General Well-Being Scale (GWBS) of the Pediatric Quality of Life Inventory score	The GWBS of the Pediatric Quality of Life Inventory uses uses a 5-point response scale, contains seven items, and measures two dimensions: general wellbeing (6 items) and general health (1 item). Each item is scored from 0 to 4, and the total score is linearly transformed to a 0 to 100 scale. High scores reflect fewer perceived problems and greater well-being.
GnRH analogue	GnRH analogues competitively block GnRH receptors to prevent the spontaneous release of two gonadotropin hormones, Follicular Stimulating Hormone (FSH) and Luteinising Hormone (LH) from the pituitary gland. The reduction in LH and FSH secretion reduces oestradiol secretion from the ovaries in those whose sex assigned at birth was female and testosterone secretion from the testes in those whose sex assigned at birth was male.
Patient Health Questionnaire Modified for Teens score (PHQ 9_Modified for Teens)	The PHQ 9_Modified for Teens is a validated tool to assess depression, dysthymia and suicide risk. The tool consists of 9 questions scored from 0 to 3 (total score 0 to 27), plus an additional 4 questions that are not scored. A score of 0 to 4 suggests no or minimal depressive symptoms, 5 to 9 mild, 10-14 moderate, 15-19 moderate and 20-27 severe symptoms.
Quick Inventory of Depressive Symptoms (QIDS)	Both the clinician- and self-reported QIDS are validated tools to assess depressive symptoms. The tool consists of 16 items, with the highest score for 9 items (sleep, weight, psychomotor changes, depressed mood, decreased interest, fatigue, guilt, concentration, and suicidal ideation) are added to give a total score ranging from 0 to 27. A score of 0 to 5 is suggestive of no depressive symptoms, 6 to 10 mild symptoms, 11 to 15 moderate symptoms, 16-20 severe symptoms and 21 to 27 very severe symptoms.
Quality of Life Enjoyment and Satisfaction Questionnaire (QLES-Q-SF)	QLES-Q-SF is a validated questionnaire, consisting of 15 questions that rate quality of life on a scale of 1 (poor) to 5 (very good).
Screen for Child Anxiety Related Emotional Disorders (SCARED) questionnaire	SCARED is a validated, 41-point questionnaire, with each item scored 0 to 2. A total score of 25 or more is suggestive of anxiety disorder, with scores above 30 being more specific. Certain scores for specific questions may indicate the presence of other anxiety-related disorders: A score of 7 or more in questions related to panic disorder or significant somatic symptoms may indicate the presence of these. A score of 9 or more in questions related to generalised anxiety disorder may indicate the presence of this. A score of 5 or more in questions related to separation anxiety may indicate the presence of this. A score of 8 or more in questions related to social anxiety disorder may indicate the presence of this. A score of 3 or more in questions related to significant school avoidance may indicate the presence of this.
State-Trait Anxiety Inventory (STAI) score	STAI is a validated and commonly used measure of state anxiety (current state of anxiety) and trait anxiety (general state of calmness, confidence and security). It has 40 items, the first 20 covering state anxiety, the second 20 covering trait anxiety. STAI

	can be used in clinical settings to diagnose anxiety and to distinguish it from depressive illness. Each subtest (state and trait) is scored between 20 and 80, with higher scores indicating greater anxiety. There is no published minimal clinically meaningful difference (MCID) for STAI or thresholds for anxiety severity.
Strengths and Difficulties Questionnaire (SDQ, Spanish version	The SDQ, Spanish version includes 25-items covering emotional symptoms, conduct problems, hyperactivity/ inattention, peer relationship problems and prosocial behaviour. The authors state that a score of more than 20 is considered indicative of risk of having a disorder (normal: 0-15; borderline: 16-19, abnormal: 20-40).
Tanner stage	Tanner staging is a scale of physical development.
Transgender (including transmale and transfemale)	Transgender is a term for someone whose gender identity is not congruent with their birth-registered sex. A transfemale is a person who identifies as female and a transmale is a person who identifies as male.
Utrecht Gender Dysphoria Scale (UGDS)	The UGDS is a validated screening tool for both adolescents and adults to assess gender dysphoria. It consists of 12 items, to be answered on a 1- to 5-point scale, resulting in a sum score between 12 and 60. Higher scores indicate higher levels of gender dysphoria.

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CHILD & ADOLESCENT
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RESEARCH **Open Access**

Two years of gender identity service for minors: overrepresentation of natal girls with severe problems in adolescent development

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Abstract

Background: Increasing numbers of adolescents present in adolescent gender identity services, desiring sex reassignment (SR). The aim of this study is to describe the adolescent applicants for legal and medical sex reassignment during the first two years of adolescent gender identity team in Finland, in terms of sociodemographic, psychiatric and gender identity related factors and adolescent development.

Methods: Structured quantitative retrospective chart review and qualitative analysis of case files of all adolescent SR applicants who entered the assessment by the end of 2013.

Results: The number of referrals exceeded expectations in light of epidemiological knowledge. Natal girls were markedly overrepresented among applicants. Severe psychopathology preceding onset of gender dysphoria was common. Autism spectrum problems were very common.

Conclusion: The findings do not fit the commonly accepted image of a gender dysphoric minor. Treatment guidelines need to consider gender dysphoria in minors in the context of severe psychopathology and developmental difficulties.

Keywords: Transsexualism, Gender dysphoria, Sex reassignment, Adolescent development

Introduction

According to the ICD-10 [1], transsexualism involves a desire to live and be accepted as a member of the opposite sex, usually accompanied by the wish to make one's body as congruent as possible with one's preferred sex through surgery and hormonal treatment. The desire has to be persistent and not a symptom of a mental disorder. Gender dysphoria refers to dysphoria experienced due to the incongruence between a person's inner perception of her/his gender, and the incongruous bodily reality. The term Gender Dysphoria has also recently been adopted as the diagnostic category in DSM-5 [2]. Psychotherapeutic approaches have not proven successful in relieving gender dysphoria, and social, juridical, medical and surgical sex reassignment (SR) is nowadays the treatment of choice [3]. Sex reassignment with hormonal and/or surgical treatments has been reported to improve social, psychological and sexual well-being and functioning.

Surveys based on the Child Behaviour Checklist [4] report that 2-5% of children aged up to seven, as reported by their parents, "behaves like opposite sex" and 1-2% "wishes to be of opposite sex", but cultural issues likely play a major role in whether a child's behavior is perceived as gender atypical. Consultations due to gender identity are generally more often sought for boys than girls, which may suggest greater gender variation in boys, but also that effeminate behaviours in boys are perceived as more of a problem than tom-boyishness in girls [5,6].

Of children with even severe gender dysphoria and cross-sex identification, about 85% do not develop a persistent transsexual identity in adolescence (reviewed in [7]). Reliable indicators are not so far available regarding which gender dysphoric children cease to be so in puberty and who develop transsexual identity [8]. Medical interventions are therefore not warranted in pre-

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pubertal children. In light of current knowledge, transsexual identity in adolescence is persistent and medical interventions may be appropriate. According to the treatment model developed in the Netherlands (Dutch model), early treatment may include delaying puberty after its first stages with GnRh analogues, and administering cross-sex hormones from about age 16 [9,10]. This approach is recommended when childhood gender dysphoria exacerbates in puberty, no (primary) severe psychopathology is present, and the young person has appropriate developmental support and support for the process from her/his primary caregivers (parents). The rationale with GnRh analogue treatment is to prevent the undesired development of secondary sex characteristics and thereby facilitating later transition to the desired role, and postponing complicated and irreversible treatment decisions to a more mature age. Psychopathology largely attributed secondary to gender dysphoria is expected to be relieved by puberty blocking and resolved by sex reassignment [5,11,12].

In the past decade, the numbers of referrals to child and adolescent gender identity services have been on the increase across Europe (personal communications in 2013 and 2014 from UK, NL, Spain, Sweden child and adolescent gender identity teams) and in Canada [13]. It is not known whether this represents a true increase in gender dysphoria, lowered thresholds for seeking help for it or perhaps cultural developments that promote the conceptualization of developmental challenges as being rooted in sex and gender.

In Finland, the legislation stipulates that a transsexual person may be recognized in law as a member of the desired sex and have access to hormonal and surgical sex reassignment (in public health care) (act 2002/563). A psychiatric assessment by a specialized gender identity team is a prerequisite for legal as well as surgical sex reassignment, both of which have a lower age limit of 18. The specialized psychiatric assessment by a gender identity team is centralized to two university hospital psychiatric clinics, Tampere and Helsinki University Hospitals, in the country (codes 1053/2002 and 476/2010).

Since 2011, specialized adolescent psychiatric gender identity teams have been available for minors at the above mentioned two university hospitals. The excessive number of referrals, exceptional sex ratio and severity of general psychopathology among the applicants compared to what might have been anticipated on the basis of the literature called for clinical attention from the beginning of the service. The aim of this study is to describe the adolescent applicants for legal and medical sex reassignment in terms of sociodemographic, psychiatric and gender identity related factors and adolescent development in order to initiate a scientific discussion on the meaning of these observations.

Materials and methods

The study comprises a retrospective chart review of all the SR applicants attending for assessment by one of the two adolescent gender identity services in Finland (Tampere University Hospital, Department of Adolescent Psychiatry) in 2011–2013. Altogether 49 adolescents were referred to assessment for sex reassignment and invited to their first meeting during the study periods, but two adolescents declined to start the evaluation. Thus 47 adolescents are included in this study. Of these, one was mutistic and did not provide any information; for this young person, information on personal experiences is missing but information from case records and parents could be used.

The assessments take place in an outpatient setting and comprise structured and free format assessments and interviews with an adolescent psychiatrist, a psychiatric nurse, a social worker and a psychologist. The adolescent and her/his parents/guardians are seen together and separately by all the multi-disciplinary team members. Psychiatric and medical files are requested from all previous health care contacts of the adolescent, with due permission from her/him and her/his parents. After completing all the assessments, the multi-disciplinary team discusses the diagnosis as to gender identity and mental disorders, eligibility for hormonal SR treatments and possible other needs to be met and recommendations to be given regarding gender identity needs and mental health needs when appropriate. All the below described measures were collected using all the material available after the assessment. The study received approval from the ethics committee of Pirkanmaa Hospital District.

Measures

Sociodemographic variables collected were age, natal sex, family structure (living with both parents/one parent/neither parent) and parental education (professional/intermediate/skilled non-manual/skilled manual/unskilled or not in employment). Further background information included the reason for referral (sex reassignment, definite wish/sex reassignment, possible reassignment/other) and parental homosexuality or transsexualism (yes/no).

Throughout the discussion of our own research we use the terms “gender dysphoria” and “gender dysphoric” to refer to the experienced gender incongruence among our applicants, regardless of whether they fulfill the diagnostic criteria for Gender Dysphoria in the DSM-5. For the present study we recorded whether there had been signs of gender dysphoria/gender incongruence in childhood (before age 12) (Table 1). Age of onset of conscious gender concerns and age when the applicant was convinced that s/he is transsexual were recorded. If the adolescent was already living in the desired role (Table 1), it was recorded for how long.

Table 1 Variable descriptions for childhood gender dysphoria, bullying and social isolation

Gender dysphoria/gender incongruence in childhood (<12 years of age)	
Childhood gender dysphoria/incongruence present	Childhood gender dysphoria/incongruence not present
• explicit gender dysphoria or marked and persistent cross-gender identification on behavioural level even without explicit verbalization of one's gender related thoughts and feelings in childhood	• no signs of gender dysphoria/incongruence in childhood
Gender presentation, living in desired role	
Classified as living in the desired role	Not classified as living in the desired role
• the applicant had officially changed her/his name to a gender neutral one or arranged his/her registration in school, and being consistently called, by a name suggesting the desired sex; being always presented to new people as being of the desired sex; being treated by family, teachers/ employers, friends, schoolmates as well as by new people as a member of the desired sex • some of these young people had explicitly "come out" in school and openly made a transition to the desired role; some, with the support of some community key adults, had adults, had totally concealed their natal sex from the school/workplace	• the adolescent had not made any attempt to live and be treated in the desired role • the adolescent dressed gender neutrally and asked the family to use a name indicative of the desired sex, but was actually not living in any social role outside the family due to isolation from social interactions • some of the adolescents in this group were almost totally isolated in their homes (not going to school or work, not meeting peers), some attended school but were isolated from social interactions there and elsewhere
Bullying	
Significantly subjected to bullying	Not subjected to bullying
• the applicant and/or her/his parents considered that there had been significant and traumatic victimization. • a) related to gender presentation or sexual identity: name-calling, spreading rumours and the like related to gender presentation/sexual identity • b) not related to gender or sexual identity: bullying was related to other issues like weight, interests, belonging or not belonging to a certain group etc.	• no recollection of being bullied • if ever bullied, the adolescent described it as non-significant ("maybe sometimes", "not more than anyone else").
Isolation	
Periods of isolation	No isolation
• periods of not having contact with peers outside of arranged study-related activities at school - or not even that, if not attending school • having same-age contacts only with one's own siblings • keeping (tenuous, infrequent) contact with one or two peers only despite previously having been normatively engaged with peers • contacts outside the family only via Internet	• no interruptions in attending age appropriate daily programme (usually school), having age-appropriate contacts with peers

Previous and current psychiatric history was recorded. Previous files were not always complete, and diagnoses were not always accurately defined in terms of ICD-10 diagnostic codes. Thus, we recorded 1) whether the young person had been in contact with psychiatric services prior to entering the gender identity service (yes/no), 2) whether the previous contact had been because of gender concerns or psychiatric symptoms (gender issues only/psychiatric symptoms only/both), 3) what kind of problems the young person had displayed (anxiety, depression, suicidal behaviours, conduct problems, autism spectrum related problems, substance abuse, psychotic symptoms, other; all recorded yes/no), and 4) the temporal relationship between psychiatric symptoms and gender dysphoria/identity concerns (psychiatric symptoms emerged earlier/gender dysphoria and gender identity concerns emerged first).

Peer-related difficulties were recorded being subjected to bullying at school (yes/no) and isolation from peers (yes/no) (Table 1). Of bullying it was recorded whether it happened before, after or both before and after of the onset of gender dysphoria, and whether it was related to gender presentation or sexual orientation. Of social isolation it was recorded whether it occurred before, after or both before and after the onset of gender dysphoria.

Statistical analyses

All the variables were recorded in a structured form developed for this research. Descriptive analysis was conducted using statistical methods for quantitative data. We report frequencies and means (sd) where appropriate. Between groups comparisons are made with crosstabulations and chi-square statistics/Fisher's exact test, and with t-test where appropriate.

Qualitative observations

The qualitative content analysis approach [14] was applied to illustrate, based on all material recorded in case histories, different groups of gender dysphoric adolescents, or different developmental pathways resulting in the adolescent now perceiving the need to apply for sex reassignment. This was carried out by condensing and extracting from all material recorded in the case histories similar and different developmental patterns and descriptions of experiences that could be used to create mutually exclusive model stories, or trajectories that would include all the studied adolescents and not allow for assigning a given adolescent to more than one trajectory. The model stories were not defined in advance but they were formed in a data-driven process, the outcome of which is presented.

41 girls
6 boys

PARENTS

49% both
39% one
13% foster

GENDER ?
BEGAN

32% before 12
62% after 12
6% unknown

20% most
common at age
14

64% —no
recollection
of early gender
issues
11%, early onset
persistent
6% early onset
transient
19% tomboy
girls w/o ? gender
or dysphoria

Results

Demographics

Of the applicants included in the present study, 41 were natal girls and 6 were natal boys. Their mean age (sd) at entering assessment was 16.04 (0.57) years for natal boys and 16.66 (1.07) for natal girls (p = 0.18). Of these, 49% (23) were living with both their biological parents, 39% (18) with one biological parent, and 13 % (6) in child welfare foster placements or independently. Parental education was distributed as follows: 16% (8) professional, 5% (2) intermediate, 22% (10) skilled non-manual, 43% (20) skilled manual, and 14% (7) were unskilled or not participating in work life. None of the applicants had transsexual or homosexual parents.

Gender dysphoria

Of the applicants, 32% (14/47) reported having started to consciously question their gender before age 12, 62% (30/47) at 12 or later, and three applicants (6%) could not define this. Most commonly (one in five) these concerns had started at age 14. There were altogether five applicants (11%) who during childhood had persistently expressed gender dysphoria and/or identified with the opposite sex, and three (6%) who during childhood had transiently displayed gender dysphoria and a desire to be of the opposite sex. A further nine applicants (19%) had been tomboyish girls but had not questioned their gender or experienced dysphoria, and as to most of the applicants (30/47, 64%), neither the young person nor her/his parents recalled gender dysphoria or cross-gender behaviors during childhood.

During the assessment process, 72% (34/47) of the applicants were sure about feeling they were of the opposite sex to their natal and about pursuing sex reassignment, but 28% (13/47) were not sure about their feelings regarding gender identity and/or sex reassignment. There was no difference between natal girls and natal boys in this regard. Of those who felt sure about their cross-gender identity, 15% (5/34) recalled reaching the conclusion before age 12, 79% (27/34) at 12 or later, and two (6%) could not define at what age they had reached the conclusion. There was no difference between natal girls and natal boys. The time frame from first becoming aware of gender dysphoria to being sure of one's own cross-gender identity ranged from 0 to 7 years, with mean 1.6 (sd 2.1) years.

Of all the applicants, 38% (17/47) were living in the desired role when the assessment was completed, 50% (3/6) of the natal boys and 37% (15/41) of the natal girls (p = 0.41). Of those applicants who expressed certainty about being of other than their natal sex and desiring physical and legal sex reassignment, 47% (16/34) were living in the desired role. Of those who were living in the desired role, the mean (sd)/median time of living in the role was 28.3 (17.9)/24.0 months for natal boys, and 29.8 (39.2)/12 months for natal girls (p = ns).

Peer relationship difficulties

Of the applicants, 57% (27/47) had been significantly bullied at school, 53% (25/47) in primary school (grades 1–6, ages 7–13 yrs) and 45% (21/47) in secondary school (grades 7–9, ages 13–16 yrs). Of those who had been victims of bullying, 73% (19/27) had been bullied before they came to think about their gender identity, 8% (2/27) after starting to think about gender issues, and 19% (5/27) both before and after. Of those bullied, 27% (7/26) reported that bullying had been related to gender presentation or sexual identity, and 73% (19/26) had been bullied due to some other reasons (see Table 1).

Natal girls and natal boys had been bullied equally frequently. Natal girls tended more often to report having been bullied only before the onset of gender dysphoria, and natal boys more often both before and after the onset of gender dysphoria (girls: 78% (17/23) only before, 9% (2/23) only after, 13% (3/23) before and after vs. boys: 33% (1/3) only before, none only after, 67% (2/3) both before and after, p = 0.08). Among natal boys gender presentation and/or sexual identity had always been the topic of the bullying, among natal girls 83% (19/23) had been bullied for something else and 17% (4/23) due to gender presentation/sexual identity (p = 0.01).

Of the applicants, 45% (21/47) had presented with periods of isolation from peer relationships; 32% (15/47) before and 40% (19/47) after the onset of gender dysphoria, and 43% (20/47) were socially isolated during the SR assessment. Twenty-eight per cent (13/47) were isolated in all three observed periods. Social isolation was equally common among natal boys and girls applicants.

75% seeing psych for issues other than GD

64% depression
55% anxiety
53% SI or self harm
13% psychosis
9% conduct d/o
4% substance abuse
26% ASD
11% ADHD

68% first contact with psych was not for GD

Psychiatric treatment and psychopathology

Seventy-five per cent of the applicants (35/47) had been or were currently undergoing child and adolescent psychiatric treatment for reasons other than gender dysphoria when they sought referral to SR assessment, and two more were contacted with general adolescent psychiatric services soon after entering the SR assessment. Sixty-four per cent (30/47) were having or had had treatment contact due to depression, 55% (26/47) due to anxiety disorders, 53% (25/47) due to suicidal and self-harming behaviours, 13% due to psychotic symptoms (6/47), 9% (4/47) due to conduct disorders, 4% (2/47) due to substance abuse, 26% (12/47) due to autism spectrum disorder, and 11% (5/47) due to ADHD. One severe case of anorexia nervosa was noted. Of the applicants, 68% (32/47) had had their first contact with psychiatric services due to other reasons than gender identity issues. Natal boys and natal girls had equally commonly been treated for psychiatric disorders except for ADHD which had been more commonly treated in natal boys (50% vs.5%, $p = 0.01$). The mean number of distinct psychiatric problems was 2.3 (sd 1.7), with no difference between natal girls and natal boys.

The different groups

Five different mutually exclusive groups (a - e below) were identified that differed as to onset of gender dysphoria and cross-gender identification, psychopathology and adjustment/difficulties in social relationships, and the temporal relationships between these. They are presented in Table 2.

We carried out logistic regression analyses to detect what kind of presenting features were associated with belonging to the last, confused group of adolescents with gender dysphoria (e) when entered in the model simultaneously. This was appropriate because psychiatric symptoms and psychosocial functioning are strongly interrelated. Age and natal sex were not predictive of belonging to the confused group. Each psychiatric problem, being subjected to bullying, presenting with periods of isolation, number of different psychiatric problems, and months living in desired role were each in turn entered as independent variables, controlling for age and natal sex. When controlling for age and natal sex, group memberships was predicted by anxiety (OR 4.8, 95% CI 1.4-17.0), suicidality (OR 5.7, 95% CI 1.7-20.3), number of different psychiatric symptoms (OR

Table 2 The different groups of gender dysphoric adolescents seeking SR

Early onset gender dysphoria, exacerbates in puberty	
a) with no with no significant psychopathology and developmental problems (n = 2)	b) with considerable psychopathology and developmental problems (n = 3)
• very mild or no psychopathology across childhood and until the assessment	• severe psychopathology that had previously and currently required specialist level child and adolescent psychiatric care (autism spectrum disorder, OCD, Tourette, anorexia nervosa, suspected psychotic episodes or psychosis high risk, specific learning difficulties)
Adolescent onset gender dysphoria, where transsexual identity appeared established	
c) without, or with only mild psychopathology and developmental difficulties (n = 10)	d) with severe psychopathology and developmental difficulties (n = 9)
• mild to moderate depression or anxiety, could be considered secondary to gender dysphoria, or was transient, and did not impair functioning in social relationships or school	• psychiatric problems that warranted specialist level adolescent psychiatric treatment, either in treatment at the beginning of their SR assessment, or treatment contact was arranged during the SR assessment
• age-appropriate social relationships and leisure time activities, participation in age-appropriate educational activities (comprehensive, vocational or upper secondary school)	• autism spectrum disorders (3), major depression (3), social phobia (5), substance abuse problems (1) or a history of conduct disorder and trauma (2) (several had two disorders); clearly more severe psychopathology than what was seen in group c
e) Adolescent onset gender dysphoria, identity confused development (n = 23)	
• In childhood, no gender dysphoria nor cross-gender behaviors	
• For most of their primary school years (age 7–12 years) felt excluded	
• Persistent experiences of bullying before the onset of gender dysphoria	
• In adolescence, social anxiety and depression, most often with self-harm and suicidal preoccupation if not suicide attempts	
• Isolated	
• Long periods of not attending school, or if attended school, did not engage in peer contacts outside learning situations arranged by teachers.	
• Did not meet with same-aged peers in leisure time, or they met with few peers and only if their parents arranged it; many in contact only with their family members.	
• Socially and/or academically marginalized	
• Very high expectations that SR would solve their problems in social, academic, occupational and mental health domains	

1.7, 95% CI 1.1-2.6), and presenting with periods of isolation (OR 9.0, 95% CI 2.3-34.7). However, when presenting with periods of social isolation was entered into any other model, the other independent variables were leveled out, suggesting that social isolation was the strongest factor predicting membership of the problematic, identity confused group.

Discussion

The number of referrals exceeded expectations. Given the most cited epidemiological figures among adults, 1:10 000–1:30000 MtF and 1:40 000–1:100 000 FtM [6], in Finnish population, 6–18 boy-to-girl adolescents and 2–4 girl-to-boy adolescents aged 13–18 would be expected. The number of referrals to the study unit already doubled the less conservative estimates based on adult figures. Referrals to the other adolescent gender identity unit amount to equal numbers, and the natal girl:boy ratio in referrals is also similar in the other unit (Tainio V-M, personal communication). Valid epidemiological research on incidence and prevalence of transsexualism or gender dysphoria at large among adolescents is not available [6]. The adult figures cited above are based on treatment seeking, as are the numbers presented in the present study. Gender dysphoria may be more common among adolescents than among adults, or it may be increasing in younger age cohorts.

Not all applicants could be seen as presenting with established transsexual identity, even though they suffered gender dysphoria. Excluding the confused (e) group in our data, 3 boy-to-girl and 21 girl-to-boy applicants were identified who displayed transsexual identity that appeared established, unique, and not part of more general identity confusion or secondary to severe mental disorders. Given that these numbers are based on half of the adolescent gender identity assessments in Finland, the findings further suggest that severe and persistent gender dysphoria/transsexualism in adolescence may be more common than hitherto assumed.

The natal girl:boy ratio among the adolescent SR applicants was very high. In prepubertal children referred to gender identity services, boy:girl ratio is reportedly 3–6:1, with some variation across countries presumably due to cultural reasons [5,13]. Previously a more even boy:girl ratio has been suggested in adolescents seeking sex reassignment than among child samples [13], and a recent paper from Germany reported natal boy:natal girl ratio of 0.81 among 268 minors diagnosed with gender identity disorder from 1987–2013 [15]. Among adults, there seems to be remarkable variation across countries in the ratio of natal men:natal women seeking for sex reassignment [16]. In Western countries natal male transsexuals exceed natal females transsexuals. A German study demonstrated that the natal male:natal female ratio among transsexual people has changed to more equal towards 2000's that what it was in earlier decades [16]. However, the overrepresentation of girls on our sample differs still from these more recent trends, and it is similar in both the two Finnish centers. We have so far no explanation for this great overrepresentation of natal girls seen in our material, and equalizing of sex ratio demonstrated by others [13,15,16]. Cultural trends may somehow influence this. May be more permissive societal attitudes allow "coming out" as gender variant more easily than before. However, why this would concern primarily girls remains an open question.

Of children and adolescents, 10-15% are regularly (weekly) involved in school bullying [17]. Of the adolescent SR applicants, more than a half had been subjected to bullying. Even if in the present study it was not possible to verify exactly how frequently the applicants had been bullied, we only recorded bullying that the adolescent and her/his parents perceived as significant: particularly intensive, vicious, long-term and traumatizing. However, in more than two thirds of the cases, bullying had occurred before the onset of gender dysphoria, and was not targeted at gender or sexual identity. Bullying is an unspecific risk factor for developmental problems rather than a problem specifically related to gender identity. That natal boys were more commonly bullied because of gender presentation suggests that effeminate characteristics in boys are less tolerated than masculine self-presentation in girls.

Peer relationships are of the outmost importance during adolescent development [18-20], and social isolation from peer relationships suggests developmental difficulties and impaired mental health [21-24]. In the present sample, isolation was extremely common and also the strongest predictor of membership of the "confused" group.

More than three quarters of the adolescent SR applicants had needed and/or currently needed specialist level child and adolescent psychiatric services due to psychiatric problems other than gender dysphoria. Specialist level child and adolescent psychiatric services are provided exclusively for severe disorders in Finland [25,26]. The recorded comorbid disorders were thus severe and could seldom be considered secondary to gender dysphoria. This utterly contradicts the findings in the Dutch child and adolescent gender identity service, where two thirds of adolescent SR applicants did not have psychiatric comorbidity [27]. In a recent German study, 43% of children and adolescents seen in a specific gender identity unit suffered from major psychopathology [15]. For the time being, we are unable to explain why Finnish adolescent SR applicants appear psychiatrically much more disturbed than has been reported elsewhere, but our findings warrant attention. The treatment guidelines for adolescent gender dysphoria may require extensions taking into account the needs of those with severe psychopathology and identity confusion, very unlikely currently eligible to medical SR.

The overlap between autism spectrum disorders and gender dysphoria has been recognized before [28]. In a Dutch gender identity service, 9.4% of adolescents presented with autism spectrum disorder. In our sample, 26% of the adolescent SR applicants were diagnosed to be on the autism spectrum. These diagnoses had mainly been made during the adolescents' previous psychiatric treatment in our hospital or elsewhere, but three such diagnoses were also made by our team. In our hospital, the ADOS [29] is used with the minors, and the 3Di [30] or ADI-R [31] with parents to diagnose autism spectrum disorders. We could not systematically review with which protocols the diagnoses had been made elsewhere in the country, but in our clinical opinion there was no reason to doubt them. It is currently not known why autism spectrum is overrepresented in gender dysphoric children and adolescents. The conditions could be truly co-occurring. Prenatal exposure to high levels of testosterone could be involved in the development of both conditions, especially for girls with autism spectrum disorder, but this leaves the comorbidity in males unexplained. Gender identity issues could arise from autism spectrum people's predisposition toward unusual interests, or gender dysphoria in ASD could represent OCD rather than genuine gender identity issues. The cross-gender behaviour in ASD minors could also rather represent non-normative sexual interests or unusual sensory preferences [28]. Our clinical impression is that a long-standing feeling of being different and an outsider among peers could play a role in ASD children developing gender dysphoria in adolescence. In our clinical sample of gender dysphoric adolescents, autism spectrum disorders by far exceeded the prevalence of 6/1000 suggested for general population [32], and almost three-fold that in the sample of deVries et al. [28]. Autism spectrum needs to be taken seriously in considering treatment guidelines for child and adolescent gender dysphoria. Given the nature of ASD, particularly ASD children's and adolescents' difficulties in adjusting to changes, profound changes in their own bodies with SR treatments may pose a major challenge to psychological adjustment, and ASD adolescents may be particularly rigidly unwilling to consider this in advance.

In the international literature on gender dysphoria in minors, the most often portrayed picture is that of childhood cross-gender identification/gender dysphoria, where gender dysphoria exacerbates in puberty due to the development of secondary sex characteristics. Our findings suggest that there are many more developmental pathways that may also need different treatment approaches. In our data, most of the adolescents first presented with gender dysphoria and cross-gender identification well after the onset of puberty, and the vast majority suffered significant psychopathology and broader identity confusion than gender identity issues alone. It is important to be able to openly discuss these alternative presentations of gender dysphoria in order to find appropriate treatment options.

Adolescence is a period of identity formation. From early to late adolescence, identity develops from fragmented and contextual identity experience to endogenous, permanent and integral identity that remains constant across contexts and interactions [33]. Identity is formed through diverse physical and psychological developments and in relation to other people and the social environment [34,35]. An adolescent also faces fundamental identity challenges in the domains of religion, worldview, ethnicity, sexuality and the like. Identification with various groups is often passionate during adolescence, but the object of identification may also change, even several times [34-37]. Adolescents are more suggestible and submit more readily to group pressure to gain acceptance [38]. Adolescence is a period of maturation of social cognition, and a prerequisite for the maturation of social cognition is the maturation of the central nervous system that continues to the third decade of life [39]. During puberty and adolescent development there may be some overlap between normative testing of sexuality and gender roles in the one end, and gender dysphoria as a disorder in the other end of the spectrum. This would implicate that GD in adults and in adolescence may not be the same issue in general. For these reasons it is more challenging to assess whether the gender identity of an adolescent is so firmly established that physical intervention is indicated than it is to assess this among adults.

