

## The Meaning and Importance of Genetic Relatedness: Fertility Preservation Decision Making Among Israeli Adolescent Cancer Survivors and Their Parents

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### Article abstract

**Background:** With multiple options available today to become a parent, how does the matter of genetic relatedness factor into adolescent cancer patients' fertility preservation (FP) decision making? This study reports on and normatively analyzes this aspect of FP decision making. **Methods:** A convenience sample of Israeli adolescent cancer survivors and their parents were invited to participate in individual, semi-structured interviews. **Results:** In discussing the importance of genetic relatedness to future children or grandchildren, participants repeatedly brought up the interrelated issues of nature, normalcy, and personal identity. Regardless of preference or ambivalence for genetic relatedness, the majority of participants were aware of alternative parenting options and noted both their advantages and disadvantages. However, knowledge of alternative parenting options was not uniform. **Conclusions:** To ensure that adolescent patients and their parents make informed FP decisions that meet their personal goals and values, it is important for physicians to discuss alternative parenting options with them in a culturally sensitive manner. Greater credence also should be given to those who question the importance of genetic relatedness.

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# The Meaning and Importance of Genetic Relatedness: Fertility Preservation Decision Making Among Israeli Adolescent Cancer Survivors and Their Parents

Dorit Barlevy<sup>a</sup>, Bernice S. Elger<sup>a</sup>, Tenzin Wangmo<sup>a</sup>, Shifra Ash<sup>b</sup>, Vardit Ravitsky<sup>c</sup>

## Résumé

**Contexte** : Avec les multiples options disponibles aujourd'hui pour devenir parent, comment la question de la parenté génétique est-elle prise en compte dans la décision de préservation de la fertilité (PF) des adolescents atteints de cancer? Cette étude rend compte et analyse de manière normative cet aspect de la prise de décision en matière de PF. **Méthodes** : Un échantillon de commodité d'adolescents survivants israéliens du cancer et leurs parents a été invité à participer à des entretiens individuels semi-structurés. **Résultats** : En discutant de l'importance de la parenté génétique des futurs enfants ou petits-enfants, les participants ont soulevé à plusieurs reprises les questions interdépendantes de la nature, de la normalité et de l'identité personnelle. Indépendamment de leur préférence ou de leur ambivalence à l'égard de la parenté génétique, la majorité des participants étaient conscients des autres options parentales et en ont noté les avantages et les inconvénients. Cependant, la connaissance des options parentales alternatives n'était pas uniforme. **Conclusions** : Afin de garantir que les patients adolescents et leurs parents prennent des décisions relatives à la PF qui répondent à leurs objectifs et valeurs personnels, il est important que les médecins discutent avec eux des options parentales alternatives en tenant compte de leur culture. Il faut également accorder plus de crédit à ceux qui remettent en question l'importance de la parenté génétique.

## Mots-clés

préservation de la fertilité, oncofertilité, prise de décision, lien génétique, options parentales alternatives

## Abstract

**Background**: With multiple options available today to become a parent, how does the matter of genetic relatedness factor into adolescent cancer patients' fertility preservation (FP) decision making? This study reports on and normatively analyzes this aspect of FP decision making. **Methods**: A convenience sample of Israeli adolescent cancer survivors and their parents were invited to participate in individual, semi-structured interviews. **Results**: In discussing the importance of genetic relatedness to future children or grandchildren, participants repeatedly brought up the interrelated issues of nature, normalcy, and personal identity. Regardless of preference or ambivalence for genetic relatedness, the majority of participants were aware of alternative parenting options and noted both their advantages and disadvantages. However, knowledge of alternative parenting options was not uniform. **Conclusions**: To ensure that adolescent patients and their parents make informed FP decisions that meet their personal goals and values, it is important for physicians to discuss alternative parenting options with them in a culturally sensitive manner. Greater credence also should be given to those who question the importance of genetic relatedness.

## Keywords

fertility preservation, oncofertility, decision making, genetic relatedness, alternative parenting options

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## INTRODUCTION

Due to improved treatment, overall survival rates for adolescent cancer have dramatically improved to a rate of 84% (1). Oncofertility research indicates that survivors of adolescent cancers have a strong desire to parent (2-5). Implied more often than explicitly stated, this desire is to parent genetically-related children (6,7). With multiple options available today to become a parent (such as gamete donation, surrogacy, or adoption), how does the matter of genetic relatedness factor into cancer patients' fertility preservation (FP) decision making?

Discussion of genetic relatedness within the literature on oncofertility is mainly limited to theoretical analysis. There is a dearth of empirical research on how and why individuals value genetic relatedness between parent and child. Dondorp and De Wert claim that fertility preservation attaches *too* much importance to biological parenthood, but assert that such importance is deeply rooted, both culturally and biologically, within humans (8). Dorothy Roberts maintains that female FP techniques are paradoxical in that they promote gender equity by providing female cancer patients the opportunity to bear a child, placing them on equal footing with their male counterparts, but also reinforces the assumption that all women should become mothers, ideally bearing children who are genetically related to them (9). Such feminist critiques of FP question societal dogmas that valorize biological parenthood, emphasizing that infertility does not necessarily affect quality of life and recommending counselling on alternative ways to become a parent (10). However, Pennings and Mertes hold that it is possible to maintain such feminist critiques while defending FP for people with cancer.

