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Original Article

Transgender Youth Fertility Attitudes Questionnaire: Measure Development in Nonautistic and Autistic Transgender Youth and Their Parents

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ABSTRACT

Purpose: The objective of this study was to assess transgender youth and parent attitudes regarding (1) the potential impact of gender-affirming hormone therapy on fertility and (2) fertility preservation (FP) options.

Methods: The Transgender Youth Fertility Attitudes Questionnaire was developed through a multistage participatory process with gender specialists and key stakeholders (transgender youth and their parents, N = 35). As up to 25% of youth gender referrals have co-occurring autism, measure development included a well-characterized supplementary sample of autistic transgender youth to maximize the applicability of the questionnaire. Following its development and refinement, the Transgender Youth Fertility Attitudes Questionnaire was pilot tested with transgender youth (nonautistic and autistic) and their parents (N = 51).

Results: The participatory process produced parallel child and parent questionnaires addressing fertility and FP knowledge and attitudes. In the pilot trial, youth and parents expressed generally similar attitudes about fertility and FP. Most youth (92%) reported learning about gender-affirming hormone therapy-related fertility issues online. Although many transgender youth endorsed a wish to parent children at some point, few (24%) expressed desire to have their own biological child. However, many youth wondered, or did not know, if their feelings about having a biological child might change in the future.

Conclusions: This study presents a novel procedure for developing instruments for use with transgender youth. Although a majority of transgender youth in this study were uninterested in using FP, extending exploration of this topic with young people may be useful given findings of their openness to the idea that fertility attitudes may change in adulthood.

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IMPLICATIONS AND CONTRIBUTION

Gender specialists, transgender youth, and parents collaborated to develop a fertility attitudes questionnaire for those facing potential infertility related to medical gender treatments. The resulting instrument assesses knowledge about the risks of infertility, feelings concerning having a biological child, and knowledge of fertility preservation procedures.

Conflicts of Interest: The authors have no conflicts of interest to disclose.

All persons who made significant contributions to this study and the manuscript are included in the present authorship list.

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Gender-affirming hormone therapy (GAH, formerly *cross-sex hormone therapy*) is a medical approach for supporting transgender individuals' physical gender-related needs. GAH and related medical gender approaches are often associated with improvements in psychological functioning, quality of life, and long-term outcomes [1–3]. For example, transgender youth supported by the “Dutch protocol,” including comprehensive gender assessments, medical puberty suppression at Tanner stage II, GAH starting at age 16, and gender-affirming surgical procedures in young adulthood, had psychological/adjustment outcomes indistinguishable from cisgender (nontransgender) peers [4].

GAH can interfere with fertility in individuals with ovaries or testes, and the effects may be long term or permanent, even if GAH is discontinued [5,6]. Infertility in the general population is associated with reduced psychological well-being and quality of life [7,8]. A range of medical techniques, collectively known as fertility preservation (FP), have been developed to preserve reproductive materials for individuals who could become infertile [9,10]. Two studies of FP utilization in transgender youth found low rates of FP usage among adolescents. Nahata et al. found that only 2 of 72 youth counseled about FP before beginning puberty suppression or GAH attempted FP [11]. Chen et al. found that 12.4% of their adolescent sample was seen for FP consultations, with only 4.8% of the sample ultimately attempting FP [12]. In contrast, two studies have reported that transgender adults may have a stronger desire for biological children and may regret that options for FP were not offered before commencing medical gender treatments [13,14]. Nahata et al. suggest that attitudes about fertility may change as transgender individuals enter adulthood [11].

Like GAH, cancer treatments can impact fertility; there is a literature on attitudes concerning fertility and/or FP in individuals with cancer [7,8,15]. Findings in cancer-related studies of youth and adults indicate high levels of worry about infertility both in cancer survivors [15] and in healthy youth thinking hypothetically about infertility from cancer treatments [16]. Parents are also concerned about the potential loss of their children's fertility and often express the wish to preserve their children's fertility before cancer treatments [17]. International guidelines recommend that physicians discuss with all patients of reproductive age the risk of infertility from their cancer or treatment, as well as FP options [10,18,19]. The present study builds on existing approaches and measures developed to assess fertility attitudes in youth with cancer and their parents [15,16,20] to systematically investigate attitudes to fertility in transgender youth and their families. The goal of the present study was to create a measure to assess attitudes and to support clinical conversations with patients and their families. The use of health-related questionnaires followed by clinical conversations may improve provider-patient communication by introducing key topics in a multimodal format [21].