In the majority of the applicants, gender dysphoria presented in the context of wider identity confusion, severe psychopathology and considerable challenges in the adolescent development. At this point it is not possible to predict how gender dysphoria in this group will develop: will gender dysphoria in these adolescents cease with the resolution of wider developmental problems, or perhaps consolidate later into transsexual identity, with the completion of the developmental tasks of adolescence.

Methodological considerations

The present paper is based on information on all adolescents who entered the assessment for sex reassignment in Finland in 2011–2013 by one of the two centralized adolescent gender identity teams in the country. The basis for choosing one or another of the two centers was geographical and not likely to create bias due to subject selection. It is further known that number of referrals during the study period well as natal girl:natal boy ratio are similar in both centers.

The data collection was systematic and structured, which adds to the reliability of the findings. The data collection took place in the form of retrospective chart review of files created during a comprehensive assessment period by a multi-disciplinary team. Thus data collection was unlikely to bias the assessments in any way. Comprehensive assessments by a multi-disciplinary team are likely to provide reliable and valid data. The multidisciplinary team collected information from the applicants themselves, from their parents, from previous case histories and by their own psychometric measurements. The applicants themselves might be prone to interpret a variety of their problems as being a result of gender incongruence, even if the problems actually were independent of gender identity issues or even predisposing to gender incongruence. In this study we attempted to avoid bias due to subjects' interpretation by using multiple source of information.

However, the data is relatively small and does not permit complex analyses. The study remains descriptive and cannot shed light on causal relationships. Some information of interest for the research was occasionally missing in the files, because the files were primarily created for clinical purposes, not for research.

The validity of the diagnoses in previous psychiatric contacts needs to be considered with certain caution. Previous files were not always complete and did not provide diagnoses according to ICD-10, and we were not able to check in the databases of the previous treatment providers what ICD diagnoses were recorded there. Thus, we recorded reasons for previous treatment based on verbalizations in the referrals and available copies of previous files. This only allowed a rough descriptive classification to problems related to anxiety, depression, suicidal behaviours, conduct problems, autism spectrum related problems, substance abuse, psychotic symptoms and other. We only recorded these problems if the adolescent had had a psychiatric treatment contact. The data gives a picture of the primary problems in previous psychiatric treatment contacts but not of all possible symptoms. Thus, our figures for problems related to anxiety, depression etc. are likely underestimates. It was also not possible to obtain exact information of when the various symptoms and disorders had been present and for how long time, except for autism which is of course assumed a lifetime condition. However, as clinical research on adolescent SR applicants is scarce, descriptive studies are valuable in providing a basis for discussion and international comparisons that are needed in order to create optimal clinical treatment guidelines.

Psychotic symptoms in our data mainly comprise brief and limited hallucinatory experiences. Psychotic symptoms were recorded if there were descriptions of hallucinations in the files, or of the previous files mentioned "psychotic symptoms" even when not giving more detailed descriptions. However, none of the applicants had a diagnosis of schizophrenia or schizoaffective disorder. Assessing gender dysphoria in the context of schizophrenia spectrum psychoses would be inappropriate. Doctors/units primarily contacted would very unlikely refer a patient with schizophrenia or schizoaffective disorder in gender identity assessments. Current psychotic symptoms would result in the gender identity team promptly referring the young person to general adolescent psychiatric care.

The findings cannot be generalized to all adolescents experiencing gender variation. Not all gender incongruent people perceive a need to seek for SR, or find it timely during adolescence.

Conclusion

Adolescents seeking sex reassignment represent a variety of developmental pathways differentiated by the timing of onset of gender dysphoria, psychopathology and developmental difficulties. It is important to be aware of the different groups, or developmental pathways, in gender dysphoric adolescents in order to be able to find appropriate treatment options. In the presence of severe psychopathology and developmental difficulties, medical SR treatments may not be currently advisable. Treatment guidelines need to be reviewed extended to appreciate the complex situations.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

All authors participated in designing the present study and formulating the study questions. RKH and MS collected the data from case files. RKH performed the data analysis. All the authors participated in discussing the results and writing the manuscript. All authors read and approved the final manuscript.

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ORIGINAL PAPER

Individuals Treated for Gender Dysphoria with Medical and/or Surgical Transition Who Subsequently Detransitioned: A Survey of 100 Detransitioners

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Abstract

The study's purpose was to describe a population of individuals who experienced gender dysphoria, chose to undergo medical and/or surgical transition and then detransitioned by discontinuing medications, having surgery to reverse the effects of transition, or both. Recruitment information with a link to an anonymous survey was shared on social media, professional listservs, and via snowball sampling. Sixty-nine percent of the 100 participants were natal female and 31.0% were natal male. Reasons for detransitioning were varied and included: experiencing discrimination (23.0%); becoming more comfortable identifying as their natal sex (60.0%); having concerns about potential medical complications from transitioning (49.0%); and coming to the view that their gender dysphoria was caused by something specific such as trauma, abuse, or a mental health condition (38.0%). Homophobia or difficulty accepting themselves as lesbian, gay, or bisexual was expressed by 23.0% as a reason for transition and subsequent detransition. The majority (55.0%) felt that they did not receive an adequate evaluation from a doctor or mental health professional before starting transition and only 24.0% of respondents informed their clinicians that they had detransitioned. There are many different reasons and experiences leading to detransition. More research is needed to understand this population, determine the prevalence of detransition as an outcome of transition, meet the medical and psychological needs of this population, and better inform the process of evaluation and counseling prior to transition.

Keywords Gender dysphoria · Detransition · Transgender

Introduction

Detransition is the act of stopping or reversing a gender transition. The visibility of individuals who have detransitioned is new and may be rapidly growing. As recently as 2014, it was challenging for an individual who detransitioned to find another person who similarly detransitioned (Callahan, 2018). Between 2015 and 2017, a handful of blogs written by individual detransitioners started to appear online, private support groups for detransitioners formed, and interviews with detransitioners began to appear in news articles, magazines, and blogs (Anonymous, 2017; 4thwavenow, 2016; Herzog, 2017; McCann, 2017). Although few YouTube videos about detransition existed prior to 2016, multiple detransitioners started to post videos documenting their experiences in 2016 and the numbers of these videos continues to increase.[1] In late 2017, the subreddit r/detrans (r/detrans, 2020) was revitalized and in four years has grown from 100 members to more than 21,000 members. A member poll of r/detrans conducted in 2019 estimated that approximately one-third of the members responding to the survey were desisters or detransitioners (r/detrans, 2019). The Pique Resilience Project, a group of four detransitioned or desisted young women, was founded in 2018 as a way to share the experiences of detransitioners with the public (Pique Resilience Project, 2019). In late 2019, the Detransition Advocacy Network, a nonprofit organization to "improve the well-being of detransitioned people everywhere" was launched (The

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[1] A search of the word "detransition" in YouTube can be filtered by date of upload. https://www.youtube.com/results?search_query=%22detransition%22&sp=CAI%253D22.

Detransition Advocacy Network, 2020) and the first formal, in-person conference for detransitioned people was held (Bridge, 2020). In the face of this massive change, clinicians have called for more research into the experiences of detransitioners (Butler & Hutchinson, 2020; Entwistle, 2021; Marchiano, 2020).

Although there were rare published reports about detransitioners prior to 2016, most of the published literature about detransition is recent (Callahan, 2018; D'Angelo, 2018; Djordjevic et al., 2016; Kuiper & Cohen-Kettenis, 1998; Levine, 2018; Marchiano, 2017; Pazos Guerra et al., 2020; Stella, 2016; Turban & Keuroghlian, 2018; Turban et al., 2021; Vandenbussche, 2021). The prevailing cultural narratives about detransition are that most individuals who detransition will retransition and that the reasons for detransition are discrimination, pressures from others, and nonbinary identification (Turban et al., 2021). However, case reports are shedding light on a broader and more complex range of experiences that include trauma, worsened mental health with transition, re-identification with natal sex, and difficulty separating sexual orientation from gender identity (D'Angelo, 2018; Levine, 2018; Pazos Guerra et al., 2020).[2] Detransitioners and desisters, in their own words, have provided additional depth to the discussion, describing that:

1. Trauma (including sexual trauma) and mental health conditions contributed to their transgender identification and transition (Callahan, 2018; Herzog, 2017; twitter.com/ftmdetransed & twitter.com/radfemjourney, 2019)
2. Their dysphoria and transition were due to homophobia and difficulty accepting themselves as homosexual (Bridge, 2020; Callahan, 2018; upperhandMARS, 2020)
3. Peers, social media, and online communities were influential in the development of transgender identification and desire to transition (Pique Resilience Project, 2019; Tracey, 2020; upperhandMARS, 2020)
4. Their dysphoria was rooted in misogyny (Herzog, 2017)

Two recently published convenience sample reports provide additional context about the topic of detransition. First, Turban et al. (2021) analyzed data from the United States Trans Survey (USTS) (James et al., 2016). The USTS contains data from 27,715 transgender and gender diverse adults from the U.S. who were recruited through lesbian, gay, bisexual, transgender, queer (LGBTQ), and allied organization outreach. The USTS included the question, "Have you ever detransitioned? In other words, have you ever gone back to living as your sex assigned at birth, at least for a while?" with the multiple choice options of "yes," "no," and "I have never transitioned." For the 2,242 participants who answered "yes," Turban et al. analyzed the responses to the multiple choice question, "Why did you detransition? In other words, why did you go back to living as your sex assigned at birth? (Mark all that apply)." Although most of the offered answer options were about external pressures to detransition (pressure from spouse or partner, pressure from family, pressure from friends, pressure from employer, discrimination, etc.), participants could write in additional reasons that were not listed. Turban et al.'s sample included more natal males (55.1%) than natal females (44.9%). Roughly half (50.2%) had taken cross-sex hormones and 16.5% had obtained surgery. The findings revealed that most (82.5%) of the sample expressed at least one external factor for detransitioning and 15.9% expressed at least one internal factor (factors originating from self).

The second study by Vandenbussche (2021) recruited detransitioners from online communities of detransitioners and analyzed data for the participants who answered affirmatively to the question, "Did you transition medically and/or socially and then stopped?" The sample of 237 participants was predominantly natal female (92%), and from the U.S. (51%) and Europe (32%). Most (65%) had transitioned both medically and socially. Participants selected from multiple choice options to indicate why they detransitioned with options covering a range of experiences. Respondents also had the option to write in additional reasons. Frequently endorsed reasons for detransition included realizing that their gender dysphoria was related to other issues (70%); health concerns (62%); observing that transition did not help their dysphoria (50%); and that they found alternatives to deal with their dysphoria (45%). In contrast to Turban et al. (2021), external factors such as lack of support, financial concerns, and discrimination were less common (13%, 12%, and 10%, respectively). Many in the sample described that when they detransitioned they lost support or were ostracized from lesbian, gay, bisexual, and transgender (LGBT) communities, suggesting that many of the participants in Vandenbussche (2021) would not have been reached by the recruitment efforts of the USTS (James et al., 2016).

The objective of the current study was to describe a population of individuals who experienced gender dysphoria, chose to undergo medical and/or surgical transition and then detransitioned by discontinuing medications, having surgery to reverse the effects of transition, or both. In contrast to Turban et al. (2021) and Vandenbussche (2021), this study focused only on

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[2] The debate about the terminologies used to describe an individual's sex (including "assigned sex at birth," "biological sex," "natal sex," "birth sex," "sex," etc.) is far from settled. Although some professionals have argued for the use of "assigned sex at birth," others argue that this terminology is misleading and not consistent with the events that occur at birth and prior to birth (Bouman et al., 2017; Byng et al., 2018; Dahlen, 2020; Griffin et al., 2020). Supporting the unsettled nature of the discussion, I received conflicting comments from the reviewers of this manuscript about my selection of natal sex terms–one reviewer asked that I justify my preference for natal sex over the other terminologies; another reviewer expressed support for my use of natal sex. I prefer to use "natal sex" and "birth sex" because they are accurate and objective. Further, I propose that "natal sex" and "birth sex" might be seen as reasonable, polite compromise terms between "biological sex" and "assigned sex at birth."

individuals who transitioned and detransitioned medically, surgically, or both. For the purpose of this study, medical transition refers to the use of puberty blockers, cross-sex hormones, or anti-androgens and surgical transition refers to any of a variety of surgical procedures (common surgical procedures include mastectomy, genital surgery, and breast augmentation). This study does not describe the population of individuals who undergo medical or surgical transition without issue nor is it designed to assess the prevalence of detransition as an outcome of transition. Instead, the goal was to identify detransition reasons and narratives in order to inform clinical care and future research.

Method

Participants and Procedure

During the recruitment period, 101 individuals who met the study criteria completed online surveys. Inclusion criteria were (1) completion of a survey via Survey Monkey; (2) answering that they had taken or had one or more of the following for the purpose of gender transition: cross-sex hormones, anti-androgens, puberty blockers, breast surgery, genital surgery, other surgery; and (3) answering that they had done any of the following for the purpose of detransitioning: stopped taking cross-sex hormones, stopped taking anti-androgens, stopped taking puberty blockers, had any surgery to reverse transition. One survey was excluded for nonsense answers leaving 100 surveys for analysis. The sample included more natal females (69.0%) than natal males (31.0%) with respondents who were predominantly White (90.0%), non-Hispanic (98.0%), resided in the U.S. (66.0%); had no religious affiliation (63.0%), and support the rights of gay and lesbian couples to marry legally (92.9%) (see Table 1). At the time of survey completion, the mean age of respondents was 29.2 years (SD = 9.1) though natal females were significantly younger ($M = 25.8$; SD = 5.0) than natal males ($M = 36.7$; SD = 11.4), $t(98) = -6.56$, $p < .001$. Prior to transitioning, natal females were more likely to report an exclusively homosexual sexual orientation and natal males were more likely to report an exclusively heterosexual sexual orientation.

A 115-question survey instrument with multiple choice, Likert-type, and open-ended questions was created by the author and two individuals who had personally detransitioned. The author had met both detransitioners by way of introductions from colleagues. The author and both individuals who had detransitioned created questions for the survey, provided feedback, and revised the survey questions collaboratively with a focus on content, clarity, and relevance to a variety of transition and detransition experiences. The survey instrument included two questions that were adapted from an online survey of female detransitioners (Stella, 2016). Once completed, the survey was uploaded onto Survey Monkey (SurveyMonkey, Palo Alto, CA) via an account that was HIPAA-enabled.

Recruitment information with a link to the survey was posted on blogs that covered detransition topics and shared in a private online detransition forum, in a closed detransition Facebook group, and on Tumblr, Twitter, and Reddit. Recruitment information was also shared on the professional listservs for the World Professional Association for Transgender Health, the American Psychological Association Section 44, and the SEXNET listserv (which is a listserv of sex researchers and clinicians) and the professionals on the listservs were asked to share recruitment information with anyone they knew who might be eligible. Efforts were made to reach out to communities with varied views about the use of medical and surgical transition and recruitment information stated that participation was sought from individuals regardless of whether their transition experiences were positive, negative or neutral. Potential participants were invited to share recruitment information with any potentially eligible person or community with potentially eligible people. The survey was active from December 15, 2016 to April 30, 2017 (4.5 months). The median time to complete a survey was 49 min; 50% of the surveys were completed between 32 and 71 min. There were no incentives offered for participating. Data were collected anonymously, without IP addresses, and stored securely with Survey Monkey.

Participation in this study was voluntary. Electronic consent was obtained from all participants in the following manner. The first page of the online survey informed respondents about the research purpose, potential risks and benefits, that participation was voluntary, and provided contact information for the researcher. Survey questions were only displayed if the participant clicked "agree" which indicated that they read the information, voluntarily agreed to participate and were at least 18 years of age.

Measures

Demographic and Baseline Characteristics

Information was collected about participant age, natal sex, race/ethnicity, country of residence, educational attainment, socioeconomic status, religion, attitudes about legal marriage for gay and lesbian couples, and where they first heard about the study. The term sexual orientation in this article is intended to refer to the natal sex of the participant and the natal sex of the individuals with whom they are sexually attracted. Participants were asked to select one or more labels for how they identified their sexual orientation prior to transition with options inclusive of participant sex (e.g., asexual female, bisexual female, heterosexual female, etc.). These responses were coded to be consistent with participant natal sex and were categorized into homosexual, heterosexual, bisexual, pansexual, asexual, and multiple. The multiple category included respondents who

Table 1 Demographic and baseline characteristics

	Natal female *N* (%) $N=69$	Natal male *N* (%) $N=31$
*Race/ethnicity**		
White	62 (89.9%)	28 (90.3%)
Multiracial	6 (8.7%)	3 (9.7%)
Other	4 (5.8%)	0 (0%)
Asian	1 (1.4%)	1 (3.2%)
Hispanic	1 (1.4%)	1 (3.2%)
Black	0 (0%)	0 (0%)
Country of residence		
USA	46 (66.7%)	20 (64.5%)
UK	8 (11.6%)	1 (3.2%)
Canada	5 (7.2%)	4 (12.9%)
Australia	2 (2.9%)	2 (6.5%)
Other	8 (11.6%)	4 (12.9%)
Education		
Bachelor's or graduate degree	29 (42.0%)	18 (58.1%)
Associates degree	3 (4.3%)	1 (3.2%)
Some college but no degree	28 (40.6%)	9 (29.0%)
High school graduate or GED	8 (11.6%)	2 (6.5%)
< High school	1 (1.4%)	0 (0%)
Other	0 (0%)	1 (3.2%)
Socioeconomic status compared to others in country of residence		
Above average (somewhat or very much)	19 (27.5%)	12 (38.7%)
About average	20 (29.0%)	7 (22.6%)
Below average (somewhat or very much)	27 (39.1%)	12 (38.7%)
Prefer not to say	3 (4.3%)	0 (0%)
Categorized sexual orientation (by natal sex) prior to transition[a]		
Homosexual	18 (26.1%)	2 (6.5%)
Heterosexual	6 (8.7%)	12 (38.7%)
Bisexual	15 (21.7%)	8 (25.8%)
Pansexual	4 (5.8%)	1 (3.2%)
Multiple	20 (29.0%)	5 (16.1%)
Asexual	6 (8.7%)	3 (9.7%)
Religious affiliation		
No religious affiliation	41 (59.4%)	22 (73.3%)
Liberal Christian	5 (7.2%)	3 (10.0%)
Liberal Jewish	5 (7.2%)	0 (0%)
Conservative Christian	1 (1.4%)	2 (6.7%)
Liberal Muslim	1 (1.4%)	0 (0%)
Conservative Jewish	0 (0%)	0 (0%)
Conservative Muslim	0 (0%)	0 (0%)
Other	16 (23.2%)	3 (10.0%)
Legal marriage for gay and lesbian couples		
Favor	65 (97.0%)	26 (83.9%)
Oppose	1 (1.5%)	5 (16.1%)
Don't know	1 (1.5%)	0 (0%)
Source where participant first heard about study		
Detransition blogs	26 (37.7%)	15 (48.4%)
Other social media	37 (53.6%)	11 (35.5%)
A person they know	3 (4.3%)	3 (9.7%)
Other	3 (4.3%)	2 (6.5%)

*May select more than one answer

[a] Natal females were more likely to express an exclusively homosexual sexual orientation prior to transition ($\chi^2=5.15$. The *p*-value is .023). Natal males were more likely to express an exclusively heterosexual sexual

Table 1 (continued)

orientation prior to transition ($\chi^2 = 13.05$. The p value is $< .001$). Natal sex differences were not significant for individuals expressing pre-transition sexual orientations of bisexual, pansexual, multiple, and asexual. For bisexual sexual orientation, $\chi^2 = 0.20$. For pansexual sexual orientation, $\chi^2 = 0.29$. For multiple sexual orientations reported, $\chi^2 = 1.88$. For asexual sexual orientation, $\chi^2 = 0.02$

selected more than one response where responses indicated more than one pattern of sexual attraction (e.g., lesbian female and heterosexual female). Other questions about baseline characteristics included questions about diagnosed psychiatric disorders and neurodevelopmental disabilities, trauma, and non-suicidal self-injury (NSSI) before the onset of gender dysphoria.

Gender Dysphoria Onset and Typologies

Participants were asked how old they were when they first experienced gender dysphoria and whether this was during childhood, at the onset of puberty, during puberty, or later. Respondents were categorized as having early-onset gender dysphoria if they indicated that their gender dysphoria began "during childhood" and late-onset gender dysphoria if their gender dysphoria began "at the onset of puberty" or later. To evaluate typologies, participants were characterized by Blanchard's (1985, 1989) typology as homosexual (if the sexual orientations listed prior to transition were exclusively homosexual) or non-homosexual which includes heterosexual, asexual, bisexual, pansexual, and multiple responses.

Transition

Participants were asked for their age and the year that they first sought care to transition, sources that encouraged them to believe that transition would be helpful to them, and whether they felt pressured to transition. The friendship group dynamics that were identified in previous work were assessed by asking respondents whether their friendship group mocked people who were not transgender, whether people in their pre-existing friend group transitioned before the participant decided to transition, and how participant popularity changed after announcing that they would transition (Littman, 2018). Questions were asked about participant experiences with clinicians, the social, medical, and surgical steps they took to transition, and the duration of time spent taking each medication.

Detransition

Participants were asked for their age and the year that they decided to detransition, how long they were transitioned before deciding to detransition, their reasons for wanting to detransition, what sources encouraged them to believe that detransition would be helpful to them, and whether they felt pressured to detransition. Participants were also asked which social, medical, and surgical steps they took to detransition and whether they contacted the doctor or clinic that they used for their transition to tell them that they detransitioned.

Transition and Detransition Narratives

In this article, "narratives" denote participant interpretations of their experiences and rationales surrounding their decisions to transition and detransition. To associate each participant survey with a set of relevant narratives, the data were reviewed with horizontal (beginning to end) passes and vertical passes for selected questions (these questions are listed in the supplemental materials). Surveys were coded as belonging to zero or more of the following narrative categories: discrimination, nonbinary, retransition, trauma and mental health, internalized homophobia, social influence, and misogyny. Each narrative and the responses that were associated with them are detailed below. Example quotes were selected with care taken to avoid quoting a participant more than once per narrative. Narratives are ordered and reported with the more commonly accepted narratives first and the newer narratives next.

The *discrimination* narrative was defined as when someone detransitioned due to experiencing discrimination or external social pressures. The *nonbinary* narrative consisted of answering that their current identification was "nonbinary/genderqueer" or providing open-text responses that described aspects of discovering or maintaining a nonbinary identification. Although there were no questions in the survey specifically asking about retransition, the *retransition* narrative was identified if participants expressed that they had retransitioned or resumed transition in any of the open-text responses in the survey. The *gender dysphoria was caused by trauma or a mental health condition* narrative was identified by selection for the answers, "what I thought were feelings of being transgender were actually the result of trauma," "what I thought were feelings of being transgender were actually the result of a mental health condition," "I discovered that my gender dysphoria was caused by something specific (ex. trauma, abuse, mental health condition)" or open-text responses consistent with these reasons. The *internalized homophobia/difficulty accepting oneself as a lesbian female, gay male, or bisexual person* narrative consisted of descriptions that the respondents' discomfort and distress about being lesbian, gay, or bisexual was related to their gender dysphoria, transition, or detransition, or that they assumed they were transgender because they did not yet understand themselves to be lesbian, gay or bisexual. The *social pressure to transition* narrative was identified with an affirmative answer to whether they felt pressured to transition with an open-text response indicating that the pressure came from a person or group of people. The *misogyny* narrative was identified for natal female respondents with open-text responses using the word "misogyny" or expressing a hatred of femaleness.

Gender Identification at Start of Transition and at Survey Completion

Participants were asked how they identified their gender when they started their transition and at the time of survey completion. They were given options of female, male, nonbinary/genderqueer, trans man/FTM, trans woman/MTF, none of the above, and other. Responses were coded by natal sex and categorized as transgender, birth sex, nonbinary, and other. Answers that were combinations of the above categories were reported as combinations such as "birth sex and nonbinary."

Self-Appraisal of Transition and Detransition

One question asked if participants believe they were helped and another if they were harmed by their transition with options of "very much," "a little," or "not at all." These results were categorized into exclusively helped, exclusively harmed, and both helped and harmed. Participants were asked which of the following reflected their feelings about their transition: "I am glad that I transitioned," "I wish I had never transitioned," "Transitioning distracted me from what I should have been doing," "Transition was a necessary part of my journey." Participants were asked to rate their regret about their transition ("no regrets," "mild regrets," "strong regrets," and "very strong regrets") and were asked to indicate their satisfaction with their decisions to transition and detransition ("extremely satisfied," "very satisfied," "somewhat satisfied," "somewhat dissatisfied," "very dissatisfied," and "extremely dissatisfied"). Satisfaction options were collapsed into "satisfied" and "dissatisfied." In addition, participants were asked if they knew then what they know now, would they have chosen to transition.

Data Analysis

After data were cleaned, statistical analyses were performed using google sheets. Results are presented as frequencies, percentages, medians, means and standard deviations. *t* tests and chi-square tests were performed for selected variables and were considered significant for $p < .05$. Qualitative data were obtained from the open-text answers to questions that allowed participants to provide additional information. Selected open-text responses were categorized, tallied, and reported numerically. Salient respondent quotes and summaries from the qualitative data were selected to illustrate the quantitative results and to provide relevant examples.

Results

Before Transition

Mental health diagnoses and traumatic experiences before the onset of gender dysphoria. Table 2 shows data about psychiatric disorders, neurodevelopmental disabilities, NSSI, and trauma that were reported as occurring prior to the onset of gender dysphoria. Because these conditions and events occurred before participants began to feel gender dysphoric, they cannot be considered to be secondary to gender incongruence or transphobia.

Gender dysphoria onset and typology. Most participants (82.0%) were living with one or both parents when they first experienced gender dysphoria at a mean age of 11.2 years (SD = 5.6). The mean age of gender dysphoria onset was not statistically different between natal females ($M = 11.3$; SD = 5.4) and natal males ($M = 11.0$; SD = 5.9), $t(96) = 0.25$. By Blanchard typologies, 26.1% of natal females were exclusively homosexual and 73.9% non-homosexual while 6.5% of natal males were exclusively homosexual and 93.5% non-homosexual (Blanchard, 1985, 1989). Slightly more than half of the respondents (56.0%) experienced early-onset gender dysphoria and slightly less than half (44.0%) experienced late-onset gender dysphoria. Although late-onset gender dysphoria in natal females was largely absent from the scientific literature prior to 2012 (Steensma et al., 2013; Zucker & Bradley, 1995; Zucker et al., 2012a), 55.1% of the natal female participants reported that their gender dysphoria began with puberty or later. Because the information about the timing of gender dysphoria onset was obtained from participants reporting on their own experiences, it can be assumed that these cases were indeed late-onset rather than early-onset gender dysphoria that was concealed from parents and other people.

Transition reasons. Table 3 shows data about the reasons that individuals wanted to transition and the most frequently endorsed were: wanting to be perceived as the target gender (77.0%); believing that transitioning was their only option to feel better (71.0%); the sensation that their body felt wrong the way it was (71.0%), and not wanting to be associated with their natal sex (70.0%). Most participants believed that transitioning would eliminate (65.0%) or decrease (63.0%) their gender dysphoria and that with transitioning they would become their true selves (64.0%).

Sources of transition encouragement and friend group dynamics. Participants identified sources that encouraged them to believe transitioning would help them. Social media and online communities were the most frequently reported, including YouTube transition videos (48.0%), blogs (46.0%), Tumblr (45.0%), and online communities (43.0%) (see supplemental materials). Also common were people who the respondents knew offline such as therapists (37.0%); someone (28.0%) or a group of friends (27.0%) that they knew in-person. A subset of

Table 2 Mental health diagnoses and traumatic experiences prior to the onset of gender dysphoria

	Natal female N (%) $N = 69$	Natal male N (%) $N = 31$
*Diagnosed with a mental illness or neurodevelopmental disability**[a]		
Depression	27 (39.1%)	5 (16.1%)
Anxiety	22 (31.9%)	5 (16.1%)
Attention deficit hyperactivity disorder (ADHD)	10 (14.5%)	2 (6.5%)
Post-traumatic stress disorder (PTSD)	10 (14.5%)	1 (3.2%)
Eating disorders	10 (14.5%)	0 (0%)
Autism spectrum disorders	9 (13.0%)	1 (3.2%)
Bipolar disorder	9 (13.0%)	0 (0%)
Obsessive compulsive disorder	6 (8.7%)	3 (9.7%)
Borderline personality disorder	5 (7.2%)	0 (0%)
Schizophrenia or other psychotic disorders	1 (1.4%)	0 (0%)
None of the above	28 (40.6%)	17 (54.8%)
Other	7 (10.1%)	2 (6.5%)
Non-suicidal self-injury (NSSI)[b]		
Engaged in NSSI before the onset of gender dysphoria	19 (27.5%)	5 (16.1%)
Trauma[c]		
Experienced a trauma less than one year before the start of gender dysphoria	33 (47.8%)	4 (12.9%)

*May select more than one answer

[a] Natal sex difference for one or more pre-existing diagnoses (100-none of the above) was not significant [$\chi^2(1, 100) = 1.76$]

[b] Natal sex differences for NSSI before the onset of gender dysphoria was not significant ($\chi^2 = 1.52$)

[c] Experiencing a trauma less than one year before the start of gender dysphoria was statistically different [$\chi^2(1, 100) = 11.19$, $p < .001$] with natal females > natal males

Table 3 Transition reasons

	Natal female N (%) $N = 69$	Natal male N (%) $N = 31$
*Reasons for transition**		
I wanted others to perceive me as the target gender	53 (76.8%)	24 (77.4%)
I thought transitioning was my only option to feel better	50 (72.5%)	21 (67.7%)
My body felt wrong to me the way it was	50 (72.5%)	21 (67.7%)
I didn't want to be associated with my natal sex/natal gender	51 (73.9%)	19 (61.3%)
It made me uncomfortable to be perceived romantically/sexually as a member of my natal sex/natal gender	49 (71.0%)	18 (58.1%)
I thought transitioning would eliminate my gender dysphoria	43 (62.3%)	22 (71.0%)
I felt I would become my true self	42 (60.9%)	22 (71.0%)
I identified with the target gender	40 (58.0%)	24 (77.4%)
I thought transitioning would lessen my gender dysphoria	45 (65.2%)	18 (58.1%)
I felt I would fit in better with the target gender	36 (56.5%)	20 (64.5%)
I felt I would be more socially acceptable as a member of the target gender	38 (55.1%)	11 (35.5%)
I felt I would be treated better if I was perceived as the target gender	35 (50.7%)	14 (45.2%)
I saw myself as a member of the target gender	31 (44.9%)	18 (58.1%)
I thought transitioning would reduce gender-related harassment or trauma I was experiencing	35 (50.7%)	5 (16.1%)
I had erotic reasons for wanting to transition	9 (13.0)	12 (38.7%)
Other	9 (13.0%)	3 (9.7%)

*May select more than one answer

participants experienced the friendship group dynamics identified in previous work, including belonging to a friendship group that mocked people who were not transgender (22.2%), having one or more friend from the pre-existing friend group transition before the participant decided to transition (36.4%), and experiencing an increase in popularity after announcing plans to transition (19.6%) (Littman, 2018). Most did not have this experience (68.7%, 61.6%, and 62.9%, respectively).