The small body of empirical research on genetic relatedness with relation to oncofertility includes: an English qualitative study of adolescent and young adult cancer survivors which notes (a) females' greater frequency and depth of thought on alternative options for parenthood (as compared to males), and (b) most survivors' preference for biological parenthood as well as their preference for adoption over the use of donor gametes, with the caveat that romantic partners' views could influence such decision making (11); an American qualitative survey which finds female cancer survivors who parent non-biological children are less distressed than those who do not parent but more distressed than those who parent biological children (12); an American quantitative survey which concludes that female young adult cancer survivors are significantly more interested in adoption than the general population, with their primary concerns about this alternative being personal preference for a biological child, discrimination by adoption agencies, and the need for more information about the process (13); and an American mixed method study which finds about half of newly diagnosed adolescent and young adult males and most parents are willing to consider alternatives to future biological children such as adoption or sperm donation (14).

This paper adds to the small body of empirical research on the topic, reporting on a subset of findings from a qualitative study of Israeli adolescent cancer survivors and their parents' FP decision making. Specifically, these findings relate to the perceived importance of a genetic link between parent and child. Participants' comments are reported and then critically analyzed and contextualized within the cultural values and norms of Israeli society, which is communitarian and pronatalist, valorizing genetic relatedness and stigmatizing infertility (15-18).

## MATERIALS AND METHODS

The study was approved by the Institutional Review Board (IRB) of Schneider Children's Medical Center of Israel (0309-15). Between January and June 2016, semi-structured interviews were conducted separately with adolescent cancer survivors and their parents. Those invited to participate in the study included adolescents treated at Schneider Children's Medical Center, who had been given the option to undergo FP (to cryopreserve ova, ovaries, or sperm), were in remission for at least 2 months, and currently between 12 and 19 years of age, as well as their parents. Individuals who declined to participate were not asked to explain their reasons for refusal. All participants signed consent forms prior to being interviewed. Parents of adolescents below the age of 18 also provided consent for their child to be interviewed. (For further details on study recruitment please refer to (19))

During these semi-structured interviews, adolescent participants were specifically asked, "When faced with the decision to save your ovaries/eggs/sperm, how important was it for you to have children with your own eggs/sperm." Likewise, parent participants were specifically asked, "When faced with the decision to preserve your son/daughter's fertility, how important was it to you for your son/daughter to have genetically-related children?" All participants were also asked whether they were aware of or told by physicians about other reproductive/parenting options. If they answered in the affirmative, they were further asked what they thought were the advantages and disadvantages of such options.

Interviews, conducted in Hebrew, were digitally recorded and then translated and transcribed into English, the language understood by all coauthors. For accuracy of translation, an independent person, fluent in both Hebrew and English, checked translated English transcripts against the Hebrew recordings. Transcripts' semantic content specifically addressing the above subset of questions was thematically analyzed with a contextualist approach that blends essentialist and constructionist elements (20). This contextualist approach acknowledges the ways individuals make meaning of their experiences (essentialist approach) but situates those meanings within the broader social context to consider how the latter influences the former (constructionist approach). By semi-structuring the interview guide, thematic analysis was conducted both deductively and inductively. Some themes were pre-determined according to specific probing questions (deduction), while others developed from participants' repeated words and phrasing (induction). MAXQDA 12 software was used to assist with the reiterative process of identifying and organizing prevalent patterned responses, or themes. All transcripts were reviewed and coded by the first author, while a second author reviewed thematic codes based on her full reading of a quarter of all transcripts. Both authors discussed thematic codes to reach mutual agreement in cases when there were initial discrepancies.

## RESULTS

A convenience sample of 28 adolescents – 14 females and 14 males – and their parent(s) were invited to participate in the study, as well as 2 parents whose female adolescents were not invited because they were unaware that FP had been discussed.<sup>1</sup> In total, sixteen adolescents – 10 females and 6 males – and 24 parents – 14 individuals and 5 pairs – agreed to be interviewed, collectively representing 20 cases of FP decision making (see (19) for demographic details). The following findings are based on the subset of questions described above in the methods section. Pseudonyms (e.g., David, Gila) are used throughout, thereby preserving participants' anonymity. All cases involve use of FP unless specifically stated otherwise.

### Genetic relatedness

Of the 16 interviewed, 15 adolescents noted that having genetically-related children is important to them (one adolescent did not seem to understand the question). Their responses ranged from a strong preference ( $n = 8$ ) to a simple preference ( $n = 3$ )

<sup>1</sup> Protocol at Schneider is to inform minor patients' parents about FP and to encourage inclusion of minor patients in these discussions.

to ambivalence ( $n = 4$ ) (see Table 1). In the coding of the transcripts, simple preference refers to responses that express the importance of genetic relatedness to one's children. Strong preference refers to responses that express this importance but also use additional positive modifiers, such as "very," and/or emphasize a desire for genetic relatedness. Responses were coded as ambivalent if adolescents initially said that having genetically-related children is important to them, but then also noted that other means to parenthood are acceptable. While these three groups have distinct attitudes, nearly all expressed at some level the idea that having genetically-related children is important to them.

