Assessing Barriers for Fertility Preservation Among Transgender Youth: Insurance, Costs, and State-Specific Policies

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Culminating Experience Paper

In Partial Fulfillment of the Requirements of the Joint PhD/MPH Program in Medical Anthropology

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Abstract

Increasingly, children, adolescents and young adults with a diagnosis of gender dysphoria are presenting for care desiring medical interventions to align their bodies and gender identities. For patients for whom pubertal development has progressed to Tanner stage 4 or 5, interventions include treatment with testosterone for birth-assigned males and estrogen for birth-assigned females. For younger children, puberty "blockers" can delay unwanted physical maturation until a decision is made about either stopping blockers and progressing through their endogenous puberty or initiating gender-affirming hormone treatment. These gender-affirming treatments may compromise gonadal function leading to infertility or biological sterility. Fertility preservation (egg and sperm "freezing") prior to gender-affirming hormone treatment offers youth pursuing these treatments options for future biological parenthood. This paper begins with an overview of currently available medical treatments and the costs for procedures in this unique population. Subsequently, a review of both state and federal insurance coverage policies regarding fertility preservation and other fertility care procedures is offered, focusing specifically on the case studies of Illinois, Connecticut, and Rhode Island where recent changes in state insurance codes have expanded coverage for these medical services. Finally, the paper provides an analysis and discussion of relevant qualitative interview data from the Trans Youth Fertility Study (TYFS), an ongoing project using qualitative interviews with transgender youth and parents to investigate their experiences with navigating medical insurance and costs associated with fertility preservation.

Introduction

Increasingly, children and adolescents and young adults (AYA) with a diagnosis of gender dysphoria[1] are presenting for care desiring medical interventions to align their bodies and gender identities at younger ages. The medical needs of gender-diverse and transgender (i.e. trans) youth and children are evolving. Available interventions depend on age and pubertal status along with individualized desires and goals for gender transition; an adolescent's psychological functioning and readiness for interventions typically informs what care is offered. Treatment with testosterone for birth-assigned males and estrogen for birth-assigned females is indicated for patients for whom development has progressed into later stages of puberty (Tanner IV or V; See Tanner Stages below).[2] With support from a parent or guardian, transgender youth can now access medically-supported gender-affirming hormone treatment and some surgeries during adolescence.[3,4]

Figure 1. Tanner Stages of Puberty (Male & Female) [5]

	Breast	Pubic Hair	Genitals	Pubic Hair
Stage 1	Small nipples. No breast.	No pubic hair.	No signs of puberty. Scrotum, testes, and penis as in childhood.	No pubic hair.
Stage 2	Breast and nipples have just started to grow. The areola has become larger. Breast tissue bud feels firm behind the nipple.	Initial growth of long pubic hairs. These are straight, without curls, and of light color.	Initial growth of scrotum and testes. The skin on the scrotum has become redder, thinner, and more wrinkled. The penis may have grown a little in length.	Few hairs around the root of the penis. The hairs are straight, without curls, an of light color.
Stage 3	Breast and nipples have grown additionally. The areola has become darker. The breast tissue bud is larger.	The pubic hair is more widespread. The hair is darker, and curls may have appeared.	The penis has now grown in length. Scrotum and testes have grown. The skin of the scrotum has become darker and more wrinkled.	Hairs are darker and curlier and still sparse, mostly located at the penis root.
Stage 4	Nipples and areolas are elevated and form an edge towards the breast. The breast has also grown a little larger.	More dense hair growth with curls and dark hair. Still not entirely as an adult woman.	The penis has grown in both length and width. The head of the penis has become larger. The scrotum and testes have grown.	More dense, curly, and dark hair. The hair growth is reaching the inner thighs.
Stage 5	Fully developed breast. Nipples are protruding, and the edge between areola and breast has disappeared.	Adult hair growth. Dense, curly hair extending towards the inner thighs.	Penis and scrotum as an adult.	Pubic hair extends upwards to the umbilicus. It is dense and curly.

Access to comprehensive gender affirming care is still limited in the United States, but research suggests gender-affirming hormone treatment can impair gonadal function leading to infertility or biological sterility.[6,2] Longer-term exposure to exogenous hormones, which is common in ongoing hormone treatment for gender dysphoria, almost certainly negatively impacts fertility and reproductive functioning.[7–9] In the case of peri-pubertal youth (Tanner Stages II or III), current clinical practice guidelines recommend pubertal suppression treatment using gonadotropin releasing hormone analogues (GnRHa) to alleviate the psychological distress of anticipated, unwanted physical maturation characteristic of the child's birth-assigned sex. [10–12] These "puberty blockers" are considered a reversible intervention that suppresses sex hormone production and prevents pubertal changes insofar as puberty resumes normally upon discontinuation of GnRHa. [10–12]

While the use of puberty blockers has revolutionized treatment for transgender youth, allowing them more time to consider whether to progress through their endogenous puberty or that of an affirmed gender with gender-affirming testosterone or estrogen, these medications also suspend germ cell (i.e. precursor to egg and sperm) maturation. Treatment with blockers is reversible, and full sexual maturation will occur if youth discontinue these medications; however, for transgender youth, progressing through endogenous puberty would bring upon undesired physical changes. Thus, the majority of transgender youth initiate gender-affirming hormone treatment (i.e. testosterone for birth-assigned females, estrogen for birth-assigned males) following a period of pubertal suppression treatment, and germ cells do not mature, compromising options for biological parenthood. [13–15] Albeit limited, an expanding body of research suggests that transgender adults do desire biological children;[16–19] similarly, studies on adult survivors of childhood cancers who were not given or did not pursue fertility preservation options indicate regret in some instances about being unable to have biological children.[20] Given the fertility risks associated with both puberty blockers and hormone treatment, the World

Professional Association of Transgender Health (WPATH), the Endocrine Society, and the American Society of Reproductive Medicine (ASRM), while supporting the use of gender-affirming hormones, all recommend patients receive counseling regarding the potential loss of fertility and future reproductive options prior to initiating treatment. [2,21,22]

Currently Available Fertility Preservation Procedures

Post-Pubertal Adolescents

Deregulated gamete cryopreservation (egg/sperm "freezing") offers youth pursuing gender-affirming hormone treatment fertility preservation options. Sperm cryopreservation technologies are more than fifty years old, [23] but it was not until 2012 that the American Society for Reproductive Medicine recommended oocyte cryopreservation (i.e. egg freezing) be reclassified as an elective procedure following the development of quick-freeze "vitrification" for harvested eggs.[24] Expanding access to oocyte cryopreservation also generated new and diverse patient populations desiring egg freezing, ranging from younger women hoping to delay motherhood to cancer patients undergoing fertility-compromising treatments to transgender individuals and those with differences/disorders of sexual development that affect fertility. [25–28] Legal and ethical regulations in the United States for these new users of gamete cryopreservation technologies and other downstream reproductive technologies including *in vitro* fertilization have evolved, and the need for insurance coverage for treatment has also become increasingly recognized by state governments[29].

Pre-Pubertal Children

For minors, particularly young children who may not be able to fully participate in decision-making or understand treatment effects on fertility, parents are largely responsible for making medical decisions that can affect their child's future potential to have biological children. Further complicating the decision-making process, potential fertility preservation options,

including experimental and at present unproven methods of storing pre- and peri-pubertal children's reproductive tissues or cells for future use, are rapidly changing.