A challenge developing measures for transgender individuals is the common co-occurrence of autism spectrum disorders (ASDs), with 9.7%–25% of gender dysphoric adolescents presenting with co-occurring ASD [22,23] and gender dysphoric feelings occurring in >5% of individuals with ASD [24,25]. Co-occurrence of ASD and gender dysphoria (GD) may impact gender assessments and consent for treatment, but many individuals with the co-occurrence are found appropriate for gender-related treatments [26]. Given the common co-occurrence, measures for transgender individuals should be developed and tested in ASD. This is particularly important for a fertility attitudes measure, as

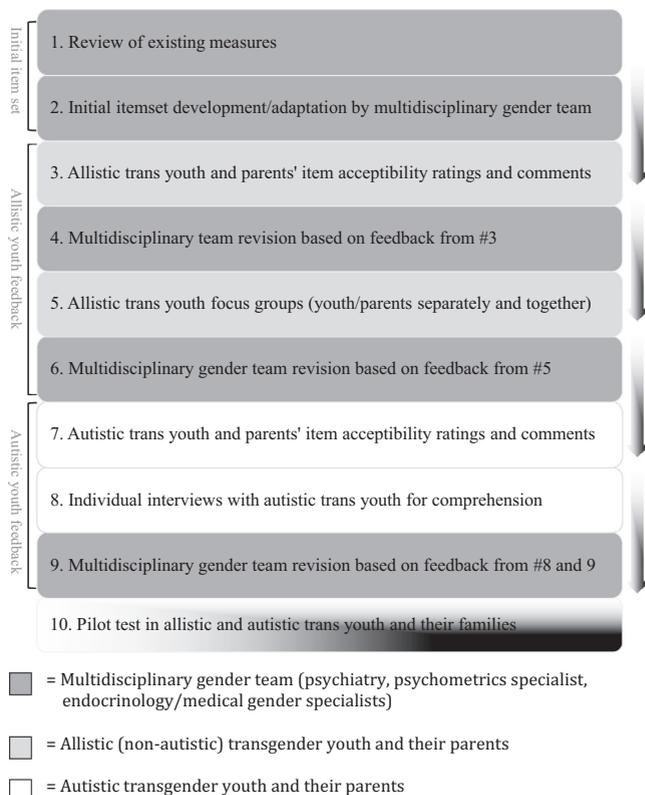


Figure 1. Participatory paradigm for measure development in transgender youth.

autistic individuals may struggle with self-awareness, future thinking and planning [27,28], requisite skills when considering treatments with potential long-term impacts, such as on fertility. The present study presents a novel measure development procedure for transgender assessments and evaluates the resulting Transgender Youth Fertility Attitudes Questionnaire (TYFAQ) in transgender youth and their parents.

Methods

Two studies occurred in sequence: (1) participatory process development of the TYFAQ and (2) TYFAQ piloting in transgender teens and their parents. Each study had a separate institutional review board approval.

Participatory process development of the Transgender Youth Fertility Attitudes Questionnaire

To maximize the acceptability and the applicability of the measure, we employed a nine-stage participatory process measure development procedure, parallel to established iterative participatory development methods [29,30], partnering with key stakeholders to create the TYFAQ (Figure 1). In the present study, the term *allistic*, used in the neurodiversity and autism self-advocacy movement, refers to nonautistic individuals [31]. Five groups were involved in the development process (N = 35): a multidisciplinary team of 6 gender specialists (two pediatric gynecologists, two child psychiatrists, a pediatrician, and a neuropsychologist); 6 allistic transgender youth (ages 14–17); 7

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