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FERTILITY PRESERVATION

Health care provider perceptions of fertility preservation barriers and challenges with transgender patients and families: qualitative responses to an international survey

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Abstract

Purpose To examine provider perceptions of practice behaviors and barriers related to fertility counseling, fertility preservation, and family building among transgender patients.

Methods Participants were medical and mental health professionals who treat adult and youth transgender patients. Recruitment occurred online and in person, via professional listservs for transgender professionals, conferences, and gender clinics. From August–November 2017, 110 participants representing nine countries responded to four open-ended questions included on a survey related to provider practice behaviors and perceived barriers to fertility counseling, fertility preservation, and family building with transgender patients. Thematic coding analysis was used to identify themes.

Results Multiple themes were identified including the following: access and cost issues; urgency for gender-affirming treatment; patient maturity and inability to make future-oriented decisions; and provider-related challenges pertaining to knowledge, role, and general lack of information in the nascent field of transgender reproductive health.

Conclusion(s) This study yielded insights into practice behaviors, challenges, and perceived barriers to fertility counseling with transgender individuals and can serve as a basis for intervention development to optimize clinical practices with this population.

Keywords Transgender · Fertility preservation · Fertility counseling · Gender-affirming hormones · Reproductive health · Qualitative research

Introduction

Fertility preservation (FP) has allowed a path to genetic parenthood for many patients undergoing gonadotoxic medical treatment. Established methods for FP include cryopreservation of sperm, oocytes, and embryos, and experimental methods include ovarian tissue and testicular tissue cryopreservation for pre-pubertal patients. FP and associated reproductive counseling are considered standard of care for adolescent and young adults (AYA) of reproductive age with cancer [1].

Most recently, FP has been extended beyond oncofertility to other patient populations at risk for future infertility, such as patients with autoimmune disorders requiring gonadotoxic therapy and patients with post-surgical subfertility [2]. Also,

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a clinical report recently published by the American Academy of Pediatrics offers guidance for providers working with pediatric patients who may experience infertility and or sexual health impacts from an array of congenital or acquired conditions [3]. Among those at risk for diminished fertility or infertility are transgender youth and adults pursuing gender-affirming medical/surgical interventions [4]. Transgender individuals assert a gender identity which is not aligned with their assigned sex at birth. Some transgender individuals choose to seek medical interventions, including gender-affirming hormone (GAH) treatment, to align their bodies with their affirmed gender identity. Though long-term effects of GAH treatments remain understudied, concerns have been raised about a potential negative impact on future fertility. For instance, one study suggests the effect of exogenous hormonal therapy on sperm could be irreversible [5]; this is as of yet unclear as research has indicated heterogeneity, with some transgender individuals maintaining normal spermatogenesis after varying lengths of self-reported GAH treatment [6, 7]. For individuals who were assigned female at birth, the literature is mixed regarding the impact on fertility from testosterone use, with some transgender men becoming pregnant and giving birth after taking testosterone for various amounts of time [8]. Other research suggests risks for symptoms similar to polycystic ovarian syndrome (PCOS) with long-term testosterone use; this is of concern as PCOS is associated with infertility [9, 10]. Given uncertainty regarding the impact of hormones on fertility, contraception is recommended for transgender individuals on GAH engaging in sex that could result in a pregnancy [11].

FP counseling is recommended by the World Professional Association of Transgender Health (WPATH), the American Society of Reproductive Medicine (ASRM), and the Endocrine Society for all patients prior to initiating any gonadotoxic gender-affirming medical/surgical interventions [12–14]. Yet, these organizations do not provide guidance on best practices for engaging in such counseling. This is important, as desire for parenthood is well documented among transgender adults [15–17]. For example, there are case studies of adult transgender men who underwent FP and had their partners carry pregnancies [18] and transgender women who have frozen sperm [19]. Nevertheless, recent studies suggest minimal levels of FP utilization in transgender youth [20, 21] which is concerning given the research suggesting some of these individuals may desire genetic children as adults [15, 22]. In one study of pediatric patients, 54% of transgender girls and 40% of transgender boys had no documented FP counseling upon chart review [23]. In another retrospective chart review of transgender youth presenting for GAH treatment, documented reasons for FP refusal included patient plans to adopt, disinterest in having children, expense, discomfort with masturbation, and concern about GAH initiation delay [20]. Similarly, another chart review study found many of the same concerns, but in addition, patients named treatment invasiveness and one mentioned a concern about being misgendered and/or mistreated by a sperm bank technician [21]. Both studies found less than 5% of individuals engaged in FP interventions despite documented counseling about fertility.