For peri-pubertal children beginning blockers, the only current option would be experimental testicular or ovarian tissue preservation[30,31] with the expectation that this tissue may be useful for deriving mature sperm and oocytes, respectively [32–34]. These techniques are still considered investigational by the ASRM, as limited peer-reviewed research on their safety and effectiveness has been published. Access to these technologies is only available if a child meets criteria for an approved study investigating the technique at an accredited medical center with oversight from an institutional review board. These centers may not be in the same city or even state where a child is receiving gender-related care, and in many cases surgery to remove tissue would be considered unnecessarily invasive without a concurrent diagnosis requiring surgery as with certain cancer treatment protocols.

Ovarian tissue cryopreservation can preserve thousands of primordial (undeveloped) ovarian follicles rather than the limited number of oocytes that can be retrieved using stimulation of the mature ovary post-puberty. [35] For individuals whose ovaries remain intact, such as women undergoing certain types of cancer treatments, cortical ovarian tissue can be transplanted or grafted near the remaining ovary (a pelvic or orthotopic graft) or to an extrapelvic site such as the forearm or abdominal wall (heterotopic graft) [31]. With orthotopic grafts, some women have resumed ovulatory menstrual cycles [31]; in the case of heterotopic grafts, mature oocytes must be retrieved for *in vitro* fertilization. As of 2015, at least 35 live births have occurred after transplantation of cryopreserved ovarian tissue in adult patients, and at least one instance of a live birth using ovarian tissue harvested at a pre-pubertal age. [36,37] The success of these procedures has only been documented in cisgender women, predominantly cancer patients who retained some portion of their reproductive organs and had not been exposed to any exogenous hormones. Viability of grafts may be limited in transgender adults who undergo elective

oophorectomy and/or hysterectomy or whose ovaries are compromised by exposure to gender-affirming hormones. [7,8,38] Research on *in vitro* maturation cultures for preserved immature human ovarian follicles is active, although these bio-engineered culture systems have yet to produce a mature oocyte viable for fertilization in humans.[39–41] These evolving, investigational alternatives may offer viable fertility preservation option for transgender children who have not progressed through endogenous puberty and wish continue with GnRHa treatment, but at present, no research has been published focusing on success in this patient population.

Testicular tissue cryopreservation is still similarly experimental. Research lags behind investigations of ovarian tissue cryopreservation, but offers potentially viable option for prepubertal and adolescent males if technologies continue to develop.[42] Currently, protocols have not been standardized, but three options present as potential routes for spermatogenesis in adulthood using testicular tissue preserved in childhood. The first calls for immature testicular tissue to be biopsied, frozen, and then later grafted onto adult testicular tissue to induce spermatogenesis.[42,43] This technique has been used to produce live offspring in mice and pigs, but has yet to be successful in humans.[44] A second option is a heterotopic graft of testicular tissue to a different part of the body, where spermatogenesis and maturation can occur and mature sperm can subsequently be harvested for *in vitro* fertilization.[42] The third technique under investigation uses *in vitro* techniques to induce spermatogenesis from frozen testicular tissue. [45,46] This third option may be the most viable for pre and peri-pubertal transgender children, as the complexities of treatment for gender-diverse and transgender patients, including the effects of gender-affirming hormone treatment and potential gender-affirming surgeries to remove gonadal tissues could further complicate the future use of cryopreserved tissue.

Summary Table of Available Treatments [47]

Table 1. Summary of current fertility preservation options [17].

FP Method	Description	Special considerations
Female Options		
Oocyte cryopreservation	Hormonal stimulation and aspiration of follicles with vitrification of unfertilized oocytes. Can be thawed and fertilized to create embryos for transfer in future.	• Established method • Do not need sperm source • Intracytoplasmic sperm injection (ICSI) required upon thawing • Live birth rates similar to fresh embryos (23)
Embryo cryopreservation	Hormonal stimulation and aspiration of oocytes for in vitro fertilization to create embryos that are cryopreserved for future transfer.	• Established method • Requires sperm source (partner or donor)
In vitro maturation (IVM)	Aspiration of immature oocytes from an unstimulated ovary.	• Investigational method • Case reports demonstrating viable embryos (24). • One live birth reported (25)
Ovarian tissue cryopreservation	Removal and cryopreservation of outer layer of the ovary (cortex), which contains immature oocytes.	• Investigational method • Only option available to prepubertal females • Outpatient surgical procedure • Future uses include transplantation of thawed tissue or in vitro maturation of follicles and fertilization of oocytes. • 20 human live births from transplantation reported (11, 23); none from in vitro maturation of follicles
Male Options		
Sperm cryopreservation	Cryopreservation of ejaculated sperm.	• Established method • Future uses include intrauterine insemination (IUI) or IVF +/−ICSI
Surgical sperm extraction	Percutaneous aspiration of sperm from the testis or epididymis.	• Established method • Outpatient surgical procedure • Can be used for IVF with ICSI
Immature testicular tissue cryopreservation	Surgical biopsy of testicular tissue from pre-pubertal males.	• Investigational method • Currently only option for pre-pubertal males

Transgender Youth: A Unique Population

Professional practice societies, including ASRM, WPATH, and World Health Organization (WHO) have debated the merits of extending medically-supported reproductive technologies to single individuals, same-sex couples, or limiting access by age or pre-existing conditions including cancer patients whose fertility is compromised by care. [48] WPATH firmly endorses parenthood options for transgender patients, biological or otherwise, declaring, "transsexual, transgender, and gender nonconforming people should not be refused reproductive options for any reason".[49]

Although parallels have been drawn between transgender patients and the oncofertility population—that is, patients with cancer undergoing treatments that may compromise fertility[50]—the differences in diagnosis and prognosis are considerable. For individuals who begin hormone therapy post-puberty, research on infertility or gonadal impairment after treatment is inconclusive. [7–9,51]

Case studies of transgender individuals who discontinued hormone treatment and were

able to regain gamete function and become biological parents circulate in the medical community and in the media. Highly publicized pregnancies, including those of Thomas Beattie,[52] Trystan Reese,[53] and other transgender men who discontinued testosterone treatment to have biological children [54] as well as transgender women who discontinued hormone treatment and were able to produce motile sperm for donation or to use with a cisgender female partner,[55] imply reduced fertility due to gender-affirming hormone treatment may be reversible. For children who initiate puberty blockers in early stages of puberty (Tanner Stages 2 or 3), however, gonadal development is significantly impaired (see Figure 1 above).

These children do not progress through the puberty of their birth-assigned sex, and thus will have neither functional eggs nor sperm if they continue on to gender-affirming hormones during adolescence. The long-term psychological and social benefits of early gender-affirming medical interventions may be offset by almost certain infertility; personal values also mediate the impact of the loss of fertility or options for biological parenthood. Current preservation options for prepubertal and peri-pubertal children (i.e., those who do not yet possess fully mature gametes; see *Currently Available Fertility Preservation Procedures*) are experimental and may be limited because these youth will not progress through endogenous puberty and thus will not have viable adult testicular or ovarian tissue for future transplant of cryopreserved tissues harvested and frozen as children. As a result, patients who initiate blocker treatment during peri-pubertal stages and continue on to gender affirming hormones in adolescence can be more clearly diagnosed as infertile, which has implications for treatment protocols, standards of care, and associated insurance coverage for care.