**Table 1: Adolescent responses regarding importance of genetic relatedness between her/himself and possible future child(ren)**

<b>Strong Preference</b>	<b>Simple Preference</b>	<b>Ambivalence</b>
David (age 14, diagnosed 13): It's, I want, like, a child of my own. Like, that he will... Like, that, that I brought him. Not that, like, someone else.	Idan (age 14, diagnosed 12): Important. Important. Interviewer: So, can you maybe explain to me a little more about this? Idan: What do you mean? Interviewer: Ah, why is it so important? Idan: I don't know. That they will be mine. What? My children.	Ofer (age 15, diagnosed 14): Like, of course, it's important. But if there isn't any other possibility, then adoption is possible. But of course, it's a bonus. Like, [clears throat] if there's the possibility, then of course it's good that they will be from your sperm. Like, they will be part of you. And if not, then it's not so bad. Then we'll adopt.
Interviewer: And, when you decided to save the eggs and the ovary, how important was it that you would have genetic children? As in- Rachel (age 16, diagnosed 14): Important. Interviewer: made from your eggs. Important to you? Rachel: It's the best. Interviewer: The best? And why do you think this way? Rachel: Because then the child is really yours.	Tamara (age 17, diagnosed 15): Ah. Important. [giggles] Yes. Interviewer: OK. Can you explain a little more? Tamara: Eh...I want that it will be children, like, from my genes. Like, from me.	Gila (age 16, diagnosed 14): I don't know how important [the genetic link] is. It is important to me. Eh. But I know that if I won't have that option, I will do it via options, like other ways.
Dalia (age 16, diagnosed 15): Really. It's the most important thing. Because, I don't know. Because, I...I don't see myself not having – I don't know how to explain it. I don't see myself having children that aren't mine. And I also know that the situation will be very difficult if something like this will happen. In the end, clearly, I will have children. But...I don't see any other option – that they won't be mine.	Tomer (age 18, diagnosed 16): Eh... important for everyone, I think, who wants his own child.	Lily (age 17, diagnosed 16): It's very important. Like it's not, [clicks tongue] Like I said, I think about adopting, so it's not...if it won't be mine, then it won't really be my child. Like, I think it's very dependent in the way that you raise them and the way that you...that you're with them. Like, it's your children for everything. Ehm. But it's nice that like, you know that it's from you. Like you went through the whole process of the pregnancy, of the birth, of the growth from zero.
Leena (age 17, diagnosed 13): It's...it's... You know, it's very important to me. Yes, of course.		Einav (age 18, diagnosed 14): Today I think of it because I don't know, but I believe that to be a mother to a biological child that's yours, it, it's a powerful experience. The pregnancy, the labor, everything. Ehm, but it's clear to me that if I can't have children then I will have children in another way.
Irit (age 17, diagnosed 15): I want that the children will be mine. What?...That's it. [giggles] There isn't too much to philosophize about it.		
Inbar (age 18, diagnosed 16): Very. It's like, it was obvious that like they will be mine. Like also, I really remember, how I cared for the three eggs that weren't sure. Like...if eh, if they, if they will be mature or not. Despite that I already have nine, but I cared for those three. [giggles] So like, it, it's important. It permeates. A baby is something that, that you create. So, like, from you and from the partner.		

<p>Ze'ev (age 18, diagnosed 16): Of course it's important. What?          Interviewer: OK.          Ze'ev: Obviously it's the children that are mine. What?          Interviewer: OK. Can you maybe explain a little more about this?          Ze'ev: What do you mean? OK. What can I tell you? There's, there's nothing to tell you. Like, think about it like this that, if you want that your child will be actually yours, would you want it with the sperm of someone else? Probably you want the sperm to be yours. So, you will preserve it. You will do something that it'll be your children.</p>		
<p>Na'amah (age 19, diagnosed 15): It's important for me that they will be from my genes. Of course.</p>		

When asked to elaborate on the importance of genetic relatedness, some adolescents struggled to explain, while others offered different reasons. Leena (age 17, diagnosed at 13) admitted, "I can feel it, but it's something that's difficult to say," and Na'amah (age 19, diagnosed at 15) shared, "It's very important. I don't know how to explain it." On the other hand, some adolescents interpreted genetic relatedness to one's children as an indication that the children are really hers/his. "That they will be mine," was a common refrain. Some adolescents justified their preference for genetic relatedness by appealing to "nature." Tamara (age 17, diagnosed at 15) said, "it seems to me natural like this, that someone wants...a child from him." In developing his rationale for why everyone who wants to bring a child into the world wants it to be genetically-related to oneself, Tomer (age 18, diagnosed at 16) explained, "Because...that's how nature is." Similarly, Inbar (age 18, diagnosed at 16) says, "In general, like, the natural way it, it seems to me preferred because it's just natural." For Dalia (age 16, diagnosed at 15) being genetically-related to her children forms part of her personal identity. She said, "I don't see myself not having children that aren't mine.... In the end, clearly, I will have children. But...I don't see any other option – that they won't be mine."

Adolescents who expressed ambivalence regarding the importance of genetic relatedness offered other explanations for such a preference. Ofer (age 15, diagnosed at 14) claimed that being genetically-related to his future children is a "bonus," musing, "You feel [the child is] part of you. It's not critical. But, eh, of course it's preferred." Additionally, two females focused on the significance of pregnancy. Lily (age 17, diagnosed at 16) said, "But it's nice that like, you know that it's from you. Like you went through the whole process of the pregnancy, of the birth, of the growth from zero." Similarly, Einav (age 18, diagnosed at 14) said, "I believe that to be a mother to a biological child that's yours, it, it's a powerful experience. The pregnancy, the labor, everything. Ehm, but it's clear to me that if I can't have children then I will have children in another way."

Parent responses regarding the importance of genetic relatedness between their child and possible grandchildren also ran the gamut from strong preference (n = 10) to simple preference (n = 3) to ambivalence (n = 4) (see Table 2). (Two interviewed mothers did not directly address this question.) A third of cases (5/15) where both adolescent and parent(s) were interviewed indicated matching responses. Three cases of adolescent strong preference corresponded to their parent's strong preference and two cases of adolescent ambivalence corresponded to their parent's ambivalence. There was no correspondence in simple preference between parents and adolescents.