Pressure to transition. More than a third of the participants (37.4%) felt pressured to transition. Natal sex differences in feeling pressured to transition were significant by chi-square test with natal females > natal males $\chi^2(1, 99) = 4.22$, $p = .04$. Twenty-eight participants provided open-text responses of which 24 described sources of pressure (17 described social pressures and 7 described sources that were not associated with other people). Clinicians, partners, friends, and society were named as sources that applied pressure to transition, as seen in the following quotes: "My gender therapist acted like it [transition] was a panacea for everything;" "[My] [d]octor pushed drugs and surgery at every visit;" "I was dating a trans woman and she framed our relationship in a way that was contingent on my being trans;" "A couple of later trans friends kept insisting that I needed to stop delaying things;" "[My] best friend told me repeatedly that it [transition] was best for me;" "The forums and communities and internet friends;" "By the whole of society telling me I was wrong as a lesbian;" and "Everyone says that if you feel like a different gender…then you just are that gender and you should transition." Participants also felt pressure to transition that did not involve other people as illustrated by the following: "I felt pressured by my inability to function with dysphoria" and "Not by people. By my life circumstances."

Experiences with clinicians. When participants first sought care for their gender dysphoria or desire to transition, more than half of the participants (53.0%) saw a psychiatrist or psychologist; about a third saw a primary care doctor (34.0%) or a counselor (including licensed clinician social worker, licensed professional counselor, or marriage and family therapist) (32.0%); and 17.0% saw an endocrinologist. For transition, 45.0% of participants went to a gender clinic (44.4% of those attending a gender clinic specified that the gender clinic used the informed consent model of care); 28.0% went to a private doctor's office; 26.0% went to a group practice; and 13.0% went to a mental health clinic (see supplemental materials).

The majority (56.7%) of participants felt that the evaluation they received by a doctor or mental health professional prior to transition was not adequate and 65.3% reported that their clinicians did not evaluate whether their desire to transition was secondary to trauma or a mental health condition. Although 27.0% believed that the counseling and information they received prior to transition was accurate about benefits and risks, nearly half reported that the counseling was overly positive about the benefits of transition (46.0%) and not negative enough about the risks (26.0%). In contrast, only a small minority found the counseling not positive enough about benefits (5.0%) or too negative about risks (6.0%) suggesting a bias toward encouraging transition.

Transition

Participants were on average 21.9 years old (SD = 6.1) when they sought medical care to transition with natal females seeking care at younger ages ($M = 20.0$; SD = 4.2) than natal males ($M = 26.0$; SD = 7.5), $t(97) = -5.07$, $p < .001$. Given that the majority of natal males were categorized as Blanchard typology non-homosexual, the finding that natal males sought medical care to transition at older ages than natal females is concordant with previous research (Blanchard et al., 1987). The average year for seeking care was more recent for natal females ($M = 2011$; SD = 3.8) than natal males ($M = 2007$; SD = 6.9), $t(96) = 2.78$, $p = .007$, and thus, there may have been differences in the care they received due to differences in the culture surrounding transition and the prevailing medical approaches to gender dysphoria for the time.

At the start of transitioning, nearly all (98.0%) of the participants identified as either transgender (80.0%), nonbinary (15.0%), or both transgender and nonbinary (3.0%). Participants identified which social, medical, and surgical steps they had taken to transition. Table 4 shows these steps, separated by natal sex where appropriate. Most respondents adopted new pronouns (91.0%) and names (88.0%), and the vast majority (97.1%) of natal females wore a binder. Most participants took cross-sex hormones (96.0%) and most natal males took anti-androgens (87.1%). The most frequent transition surgery was breast or chest surgery for natal females (33.3%). Genital surgery was less common (1.4% of natal females and 16.1% of natal males). Natal females took testosterone for a mean duration of 2.0 years (SD = 1.6). Natal males took estrogen for a mean duration of 5.1 years (SD = 5.9) and anti-androgens for 2.8 years (SD = 2.6). The minority of patients who took puberty blockers took them for a mean duration of less than a year ($M = 0.9$ years; SD = 0.6).

Detransition

Before deciding to detransition, participants remained transitioned for a mean duration of 3.9 years (SD = 4.1) with natal females remaining transitioned for a shorter period of time ($M = 3.2$ years; SD = 2.7) than natal males ($M = 5.4$ years; SD = 6.1), $t(96) = -2.40$, $p = .018$. When participants decided to detransition they were a mean age of 26.4 years old (SD = 7.4) though natal females were significantly younger ($M = 23.6$; SD = 4.5) than natal males ($M = 32.7$; SD = 8.8), $t(97) = -6.75$, $p < .001$. The mean calendar year when participants decided to detransition was 2014 ($M = 2014$; SD = 3.3), but the difference

Table 4 Steps taken for social, medical, and surgical transition

	N (%)
*Social transition**	
Pronouns	91 (91.0%)
Different name	88 (88.0%)
Clothes/hair/makeup	90 (90.0%)
Legal name change	49 (49.0%)
Gender/sex changed on government documents	36 (36.0%)
Voice training	20 (20.0%)
Natal female	
Wore a binder	67 (97.1%)
*Medical transition**	
Cross-sex hormones	96 (96.0%)
Puberty blockers	7 (7.0%)
Natal male	
Anti-androgens	27 (87.1%)
*Surgical transition**	
Face/neck surgery	5 (5.0%)
Natal female	
Breast/chest surgery	23 (33.3%)
Genital surgery (to create a penis)	1 (1.4%)
Natal male	
Breast implants	5 (16.1%)
Genital surgery (to create a vagina)	5 (16.1%)

*May select more than one answer

between natal females and natal males was not significant ($M=2014$, SD = 3.3; $M=2014$, SD = 3.5), $t(95)=0.52$.

Respondents detransitioned for a variety of reasons and most (87.0%) selected more than one reason. The most frequently endorsed reason for detransitioning was that the respondent's personal definition of male and female changed and they became comfortable identifying with their natal sex (60.0%) (see Table 5). Other commonly endorsed reasons were concerns about potential medical complications (49.0%); transition did not improve their mental health (42.0%); dissatisfaction with the physical results of transition (40.0%); and discovering that something specific like trauma or a mental health condition caused their gender dysphoria (38.0%). External pressures to detransition such as experiencing discrimination (23.0%) or worrying about paying for treatments (17.0%) were less common.

Encouragement and pressure to detransition. Participants were asked to select sources that encouraged them to believe that detransitioning would help them. These included blogs (37.0%), Tumblr (35.0%), and YouTube detransition videos (23.0%) (see supplemental materials). At some point in their process, 23.2% felt pressured to detransition. There was no significant difference between natal females and natal males for feeling pressured to detransition, $\chi^2(1, 99)=1.11$. Of the 21 open-text responses provided, 14 respondents expressed social pressure to detransition; three expressed internal pressure to detransition and four provided responses that were neither

Table 5 Reasons for detransitioning

	Natal female *N* (%) *N* = 69	Natal male *N* (%) *N* = 31
*Reasons for detransitioning**		
My personal definition of female or male changed and I became more comfortable identifying as my natal sex	45 (65.2%)	15 (48.4%)
I was concerned about potential medical complications from transitioning	40 (58.0%)	9 (29.0%)
My mental health did not improve while transitioning	31 (44.9%)	11 (35.5%)
I was dissatisfied by the physical results of the transition/felt the change was too much	35 (50.7%)	5 (16.1%)
I discovered that my gender dysphoria was caused by something specific (ex, trauma, abuse, mental health condition)	28 (40.6%)	10 (32.3%)
My mental health was worse while transitioning	27 (39.1%)	9 (29.0%)
I was dissatisfied by the physical results of the transition/felt the change was not enough	22 (31.9%)	11 (35.5%)
I found more effective ways to help my gender dysphoria	25 (36.2%)	7 (22.6%)
My physical health was worse while transitioning	21 (30.4%)	11 (35.5%)
I felt discriminated against	12 (17.4%)	11 (35.5%)
I had medical complications from transitioning	12 (17.4%)	7 (22.6%)
Financial concerns about paying for transition care	11 (15.9%)	6 (19.4%)
My gender dysphoria resolved	10 (14.5%)	5 (16.1%)
My physical health did not improve while transitioning	9 (13.0%)	2 (6.5%)
I resolved the specific issue that was the cause of my gender dysphoria	6 (8.7%)	4 (12.9%)
I realized that my desire to transition was erotically motivated	1 (1.4%)	5(16.1%)
Other	19 (27.5%)	6 (19.4%)

*May select more than one answer

or unclear. Regarding social pressure to detransition, seven participants expressed that the pressure came from partners, parents, or other family members as shown in the following example quotes: "I was threatened that if I did not immediately detransition I would NEVER see my […] children again," "My father very much wanted me to desist," and "Parents constantly encouraging me to detransition." Five participants expressed societal pressure to detransition as expressed in the following quotes: "I did not pass, I was mocked in public, I could not get a job. It was not ok to be trans" and "Well, I mean basically the entire world was against me transitioning, so yeah." One participant felt pressured by doctors and another one from a blog.

Detransition steps. Table 6 shows data about the social, medical, and surgical steps participants took to detransition. Nearly all participants medically detransitioned by ceasing cross-sex hormones (95.0%). Social detransition steps were also common and included returning to the use of previously used pronouns (63.0%) and birth names (33.0%) and changing one's clothes and hair presentations (48.0%). Surgical detransition steps were less common (9.0%).

Finding better ways of coping with gender dysphoria**.** Participants were asked to select responses that that they considered to have been better ways for them to cope with their gender dysphoria. Responses included community (44.0%), mindfulness/meditation (41.0%), exercise (39.0%), therapy (24.0%), trauma work (24.0%), medication to treat a mental health condition (18.0%), and yoga (14.0%).

Table 6 Social, medical, and surgical detransition steps

	N (%)
*Social detransition**	
Previous pronouns	63 (63.0%)
Clothes/hair/makeup	48 (48.0%)
Birth name	33 (33.0%)
New name (not birth name)	24 (24.0%)
None of the above	2 (2.0%)
*Medical detransition**	
Stopped cross-sex hormones	95 (95.0%)
Stopped puberty blockers	4 (4.0%)
Started hormones consistent with natal sex	14 (14.0%)
Natal male	
Stopped anti-androgens	17 (54.8%)
*Surgical detransition**	
Surgery to reverse changes from transition	9 (9.0%)

*May select more than one answer

Transition and Detransition Narratives

Several transition and detransition narratives emerged from the data. A sizable minority of participants (41.0%) expressed more than one narrative in their responses.

The *discrimination and external pressures to detransition* narrative was described by 29.0% of participants. Examples include: "I had to detransition in order to get a job"; "I was afraid of being homeless and unable to support myself"; "I felt much happier with myself but I couldn't go anywhere without being afraid. I passed okay but not perfectly. I was stared down and sneered at in the women's clothes section, I wouldn't dare use a public toilet because I'd find either violent men or women who wished an encounter with a violent man on me."

A *nonbinary* narrative was expressed by 16.0% of participants. Some described that they discovered their nonbinary gender identity during their transition, as in the following quotes: "I still was uncomfortable with my body and figured I should stop and make sure I really wanted to keep going. I didn't and I decided I must be nonbinary, not FTM"; "Transitioning didn't do what I thought I wanted it to. I had transitioned to the wrong gender. I still felt wrong. Then, I realized I was not male, but genderqueer. I detransitioned to suit my true identity." And others described a consistent nonbinary identification, as in the following quote, "I identified the same way that I did before. I had gotten what I wanted out of HRT and was ready to stop taking it." (Cross-sex hormones are sometimes referred to as "hormone replacement therapy" and abbreviated as HRT).

Three participants (3.0%) expressed the *retransition* narrative in open-text answers indicating that they had retransitioned, including the following quotes: "I am now transitioning for a second time"; I retransitioned after 5 years of detransitioning"; and "Anyway, I retransitioned over 10 years after detransitioning."

Most participants (58.0%) expressed the *gender dysphoria was caused by trauma or a mental health condition* narrative which included endorsing the response options indicating that their gender dysphoria was caused by something specific, such as a trauma or a mental health condition. More than half of the participants (51.2%) responded that they believe that the process of transitioning delayed or prevented them from dealing with or being treated for trauma or a mental health condition. The following are example quotes that were in response to why participants chose to detransition: "I slowly began addressing the mental health conditions and traumatic experiences that caused such a severe disconnect between myself and my body…"; "I was starting to become critical of transition because I felt that many people were doing it out of self-hatred and started to realize that applied to me as well"; "I was deeply uncomfortable with my secondary sex characteristics, which I now understand was a result of childhood trauma and associating my secondary sex characteristics with those events."

Despite the absence of any questions about this topic in the survey, nearly a quarter (23.0%) of the participants expressed the *internalized homophobia and difficulty accepting oneself as lesbian, gay, or bisexual* narrative by spontaneously describing that these experiences were instrumental to their gender dysphoria, their desire to transition, and their detransition. All of the participants in this category indicated that they were either same-sex attracted exclusively or were same-sex attracted in combination with opposite-sex attraction (such as bisexual, pansexual, etc.). The following responses were written in as "other" for the question about why participants transitioned: "Transitioning to male would mean my attraction to girls would be 'normal'"; "being a 'gay trans man' (female dating other females) felt better than being a lesbian, less shameful"; "I felt being the opposite gender would make my repressed same-sex attraction less scary"; "I didn't want to be a gay man." Some participants described that it took time for them to gain an understanding of themselves as lesbian, gay, or bisexual as seen in the following: "At the time I was trying to figure out my identity and felt very male and thought I was transgender. I later discovered that I was a lesbian…"; and "Well, after deep discovery, I realized I was a gay man and realized that a sexual trauma after puberty might [have] confused my thought. I wanted to live as a gay man again." Several natal female respondents expressed that seeing other butch lesbians would have been helpful to them as shown by the following: "What would have helped me is being able to access women's community, specifically lesbian community. I needed access to diverse female role-models and mentors, especially other butch women."

The *social influence* narrative was identified where participants added information to the question about if they had felt pressured to transition and the response described pressure from a person or people. One-fifth (20.0%) of participants expressed that they felt pressured by a person or people to transition. Example quotes for social influence were described in a previous section.

Of the natal females, 7.2% expressed the *misogyny* narrative. Example quotes include: "…I realized how much of it [dysphoria] may have been caused by internalized misogyny and homophobia"; "Finally realizing there's nothing wrong or disgusting or weak about being female"; and "My transition was a desperate attempt to distance myself from womanhood and femaleness due to internalized lesbophobia and misogyny combined with a history of sexual trauma."

After Detransition

Disposition. At the time of survey completion, most participants had returned to identifying solely as their birth sex (61.0%) with an additional 10.0% identifying as their birth sex plus another identification. Fourteen percent of the participants identified solely as nonbinary with an additional 11.0% identifying as nonbinary plus a second identification. Eight percent of the participants identified solely as transgender with an additional 5.0% identifying as transgender plus another identification. Four percent of the responses did not fit into the above categories and were coded as "other." Figure 1 illustrates the distribution of participants' current gender identification (post-detransition). Only 24.0% of participants had informed the doctor or clinic that facilitated their transitions that they had detransitioned.

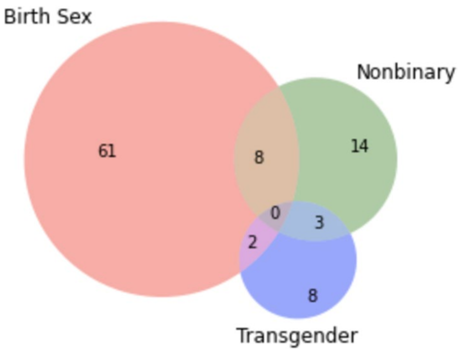

Fig. 1 Distribution of participants' current gender identification (after detransition) (n = 100). *Notes*: The sum of the numbers appearing in the "Birth Sex" circle indicates the number of participants who returned to identifying with their birth sex (71)—either as birth sex alone (61) or birth sex in addition to a second identification (10) represented in the overlap between two circles. For example, eight participants identify as their birth sex and as nonbinary. The sum of the numbers appearing in the "Nonbinary" circle indicates the number of participants who identify as nonbinary (25)—either as nonbinary alone (14) or nonbinary in addition to a second identification (11). The sum of the numbers appearing in the "Transgender" circle indicates the number of participants who identify as transgender (13)—either as transgender alone (8) or transgender in addition to a second identification (5). Four participants had responses that did not fit the categories above and were coded as "other"

Self-appraisal of past transgender identification. Table 7 presents the data for responses endorsed by participants to reflect how they feel currently about having identified as transgender in the past. The statements most frequently selected included: "I thought gender dysphoria was the best explanation for what I was feeling" (57.0%), "My gender dysphoria was similar to the gender dysphoria of those who remain transitioned" (42.0%), "What I thought were feelings of being transgender actually were the result of trauma" (36.0%), "What I thought were feelings of being transgender actually were the result of a mental health condition" (36.0%).

Self-appraisal of transition and detransition. When asked to select which statement best reflects their feelings about their transition, nearly a third (30.0%) indicated that they wish they had never transitioned while 11.0% indicated they were glad they transitioned. Some (34.0%) selected the statement that transition "was a necessary part of [their] journey" but others (21.0%) indicated that the process of transitioning distracted them from what they should have been doing. Responses about whether transition helped or harmed them were also complicated. While 50.5% selected answers consistent with being both helped and harmed, 32.3% indicated that they were only harmed and 17.2% indicated that they were only helped. The majority of respondents were dissatisfied with their decision to transition (69.7%) and satisfied with their decision to detransition (84.7%). At least some amount of transition regret was

Table 7 Self-appraisal of past transgender identification

	Natal female *N* (%) *N*=69	Natal male *N* (%) *N*=31
*Self-appraisal about identifying as transgender in the past**		
I thought gender dysphoria was the best explanation for what I was feeling	39 (56.5%)	18 (58.1%)
My gender dysphoria was similar to the gender dysphoria of those who remain transitioned	32 (46.4%)	10 (32.3%)
What I thought were feelings of being transgender actually were the result of trauma	31 (44.9%)	5 (16.1%)
What I thought were feelings of being transgender actually were the result of a mental health condition	28 (40.6%)	8 (25.8%)
Someone else told me that the feelings I was having meant that I was transgender and I believed them	25 (36.2%)	10 (32.3%)
I still identify as transgender	20 (29.0%)	10 (32.3%)
I believed I was transgender then, but I was mistaken	16 (23.2%)	6 (19.4%)
I was transgender then but I am not transgender now	15 (21.7%)	7 (22.6%)
I formerly identified as transgender and now identify as genderqueer/nonbinary	12 (17.4%)	5 (16.1)
My gender dysphoria was different from the gender dysphoria of those who remain transitioned	11 (15.9%)	4 (12.9%)
I was never transgender	8 (11.6%)	3 (9.7%)
I thought I had gender dysphoria but I was mistaken	4 (5.8%)	4 (12.9%)
I never had gender dysphoria	1 (1.4)	2 (6.5%)
N/A as I did not identify as transgender in the past	0 (0%)	1 (3.2%)
Other	18 (26.1%)	5 (16.1%)

*May select more than one answer

common (79.8%) and nearly half (49.5%) reported strong or very strong regret. Most respondents (64.6%) indicated that if they knew then what they know now, they would not have chosen to transition.

Discussion

This study was designed to explore the experiences of individuals who obtained medical and surgical treatment for gender dysphoria and then detransitioned by discontinuing the medications or having surgery to reverse the changes from transition. The findings of this study, however, should not be assumed to be representative of all individuals who detransition. Although this study further documents that detransitioners exist, the prevalence of detransition as an outcome of transition is unknown. Only a small percentage of detransitioners (24.0%) informed the clinicians and clinics that facilitated their transitions that they had detransitioned. Therefore, clinic rates of detransition are likely to be underestimated and gender transition specialists may be unaware of how many of their own patients have detransitioned, particularly for patients who are no longer under their care.

This research demonstrates that the experiences of individuals who detransition are varied and the reasons for detransition are complex. Nearly all participants identified as transgender or nonbinary at the start of their transition and most sought transition because they did not want to be associated with their natal sex, their bodies felt wrong the way they were, and they believed that transition was the only option to relieve their distress. Some were helped by transition and only detransitioned because they were pressured to do so by people in their lives, society, or because they had medical complications. Some were harmed by transition and detransitioned because they concluded that their gender dysphoria was caused by trauma, a mental health condition, internalized homophobia, or misogyny—conditions that are not likely to be resolved with transition. These findings highlight the complexity of gender dysphoria and suggest that, in some cases, failure to explore co-morbidities and the context in which the gender dysphoria emerged can lead to misdiagnosis, missed diagnoses, and inappropriate gender transition. Some individuals detransitioned because their gender dysphoria resolved, because they found better ways to address their symptoms, or because their personal definitions of male and female changed and they became comfortable identifying as their natal sex.

The study sample was predominantly young natal females, many of whom experienced late-onset gender dysphoria which mirrors the recent, striking changes in the demographics of gender dysphoric youth seeking care as well as the youth described by their parents in Littman (2018) (see also Aitken et al., 2015; de Graaf et al., 2018; Zucker, 2019). Concerns have been raised that this new cohort of gender dysphoric individuals is unlike previous cohorts. Professionals have started to call for caution before treating this cohort with interventions with permanent effects because the etiologies, desistance and persistence rates, expected duration of symptoms, and whether this new population is helped or harmed by gender transition is still unknown (D'Angelo et al., 2021; Kaltiala-Heino et al., 2018). The natal females and natal males in this sample differed on several dimensions, including that natal females were younger than natal males when they sought transition, when they decided to detransition, and at the time of survey completion. Natal females were more likely than natal males to have experienced a trauma less than one year before the onset of their gender dysphoria and were more likely to have felt pressured to transition. Compared to natal males, natal females remained transitioned for a shorter duration of time before deciding to detransition. Additionally, natal females transitioned more recently than natal males, so their experiences may vary due to changing trends in the clinical management of gender dysphoria and the cultural settings in which they became gender dysphoric.

The study findings covered a wide range of detransition experiences that are consistent with the diversity of experiences described in previously published clinical case reports and case series. Overlap of findings include: transition regret; absence of transition regret; re-identification with birth sex; continued identification as transgender; improvement or worsening of well-being with transition; retransitioning; detransitioning due to external social pressures; nonbinary identification; and recognizing and accepting oneself as homosexual or bisexual (D'Angelo, 2018; Djordjevic et al., 2016; Levine, 2018; Pazos Guerra et al., 2020; Turban & Keuroghlian, 2018; Turban et al., 2021; Vandenbussche, 2021). The population in this study is similar to the population in Vandenbussche in that both were predominantly natal females in their mid-20s. Because the current study recruited in 2016–2017 and Vandenbussche recruited in 2019, the similar mean age of participants may reflect the age of individuals who can be reached in online detransitioner communities. Several findings in this study were consistent with Vandenbussche's findings, including similar reasons for detransition (realizing that their gender dysphoria was related to other issues, finding alternatives to address gender dysphoria, gender dysphoria resolved, etc.). Although these two studies were recruited in different years, had different eligibility criteria, and included participants from several countries, it is possible that there may be some overlap of study populations.

The current study findings provide additional insight into the complex relationships between internalized homophobia, gender dysphoria, and desire to transition. Contrary to arguments against the potential role of homophobia in gender transitions (Ashley, 2020), participants reported that their own gender dysphoria and desire to transition stemmed from the discomfort they felt about being same-sex attracted, their desire to not be gay, and the difficulties that they had accepting themselves as lesbian, gay or bisexual. For these individuals, exploring their distress and discomfort around sexual orientation issues may have been more helpful to them than medical and surgical transition or at least an important part of exploration before making the decision to transition. This research adds to the existing evidence that gender dysphoria can be temporary (Ristori & Steensma, 2016; Singh et al., 2021; Zucker, 2018). It has been established that the most likely outcome for prepubertal youth with gender dysphoria is to develop into lesbian, gay, bisexual (LGB) (non-transgender) adults (Ristori & Steensma, 2016; Singh et al., 2021; Wallien & Cohen-Kettenis, 2008; Zucker, 2018). And, temporary gender dysphoria may be a common part of LGB identity development (Korte et al., 2008; Patterson, 2018). Therefore, intervening too soon to medicalize gender dysphoric youth risks iatrogenically derailing the development of youth who would otherwise grow up to be LGB non-transgender adults. Participants who detransitioned because they became comfortable identifying as their natal sex and because their gender dysphoria resolved further support that gender dysphoria is not always permanent.

The data in this study strengthen, with first-hand accounts, the rapid-onset gender dysphoria (ROGD) hypotheses which, briefly stated, are that psychosocial factors (such as trauma, mental health conditions, maladaptive coping mechanisms, internalized homophobia, and social influence) can cause or contribute to the development of gender dysphoria in some individuals (Littman, 2018). Littman also postulated that certain beliefs could be spread by peer contagion, including the belief that a wide range of symptoms should be interpreted as gender dysphoria (and proof of being transgender) and the belief that transition is the only solution to relieve distress. The current study supports the potential role of psychosocial factors in the development of gender dysphoria and further suggests, by participant responses that transitioning prevented or delayed them from addressing their underlying conditions, that maladaptive coping mechanisms may be relevant for some individuals. The potential role of social influence is demonstrated as well. First, when respondents were asked to describe how they currently feel about having identified as transgender in the past, more than a third endorsed the option, "Someone told me that the feelings I was having meant that I was transgender, and I believed them." Second, a subset of participants experienced the unique friendship group dynamics reported in Littman where peer groups mocked people who were not transgender and popularity within the friend group increased when respondents announced their plan to transition. Additionally, respondents identified several social sources that encouraged them to believe that transitioning would help them including: YouTube transition videos, blogs, Tumblr, and online communities. And finally, 20.0% of participants felt pressured to transition by social sources that included friends, partners, and society. More research is needed to further explore these hypotheses.

The current study and the Turban et al. (2021) analysis of the USTS data share some similarities and differences. Similarities include the use of convenience samples, targeted recruitment, and anonymous data collection. The findings of Turban et al. (including external pressures to detransition and transgender identification after detransition) are a subset of the array of experiences described in the current study. The current study differed from James et al. (2016) and Turban et al. in that it enrolled participants based on the criterion of detransition after medical or surgical transition regardless of how they currently identified, recruited from communities with diverse perspectives about transition and detransition, used a precise definition for detransition that specifies the use of medication or surgery, and included answer options that were relevant to many different types of detransition experiences. In contrast, the USTS only enrolled transgender-identifying individuals regardless of whether they medically or surgically transitioned, recruited from communities likely to have similar perspectives about transition and detransition, and provided multiple choice answer options that were relevant to a narrower range of detransition experiences (James et al., 2016). Further, the definition used by the USTS for "detransitioned" (having "gone back to living as [their] sex assigned as birth, at least for a while") is quite vague. Although Turban et al. provide valuable information about the subset of transgender-identifying people who may have detransitioned, the current study provides a more comprehensive view of individuals who detransition after medical or surgical transition.

Over the past 15 years, there have been substantial changes in the clinical approach to gender dysphoric patients notable for a shift from approaches that employ thorough evaluations and judicious use of medical and surgical transition (the watchful waiting or Dutch approach, the developmentally informed approach, and the medical model of care) to approaches with minimized or eliminated evaluation and liberal use of transition interventions (the affirmative approach and the informed consent model of care) (Cavanaugh et al., 2016; de Vries & Cohen-Kettenis, 2012; Meyer et al., 2002; Rafferty et al., 2018; Schulz, 2018; Zucker et al., 2012b). This trend is prominent in the U.S. where the American Academy of Pediatrics endorsed the affirmative approach in 2018 and Planned Parenthood currently uses the informed consent model to provide medical transition in more than 200 clinics in 35 states (Planned Parenthood, 2021; Rafferty et al., 2018). It is plausible that an unintended consequence of these clinical shifts may be an increase in people who detransition. Many participants in this study believe that they did not receive an adequate evaluation by a clinician before transition. The definition of "adequate evaluation" was not provided in the survey and may be open to respondent interpretation. But given the complexities of the gender dysphoria described in the current study, one might consider a low bar of "adequate" to be the exploration of factors that could be misinterpreted as non-temporary gender dysphoria as well as factors that could be underlying causes for gender dysphoria. The most recently emerging approach to gender dysphoria is called the "exploratory approach" which is a neutral psychotherapeutic approach to help individuals gain a deeper understanding of their gender distress and the factors contributing to their dysphoria (Churcher Clarke & Spiliadis, 2019; Spiliadis, 2019). The study's findings suggest that an exploratory type of approach may have been beneficial to some of the respondents. Future research is needed to determine which patients are best treated by which approaches long term.

Patients considering medical and surgical interventions deserve accurate information about the risks, benefits, and alternatives to that treatment. In this sample, nearly half of the participants reported that the counseling they received about transition was overly positive about the benefits of transition and more than a quarter reported that the counseling was not negative enough about the risks. Several participants felt pressured to transition by their doctors and therapists. If these types of clinical interactions are verified, exploration is needed to determine the extent to which this situation occurs and what measures might be taken to ensure that clinicians provide patients with their options accurately and dispassionately.

There are several obstacles to obtaining accurate rates of detransition and desistance, including stigma and the low numbers of detransitioners who inform their clinicians that they detransitioned. One approach to bypass some of these barriers would be to incorporate non-judgmental questions about detransition and desistance into nationally representative surveys that collect health data. For example, the Behavioral Risk Factor Surveillance System contains an optional module about sexual orientation and gender identity that includes two questions to explore gender issues (Downing & Przedworski, 2018). By changing one existing question, "Do you consider yourself to be transgender?" into two questions, "Have you ever, at any point in your life, considered yourself to be transgender?" and "Do you currently consider yourself to be transgender?" and by adding a follow-up question if answers indicate past but not current transgender identification, "Did you ever take puberty blockers, cross-sex hormones, anti-androgens, or have any surgery as part of your transition?", valuable information about desistance, detransition, and current transgender identification could be obtained. These types of questions may also be of use in clinical practice and electronic medical records. The information gained about rates of detransition and desistance would enhance transgender healthcare by aiding informed consent processes at the start of any medical or surgical transition.

One of the strengths of this study is that it is one of the largest samples of detransitioners to date. Other strengths include the use of a precise definition for detransition, enrollment of detransitioners regardless of their post-detransition gender identification, recruitment from communities with likely divergent views about transition and detransition, and collaboration with two individuals who had detransitioned which helped to create a survey instrument with questions relevant to a variety of detransition experiences and enhanced the recruitment efforts.