Barriers to Care

For transgender youth do who preserve ovarian/testicular tissue or gametes, biological parenthood options include use thawed eggs or sperm with an intimate partner who had corresponding gametes, using donor gametes, and/or gestational surrogacy in any number of

configurations. Ovarian/testicular tissue freezing is still experimental, and future *in vitro* or *in vivo* maturation of tissue preserved prior to puberty to produce viable gametes remains uncertain. The social, financial, and biological realities of queer reproduction, including the potential costs of donor gametes and gestational surrogacy, as well as the legal and ethical implications of using assisted reproductive technologies, further complicate the path to future biological parenthood for gender diverse and trans youth.

While theoretically available to transgender patients, and increasingly sought out by a small but growing number of adolescents initiating gender-affirming hormones, [56,57] barriers to care in vulnerable populations often prevent gamete cryopreservation and long-term storage, particularly immediate and future costs. [26,57,58] Even in cases when youth had access to comprehensive, multidisciplinary medical and mental health care, including counseling regarding the risks of hormones on fertility and referrals to fertility medical services, two recent studies revealed less than 5% of transgender adolescents chose to complete fertility preservation.[56,57] The high short- and long-term costs to retrieve and store gametes (see subsequent section) are considered by medical providers the primary barriers to fertility preservation in adolescents. [48]

Body dysphoria among transgender youth can also affect care. Standard fertility preservation procedures include trans-vaginal ultrasounds during routine ovarian stimulation procedures prior to egg retrieval for cryopreservation and masturbatory emission for sperm retrieval and may be a source of significant distress for transgender adolescents and young adults. Accordingly, utilization rates for fertility preservation may remain low even if insurance coverage and costs were not as significant a burden for patients.

Costs for Currently Available Treatments

Given the significant financial and potentially emotional burden associated with egg and sperm retrieval procedures, it may be assumed that transgender youth who pursue

cryopreservation would pursue the minimum number of retrieval procedures. For sperm retrieval, several office visits might be required to produce adequate samples for cryopreservation. For egg retrieval, particularly in younger patients who likely have higher ovarian reserve and quality, transgender men (birth-assigned girls) would likely undergo only one cycle of ovarian stimulation and oocyte retrieval for cryopreservation. These procedures are particularly expensive. Average cost of one reproductive cycle of oocyte cryopreservation can be extrapolated from the costs for the stimulation and retrieval costs for a single *in vitro* fertilization treatment. In the United States, the national average cost of one cycle is an estimated at $12,737. [48,59,60] These costs, including laboratory testing, medications to stimulate egg maturation, retrieval procedure costs, nursing, anesthesia and office physician charges are consistent with estimates from the Society for Assisted Reproductive Technology (SART) member clinics and the National Infertility Association.[61] Currently, these procedures are rarely, if ever, covered for individuals under age 18 insured on their parent's health care plans, nor are they covered through Medicaid or the Children's Health Insurance Plan (CHIP), both primary insurance providers for many lower income children in the United States [62].

For transgender women (birth-assigned boys), sperm retrieval is less expensive, but still incurs significant costs. Sperm retrieval by masturbatory emission, typically completed over the course of several clinical visits to obtain adequate samples, can cost upwards of $1,000 out-of-pocket including semen analysis, infectious disease screening, initial processing and freezing costs. [63,64] Testicular sperm extraction (TSE) or open surgical sperm retrieval, an alternative and in some cases medically-necessary procedure for individuals with azoospermia (semen that contains no viable sperm) can cost upwards of $7,000 including surgical, anesthesia, and facility fees. [63,64] Long term storage costs for frozen egg and sperm samples vary, but average around $400 per year.[63,64] With pre-medical gender transition oocyte and sperm cryopreservation also comes the future costs of reproductive technologies to use frozen gametes. *In vitro* fertilization to

use thawed gametes, which similar to oocyte retrieval, can cost between $7,000 and $15,000 for a cycle in the United States and is not always covered by insurance,[60] as well as the potential costs of donor gametes or a gestational surrogate. The current costs may vary significantly depending on procedures and geographic location; costs for future *in vitro* procedures or gestational surrogacy may also change significantly by the time patients are using gametes for reproduction, making it difficult for providers and insurers to give accurate total-cost estimates.

Insurance Coverage for Fertility Preservation: An Overview

Definition of Infertility

Infertility is defined by the American Society for Reproductive Medicine as: "the failure to achieve a successful pregnancy after 12 months or more of appropriate, timed unprotected intercourse or therapeutic donor insemination. Earlier evaluation and treatment may be justified based on medical history and physical findings and is warranted after 6 months for women over age 35 years." [65] This definition does not consider necessary medical treatments that may affect fertility. This exclusion of fertility-compromising diagnoses and treatments from the definition of infertility has been publicly contested by oncologists, cancer survivors and patient advocates, since common cancer treatments including radiation, chemotherapy, and surgeries can compromise or destroy fertility and reproductive functioning for both men and women. [29,48]

State Specific Infertility Care Coverage

In the United States, coverage for infertility services, including reproductive technologies like *in vitro* fertilization and gamete/embryo cryopreservation, varies widely by state, and is predicated on various working definitions of "infertility" (not limited to the aforementioned approved ASRM definition of fertility) housed within each state's insurance code. Some of these definitions apply only to married, heterosexual women between certain age brackets and others require the patient to be "otherwise healthy." These restrictions, on the basis of sex, age, gender, and health status, often exclude prospective patients from qualifying for fertility preservation

coverage. [29] Since the late 1980s, fifteen US states—Arkansas, California, Connecticut, Hawaii, Illinois, Louisiana, Maryland, Massachusetts, Montana, New Jersey, New York, Ohio, Rhode Island, Texas and West Virginia—have passed laws requiring state-based insurers to offer coverage for infertility diagnosis and treatment. These laws, however, have often been limited in scope, requiring only employment-linked benefits for larger companies that offer insurance plans to employees within the state. For example, in Illinois, if an employer has its main operational headquarters and human resources departments out of state, is self-insured, or has fewer than 25 employees, plans are exempt from codified Illinois insurance mandates.[66] Federal government health insurance plans, including those for federal employees and military members, veterans and their families, as well as Medicaid/Medicare do not adhere to state mandates. Of the fifteen states with some form of coverage for infertility care, thirteen states have laws requiring coverage of both diagnosis of infertility and treatment, which can be more expensive than diagnostic coverage alone and typically comprises the bulk of patient/insurer costs. California, Louisiana and New York have laws that specifically *exclude* coverage for *in vitro* fertilization.

State-Specific Fertility Preservation Coverage

Previous state-level legislative efforts to extend coverage for fertility preservation have been limited to fertility preservation in cancer patients. The New Jersey Senate Bill 788 failed to pass in 2004 after referral to the Health, Human Services, and Senior Citizens Committee.[48] The bill proposed extending insurance coverage for fertility preservation in women undergoing cancer or radiation treatments that threatened future reproduction only. In California, Assembly Bill AB-912 was introduced to the state legislature mandating large-group insurers to cover fertility preservation for patients facing any fertility-threatening treatment. The bill passed both branches of the state legislature in 2013 but was vetoed by the governor due to concerns over state-backed costs. Following passage of the federal Affordable Care Act (ACA) in 2010, states were required to alter insurance codes to be in compliance with new federal healthcare laws, and