**Table 2: Parent responses regarding importance of genetic relatedness between their child and possible future grandchild(ren)**

Strong Preference	Simple Preference	Ambivalence
<p>Interviewer: And when you were deciding to save his fertility, how important was it for you that he would have genetic children?            Ms. Boaz (mother of Alon, who was not interviewed): Very important. Of course. Yes.</p>	<p>Ms. Levy (mother of Gila): I am more concerned that I want that my daughter will give birth to children as compared to one day I will have to tell her, "OK. You need to adopt children."</p>	<p>Ms. Stein (mother of Rachel): Because I know that also if the worst case, there are always options. There always are...If she will get married and...this...it's possible. I can also donate an egg or someone could...            Interviewer: And when you decided to save Rachel's fertility, how important was it for you that her children would be genetic? You said that it's very important to her that –            Ms. Stein: To her. For me, it wasn't so important.</p>

<p>Ms. Katz (mother of Dalia): Yes. Eh, 100% it was important for me.</p>	<p>Ms. Paz (mother of Maya, who was not interviewed): Look, I would prefer that it would be surrogacy. Interviewer: OK. Ms. Paz: And not adoption. I would prefer that it would be something of hers. But again, I say, in case she won't be able to raise, I know that, if there are eggs and she will have...also if she won't have a husband, she can fulfill this dream and to be a mother. Of her own.</p>	<p>Ms. Dagan (mother of Tomer): The main thing that he will have a child. What does it matter-. First of all, first of all, it's the health. That's the first thing – that he'll get better. Afterwards, if it does not go in this way, then there's always the other options. It's good that there are the other options.</p>
<p>Interviewer: And when you were before the decision to freeze Ofer's sperm, how important was it for you that he will have genetic children, made from his sperm? Mr. Peretz (father of Ofer): Yes. Ms. Peretz (mother of Ofer): Very.</p>	<p>Ms. Kalir (mother of Ze'ev): Obviously, every mother wants that it will be her genes. Obviously. Everyone. And if it exists with my son. Just and what...we'll take my son. Actually, we're talking about him. So, I will be happy. But, Heaven forbid, Heaven forbid, and it's not...I don't have any problem that he'll turn to other places so that he'll have a home. Home, I mean children and such.</p>	<p>Interviewer: Ah...and how important was it for you, when you were deciding to preserve her eggs, that she will have genetic children? Ms. Tenenbaum (mother of Lily): For me, it's not so important. Interviewer: OK. Ms. Tenenbaum: I told you. Also, it's not important for me. Really not. If she will decide, after all, not to use these eggs at all – for me, it's completely alright.</p>
<p>Mr. and Ms. Cohen (parents of Tamara): It's important. Ms. Cohen: It's important also that she's healthy. Mr. Cohen: Very important. Ms. Cohen: And also...[clicks tongue] It's [chuckles], it's our essence. What do you mean? It's important that she will have a continuation. Very important. Of course. Because of this, also...</p>		<p>Mr. Barzilai (father of Einav): Like, it wasn't on my mind on the level that it's very important for me that I will pass down my genes, like you know that it's something that's eh such. I didn't think of it at this level. But I did think of it that Einav will want for it to happen.</p>
<p>Ms. Portman (mother of David): One hundred percent, it's important. Of course. Mr. Portman (father of David): Very important. Ms. Portman: Clearly it's important.</p>		
<p>Ms. Mizrachi (mother of Idan): Very important. Very important that...that he'll have biological children, at all, of his own. It's, I think, one of the important things, as far as I'm concerned, as his mother. I think also for his father, that he'll have biological children of his own. Because, because to experience it, that you have a biological child of your own, it's not like you experience that you have a child that's not yours, or child that goes through a different process, eh, like...</p>		
<p>Interviewer: Ah, how important was it for you – or still important for you, today – that Anna will have children made of her eggs? Ms. Biton (mother of Anna, who was not interviewed): Very.</p>		
<p>Ms. Abrami (mother of Avi): Very important for me that it will be his children and not...like to take sperm from someone else.</p>		
<p>Ms. Talby (mother of Gadi, who was not interviewed): Very important. Interviewer: That he will have children made of his sperm. Ms. Talby: The most important. It's the most important in the world.</p>		

<p>Interviewer: And when you were facing the decision about saving the tissue, how important was it for you that Irit will have children made of her eggs?  Ms. Bloch (mother of Irit): Very.  Interviewer: Can you explain to me why and how much?  Ms. Bloch: Because it-, the more that the thing is more natural and normal and regular, like this you want it more.</p>		
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Parents offered a variety of reasons for preferring genetic relatedness. Similar to adolescents, some parents appealed to “nature” as their rationale for their preference. Ms. Paz (mother of Maya, who was not interviewed) said, “Of course that if it was in a natural way, it would be preferable.” Ms. Bloch (mother of Irit) explained that “the more that the thing is more natural and normal and regular, like this you want it more.” Another reason is to attempt to normalize the adolescent. Ms. Boaz (mother of Alon, who was not interviewed) explained that even though her son has cancer, “it’s something that I want for all of my children. Eh – children, grandchildren. And from this aspect, he’s like everyone. Exactly what I want for his siblings, I want also for him.” Ms. Peretz (mother of Ofer) said, “I think that everyone wants one of his own. It seems to me.” Ms. Abrami (mother of Avi) stated that since her son has already had difficulty in life (by having cancer), she does not want him to experience reproductive difficulties so that, “he won’t feel that he’s different from other people.” Yet another reason for the preference is the importance of knowing the (genetic) history of the children that one raises. Ms. Biton (mother of Anna, who was not interviewed), whose daughter did not undergo FP, said, “it’s very important to know – what is the history of the child.” Ms. Kalir (mother of Ze’ev) believed having a genetic link with one’s children is “[i]mportant, because I know that it’s the same genes.” Finally, one mother offered a metaphysical or possibly religious reason for the preference. Ms. Cohen (mother of Tamara) says, “it’s our essence. What do you mean? It’s important that she will have a continuation. Very important. Of course.”

