving the family line as well as interests of all children in the family. For example, what are the rights of parents who have only one child and wish to preserve the family line through biological grandchildren whose 13-year-old daughter refuses to undergo an experimental procedure to create an option for future parenthood? In a patriarchal culture, does the great-grandfather have the right to demand that a grandchild’s fertility be maintained? Expense is not an insignificant factor. What is the parents’ or family’s responsibility to pay for fertility-related treatments, since it is likely to be very expensive and not covered by insurance? Could this expense put higher education or other goals out of reach for other children in the family? Does the family have an obligation to, for example, mortgage their home in order to pay for these treatments? At what point do the expenses become the child’s burden and responsibility? Davis points out that costs in the range of US \$50,000 are not unheard of in the realm of “directed procreation” (such as pre-implantation genetic diagnosis) [31]. Davis argues that making certain investments (financial and otherwise) in children may result in parents feeling as if they have an entitlement to the choices the child makes in the future.

Difficulties and Assumptions Inherent in Language Used by Biomedicine

Biomedical language is often constructed to fit the needs of the healthcare providers and the healthcare system. However, there may be biases inherent in such language. In this particular context, the language of cancer, its treatments, and its potential consequences on fertility are often unclear.

First, despite the scientific terminology, risks, benefits, and sequelae are often presented in non-specific terms related to the unknown future. That is, one cannot say with complete confidence how long one has to live, if a treatment will result in infertility, if a treatment will result in a response (even what a “treatment response” is may be somewhat subjective and the clinical connotation may not be clear to the parent), and so on. There is vast evidence that most people do not understand health risk information [32–38]. This information is often presented as percentages and probabilities filtered through the lens of the particular healthcare practitioner and his or her professional biases and experiences. How can informed decision be made if the implications are not clear to the decision makers?

Second, the terminology used promotes a normative expectation that holding to an ideal of a body and future unaffected by cancer is the desired standard. For example, fertility-related language includes terms such as “fertility preservation” and “loss of fertility,” implying that a change in a biological function is seen as a change from the norm and as a loss that must be rescued. In addition, presenting even experimental fertility-related options to children and their families may imply that all children, and particularly all girls, will want to be biological parents. The idea that femininity is tied to biological motherhood and that one’s role as a mother should be protected is not new. However, just as a child has acquired the label of “cancer patient,” the introduction of fertility and other late effects of cancer move the child into the realm of “cancer survivor” and even, though she may be prepubescent, “infertile.” The social, medical, and even insurance implications of this labeling are far from clear.

Discussions at Time of Treatment

Given the stresses and time pressures emerging as families face a child’s cancer diagnosis and then the fertility-related issues, reflective decision making is challenging. A request that parents consider enrolling their daughter in a clinical trial aimed at preserving fertility arrives at a time when parents may be in a state of shock. Another medical procedure of uncertain benefit may be more than they are willing to consider, especially if they perceive it would upset their daughter or there are other extenuating circumstances such as money or family tension [19].

What rights would the pre-teen or teenage daughter wish for in this situation? In a study of teen and young adult cancer survivors, the respondents strongly supported telling patients about the potential impact of the treatment on fertility at the time of diagnosis and indicated a desire to be treated as partners by their medical professionals, thus prioritizing their input over that of their parents [39]. In their analysis of healthcare providers’ perceptions of children’s decision making in healthcare, Runeson, Enskar, Elander, and Hermeren found timing and staff attitudes affected a child’s role in the process [40]. In addition to showing respect for the adolescent, the AAP also suggests a model of decision making in which the physician or parent could play the role of “educator, discussant, challenger, and shared decision maker” [4, p. e1447]. In this way, disagreements between child and parent can be examined in a discussion that allows each party to think through his or her feelings, values, and concerns. Similarly, some advocate asking parents difficult questions in order to engage family members in a process of being truly informed and ensure that parents consider the best interests of the child as potentially separate from their own interests [41].