To date, research has not explored healthcare provider behaviors and perceptions regarding FP counseling with transgender patients. In drawing parallels to oncofertility, studies have shown gaps in provider knowledge and inconsistent practices of offering FP to AYA with cancer have resulted in low utilization [24], and that more standardized counseling results in higher FP rates [25, 26]. Thus, it is imperative to understand current practice behaviors and challenges for providers who are tasked with counseling transgender individuals and their families about fertility issues prior to medical treatments, especially given the risks in this population for future decisional regret regarding potentially irreversible choices. The current study adds to the literature by querying providers directly about their perceptions of fertility counseling, as a first step to informing the development of more specific guidelines and other clinician supports for those engaged in the treatment of transgender individuals. We examined qualitative responses derived from an international survey of healthcare providers treating pediatric and adult transgender patients, aiming to provide depth and nuance to the understanding of fertility counseling, fertility preservation, and family building among transgender individuals.

Materials and methods

Context

This study received exempt status by the Institutional Review Boards at Ann & Robert H. Lurie Children's Hospital of Chicago, Nationwide Children's Hospital, and Boston Children's Hospital. A team of researchers developed a survey with 46-quantitative items, including four qualitative items for healthcare providers of transgender patients [27]. Only qualitative data are examined in the present study. The four qualitative items asked open-ended questions for respondents to elaborate on practice behaviors, barriers, and a general open comments section in relation to the topic: (1) "Is there anything else you would like us to know regarding your practice behaviors related to fertility counseling/fertility preservation for your transgender patients and/or their parents/guardians?," (2) "Is there anything else you would like us to know regarding barriers to fertility counseling/fertility preservation for your transgender patients?," (3) "The most significant primary barrier to discussing fertility preservation with transgender patients is … Other, please specify:," and (4)"Is there anything else you would like to share about your thoughts on

fertility preservation or family building for transgender individuals?."

Study participants and recruitment

From August–November 2017, a survey link was disseminated via WPATH and three regional listservs of mental health clinicians (in New England and Chicago), to attendees of national/regional transgender health professional conferences, and emailed to the contact person listed on the Human Rights Campaign directory of gender-affirming pediatric healthcare providers and clinics and the Trans Health Clinics listed on Trans-Health.com. Paper surveys were administered at a workshop on ethical issues in transgender youth care at the 2017 annual meeting of the American Psychological Association, at the 2017 International Meeting of the Pediatric Endocrinology Society (PES) transgender health Special Interest Group (SIG), and at the 2017 Oncofertility Consortium meeting.

Eligibility was determined by two screening questions: whether respondents participated in the clinical care of adult transgender individuals, and/or pediatric transgender individuals. Respondents answering "no" to both questions were disqualified. Respondents answering positively to either or both of the questions were administered the survey.

Data analysis

Data were analyzed using inductive content analysis and the constant comparison method [28] and guided by quality standards for qualitative research [29–31]. We used thematic content analysis to characterize providers' responses to each question (practice behaviors, barriers, most significant barrier, and open comments) [32]. Open coding was applied to inductively identify themes within each question. Themes were considered if they represented a meaningful pattern in the data. Using an Excel file created from all responses and divided by the question to which it pertained, three coders (MS, AS, GQ) reviewed all responses and generated a list of potential codes, noting the strength of the pattern in the data (e.g., the majority, a few). Each code was refined via comparison and discussion, and reorganized into key themes and sub-themes until consensus was reached. Consistent with the iterative nature of qualitative inquiry, the analytic phases were repeated until all coding discrepancies were resolved and novel codes no longer emerged (i.e., saturation). Inter-rater reliability was calculated among the three initial coders by creating a numbered list of all comments within each of the four questions and identifying the numbers of times each coder had labeled/rated the comment as belonging with one of the finalized codes. The level of agreement between the three coders was 0.90 (kappa coefficient) [33]. A fourth coder (AT) reviewed and independently coded each response, and provided feedback and definitions for the coding scheme, which was refined and collapsed into final themes. Results are organized by key themes and sub-themes and exemplar quotes are used to further describe each theme. Summaries of each code and representative quotes are provided below.

Results

There were 255 respondents to the main survey who met eligibility criteria and 110 respondents (representing nine countries) provided comments to one or more of the open-ended questions in the survey. Participants represented four provider types: (1) physicians ($n = 44$), (2) psychologists ($n = 29$), (3) masters-level mental health providers ($n = 18$), and (4) advanced practice nurses/registered nurses/physician assistants ($n = 19$).

Four main themes were identified: fertility and contraception counseling practices, perceptions of role responsibility, perceptions of parental role in decision-making, and barriers. Within barriers, four sub-themes were identified: structural, medical intervention, patient-related, and provider-related barriers. Notably, themes regarding fertility and contraception counseling practices were primarily generated by medical providers, with only one relevant mental health provider comment identified. Otherwise, systematic differences were not found between medical and mental health provider responses; therefore, they are not presented separately.

Fertility and contraception counseling practices

Several adult and pediatric providers commented on awareness that puberty blockers and GAH could cause temporary or permanent infertility and noted they always discussed this risk with their patients:

> Impact on fertility and basic options discussed with every patient starting any medications.