the costs of adding any new mandates to state insurance codes were henceforth to be covered entirely by the state budget.[48] In January 2017, the same bill (now SB-172) was introduced to the California state legislature; the bill was amended, passed, and referred to the Senate Appropriations Committee, where it was placed on the Appropriations Suspense file where it remains.[67] Two states, Hawaii (SB-271)[68] and New York (SB-S7219),[69] had bills extending fertility preservation coverage for men and women undergoing cancer treatments under review in the state legislature but were not passed. In January 2018, Hawaii re-introduced a similar bill (HB-2669).[70] It was referred to the state Health and Human Services Committee, which recommended the measure be deferred. Both the Hawaii and New York bills are specifically related to fertility preservation for individuals with a cancer diagnosis undergoing fertility-threatening treatment. In March 2017, Oregon (SB-859) introduced a narrower bill that would require physicians to discuss fertility with adolescent oncology patients. [71] Importantly for the transgender community and transgender adolescents who have progressed through endogenous puberty, the New York bill (SB-S7219) introduced in April 2016 would have mandated insurance coverage for standard fertility preservation services for patients undergoing *any* medically necessary treatments that may directly or indirectly cause infertility.[69] An analogous bill was introduced in Illinois (HB-2617) in February 2017 and passed initial review by the House.[71] The congressional session will resume in May 2018 when the final fate of the bill will be decided. The Illinois bill includes language that prohibits discrimination in providing fertility preservation care, specifically, "that in determining coverage for these expenses, an insurer shall not discriminate based on an individual's expected length of life, present or predicted disability, degree of medical dependency, quality of life, or other health conditions, nor based on personal characteristics, including age, sex, sexual orientation, or marital status."[72] Similarly broad bills have been introduced in Kentucky (SB-95) [73] and Maryland (SB-271/HB-908) [74] in 2018 where

each is still under consideration; a bill in Mississippi (HB-1198) [75] died after passing in the House in 2018.

On the federal level, the Family Act S 881/HR 1951 was introduced to Congress in May 2013 with the aim of offering a tax credit to cover half of qualified infertility treatment expenses. The bill did not leave the committee level of the House of Representatives and had only one Republican supporter.

Case Studies: Changing the Definition of "Infertility" in Illinois, Connecticut, and Rhode Island

Illinois is one of the 15 states with a legal mandate requiring insurers to offer coverage for infertility diagnosis and treatment. Illinois Senate Bill SB-1764, passed in 2016, changed the official definition of infertility in the Illinois Insurance code from "the inability to conceive after one year of unprotected intercourse or the inability to sustain a successful pregnancy" to "the inability to conceive after one year of unprotected sexual intercourse, the inability to conceive after one year of attempts to produce conception, the inability to conceive after an individual is diagnosed with a condition affecting fertility, or the inability to sustain a successful pregnancy."[76] The expanded definition includes diagnosis of a condition that affects fertility, and while this definition does not extend to *treatments* for a diagnosed condition that *may* affect fertility, it opens the door to consider this possibility. A diagnosis of gender dysphoria does not in and of itself impact fertility, but standard-of-care treatment with gender-affirming hormones and surgery certainly does compromise fertility. Expanding the definition of "infertility" could have significant impact on coverage for fertility treatment for transgender patients.

In Rhode Island, a recent 2017 change to the insurance code now explicitly requires coverage of fertility preservation services for "a patent about to undergo a medical treatment—surgery, radiation, or chemotherapy – that may have deleterious effects on the gonads."[29] This language alteration aimed to require insurance policies to offer complete coverage for fertility

preservation in cancer patients undergoing fertility-compromising treatments. The amendment further called for "standard fertility preservation services when a medically necessary treatment may directly or indirectly cause iatrogenic infertility to a covered person." [29] The amendment further defines "standard" procedures to include "procedures consistent with established medical practices and professional guidelines published by the American Society for Reproductive Medicine, the American Society of Clinical Oncology, or other reputable professional medical organizations"—allowing coverage to adapt as technology advances and standards of care for fertility preservation evolve.[29] "Iatrogenic infertility" is defined within the parameters of the bill passed in Rhode Island as "impairment of fertility by surgery, radiation, chemotherapy or other medical treatment affecting reproductive organs or processes," and treatment that "may directly or indirectly cause iatrogenic infertility" as "treatment with a likely side effect of infertility as established by the American Society for Reproductive Medicine, the American Society of Clinical Oncology, or other reputable professional organizations." [29]

The Rhode Island Office of the Health Insurance Commissioner has confirmed to the American Civil Liberties Union of Rhode Island that the new language will be interpreted to provide coverage to individuals who have compromised fertility due to "medically necessary hormone treatment (HRT) or sex-reassignment surgery." The Office of the Health Commissioner indicated all four of Rhode Island's major commercial insurers, which provide the majority of coverage in the small state, have confirmed coverage for transgender patients over 18 who have progressed through endogenous puberty and are initiating gender-affirming hormone treatment.

Like the Rhode Island language changes, state-level language changes to the definition of infertility, while not always intentionally engineered to extend coverage to transgender patients, may lead to opportunities for transgender patients to receive fertility preservation care. Further, the Mental Health Parity Act (1997) requires insurers treat mental health diagnoses as analogous to physical health diagnoses when considering coverage for care, [77] potentially bringing a

diagnosis of gender dysphoria on par with that of cancer or another physical condition the treatment for which can affect fertility.

Conversely, language can be used to limit the scope of fertility care. In Connecticut, changes were made to the state insurance code to specifically address fertility preservation coverage in cancer-related cases, including clauses limiting the expanded insurance coverage for fertility preservation to these populations. While these changes are a step in the right direction, cancer-exclusive coverage fails to account for the variety of medical conditions and medically-necessary treatments that can compromise fertility.

In an editorial review detailing the impact of changes in Connecticut and Rhode Island insurance codes to expand fertility preservation, Cardozo and colleagues (2017) emphasize that there is no free market-based solution for the issues surrounding mandated fertility preservation coverage. [29] Patients who do not receive fertility preservation services will not require future fertility treatments (such as *in vitro* fertilization) that may have required coverage and associated expenses. Thus, insurers have no incentive to offer fertility preservation coverage earlier in life, in cases such as oncology patients or transgender individuals using gender-affirming hormone treatment. These barriers are further conflated by confusing fertility preservation secondary to medically necessary gonadotoxic therapies with the rise of elective or so-called "social" egg freezing by cisgender women hoping to preserve oocytes at a younger age to postpone biological parenthood.[78] In cases where patients are otherwise mentally and physically healthy, practice guidelines do not recommend routine, elective use of fertility preservation services.[78]

Some anecdotal evidence indicates insurance companies have covered fertility preservation for cancer patients undergoing fertility-compromising treatments, but in these cases, patients were typically aided by a patient navigator and/or were extremely medically savvy. Without widespread legislation, fertility preservation is likely to be limited only to those who can pay out-of-pocket for costly screening, cryopreservation procedures, and long-term storage of

frozen gametes. Some nonprofit organizations including the California-based Alliance for Fertility Preservation, the Oncofertility Consortium, and the LIVESTRONG Fertility Discount Program offer grants and discounted rates for fertility preservation procedures for cancer patients.[79] These support mechanisms, while privately in favor of extending fertility preservation to other populations including transgender individuals, often limit both financial backing and governmental lobbying to support coverage of cancer patients only for political and economic reasons. Moreover, charitable organizations often only cover initial screening procedures, retrieval and the first year of gamete storage, not long term storage fees or future use of frozen gametes. [79]

Cost Concerns Among Patients and Families: Qualitative Data from the Trans Youth Fertility Study

The Trans Youth Fertility Study

In an effort to gather data to better understand current concerns among transgender youth and their parents around costs and coverage for fertility preservation, our team analyzed data drawn from semi-structured qualitative interviews with a cohort of transgender adolescents and parents of transgender adolescent and young adults as part of the broader Trans Youth Fertility Study. Adolescents and young adults (AYA) ages 14-24 receiving treatment related to gender identity, and parents of this patient population, were recruited from the Ann & Robert H. Lurie Children's Hospital of Chicago Gender and Sex Development Program (GSDP) clinic via clinician referral, online advertisements and circulated fliers, as well as from community-based organizations serving transgender youth and families. GSDP has treated over 650 gender-expansive children, adolescents, and young adults from diverse racial/ethnic and socioeconomic backgrounds. Participation by both a parent and a child was not required for enrollment. Written informed consent, including written parental permission for youth under age 18 and a youth assent form, was obtained prior to each interview. Youth ages 18-24 and parents who were

participating in the study signed a consent form. All participants were given ample time to read over the consent/assent forms with the research assistant (Author 2) and had an opportunity to ask questions about the study. All participants were given a copy of consent/assent/parental permission forms for their records. Study protocol and all materials were approved by the Ann & Robert H. Lurie Children's Hospital of Chicago Institutional Review Board.