Parents who expressed ambivalence over genetic relatedness focus on the variety of alternative ways to become a parent. Ms. Stein (mother of Rachel) said, “Because I know that also if the worst case, there are always options. There always are... If she will get married and...this...it’s possible. I can also donate an egg or someone could...” Similarly, Ms. Dagan (mother of Tomer) explained that if her son is unsuccessful at becoming a parent via coitus, “then there’s always the other options. It’s good that there are other options.” Ms. Tenenbaum (mother of Lily) admitted, “it’s not important for me. Really not. If she will decide, after all, not to use these eggs at all – for me, it’s completely alright.”

The salience of the pregnancy experience came up in responses from one mother who expressed a simple preference and a father who expressed ambivalence over genetic relatedness. Ms. Levy (mother of Gila), whose daughter did not undergo FP, said,

I think as a woman, yes, I did think of this, of experience. That I want her to have this experience. And there wouldn’t be a situation where she will sit with me in another 20 years, I don’t know. Really 20 or 15 years, and she’ll say to me how sad she is that she can’t give birth to children because we weren’t smart enough to check for her all the options. Eh, and yes, a motherly feeling arises in me that I said to myself that it’s an experience that created, defined me and I would want it for my daughter. Eh, it interested me...

Mr. Barzilai (father of Einav) acknowledged that when deciding on FP genetic relatedness was important,

More in the matter that she [daughter] – maybe, she, as a woman, will want to experience pregnancy, to experience labor. Eh, things like this that a woman, I assume, would want to experience. I’m not a woman, but I assume ... wants to experience eh things like this. Even that labor is not an easy thing, but ... I, at least, from what I hear and women that I talked with, they wouldn’t give up on this experience.

However, not all participants specifically considered the importance of genetic relatedness when making FP decisions. One female adolescent, Einav (age 18, diagnosed at 14), said, “I didn’t think of this at all.” Another female adolescent, Irit (age 17, diagnosed at 15), admitted, “I don’t remember. But I guess [giggles] it was important.” One mother, Ms. Paz (mother of Maya, who was not interviewed), shared, “I didn’t give it thought at that time.” Another mother, Ms. Portman (mother of David), acknowledged that while genetic relatedness is important, at the time of the decision, she did not think about genetics and whether her son will have children. One father, Mr. Barzilai (father of Einav), explained,

It wasn’t on my mind at the same moment, but it was important. Like, it wasn’t on my mind on the level that it’s very important for me that I will pass down my genes, like you know that it’s something that’s eh such. I didn’t think of it at this level. But I did think of it that Einav [daughter] will want for it to happen.

## Alternative parenting options

Awareness of alternative parenting options – i.e., other than via coitus<sup>2</sup> – was widespread among participants. When asked if they were aware of other ways to become a parent, all adolescents except for one female, Leena (age 17, diagnosed at 13), and one male, Avi (age 15, diagnosed at 13), answered in the affirmative. Another female, Na'amah (age 19, diagnosed at 15), said, "I know that there are treatments. But I don't know what it is and I also don't want to know." She further added, "With the Lord's help, I will also not need to know it." All parents, except two mothers, Ms. Talby (mother of Gadi, who was not interviewed) and Ms. Hadad (mother of Leena), said they know of alternative parenting options. Study participants claimed they gained this knowledge via media, specifically newspapers, television, and internet. Adolescents knew of methods involving assisted reproductive technologies (ARTs), such as (primarily) in vitro fertilization (IVF), surrogacy, and (to a lesser extent) donor gametes, as well as the possibility of adoption. Parents' had similar knowledge, however with greater awareness of donor gametes and one mother, Ms. Mizrachi (mother of Idan), mentioning fostering.

Participants had little recall of physicians discussing alternative parenting options prior to or during FP decision making. When asked whether such options were discussed with them, all interviewed adolescents answered in the negative except for one female adolescent, Lily (age 17, diagnosed at 16), who seemed to remember either her physicians or parents explaining them to her. She added, "I also, like, know beforehand, what it is." None of the interviewed parents recollected physicians discussing alternative parenting options except for Ms. Katz (mother of Dalia), who says the topic arose. One mother, Ms. Tenenbaum (mother of Lily), asserted that she doesn't think physicians needed to talk to her about this, adding, "Of course that there are other ways. Everyone knows what are the other ways."

### Advantages

Participants who expressed a preference for genetic relatedness as well as those who are ambivalent regarding it claim that there are advantages to alternative parenting options. Generally, the main advantage that adolescents see with these options is that they benefit those who want to be parents but can't via coitus. Ze'ev (age 18, diagnosed at 16) believed "it's something that helps the people, in the case of need that they can't...do it. Another way." Lily (age 17, diagnosed at 16) stated, "There is a very clear advantage to it. That it gives children to those that can't have in the normal, bodily way." In talking about adoption, Gila (age 16, diagnosed at 14), who did not undergo FP, noted the benefit it has for the child, saying that it gives "a home to someone who, like, it's not certain that there's a home he could have." Ofer (age 15, diagnosed at 14) waxed a bit more than other adolescents on the topic of alternative parenting options, sharing,

I think that, as long as you have a child, it doesn't matter. Like if he is yours, you adopted him. Also, if it's a test tube child, it really doesn't matter. Like, it's just they took from the man the sperm and from the woman the egg and created it simply. They inserted it into her stomach. It...it doesn't matter if it's a child like this or a child like that. It doesn't matter. For me it doesn't matter.