However, these same providers noted that it was equally important to talk about the need for contraception, as neither treatment was a reliable form of birth control:

> If you have sperm egg sex, you can get or cause a pregnancy even if [on] gender affirming hormones.

> We also emphasize that [hormone replacement therapy] is NOT a method of [contraception] and that it is possible to get pregnant while on testosterone and to impregnate others while on estrogen.

A few providers noted discussions encompassing both fertility and contraception were challenging:

> I always find it difficult to talk about the potential decrease in fertility that may happen over time with testosterone

while impressing the importance of contraception use if involved with someone making sperm. These two seemingly opposite points are so important and can be difficult for me … to talk about at the same time with my patients.

Perceptions of role responsibility

Several providers discussed the differentiation of roles for providers from medical versus mental health disciplines with regard to fertility counseling, employing an interdisciplinary approach:

> As a psychologist, I am no expert on the complex medical issues surrounding transition and fertility. My role is to bring up the issue, refer them to a medical person well versed in the issues, and discuss their perceived options to help them make the most informed decision possible.

> I talk to the clients about their desires to have kids (bio and/or otherwise), tell them there are fertility considerations for [hormone replacement therapy], and refer them to a medical specialist to give them the specifics. As a [licensed clinical social worker] I am not qualified to tell them the medical specifics.

Other providers emphasized the important function of counseling:

> There have been instances where some of the patients admit that the area of fertility has not been given much thought until being introduced in our counseling session. Fertility is an important area to cover with these clients.

> I always encourage the patients to continue to engage in the discussion as a family and also with their mental health provider.

Perceptions of parental role in decision-making

Providers agreed on the importance of involving parents as an essential part of their child's FP decision-making process:

> I emphasize to the parents of adolescents the significance of their decision on their adolescent's future life.

> Fertility preservation is often, understandably, a much bigger concern for parents than it is for our minor patients; we work a lot with parents and teens on weighing the risks and benefits of preserving fertility with the risks and benefits of delaying treatment for gender dysphoria, given unique family and cultural backgrounds.

For several providers, parents' involvement in FP counseling offered the opportunity to discuss FP in more concrete terms with younger patients:

> In particular with my adolescent clients, I always attempt to promote an active conversation between the minor and their parents about how they feel as a family about the [minor's] reproductive future. For example, engage minor in considering how their parents may or may not feel about grandchildren.

> I always explore with parents their own fertility, hopes for children and how life would have been if they did not have children to ground them into being more open to either preserving, or being cautious about medical and or physical interventions.

Barriers to fertility preservation

Structural barriers For providers in the USA, an important structural barrier observed by the majority of respondents entailed costs of FP, both in terms of out of pocket costs and lack of insurance coverage in the USA:

> The ability for patients to meaningfully engage in the conversation about FP appears to me to be greatly influenced by their financial access to preservation care.

> We always hit a wall [because] FP is extremely expensive and families have a hard time figuring out how to balance that with their child's need to transition.

Respondents also noted that costs differed by assigned sex at birth:

> Sperm banking is cheaper than freezing eggs so for that reason I said that trans women have an 'easier' time preserving fertility than trans men.

Some participants from outside the USA noted that costs were less of an issue:

> From where I write, gamete storage for trans people is routinely funded.

> Across [my country] there are different funding agreements for FP which can affect the choices young people have.

Medical intervention barriers Some respondents observed that medical interventions differ based on assigned sex at birth;

they noted the process of FP is vastly different for birth-assigned males versus birth-assigned females:

> When I treat [male-to-female] patients who have FP insurance coverage or personal financial resources, I have had several who have delayed transition to sperm bank. I have had no [trans men] ask for further resources …

> The barrier differs based on [male-to-female] (often delay and money barriers) or [female-to-male] (invasive procedure, VERY expensive, and delay barriers).

Patient-related barriers: developmental stage, priorities, and desire for children Many providers reported that transgender youth (particularly in the early developmental years) denied a desire for biological children, and expressed concerns that these youth cannot fully comprehend their future parenting goals:

> With those under 18, almost always they are 100% sure that they do not want any children. They cannot always know what the next 20-30 years hold for them.

> … my biggest concern for the pediatric population is that they do not have the maturity to make such a major life-altering decision such as medical/surgical treatments that would render them sterile and incapable of having genetically related children after transition.

Providers for transgender youth indicated affirming gender identity may be a greater priority than FP for patients, in light of gender dysphoria (GD) and related issues:

> It can be important for youth to choose identity now over future fertility … at present, more persons have died/committed suicide from having their transgender identity denied than have over fertility issues. …

> … most transgender adolescents I've worked with seem to be firm in their belief that they do not want biological children (and it is unclear if this is an established belief or if it is influenced by not wanting to delay treatment).