There are several limitations to this study that should be considered when interpreting the findings. Like Vandenbussche (2021), James et al. (2016), and Turban et al. (2021), this study used a cross-sectional design, anonymous surveying, and a convenience sample and therefore shares the same limitations that are inherent to these methodologies. These limitations include that conclusions about causation cannot be determined, identities of participants cannot be verified, and the findings of this study may not be generalizable to the entire population of people who detransition or to people outside of the countries where participants were from. Although this study reached out to communities with differing perspectives about transition and detransition, targeted recruitment and convenience samples always introduce the limitations associated with selection biases which should be addressed in future research. Finally, many of the participants in this study had less than ideal outcomes to their medical and surgical transitions, and it is possible that these experiences may have colored some of the responses.

Additional research is needed to determine the prevalence of detransition as an outcome of transition and to identify and meet the psychological and medical needs of the emerging detransitioned population. Because many individuals who detransition re-identify with their birth sex, are no longer connected to LGBT communities, and don't return to gender clinics, future research about detransition needs to expand recruitment efforts beyond gender clinics and transgender communities. The development and testing of non-medical interventions for gender dysphoria could provide valuable options to be used as alternatives or in conjunction with medical and surgical treatments. Because of the potential for some to experience trauma, mental health conditions, internalized homophobia, and misogyny as gender dysphoria, research needs to be conducted on the evaluation process before transition to find approaches that respectfully and collaboratively explore factors that might contribute to gender-related distress. There continues to be an absence of long-term outcomes evidence for youth treated with medical and surgical transition and a lack of information about the trajectories of youth experiencing late-onset gender dysphoria–research is needed to address these gaps. Continued work is needed to reduce rigid gender roles, increase representation of gender stereotype nonconformity, and to address discrimination and social pressures exerted against people who are transgender, lesbian, gay, bisexual, and gender stereotype non-conforming.

Conclusion

This study described individuals who, after transitioning with medications or surgery, have detransitioned. The prevalence of detransitioning after transition is unknown but is likely underestimated because most of the participants did not inform the doctors who facilitated their transitions that they had detransitioned. There is no single narrative to explain the experiences of all individuals who detransition and we should take care to avoid painting this population with a broad brush. Some detransitioners return to identifying with their birth sex, some assume (or maintain) a nonbinary identification, and some continue to identify as transgender. Some detransitioners regret transitioning and some do not. Some of the detransitioners reported experiences that support the ROGD hypotheses, including that their gender dysphoria began during or after puberty and that mental health issues, trauma, peers, social media, online communities, and difficulty accepting themselves as lesbian, gay, or bisexual were related to their gender dysphoria and desire to transition. Natal female and natal male detransitioners appear to have differences in their baseline characteristics and experiences and these differences should be further delineated. Future research about gender dysphoria and the outcomes of transition should consider the diversity of experiences and trajectories. More research is needed to determine how best to provide support and treatment for the long-term medical and psychological well-being of individuals who detransition. Findings about detransition should be used to improve our understanding of gender dysphoria and to better inform the processes of evaluation, counseling, and informed consent for individuals who are contemplating transition.

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Declarations

Conflict of interest The author has no relevant financial or non-financial conflicts of interest to disclose.

Consent to Participate Electronic consent was obtained from all participants included in the study. On the first page of the online survey, participants were informed of the research purpose and potential risks and benefits of participating, that their participation was voluntary, and were presented with a way to contact the researcher. The research survey questions were displayed only if the participant clicked "agree" which indicated that the participant read the information, voluntarily agreed to participate, and were at least 18 years of age.

Ethical Approval The research was determined to be Exempt Human Research by the Program for the Protection of Human Subjects of the Icahn School of Medicine at Mount Sinai in New York, NY. All procedures were performed in accordance with the ethical standards of the Program for the Protection of Human Subjects at the Icahn School of Medicine at Mount Sinai and with the 1964 Declaration of Helsinki and its later amendments or comparable ethical standards.

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REVIEW ARTICLE

Gender dysphoria in childhood

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ABSTRACT
Gender dysphoria (GD) in childhood is a complex phenomenon characterized by clinically significant distress due to the incongruence between assigned gender at birth and experienced gender. The clinical presentation of children who present with gender identity issues can be highly variable; the psychosexual development and future psychosexual outcome can be unclear, and consensus about the best clinical practice is currently under debate.

In this paper a clinical picture is provided of children who are referred to gender identity clinics. The clinical criteria are described including what is known about the prevalence of childhood GD. In addition, an overview is presented of the literature on the psychological functioning of children with GD, the current knowledge on the psychosexual development and factors associated with the persistence of GD, and explanatory models for psychopathology in children with GD together with other co-existing problems that are characteristic for children referred for their gender. In light of this, currently used treatment and counselling approaches are summarized and discussed, including the integration of the literature detailed above.

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Gender identity; gender dysphoria; childhood; psychosexual development; persistence; treatment

Introduction

Children can vary in the extent to which they show gender role expressions, behaviours, interests, and preferences. For most children these expressions are largely congruent with their experience of being male or female – their gender identity – and in line with the gender assigned at birth. This is in contrast to children who experience gender dysphoria (GD). These children show extreme and enduring forms of gender nonconforming/gender variant behaviours, preferences, and interests because they do not identify with their birth-assigned gender. Because of the incongruence between their assigned gender and experienced gender, these children may experience clinically significant distress and are consequently often in need of clinical attention (American Psychiatric Association, 2013).

Although there has been much opposition against diagnosing GD in prepubescent children, primarily due to the stigmatizing effect of having a mental disorder (e.g. Drescher, 2013), the condition is included in the current edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) (American Psychiatric Association, 2013) as well as in the *International Classification of Diseases* (ICD-10; World Health Organization, 1992). The World Health Organization (WHO) is, however, in the process of revising the tenth version of the ICD; but instead of removal of the childhood diagnosis the terminology will most likely be changed from ‘gender identity disorder of childhood’ into ‘gender incongruence of childhood’ (Drescher, Cohen-Kettenis, & Winter, 2012).

According to the DSM-5, a diagnosis of GD of childhood can be made if a child experiences a marked incongruence between one’s experienced/expressed gender and assigned gender, of at least 6 months’ duration, as manifested by six out of eight criteria. One *sine qua non* criterion must be the experience of a strong desire to be of another gender or an insistence to be another gender. In addition to this, there are two criteria focusing on anatomic dysphoria; a dislike of one’s sexual anatomy and the desire for primary/secondary sex characteristics of the experienced gender. In addition there are five behavioural criteria. The behavioural criteria concern the preference for cross-dressing; adopting cross-gender roles in fantasy play; a strong preference for toys, games and activities of the other gender; a preference for playmates of the other gender; and a strong aversion or rejection of typically gender congruent roles, interests, preferences and behaviours. Furthermore, the condition is associated with clinically

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significant distress or impairment in social, school, or other important areas of functioning (American Psychiatric Association, 2013).

Valid information on the prevalence of childhood GD is not available yet due to the absence of formal prevalence studies. An estimate of the prevalence of gender nonconforming/gender variant behaviours can, however, be made on the basis of studies where the Child Behavior Checklist (CBCL) (Achenbach & Edelbrock, 1983) was used. On the CBCL – a parent-report questionnaire on behavioural problems – two items are related to gender variance: Item 5 ('Behaves like opposite sex') and item 110 ('Wishes to be of opposite sex'). Information from the Dutch normative sample of the CBCL shows that in children, both items are more frequently endorsed by parents of girls than of boys; 'Behaves like opposite sex' in 2.6% of the boys and 5.0% of the girls, 'Wishes to be of opposite sex' in 1.4% of the boys and 2.0% of the girls (Verhulst, van der Ende, & Koot, 1996). These findings are in concordance with data from the normative sample of the CBCL in North-America (Achenbach & Edelbrock, 1981; Zucker, Bradley, & Sanikhani, 1997), and are largely replicated in a study of Dutch twins (N = 23,393) at ages 7 and 10 (Van Beijsterveldt, Hudziak, & Boomsma, 2006). Therefore, gender variance/gender nonconformity seems to be present in a small percentage of children and is more prominent in girls than in boys.

Interestingly, from what we know about the referrals to specialized gender identity clinics, the sex ratios for referred prepubescent children have always been in favour of natal men, which may be a direct effect of a difference in increased acceptance of masculinity in girls compared to femininity in boys (e.g. Blakemore, 2003; Cohen-Kettenis et al., 2003; Steensma et al., 2014; Wallien, Veenstra, Kreukels, & Cohen-Kettenis, 2010; Zucker, Wilson-Smith, Kurita, & Stern, 1995). Over the last decades the reported sex ratios have, however, gradually changed. For example, in the period before 2000 the ratio between boys and girls was 5.75:1 in Canada and 2.93:1 in the Netherlands (Cohen-Kettenis et al., 2003). In the period after 2000, the sex ratios decreased in Canada to 3.41:1 (2008–2011) for boys and girls respectively (Wood et al., 2013); and a similar pattern was observed in the Netherlands with a sex ratio of 1.68:1 between 2008 and 2011 (Steensma, 2013). For both countries this change in ratios is caused by fewer referrals of boys. Although empirical evidence is currently not available, the decrease of referrals in boys may indicate an increasing tolerance over time towards gender nonconforming behaviours in both countries.

Psychological functioning, social tolerance, and other co-existing problems

Besides the gender nonconforming presentation, children with GD who are referred to clinical settings have been shown to be more psychologically vulnerable in comparison to non-referred controls (Bates, Bentler, & Thompson, 1973, 1979) and in comparison to the general population (e.g. Cohen-Kettenis et al., 2003; Singh, Bradley, & Zucker, 2011; Steensma et al., 2014). Furthermore, these studies show that these psychological problems are more of an internalized nature (such as depression, social withdrawal, and anxiety), instead of an externalizing nature (such as aggression) (Bates et al., 1973, 1979; Coates & Person, 1985; Rekers & Morey, 1989; Zucker & Bradley, 1995; Cohen-Kettenis et al., 2003; Steensma et al., 2014). However, as Zucker, Wood, and VanderLaan (2014) recently concluded from their summary of studies reporting on the psychological functioning of gender-referred children, there is a considerable variability across the different studies. For example, the percentage of clinical-range cases reported in studies using the total behaviour problem score of the CBCL, ranged from 12.5% up to 84% of the described children over the different studies (for an overview see Zucker et al., 2014).

To understand this association between GD and the variability of psychological functioning within the population of children with GD, the empirical literature indicates the effect is largely mediated through social (in)tolerance towards gender nonconformity/gender variance. Indeed, a wide range of studies in children from the general population showed that gender nonconforming behaviour is often evaluated negatively by other children (e.g. Carter & McCloskey, 1984; Levy, Taylor, & Gelman, 1995; Ruble et al., 2007; Signorella, Bigler, & Liben, 1993; Stoddart & Turiel, 1985). Peer relations in general are therefore poorer for clinically referred children with GD than for non-referred children/youth (e.g. Cohen-Kettenis et al., 2003; Zucker et al., 1997, 2012); and, as we might expect, poor peer relations are associated with a negative well-being and poor psychological functioning in children with GD (e.g. Cohen-Kettenis et al. 2003; Steensma et al., 2014). Consequently the variability in psychological functioning detailed within the literature is likely inversely correlated with the intensity of social intolerance experienced by the children with GD. For example, a cross-national study between children referred for their gender from Canada and from the Netherlands showed a much higher prevalence of emotional and behavioural problems in the Canadian children than in the Dutch children. Interestingly, quality of peer relations rather than IQ, parental social class, marital status, or ethnicity, turned out to be the strongest predictor in both countries. Furthermore, the quality of peer relations was lower in Canada than in the Netherlands. This indicates that psychological functioning is highly dependent upon how gender nonconformity is accepted within a certain culture or environment (Steensma et al., 2014).

However, this may not be the only factor that results in poorer psychological functioning. Over the years other models postulated in the literature focused, for example, upon generic risk factors for psychopathology and behavioural problems (such as parental psychopathology, social class background) in relation to GD; and considered them as an inherent cause of psychological problems in children with GD. Evidence for these relations is, however, still scarce and both models are under-studied in comparison to other factors such as social (in)tolerance (Zucker et al., 2014).

As far as co-occurring problems in children with GD are concerned, the relationship between Autistic Spectrum Disorders (ASD) and GD is important to mention. Although there are few studies investigating the relationship between the two, one study by de Vries, Noens, Cohen-Kettenis, van Berckelaer-Onnes, & Doreleijers (2010) showed that in a sample of 108 gender-referred children ASD was present in 6.4% of the children. This is significantly higher than the prevalence of 0.6–1% of ASD in the general population (Fombonne, 2005). Corresponding with these findings, a study by VanderLaan et al. (2015) of children referred for gender studied obsessional interests – which may be an indication of ASD – and showed that obsessions were more frequently reported by children referred for their gender in comparison with the general population. With regard to how ASD and GD are related, the question arises as to whether GD is an expression of ASD, or whether ASD is a symptom of GD; alternatively, of course, the two may be present without being related to each other (see van der Miessen et al., this issue).

Psychosexual development and related factors for persistence of GD

A central question in the counselling of children with GD is what their psychosexual outcome will be. Will the child grow up and identify as a gay man, lesbian woman, bisexual man or woman, or heterosexual man or woman without experiencing feelings of gender incongruence which require any intervention; or will the child need medical treatment in the future because the gender dysphoric feelings will persist and further intensify?

To date, there are 10 prospective follow-up studies described in the literature, together reporting on 317 gender nonconforming children who were followed-up in adolescence or early adulthood. The follow-up information in Zucker & Bradley (1995) is not included in this summary. In personal correspondence with Dr. Zucker it became clear that the 45 cases described are also included in the samples of Drummond, Bradley, Peterson-Badali, & Zucker (2008) (5 natal girls) and Singh (2012) (40 natal boys).

The conclusion from these studies is that childhood GD is strongly associated with a lesbian, gay, or bisexual outcome and that for the majority of the children (85.2%; 270 out of 317) the gender dysphoric feelings remitted around or after puberty (see Table 1).

However, there may be a number of arguments to nuance this high percentage of desistence. As is shown in Table 1 there is much variation in the reported persistence rates between the studies, ranging from 2% to 39%. Interestingly the studies before the year 2000 reported much lower persistence rates in comparison to the more recent studies after the year 2000. Furthermore, the persistence rates reported in two Canadian studies (Drummond et al., 2008; Singh, 2012) were identical (12%) but clearly lower in comparison to the follow-up study by Wallien & Cohen-Kettenis (2008) from the Netherlands. The explanation for these differences may be threefold:

First, the variation in intensity of GD in the children included differs across studies: The lower persistence rates in the earlier studies, compared to the more recent studies after 2000, may be the result of the inclusion of less extreme cases in the earlier studies than in later studies. For example, before the publication of DSM-III in 1980 there was no formal diagnosis of GD for children (Drescher, 2014). It could therefore be that the children included in the studies before 1980 would in retrospect not meet the full criteria for a diagnosis. Also, the recent

Table 1. Follow-up studies in children with GD.

Study	Sample	Age at follow-up (range)	Persistence rate
Bakwin (1968) Lebovitz (1972) Zuger (1984) Money & Russo (1979) Davenport (1986) Kosky (1987)	55 natal boys	(13–36)	9% (5 out of 55)
Green (1987)	44 natal boys	19 (14–24)	2% (1 out of 44)
Drummond et al. (2008)	25 natal girls	23 (15–37)	12% (3 out of 25)
Wallien & Cohen-Kettenis (2008)	40 natal boys 14 natal girls	19 (16–28)	39% (21 out of 54)
Singh (2012)	139 natal boys	21 (13–39)	12% (17 out of 139)

studies consisted of clinically referred samples of children, which was not the case for the earlier studies. For example, in the study by Green (1987) the sample of feminine boys was recruited through advertisement.

Secondly, and in line with the intensity explanation, there are possible cultural differences in referral: As described earlier, the sex ratios of child referrals in Canada are historically in greater favour of boys than girls as compared to the Netherlands. This may indicate that femininity in boys is experienced as more problematic in Canada –resulting in more referrals of boys with less extreme GD than in the Netherlands. As a result, the persistence rates are higher in the Netherlands compared to Canada.

Thirdly, we can consider the time of follow-up: As can be seen in Table 1, the time of follow-up differed across the studies and one could hypothesize that the studies with a later follow-up age (of older adolescents or adults) and those having a longer follow-up time, would report higher persistence rates than the studies where the follow-up took place at a younger age (i.e. shorter follow-up time). This trend is however not observed over the reported studies. To test this hypothesis, Steensma & Cohen-Kettenis (2015) recently published a report on the first 150 childhood cases from Amsterdam, the Netherlands, and checked whether a longer follow-up period would result in higher persistence rates. The children were at the time of first assessment – between 5 to 12 years old and between 19 to 38 years of age at the time of follow-up. Out of the 150 cases, 40 re-entered the clinic during adolescence (12–18 years of age) and turned out to be persisters (26.7%). However, after checking the files of the adult clinic (which sees nearly all adults with gender dysphoria in the Netherlands), it appeared that five individuals applied for treatment after the age of 18, raising the persistence rate to 30% and showing the importance of long-term follow-ups. Based on this information, it seems reasonable to conclude that the persistence of GD may well be higher than 15%. However, desistence of GD still seems to be the case in the majority of children with GD.

Two other clinically relevant questions are (1) whether we know anything with regard to the factors that are associated with the persistence or desistence of childhood GD and (2) how the process of persistence or desistence is experienced.

As to the factors associated with the persistence of GD, knowledge is still limited but fortunately slowly increasing. A central finding from all quantitative studies focusing on the topic is that the persistence of GD is most closely linked to the intensity of the GD in childhood and the amount of reported cross-gendered behaviour; in other words the more intense GD is in childhood, and the more cross-gendered behaviour is reported by parents or through self-report, the higher the chance that the GD persists (Drummond et al., 2008; Singh, 2012; Steensma, McGuire, Kreukels, Beekman, & Cohen-Kettenis, 2013; Wallien & Cohen-Kettenis, 2008). In addition to this, several other factors are linked to persistence of GD: For example, Steensma et al. (2013) and Wallien & Cohen-Kettenis (2008) showed that the persistence rate is generally higher in natal girls than in natal boys; And Steensma et al. (2013) and Singh (2012) found that the assessment age in childhood was higher in children where the GD persisted than for desisters; Further, Singh (2012) reported a higher social class in the parents of desisters compared to the parents of persisters.

In addition, Steensma et al. (2013) found that a social transition in childhood, especially in natal boys, and verbal identification with the desired/experienced gender was predictive for the persistence of GD. Interestingly, the identification finding was reported in an earlier qualitative study by Steensma, Biemond, de Boer & Cohen-Kettenis (2011) who observed differences in reported experiences of GD between persisters and desisters who were interviewed. For example, the persisters explicitly indicated that they felt they *were* the 'other' sex and the desisters indicated that they only *wished* they were the 'other' sex. The primary aim of the Steensma et al. (2011) study was to get a better understanding of the processes that contribute to the persistence and desistence of childhood GD. By interviewing adolescents (14 persisters, 11 desisters) who all fulfilled the DSM-IV or DSM-IV-TR criteria of a gender identity diagnosis in childhood (APA, 1994, 2000), it became clear that the period between 10 and 13 years was considered crucial. Both persisters and desisters stated that the changes in their social environment, the anticipated and actual feminization or masculinization of their bodies, and the first experiences of falling in love and sexual attraction in this period, contributed to an increase (in the persisters) or decrease (in the desisters) of their gender related interests, behaviours, and feelings of gender discomfort.

Treatment and counselling of children with GD

Over the last decade, the care for prepubescent children with GD has been rapidly changing and there is a growing number of specialized gender clinics for young people (Hsieh & Leininger, 2014; Khatchadourian, Ahmed, & Metzger, 2014; Riittakerttu, Sumia, Työläjärvi, & Lindberg, 2015). Best clinical practice in gender referred children is still controversial and raises debates among dedicated professionals. General agreement does, however, exist that the care for children with

GD should be focused on reducing the child's distress related to their GD; on help with other psychological difficulties; and optimizing psychological adjustment and wellbeing (e.g. Byne et al., 2012; Coleman et al., 2011). As for the counselling of the gender dysphoric feelings in children with GD; empirical treatment models do not exist and general consensus between clinicians is not always easy to obtain (Byne et al., 2012). In the current professional literature, three treatment models for the care of gender variant children can be distinguished (e.g. Byne et al., 2012; Drescher, 2013) and it is these to which we now turn.

The first approach focuses on working with the child and caregivers to lessen cross-gender behaviour and identification, to persuade the child that the 'right gender' is the one assigned at birth (Giordano, 2012), to decrease the likelihood that GD will persist into adolescence, and prevent adult transsexualism. Critics of this approach have linked it to 'reparative therapy', a term more commonly used to describe efforts to change same sex attraction to heterosexuality in gay adults or 'pre-homosexual' children (Drescher, 2013). In the past, such behavioural and psychodynamic therapies to lessen the GD have been largely used in children with GD with overall unsatisfactory results (Byne et al., 2012; Möller, Schreier, Li, & Romer, 2009). Instead, children often seem to become distressed if their preferences and/or behaviours are blocked (Richardson, 1999). At present, interventions aimed to lessen GD are referred to as unethical by the World Professional Association for Transgendered Health (WPATH: Coleman et al., 2011) and many other international professional organizations. The American Academy of Child & Adolescent Psychiatry, for example, has explicitly formulated their position against any psychological treatment aimed to change gender nonconforming behaviours (Adelson, 2012).

The second approach is focused on dealing with the potential social risks for the child (Byne et al., 2012). Because its aim is to allow the progress of the GD in the child to unfold in a natural way, it is often referred to as 'watchful waiting' (Drescher, 2013). Counselling based on this approach may include interventions that focus on the co-existing problems of the child and/or the family; helping parents and the child to bear the uncertainty of the child's psychosexual outcome; and providing psychoeducation to help the child and the family to make balanced decisions regarding topics such as the child's coming out, early social transitioning, and/or how to handle peer rejection or social ostracism. In practice, the child and parents are encouraged to find a balance between an accepting and supportive attitude toward GD, while at the same time protecting the child against any negative reactions and remaining realistic about the chance that GD feelings may desist in the future. Parents are encouraged to provide enough space for their child to explore their gender dysphoric feelings, while at the same time keeping all future outcomes open (e.g., de Vries & Cohen-Kettenis, 2012; Di Ceglie, 1998, 2014).

The third approach is focused on affirming the child's (trans)gender identification and helps the child to build a positive self-identity and gender resilience. In particular, the child is supported in transitioning to the desired/experienced gender role. The rationale for supporting social transition before puberty is that children can revert to their originally assigned gender if necessary since the transition is solely at a social level and without medical intervention (e.g. Byne et al., 2012; Drescher, 2013; Hill, Menvielle, Sica, & Johnson, 2010). Critics of this approach believe that supporting gender transition in childhood may indeed be relieving for children with GD but question the effect on future development. The debate thereby focuses on whether a transition may increase the likelihood of persistence because, for example, a child may 'forget' how to live in the original gender role and therefore will no longer be able to feel the desire to change back; or that transitioned children may repress doubts about the transition out of fear that they have to go through the process of making their desire to socially (re)transition public for a second time (Steensma, 2013). The fact that transitioning for a second time can be difficult was indeed shown in the qualitative study by Steensma et al. (2011) where children who transitioned early in childhood reported a struggle with changing back to their original gender role when their feelings desisted, with the fear of being teased or excluded by their peers reported as the main reason for this.

Unfortunately, empirical answers about the best way to counsel children with GD and their caregivers are currently not available. The WPATH have therefore formulated a balanced position in their Standards of Care (Coleman et al., 2011), where clinicians are encouraged to help families by providing information about what is known about the development of children with GD and to help them to make decisions where the potential benefits and challenges of particular choices are weighted.

Conclusion

According to the DSM-5 diagnostic criteria for gender dysphoria, children with GD experience clinically significant distress because of the incongruence between their assigned gender at birth and experienced gender (APA, 2013). The clinical presentation of children who present with gender identity issues is characterized by gender-nonconformity and a vulnerability to having psychological problems – primarily of an internalized nature (e.g. Cohen-Kettenis et al., 2003; Steensma et al., 2014), and an increased likelihood of ASD symptomatology (de Vries et al., 2010; VanderLaan et al., 2015). The extent and intensity of all three characteristics can be variable.

When considering the development of children with GD; studies show that gender dysphoric feelings eventually desist for the majority of children with GD, and that their psychosexual outcome is strongly associated with a lesbian, gay, or bisexual sexuality which does not require any medical intervention, instead of an outcome where medical intervention is required (e.g. Drummond et al., 2008; Wallien & Cohen-Kettenis, 2008; Singh, 2012). Factors predictive for the persistence of GD have been identified on a group level, with higher intensity of GD in childhood identified as the strongest predictor for a future gender dysphoric outcome (Steensma et al., 2013). The predictive value of the identified factors for persistence are, however, on an individual level less clear cut, and the clinical utility of currently identified factors is low.

Taken together this shows that there can be a great variability with regard to presentation of children with GD and their psychosexual outcome. The counselling of children with GD can therefore be complex and clinically challenging. To date, there is general agreement that the care for children with GD should not be aimed at avoiding adult same sex attraction or transsexualism; that no medical intervention should be provided in childhood (before puberty); that counselling should therefore be focused on reducing the child's distress related to the GD, on help with other psychological difficulties, and on optimizing psychological adjustment and wellbeing (e.g. Byne et al., 2012; Coleman et al., 2011).

However, besides these basic clinical values, there is currently no general consensus about the best approach to dealing with the (uncertain) future development of children with GD, and making decisions that may influence the functioning and/or development of the child – such as a social transition. Different clinical approaches are presented in the literature, and indeed taking the variability in presentation of children with GD into account, it seems important to underline that a 'one size fits all' approach is not best practice for children with GD. Therefore, different kinds of treatment options should be available which respect the unique needs of every child. In particular, the child's clinical psychological profile and gender development, as well as the contextual psychosocial characteristics of the child's family (e.g. belief system, supportive behaviours, access to health care) should always be taken into account in order to make balanced decisions. Currently, the limited empirical evidence in favour of a particular treatment makes treatment of teenagers with GD a controversial issue that raises intense, and often polarized, debate. Therefore, studies comparing different psychological treatment options are needed as well as research which aims to identify the factors involved in the persistence process of GD on an individual level. The primary goal is therefore to determine the safest and most efficacious mental and medical approach for the individual child with GD.

Declaration of interest

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

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Long-Term Follow-Up of Transsexual Persons Undergoing Sex Reassignment Surgery: Cohort Study in Sweden

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Abstract

Context: The treatment for transsexualism is sex reassignment, including hormonal treatment and surgery aimed at making the person's body as congruent with the opposite sex as possible. There is a dearth of long term, follow-up studies after sex reassignment.

Objective: To estimate mortality, morbidity, and criminal rate after surgical sex reassignment of transsexual persons.

Design: A population-based matched cohort study.

Setting: Sweden, 1973-2003.

Participants: All 324 sex-reassigned persons (191 male-to-females, 133 female-to-males) in Sweden, 1973–2003. Random population controls (10:1) were matched by birth year and birth sex or reassigned (final) sex, respectively.

Main Outcome Measures: Hazard ratios (HR) with 95% confidence intervals (CI) for mortality and psychiatric morbidity were obtained with Cox regression models, which were adjusted for immigrant status and psychiatric morbidity prior to sex reassignment (adjusted HR [aHR]).

Results: The overall mortality for sex-reassigned persons was higher during follow-up (aHR 2.8; 95% CI 1.8–4.3) than for controls of the same birth sex, particularly death from suicide (aHR 19.1; 95% CI 5.8–62.9). Sex-reassigned persons also had an increased risk for suicide attempts (aHR 4.9; 95% CI 2.9–8.5) and psychiatric inpatient care (aHR 2.8; 95% CI 2.0–3.9). Comparisons with controls matched on reassigned sex yielded similar results. Female-to-males, but not male-to-females, had a higher risk for criminal convictions than their respective birth sex controls.

Conclusions: Persons with transsexualism, after sex reassignment, have considerably higher risks for mortality, suicidal behaviour, and psychiatric morbidity than the general population. Our findings suggest that sex reassignment, although alleviating gender dysphoria, may not suffice as treatment for transsexualism, and should inspire improved psychiatric and somatic care after sex reassignment for this patient group.

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Introduction

Transsexualism (ICD-10),[1] or gender identity disorder (DSM-IV),[2] is a condition in which a person's gender identity - the sense of being a man or a woman - contradicts his or her bodily sex characteristics. The individual experiences gender dysphoria and desires to live and be accepted as a member of the opposite sex.

The treatment for transsexualism includes removal of body hair, vocal training, and cross-sex hormonal treatment aimed at making the person's body as congruent with the opposite sex as possible to alleviate the gender dysphoria. Sex reassignment also involves the surgical removal of body parts to make external sexual characteristics resemble those of the opposite sex, so called sex reassignment/confirmation surgery (SRS). This is a unique intervention not only in psychiatry but in all of medicine. The present form of sex reassignment has been practised for more than half a century and is the internationally recognized treatment to ease gender dysphoria in transsexual persons.[3,4]

Despite the long history of this treatment, however, outcome data regarding mortality and psychiatric morbidity are scant. With respect to suicide and deaths from other causes after sex reassignment, an early Swedish study followed 24 transsexual persons for an average of six years and reported one suicide.[5] A subsequent Swedish study recorded three suicides after sex reassignment surgery of 175 patients.[6] A recent Swedish follow-up study reported no suicides in 60 transsexual patients, but one death due to complications after the sex reassignment surgery.[7] A Danish study reported death by suicide in 3 out of 29 operated male-to-female transsexual persons followed for an average of six years.[8] By contrast, a Belgian study of 107 transsexual persons followed for 4–6 years found no suicides or deaths from other causes.[9] A large Dutch single-centre study (N = 1,109), focusing on adverse events following hormonal treatment, compared the outcome after cross-sex hormone treatment with national Dutch standardized mortality and morbidity rates and found no increased mortality, with the exception of death from suicide and AIDS in male-to-females 25–39 years of age.[10] The same research group concluded in a recent report that treatment with cross-sex hormones seems acceptably safe, but with the reservation that solid clinical data are missing.[11] A limitation with respect to the Dutch cohort is that the proportion of patients treated with cross-sex hormones who also had surgical sex-reassignment is not accounted for.[10]

Data is inconsistent with respect to psychiatric morbidity post sex reassignment. Although many studies have reported psychiatric and psychological improvement after hormonal and/or surgical treatment,[7,12,13,14,15,16] other have reported on regrets,[17] psychiatric morbidity, and suicide attempts after SRS.[9,18] A recent systematic review and meta-analysis concluded that approximately 80% reported subjective improvement in terms of gender dysphoria, quality of life, and psychological symptoms, but also that there are studies reporting high psychiatric morbidity and suicide rates after sex reassignment.[19] The authors concluded though that the evidence base for sex reassignment "is of very low quality due to the serious methodological limitations of included studies."

The methodological shortcomings have many reasons. First, the nature of sex reassignment precludes double blind randomized controlled studies of the result. Second, transsexualism is rare [20] and many follow-ups are hampered by small numbers of subjects.[5,8,21,22,23,24,25,26,27,28] Third, many sex reassigned persons decline to participate in follow-up studies, or relocate after surgery, resulting in high drop-out rates and consequent selection bias.[6,9,12,21,24,28,29,30] Forth, several follow-up studies are hampered by limited follow-up periods.[7,9,21,22,26,30] Taken together, these limitations preclude solid and generalisable conclusions. A long-term population-based controlled study is one way to address these methodological shortcomings.