Like adolescents, parents noted alternative parenting options' benefits to potential parent(s) and children. Mr. Cohen (father of Tamara) felt "these ways are solutions for those who are in real distress that aren't able to bring children to the world." Specifically, with respect to adoption, Ms. Boaz (mother of Alon, who was not interviewed) said, "I think it's good for both cases. Also for the child itself, who is adopted, and also for the parent, who adopted." Ms. Katz (mother of Dalia) mused, "It looks to me awesome to adopt. Really. It looks to me awesome on the one hand, like to adopt. To do something great. Like, to take a child..."

### Disadvantages

Adolescents – both those who have a preference for and those ambivalent about genetic relatedness – named multiple disadvantages of alternative parenting options. The primary disadvantage adolescents saw with these methods is that it results in parenting a child that "is not hers/his." For example, Dalia (age 16, diagnosed at 15) claimed, "It's not you. It's not your children." Adolescents noted the absence of "nature" as another disadvantage with these options. Irit (age 17, diagnosed at 15) said, "That it's not something that's natural, of the body. That it's not something that's done in a natural way, that this is also what's healthier for the body." Ofer (age 15, diagnosed at 14) believed that "it's not a natural way that you bring a regular child to the world." He further added, "It's a lot of time. Maybe money. Eh, a lot of time – a lot of energy. It's difficult." In thinking about technologically assisted reproduction, Ze'ev (age 18, diagnosed at 16) wondered aloud, "maybe it really harms in the way of [creating the child], but only more in emotional terms." With respect to adoption, Einav (age 18, diagnosed at 14) focused on the lack of experiencing pregnancy. She said, "I think that the disadvantage in adoption is that I didn't have the child. That he's not biologically mine. But...I don't think that it needs to change something. Like...a child is a child and if he's mine then it doesn't matter how I had him."

Parents – both those who have a preference for and those ambivalent about genetic relatedness – also identified multiple disadvantages of alternative parenting options. Comparable to adolescent views of parenting a child that "is not theirs," Ms. Peretz (mother of Ofer) said, "Disadvantage is that it's not...your own meat. It's not yours. Like, it's yours, but eh... There's something magical in creating it." In a similar vein, Ms. Bloch (mother of Irit) claimed, "The disadvantages is that you want it to come in a natural and regular way. And that the genes of your child will come from you. That's to say, it's not children of

<sup>2</sup> We note that coitus is the "default" option within a heteronormative framework that takes fertility for granted until reproductive difficulties arise. Though infertility may be due to medical or social reasons, within a heteronormative framework it is most commonly defined as the inability of a heterosexual couple to get pregnant despite frequent, unprotected sex for at least a year.



someone else.” More often than adolescents, parents mentioned the difficulties associated with alternative parenting options – specifically the stress of fertility treatments and the bureaucracy of adoption. For example, Ms. Mizrachi (mother of Idan) said, “Fertilizations and such, I...also looks to me a little stressful...” Similarly, Ms. Dagan (mother of Tomer) stated,

(In vitro) fertilizations are difficult to undergo. You see eh...I think that...Life, if, if the partnership is really, really good, then you can get through it better. If the partnership is a little...it can a little bit destroy. Like, I have an example like this and an example like that. So...everything is dependent on that, I think.

With respect to adoption, Ms. Bloch (mother of Irit) noted the bureaucracy required and Ms. Paz (mother of Maya, who was not interviewed), who once pursued adopting a soldier said, “I saw what a procedure and what a story it is.” In considering adoption, Ms. Dagan (mother of Tomer) pondered about its effects on siblings within the family unit, saying “maybe it’s ... they’ll feel that it comes something at their cost or something like this, but...I don’t know.” Furthermore, Ms. Katz (mother of Dalia) contemplated the difference in adopting out of choice versus necessity. She explained,

Like a woman who wants to have a child and can’t. It sucks. Like...it’s terrible. It’s really difficult... So...it’s not simple. It’s not easy. [giggles] To adopt because it’s not possible to have. Maybe...as long as you have a choice in life. When it comes from choice...it’s different. But because you can’t have and you need, the purpose, then it’s difficult.

Ms. Katz describes adoption out of necessity as a situation that “sucks” and that is “difficult.” She suggests that adoption out of choice is “different,” which in this context would mean it could be a better experience. While she expresses these sentiments in general, and not specifically within the context of cancer survivorship, in the context of this study she is arguably trying to express a concern that without fertility preservation, cancer survivors may be forced to turn to adoption as a last resort if they wish to become parents, i.e., “out of necessity.” This, to her, is a worse situation than choosing to adopt a child regardless of fertility status.

## DISCUSSION

For those facing the prospect of diminished fertility as a result of cancer and/or its treatment, FP provides the potential to have genetically-related children. Considering the multiple options that exist today for people to become parents – either traditionally (e.g., via coitus, adoption, fostering) or with technological assistance (e.g., IVF, donor gametes, surrogacy) – this study tried to explore the implications of genetic relatedness for FP decision making. According to the findings described above, adolescent participants overwhelmingly prefer genetically-related children. Likewise, the majority of parents prefer for their child to have the possibility of a genetic link with potential grandchildren. It is thus not surprising that the majority of cases in this study (18/20) chose to use FP (19).