Discussions about Sexuality

Communication about fertility is, by necessity, communication about sexuality. The ease with which parents may address the issue of future fertility will depend, in part, on the family history of open sexual communication. Research on parental communication about sex indicates that mothers are the primary communicators on sexual topics, although friends are the main source of sexual information. Fathers may discuss sociosexual issues with their

adolescent daughters [42]. Some parents remain uncertain about how and when to initiate such conversations because they lacked good role models in their own lives [42]. Others report difficulty discussing sexuality because they doubt their own knowledge and skills, worry that their children will not take them seriously, or believe that raising the topic could be considered providing permission to engage in sexual activity [43]. Whereas sexually healthy families are characterized by effective and flexible communication patterns that support intimacy, sexually neglectful families exhibit an absence of discussion on the topic, and sexually abusive families reflect a perpetrator-victim pattern with limited communication [44]. Yet, Warren asserts that satisfaction with family discussion about sex is dependent on mutual dialogue [45]; this occurs when parents facilitate conversations and an attitude of openness prevails. By extension, discomfort discussing sexuality challenges parental perceptions of their own competence and willingness to discuss fertility.

Parental anxiety regarding discussing sex contributes to the following questions: Are parents who have avoided or downplayed discussions of sexuality prepared to hold such conversations about fertility and potential fertility loss under high-anxiety conditions? Are they obligated to find a medical professional or another known adult to represent them in such conversations? Communicating about a potential surgery or other fertility preservation procedure with no immediate benefit requires that parents view their children as sexual beings. Parents who are already uncomfortable discussing sex and sexuality are now confronted with the need for the discussion, perhaps even earlier than they would have thought necessary. They have to think about sex in a medical context (which could make the task easier or harder for them, depending on their views). This also requires considering how to “simultaneously retain and abandon the sense of the innocence of the child, while introducing the violation and risk of surgery and the consideration of the child’s future sexual preferences, plans and reproductive life” [46, p. 23]. However, if it is unknown whether or not she is infertile, these discussions also highlight the need to discuss birth control to avoid unintended pregnancy.

Disclosing the Decision in the Future

To what extent is there an ethical obligation to talk about the fertility-related decision as a very young child ages? When and how should she learn that her parents rejected or accepted the optional treatments or procedures? How is the choice to reject the option explained? How is the treatment discussed if a daughter does not remember undergoing a fertility preservation procedure? In certain cases, the initial explanation may need elaboration as childhood patients move toward adulthood. In other cases, parents may disclose that a daughter might have serious to minor difficulty achieving pregnancy.

For some young children, the issue is likely to emerge years later, often due to the need for hormone treatments or when infertility issues arise. If a family was not open in discussing sexuality, it will be more difficult to discuss the “unknown” or vaguely remembered procedure. Veiled comments may be expected to suffice when clarity and detail are needed. As evidence of such parent–child communication discomfort, Balen and Glaser report that medical practitioners find that taking medical histories may be complicated when dealing with treatments during childhood if the young person’s parent is present [47]. They found adolescent patients were embarrassed about discussing topics such as menstruation and sexual intercourse and only did so when parents prompted it. Yet an adolescent who is alone with a healthcare provider, but is unaware of her potential fertility problems cannot give an accurate history and may not understand what the practitioner is discussing.

A child who needs to see an endocrinologist in order to enter puberty will likely have these discussions in a medicalized context. This may reduce the burden on the parents to discuss the technical details of sexuality and fertility, but it does not negate the need to address the

emotional components of this revelation nor allow the parents to rely on the adolescent to have a complete understanding of her situation. As she matures both emotionally and cognitively, these conversations are likely to reoccur.

In their study of teenagers and young adults faced with possible or actual fertility impairment following cancer treatment, Crawshaw and Sloper interviewed 38 cancer survivors (ages 16–30) [39], who were aware that their fertility might have been affected. Many did not learn about the fertility concerns until sometime after treatment. Some respondents found it difficult to talk openly with any family members about fertility issues. Families were much less likely to talk about cancer-related fertility issues than cancer issues at any time after treatment.

Keeping the Topic a Secret

Secrets, such as a choice to pass on a fertility-related procedure or an undisclosed fertility-related procedure, leak over time. Attempts to conceal decisions related to a young daughter's future fertility limit family communication in unforeseen ways. It may transform, and potentially undermine, the child–parent relationship in later years. This becomes a toxic secret, a secret that impacts healthy relationships, disorients family identity, and limits member's abilities to make clear choices [48], eventually eroding trust in the parent–child relationship. If and when the secret is discovered through indirect means (e.g., a relative's comment or medical record access), the complications are multiplied. Finally, if and when a former patient, who was old enough at time of treatment to understand the implications, learns that the fertility threat was consciously withheld from her before cancer treatments began, painful family conflicts may follow.