Qualitative Interviews and Demographic Survey

A trained BA-level research assistant (Author 2) conducted all interviews, using a semi-structured interview guide. The interview guide was adapted from a similar guide developed for interviews relating to fertility decision-making and preservation among parents of children with differences of sexual development. Prior to beginning interviews, the sole interviewer (Author 2) and the principal investigator (Author 3) conducted several mock interviews to assess length of time and ensure the interview guide was comprehensive. Participants were asked open-ended questions about: 1) gender-affirming and fertility-related medical care received or desired, 2) knowledge about the effect of gender affirming hormones on fertility, 3) options available to medically transitioned transgender individuals for parenthood, and 4) decision-making and current opinion regarding fertility preservation. Participants were also asked probe questions about the importance of costs in decision-making about fertility preservation and personal experiences with navigating costs and insurance coverage for fertility preservation.

Interviews were audio-recorded using a digital voice recorder. Interviews were de-identified and transcribed verbatim by Author 1, Author 2, and by professional transcription services. A member of the research team not involved in transcription conducted quality monitoring of each interview to ensure concordance of audio and transcribed text. Participants were also asked to complete a survey of basic demographics as well as to answer specific questions about clinical experiences and medical care related to their gender and fertility.

Qualitative Analysis

Cleaned verbatim transcripts were uploaded to Dedoose, a cloud-based, encrypted online data analysis package (Dedoose Version 6.2.10) used for qualitative analysis and to house descriptive data and statistics. Interview text was coded using emerging major and minor themes in batches of three to five interviews, using directed content analysis [80] and a constant comparative approach to develop a working codebook within the domain of interest. [81,82] During the coding phase of the project, the primary research team (Authors 1, 2, and 3) met weekly to review interview coding and refine themes. Transcripts were coded using this continually refined codebook, modifying and expanding codes until saturation, when no new themes relating to costs or insurance coverage emerged, was reached. In the course of analysis, we identified data on how cost and/or insurance coverage would affect decision-making around fertility preservation emerging from several components of the interview, including responses about fertility-related counseling prior to care, as well as during individual discussions of their (or their child's) overall gender-based medical care and treatment. Parents and patients factored costs, social and medical realities into decision-making around fertility preservation.

Results

Eighteen transgender AYA ages 15-24 years (*M*=18.4 years, *SD*=2.3; 12 transmasculine, 6 transfeminine; 39% racial/ethnic minority; 89% currently on hormones) participated in semi-structured interviews lasting approximately one hour and were included in the final sample (60% participation rate of 30 potential participants approached). Thirteen parents were participated in semi-structured interviews (*M*= 50.5 years, *SD*=3.9; 100% cisgender; 12 female/1 male; 15.4% racial/ethnic minority) lasting approximately one hour, although three interviews exceeded 90 minutes in length. Ten parent participants had a child also participating in the study, and for these parent-child dyads only an single parent was involved individually in the study, although all parents were invited to participate. Not all youth participants had a parent participate or vice versa. No parent had more than one child enrolled in the study. Of the eighteen youth

participants, eleven were assigned female at birth. Parents all identified as cisgender. For the purposes of this analysis, AYA are described by their birth-assigned sex, and then by their individual, self-affirmed gender identities, to provide clarity about the type of fertility preservation the youth would consider (i.e. freezing either eggs or sperm).

[TABLES 3 & 4 HERE]

Prior to January 2015, patients and families at Lurie Children's GSDP expressing interest in fertility preservation were referred directly to the adult fertility specialists at Northwestern Medicine in Chicago, IL. After January 2015, interested patients and families were referred to a dedicated in-house provider, an Advanced Practice Nurse who primarily works with the oncofertility population at Lurie Children's, and then subsequently referred to adult fertility specialist at Northwestern Medicine if still interested in fertility preservation.[56] Of the 18 AYA participants, all of whom were offered the option of a fertility preservation consultation, nine declined to undergo an in-depth fertility consultation with a fertility specialist or take further steps to preserve fertility prior to initiating gender affirming gender-affirming hormone treatment. The other nine in the group consulted with a fertility specialist (depending on date of consultation, either the dedicated Advanced Practice Nurse at Lurie Children's or through Northwestern Medicine) and six of these nine completed fertility preservation procedures. Relevant data on the role of cost in fertility preservation emerged from several sections of interviews with patients and with parents, including responses about fertility-related counseling prior to care, as well as a part of an individual's overall gender-based medical care and treatment. These question prompts are included in Table 3 and the complete Interview Guides for the youth and parent cohorts are included in the Appendix.

Of 13 parents interviewed, all indicated costs should be discussed as part of medical care around a child's gender and fertility preservation. Of 18 youth interviewed, all indicated clarity and discussion of costs should be a part of care prior to initiating gender-affirming hormones. In

the course of thematic content analysis, we discovered five recurrent, major themes regarding knowledge of fertility preservation insurance coverage and costs. First, we discuss the theme of parent and youth knowledge about insurance coverage for fertility preservation. Next, we discuss the overall lack of uniformity in the information both parents and youth had received from providers and other sources about fertility preservation costs. We then focus on youth and parent concerns about the timelines for disclosing these costs in the course of gender-related care. To conclude, we discuss the role of cost considerations in decision-making about pursuing or foregoing fertility preservation prior to medical gender transition, and the last theme related to the potential emotional and psychosocial impact of costs as a barrier to fertility preservation.