### The importance of genetic relatedness for study participants

In discussing reasons behind the preference for genetic relatedness, a number of interrelated issues came up. First and foremost is the concept of *nature*. Numerous adolescents and parents explained their preference for genetic relatedness as the result of the importance they accord to having a child in a *natural* way, with quotes such as: “that’s how nature is” or “it’s just natural.” Associated with the concept of *nature* is the notion of *normalcy*, as this use of the concept of *nature* might be conflated with a preference for what is perceived as *normal* conception and parenthood, or *normal* family relationships.<sup>3</sup> Adolescents and parents repeatedly claimed that *everyone* wants genetically-related children. Some parents’ responses indicated how protective they are of their children, not wanting them to feel different from their peers, especially due to cancer and/or its effects.

Entwined with the concepts of *nature* and *normalcy* is that of *personal identity*, or a sense of self, defined as the collective properties that define a person and make her/him distinguishable from others (21).<sup>4</sup> As Gayle Letherby notes, “dominant perceptions of what is ‘natural’, ‘normal’ and ‘proper’ can affect the sense of self, status and experience of those who do things differently” (22). Therefore, it is not surprising that one girl – Dalia (age 16, diagnosed at 15) – said she can only imagine herself having genetically-related children, since this is the norm. Such a specific relationship constitutes part of her personal identity.<sup>5</sup> Another qualitative study of adolescent and young adult cancer survivors from England, found that a desire to parent closely aligns with one’s sense of self (11). It is conceivable that in some cases, one’s personal identity is not only aligned with the general desire to parent, but more specifically with the desire to parent a genetically-related child, a stance that puts great weight on a genetic link as significant or valuable. Some authors dispute this idea (23,24) and others note that genetic relatedness can be just one aspect of a multifaceted parent-child relationship (25,26).

<sup>3</sup> Logically speaking, all that is natural is not necessarily normal (e.g., multiple conception, such as twins or triplets, can naturally occur but is not an average occurrence among humans) and all that is normal is not necessarily natural (e.g., in Western society, IVF has become a normalized means to conceive but remains unnatural in that fertilization of the egg occurs outside the body).

<sup>4</sup> It is perhaps not entirely surprising that matters of personal identity should come up in such discussions with adolescents, since Erik Erikson’s stages of psychosocial development indicate that they are in the midst of exploring personal values, beliefs, and goals in search of their sense of self, or personal identity.

<sup>5</sup> Though her comment may be construed as a reference to societal pressure to have genetically-related children, it indicates internalization of such external pressure so that it constitutes her conception of self.

A nuance that Ms. Katz raised regarding genetic relatedness and personal identity relates to the distinction between choice and necessity in having children via alternative parenting options, i.e., resorting to these options out of choice or because it is not possible to become a parent via coitus (27). When an individual cannot become a parent via coitus, s/he may need to come to terms with this reality and adapt to a new sense of self – that of infertility (28).

Another aspect related to personal identity is the formative nature of pregnancy and labor. As noted by Ms. Levy (mother of Gila), since these events shaped her, she hopes that her daughter will have the opportunity to experience them as well. Two female adolescents perceived pregnancy and labor as positive or powerful experiences that they wish to have. Such a desire may be innate (29), socially constructed (30), or both. While in principle pregnancy does not necessarily entail genetic relatedness to one's children, as in the case of donor eggs/embryos or gestational surrogacy, adolescents who choose FP prior to cancer treatment intend to use preserved gametes or reproductive organs/tissue themselves and become pregnant (19). Thus, for some female adolescents, FP is associated not just with genetic relatedness but also with the possibility of experiencing pregnancy and labor.

To put this finding in context, it is important to note that while pregnancy and labor may be desired experiences that can greatly contribute to the formation of some women's sense of self, they are not universally desired, and furthermore, their absence from one's life does not necessarily involve a great loss. First, parenthood may not be a goal desired by all. Second, parenthood can be achieved by various means, as noted above, and not all of them involve pregnancy, labor, or genetic relatedness. It is thus important to remember the role that cultural and societal values play in the construction of the desire for experiencing pregnancy and labor, as well as the desire for genetic relatedness. A critical stance with regards to these desires can help contextualize and deconstruct them, with a view to reducing the pressure individuals feel when they perceive these elements as indispensable in the formation of their adult sense of self.

### Views of non-genetic parenthood

Despite the preference for genetic relatedness, some adolescents and parents acknowledged the benefits of alternative parenting options. Participants noted that options involving ART provide opportunities for persons with compromised fertility to become parents. They also noted that traditional alternative paths to parenthood, such as adoption, provide a family to children in need. These advantages thus refer to the desires and needs of both parents and children.

However, overall, adolescents and parents in this study viewed the absence of genetic relatedness to children or grandchildren as a disadvantage. They conveyed a sense that in such scenarios something "natural" or "magical" is missing. Parents also noted the psychological duress associated with ART<sup>6</sup> and the bureaucratic difficulties associated with adoption, especially those who have already experienced cumbersome adoption procedures. It is worthwhile noting that stress, burden, and difficulties associated with ART and adoption can be reduced if appropriately addressed. For example, greater resources can be invested in psycho-social support for those undergoing ART and barriers to adoption can be reduced via systemic changes to policy. The preference for genetic relatedness thus needs to be understood within the broader context of existing alternatives. While these patients' desire to parent genetically related children can only be fulfilled via coitus or successful FP, in cases where this preference stems from a sense that alternatives are cumbersome, making the alternatives more accessible can be an important solution.