Here, we assessed mortality, psychiatric morbidity, and psychosocial integration expressed in criminal behaviour after sex reassignment in transsexual persons, in a total population cohort study with long-term follow-up information obtained from Swedish registers. The cohort was compared with randomly selected population controls matched for age and gender. We adjusted for premorbid differences regarding psychiatric morbidity and immigrant status. This study design sheds new light on transsexual persons' health after sex reassignment. It does not, however, address whether sex reassignment is an effective treatment or not.

Methods

National registers

The study population was identified by the linkage of several Swedish national registers, which contained a total of 13.8 million unique individuals. The Hospital Discharge Register (HDR, held by the National Board of Health and Welfare) contains discharge diagnoses, up to seven contributory diagnoses, external causes of morbidity or mortality, surgical procedure codes, and discharge date. Discharge diagnoses are coded according to the 8th (1969-1986), 9th (1987–1996), and 10th editions (1997-) of the International Classification of Diseases (ICD). The register covers virtually all psychiatric inpatient episodes in Sweden since 1973. Discharges that occurred up to 31 December 2003 were included. Surgical procedure codes could not be used for this study due to the lack of a specific code for sex reassignment surgery. The Total Population Register (TPR, held by Statistics Sweden) is comprised of data about the entire Swedish population. Through linkage with the Total Population Register it was possible to identify birth date and birth gender for all study subjects. The register is updated every year and gender information was available up to 2004/2005. The Medical Birth Register (MBR) was established in 1973 and contains birth data, including gender of the child at birth. National censuses based on mandatory self-report questionnaires completed by all adult citizens in 1960, 1970, 1980, and 1990 provided information on individuals, households, and dwellings, including gender, living area, and highest educational level. Complete migration data, including country of birth for immigrants for 1969–2003, were obtained from the TPR. In addition to educational information from the censuses, we also obtained highest educational level data for 1990 and 2000 from the Register of Education. The Cause of Death Register (CDR, Statistics Sweden) records all deaths in Sweden since 1952 and provided information on date of death and causes of death. Death events occurring up to 31 December 2003 are included in the study. The Crime Register (held by the National Council of Crime Prevention) provided information regarding crime type and date on all criminal convictions in Sweden during the period 1973–2004. Attempted and aggravated forms of all offences were also included. All crimes in Sweden are registered regardless of insanity at the time of perpetration; for example, for individuals who suffered from psychosis at the time of the offence. Moreover, conviction data include individuals who received custodial or non-custodial sentences and cases where the prosecutor decided to caution or fine without court proceedings. Finally, Sweden does not differ considerably from other members of the European Union regarding rates of violent crime and their resolution.[31]

Study population, identification of sex-reassigned persons (exposure assessment)

The study was designed as a population-based matched cohort study. We used the individual national registration number, assigned to all Swedish residents, including immigrants on arrival, as the primary key through all linkages. The registration number consists of 10 digits; the first six provide information of the birth date, whereas the ninth digit indicates the gender. In Sweden, a person presenting with gender dysphoria is referred to one of six specialised gender teams that evaluate and treat patients principally according to international consensus guidelines: Standards of Care.[3] With a medical certificate, the person applies to the National Board of Health and Welfare to receive permission for sex reassignment surgery and a change of legal sex status. A new national registration number signifying the new gender is assigned after sex reassignment surgery. The National

Board of Health and Welfare maintains a link between old and new national registration numbers, making it possible to follow individuals undergoing sex reassignment across registers and over time. Hence, sex reassignment surgery in Sweden requires (i) a transsexualism diagnosis and (ii) permission from the National Board of Health and Welfare.

A person was defined as exposed to sex reassignment surgery if two criteria were met: (i) at least one inpatient diagnosis of gender identity disorder diagnosis without concomitant psychiatric diagnoses in the Hospital Discharge Register, and (ii) at least one discrepancy between gender variables in the Medical Birth Register (from 1973 and onwards) or the National Censuses from 1960, 1970, 1980, or 1990 and the latest gender designation in the Total Population Register. The first criterion was employed to capture the hospitalization for sex reassignment surgery that serves to secure the diagnosis and provide a time point for sex reassignment surgery; the plastic surgeons namely record the reason for sex reassignment surgery, i.e., transsexualism, but not any co-occurring psychiatric morbidity. The second criterion was used to ensure that the person went through all steps in sex-reassignment and also changed sex legally.

The date of sex reassignment (start of follow-up) was defined as the first occurrence of a gender identity disorder diagnosis, without any other concomitant psychiatric disorder, in the Hospital Discharge Register after the patient changed sex status (any discordance in sex designation across the Censuses, Medical Birth, and Total Population registers). If this information was missing, we used instead the closest date in the Hospital Discharge Register on which the patient was diagnosed with gender identity disorder without concomitant psychiatric disorder prior to change in sex status. The reason for prioritizing the use of a gender identity disorder diagnosis *after* changed sex status over *before* was to avoid overestimating person-years at risk of sex-reassigned person.

Using these criteria, a total of 804 patients with gender identity disorder were identified, whereof 324 displayed a shift in the gender variable during the period 1973–2003. The 480 persons that did not shift gender variable comprise persons who either did not apply, or were not approved, for sex reassignment surgery. Moreover, the ICD 9 code 302 is a non specific code for sexual disorders. Hence, this group might also comprise persons that were hospitalized for sexual disorders other than transsexualism. Therefore, they were omitted from further analyses. Of the remaining 324 persons, 288 were identified with the gender identity diagnosis *after* and 36 *before* change of sex status. Out of the 288 persons identified *after* changed sex status, 185 could also be identified *before* change in sex status. The median time lag between the hospitalization *before* and *after* sex change for these 185 persons was 0.96 years (mean 2.2 years, SD 3.3).

Gender identity disorder was coded according to ICD-8: 302.3 (transsexualism) and 302.9 (sexual deviation NOS); ICD-9: 302 (overall code for sexual deviations and disorders, more specific codes were not available in ICD-9); and ICD-10: F64.0 (transsexualism), F64.1 (dual-role transvestism), F64.8 (other gender identity disorder), and F64.9 (gender identity disorder NOS). Other psychiatric disorders were coded as ICD-8: 290-301 and 303-315; ICD-9: 290-301 and 303-319; and ICD-10: F00-F63 as well as F65-F99.

Identification of population-based controls (unexposed group)

For each exposed person (N = 324), we randomly selected 10 unexposed controls. A person was defined as unexposed if there were no discrepancies in sex designation across the Censuses, Medical Birth, and Total Population registers *and* no gender identity disorder diagnosis according to the Hospital Discharge Register. Control persons were matched by sex and birth year and had to be alive and residing in Sweden at the estimated sex reassignment date of the case person. To study possible gender-specific effects on outcomes of interest, we used two different control groups: one with the same sex as the case individual at birth (birth sex matching) and the other with the sex that the case individual had been reassigned to (final sex matching).

Outcome measures

We studied mortality, psychiatric morbidity, accidents, and crime following sex reassignment. More specifically, we investigated: (1) all-cause mortality, (2) death by definite/uncertain suicide, (3) death by cardiovascular disease, and (4) death by tumour. Morbidity included (5) any psychiatric disorder (gender identity disorders excluded), (6) alcohol/drug misuse and dependence, (7) definite/uncertain suicide attempt, and (8) accidents. Finally, we addressed court convictions for (9) any criminal offence and (10) any violent offence. Each individual could contribute with several outcomes, but only one event per outcome. Causes of death (Cause of Death Registry from 1952 and onwards) were defined according to ICD as suicide (ICD-8 and ICD-9 codes E950-E959 and E980-E989, ICD-10 codes X60-X84 and Y10-Y34); cardiovascular disease (ICD-8 codes 390-458, ICD-9 codes 390-459, ICD-10 codes I00-I99); neoplasms (ICD-8 and ICD-9 codes 140-239, ICD-10 codes C00-D48), any psychiatric disorder (gender identity disorders excluded); (ICD-8 codes 290-301 and 303-315, ICD-9 codes 290-301 and 303-319, ICD-10 codes F00-F63 and F65-F99); alcohol/drug abuse and dependence (ICD-8 codes 303-304, ICD-9 codes 303-305 (tobacco use disorder excluded), ICD-10 codes F10-F16 and F18-F19 (x5 excluded); and accidents (ICD-8 and ICD-9 codes E800-E929, ICD-10 codes V01-X59).

Any criminal conviction during follow-up was counted; specifically, violent crime was defined as homicide and attempted homicide, aggravated assault and assault, robbery, threatening behaviour, harassment, arson, or any sexual offense.[32]

Covariates

Severe psychiatric morbidity was defined as inpatient care according to ICD-8 codes 291, 295-301, 303-304, and 307; ICD-9 codes 291-292, 295-298, 300-301, 303-305 (tobacco use disorder excluded), 307.1, 307.5, 308-309, and 311; ICD-10 codes F10-F16, F18-F25, F28-F45, F48, F50, and F60-F62. Immigrant status, defined as individuals born abroad, was obtained from the Total Population Register. All outcome/covariate variables were dichotomized (i.e., affected or unaffected) and without missing values.

Statistical analyses

Each individual contributed person-time from study entry (for exposed: date of sex reassignment; for unexposed: date of sex reassignment of matched case) until date of outcome event, death, emigration, or end of study period (31 December 2003), whichever came first. The association between exposure (sex reassignment) and outcome (mortality, morbidity, crime) was measured by hazard ratios (HR) with 95% CIs, taking follow-up time into account. HRs were estimated from Cox proportional hazard regression models, stratified on matched sets (1:10) to account for the matching by sex, age, and calendar time (birth year). We present crude HRs (though adjusted for sex and age through matching) and confounder-adjusted HRs [aHRs] for all outcomes. The two potential confounders, immigrant status (yes/no) and history of severe psychiatric morbidity (yes/no) prior to sex reassignment, were chosen based on previous research[18,33] and different prevalence across cases and controls (Table 1).

Gender-separated analyses were performed and a Kaplan-Meier survival plot graphically illustrates the survival of the sex reassigned cohort and matched controls (all-cause mortality) over time. The significance level was set at 0.05 (all tests were two-sided). All outcome/covariate variables were without missing values, since they are generated from register data, which are either present (affected) or missing (unaffected). The data were analysed using SAS version 9.1 (SAS Institute Inc., Cary, NC, USA).

Ethics

The data linking of national registers required for this study was approved by the IRB at Karolinska Institutet, Stockholm. All data were analyzed anonymously; therefore, informed consent for each individual was neither necessary nor possible.

Results

We identified 324 transsexual persons (exposed cohort) who underwent sex reassignment surgery and were assigned a new legal sex between 1973 and 2003. These constituted the sex-reassigned (exposed) group. Fifty-nine percent (N = 191) of sex-reassigned persons were male-to-females and 41% (N = 133) female-to-males, yielding a sex ratio of 1.4:1 (Table 1).

The average follow-up time for all-cause mortality was 11.4 (median 9.1) years. The average follow-up time for the risk of being hospitalized for any psychiatric disorder was 10.4 (median 8.1).

Characteristics prior to sex reassignment

Table 1 displays demographic characteristics of sex-reassigned and control persons prior to study entry (sex reassignment). There were no substantial differences between female-to-males and male-to-females regarding measured baseline characteristics. Immigrant status was twice as common among transsexual individuals compared to controls, living in an urban area somewhat more common, and higher education about equally prevalent. Transsexual individuals had been hospitalized for psychiatric morbidity other than gender identity disorder prior to sex reassignment about four times more often than controls. To adjust for these baseline discrepancies, hazard ratios adjusted for immigrant status and psychiatric morbidity prior to baseline are presented for all outcomes [aHRs].

Mortality

Table 2 describes the risks for selected outcomes during follow-up among sex-reassigned persons, compared to same-age controls of the same birth sex. Sex-reassigned transsexual persons of both genders had approximately a three times higher risk of all-cause mortality than controls, also after adjustment for covariates. Table 2

Table 1. Baseline characteristics among sex-reassigned subjects in Sweden (N = 324) and population controls matched for birth year and sex.

Characteristic at baseline	Sex-reassigned subjects (N = 324)	Birth-sex matched controls (N = 3,240)	Final-sex matched controls (N = 3,240)
Gender			
Female at birth, male after sex change	133 (41%)	1,330 (41%)	1,330 (41%)
Male at birth, female after sex change	191 (59%)	1,910 (59%)	1,910 (59%)
Average age at study entry [years] (SD, min-max)			
Female at birth, male after sex change	33.3 (8.7, 20–62)	33.3 (8.7, 20–62)	33.3 (8.7, 20–62)
Male at birth, female after sex change	36.3 (10.1, 21–69)	36.3 (10.1, 21–69)	36.3 (10.1, 21–69)
Both genders	35.1 (9.7, 20–69)	35.1 (9.7, 20–69)	35.1 (9.7, 20–69)
Immigrant status			
Female at birth, male after sex change	28 (21%)	118 (9%)	100 (8%)
Male at birth, female after sex change	42 (22%)	176 (9%)	164 (9%)
Both genders	70 (22%)	294 (9%)	264 (8%)
Less than 10 years of schooling prior to entry vs. 10 years or more			
Females at birth, males after sex change	49 (44%); 62 (56%)	414 (37%); 714 (63%)	407 (36%); 713 (64%)
Males at birth, females after sex change	61 (41%); 89 (59%)	665 (40%); 1,011 (60%)	595 (35%); 1,091 (65%)
All individuals with data	110 (42%); 151 (58%)	1,079 (38%); 1,725 (62%)	1,002 (36%); 1,804 (64%)
Psychiatric morbidity* prior to study entry			
Female at birth, male after sex change	22 (17%)	47 (4%)	42 (3%)
Male at birth, female after sex change	36 (19%)	76 (4%)	72 (4%)
Both genders	58 (18%)	123 (4%)	114 (4%)
Rural [vs. urban] living area prior to entry			
Female at birth, male after sex change	13 (10%)	180 (14%)	195 (15%)
Male at birth, female after sex change	20 (10%)	319 (17%)	272 (14%)
Both genders	33 (10%)	499 (15%)	467 (14%)

Note:
*Hospitalizations for gender identity disorder were not included.
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Table 2. Risk of various outcomes among sex-reassigned subjects in Sweden (N = 324) compared to population controls matched for birth year and birth sex.

	Number of events cases/ controls 1973–2003	Outcome incidence rate per 1000 person-years 1973–2003 (95% CI)		Crude hazard ratio (95% CI) 1973–2003	Adjusted* hazard ratio (95% CI) 1973–2003	Adjusted* hazard ratio (95% CI) 1973–1988	Adjusted* hazard ratio (95% CI) 1989–2003
		Cases	Controls				
Any death	27/99	7.3 (5.0–10.6)	2.5 (2.0–3.0)	2.9 (1.9–4.5)	2.8 (1.8–4.3)	3.1 (1.9–5.0)	1.9 (0.7–5.0)
Death by suicide	10/5	2.7 (1.5–5.0)	0.1 (0.1–0.3)	19.1 (6.5–55.9)	19.1 (5.8–62.9)	N/A	N/A
Death by cardiovascular disease	9/42	2.4 (1.3–4.7)	1.1 (0.8–1.4)	2.6 (1.2–5.4)	2.5 (1.2–5.3)	N/A	N/A
Death by neoplasm	8/38	2.2 (1.1–4.3)	1.0 (0.7–1.3)	2.1 (1.0–4.6)	2.1 (1.0–4.6)	N/A	N/A
Any psychiatric hospitalisation‡	64/173	19.0 (14.8–24.2)	4.2 (3.6–4.9)	4.2 (3.1–5.6)	2.8 (2.0–3.9)	3.0 (1.9–4.6)	2.5 (1.4–4.2)
Substance misuse	22/78	5.9 (3.9–8.9)	1.8 (1.5–2.3)	3.0 (1.9–4.9)	1.7 (1.0–3.1)	N/A	N/A
Suicide attempt	29/44	7.9 (5.5–11.4)	1.0 (0.8–1.4)	7.6 (4.7–12.4)	4.9 (2.9–8.5)	7.9 (4.1–15.3)	2.0 (0.7–5.3)
Any accident	32/233	9.0 (6.3–12.7)	5.7 (5.0–6.5)	1.6 (1.1–2.3)	1.4 (1.0–2.1)	1.6 (1.0–2.5)	1.1 (0.5–2.2)
Any crime	60/350	18.5 (14.3–23.8)	9.0 (8.1–10.0)	1.9 (1.4–2.5)	1.3 (1.0–1.8)	1.6 (1.1–2.4)	0.9 (0.6–1.5)
Violent crime	14/61	3.6 (2.1–6.1)	1.4 (1.1–1.8)	2.7 (1.5–4.9)	1.5 (0.8–3.0)	N/A	N/A

Notes:
*Adjusted for psychiatric morbidity prior to baseline and immigrant status.
‡Hospitalisations for gender identity disorder were excluded.
N/A Not applicable due to sparse data.
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separately lists the outcomes depending on when sex reassignment was performed: during the period 1973-1988 or 1989–2003. Even though the overall mortality was increased across both time periods, it did not reach statistical significance for the period 1989–2003. The Kaplan-Meier curve (Figure 1) suggests that survival of transsexual persons started to diverge from that of matched controls after about 10 years of follow-up. The cause-specific mortality from suicide was much higher in sex-reassigned persons, compared to matched controls. Mortality due to cardiovascular disease was moderately increased among the sex-reassigned, whereas the numerically increased risk for malignancies was borderline statistically significant. The malignancies were lung cancer (N = 3), tongue cancer (N = 1), pharyngeal cancer (N = 1), pancreas cancer (N = 1), liver cancer (N = 1), and unknown origin (N = 1).

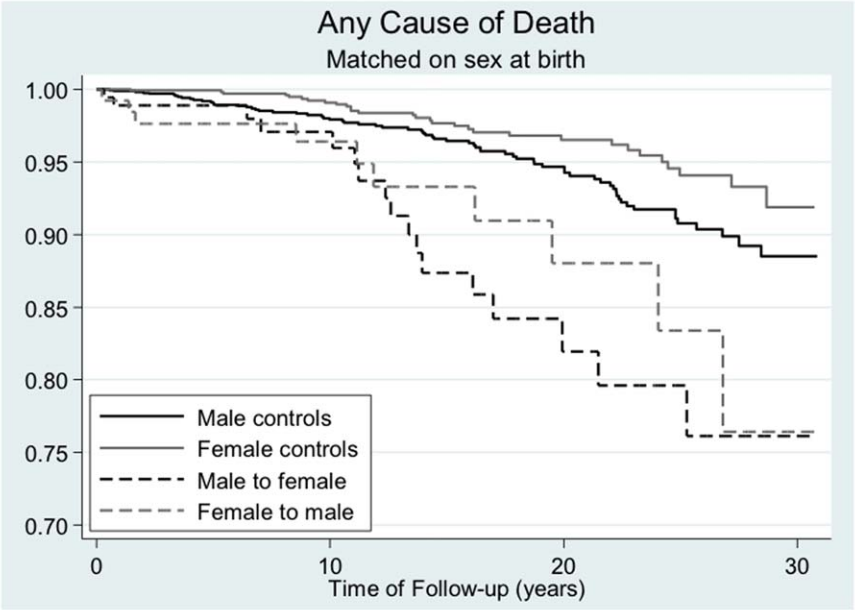

Figure 1. Death from any cause as a function of time after sex reassignment among 324 transsexual persons in Sweden (male-to-female: N = 191, female-to-male: N = 133), and population controls matched on birth year.
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Psychiatric morbidity, substance misuse, and accidents

Sex-reassigned persons had a higher risk of inpatient care for a psychiatric disorder other than gender identity disorder than controls matched on birth year and birth sex (Table 2). This held after adjustment for prior psychiatric morbidity, and was true regardless of whether sex reassignment occurred before or after 1989. In line with the increased mortality from suicide, sex-reassigned individuals were also at a higher risk for suicide attempts, though this was not statistically significant for the time period 1989–2003. The risks of being hospitalised for substance misuse or accidents were not significantly increased after adjusting for covariates (Table 2).

Crime rate

Transsexual individuals were at increased risk of being convicted for any crime or violent crime after sex reassignment (Table 2); this was, however, only significant in the group who underwent sex reassignment before 1989.

Gender differences

Comparisons of female-to-males and male-to-females, although hampered by low statistical power and associated wide confidence intervals, suggested mostly similar risks for adverse outcomes (Tables S1 and S2). However, violence against self (suicidal behaviour) and others ([violent] crime) constituted important exceptions. First, male-to-females had significantly increased risks for suicide attempts compared to both female (aHR 9.3; 95% CI 4.4–19.9) and male (aHR 10.4; 95% CI 4.9–22.1) controls. By contrast, female-to-males had significantly increased risk of suicide attempts only compared to male controls (aHR 6.8; 95% CI 2.1–21.6) but not compared to female controls (aHR 1.9; 95% CI 0.7–4.8). This suggests that male-to-females are at higher risk for suicide attempts after sex reassignment, whereas female-to-males maintain a female pattern of suicide attempts after sex reassignment (Tables S1 and S2).

Second, regarding any crime, male-to-females had a significantly increased risk for crime compared to female controls (aHR 6.6; 95% CI 4.1–10.8) but not compared to males (aHR 0.8; 95% CI 0.5–1.2). This indicates that they retained a male pattern regarding criminality. The same was true regarding violent crime. By contrast, female-to-males had higher crime rates than female controls (aHR 4.1; 95% CI 2.5–6.9) but did not differ from male controls. This indicates a shift to a male pattern regarding criminality and that sex reassignment is coupled to increased crime rate in female-to-males. The same was true regarding violent crime.

Discussion

Principal findings and comparison with previous research

We report on the first nationwide population-based, long-term follow-up of sex-reassigned transsexual persons. We compared our cohort with randomly selected population controls matched for age and gender. The most striking result was the high mortality rate in both male-to-females and female-to males, compared to the general population. This contrasts with previous reports (with one exception[8]) that did not find an increased mortality rate after sex reassignment, or only noted an increased risk in certain subgroups.[7,9,10,11] Previous clinical studies might have been biased since people who regard their sex reassignment as a failure are more likely to be lost to follow-up. Likewise, it is cumbersome to track deceased persons in clinical follow-up studies. Hence, population-based register studies like the present are needed to improve representativity.[19,34]

The poorer outcome in the present study might also be explained by longer follow-up period (median >10 years) compared to previous studies. In support of this notion, the survival curve (Figure 1) suggests increased mortality from ten years after sex reassignment and onwards. In accordance, the overall mortality rate was only significantly increased for the group operated before 1989. However, the latter might also be explained by improved health care for transsexual persons during 1990s, along with altered societal attitudes towards persons with different gender expressions.[35]

Mortality due to cardiovascular disease was significantly increased among sex reassigned individuals, albeit these results should be interpreted with caution due to the low number of events. This contrasts, however, a Dutch follow-up study that reported no increased risk for cardiovascular events.[10,11] A recent meta-analysis concluded, however, that data on cardiovascular outcome after cross-sex steroid use are sparse, inconclusive, and of very low quality.[34]

With respect to neoplasms, prolonged hormonal treatment might increase the risk for malignancies,[36] but no previous study has tested this possibility. Our data suggested that the cause-specific risk of death from neoplasms was increased about twice (borderline statistical significance). These malignancies (see Results), however, are unlikely to be related to cross-hormonal treatment.

There might be other explanations to increased cardiovascular death and malignancies. Smoking was in one study reported in almost 50% by the male-to females and almost 20% by female-to-males.[9] It is also possible that transsexual persons avoid the health care system due to a presumed risk of being discriminated.

Mortality from suicide was strikingly high among sex-reassigned persons, also after adjustment for prior psychiatric morbidity. In line with this, sex-reassigned persons were at increased risk for suicide attempts. Previous reports [6,8,10,11] suggest that transsexualism is a strong risk factor for suicide, also after sex reassignment, and our long-term findings support the need for continued psychiatric follow-up for persons at risk to prevent this.

Inpatient care for psychiatric disorders was significantly more common among sex-reassigned persons than among matched controls, both before and after sex reassignment. It is generally accepted that transsexuals have more psychiatric ill-health than the general population prior to the sex reassignment.[18,21,22,33] It should therefore come as no surprise that studies have found high rates of depression,[9] and low quality of life[16,25] also after sex reassignment. Notably, however, in this study the increased risk for psychiatric hospitalisation persisted even after adjusting for psychiatric hospitalisation prior to sex reassignment. This suggests that even though sex reassignment alleviates gender dysphoria, there is a need to identify and treat co-occurring psychiatric morbidity in transsexual persons not only before but also after sex reassignment.

Criminal activity, particularly violent crime, is much more common among men than women in the general population. A previous study of all applications for sex reassignment in Sweden up to 1992 found that 9.7% of male-to-female and 6.1% of female-to-male applicants had been prosecuted for a crime.[33] Crime after sex reassignment, however, has not previously been studied. In this study, male-to-female individuals had a higher risk for criminal convictions compared to female controls but not compared to male controls. This suggests that the sex reassignment procedure neither increased nor decreased the risk for criminal offending in male-to-females. By contrast, female-to-males were at a higher risk for criminal convictions compared to female controls and did not differ from male controls, which suggests increased crime proneness in female-to-males after sex reassignment.

Strengths and limitations of the study

Strengths of this study include nationwide representativity over more than 30 years, extensive follow-up time, and minimal loss to follow-up. Many previous studies suffer from low outcome ascertainment,[6,9,21,29] whereas this study has captured almost the entire population of sex-reassigned transsexual individuals in Sweden from 1973–2003. Moreover, previous outcome studies have mixed pre-operative and post-operative transsexual persons,[22,37] while we included only post-operative transsexual persons that also legally changed sex. Finally, whereas previous studies either lack a control group or use standardised mortality rates or standardised incidence rates as comparisons,[9,10,11] we selected random population controls matched by birth year, and either birth or final sex.

Given the nature of sex reassignment, a double blind randomized controlled study of the result after sex reassignment is not feasible. We therefore have to rely on other study designs. For the purpose of evaluating whether sex reassignment is an effective treatment for gender dysphoria, it is reasonable to compare reported gender dysphoria pre and post treatment. Such studies have been conducted either prospectively[7,12] or retrospectively,[5,6,9,22,25,26,29,38] and suggest that sex reassignment of transsexual persons improves quality of life and gender dysphoria. The limitation is of course that the treatment has not been assigned randomly and has not been carried out blindly.

For the purpose of evaluating the safety of sex reassignment in terms of morbidity and mortality, however, it is reasonable to compare sex reassigned persons with matched population controls. The caveat with this design is that transsexual persons before sex reassignment might differ from healthy controls (although this bias can be statistically corrected for by adjusting for baseline differences). It is therefore important to note that the current study is only informative with respect to transsexuals persons health after sex reassignment; no inferences can be drawn as to the effectiveness of sex reassignment as a treatment for transsexualism. In other words, the results should not be interpreted such as sex reassignment *per se* increases morbidity and mortality. Things might have been even worse without sex reassignment. As an analogy, similar studies have found increased somatic morbidity, suicide rate, and overall mortality for patients treated for bipolar disorder and schizophrenia.[39,40] This is important information, but it does not follow that mood stabilizing treatment or antipsychotic treatment is the culprit.

Other facets to consider are first that this study reflects the outcome of psychiatric and somatic treatment for transsexualism provided in Sweden during the 1970s and 1980s. Since then, treatment has evolved with improved sex reassignment surgery, refined hormonal treatment,[11,41] and more attention to psychosocial care that might have improved the outcome. Second, transsexualism is a rare condition and Sweden is a small country (9.2 million inhabitants in 2008). Hence, despite being based on a comparatively large national cohort and long-term follow-up, the statistical power was limited. Third, regarding psychiatric morbidity after sex reassignment, we assessed inpatient psychiatric care. Since most psychiatric care is provided in outpatient settings (for which no reliable data were available), underestimation of the *absolute* prevalences was inevitable. However, there is no reason to believe that this would change the *relative risks* for psychiatric morbidity unless sex-reassigned transsexual individuals were more likely than matched controls to be admitted to hospital for any given psychiatric condition.

Finally, to estimate start of follow-up, we prioritized using the date of a gender identity disorder diagnosis *after* changed sex status over *before* changed sex status, in order to avoid overestimating person-years at risk after sex-reassignment. This means that adverse outcomes might have been underestimated. However, given that the median time lag between the hospitalization before and after change of sex status was less than a year (see Methods), this maneuver is unlikely to have influenced the results significantly. Moreover, all deaths will be recorded regardless of this exercise and mortality hence correctly estimated.

Conclusion

This study found substantially higher rates of overall mortality, death from cardiovascular disease and suicide, suicide attempts, and psychiatric hospitalisations in sex-reassigned transsexual individuals compared to a healthy control population. This highlights that post surgical transsexuals are a risk group that need long-term psychiatric and somatic follow-up. Even though surgery and hormonal therapy alleviates gender dysphoria, it is apparently not sufficient to remedy the high rates of morbidity and mortality found among transsexual persons. Improved care for the transsexual group after the sex reassignment should therefore be considered.

Supporting Information

Table S1 Risk of various outcomes in sex-reassigned persons in Sweden compared to population controls matched for birth year and *birth sex*.
(DOCX)

Table S2 Risk of various outcomes in sex-reassigned persons in Sweden compared to controls matched for birth year and *final sex*.
(DOCX)

Author Contributions

Conceived and designed the experiments: CD PL AJ NL ML. Performed the experiments: MB AJ. Analyzed the data: CD PL MB AJ NL ML. Contributed reagents/materials/analysis tools: PL NL AJ. Wrote the paper: CD PL MB AJ NL ML.

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Mental Health of Transgender and Gender Nonconforming Youth Compared With Their Peers

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abstract

BACKGROUND: Understanding the magnitude of mental health problems, particularly life-threatening ones, experienced by transgender and/or gender nonconforming (TGNC) youth can lead to improved management of these conditions.

METHODS: Electronic medical records were used to identify a cohort of 588 transfeminine and 745 transmasculine children (3–9 years old) and adolescents (10–17 years old) enrolled in integrated health care systems in California and Georgia. Ten male and 10 female referent cisgender enrollees were matched to each TGNC individual on year of birth, race and/or ethnicity, study site, and membership year of the index date (first evidence of gender nonconforming status). Prevalence ratios were calculated by dividing the proportion of TGNC individuals with a specific mental health diagnosis or diagnostic category by the corresponding proportion in each reference group by transfeminine and/or transmasculine status, age group, and time period before the index date.

RESULTS: Common diagnoses for children and adolescents were attention deficit disorders (transfeminine 15%; transmasculine 16%) and depressive disorders (transfeminine 49%; transmasculine 62%), respectively. For all diagnostic categories, prevalence was severalfold higher among TGNC youth than in matched reference groups. Prevalence ratios (95% confidence intervals [CIs]) for history of self-inflicted injury in adolescents 6 months before the index date ranged from 18 (95% CI 4.4–82) to 144 (95% CI 36–1248). The corresponding range for suicidal ideation was 25 (95% CI 14–45) to 54 (95% CI 18–218).