Recognizing the costs of secrecy does not result in a clear and easy path. Revisiting a pediatric cancer experience is difficult for many families; some address the experience in very different ways for years to come. Long range research on parents and pediatric cancer survivors indicates that many parents experienced a higher level of concern about their child's health status and experienced more recurring thoughts about the child's cancer than did the patient [49]. Such ongoing cancer-related anxiety, coupled with a fertility-related toxic secret, would serve to alter the parent–child relationship in the years following treatment. Just as family members who do not wish to address a genetic disorder openly engage in scanning relatives' behavior in an attempt to see any signs of the disease [50], families that maintain such secrecy are likely to scan for signs of fertility-affected outcomes (e.g., absence of menstruation onset, long period of attempts to achieve pregnancy) as predictors of problems. If signs appear, more direct communication may follow. If a cancer survivor discovers, as an adolescent or young adult, that self-identity dreams, perhaps as a future biological mother, are not likely or possible, the relational “destruction” may be as serious as the news itself.

Decision Making Based on Current Child, Not Forecasted Adult Child

A final set of concerns deals with the uncertain nature of the cancer treatments and their consequences. Parents are making decisions based on who a child is at the time of diagnosis, but, even if the child survives, she may have serious physical or cognitive problems depending on the type of treatments necessary. If the child becomes cognitively impaired, what happens to the stored tissue, eggs, or embryos? Who decides if the child, upon reaching adulthood, can or should have access to the stored tissue and any procedures necessary to turn the tissue or embryos to infancy? The parents do not yet know what disabilities their child may have, nor do they have experience in caring for a disabled child. Certainly, there are many people with cognitive or intellectual difficulties who become

parents, but what rights do they have or maintain when considering parenthood using assisted reproduction, as would be necessary if using stored tissue?

Conclusion

Female cancer survivors have reported that facing infertility can be as difficult as dealing with the cancer and related treatments [51]. This chapter has identified both a family-centered framework through which to examine fertility preservation for girls and their parents as well as presented a number of issues and complications related to ethics and communication in the pediatric cancer context. There are three important omissions in much of the bioethics literature regarding families and participation in decision making. First, there is no majority family form in the United States, yet much of the bioethics literature assumes two biological parents will be involved in decision making. Second, the literature also seems to assume that if there are conflicts or difficulties, these will be between the child and (two) parents – not that parents might disagree with one another. Third, little attention is given to the role of others, such as a grandparent who may serve as the family matriarch or patriarch and a healthcare decision maker. Furthermore, the decisions made have long-lasting repercussions on the child, some of which she may not be aware at the time of treatment. How to discuss sexuality and fertility, when to discuss and revisit the discussions, and how to ensure that the child both understands and develops her comprehension as she grows are all topics that must be contemplated and addressed. Healthcare professionals and family members face multiple ethical and personal challenges when a daughter faces potentially fertility-threatening cancer treatments – yet these challenges reflect the significant medical advances that are developing fertility preservation options. Skilled healthcare providers (perhaps including counselors and social workers) may be able to ensure that all voices are heard and that ethically responsible decisions are being made with children and families. Hopefully, the communication involving professionals and family members will lead to family-specific resolutions consonant with their beliefs and values.

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Table 33.1

Steps for ensuring a child has enough information needed to give rational consent (adapted from Foreman [1, 4])

1	Inform the child of what will happen if nothing is done
2	Describe the intervention
3	Explain how this intervention will improve the situation
4	Ask the child whether or not he or she agrees that this intervention produces a better outcome than the alternative – doing nothing
5	Seeking the child's consent to initiate the intervention

Table 33.2Four of Foreman's five situations for-child and family decision making^a

Consent	Family rule	
	Child agrees	Child does not agree
Child can consent	Agreement	Child's wishes should be respected
Child cannot consent	Parents decide; child must be informed	Healthcare team may broker an understanding between the parties

^aThe fifth situation is an extreme one in which the parents do not have the child's best interests in mind.