However, providers who worked with adult patients noted they were often interested in pursuing FP to maintain reproductive options in the future:

> Rush to treat dysphoria can get in the way of thorough consideration. But mostly I find that my patients just get past those barriers and do it to check it off the list of things to do before starting hormones, knowing they want to keep their options for reproduction open.

Other providers noted discussion of FP may be overstated in light of shifting parental desire among the general youth population:

> More and more youth, both trans and cis, express zero interest in the stress and work of having children.

Providers observed patients often mentioning adoption as a desired option for family building, acknowledging a concern that youth may lack an understanding of the challenges:

> My patients generally aren't concerned about biological parenting and most often speak to adoption or other methods of parenting. Their understanding seems to be that adoption is easy.

> … They frequently say 'I'll just adopt' without having the first clue what that entails.

Many providers indicated patients or families do not want a referral to discuss fertility options:

> Families rarely want to see fertility specialists despite their availability.

There was an emphasis on meeting patients and families where they are in terms of desire for discussing fertility options, developmental age, or stage of transition:

> I use an informed consent model to help client's make [the] best choices with regard to future functioning.

> Again, there is no right answer for the client, just to have the conversation so that we all know this is where we we're at. When a client looks back, they know that on that day it was discussed and they made some active decisions that were right for them in that moment.

Some adult providers noted fertility discussions were at times irrelevant since fertility-related decisions had already been made by the time they encountered patients:

> Since I only see adults, most have already made decisions about fertility when I first seen [sic] them.

> All of my patients are living with HIV and most have already been on hormones before I see them, so I rarely am initiating therapy.

A number of providers commented on the need for continuous discussion over time, for both adult and pediatric patients:

> We can continue to discuss these needs as both your gender identity, and adult role and spouse or partner needs evolve over time …

Provider-related barriers: knowledge, research, and training

Several providers identified barriers related to personal knowledge gaps surrounding FP:

> I would like to have better information about fertility preservation. I have attended several WPATH trainings and still feel relatively uninformed.

> I am also much clearer on the potential for successful options for [male-to-female]. I would greatly benefit from more scholarly research in [female-to-male] fertility preservation best practices.

Providers noted the difficulty of counseling patients without research on FP outcomes:

> I did get a little info from our house endocrinologist, but even they admitted they were not super familiar with the issue.

> We offer this as an option but in reality none of us know how effective preservation is.

> Research on outcomes of fertility decisions may be helpful in discussing fertility options with teens, parents and adults.

One response suggested that some providers may believe that bringing up the topic again is inappropriate once a patient has declined:

> I've [heard] providers ask about fertility repeatedly even when the patient says they understand their options or do not want to have children. There is a lot of cissexist heterocentric bias involved in this interrogation.

Providers commented on the need for general guidelines in order to counsel patients more effectively:

> We need more information and resources for our community with regards to fertility preservation.

Discussion

This qualitative study highlights practice behaviors and concerns faced by providers who counsel transgender adults and youth on fertility as they contemplate gender-affirming interventions, which may have a deleterious impact on their future ability to have genetic children. The providers in our study represent a wide range of healthcare disciplines and locales internationally. Despite this diversity, robust and consistent themes were identified, particularly related to multiple barriers and challenges across a spectrum of considerations. These ranged from access and cost (structural), factors related to urgency for gender-affirming treatment, maturity, and ability to make future-oriented decisions among younger adolescents, and provider-related challenges pertaining to knowledge, role, and general lack of information in the nascent field of transgender reproductive health. Analyses of participant comments also yielded themes related to provider perceptions of transgender youths' parenting goals, including possible generational issues, such as a potential disagreement between transgender youth and their parents around pursing FP. Respondents noted that cisgender and transgender youth of the current generation may not be as strongly drawn to biological/genetic parenthood as in previous generations and that this may be especially true among gender diverse individuals where heteronormative values may not be widely held [34].

The cost of FP emerged as a profound barrier to undertaking fertility-sparing [34] options. Cost may be particularly prohibitive in countries such as the USA where there is limited or no financial assistance. In addition, regardless of financial limitations, FP interventions may be aversive to transitioning youth, and respondents frequently noted that both cost and invasiveness of FP interventions were more severe for birth-assigned females than birth-assigned males. Some have posited that low FP utilization in the transgender community may be due to emotional considerations around embodying another gender [35]. Armuand et al. found that some transgender men undergoing FP developed coping strategies to combat the distress of gender incongruence caused by halting GAH use and physical changes associated with hormonal stimulation for oocyte cryopreservation [36]. Importantly, this study took place in Sweden where transgender individuals do not have the same financial concerns related to pursuing FP as in the USA [37, 38].

Age and maturity of the patient were also important factors among the patient-related themes. This is consistent with other literature which highlights the difficulties in general of

counseling about fertility in pediatrics, when a condition has potential to detrimentally impact the ability to have genetic children, yet youth lack the vantage point of adults [3, 20, 39]. This complexity is especially salient with regard to the pre-adolescent child (as young as 8–9 years of age) at Tanner stage 2 who may present for gonadotropin-releasing hormone (GnRH) analogues to suppress puberty. If patients proceed to GAH intervention without progressing through their endogenous puberty, it may be particularly difficult or impossible to recover and/or preserve fertility in the future.