[TABLES 3, 4 & 5 HERE]

Knowledge of Insurance Coverage for Fertility Preservation

Parents and youth displayed varying levels of knowledge about the current state of insurance coverage in for fertility preservation, including coverage for gamete retrieval or long-term cryopreservation storage costs. To date in Illinois (April 2018), the state in which all participants and families resided and in which participants received medical and mental health care, there is no statewide insurance mandate to coverage of fertility preservation for transgender AYA initiating gender-affirming hormones; no patient in the study had successfully petitioned to have fertility preservation covered by an existing insurance plan. Despite the universal lack of coverage for fertility preservation, many parents and youth expressed confusion and misinformation regarding potential coverage, offset costs, and out-of-pocket costs for gamete retrieval and storage. Participant 102, a 20-year-old Black/African American trans-man assigned female at birth who completed fertility preservation stated:

102: *I think if I switched insurance companies, I think something would have happened [for fertility preservation coverage]. I don't know. But like there wasn't that much information about coverage as in cost and stuff. I feel like they should possibly talk to the insurance company more about that.*

Similarly, misinformation about different insurance providers covering any component of fertility preservation was common. Participant 105, an 18-year-old Black/African-American transgender man who did not seek a consult or complete fertility preservation stated:

105: *I feel like they should be like okay, these insurance providers provide this much coverage for this procedure, and just each procedure, you know, which one has a higher chance of getting covered, and do you have to do a sliding scale payment and stuff like that. I feel like there should be better insurance and like just nationwide. Like there's only a few, like New York and California, you know. And, I mean, that's only two that I really can think of right now. And, I mean, because their insurance is geared towards more trans related stuff, and it's not as expensive. There are some insurance companies that I'm aware of in Illinois, but there's like loopholes…like you have to start this form of medication, and it'll cover the deductible and stuff like that. It's just like it's just so much. There's always so many things you have to get through to get something done. It's like tying a bow or something. It's just too much.*

This participant was speaking more generally about health insurance coverage for gender-related medical care, but also incorrectly perceived that certain states offered more comprehensive coverage for procedures like fertility preservation prior to initiating gender-affirming hormone treatment. Navigating the often-confusing insurance coverage process was also brought up by participant 203, a 48-year-old, White mother of a 17-year-old transgender AYA assigned male at birth:

203: *Certain insurance are covering specific things, so what's out of pocket, if there's a difference out of the pocket in the coverage. Yeah, the costs. It's important.*

Two participants, one parent and one young adult, discussed "sliding-scale" payments for those who cannot afford coverage. At present, however, sliding-scale coverage, payment plans or other mechanisms to offset costs related to fertility preservation procedures do not exist.

Information About Fertility Preservation Costs

Parents and youth in the study had a wide range of knowledge on the actual costs of fertility preservation (for both egg and sperm cryopreservation). Participants also desired clarity from providers and clinical information on the long- and short-term costs. Participants indicated they had learned about the costs of fertility preservation from a number of sources, including

online research, from their or their child's gender-care providers, and from fertility specialists during designated appointments or phone consultations to discuss fertility preservation options following a referral. The lack of continuity of information, including providers who counseled about fertility preservation but could not provide adequate cost estimates, was a particular concern. Participant 116, an 18-year-old White transgender woman assigned male at birth who completed fertility preservation stated:

116: *[My endocrinologist] did not know price [for fertility preservation]. So she referred us to the urologist, and even that meeting we had to pay for. But we were already referred and paying for the visit. That was the first time where we saw the prices.*

Participants also desired clarity on the differences between short- and long-term costs of cryopreservation. Another participant, 215, a 48-year-old White mother of an 18-year-old transgender child assigned female at birth mentioned downstream costs and annual storage fees for cryopreserved eggs:

215: *And having an idea about not only just the process of [in my child's case] harvesting eggs, but the storage of them for years going forward—how many years would they be viable, and how much is it going to cost you year over year over year to preserve.*

The expected versus actual costs of fertility preservation and long-term storage costs were also surprising to most youth and parents, which in turn affected decision-making for patients who had previously considered pursuing cryopreservation like Participant 110, an 18-year-old Black/African-American transgender woman assigned male at birth who sought a fertility preservation consult but did not complete fertility preservation:

111: *I went to see the price of it. I thought it was gonna be like $20 maybe even a $100..like no... $400 or $500 for like one sperm sample and I was like, huh, I'm gonna need at least 3.*

Participant 120, a 19-year-old White transgender woman assigned male at birth, although she did complete fertility preservation, was similarly surprised about the costs of procedures and storage:

120: *And the biggest decision factor for me was cost. I absolutely had no idea how much it was going to cost.*

Immediate and Future Costs: Key Factor in Decision Making about Fertility Preservation

Despite not always knowing the exact price tag of fertility preservation, parents and youth universally expressed that costs were a consideration for many families making decisions about fertility preservation. A third major theme that emerged was the potential negative emotional impact of the costs of fertility preservation, although participants had various ideas about how the mitigate this impact. The timeline of when (and by whom) fertility preservation costs should be discussed was a focus of one adolescent patient, a 15-year-old White non-binary transgender man assigned female at birth who was not yet taking gender-affirming hormones and had not completed a fertility consultation or preservation:

104: *Like before even a thing happens [with fertility preservation], you should see what all sorts of different insurance companies will cover in this area. Especially for fertility, 'cause like you don't want to bring someone's hopes up and then crash them down...it'd be pointless to get their hopes up and then find out they won't be able to afford it cause it's just, worse for them.*

This young person felt cost discussions should be foregrounded by providers, since it could be difficult emotionally to be offered a procedure you or your family could not afford. Conversely, when asked how providers should bring up costs with patients and families, a 45-year-old White mother of an 18 year-old transgender child assigned female at birth stated:

204: *I don't know if…I don't know. I think that the focus should be more on what it's all about instead of the cost. Because if I'm looking at all this stuff and okay, here's how the procedure is done, I should be focusing on how the procedure is done, not a price tag sitting up in a corner, $90,000 or $5,000, $600, whatever it is…But I don't think, when you're explaining the whole idea of fertility and preservation and procedures and stuff like that, I don't think there should be price tags thrown in there. I think it's too much of a distraction, and people aren't going to be focusing on what they should. They're going to be looking at cost instead of looking at the important part of it.*

Many of the parents involved in this study provided insurance coverage for their AYA children. Although all 13 interviewed for this project indicated costs should be considered, they varied on the timeline of these discussions, and whether dependent youth should be a part of cost discussions and decision-making. Many parents and youth discussed costs as a major component

of the decision-making process and this theme was repeated by participant 106, a 20-year-old Asian-American man assigned female at birth who did not complete fertility preservation:

S106: *The most important is being aware of costs. I think very important and does kind of pertain to a decision [about fertility preservation].*

Participant 117, a 16-year-old Black/African-American transgender woman assigned male at birth who did complete fertility preservation discussed her decision process:

> *So we [my family and I] came to the conclusion by, like, talking and talking a lot about, like, costs and talking about, like, just kind of benefits of it, but also a lot of times of cost.*

Several parent and youth participants identified cost as the single limiting factor in making a decision about pursuing fertility preservation in the course of interviews, including participant 110, an 18-year-old Black/African American transgender woman assigned male at birth who did not complete fertility preservation but would have desired sperm cryopreservation:

Interviewer: *Can I ask, if financial pieces were not playing a part, do you think that your decision [about fertility preservation] would have been different?*

S110: *Yep, yes yes most definitely. I'd be like, you know what, I will not be doing [hormones] without freezing my sperm so I can have a biological child of my own if financial issues weren't in play.*

Parents did not hesitate to discuss the role of their family's financial situation in relationship to gender-related care for their child, including fertility preservation, particularly less wealthy parents like participant 203, a 48-year-old White mother of a 17-year-old transgender child assigned female at birth:

S203: [*There's no way that we—there's no, I mean, in our financial situation there's no way. I mean, even if we were like 'Oh yeah, we want to preserve eggs,' we can't.*

Interviewer: *Do you think, since you brought it up, do you think that if financial factors weren't necessarily a big factor, if you think that, if you would have been—*

S203: *It would be one more thing to consider it more seriously, yes.*

Interviewer: *Do you think that would have led to a different kind of decision?*

S203: *I don't know. I don't know.*

More affluent families also discussed the extensive costs of gender-related medical care and included financial considerations in their decision-making about fertility preservation.