CONCLUSIONS: TGNC youth may present with mental health conditions requiring immediate evaluation and implementation of clinical, social, and educational gender identity support measures.

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Drs Becerra-Culqui and Goodman conceptualized and designed the study, contributed to the acquisition of data, conceptualized the analysis plan, coordinated the interpretation of results (including contributing expertise in epidemiologic methods and childhood developmental and/or psychological outcomes), and drafted and finalized the manuscript; Drs Getahun, Nash, Quinn, Roblin, and Silverberg and Ms Hunkeler conceptualized and designed the study, contributed to the acquisition of data, critically reviewed the manuscript for important intellectual content

WHAT'S KNOWN ON THIS SUBJECT: Small, specialized, clinic-based studies reveal a high prevalence of mental health diagnoses and self-reported emotional and behavioral problems among transgender and/or gender nonconforming youth.

WHAT THIS STUDY ADDS: In this large cohort study of an unselected transgender and/or gender nonconforming group, youth experienced a high relative prevalence of mental health conditions such as anxiety, depression, and attention deficit disorders compared with their cisgender counterparts.

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As gender identity develops, it may not match the gender of rearing or gender assigned at birth, which are typically based on the appearance of external genitalia.[1–3] When gender identity differs from the one assigned at birth, the terms gender diverse or gender nonconforming may apply.[4,5] Although the natural history of gender nonconformity presented in early childhood remains an area of ongoing research, some gender nonconforming children may go on to adopt an identity that is different from their assigned gender (10%–30%, according to reported estimates).[6,7] Researchers in studies of gender development in the general population support that gender-typed behavior is noticeable and stable between 3 and 8 years of age, especially in children with relatively high or low gender-typical behavior.[8,9] Individuals may identify as transgender, a term that refers more narrowly to those whose identity is "opposite" of their assigned gender.[10] Conversely, individuals who identify with the gender assigned to them at birth are sometimes referred to as cisgender.[10]

An important priority for the health of transgender and/or gender nonconforming (TGNC) children and adolescents is the identification and management of mental health conditions.[11–13] These conditions may be related to gender dysphoria, which is defined as a feeling of distress when one's assigned gender does not match their identity.[14] In addition, children with gender nonconforming behavior may experience stress from prejudice and discrimination because of being part of a minority group, which can create or exacerbate emotional and behavioral problems.[15]

The literature on TGNC youth consistently reveals a high prevalence of self-reported emotional and behavioral problems and mental health diagnoses.[16–23] Most of the available data used to address the mental health status of TGNC youth come from specialized clinics providing care to this population.[24] Although researchers in clinic-based studies offer detailed and high-quality data,[25,26] they often lack information on individuals who have not sought or had no access to specialized care. Moreover, a reliance on specialized clinics to identify study participants may yield relatively small sample sizes, making it difficult to select comparable reference groups from the same underlying population.[27]

These issues motivated the researchers in the Study of Transition, Outcomes, and Gender (STRONG), which was designed to assess morbidity among TGNC people overall and in the transfeminine and transmasculine subgroups of different ages, and captured in any care setting. However, this study communication is focused on cohort members who first presented as TGNC before their 18th birthday. Our objectives in this study were to estimate the prevalence of mental health diagnoses among transfeminine and transmasculine children and adolescents at the time of their initial presentation (index date) and compare their mental health status to that of their cisgender counterparts.

METHODS

The STRONG was designed as an electronic medical record (EMR)–based retrospective and prospective cohort study of members at 3 Kaiser Permanente (KP) sites (Georgia, Northern California, and Southern California) in partnership with the coordinating center at the Emory University Rollins School of Public Health. These KP sites provide comprehensive health services to >8.8 million members who are sociodemographically diverse and representative of their respective communities.[28,29] In the clinical setting, the identification of TGNC youth may begin at age 13 years during physical examinations as part of the psychosocial and/or behavioral assessment recommended by the American Academy of Pediatrics[30]; however, some TGNC children may be identified earlier or later in life. All activities were reviewed and approved by the institutional review boards of the 4 participating institutions.

As described previously,[31,32] persons with first evidence of TGNC status between January 1, 2006, and December 31, 2014, were identified on the basis of *International Classification of Diseases, Ninth Edition* (ICD-9) codes and the presence of specific keywords in free-text clinical notes (Supplemental Table 5). TGNC status was then verified (Supplemental Fig 1). A second free-text program was developed with additional anatomy-related or gender-affirmation keywords, which were reviewed and adjudicated for transfeminine or transmasculine status (Supplemental Table 6). Transfeminine and/or transmasculine status was assigned by using demographic information from the EMRs of 220 children whose gender assignment could not be determined from text strings because a validation revealed that the demographic variable accurately reflected assigned gender in 96% of youth. Subjects with evidence of disorders of sex development (eg, variation of chromosomal, gonadal, and/or anatomic sex development) were excluded because they may have distinct medical histories and gender identity trajectories.[33]

Ten male and 10 female cisgender KP enrollees were matched to each member of the final validated TGNC cohort on the basis of year of birth, race and/or ethnicity, site, and membership year of the index date. Because reference group enrollees had not been identified as TGNC by the methods described above, they

TABLE 1 Characteristics of the TGNC Children and Adolescents Enrolled in the STRONG

Child and Adolescent Characteristics	Transfeminine Cohort			Transmasculine Cohort		
	Transfeminine Cohort, *n* (%)	Reference Males, *n* (%)	Reference Females, *n* (%)	Transmasculine Cohort, *n* (%)	Reference Males, *n* (%)	Reference Females, *n* (%)
Age,[a] y						
3–9	161 (27)	1605 (28)	1598 (28)	90 (12)	892 (12)	888 (12)
10–17	427 (73)	4206 (72)	4204 (72)	655 (88)	6448 (88)	6459 (88)
Health plan site						
KPNC	344 (59)	3392 (58)	3378 (58)	431 (58)	4238 (58)	4245 (58)
KPSC	227 (39)	2249 (39)	2254 (39)	295 (40)	2915 (40)	2912 (40)
KPGA	17 (2.9)	170 (2.9)	170 (2.9)	19 (2.6)	187 (2.6)	190 (2.6)
Race and/or ethnicity						
Non-Hispanic white	268 (46)	2633 (45)	2629 (45)	374 (50)	3663 (50)	3671 (50)
Non-Hispanic African American	53 (9.0)	523 (9.0)	521 (9.0)	57 (7.7)	564 (7.7)	564 (7.7)
Asian American and/or Pacific Islander	37 (6.3)	367 (6.3)	370 (6.4)	60 (8.1)	596 (8.1)	594 (8.1)
Hispanic	179 (30)	1779 (31)	1772 (31)	204 (27)	2018 (27)	2020 (27)
Other and/or unknown	51 (8.7)	509 (8.8)	510 (8.8)	50 (6.7)	499 (6.8)	498 (6.8)
Use ever before index date (average visits per y)						
0	22 (3.7)	325 (5.6)	321 (5.5)	23 (3.1)	367 (5.0)	350 (4.8)
<1	15 (2.6)	568 (9.8)	530 (9.1)	25 (3.4)	763 (10)	746 (10)
1–3	127 (22)	1815 (31)	1879 (32)	154 (21)	2583 (35)	2562 (35)
>3–6	171 (29)	1712 (29)	1781 (31)	240 (32)	2200 (30)	2235 (30)
>6–9	115 (20)	757 (13)	763 (13)	107 (14)	795 (11)	777 (11)
>9	137 (23)	631 (11)	528 (9.1)	196 (26)	630 (8.6)	675 (9.2)
Unknown	1 (0.2)	3 (0.1)	0 (0.0)	0 (0.0)	2 (0.0)	2 (0.0)
Use 6 mo before index date (average visits per mo)						
0	101 (17)	2225 (38)	2062 (36)	111 (15)	2825 (39)	2502 (34)
<1	258 (44)	2846 (49)	2903 (50)	277 (37)	3531 (48)	3640 (50)
1–2	141 (24)	552 (9.5)	625 (11)	195 (26)	757 (10)	901 (12)
>2	87 (15)	186 (3.2)	212 (3.7)	162 (22)	225 (3.1)	302 (4.1)
Unknown	1 (0.2)	2 (0.0)	0 (0.0)	0 (0.0)	2 (0.0)	2 (0.0)
Total	588 (2.1)	5811 (21)	5802 (21)	745 (2.7)	7340 (27)	7347 (27)

KPGA, Kaiser Permanente Georgia; KPNC, Kaiser Permanente Northern California; KPSC, Kaiser Permanente Southern California.

[a] Assessed at index date (date of first evidence of transgender status in EMRs).

were assumed to be cisgender (ie, no evidence that gender identity does not correspond to assigned gender at birth). The race and/or ethnicity categories used were non-Hispanic white, non-Hispanic African American, Asian American and/or Pacific Islander, Hispanic, and other races. Index date was defined on the basis of the first recorded evidence of TGNC status. For some TGNC cohort members, <10 matched reference cisgender males or females were available; no TGNC individual was matched to <7 referents of either sex.

Subjects 3 through 17 years old at the index date were included in this study. Children <3 years old were excluded to reduce possible instability in gender identification and mental health diagnoses among the cohort.[8] The ICD-9 codes for mental health diagnoses were grouped into categories of conditions according to recommendations from the Mental Health Research Network[34]: anxiety disorders, attention deficit disorders, autism spectrum disorders, bipolar disorders, conduct and/or disruptive disorders, depressive disorders, eating disorders, other psychoses, personality disorders, schizophrenia spectrum disorders, self-inflicted injuries (including poisonings), substance use disorders, and suicidal ideation (Supplemental Table 7). People could be represented more than once if they had multiple diagnoses and were thus counted in each category for which they had a diagnosis.

The prevalence of mental health conditions in each of these categories was calculated for 2 time windows: any time (ever) and within 6 months before the index date. These 2 time windows were selected to examine mental health status just proximal to TGNC identification and to capture longer-standing conditions diagnosed at earlier ages (eg, autism spectrum disorders). In these calculations, the numerator for each disorder or group of disorders included persons with at least 1 relevant diagnostic code recorded during the time interval of interest. All prevalence estimates were calculated separately for transfeminine and transmasculine subjects within 2 age groups: 3 to 9 years (children) and 10 to 17 years (adolescents). Age categorization was selected to separately represent young school-aged children and adolescents by using the adolescent starting age of 10 years, corresponding to the World Health Organization's definition.[35] To assess differences in the severity of the conditions of interest, additional

TABLE 2 Prevalence of Mental Health Diagnoses in TGNC Children Ages 3–9 Years Relative to Those in Referent Groups

Categories of Mental Health Disorders	Prevalence in Transfeminine Subjects, *N* (%)	PR (95% CI)[a] in Transfeminine Subjects		Prevalence in Transmasculine Subjects, *N* (%)	PR (95% CI)[a] in Transmasculine Subjects	
		Versus Reference Males	Versus Reference Females		Versus Reference Males	Versus Reference Females
All diagnoses of interest						
Ever before index date	51 (31.7)	3.0 (2.3–3.9)	5.7 (4.2–7.7)	31 (34.4)	3.3 (2.3–4.6)	5.4 (3.7–7.8)
6 mo before index date	46 (28.6)	6.0 (4.3–8.4)	13.0 (8.7–19.6)	26 (28.9)	5.9 (3.8–9.0)	10.7 (6.4–17.8)
Anxiety disorders						
Ever before index date	19 (11.8)	4.4 (2.6–7.4)	6.3 (3.6–10.9)	14 (15.6)	6.3 (3.3–11.9)	6.0 (3.2–11.3)
6 mo before index date	15 (9.3)	16.3 (6.7–41.4)	23.3 (8.8–68.5)	9 (10.0)	9.8 (3.4–27.6)	12.2 (4.0–37.3)
Attention deficit disorders						
Ever before index date	24 (14.9)	3.3 (2.1–5.0)	6.1 (3.8–9.9)	14 (15.6)	2.8 (1.6–4.9)	6.9 (3.6–13.2)
6 mo before index date	22 (13.7)	5.0 (3.1–8.1)	10.9 (6.1–19.6)	14 (15.6)	4.2 (2.3–7.6)	12.6 (5.9–26.8)
Autism spectrum disorders						
Ever before index date	8 (5.0)	2.2 (0.9–4.9)	11.8 (3.7–38.9)	0	NC	NC
6 mo before index date	8 (5.0)	3.9 (1.5–9.5)	20.8 (5.5–95.3)	0	NC	NC
Conduct and/or disruptive disorders						
Ever before index date	12 (7.5)	3.3 (1.5–6.7)	14.2 (5.4–38.8)	7 (7.8)	6.2 (2.0–17.5)	12.3 (3.5–45.5)
6 mo before index date	8 (5.0)	8.3 (2.8–23.8)	83.0 (11.0–3707.3)	[b]	13.7 (2.3–95.1)	20.5 (2.9–229.2)
Depressive disorders						
Ever before index date	9 (5.6)	6.7 (2.5–17.0)	7.8 (2.9–20.6)	10 (11.1)	27.5 (7.7–123.0)	12.3 (5.0–30.5)
6 mo before index date	6 (3.7)	8.8 (2.4–31.1)	12.3 (3.1–51.5)	8 (8.9)	43.0 (8.4–422.3)	28.5 (6.7–170.2)
Eating disorders						
Ever before index date	[b]	3.7 (0.8–12.6)	6.7 (1.4–28.8)	0	NC	NC
6 mo before index date	[b]	10.0 (0.1–787.4)	10.0 (0.1–784.0)	0	NC	NC

NC, not calculated because there were 0 cases among transgender subjects.

[a] Logistic regression with exact 95% CIs for rare events (prevalence $\leq$10% in both the transgender and referent cohorts) or logistic regression with log link and approximate 95% CIs for not-rare events (>10% prevalence in either the transgender or referent cohorts).

[b] Fewer than 5 cases were not reported.

analyses were conducted for admittance or most serious diagnoses associated with hospitalizations.

Each prevalence estimate in the TGNC cohort was compared with corresponding estimates among matched cisgender male and female referents. For ease in presenting results, cisgender males and females will be referred to as male or female referents. Referents were assigned the same index date as the matched TGNC cohort member. For rare events (prevalence $\leq$10% in both the TGNC and referent cohorts), the prevalence ratios (PRs) were approximated by calculating the odds ratios with exact 95% confidence intervals (CIs). For events with >10% prevalence in either group, PRs and CIs were calculated by using logistic regression with the log link option.

In addition to the primary analysis that captures the true prevalence of mental health conditions, we conducted sensitivity analyses to address possible differences in the prevalence of mental health conditions because of differences in health care visit frequency (use) between TGNC cohort members and those in the referent groups. We excluded the index date from the time window, and when the sample size was sufficient (>5 cases in each group), the PR estimates were adjusted for use of care. Average health care use was calculated for each individual by dividing the total number of visits by the cumulative duration of enrollment; this was expressed as the number of visits per year of enrollment in the analyses of "ever" prevalence and as the number of visits per month of enrollment in the analyses within 6 months before the index date. In adjusted analyses, average use was dichotomized for each time interval as above (high) or below (low) the median by using cutoffs for the overall population.

Analyses were conducted by using SAS version 9.4 (SAS Institute, Inc, Cary, NC) with custom macros developed at the Biostatistics and Bioinformatics Shared Resource at the Winship Cancer Institute of Emory University.[36]

RESULTS

A total of 2164 cohort candidates 3 to 17 years of age at the index date were initially identified in the EMR. After validation, 1347 (62%) were confirmed as TGNC. People excluded from the TGNC cohort were most often those with keywords referring to family or partners, standard disclaimers not related to care (eg, listing indications for hormone use), or evidence of disorders of sex development. After excluding subjects with unknown gender assigned at birth ($N = 14$), the final analysis data set was based on a cohort of 1333 subjects matched with

TABLE 3 Prevalence of Mental Health Diagnoses in TGNC Adolescents Ages 10–17 Years Relative to Those in Referent Groups

Categories of Mental Health Disorders	Prevalence in Transfeminine Subjects, *N* (%)	PR (95% CI)[a] in Transfeminine Subjects		Prevalence in Transmasculine Subjects, *N* (%)	PR (95% CI)[a] in Transmasculine Subjects	
		Versus Reference Males	Versus Reference Females		Versus Reference Males	Versus Reference Females
All diagnoses of interest						
Ever before index date	303 (71.0)	3.0 (2.8–3.3)	3.6 (3.3–3.9)	488 (74.5)	3.0 (2.8–3.2)	3.7 (3.4–3.9)
6 mo before index date	253 (59.3)	7.8 (6.8–8.9)	8.6 (7.5–9.8)	429 (65.5)	7.8 (7.1–8.7)	8.7 (7.8–9.6)
Anxiety disorders						
Ever before index date	159 (37.2)	5.0 (4.2–5.8)	4.2 (3.6–4.9)	255 (38.9)	4.9 (4.3–5.6)	4.0 (3.5–4.5)
6 mo before index date	106 (24.8)	18.0 (13.3–24.4)	9.2 (7.2–11.8)	175 (26.7)	15.7 (12.5–19.6)	8.7 (7.2–10.5)
Attention deficit disorders						
Ever before index date	107 (25.1)	2.0 (1.7–2.4)	5.3 (4.3–6.5)	106 (16.2)	1.3 (1.0–1.5)	3.3 (2.7–4.1)
6 mo before index date	68 (15.9)	3.8 (2.9–4.9)	9.0 (6.6–12.4)	69 (10.5)	2.5 (1.9–3.3)	6.4 (4.6–8.8)
Autism spectrum disorders						
Ever before index date	31 (7.3)	4.1 (2.6–6.4)	25.2 (12.7–52.9)	24 (3.7)	1.8 (1.1–2.8)	7.6 (4.3–13.5)
6 mo before index date	25 (5.9)	8.1 (4.6–14.3)	260.8 (42.5–10 733.9)	17 (2.6)	3.4 (1.8–6.1)	17.2 (7.4–42.1)
Bipolar disorders						
Ever before index date	23 (5.4)	9.9 (5.3–18.5)	10.3 (5.5–19.5)	34 (5.2)	8.6 (5.2–13.9)	8.0 (4.9–12.9)
6 mo before index date	16 (3.8)	18.1 (7.5–46.9)	14.8 (6.4–35.6)	19 (2.9)	11.3 (5.5–23.3)	14.8 (6.9–32.8)
Conduct and/or disruptive disorders						
Ever before index date	60 (14.1)	2.8 (2.1–3.7)	6.6 (4.8–9.0)	59 (9.0)	1.7 (1.3–2.3)	4.5 (3.2–6.2)
6 mo before index date	22 (5.2)	5.3 (3.0–9.1)	12.6 (6.4–25.2)	27 (4.1)	5.5 (3.3–9.0)	10.6 (5.9–19.1)
Depressive disorders						
Ever before index date	207 (48.5)	5.8 (5.1–6.7)	4.4 (3.9–5.0)	403 (61.5)	7.0 (6.4–7.8)	5.7 (5.2–6.2)
6 mo before index date	172 (40.3)	23.5 (18.2–30.4)	10.1 (8.4–12.2)	326 (49.8)	22.8 (19.0–27.3)	13.3 (11.5–15.4)
Eating disorders						
Ever before index date	18 (4.2)	7.7 (3.9–14.9)	3.3 (1.8–5.7)	28 (4.3)	6.0 (3.6–9.8)	3.2 (2.0–5.0)
6 mo before index date	11 (2.6)	18.5 (6.2–61.2)	6.1 (2.6–13.8)	19 (2.9)	27.5 (11.0–77.6)	8.7 (4.4–17.0)
Psychoses						
Ever before index date	19 (4.5)	19.5 (8.6–47.3)	12.2 (5.9–25.5)	32 (4.9)	12.2 (7.0–21.3)	14.4 (8.1–25.9)
6 mo before index date	10 (2.3)	20.1 (6.2–75.4)	100.6 (14.2–4375.0)	18 (2.8)	22.7 (9.4–60.6)	30.4 (11.5–93.8)
Personality disorders						
Ever before index date	10 (2.3)	14.4 (4.9–44.7)	11.2 (4.1–31.2)	15 (2.3)	11.6 (5.1–26.6)	7.9 (3.7–16.6)
6 mo before index date	[b]	19.8 (2.8–220.0)	19.8 (2.8–219.9)	9 (1.4)	29.9 (7.4–172.1)	29.9 (7.4–172.4)
Schizophrenia spectrum disorders						
Ever before index date	5 (1.2)	49.7 (5.5–2357.0)	24.9 (4.1–261.7)	13 (2.0)	21.7 (7.7–69.9)	32.6 (10.0–137.8)
6 mo before index date	[b]	[c]	14.8 (1.7–178.2)	10 (1.5)	99.8 (14.2–4338.3)	50.0 (10.6–470.2)
Self-inflicted injuries						
Ever before index date	11 (2.6)	3.9 (1.8–8.2)	4.1 (1.8–8.6)	54 (8.2)	14.0 (9.1–21.8)	8.7 (5.9–12.8)
6 mo before index date	7 (1.6)	69.9 (9.0–3159.2)	17.5 (4.4–81.7)	28 (4.3)	143.7 (36.1–1247.8)	20.5 (10.4–42.4)
Substance use disorders						
Ever before index date	33 (7.7)	3.0 (1.9–4.5)	3.7 (2.4–5.6)	46 (7.0)	2.4 (1.7–3.4)	3.3 (2.3–4.7)
6 mo before index date	24 (5.6)	5.8 (3.3–9.8)	8.9 (4.9–16.0)	34 (5.2)	4.5 (2.9–6.9)	8.2 (5.0–13.2)
Suicidal ideation						
Ever before index date	32 (7.5)	17.8 (9.7–33.6)	11.3 (6.5–19.4)	68 (10.4)	21.2 (13.8–33.2)	11.0 (7.7–15.9)
6 mo before index date	21 (4.9)	54.2 (18.2–218.3)	31.0 (12.6–86.7)	47 (7.2)	45.2 (22.9–97.1)	24.9 (14.3–44.6)

[a] Logistic regression with exact 95% CIs for rare events (prevalence ≤10% in both the transgender and referent cohorts) or logistic regression with log link and approximate 95% CIs for not-rare events (>10% prevalence in either the transgender or referent cohorts).

[b] Fewer than 5 cases were not reported.

[c] Not calculated because there were 0 cases among referents.

TABLE 4 Prevalence of Hospitalization for Mental Health Diagnoses in TGNC Children Ages 10–17 Years Relative to Those in Referent Groups

Categories of Mental Health Disorders	Prevalence in Transfeminine Subjects, *N* (%)	PR (95% CI)[a] in Transfeminine Subjects		Prevalence in Transmasculine Subjects, *N* (%)	PR (95% CI)[a] in Transmasculine Subjects	
		Versus Reference Males	Versus Reference Females		Versus Reference Males	Versus Reference Females
All diagnoses of interest						
Ever before index date	58 (13.6)	9.9 (6.9–14.0)	8.9 (6.3–12.5)	99 (15.1)	10.2 (7.8–13.3)	7.8 (6.1–10.0)
6 mo before index date	33 (7.7)	43.9 (19.7–110.7)	35.1 (16.7–80.4)	59 (9.0)	35.3 (20.4–64.1)	21.9 (13.7–35.8)
Anxiety disorders						
Ever before index date	9 (2.1)	9.0 (3.2–24.9)	6.0 (2.3–14.8)	25 (3.8)	15.0 (7.7–29.8)	13.4 (7.1–26.0)
6 mo before index date	6 (1.4)	59.8 (7.2–2757.2)	29.9 (5.3–303.7)	13 (2.0)	43.4 (11.9–238.3)	32.6 (10.0–137.8)
Attention deficit disorders						
Ever before index date	20 (4.7)	9.8 (5.0–19.1)	14.7 (7.0–31.7)	14 (2.1)	4.0 (2.0–7.7)	9.4 (4.2–20.9)
6 mo before index date	6 (1.4)	19.9 (4.2–123.6)	59.8 (7.2–2755.8)	[b]	[c]	9.9 (1.3–74.0)
Autism spectrum disorders						
Ever before index date	[b]	6.6 (1.4–28.0)	39.7 (3.9–1957.7)	5 (0.8)	5.0 (1.3–16.0)	8.3 (2.0–32.6)
6 mo before index date	[b]	[c]	[c]	[b]	3.3 (0.1–41.0)	[c]
Bipolar disorders						
Ever before index date	12 (2.8)	30.3 (9.1–129.6)	13.5 (5.2–36.4)	18 (2.8)	10.1 (4.9–20.7)	9.1 (4.5–18.2)
6 mo before index date	[b]	39.7 (3.9–1958.7)	19.8 (2.8–219.9)	8 (1.2)	15.9 (4.6–62.0)	19.9 (5.3–90.7)
Conduct and/or disruptive disorders						
Ever before index date	10 (2.3)	16.8 (5.5–56.4)	16.8 (5.5–56.4)	10 (1.5)	5.9 (2.4–13.6)	6.7 (2.7–15.9)
6 mo before index date	5 (1.2)	49.7 (5.5–2357.0)	[c]	[b]	39.6 (3.9–1951.1)	39.6 (3.9–1954.4)
Depressive disorders						
Ever before index date	41 (9.6)	21.1 (12.1–38.1)	10.3 (6.4–16.4)	83 (12.7)	17.8 (12.5–25.2)	9.1 (6.8–12.1)
6 mo before index date	26 (6.1)	68.0 (23.4–269.3)	54.3 (20.4–182.2)	49 (7.5)	104.0 (41.5–335.9)	21.7 (12.9–37.2)
Eating disorders						
Ever before index date	[b]	6.6 (0.5–57.7)	2.8 (0.3–14.9)	6 (0.9)	29.8 (5.3–302.1)	4.0 (1.3–10.9)
6 mo before index date	[b]	[c]	3.3 (0.1–41.0)	[b]	29.8 (5.3–302.1)	4.0 (1.3–10.9)
Psychoses						
Ever before index date	8 (1.9)	26.7 (6.4–156.9)	11.4 (3.6–37.2)	10 (1.5)	20.0 (6.2–74.7)	12.5 (4.4–36.6)
6 mo before index date	5 (1.2)	49.7 (5.5–2357.0)	49.7 (5.5–2355.8)	[b]	19.8 (2.8–219.1)	9.9 (1.8–53.3)
Personality disorders						
Ever before index date	[b]	39.7 (3.9–1958.7)	19.8 (2.8–219.9)	8 (1.2)	26.5 (6.3–155.7)	8.9 (3.0–26.0)
6 mo before index date	0 (0)	NC	NC	7 (1.1)	[c]	69.7 (8.9–3144.6)
Schizophrenia spectrum disorders						
Ever before index date	[b]	[c]	14.8 (1.7–178.2)	[b]	9.9 (1.8–53.2)	13.2 (2.2–90.4)
6 mo before index date	0 (0)	NC	NC	[b]	9.9 (0.1–773.9)	9.9 (0.1–775.2)
Self-inflicted injuries						
Ever before index date	[b]	6.6 (0.5–57.7)	4.9 (0.4–34.6)	13 (2.0)	65.2 (14.7–596.2)	13.0 (5.3–33.4)
6 mo before index date	[b]	[c]	[c]	7 (1.1)	[c]	34.8 (6.6–344.4)
Substance use disorders						
Ever before index date	8 (1.9)	5.7 (2.1–14.7)	4.2 (1.6–10.1)	16 (2.4)	6.2 (3.1–12.0)	6.2 (3.1–12.1)
6 mo before index date	6 (1.4)	29.9 (5.3–303.9)	12.0 (3.0–49.7)	9 (1.4)	11.2 (3.8–33.5)	11.2 (3.8–33.6)
Suicidal ideation						
Ever before index date	9 (2.1)	15.1 (4.8–51.7)	5.6 (2.2–13.6)	29 (4.4)	19.8 (10.2–40.1)	11.5 (6.5–20.4)
6 mo before index date	7 (1.6)	[c]	23.3 (5.3–140.2)	17 (2.6)	24.5 (9.6–70.1)	21.5 (8.7–57.7)

NC, not calculated because there were 0 cases among transgender subjects.

[a] Logistic regression with exact 95% CIs for rare events (prevalence ≤10% in both the transgender and referent cohorts) or logistic regression with log link and approximate 95% CIs for not-rare events (>10% prevalence in either the transgender or referent cohorts).

[b] Fewer than 5 cases were not reported.

[c] Not calculated because there were 0 cases among referents.

13 151 reference males and 13 149 reference females.

The cohort included 588 (44%) transfeminine and 745 (56%) transmasculine children and adolescents (Table 1). Children <10 years old represented 27% of the transfeminine cohort and 12% of the transmasculine cohort. Compared with TGNC children (*n* = 251), in which 36% (*n* = 90) were transfeminine, 61% (*n* = 655) of adolescents (*n* = 1082) were transmasculine. More than 45% of subjects in both groups were white; Hispanics represented 30% of transfeminine and 27% of transmasculine subjects, whereas the remainder of the study population was approximately equally distributed among African Americans, Asian Americans and/or Pacific Islanders, and persons whose race and/or ethnicity was characterized as other or unknown. Health care use levels were much higher in both transfeminine and transmasculine subjects than in those in the corresponding reference groups.

The most common diagnostic categories among TGNC children 3 to 9 years of age were attention deficit disorders (15% transfeminine; 16% transmasculine) and anxiety disorders (12% transfeminine; 16% transmasculine; Table 2). The PR (95% CI) estimates for attention deficit disorders ranged from 2.8 (95% CI 1.6–4.9) to 13 (95% CI 5.9–27). The PR (95% CI) estimates for anxiety disorders ranged from 4.4 (95% CI 2.6–7.4) to 23 (95% CI 8.8–69) depending on the time window before the index date and the reference group. Among transfeminine children, 5% had an autism spectrum disorder diagnosis; however, no cases were observed in transmasculine children. For all the diagnostic categories, the most pronounced PR estimates were observed within the 6-month period before the index date. Among transfeminine children, the highest PR (95% CI) estimate was for conduct and/or disruptive disorders relative to reference females (83 [95% CI 11–3707]). Among transmasculine children, the highest PR (95% CI) estimate was for depressive disorders relative to reference males (43 [95% CI 8.4–422]). Additional analyses of the prevalence of hospitalizations by mental health diagnostic category were not possible in this age group because of small sample sizes.

In the adolescent group (age 10–17 years), like in the younger age group, attention deficit disorders and anxiety disorders remained common (“ever” prevalence: 25% transfeminine and 16% transmasculine; 40% both transfeminine and transmasculine, respectively; Table 3). The diagnostic category with the highest prevalence in this age group was depressive disorders, which were found in 49% of transfeminine and 62% of transmasculine subjects. For all diagnostic categories, PR estimates used to compare STRONG adolescents to matched reference groups were highest within 6 months before the index date. Compared with reference females, transfeminine and transmasculine adolescents experienced particularly pronounced increased prevalence in psychoses (PR 101 and 95% CI 14–4375; PR 30 and 95% CI 12–94, respectively). Additionally, the PR estimates among transfeminine subjects were particularly elevated for autism spectrum disorders (PR 261; 95% CI 43–10 734) and among transmasculine subjects for schizophrenia spectrum disorders (PR 50; 95% CI 11–470) compared with reference females. Compared with reference males, PR estimates for suicidal ideation and self-inflicted injuries for transfeminine subjects were 54 (95% CI 18–218) and 70 (95% CI 9.0–159), respectively, which were also high among transmasculine subjects, (45 [95% CI 23–97] and 144 [95% CI 14–4338], respectively).