Respondents identified lack of information and the relatively recent advent of medical interventions for transgender individuals as significant hurdles. At this point in time, detailed guidelines for FP counseling in this population are unavailable, despite recommendations that such counseling take place [12–14, 40]. Guidelines addressing specific complexities, such as actual fertility risks of various GAH treatments, which FP options are appropriate and at what point in physical and emotional development, and optimal approaches to counseling by patient age and/or stage in the medical intervention process, would help to standardize counseling practice and give needed support to providers. The absence of this guidance is potentially another obstacle for providers who are motivated to appropriately counsel patients and families. It is possible that shared decision-making models (e.g., Ottawa Decision Support Framework) [41] could be adapted for use with transgender youth until decision aids are developed specifically for this population. Systematic research on the rate of decisional regret in transgender adults who experience infertility or subfertility is thus far not available. In the current study, many providers reported that their patients intend to adopt. Yet, research has not examined adoption experiences of transgender adults, and/or whether they experience biases or other obstacles secondary to their transgender identity.

Several expected barriers were not identified from qualitative responses. Only one provider mentioned suicide as a potential patient risk in the context of delaying GAH to engage in FP. No participants mentioned patient mental health considerations as an obstacle during the process of fertility counseling or as potentially impacting patient decisional processes. This is surprising, given that a recently published case report documented a transgender adolescent declining FP specifically due to concerns for worsening GD and mental health functioning [42]. Moreover, numerous studies show frequent co-occurring mental health concerns in transgender individuals seeking GAH intervention [43, 44]. In a chart review of 79 transgender youth, Nahata et al. found that 92.4% had been given a mental health diagnosis, including 74.7% with suicidal ideation, 55.7% with documented self-harming behaviors, and 30.4% with a history of an actual suicide attempt [45].

Mental health morbidities can negatively impact decision-making abilities. For instance, youth with suicidal ideation may struggle to contemplate future plans, and depression and anxiety associated with GD and gender-related discrimination [46] can be a distorting lens from which to forecast future desires. This can be a conundrum for transgender adolescents or adults, who may only be able to consider ultimate parenting goals after treatment for GD, when mental health concerns may subside, but fertility already impacted. Additionally, autism spectrum disorder (ASD) has been observed to frequently co-occur with GD [47, 48]. This co-occurrence recently has been questioned [49], although some experts in the area of gender diversity have observed that a number of studies have found increased clinical diagnoses of ASD in gender diverse individuals [50]. Patients with both GD and ASD present with multifaceted clinical challenges "given the social, adaptive, self-awareness, communication, and executive function complexities" characterizing ASD [51]. Others have discussed the complexities of obtaining informed assent from youth with developmental differences [52, 53]. Therefore, it is somewhat surprising that participants in this survey did not discuss some of the perceived difficulties of FP discussions with youth with neurodiversity. Such youth may be interested and adequately competent to be a parent, yet require adapted counseling and informed consent processes tailored to their needs.

We recognize a number of limitations to this study. Due to our recruitment strategy, we are unable to report a response rate. It is conceivable that providers who view FP as irrelevant or unimportant, or who lack knowledge about this subject, did not participate, yielding an unrepresentative group of providers. Participants were likely to be active on professional listservs, attend conferences, or be employed in one of the major gender centers in the USA, thus potentially yielding a skewed group of respondents who value the issue of FP and are more engaged in FP counseling than non-participating peers. Those seeking hormones in street markets or online, or youth without supportive family, are unlikely to receive care from providers represented in our study; thus, barriers to fertility care specific to high-risk transgender populations were most likely not represented. Finally, this paper reports on provider-perceived barriers to FP, which may or may not correspond with patient and/or family perceptions, important issues to address with continuing research.

To our knowledge, this is the first study to report on provider experiences, perceptions, and challenges regarding fertility counseling with their patients and corresponds to other research demonstrating a need for training in general for healthcare professionals with regard to transgender patient care. Prior studies have examined the perceived barriers for medical providers in the provision of healthcare in general for transgender patients, finding lack of training and/or knowledge to be an obstacle to care [54, 55]. Others have reported on the experiences of LGBTQ individuals seeking reproductive health care, as well as transgender adults already engaging in assisted reproduction services. For instance, Wingo et al.

found that LGBTQ individuals' assigned female at birth reported a number of barriers to accessing care, including perceived discrimination and inadequate provider competency in LGBTQ health care [56]. James-Abra et al. studied transgender adult reported experiences with assisted reproduction services, finding that some patients reported positive experiences (e.g., trans-friendly environments), while patient perceived barriers were also identified (e.g., problems with clinical documentation and challenges associated with provider heteronormative assumptions) [34]. Additionally, a number of articles have provided overviews of fertility options for transgender individuals and include some limited discussion of clinical and counseling complexities and considerations [57–59]. Yet, none of these authors empirically studied mental health and medical provider experiences with fertility counseling in transgender patients.