Discussion

Data from this qualitative study with transgender youth and parents of transgender youth indicate significant confusion about medical insurance coverage for fertility preservation, as well as a desire for more clarity in understanding insurance coverage and basic costs of fertility-related care. Finding from this study point to a need for greater information for both AYA and the parents/caregivers who may be largely responsible for the insurance coverage and costs associated with a child's gender-related care and fertility preservation. None of the adolescents included in the study had yet had biological children, and despite a relatively young age, most carefully considered fertility preservation regardless of their ultimate decision about pursing treatment. In many cases, these decisions were predicated on costs associated with care.

Significant disparities in terms of healthcare access and comprehensive gender-related care are particularly salient for this population. Both nationwide and in Illinois, AYA of color and AYA from lower-income families are less likely to have access to gender-related care, including counseling on fertility preservation options or be able to access these options. Several participants in this study were currently or had previously been in the foster care system or were otherwise cared for by state agencies including the Illinois Department of Children and Family Services. Barriers to more general medical care in transgender populations are also unique. Although procedures like oocyte cryopreservation may technically be available (through insurance coverage or adequate funds to pay for procedures and storage) to transgender adolescents, gender often plays a role ultimately accessing these services. Research from adolescent oncology indicates more medical practitioners believe cisgender assigned female at birth patients should be referred to a fertility specialist at diagnosis than those that actually make

such referrals. [83] It is unclear for transgender children and adolescents, who may be accessing gender-related care though any number of providers and institutions with varying access to or understanding of fertility preservation options, how gender may play a role in such referrals and whether disparities exist in referring birth-assigned males versus birth-assigned females. Additional research on the attitudes of providers of gender-related care about fertility preservation and referral practices is forthcoming (Chen et. al 2018, in preparation).

As state-specific insurance coverage for fertility preservation expands to all cases in which an indicated medical treatment may lead to subfertility or infertility as in Rhode Island where recently legislation mandating insurers offer fertility preservation coverage was passed, clinical practice guidelines offered by organizations including WPATH and the ASRM may evolve as was the case with oncofertility standards of care.[49,84] The Rhode Island legislation was deliberately worded to allow for updates and changes to best practices in fertility preservation procedures and standards of care and to include multiple diagnoses and treatment which compromise fertility. Such attention to legislative language will be increasingly important for transgender patients as treatment options, including puberty blockers and gender-affirming hormone regimens, as well as options for future parenthood rapidly evolve with the rise of new reproductive technologies.

In addition to the practical (information, provider referral, costs and other access issues) and emotional barriers to accessing fertility preservation, transgender AYA patients who have completed pubertal maturation must in many cases delay initiation of gender-affirming hormone treatment in order to complete fertility preservation. Like the oncofertility population, concerns about delaying treatment, particularly for oocyte cryopreservation cycles which can take several weeks for menstrual cycle synchronicity and ovarian stimulation for egg retrieval, have been demonstrated to be a major barrier to completion. [85]

Some AYA have a clear understanding of fertility preservation options, and their

opinions may differ from those of their parents or guardians. These cases are particularly difficult for post-pubertal adolescents, who may desire or reject gamete cryopreservation against their parent's wishes. Additionally, as this research demonstrated, familial financial barriers are often the ultimate deciding factor, beyond a transgender adolescent's reproductive choice.

Acknowledgements

We would like to thank the following individuals for contributing their time to this research: Emilie K. Johnson, Courtney Finlayson, Ilina Rosoklija, Anthony D'Oro, Elisa Gordon, Teresa K. Woodruff, and Robert Garofalo. Special thanks Afiya Sajwani and to all the youth and parents who participated in the Trans Youth Fertility Study and shared their experiences with us.

Funding

This work was supported by the Department of Psychiatry and Behavioral Sciences 2016-2017 Research Excellence Award from the Chairman (REACH) from Northwestern University Feinberg School of Medicine and the 2017 Targeted Research Grant from the Society of Pediatric Psychology awarded to Diane Chen, PhD. It was additionally supported by the Sexualities Project at Northwestern (SPAN) Summer 2017 Research Grant awarded to Moira Kyweluk, MA.

Statement Regarding Culminating Experience Paper and Public Health Relevance

This Culminating Experience paper will ultimately be two separate manuscripts, each of which are in preparation for publication in different journals. The first will be a brief policy report, focusing on the current US state-by-state insurance policies and regulations that govern fertility preservation for transgender individuals. Bills altering insurance mandates for fertility preservation coverage that would extend coverage for transgender patients receiving gender-

affirming hormone treatment are currently under review in several states (2018). Thus, this paper will be a timely report of use to the public health community, including clinicians involved in gender-related and fertility care, as well as transgender patients, families and their allies. The extensive policy research included as the first half of this Culminating Experience paper clearly emphasizes the importance to public health of coverage for fertility preservation, particularly for transgender youth initiating gender-affirming hormone treatment which can threaten fertility and compromise options for biological parenthood. The second paper focuses on the first-hand narratives from interviews with parents and youth in the Trans Youth Fertility Study (Ann & Robert H. Lurie Children's Hospital, Chicago IL) and provides much-needed data on patient and family understanding of fertility preservation access, current insurance coverage, and costs in this population. Transgender AYA represent an already vulnerable population, and protections for fertility preservation for those individuals who desire options for future biological parenthood would be a significant benefit to overall mental and physical health and wellbeing. Additionally, data from the TYFS suggest increased patient education around insurance coverage and costs for fertility preservation is needed to increase the health literacy of transgender youth and families.

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Table 2. Gender and Sexual Development Terminology

Terminology	Definition
assigned female/male at birth	The medically/legally assigned sex of an individual at birth, usually based on primary sex characteristics
cisgender	When an individual's gender identity/gender expression is in line with sex assigned at birth
gender dysphoria	A diagnosis based on the Diagnostic and Statistical Manual 5th Edition (American Psychological Association) used to describe adolescents and adults who experience a difference between their experienced/expressed gender and assigned gender, resulting in significant distress or problems functioning.
gender identity	The gender an individual identifies with, such as male or female, or an alternative gender, which may or may not correspond with sex assigned at birth
transgender/trans	A broad term describing persons whose gender identity and/or gender expression do not align with sex assigned at birth
transfeminine	An individual whose birth assigned sex is male who identifies with a more female or feminine gender
transmasculine	An individual whose birth assigned sex is female who identifies with a more male or masculine gender
Tanner Scale/Stages	A scale of physical development in children, adolescents, and adults describing pubertal and maturational changes.
hormone replacement therapy (HRT)/gender-affirming hormone treatment	Treatment with sex hormones (typically estrogen or testosterone) to bring about desirable physical changes associated with the gender with which an individual identifies

Table 3. Youth Demographics and Identities

ID	Age	Sex Assigned at Birth	Affirmed Gender	Race	Sexual Orientation	Currently on Hormones?	Received Fertility Consult?/ Completed FP?
101	16	Female	Trans-man	Black/African-American	Queer	Yes	No/No
102	20	Female	Man	White; Asian	Heterosexual	Yes	Yes/Yes
103	17	Female	Man	White	Demisexual	Yes	No/No
104	15	Female	Trans-man; Non-binary	White	Pansexual	No	No/No
105	18	Female	Man; Trans-man	Black/African-American	Heterosexual	Yes	Yes/No
106	20	Female	Man	Asian	Pansexual	Yes	No/No
111	17	Female	Trans-man	White	Pansexual	Yes	Yes/No
113	17	Female	Trans-man	White	Homosexual	Yes	Yes/No
114	19	Female	Man	White	Biresexual; Heteroromantic	Yes	No/No
118	23	Female	Man	White	Pansexual	Yes	No/No
119	24	Female	Trans-man	White	Queer	Yes	No/No
121	18	Female	Man; Trans-man	White	Homosexual	No	Yes/Yes
107	20	Male	Trans-woman	White	Homosexual; Demiromantic	Yes	No/No
110	18	Male	Trans-woman	Black/African-American	Not sure	Yes	No/No
112	17	Male	Woman	White; American Indian; Mexican American	Heterosexual	Yes	Yes/Yes
116	18	Male	Trans-woman	White	Pansexual	Yes	Yes/Yes
117	16	Male	Trans-woman	Black/African-American	Not sure	Yes	Yes/Yes
120	19	Male	Trans-woman	White	Pansexual	Yes	Yes/Yes