Participants also saw the absence of pregnancy and labor as a disadvantage of traditional alternative parenting options, such as adoption. Einav (age 18, diagnosed at 14), for example, was ambivalent regarding her desire for genetic relatedness, but saw the absence of pregnancy and labor as a disadvantage of adoption. Here again, female adolescents accorded importance to the experience of pregnancy. This illustrates the importance of oncofertility counselling that includes a detailed discussion of variable alternative parenting options that can address specific goals and needs. If the main concern is the desire to experience pregnancy, this can be achieved via donor eggs and does not require FP. These nuances ought to be explored with adolescents and their parents to ensure choices are based on their values.

This is all the more important in light of the finding that a minority of participants were not well informed regarding alternative parenting options and many had rather vague ideas influenced by the media. Additionally, knowledge levels among participants were not uniform. To enable all patients to make informed medical decisions, it is thus best for physicians to err on the side of caution and discuss alternative parenting options in addition to FP options with adolescent patients and their parents (31-34). Healthcare providers may not be qualified to have such discussions. It is therefore important to develop resources that can assist them and to train a professional within the team to carry out such discussions in a sensitive, nuanced, and comprehensive way (35).

### Contextualizing the findings – cultural background

The findings of this study should be understood within the context of Israeli culture, which puts an enormous emphasis on parenthood, and specifically on genetic relatedness. Israeli society is known for its pronatalist tendencies (36,37) and the dominant social discourse presents "motherhood as imminent, natural, and universally expected from all women" (16). This is

<sup>6</sup> Such comments speak to the desire for the "default" option of becoming a parent via coitus and the hope of not needing to use preserved gametes or reproductive tissue since becoming a parent via FP requires ART – specifically in vitro fertilization. Additionally, these comments may indicate that some participants overlook this requirement for successful utilization of FP.

of particular importance considering the communitarian character of Israeli society as “a society imbued with a high degree of collective consciousness, mutual concern, and interdependence” (15). In this communitarian context, parenthood is seen not just as an individual choice but rather also as answering a collective need (38). In such a heavy-handed social context, individuals are more sensitive to and concerned with being labeled as different.

### Contextualizing the findings – societal background

Marilyn Strathern argues that genetics often imply kinship, or at least the *natural*, and is thus a valorized form of kinship (39). However, such naturalization or valorization of genetics need not imply the devaluation of families that are not genetically related. With the various forms of family building that are available today, genetics should denote one possible kind of family relationship.

Additionally, the fact that laws have been set up to largely protect genetic relationships from government interference is due to social privilege rather than genetics (40). Laws can also (and in jurisdictions that lack them, should be implemented to) recognize and protect non-genetic family relationships. Appropriate legislation can help normalize non-genetic family relations. Furthermore, societal stigma of infertility can compound individual difficulties with possible identity adjustment to that of an infertile person (16,41-43). Therefore, the inclusion of social and psychological services in oncofertility discussions is crucial. There is still much that can be done to combat the stigma of infertility. Having healthcare professionals lead frank discussions about alternative parenting options is a good start.

### LIMITATIONS

The qualitative nature and participant demographics of this study limit the generalizability of its findings. Findings can be indicative of participant self-selection bias. The majority of participants were either secular or religious Jews. Israeli Arab perspectives are under-represented and Jewish orthodox perspectives are not present, as are cases of males foregoing FP. Additionally, as noted above, not all participants specifically considered the importance of genetic relatedness when making FP decisions. Furthermore, participants were not asked about their personal experience with individuals who are not genetically-related to their parents. It is unclear whether such experience or lack thereof may have influenced participants' responses. Finally, healthcare professionals were not interviewed and medical files were not reviewed for this study, omitting a third and relevant aspect of these discussions.

### CONCLUSION

Although it is clear from this study that the majority of adolescents preferred to have a genetic link with their future children and parents preferred to have a genetic link with their future grandchildren, some adolescents and parents felt ambivalent regarding this matter. To gain a more comprehensive understanding of this nuanced phenomenon, further research should strive to qualitatively investigate the importance of genetic relatedness in various cultural contexts, especially comparing communitarian societies with more individualistic ones. Additionally, it would be fruitful to explore what people believe is specifically desirable about genetic relatedness within a family.

Considering the finding of participants' preoccupation with being “normal” and Israel's communitarian character, as well as its pronatalist tendencies, it is essential for healthcare professionals to be culturally sensitive when counselling adolescent patients and their families regarding oncofertility. Patients are embedded within societal contexts. Individual values often reflect those of the society within which one resides. However, healthcare professionals must have frank discussions with their adolescent patients and their families to determine if that indeed is the case. Having a grasp of the cultural implications of oncofertility decisions enables healthcare professionals to assist patients in making decisions that best suit their individual goals and values.

Alongside culturally sensitive counselling, greater credence should be given to those who question the importance of genetic relatedness. While their voices may be significantly fewer than those of the majority, their viewpoints are no less valid. Additional opportunities should exist to discuss and challenge the dominant discourse of parenthood (specifically motherhood) in Israel, and elsewhere, especially in order to combat stigma. During oncofertility discussions, physicians should inquire about patients' specific values and reproductive interests.

These issues are complex and not always as straightforward as they first seem. Greater discussion about alternative parenting options is vital not only to assist in combating stigma, but also to inform patients of all the options that can enable them to become parents and may even aid them in understanding and voicing their own priorities. The inclusion of social and psychological services during oncofertility discussions is fundamental. Another issue to be included is the timing of these discussions. Parents of children diagnosed with cancer are in a stressed situation and might be unable to understand the long-term significance of FP decision making. Follow up fertility consultation at the end of treatment is warranted.

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None to declare

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