Our findings are significant in light of guidelines advising providers of transgender health care to counsel regarding the potential fertility impacts of intervention. This study highlights several key issues, including the following: the need for specific fertility-related training and resources for providers, an understanding that mental health and medical providers may serve different roles in counseling that should be delineated, and the need for guidance regarding ethical issues such as appropriate counseling practices when families are known not to have the financial resources to follow-through with FP interventions. It is likely that counseling transgender youth about fertility would differ somewhat from other pediatric populations, including patients counseled in the pediatric oncology context. The need for fertility counseling with transgender youth can sometimes be anticipated well in advance of medical intervention, thus allowing for more time for such counseling to take place, and patients are unlikely to be concerned about not surviving their medical treatment. Counseling transgender youth, unlike most cancer patients, would also need to take into consideration the nomenclature the youth uses for reproductive body parts and gametes. Further, although there are many cancer treatments that we know definitively will cause fertility impairment, the science is less certain for gender-affirming hormones. However, there are similarities from the oncofertility literature that would apply, including acknowledgement that the conversation could be embarrassing and recognizing the youth may not have ever stopped to consider whether they wanted genetic children. The American Academy of Pediatrics (AAP) has published general guidelines about fertility counseling in pediatrics that can be potentially helpful for providers working with transgender youth [3, 60],

The insights into perceived barriers and challenges to fertility counseling with transgender individuals reported in this study can inform future research which could ultimately serve as a basis for intervention development to optimize clinical practices with this population in general, as well as fertility counseling specifically. For instance, future studies can investigate transgender youth and adult perceptions of barriers and challenges; identify effective methods of providing fertility-related information to patients and families, including using single or multiple sessions, and online or written information in addition to verbally-imparted material; and determine whether having both medical and mental health providers engaged in counseling increases patient knowledge and satisfaction with the process.

Compliance with ethical standards

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

Informed consent This study was deemed exempt.

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References

1. Oktay K, et al. Fertility preservation in patients with cancer: ASCO clinical practice guideline update. J Clin Oncol. 2018;2018:78 1914.
2. Hirshfeld-Cytron J, Gracia C, Woodruff TK. Nonmalignant diseases and treatments associated with primary ovarian failure: an expanded role for fertility preservation. J Women's Health. 2011;20(10):1467–77.
3. Nahata L, Quinn GP, Tishelman AC. Counseling in pediatric populations at risk for infertility and/or sexual function concerns. Pediatrics. 2018;142(2):e20181435.
4. Wallace SA, Blough KL, Kondapalli LA. Fertility preservation in the transgender patient: expanding oncofertility care beyond cancer. Gynecol Endocrinol. 2014;30(12):868–871.
5. Leavy M, Trottmann M, Liedl B, Reese S, Stief C, Freitag B, et al. Effects of elevated β-estradiol levels on the functional morphology of the testis - new insights. Sci Rep. 2017;7:39931.
6. Jindarak S, Nilprapha K, Atikankul T, Angspatt A, Pungrasmi P, Iamphongsai S, et al. Spermatogenesis abnormalities following hormonal therapy in transwomen. Biomed Res Int. 2018;2018:**1**–**5**.
7. Schneider F, Neuhaus N, Wistuba J, Zitzmann M, Heß J, Mahler D, et al. Testicular functions and clinical characterization of patients with gender dysphoria (GD) undergoing sex reassignment surgery (SRS). J Sex Med. 2015;12(11):2190–200.
8. Light AD, Obedin-Maliver J, Sevelius JM, Kerns JL. Transgender men who experienced pregnancy after female-to-male gender transitioning. Obstet Gynecol. 2014;124(6):1120–7.
9. Baba T, Endo T, Honnma H, Kitajima Y, Hayashi T, Ikeda H, et al. Association between polycystic ovary syndrome and female-to-male transsexuality. Hum Reprod. 2007;22(4):1011–6.
10. Caanen MR, Soleman RS, Kuijper EAM, Kreukels BPC, de Roo C, Tilleman K, et al. Antimullerian hormone levels decrease in female-to-male transsexuals using testosterone as cross-sex therapy. Fertil Steril. 2015;103(5):1340–5.
11. Schneider F, Kliesch S, Schlatt S, Neuhaus N. Andrology of male-to-female transsexuals: influence of cross-sex hormone therapy on testicular function. Andrology. 2017;5(5):873–80.
12. Hembree WC, Cohen-Kettenis PT, Gooren L, Hannema SE, Meyer WJ, Murad MH, et al. Endocrine treatment of gender-dysphoric/gender-incongruent persons: an Endocrine Society clinical practice guideline. J Clin Endocrinol Metab. 2017;102(11):3869–903.