When prevalence estimates were limited to mental health conditions recorded during hospitalizations, the patterns among adolescents generally remained the same. In several instances, however, the PR estimates could not be calculated because of the absence of cases in the reference groups (Table 4).

The median cutoff values used for adjusted analyses were 3.2 average visits per year for the “ever” analyses and 0.2 average visits per month for the 6-month analyses. The prevalence estimates were slightly attenuated or remained approximately the same for most diagnostic categories. However, some estimates changed appreciably. For children 3 to 9 years, adjusting for use 6 months before and excluding the index date produced the largest decrease in the PR (95% CI) for anxiety disorders, from 23 (95% CI 8.8–69) to 9.0 (95% CI 2.9–29) when transfeminine children were compared with reference males (Supplemental Table 8). The PR (95% CI) for suicidal ideation among transfeminine adolescents compared with reference males within 6 months of the index date decreased from 54 (95% CI 18–218) to 38 (95% CI 12–159; Supplemental Table 9).

DISCUSSION

The results of this study reveal that among TGNC youth, mental health conditions, specifically anxiety and depression, are common and often severe among adolescents, as evidenced by diagnoses associated with hospitalizations. Gender nonconforming children (3–9 years of age) have a higher prevalence of anxiety and attention deficit disorders compared with their cisgender counterparts. In nearly all instances, mental health diagnoses were more common in the TGNC youth than in referent children and adolescents.

These results support findings from previous research in which the sample sizes were much smaller.[17,19–22,37–42] Researchers in a survey of 101 transfeminine and transmasculine patients ages 12 to 24 years in a transgender youth clinic in Los Angeles found that 35% had symptoms of depression and >50% had suicidal thoughts.[19] In comparison, we found that adolescents had a higher prevalence (40%–60%) of depression but a lower prevalence of suicidal ideation (5%–10%). In a medical record abstraction study of 97 transfeminine and transmasculine patients ages 4 to 20 years presenting to the Gender Management Service Clinic at Boston Children's Hospital, 44% presented with a significant psychiatric history, 21% had a history of self-mutilation, and 9% had documentation of suicide attempts.[22] In a UK study, a baseline chart review of children 5 to 11 years old referred to a national specialty clinic revealed that 17% had symptoms of anxiety, and 15% had a history of suicidal ideation, self-harm, and/or a diagnosis of attention-deficit/hyperactivity disorder recorded before entering services.[39] Our results for children were similar for demonstrated anxiety (9%–16%) and attention deficit disorders (14%–16%). Direct comparisons to the current study are challenging because there are methodological differences. Two important differences are the way in which mental health conditions were ascertained and presentations of age. In addition, we included a broader population of children and adolescents who were not necessarily seeking treatment for gender-related issues.

In recent years, researchers in several studies have suggested that gender dysphoria may be associated with autism spectrum disorders.[43–45] The most widely cited evidence supporting this hypothesis comes from a study of 204 children and/or adolescents referred to the Gender Identity Clinic in Amsterdam.[46] The presence of an autism spectrum disorder was established via a standardized diagnostic interview,[47] yielding a prevalence of 10% among transfeminine patients and 4% among transmasculine patients, which was reported by the authors to be higher than the 1% estimate reported in the general population. The prevalence of autism spectrum disorders in our study was somewhat lower (7% in transfeminine and 3% in transmasculine subjects across both age groups), but our case ascertainment was based on documented diagnostic codes, and the denominator in our calculations was not limited to children with established gender dysphoria. With these differences in mind, our results are generally comparable to those reported in the Dutch study.

The gender ratio in this TGNC cohort reveals that transfeminine youth may present earlier in age than transmasculine individuals, which may pose a unique challenge to the early identification of mental health needs in transmasculine children and adolescents. Historically, researchers in studies of TGNC adolescents have reported a greater proportion of transfeminine than transmasculine subjects, but in recent years, the direction of the transmasculine: transfeminine ratio appears to have changed.[48] For example, researchers in 1 recent study observed that transmasculine youth with gender dysphoria (aged 12–24 years) presented in significantly higher numbers than their transfeminine counterparts.[19] Our data, which were based on EMRs, were used to confirm this observation. Therefore, providers should also be aware of the growing transmasculine population needing timely and appropriate medical and psychosocial services.

An important contribution of the STRONG to the extant literature is its relatively large cohort, which allowed for focusing on previously understudied groups (such as young children), and an evaluation of relatively rare events (such as hospitalizations). In addition, the current study was based on children and adolescents who were not necessarily in specialized care and enrolled in a large health care system; and we did not require participant opt-in. The availability of a well-defined source population allowed for matching transfeminine and transmasculine study subjects to male and female referents of the same age, race and/or ethnicity, and geographic region. This design feature permitted direct comparisons of prevalence estimates among transfeminine, transmasculine, and cisgender referent groups.

A limitation of this study is its cross-sectional design. Although we were able to retrospectively ascertain mental health conditions before the index date and we matched on the basis of membership year, a differential ascertainment of diagnoses could have occurred. The identification of the TGNC cohort was based on health care use, which is different from the matched referent groups. Results from sensitivity analyses adjusting for use and excluding the index date revealed a similar or slight attenuation of the PR results for most diagnostic categories. However, when adjusting for use 6 months before the index date, a more notable attenuation of PRs was seen in anxiety disorders in transfeminine children and suicidal ideation in transfeminine adolescents compared with reference males, indicating possible higher surveillance of mental health conditions in the several months before cohort identification. Nevertheless, this baseline study reveals that TGNC youth experience a multitude of mental health problems before initial presentation. However, there is indication that TGNC children who receive meaningful gender identity support do not necessarily experience elevated rates of depression and anxiety.[49] As the STRONG cohort follow-up extends, it will be possible to examine temporal changes in the frequency and severity of mental health problems, particularly in relation to the age of gender affirmation, which is an area of considerable uncertainty, and the impact of interventions to treat gender dypshoria.[50–53]

CONCLUSIONS

The most important finding is the high frequency of mental health conditions that TGNC children and adolescents experience. Especially worrisome are the results for suicidal ideation and self-inflicted injuries with prevalence estimates orders of a magnitude that is higher in TGNC children and adolescents than in matched cisgender reference groups. For nearly all mental health disorders, the PRs increased during the time window closest to the index date. Overall, these data reveal that children and adolescents presenting as TGNC to health care providers may require not only thorough and immediate evaluation of mental health needs but also urgent implementation of social and educational measures of gender identity support.

ABBREVIATIONS

CI: confidence interval
EMR: electronic medical record
ICD-9: *International Classification of Diseases, Ninth Edition*
KP: Kaiser Permanente
PR: prevalence ratio
STRONG: Study of Transition, Outcomes, and Gender
TGNC: transgender and/or gender nonconforming

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Patient safety for children and young people with gender incongruence

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Patient safety for children and young people with gender incongruence

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People with gender incongruence and gender dysphoria have different wishes and needs for health services. Many people live well with their gender incongruence and manage it without health care, while others want and need health care (see glossary in Chapter 13 for explanations of terms).

When Ukom addresses the topic of gender incongruence, we look at how patient safety is ensured in care and treatment services for gender incongruence and gender dysphoria. Our aim is to ensure safe help and treatment for children and young people with gender incongruence.

There is an ongoing public debate about treatment options for gender incongruence. This is demanding, and many people are reluctant to participate in the debate. It can be challenging and difficult to participate because there are major disagreements both between groups and within groups. We see that the choice of words and understanding of the complexity is important. The situation of insecurity and disagreement affects the development of health services.

In our report, we have tried to highlight different perspectives. At the same time, it is important for us to be clear about our findings. That is, what challenges patient safety. Many people have worked and are working to establish and build good health services for people with gender incongruence and gender dysphoria, both nationally and internationally. UCOM's report builds on this work. We point out that this field now needs a boost to improve patient safety, especially for the health care to be provided to children and young people in Norway.

Executive summary

Ukom has conducted an investigation into the treatment offered to children and young people with gender incongruence. The background was notifications directly to Ukom from relatives who questioned several aspects of patient safety. Several actors, both from the authorities, health personnel and patient and relatives' organizations, questioned the soundness and organization of the treatment services.

The report deals with children and young people in general. There has been a large increase in referrals to health services from people with gender incongruence in recent years. In particular, the number of teenage children and young people seeking or being referred for assessment and treatment in specialist health services has increased significantly. The largest increase is among adolescents and young adults who are registered as girls at birth but identify as boys. Our attention has therefore been particularly focused on teenagers and young people with gender incongruence and gender dysphoria seeking health care. Children and adolescents are not fully developed physically, mentally, sexually or socially. This requires particular vigilance in terms of patient safety. Our findings and recommendations will also be relevant to the provision of care for adults.

In this report, we have divided our findings into six main areas:

Insufficient knowledge

The evidence base, especially research-based knowledge for gender affirmative treatment (hormonal and surgical), is insufficient and the long-term effects are poorly known. This is particularly true for the adolescent population where the stability of their gender incongruence is also not known. There is a lack of research-based knowledge on the treatment of patients with non-binary gender incongruence. In order to ensure patient safety, Ukom considers it necessary that the knowledge base on gender incongruence and gender dysphoria is strengthened, and that health services are organized in line with the knowledge base.

Overall governance - a guideline with a different background

The Directorate of Health's national professional guideline on gender incongruence provides guidelines for the provision of health services. It concentrates on organization, equality and rights. This may have been important at the time the guideline was drawn up, because it was necessary to establish the health service provision for people who experience gender incongruence. At the same time, we consider that deviating from the requirement to develop evidence-based guidelines has created room for uncertainty and conflicting expectations. Health professionals have been given wide scope for interpretation within a relatively narrow field that lacks systematic knowledge synthesis in Norway. The guideline provides rights without clarifying issues related to prioritization and justifiability. This is demanding for the health personnel who administer the services on a daily basis.

Due diligence requirements - particularly in relation to children and young people

The national professional guideline for gender incongruence is not very prescriptive. It does not set specific requirements for assessment or requirements for medical indications for the initiation of treatment. The reference to children's capacity to consent and parents' right to information leaves room for interpretation. The guideline does not establish an adequate standard for the provision of health services, and we believe that for some patients it may pose a patient safety risk. This may go beyond the requirement of soundness, which is broadly based in health legislation, and may also be challenging for supervisory authorities.

Right to health care - a gap in expectations

Our survey suggests that there is a gap between what the guideline outlines and what is possible, given the current available services and knowledge base. The national guideline creates expectations among patients that the health service can hardly meet. This applies, among other things, to the right to specialist health services. It is difficult for the service to meet these expectations without a well-documented evidence base and without a good overview of any negative and harmful aspects of the various treatments. Requiring the use of principles for experimental treatment will provide a framework that ensures information, thorough follow-up and contributes to more knowledge.

Care and treatment provision - variation in practice and skills

There is great variation in the services and expertise offered in different parts of the country. There is a risk of under-, over- and incorrect treatment of children and young people with gender incongruence and gender dysphoria. In addition, we see that there are challenges in establishing a decentralized service in a narrow and complex field. In order to strengthen the service, Ukom believes that it is important to strengthen the health service provision in the primary health service, build increased interdisciplinary expertise in the specialist health service at regional level and ensure that the national treatment service has sufficient capacity for the current demand.

Performance climate and interaction

We see that in the field of gender incongruence, a challenging climate of expression has developed. The climate of expression in the public sphere affects the available information for children and young people with gender incongruence and gender dysphoria and their families. There is a significant impact on children and young people, also related to treatment and health services. We hear about fears and fears of getting it wrong from all sides. Different opinions about what is the right treatment can create difficult cross-pressures. Different emphasis and discussion of what necessary at group level can confuse and undermine patient-provider relationships and a personalized approach for the person concerned. There is a need to establish a constructive community for all those committed to good health care for people with gender incongruence.

Ukom recommends

We are concerned that children and young people with gender incongruence have safe and appropriate health services. We therefore make recommendations that can help to ensure that this group receives better and safer health services in the long term. Our recommendations relate to the revision of the guideline, a safe framework for treatment offered to children and adolescents and measures to strengthen the knowledge base. The recommendations will also contribute to systematic data collection and promote follow-up research. It is important that children and young people with gender incongruence and gender dysphoria, including non-binary people, are properly cared for while health services are being developed.

Ukom recommends:

1. that the Ministry of Health and Care Services commissions the Norwegian Directorate of Health to revise the national guideline on gender incongruence. The revision must, among other things, be based on a systematic review of the evidence. We point out several elements that should be included in the revision.
2. that puberty delaying treatment (puberty blockers) and hormonal and surgical gender affirmation treatment for children and adolescents be defined as investigational treatment. This is particularly important for teenagers with gender dysphoria.
3. that the Ministry of Health and Care Services consider whether a national medical quality register should be established for the treatment of children and young people with gender incongruence and gender dysphoria. Necessary measures must be taken to establish, operate and finance such a national quality registry to contribute to an overview, improve quality and reduce unwarranted variation in patient care.

PATIENT SAFETY FOR CHILDREN AND YOUNG PEOPLE WITH GENDER INCONGRUENCE

2 Background

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Why has Ukom launched an investigation

In 2022, Ukom received two reports of concern from relatives of persons who have undergone assessment and treatment for gender incongruence in the age range 16-21 years. In the reports of concern, the relatives refer to several different aspects of the current treatment services that may have an impact on patient safety.

- The relatives question the appropriateness of the treatment.
- The assessment was demanding and the follow-up was not sufficient in relation to the vulnerable and exposed situation the relatives perceived the young people to be in.
- There was insufficient follow-up for other diagnoses or issues that the young people also had, or questioned whether gender affirmative treatment was the right treatment for their child.
- Parents felt that the assessment and treatment process created a fear among young people that they would not receive treatment or would receive the wrong treatment.
- Information on treatment, efficacy and side effects was incomplete.
- Parents and family involvement was low. This put additional strain on both the young people and their families.
- Parents feel that there are cross-pressures from different quarters and communities that affect their children.

In recent years, much attention has been paid to the health service provision for people with gender incongruence both nationally and internationally. Over the past decade, there has been a large increase in the number of people who have been referred for treatment of gender incongruence. This has presented challenges for established treatment institutions. In Norway, many have called for improved health services for people with gender incongruence. The Norwegian Directorate of Health has drawn up national guidelines to expand and make treatment services available to the group. At the same time, several actors, both from the authorities, health personnel and patient and family organizations, are questioning the justification and organization of the treatment services.

It is also controversial whether the guidelines from the Norwegian Directorate of Health, and other guidelines from the authorities in this area, provide for a proper organization of treatment services for this group in Norway. There is an ongoing debate in the media, in social media and in work with the health service about the treatment and assistance offered to people with gender incongruence.

The public debate is characterized by different approaches to the treatment of gender incongruence. The debate also shows that gender incongruence is about more than medical treatment.
Gender incongruence is about personal identity and the inclusion, acceptance and rights of a minority group. This is fundamental and applies to multiple patient groups, conditions and issues. The treatment of gender incongruence is also a policy issue. Reconciling medical and non-medical considerations has proven to be very challenging. This is reflected in the public debate.

In many areas, transgender people have poorer living conditions and quality of life than the general population. The government's new action plan for gender and sexuality diversity (2023-2026) states that the health services for people with gender incongruence have been inadequate over time.

Uncertainty about what constitutes appropriate treatment has led the authorities in some countries, such as England and Sweden, to tighten the treatment offered to people with gender incongruence. In Norway, on the other hand, guidelines have been laid down to expand and decentralize treatment services.

We started our investigation by conducting a survey of the treatment provision for people with gender incongruence. The mapping exercise revealed a number of unresolved issues with implications for patient safety that are particularly relevant for the treatment of children and young people who are developing psychologically, cognitively, physically and socially. Treatment options for gender incongruence may involve irreversible treatment with hormones and surgery that cause invasive changes. As a consequence, we concluded that it was particularly important to look at the patient safety of children and young people receiving treatment for gender incongruence.

In England, in 2022, the Healthcare Safety Investigation Branch (HSIB) published a report on the topic of gender incongruence. The starting point for their investigation was a report of concern about a young person who took his own life while waiting for assessment for gender incongruence. He was then under the care of local mental health services and there was a 24-month waiting time at the gender incongruence clinic. The survey looked specifically at the health service for young people (children and adolescents) with gender incongruence and found that there was a large increase in young people being referred to specialized units for gender incongruence. HSIB has shared experiences from its work with Ukom. The survey showed that the centralized health services lacked the capacity to accommodate the increased referral volume and had long waiting times. There was a lack of competence and capacity in non-specialized care services to attend and assess young people with gender incongruence while they were awaiting assessment. The HSIB also communicated other findings from England (the Care Quality Commission) that health professionals at specialized gender incongruence treatment unit did not always feel respected, supported and valued and reported an absence of culture of transparency. Some of the health professionals experienced pressure due to conflicts and lack of consensus on the treatment of children and young people with gender incongruence and told of fear of voicing their opinions.

With this in mind, we have conducted a study of the health care and treatment services for children and adolescents with gender incongruence. We have looked at how health care and practices work today, and how the framework and guidelines for health care affect patient safety. Ukom does not go into the details of all help and treatment measures for gender incongruence and gender dysphoria, but we point out challenges in the current services to ensure that children and young people with gender incongruence and gender dysphoria receive help in a safe environment.

The report is based on services for children and young people, but many of our findings and recommendations will be relevant to services for all people with gender incongruence and gender dysphoria.

Our findings

Our survey shows several weaknesses in the provision of services for children and young people with gender incongruence and gender dysphoria. The findings show difficult dilemmas related to medical, legal and ethical issues. We have chosen to divide our findings into the following main themes:

- Overall governance - a guideline with a different background
- Care and treatment services - variation in practice and expertise
-

Insufficient knowledge

- Duty of care - particularly in relation to children and
- young people Right to healthcare - a gap in
- expectations Climate of communication and

interaction

The next chapters deal with gender incongruence and patient and caregiver perspectives, before describing the findings in the following chapters.

PATIENT SAFETY FOR CHILDREN AND YOUNG PEOPLE WITH GENDER INCONGRUENCE

3 Briefly on gender incongruence

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Gender incongruence can be defined as a mismatch between a person's gender identity and their registered sex at birth. Gender identity can be understood as a person's self-perceived gender, the internal sense of being a boy/man, girl/woman, not belonging to a gender (non-binary) or being a different type of gender. People with gender incongruence may also experience gender dysphoria in that the mismatch between gender identity and birth sex leads to discomfort and a strong desire to remove or change some or all primary or secondary sex characteristics.

In Norway, medical treatment for gender incongruence has been available since the end of the 1950s. The National Treatment Service at Oslo University Hospital has for over 40 years had a national function for the treatment of patients with gender incongruence.

Increased inflow - new patients

4 referrals per year — 1975-1990
50-70 / yr —2007-2010
400-600 / yr. —2018-2021

The health service has seen a marked increase in recent years in the number of patients seeking gender-affirming treatment. The number of people seeking or being referred to health care for gender incongruence and gender dysphoria is also increasing in several other Western countries. In particular, the number of children and adolescents seeking or being referred for such treatment in their teenage years has increased significantly. From 1975 to 1990, there were about four referrals per year for such treatment in Norway. In the last ten years, the National Treatment Service has reported an increase in referrals from approximately 50-70 per year in 2007-2010 to 400-600 referrals per year in 2018-2021. It is unknown why there is a large increase in the number of children and young people seeking or being referred for medical treatment. The largest increase is among adolescents and young adults who are registered as girls at birth but identify as boys.

Classification

Gender incongruence was previously classified under mental and behavioral disorders in the World Health Organization (WHO) diagnostic manual International Classification of Diseases (ICD). In the latest version ICD-11, gender incongruence has been moved from the section of diagnoses for mental disorders to a new chapter for sexual health, 'conditions related to sexual health'. This means that gender incongruence should no longer be considered a mental disorder. At the same time, it was decided that it is important to keep a diagnosis, partly because it triggers rights, such as healthcare and social security benefits.

The Directorate of eHealth has the main responsibility for the implementation of ICD-11 in Norway. The implementation work is in the preparation phase and has not yet started. The implementation may take several years because it will involve extensive changes to various systems and work processes. In 2020, temporary changes were made to the codes for gender incongruence in Norway pending the implementation of ICD-11. All codes under the chapter F64 Gender identity disorders were then taken out of use. The codes were replaced by new ones under the chapter Z76.8 Contact with health services under other specified circumstances. There are now three codes for gender incongruence; Z76.80 Gender incongruence in adolescence and adulthood, Z76.81 Gender incongruence in childhood and Z76.89 Unspecified gender incongruence. These are directly translated from the corresponding codes in ICD-11. This was done as a temporary solution in the Norwegian version of ICD-10 in anticipation of ICD-11. These codes are now used for medical coding of gender incongruence and are reported to the Norwegian Patient Registry. In addition, procedure codes are used for mapping and surgical procedures. There are no separate procedure codes for the initiation of hormone therapy. Diagnosis codes are used in combination with procedure codes.

Gender diversity and different gender expressions

For many people, exploring their gender identity is a natural part of their development from child to adult. Today, there is greater acceptance in society of different gender expressions. This acceptance is partly the result of increased knowledge, information and many years of advocacy efforts by various groups and individuals. It has also been argued that social media has made it easier to share, acknowledge and be open about feeling different. Despite the greater acceptance of gender diversity in society, many people with gender incongruence still experience stigma and discrimination. This is relevant knowledge for the health services and an important backdrop for the development of support and treatment services.

Treatments for gender incongruence

For people with gender incongruence and gender dysphoria, different interventions and treatments may be appropriate. Interventions and treatment for gender incongruence and gender dysphoria may vary from less invasive help to more invasive treatment, such as various hormonal treatments and surgical treatment. These may include counseling, psychosocial support sessions, coping skills training and speech therapy sessions with voice training. Assistive devices such as wigs, breast prostheses and penile prostheses may also be used. These aids are used in the assessment as 'real life experience'. That is, the person lives as the desired gender to assess whether it feels right. These are less invasive measures.

Puberty blockers and gender affirmative treatment involve hormonal treatment, and gender affirmative treatment may also involve surgical interventions. Gender affirmative treatment is known to be invasive and irreversible with different consequences and greater risk and potential for harm than less invasive treatment.

Puberty blockers

Children and young people who have reached puberty may be given hormonal treatment with puberty blockers (puberty inhibitors) to stop or delay puberty. Puberty blockers have traditionally been given to children who reach puberty too early, but can also be given as treatment for gender incongruence and gender dysphoria in children and adolescents. The reason for delaying puberty is that children and adolescents may experience increased discomfort, gender dysphoria, when puberty starts, and they experience physical development that is not in line with their own gender identity. The treatment prevents puberty from developing further and thus prevents a possible unwanted development.

Treatment with puberty blockers appears to be most effective in the early stages of puberty, both in terms of the development of sexual characteristics such as breasts, penis, facial and body hair and growth in length. The treatment has no age limit, but can start at the beginning of puberty at the earliest. Treatment can only be given for a few years. After that, a decision must be made whether to stop all hormone treatment or to switch to feminizing or masculinizing hormones. The treatment has known side effects such as weight gain, reduced height growth, hot flushes, lack of energy, depression and reduced bone mineralization. Little is known about the long-term effects.

Gender affirmative action

Gender-affirming treatments aim to affirm a person's gender identity. Unlike puberty blockers, which stop or delay unwanted physical development, gender affirming treatment involves giving the body a development or physical characteristics that are in line with one's gender identity. There are two types of gender-affirming treatment: gender-affirming hormone therapy and surgical treatment.

Gender-affirming hormone therapy can be offered from the age of 16, according to the guideline. Testosterone is given to persons whose registered sex is female and oestrogen and antiandrogen to persons whose registered sex is male. If the person has had puberty delayed with hormones, sex hormones are given in escalating treatment to simulate the development of puberty. Gender-affirming hormone therapy must be given for life to maintain the desired effect.

In individuals with registered female gender, physical changes can be expected in the form of deepening of the voice, enlargement of the clitoris to varying degrees, increased growth of facial and body hair, cessation of menstruation, decline of breast tissue, increased sex drive and decreased body fat to muscle mass ratio. In people with registered male gender, one can expect varying degrees of breast growth, decreased sex drive and erections, decreased testicular size and increased body fat in relation to muscle mass.

Surgical treatment can be given to people over 18 years of age. Current treatments include breast removal, removal of the ovaries and uterus and surgery of the external genitalia.

Many of the changes brought about by gender confirmation treatment are irreversible. The treatment has consequences for fertility that are permanently impaired. Possible side effects of the treatment may include liver disease and negative psychological reactions. For male-to-female treatment, there is an increased risk of blood clots, high blood pressure and liver disease. For female-to-male treatment, side effects may include excessive red blood cells, scarring acne and swelling of the body. This is not an exhaustive list of all possible known effects.

4 Input from patients and families

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When discussing gender incongruence and the patient perspective, it is important to emphasize that people with gender incongruence have different wishes and needs for healthcare. Many people live well with their gender incongruence and manage it without health care, while others want and need health care.

Listening to the voices of patients, users and relatives is crucial for identifying areas of risk and improvement in health services. In conducting this study, it has been important to elicit multiple patient voices and perspectives. We have met several patients who are either undergoing treatment or have been in a treatment situation, and we have heard about a diversity of needs, preferences, opinions and experiences with the health service.

Message to health services

Here are some key messages that emerged from the conversations we had:

- Being in the process of exploring gender incongruence and gender dysphoria is demanding, and many people want support in their individual process.
- Gender-affirming treatment should be personalized. It is important that the treatment provider sees the individual with the resources and challenges they have.
- Many people with gender incongruence feel that there is a lack of expertise and comprehensive services.
- Many are concerned that respect and tolerance for gender diversity is being lost in the debate on binary gender affirmative action.
- All have highlighted the importance of thinking about the whole person and life course, including for transgender people.
- There is a fear of not being seen, not being heard and not getting the
- right help at the right time. Living with gender dysphoria over time and without help is very painful.
- Health services must offer support to both people with binary gender incongruence and non-binary gender incongruence.

> *"For many people, the most important thing is to be seen and heard. And when you have to wait nine months .... It's hard. We need to get rid of unnecessary waiting time"*

REPRESENTATIVE PATIENT ORGANIZATION/FORMER PATIENT
GENDER INCONGRUENCE

In addition, the people we have spoken to describe experiences such as powerlessness, frustration and exhaustion in their encounters with the health service. This is due to processes that are perceived as long and convoluted both in the encounter with the health service, in order to access help, and then in the assessment and treatment process. In addition, there is the burden of the time it takes to put in place a comprehensive health service for people with gender incongruence.

Need for help

Whether and to what extent gender incongruence affects health and social conditions will vary. There are many factors at play, for example, both social and biological factors influence the degree of dysphoria. High levels of gender dysphoria are very painful for the person living with it.
The burden of the disorder then greatly affects quality of life and daily functioning. For those living with dysphoria, it is very important that they receive health care.

Transgender people are a group that has been stigmatized, discriminated against and marginalized, also when dealing with health services. They have been met with attitudes where the challenges and problems caused by gender incongruence and gender dysphoria have not been recognized and understood. It is therefore important for the patient group to work for a dignified encounter with the health services at all stages of life, and to ensure that those who need treatment for gender dysphoria receive it.

One of the topics on which there are different opinions, also among patients and relatives, is who in the health service can start gender-affirming treatment and when. For example, several people tell us how important it is that a decision on gender-affirming treatment is given time and maturation. It is difficult to fully understand the consequences of the choice, and as many mention, there is "no quick fix".

"A lot of people have a breakdown after treatment. You have to work on a lot of things. Work on acceptance. For example, I always have to live with the fact that I was born in a girl's body."

REPRESENTATIVE PATIENT ORGANIZATION

At the same time, many people also talk about the importance of starting treatment early, because the changes brought about by puberty are also permanent.

"Gender affirmative treatment is life-saving treatment. Not providing treatment is also irreversible."

REPRESENTATIVE PATIENT ORGANIZATION

Everyone we spoke to emphasizes the importance of knowledge about gender incongruence at all levels of the health service, and that those who carry out assessment and treatment need specialist expertise.

> *"And then, of course, there's the fact that going through puberty is a trauma you don't want to go through, and we shouldn't take it lightly. And that balancing act, about when to start treatment and when it's not right, requires knowledge"*

PREVIOUS PATIENT ON ASSESSMENT/TREATMENT FOR GENDER INCONGRUENCE

What is common in all our meetings with people with gender incongruence is a desire to put in place better health services. There is also a unanimous wish that everyone who experiences gender incongruence and gender dysphoria should be taken seriously and receive support and help.

Safe guarding

Relatives tell us how important it is that health care professionals meet young people with gender incongruence with openness and knowledge, and that relatives are involved as supporters throughout the process.
Relatives have information that can be important both in the assessment and in the further process. The need for relatives as supporters does not stop at the age of 16 or 18.

> *"Throughout the process, she has lacked follow-up. She tells of great loneliness. We have been left out all the way. Nowhere have they worked to include us as parents. But everyone, and especially young people, need supporters"*

MOR

Many people tell us that assessment for gender-affirming treatment is a demanding process. On the one hand, it is perceived as very demanding if the process takes a long time. On the other hand, it is also demanding for many to experience time pressure, where the decision to start hormonal treatment must be made early before pubertal development gets too far along.

"We need to be able to talk honestly together. About what is difficult, about what you are unsure of, and about what might feel wrong. Now she's being cheered on, getting lots of support from everyone around her. I'm not sure if she can be honest about everything she feels with her friends, if there is room for doubt."

MOR

Parents point out that it is important that the services take the time to see the young person as a whole, take the time to involve those closest to them and find out what is bothering the individual. They believe this is necessary in order to find out what the right help is. There is no time limit for this exploration because there will be individual differences and it requires close follow-up.

"We see afterwards that it was important that the process takes time, she herself understands that now. During the assessment, it was tough. She had a feeling that she had to convince people that she deserved to get help, to be approved. This blocked communication."

MOR

Several have mentioned that it is difficult to find places they can go to safely explore their own gender expression and identity along with any other challenges they are facing. This is especially true for children and adolescents, but it is also challenging for young adults who are not affiliated with a health center.

"It would have been healthy if it was part of the program to talk to someone. So that you could talk about everything, dare to put into words everything that comes with this, what you feel. Both the good and the difficult. Then it's easier to make choices that are right for you along the way. You are more stable if the follow-up takes in the whole package. You're 16 and think that fixing your body will solve all your problems, but it doesn't."

MOR

5 Our findings: Overall governance - a guideline with a different background

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In recent years, there has been increased attention to the health care of people with gender incongruence. In 2015, the report Right to the right gender was published. Health services for people with gender incongruence and gender dysphoria were then for the first time the subject of work under the auspices of a publicly appointed working group in Norway. The Government's action plan against discrimination on the basis of sexual orientation, gender identity, gender expression and gender characteristics (2021-2024) strengthened efforts to promote the rights, living conditions and quality of life of queer people.