Table 4. Parent Demographics and Identities

ID	Age	Sex Assigned at Birth	Affirmed Gender	Race	Religious Affiliation	Marital Status	Educational Status	Occupational Status
201	55	Female	Woman	White	Unaffiliated	Seperated	Advanced Degree	Full-time employed
202	46	Female	Woman	White	Other Christian	Seperated	College degree	Full-time employed
203	48	Female	Woman	White	Agnostic	Divorced	Advanced Degree	Full-time student only
204	45	Female	Woman	White	Agnostic, Wiccan	Living with a partner in a committed relationship; Divorced	Some college/Technical degree	Unemployed
205	57	Male	Man	White	Unaffiliated, Atheist	Married	Advanced Degree	Full-time employed
206	57	Female	Woman	White	Catholic, Not Practicing	Married	Advanced Degree	Full-time employed
208	53	Female	Woman	White	Unaffiliated	Seperated	Some college/Technical degree	Full-time employed
209	48	Female	Woman	American Indian/ Mexian-American	Evangelical	Married	Some college/Technical degree	Full-time student only
211	51	Female	Woman	White	Other Christian, Unaffiliated	Married	College degree	Homemaker
212	48	Female	Woman	White	Catholic	Living with a partner in a committed relationship	Some college/Technical degree	Part-time employed
213	53	Female	Woman	White	Unaffiliated	Married	College degree	Full-time employed
214	48	Female	Woman	Black or African-American	Other Christian	Married	College degree	Full-time employed
215	48	Female	Woman	White	Protestant	Married	Advanced Degree	Full-time employed

Table 5. Theme: Medical Insurance Coverage for Fertility Preservation

Sample Interview Guide Questions on Theme	Theme Definition	Subcode	Subcode Definition	Examples
Q: What kinds of information would you like to know about fertility preservation [from your providers]? Q: What type of information would be helpful to include on a [fertility preservaiton] decision-making tool? Information about the process? New research? Costs? Testimonials from other families? Testimonials from trans adults? Others?	Discussion of current medical insurance coverage for fertility preservation procedures and gamete storage	Confusion about insurance coverage for FP	Parents and youth express confusion or have misinformation about insurance coverage for fertility preservation procedures and long-term storage costs, including misinformation about out-of-pocket costs, potential sliding scale payments, whether coverage is providedby various insurers	*S105: I think if I switched insurance companies, I think something would have happened [for fertility preservaition coverage]. I don't know. But like there wasn't that much information about coveage as in cost and stuff. I feel like they should possibly talk to the insurance company more about that.* *S203: Certain insurance are covering specific things, so what's out of pocket, if there's a difference out of the pocket in the coverage. Yeah, the costs. It's important.*

Table 6. Theme: Information about Fertility Preservation Costs

Sample Interview Guide Questions on Theme	Theme Definition	Subcodes	Subcode Definitions	Example
Q: What kinds of information would you like to know about fertility preservation [from your providers]? What kinds of information do you think is important for trans* youth and their families to know? Q: Would you want to discuss costs?	Discussions of fertility preservation cost details, ways youth and parents learned about costs from providers and others	Desire for clarity on long vs. short-term costs of FP	Parents and youth discsus the differences between up front costs of cryopreseraviton and long term storage costs	*S105: [I would like clarity on] costs, what is involved, all the blood work, mandatory tests. You know, shipping costs. You know, yearly storage fees The only issue was that it's still pretty expensive.* *S116: So the start-up costs were high [for sperm preservation], and then there's, like, a yearly maintenance cost. It's like $1,000 to do the saving process initially, maybe even a little higher, and then it's like $100 something for every year after that. So it's quite expensive... I guess it's good to have the option, but expense is a factor.* *S201: And having an idea about not only just the process of [in my child's case] harvesting eggs, but the storage of them for years going forward—how many years would they be viable, and how much is it going to cost you year over year over year to preserve.* *S213: You need to know what you're getting yourself into if you decide to do it, so you need to know the cost. And not just the cost initially, but the cost, the future costs.*
		Expected costs vs. actual costs	Parents and youth express surprise at the differences in expected costs for fertility preservation and actual costs	*S116: [My endocrinologist] did not know price [for fertility preservaiton]. So she referred us to the urologist, but before we met with the urologist, and even that meeting we had to pay for. But we were already referred and paying for the visit That was the first time where we saw the prices.* *S110: I went to see the price of it. I thought it was gonna be like $20 maybe even a $100..like no... $400 or $500 for like one sperm sample and I was like, huh, I'm gonna need at least 3.* *S120: And the biggest decision factor for me was cost. I absolutely had no idea how much it was going to cost.* *S209: Oh, yeah. 'Cause that was one of the things that [one physician] you know, they said the cost. I was just flabbergasted by the parents, that all they cared about was can we get it done over the summer! Do you not hear yourself, people?? That's just my opinion.*

Table 7. Theme: Costs in Decision-Making about Fertility Preservation

Theme Interview Guide Questions	Theme Definition	Subcodes	Subcode Definitions	Example
Q: What type of information would be helpful to include on a [fertility preservaiton] decision-making tool? Information about the process? New research? Costs? Testimonials from other families? Testimonials from trans adults? Others?	Immediate and future costs are a key factor in deicsion-making about fertility preservation	Costs prevent fertility preservation	Costs are prohibitive in accessing fertility preservation	*S106: The most important is being aware of costs. I think very important and does kind of pertain to a decision [about fertility preservaiton]* *Q: Can I ask, if financial pieces were not playing a part, do you think that your decision[about fertility preservation] would have been different?* *S110: Yep, yes yes most definitely. I'd be like, you know what, I will not be doing [hormones] without freezing my sperm so I can have a biological child of my own if financial issues weren't in play.* *S117: So we came to the conclusion by, like, talking and talking a lot about, like, costs and talking about, like, just kind of benefits of it, but also a lot of times of cost.* *S203: There's no way that we—there's no, I mean,, in our financial situation there's no way. I mean, even if we were like 'Oh yeah, we want to preserve eggs,' we can't.* *Q: Do you think, since you brought it up, do you think that if financial factors weren't necessarily a big factor, if you think that, if you would have been—* *S203: It would be one more thing to consider it more seriously, yes.* *Q: Do you think that would have led to a different kind of decision?* *S203: I don't know. I don't know.*
		Costs cause emotional distress	High costs/being unable to afford fertility preservaiton can cause significant emotional financial or psychosocial stress	*S104: Like before even a thing happens [with fertility preservation], you should see what all sorts of different insurance companies will cover in this area. Especially for fertility, 'cause like you don't want to bring someone's hopes up and then crash them down.. it'd be pointless to get their hopes up and then find out they won't be able to afford it cause it's just, worse for them*