13. ASRM. Access to fertility services by transgender persons: an ethics committee opinion. Fertil Steril. 2015;104(5):1111–5.
14. Colebunders B, De Cuypere G, Monstrey S. New criteria for sex reassignment surgery: WPATH standards of care, version 7, *Revisited*. *Inte J Transgenderism*. 2015;16(4):222–33.
15. Wierckx K, van Caenegem E, Pennings G, Elaut E, Dedecker D, van de Peer F, et al. Reproductive wish in transsexual men. Hum Reprod. 2011;27(2):483–7.
16. Tornello SL, Bos H. Parenting intentions among transgender individuals. LGBT Health. 2017;4(2):115–20.
17. Auer MK, Fuss J, Nieder TO, Briken P, Biedermann SV, Stalla GK, et al. Desire to have children among transgender people in Germany: a cross-sectional multi-center study. J Sex Med. 2018;15(5):757–67.
18. Maxwell S, Noyes N, Keefe D, Berkeley AS, Goldman KN. Pregnancy outcomes after fertility preservation in transgender men. Obstet Gynecol. 2017;129(6):1031–4.
19. Wierckx K, Stuyver I, Weyers S, Hamada A, Agarwal A, de Sutter P, et al. Sperm freezing in transsexual women. Arch Sex Behav. 2012;41(5):1069–71.
20. Nahata L, Tishelman AC, Caltabellotta NM, Quinn GP. Low fertility preservation utilization among transgender youth. J Adolesc Health. 2017;61(1):40–4.
21. Chen D, Simons L, Johnson EK, Lockart BA, Finlayson C. Fertility preservation for transgender adolescents. J Adolesc Health. 2017;61(1):120–3.
22. Pfäfflin F, et al. The desire to have children and the preservation of fertility in transsexual women: a survey. Inte J Transgenderism. 2002;6(3):97–03.
23. Schelble AP, Fisher AR, Jungheim E, Lewis C, Omurtag K. Fertility preservation (FP) referral and follow-up in male-to-female (MTF) and female-to-male (FTM) transgender patients. Fertil Steril. 2017;108(3):e115–6.
24. Flink DM, Sheeder J, Kondapalli LA. A review of the oncology patient's challenges for utilizing fertility preservation services. J Adolesc Young Adult Oncol. 2017;6(1):31–44.
25. Klosky JL, Anderson LE, Russell KM, Huang L, Zhang H, Schover LR, et al. Provider influences on sperm banking outcomes among adolescent males newly diagnosed with cancer. J Adolesc Health. 2017;60(3):277–83.
26. Shnorhavorian M, Kroon L, Jeffries H, Johnson R. Creating a standardized process to offer the standard of care: continuous process improvement methodology is associated with increased rates of sperm cryopreservation among adolescent and young adult males with cancer. J Pediatr Hematol Oncol. 2012;34(8):e315–9.
27. Chen D, Kolbuck VD, Sutter ME, Tishelman AC, Quinn GP, Nahata L. Knowledge, practice behaviors, and perceived barriers to fertility care among providers of transgender healthcare. J Adolesc Health. 2018;0(0).
28. Glaser BG. The constant comparative method of qualitative analysis. Soc Probl. 1965;12(4):436–45.
29. Levitt HM, Bamberg M, Creswell JW, Frost DM, Josselson R, Suárez-Orozco C. Journal article reporting standards for qualitative primary, qualitative meta-analytic, and mixed methods research in psychology: the APA publications and communications board task force report. Am Psychol. 2018;73(1):26–46.
30. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care. 2007;19(6):349–57.
31. Wu YP, Thompson D, Aroian KJ, McQuaid EL, Deatrick JA. Commentary: writing and evaluating qualitative research reports. J Pediatr Psychol. 2016;41(5):493–505.
32. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006;3(2):77–101.
33. Hallgren KA. Computing inter-rater reliability for observational data: an overview and tutorial. Tutor Quant Methods Psychol. 2012;8(1):23–34.
34. James-Abra S, Tarasoff LA, green, Epstein R, Anderson S, Marvel S, et al. Trans people's experiences with assisted reproduction services: a qualitative study. Hum Reprod. 2015;30(6):1365–74.
35. Mitu K. Transgender reproductive choice and fertility preservation. AMA J Ethics. 2016;18(11):1120.
36. Armuand G, Dhejne C, Olofsson JI, Rodriguez-Wallberg KA. Transgender men's experiences of fertility preservation: a qualitative study. Hum Reprod. 2017;32(2):383–90.
37. Jones CA, Reiter L, Greenblatt E. Fertility preservation in transgender patients. Inte J Transgenderism. 2016;17(2):76–82.
38. Abern L, Maguire K, Diego D, Wong A. Contraceptive use and fertility preservation among transgender individuals: are we doing enough? Fertil Steril. 2017;108(3):e115.
39. Patterson P, McDonald FEJ, Zebrack B, Medlow S. Emerging issues among adolescent and young adult cancer survivors. Semin Oncol Nurs. 2015;31(1):53–59.
40. Coleman E, Bockting W, Botzer M, Cohen-Kettenis P, DeCuypere G, Feldman J, et al. Standards of Care for the Health of transsexual, transgender, and gender-nonconforming people, version 7. Inte J Transgenderism. 2012;13(4):165–232.
41. O'Connor, A., D. Stacey, and M. Jacobsen, Ottawa decision support tutorial: improving practitioners' decision support skills Ottawa Hospital Research Institute: patient decision aids; 2011. Disponible en ligne: https://decisionaid.ohri.ca/ODST/pdfs/ODST pdf, 2014.
42. Chen D, Simons L. Ethical considerations in fertility preservation for transgender youth: a case illustration. Clinical Pract Pediatric Psychol. 2018;6(1):93–100.
43. Olson J, Schrager SM, Belzer M, Simons LK, Clark LF. Baseline physiologic and psychosocial characteristics of transgender youth seeking care for gender dysphoria. J Adolesc Health. 2015;57(4):374–80.
44. Grossman AH, D'augelli AR. Transgender youth and life-threatening behaviors. Suicide Life Threat Behav. 2007;37(5):527–37.
45. Nahata L, Quinn GP, Caltabellotta NM, Tishelman AC. Mental health concerns and insurance denials among transgender adolescents. LGBT Health. 2017;4(3):188–93.
46. Testa RJ, Michaels MS, Bliss W, Rogers ML, Balsam KF, Joiner T. Suicidal ideation in transgender people: gender minority stress and interpersonal theory factors. J Abnorm Psychol. 2017;126(1):125–36.
47. De Vries AL, et al. Autism spectrum disorders in gender dysphoric children and adolescents. J Autism Dev Disord. 2010;40(8):930–6.
48. Shumer DE, Reisner SL, Edwards-Leeper L, Tishelman A. Evaluation of Asperger syndrome in youth presenting to a gender dysphoria clinic. LGBT Health. 2016;3(5):387–90.
49. Turban JL, van Schalkwyk GI. "Gender dysphoria" and autism spectrum disorder: is the link real? J Am Acad Child Adolesc Psychiatry. 2018;**57**(1):8–9 e2.
50. Strang JF, Janssen A, Tishelman A, Leibowitz SF, Kenworthy L, McGuire JK, et al. Revisiting the link: evidence of the rates of autism in studies of gender diverse individuals. J Am Acad Child Adolesc Psychiatry. 2018;57(11):885–7.
51. Strang JF, Meagher H, Kenworthy L, de Vries ALC, Menvielle E, Leibowitz S, et al. Initial clinical guidelines for co-occurring autism spectrum disorder and gender dysphoria or incongruence in adolescents. J Clin Child Adolesc Psychol. 2018;47(1):105–15.
52. Imam B, Chulani VL. Consent and assent in adolescents with gender dysphoria and developmental disabilities. J Pediatr Adolesc Gynecol. 2018;31(2):180–2.
53. Shumer DE, Tishelman AC. The role of assent in the treatment of transgender adolescents. Inte J Transgenderism. 2015;16(2):97–102.