In 2020, the Directorate of Health's national professional guideline on gender incongruence was published.

In 2023, the Government published an Action Plan on Gender and Sexuality Diversity (2023-2026). It points out that we are still not at the finish line in the fight for a free, inclusive and safe society for all. Too many queer people live without a good quality of life and good living conditions. The Action Plan aims to improve the quality of life of queer people, ensure their rights and contribute to greater acceptance of gender and sexual diversity. The action plan includes measures related to the provision of treatment for people with gender incongruence.

The national professional guideline, gender incongruence

2020?? The Ministry of Health and Care Services commissioned the Directorate of Health to: "Prepare a normative document/professional recommendations on the treatment of gender dysphoria and gender incongruence". The assignment is also a result of an expressed wish in the professional, user and interest groups for a confirmation of the health services offered to people who experience gender incongruence. A separate chapter in the guideline on background describes this:

> *"The commission for this national guideline has a rare and special background, unlike other normative publications from the Directorate of Health. It is not common for assignments to prepare professional guidelines to be linked to established grounds for discrimination and a global and national concern for the provision of health services to a patient group. The guideline must be read and understood against this background."*

It is described by many as an important document that represents a turning point in how we think about gender identity, gender incongruence and gender dysphoria, for example in the consultation response from the Norwegian Association of General Practice's LGBT professional group.

At the same time, in the consultation round for the guideline, several people called for clearer clarification and specification, including the Norwegian Institute of Public Health (FHI) and the Norwegian Board of Health Supervision. They pointed to demanding issues related to the soundness and organization of the service.

The national professional guideline on gender incongruence does not follow the Guidance for the development of evidence-based guidelines published by the Directorate of Health, which states:

> *"The advice and recommendations provided should be specific, should help health professionals and patients to make good decisions, and should help to reduce unwanted variation and promote good quality in health and care services".*

The national guideline on gender incongruence differs in terms of content, knowledge base and standardization. The guideline is overarching, with attention to organization, equality and rights. The aim of the guideline is to provide differentiated, decentralized and comprehensive health services for people with gender incongruence.

The guideline refers to the need to strengthen the knowledge base and research on gender incongruence. It indicated the need to:

- update the evidence base for the assessment and treatment of gender incongruence
- strengthen research activities
- develop professional guidelines for health care
- establish a national medical quality register with quality indicators

There was no systematic review of the evidence on which the national guideline could be based, and the national guideline does not present a systematic and structured overview of the evidence base in line with the Guidelines for the development of evidence-based guidelines.
The Directorate of Health writes that the recommendations are mainly based on experience-based consensus and user participation/user knowledge, but what is included in the guideline's mentioned experience-based evidence base is not documented, transparent or verifiable.

The guideline points out that establishing a treatment service is an evolving process. It will require resources and time to establish a specific service, acquire the necessary expertise, develop national guidelines on clinical issues, and establish research projects.

Our investigation finds that the guidelines leave too much room for interpretation regarding who can do what, how, where and when. The scope for interpretation contributes to undesirable variation in the treatment offered for sometimes irreversible and extensive procedures, and we see that the disagreement in the professional communities and patient organizations continues. The feedback we have received from representatives of the services is that the guideline functions poorly as an aid to professional standardization, and this constitutes a patient safety risk.

In summary

Our survey shows that the guideline does not provide the service with sufficient help in developing a service offer. Despite the explanation that this is a guideline with a different background, with its focus on organization, equality and rights, it is too unclear and thus not a tool for the service. In our view, good and clear guidelines are important for the development of a field of practice. When guidelines do not provide sufficient guidance, there are many consequences for the development of health services and for patients.

PATIENT SAFETY FOR CHILDREN AND YOUNG PEOPLE WITH GENDER INCONGRUENCE

6 Our findings: Support and treatment services variety of practices and competences

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The national guideline is intended to contribute to "decentralized, differentiated and comprehensive health services". This means that services should be both close to and at all service levels, consist of different services, and the services should be coherent and coordinated. It follows from the guideline for gender incongruence that most patients should receive help either in the municipal health and care services or at regional level in the specialist health service. This is consistent with other health services, but since there is no clear specification of which tasks are to be performed by whom, it is difficult for the service to establish this.

The Directorate of Health writes in the guideline that it will take time to put in place adequate services for the group, and that the guideline is only a step along the way. As of today, three years after the guideline was issued, an adequate range of services and the desired concrete changes are not in place.

Description of practices for assessment and initiation of treatment

Health centers and GPs are often the first point of contact. GPs will often request that the patient be assessed by local mental health services before referring the patient to the National Treatment Service for Gender Incongruence at Oslo University Hospital HF. The assessment in mental health care may then consist of a survey and assessment of the patient's psychosocial situation, level of functioning and gender identity. Patients are also referred directly to the National Treatment Service by doctors in the primary health service for assessment of the indication for puberty-inhibiting or gender-affirming treatment. On the website of the National Treatment Service treatment of children and young people as of February 24, 2023, a waiting time of 3-9 months is given, although it may vary depending on the number of people being treated.

The National Treatment Service for Gender Incongruence has the national function for the treatment of patients diagnosed with gender incongruence in Norway. This means that the national treatment service has the main responsibility for gender-confirming hormonal and surgical treatment.

The assessment of gender incongruence and gender dysphoria at the National Treatment Service is a comprehensive interdisciplinary process, including mapping of physical and mental health and social challenges. Thorough assessment and the need to spend time is emphasized in order to assess whether gender-affirming treatments are the right thing for the individual. It is a requirement that all persons referred or undergoing assessment have a local treatment contact. Gender identity disorder must be present over time and not be a symptom of mental illness.

Some GPs and health centers offer hormonal gender-affirming treatment directly to patients and puberty blockers to children under 16 years of age. The City of Oslo has a health centre, Helsestasjon for gender and sexuality (HKS), which specializes in issues related to the body, sexuality and gender identity. The health center provides gender-affirming support and treatment at a low-threshold level and can, if desired, make referrals to other services. The health center also provides treatment with puberty blockers and gender-affirming hormones, and refers to mental health care and the National Treatment Service if the need is assessed. Several municipalities are considering establishing their own services for this group.

There is currently variation in what is done and emphasized in assessment, treatment and follow-up, and the professionals involved in assessments in primary care vary. There is a different understanding of diagnostic coding, guidelines and knowledge base. Management is based on individual assessments of the patient and different interpretations of the national guideline.

"Different assessments are made, including in BUP where one practitioner reads the guideline in one way and another practitioner reads it in another way."

REPRESENTATIVE OF A REGIONAL HEALTH AUTHORITY

Variation in service provision

Several people we have spoken to point out that the only possibility for many people in Norway to get help with their gender incongruence is to get a referral from their GP to the highly specialized services at the National Treatment Service. This service is located in Oslo, and requires several consultations over a longer period of time in connection with assessment and treatment. We have heard that many patients living in other parts of the country find it difficult to travel so far to get the treatment they need, especially if they do not have local follow-up. Others may live in areas where local primary care services are available. There are also variations in GP practice for children and young people with gender incongruence, with some GPs going to great lengths to meet the treatment needs of this patient group. Many children and young people who need support to explore their own identity and gender expression do not receive it locally. This can lead to an increased risk of both under- and overtreatment. For example, many may be left without the health care they need over time. It can also lead to them starting treatment on their own. Overtreatment can occur when hormonal treatment is started on the wrong basis and without sufficient opportunity to explore different options within their own gender identity.

"It's not all about gender. It's about identity and being allowed to be yourself, to be accepted. Both as masculine and feminine regardless of gender."

INFORMANT H

It therefore appears that the services provided to children and adolescents with gender incongruence are highly variable and may lead to different outcomes for the patient group based on where they live.

The regional health authorities (RHF) are now participating in a collaboration to assess which tasks can be solved regionally and to what extent they need to establish multi-regional services. The work aims to identify needs and challenges in current services across municipal health services and specialist health services.

In 2020, the regional health authorities were tasked with establishing regional treatment services for people with gender incongruence. The Government gave the health authorities until October 1, 2022 to clarify the content of the regional treatment services. In the summer of 2022, Ukom contacted the regional health authorities to obtain updated information about the services for people with gender incongruence. The responses from the regional health authorities showed that there were differences in existing and planned assessment and treatment services. An interregional collaboration is now underway to clarify clinical issues and establish treatment services in the regional health authorities. In connection with this work, various concepts and principles, for example related to prioritization, must be clarified. The guideline provides for the assessment and some of the treatment to take place at regional centers in the specialist health service. In the South-Eastern Norway Regional Health Authority, regional treatment centers are under development, and the other health regions are working to put services in place. In the spring of 2023, a pilot will be launched on a patient pathway for gender incongruence that extends from the primary health service, via a regional service in the specialist health service and to the national highly specialized service at Oslo University Hospital HF.

'We need to be aligned. This is important for patients. The regions have to do it the same way."

REPRESENTATIVE OF A REGIONAL HEALTH AUTHORITY

However, we have heard that some patient and user representatives fear that the regional services being developed will effectively become a "new waiting room" and that the treatment services they want will continue to be offered only by the national treatment service.

Lack of capacity and long waiting times

The National Treatment Service for Gender Incongruence has capacity problems due to the increased number of applicants, resulting in long waiting times for assessment, examination, initiation of treatment and follow-up. The capacity challenges are exacerbated by the fact that differentiated services are not in place in the regions.

"It took a very long time from the first time I went to the GP until I was at Rikshospitalet. That waiting time was very difficult. First of all, the GP didn't know where to refer me and at the DPS I was refused. A new doctor who had worked in a larger city and knew about this beforehand had to come before we could send a referral to the right place. And then there was the wait to get to Rikshospitalet. When I finally got there, I was greeted in a nice way, and was given a review of what gender-affirming treatment entails. Then I was referred back to a sexologist in the region. There I found out that it wasn't gender-affirming treatment I needed, and I got the counseling I needed to find out where I stand in relation to my identity, sexuality and gender expression."

INFORMANT H

We have heard that the long waiting time is one of the reasons why some people choose to start different parts of treatment on their own. Long waiting times pose a risk of sequelae and self-medication, which is a challenge to patient safety.

Need for increased skills and access to expertise

We have been told by both patient organizations and the service that there is a lack of health professionals with expertise in gender incongruence and in the follow-up of people with gender incongruence in both primary and specialist health services.

"... Many people act on the basis of their professional background ... act according to the resources they have. But they don't have expertise in trans health."

REPRESENTATIVE PATIENT ORGANIZATION

Several people we have spoken to have emphasized that children and young people with gender incongruence and gender dysphoria need access to competent health professionals, regardless of whether they need treatment, support measures or whether they want to explore gender expression and gender identity. Since in practice they will meet different professionals depending on where they are in the service, this means that there are several professional groups that need this competence. The competence needs of the different professional groups must be assessed according to the type of help offered, but knowledge of gender incongruence and how to deal with it must be at the core.

Municipal health and care services are often the first encounter with the health service for people exploring their gender identity and their relatives. We have heard that there is generally little competence and experience with gender incongruence and gender dysphoria in the municipalities. We have identified three factors that are of importance for building up help and support in the municipal health service.

- There is a need for accessible guidance for all those working in primary care settings for children and young people, such as kindergartens, schools and health centers.
- There is a need for family support and parental guidance services for families with children and young people with gender incongruence, both binary and non-binary.
- There is a need to strengthen the role of the GP.

The role of the GP is important in assessment and follow-up over time. It is essential for GPs to have access to appropriate support from specialist services when needed, as is the case for other conditions and pathways.

> *"The health professionals involved must be well trained in cooperation with the National Treatment Service. Those who will be working on this must feel competent."*

REPRESENTATIVE FROM A REGIONAL HEALTH AUTHORITY

The GPs we spoke to felt it was important that people with gender incongruence have the opportunity to openly and curiously explore gender expression in a safe environment with their GP.

> *"It is first and foremost about taking care of the person, as long as we approach gender in an open and exploratory way, and do not reject or close doors, it works well. It's important to clarify that it's not about excluding treatment, but about taking care of the person first."*

TREATMENT

In recent years, requirements have been introduced to include knowledge about gender identity and gender expression in key health education programs. In the long term, this may lead to more competence about gender incongruence in the services. However, we have heard from several people that more needs to be done to ensure that there is competence about gender incongruence in the various parts of the services that the group encounters.

A highly specialized field in need of multidisciplinary expertise

Gender incongruence and gender dysphoria is a narrow and highly specialized area of specialist health care. It is therefore fundamental to build competence in this field in order to assess, counsel and treat in a responsible and safe manner. Ukom has noted that the services want to offer as wide a range of services as possible to the patient group, but that they must also offer good quality services. It is a prerequisite for putting in place a sufficiently good service that patients are met by professionals with the right expertise.

In the assessment and treatment of gender incongruence and gender dysphoria, an interdisciplinary approach is necessary, and this places clear demands on the structure of the service. Given the complexity of the subject area, the service also needs to have a certain volume of patients in order to gain the necessary experience and knowledge. In the ongoing restructuring of services for children and young people with gender incongruence and gender dysphoria in England, the authorities have calculated that a minimum population of five million is needed to develop a separate service for this patient group. Abroad, we see examples of gender incongruence centers being located in major cities to pool expertise and build a treatment and research environment. This shows some of the challenges of building a decentralized service in Norway.

The service currently faces challenges in recruiting and retaining professionals in the field. One of the reasons given is the attrition of professionals.

Stakeholders Ukom has spoken to consider that sufficient expertise on gender incongruence in the municipal health and care services can help ensure that many people's need for health care is met. For children, young people and adults, it is also appropriate for health care to be locally based.

Several stakeholders have also pointed out to Ukom the importance of children and young people with gender incongruence being met by professionals with sexological expertise. Sexologists with whom Ukom has had a dialog say that they have special expertise in this field. The Directorate of Health's guidelines also state that sexological competence and knowledge is an important prerequisite for professionals in this field. One argument is that after the latest change in ICD-11, gender incongruence is no longer to be considered a mental diagnosis.

At the same time, sexologist is not a regulated profession with a protected title or regulated education. This means that anyone, regardless of educational and experience background, can basically call themselves a sexologist. This means that the sexologists who see patients in the services may have different competences. It may also vary whether the sexologists have a health professional education and sufficient knowledge of other diseases and mental disorders that may affect the situation of people with gender incongruence. This may contribute to variation in service provision.

Risky self-medication and private surgery

Many people with gender incongruence choose to initiate treatment for gender incongruence outside the public services. They can do this by starting hormone therapy on their own, for example by ordering drugs on the internet or by buying them abroad. They can also undergo gender confirmation surgery privately in Norway or abroad.

"I didn't want to wait for an operation at Rikshospitalet, because there was a long wait, I didn't want to listen to my therapist who told me that my chest also needed time to mature. Because the hormones will change the structure. I didn't want to listen with that ear, I wanted to fix my chest. Because that was what was visible. Everything else could be hidden, nobody saw the ovary on a daily basis. So I went to a private surgeon in Oslo. He destroyed me."

PREVIOUS PATIENT ASSESSMENT/TREATMENT GENDER INCONGRUENCE

Starting hormonal treatment on one's own outside of the public health care system entails risky self-medication. This is a significant patient safety risk, in part because patients are often not assessed before starting treatments. The person is also left alone to administer the treatment. People who have started self-medication will often seek public health services for help or to obtain prescription medication.

Gender confirmation surgery performed privately in Norway or abroad also involves patient risk. The role of private treatment providers is unclear in the national guideline.

One of the reasons for starting treatment on their own is refusal of hormonal gender-affirming treatment. Several patient and user representatives have pointed out that the current service provision is not designed and organized in such a way that it allows for a right to a second opinion, even though this right follows from the Patients' and Users' Rights Act. A possibility for a second opinion has long been requested by the patient group. Other reasons for self-medication include lack of local services and support, lack of trust in the health service and long waiting times.

"In terms of patient safety, when capacity is limited, there is a vacuum in waiting time and follow-up - where there is no local, regional or national provision. This vacuum is a risk."

PRACTITIONER AND RESEARCHER

In summary

We see that there is great variation in the services and expertise offered in different parts of the country. There is a risk of under-, over- and incorrect treatment of children and young people with gender incongruence and gender dysphoria. In addition, we see that there are challenges in establishing decentralized services in a narrow, complex field.

To strengthen services, Ukom believes that it is important to strengthen health services in primary care, build more interdisciplinary expertise in the specialist health services at regional level and ensure that the national treatment services have sufficient capacity for the current demand.

PATIENT SAFETY FOR CHILDREN AND YOUNG PEOPLE WITH GENDER INCONGRUENCE

7 Our findings: Insufficient knowledge

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The evidence base, especially research-based evidence, for gender affirmative treatment (hormonal and surgical) is insufficient. Little is known about the long-term effects. This is particularly true for the teenage population, which accounts for a large part of the increase in referrals to specialist health services over the last decade. This represents a new population for health services where evidence on treatment effects, side effects and prognosis is lacking or weak. Most often the studies are on patients with binary gender incongruence, but now there is also an increase in referrals of people with non-binary gender incongruence for which there is little research evidence. Research-based knowledge is incomplete and does not provide clear answers. This is recognized nationally and internationally. A committee set up by the health authorities in England recently described the evidence base as follows:

> *"Evidence on the appropriate management of children and young people with gender incongruence and dysphoria is inconclusive both nationally and internationally."*

Systematic review of the evidence

The lack of evidence base makes it difficult for health professionals, patients, relatives, authorities and others to get an overview of the current evidence base in the field. Systematic reviews collect and synthesize available evidence in a systematic, scientific and transparent manner based on explicit and predefined methods according to international standards for the preparation of such reviews. It should be possible for others to verify results and conclusions. This contrasts with non-systematic reviews ('traditional' reviews), which lack systematic and transparent procedures. It can be difficult to know why some research results are emphasized and others not. Differences in emphasis and coverage can give a misleading picture of the evidence base and consensus. It is important to use available knowledge and experience nationally and internationally in a systematic way.

Different groups and countries have produced different types of summaries and guidelines, for example

- An Endocrine Society Clinical Practice Guideline which was an updated 2017 clinical practice guideline from American and European medical endocrinology associations (American Association of Clinical Endocrinologists, American Society of Andrology, European Society for Pediatric Endocrinology, European Society of Endocrinology, Pediatric Endocrine Society)
- The World Professional Association for Transgender Care (WPATH) has published an update of the Standards of Care, SOC8.
- In 2022, the National Board of Health and Welfare in Sweden published an update of the evidence base for "Support, assessment and hormone treatment for gender incongruence in children and adolescents".

SOC8 was published in 2022 and is a guideline developed by the professional and advocacy organization WPATH to guide healthcare professionals to ensure safe and effective care for transgender and gender diverse people. The guideline is based on published literature and expert consensus-based opinions. The guideline and recommendations aim to promote evidence-based care, education, research, public policy and respect for transgender health globally.

Swedish health authorities have several times updated the evidence base with summaries (non-systematic and systematic) and revised recommendations for children and adolescents with gender dysphoria and gender incongruence. Swedish health authorities at the National Board of Health and Welfare considered at the last update in 2022 that the risks of puberty blockers and gender-affirming hormone therapy for the group of young people with gender incongruence as a whole outweighed the possible benefit of the treatments. This was based on their updated assessment of the evidence base where they considered it was not possible to conclude on the efficacy and safety of the treatments, and the National Board of Health and Welfare recommended that the treatments be provided within the framework of research. The report emphasized new knowledge on the prevalence of treatment regret among young adults. The National Board of Health and Welfare also highlighted the unexplained increase in the number of people seeking assistance from the health services, particularly a marked increase among adolescents and especially adolescents with registered sex female (girl) at birth.

In Norway, systematic reviews and HTAs are used to determine which treatments can be given to different patient groups. There are different types of HTAs. A so-called full HTA is a comprehensive systematic assessment of new or established methods in which efficacy, safety and/or cost-effectiveness are reviewed and assessed. The assessment often also includes questions concerning ethical, legal, organizational and societal consequences. In Norway, no systematic reviews have been conducted on puberty-delaying and gender-confirming treatments with hormones and surgery. Nor have HTAs of treatments for children and adolescents with gender dysphoria been used. The health authorities in Norway have not provided updates of the evidence base and accompanying benefit and risk assessments of various treatments as, for example, the Swedish authorities have done.

Safety and efficacy of the treatment

There are unresolved issues related to puberty blockers in adolescents. One published study shows that puberty-delaying hormones cause slower growth in height and slower increases in bone density. It is also noted that the effects on cognitive development have not been established. There are increasing questions about the unresolved side effects and long-term effects of both puberty blockers (hormone therapy) and gender-affirming hormone therapies. However, experience with other patient groups shows that long-term use of cross-sex hormones can affect disease risk. When people with gender incongruence are treated, it is with substantially longer duration and intensity of hormone treatment than hormone treatments for other conditions. When treatment is started at a young age, it will need to last a lifetime.

Long-term satisfaction with surgical gender-affirming interventions at the group level and the need for surgical reoperations are not known.

Since some of the treatments are established in practice, conducting good randomized trials is problematic. It is also ethically difficult to conduct randomized controlled trials to assess the efficacy of several of these treatments for people with gender incongruence, especially for children and adolescents. There is little and uncertain data on the rates of regret, and this is particularly relevant for the most invasive treatments such as puberty delaying and hormonal and/or surgical gender confirmation treatments. It is not a given that everyone who has received this type of treatment and regrets it will contact the treatment institution. In Sweden, for example, there is insufficient scientific evidence to assess how many people discontinue or regret treatment.

There are many studies showing improvement in gender dysphoria, quality of life, psychosocial functioning and mental health tests in the short term after drug and surgical treatment of gender incongruence and gender dysphoria. However, there are few studies of the long-term effects of the treatments, and the quality of the studies is variable. There is a lack of studies comparing outcome measures after different treatment methods and there is usually no control group in the studies. The lack of control groups means that effects are often measured against population data. Effects are often assessed at the group level, rather than the individual level, so that adverse effects for some patients may be masked by improvements in the rest of the group. Samples are often small, and patient dropout can greatly affect the results. There are few long-term studies, and those that exist started before the described increase in teenagers with gender incongruence seeking treatment. It may therefore be difficult to transfer the results of these earlier studies to those who are now being referred, since a large proportion have mental illness, developmental disorders or other conditions that were not described in the earlier studies.

Suicide incidence

Varying figures are given on the incidence of suicide in people with gender incongruence and gender dysphoria depending on the time period and the type of population studied.

The 2020 report from the National Board of Health and Welfare showed that 0.6 percent of those registered with a diagnosis of gender incongruence in Sweden (39 out of 6334 people) had committed suicide. Professionals and researchers at the Norwegian Institute of Public Health wrote in 2020 about the Swedish figures:

> *"The suicide risk was significantly higher than in the general population, but at the same level as the suicide risk of common mental disorders such as depression, bipolar disorder and autism. Since these mental disorders are so common among people with gender incongruence, it is not possible to determine whether the increased suicide risk is due to gender incongruence per se or is a consequence of mental disorders. There are also no studies that provide evidence that suicide risk is reduced as a result of gender-affirming treatment, or that suicide risk increases if gender-affirming treatment is not provided".*

Data from the follow-up of a cohort of people referred to specialist centers in the Netherlands (1972-2017), also published in 2020, showed for the period 2013-2017 an almost four times increased risk of suicide among transgender people compared to the general risk. Suicides occurred in all phases of transition, with two-thirds occurring in people still in active treatment. Trans women had a higher suicide risk than trans men. There was no change in suicide risk over time in trans men, however, there was a slight decrease in suicide risk for trans women throughout the time period. In Norway, we do not have published overview figures on suicide in persons with gender incongruence and/or gender dysphoria.

Lack of knowledge of the situation of patients

There is currently no Norwegian overview or systematic mapping of the patients' history, how many are rejected, withdraw during the course of treatment, complete the treatment or how patients with gender incongruence and gender dysphoria fare after treatment. This requires both a national registry and systematic review, neither of which is in place. Researchers at the National Treatment Service for Gender Incongruence have established a local quality registry with information on children and adolescents who have been referred to the team for gender identity investigations over the past 20 years. This is data from a selected part of the health service and does not provide a complete overview since there are several who treat children and adolescents with puberty blockers and gender affirming treatment.

The 2022 annual report from the national treatment service summarizes these figures: 915 people (268 children and 647 adults) were referred to Oslo University Hospital HF for assessment. Of the children under investigation, 70 (26.1 percent) were registered male and 198 (73.9 percent) were registered female at birth. A total of 2449 adult patients were undergoing examination, treatment (hormonal and surgical) and follow-up after surgical treatment. This was an increase of 16% from the previous year. 83 patient relationships were terminated during the assessment process by the practitioner, and 40 people terminated the patient relationship themselves. A total of 244 plastic surgeries were performed:

- 78 had their breasts
- removed 24 had breast implants
- 28 had major genital conversions (procedures)
- 96 other gender corrective surgeries (breast/genital)
- 51 gynecological operations, such as removal of the uterus and ovaries

The National Treatment Service has previously reported that 75% of those referred have a mental illness, with depression and anxiety being the most common diagnosis. A significant clustering of different conditions was also found. Approximately one in five of those referred with gender incongruence had autism spectrum conditions, ADHD/ADD or Tourette's. This is consistent with Swedish figures.
The National Board of Health and Welfare has also mapped the prevalence of gender incongruence over time and looked at co-occurring mental health and other disorders.

> *"No one knows what happens to those who are turned away - no one knows anything about groups of patients who are not followed up."*
>
> REPRESENTATIVE PATIENT ORGANIZATION

There is no national overview of gender confirmation treatment provided by private providers, neither nationally nor internationally. Furthermore, there is no overview of the extent of self-medication with the purchase of hormonal treatment via the internet.

There is a need for oversight to promote development, and medical quality registries and research studies can contribute to this. Medical quality registers collect structured information from patient care pathways. Information on assessment, treatment, follow-up and outcome of treatment provides knowledge about unwarranted variation in health care provision and quality of care. The main purpose of medical quality registers is to contribute to improving the quality of patient care.

User participation and patient-reported outcome and satisfaction measures (PROMs and PREMs) are particularly important in the field where there is a need to develop treatment provision and health services. PROMs can contribute to a comprehensive data base in the field of gender incongruence with the possibility of capturing health aspects that are important for people with gender incongruence and often not captured by more traditional measurement methods. In the process of establishing a national medical quality registry, it is important to involve patient and family representatives to ensure relevance, language and user-friendliness. It is also important to prepare good information on the purpose and use of registry data in quality assurance and research for people with gender incongruence and gender dysphoria so that there is a clear basis for consent to data collection.

About ongoing research

In general, there is a lack of research-based knowledge on the short- and long-term effects, course and prognosis of different treatments. There is a need for medical clinical and epidemiological studies with outcome studies, including on people with gender incongruence who are not offered, do not start or stop the different treatments.

> *"We have to think in terms of the life cycle. What about those who received treatment and those who did not receive treatment? (...) We should have gone to those who were treated and asked if they would do it again. I would do it again (30 years ago), but for others... not sure."*
>
> REPRESENTATIVE PATIENT ORGANIZATION

There are various opportunities for research. All health enterprises are knowledge institutions and should have patient-oriented research as an integral part of their activities. Clinical studies contribute to updated knowledge about the safety and efficacy of treatment and contribute to knowledge about treatment results in clinical practice. Clinical research in the health enterprises has long been a priority area with the aim of strengthening quality and patient safety. This is also in line with the National Action Plan for Clinical Studies for 2021-2025.

Internationally and nationally, much research on gender incongruence is ongoing in several disciplines, including medicine, psychology and sociology. Prospective and retrospective long-term studies with longer observation periods will gradually emerge. Research on rare outcomes and outcomes that can occur long after treatment (such as heart attacks, cancer and osteoporosis) will take a long time to be answered.

Various efforts are being made to produce comprehensive national overviews of the field. In Norway, the Norwegian Institute of Public Health launched the Gender Incongruence project in 2020 to study gender incongruence in people under the age of 25. The project will provide more knowledge about gender incongruence in Norway and support proper health care. Approval has been given to link data from national health registers, the National Treatment Service for Gender Incongruence and Statistics Norway. No such epidemiologic studies of gender incongruence have previously been conducted in Norway.

In summary

The teenage population, which accounts for a large proportion of the increase in referrals to specialist health services over the last ten years, is a new population of patients for which the evidence base is insufficient both nationally and internationally. The stability of gender dysphoria occurring or expressed in adolescence is not known as there is a lack of follow-up studies. It is uncertain to what extent gender incongruence and gender dysphoria persist in this patient group compared to previous patient populations. A large proportion have mental illness, developmental disorders or other conditions that were not described in previous studies. The available evidence from previous studies is therefore not necessarily transferable to the group of teenagers with gender incongruence and gender dysphoria who increasingly seek puberty-suspending and gender-affirming treatment. There is a particular lack of research-based knowledge on the treatment of patients with non-binary gender incongruence.

Ukom considers it necessary for patient safety that the knowledge base on gender incongruence and gender dysphoria is strengthened, and that health services are organized in line with the knowledge base. In Norway, no systematic review has been conducted in the field, no updated assessments of recent foreign reviews have been made, and no full health technology assessment of puberty blockers and gender-affirming treatment with hormones and surgery for children and adolescents has been conducted. No medical quality register with national status has been established to provide an overview and assess the quality of the treatments given to children and adolescents with gender incongruence and gender dysphoria in Norway. Such measures are essential to improve the knowledge base for clinical decision-making and to promote clinical research and development in the field.

PATIENT SAFETY FOR CHILDREN AND YOUNG PEOPLE WITH GENDER INCONGRUENCE

8 Our findings: Due diligence requirements - in particular related to children and young people

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In conversations with us and in the consultation process for the national guideline, several stakeholders have questioned the soundness of the health care offered to children and adolescents with gender incongruence and gender dysphoria.

When we now assess the requirement for justifiability, we focus primarily on interventions of an invasive nature with a potentially high risk of harm, such as puberty blockers, gender-affirming hormones and surgery. Less invasive measures, such as counseling, prostheses and hair removal, are measures that can contribute to coping with gender incongruence, but do not have the same risk of harm as more invasive measures. This is therefore excluded from our assessments.

The requirement of defensibility has a broad basis in health legislation. The requirement for defensibility relates to assessment, treatment and follow-up. National professional guidelines will often help in this work by describing measures and solutions based on up-to-date, recognized professional knowledge and often specify what practice should be. At the same time, professional guidelines will provide guidance on how much deviation from good practice can be accepted before the deviation leads to the service being indefensible.

The Norwegian Board of Health Supervision and the State Governor are responsible for ensuring that the service operates responsibly. It is difficult for the Norwegian Board of Health Supervision to exercise control of soundness when the professional guideline, which should be normative, is unclear and vague.

The requirement of soundness in relation to children and young people presupposes that all assessment, treatment and follow-up must be in line with the 'best interests of the child'. For all decisions made in relation to children and young people, an overall assessment must be made of