54. Snelgrove, J.W., et al., "*Completely out-at-sea*" *with* "*two-gender medicine*"*: a qualitative analysis of physician-side barriers to providing healthcare for transgender patients.* BMC Health Services Research, 2012. **12**(1): p. 110.
55. Vance SR Jr, Halpern-Felsher BL, Rosenthal SM. Health care providers' comfort with and barriers to care of transgender youth. J Adolesc Health. 2015;56(2):251–3.
56. Wingo E, Ingraham N, Roberts SCM. Reproductive health care priorities and barriers to effective care for LGBTQ people assigned female at birth: a qualitative study. Womens Health Issues. 2018;28(4):350–7.
57. De Roo C, et al. Fertility options in transgender people. Int Rev Psychiatry. 2016;28(1):112–9.
58. Mattawanon N, Spencer JB, Schirmer DA, Tangpricha V. Fertility preservation options in transgender people: a review. Rev Endocr Metab Disord. 2018;19(3):231–42.
59. Nahata L, Chen D, Moravek MB, Quinn GP, Sutter ME, Taylor J, et al. Understudied and under-reported: fertility issues in transgender youth—a narrative review. J Pediatr. 2018. https://doi.org/10.1016/j.jpeds.2018.09.009.
60. Shnorhavorian M, Harlan LC, Smith AW, Keegan THM, Lynch CF, Prasad PK, et al. Fertility preservation knowledge, counseling, and actions among adolescent and young adult patients with cancer: a population-based study. Cancer. 2015;121(19):3499–506.