Gender dysphoria

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Informed consent and childhood gender dysphoria: emerging complexities in diagnosis and treatment

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Abstract
Objective: To explore some of the emerging complexities in the management of childhood gender dysphoria.
Conclusion: The authors raise questions about the gender-affirmation approach and highlight concerns about informed consent and research ethics.

Keywords: gender, dysphoria, childhood, treatment, ethics

> 'The physician must be able to tell the antecedents, know the present, and foretell the future'
>
> Hippocrates

Gender dysphoria

The approach to gender dysphoria (GD) has become a controversial subject in medicine. GD refers to distress about a perceived mismatch between an individual's natal sex and the gender they believe themselves to be, and was previously referred to as gender identity disorder in DSM-IV. In DSM-5, the condition was changed to GD, shifting the focus towards the dysphoria associated with the incongruence and away from the notion of identity disturbance. The key elements of a GD diagnosis are that the difference between an individual's perceived/expressed/experienced gender and their natal sex creates significant distress or problems in functioning for at least 6 months. While the DSM criteria are clear, our understanding of the complex nature of childhood GD is still evolving. Indeed, major questions about the aetiology, natural history, heterogeneity, diagnostic stability, classification and treatment of the disorder remain largely unanswered.[1]

Primacy of gender affirmation

One of the main controversies arises principally in the approach to children who manifest GD. Some clinicians advocate an 'affirming' approach, based on a belief that the child's experienced gender is immutable.[2] In this model, the child's perceived/expressed/experienced gender is accepted, respected and not questioned. The focus of medical intervention is to assist the child to transition to the preferred gender as safely as possible while avoiding medical and psychosocial complications. This involves varying combinations of social transition, hormonal and surgical treatments with ongoing debate about how early these interventions should occur.

Currently, there are no long-term outcome studies that support the effectiveness of this model of treatment. Further, while initially proposed as being entirely safe and fully reversible, emerging data now indicate puberty-blocking drugs and opposite sex hormonal treatments

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have irreversible, long-lasting harmful effects on physical and emotional/cognitive health.[3–7]

Many other clinicians view the situation quite differently. While accepting that a small minority of children show gender-variant behaviours from a young age, these clinicians consider that many children adopted a gender opposite to their natal sex due to a multiplicity of influences – biological, developmental, psychological, psychiatric, social and family.[8,9] The salience of these factors can vary over time and as a result a child's sense of their gender identity is potentially fluid. This appears to be supported by the data showing that most gender-dysphoric children will 'desist' following puberty.[10,11] Social factors, in particular peer influence and social media, may also be significant in cases of adolescent onset gender dysphoria in natal females, recently termed 'rapid onset gender dysphoria' (ROGD).[12]

Rather than affirming the child's stated gender, clinicians working within this framework would explore how the child came to feel that they are in the wrong body and the context in which the child's gender experience emerged. These clinicians are cautious about facilitating a child's physical transition to the preferred gender until the complexity of the child's situation, including their family, peer and social context, have been thoroughly explored. This process also includes careful exploration of the risks involved. These clinicians will diagnose and treat comorbid disorders, believing that they may be contributing to the GD, rather than viewing them primarily as secondary to the distress of the experience of being in the wrong body. They will offer supportive and psychotherapeutic interventions to assist the child in working through their gender identity concerns. We refer to this as the 'conventional' approach to treatment.

Since 2000, there have been dramatic increases in numbers of children referred to gender clinics both internationally[13] and locally,[14] with the largest gender clinic in Australia at the Royal Children's Hospital (the RCHGS) seeing 250 new referrals per year. Despite the significant knowledge gaps, many gender clinics have adopted treatment protocols based on a gender-affirmation approach to the exclusion of competing models of care, despite limited and poor quality outcome data.[1,6] Justification for urgent medical transition in young people arises from concerns about the risks of suicide if gender reassignment is delayed. Although some studies demonstrate improvements in mood and well-being after gender reassignment,[15,16] researchers have observed higher rates of mortality, suicidal behaviour and psychiatric morbidity in gender-transitioned individuals compared to the general population.[3] It has also not been established that gender-affirming treatments reduce the risk of completed suicide, as they are commonly assumed to do. Overall, it is by no means clear that affirmation and gender transition is better than the conventional approach to treatment on psychosocial outcomes as no studies comparing the two approaches have been performed.[1,17]

The ethics of experimentation

Some gender clinics offering services to children are documenting various outcomes of affirmation-based gender transition treatment.[14] This is an acknowledgement of the paucity of information on the results of this form of treatment. These studies assume that affirmation is the 'gold standard', yet there is no evidence to support this assertion. Prospective cohort studies such as the Trans20 study currently being undertaken at the Royal Children's Hospital Gender Service do not include a treatment control group, or randomisation of individuals to affirmation or non-affirmation interventions.[14] Without the inclusion of a conventional treatment control group, these studies will not be able to determine whether the affirmation approach to GD is superior to the conventional approach, or even better than no treatment. At the moment, children entering affirmation approaches to GD are being exposed to experimental treatments without long-term evidence of efficacy or safety. In our critique of the Trans20 protocol,[18] we raised concerns that it purports to be a cohort study, but more closely resembles an uncontrolled clinical trial.

Informed consent

In view of the lack of evidence of effectiveness of rapid gender transition, and the harms involved with the application of puberty-blocking drugs and sex hormones to children with GD, the question of informed consent becomes a major issue. The technical complexities of transitioning medical interventions and their uncertain safety and long-term consequences raise the question of what level of maturity a child would need to be able to make a competent decision about this type of medical treatment. Indeed, the same concerns arise about the ability of parents to consent on behalf of their children given that so little is understood (or agreed upon) about the benefits and risks of medical treatments. In particular, are children and families made aware of the psychological and physical sequelae of puberty blockade and cross-sex hormones, including the high suicide rates and psychiatric morbidity post-transition? Are families made aware that gender affirmation has not been sufficiently validated as the best treatment for childhood gender dysphoria and that the treatment is experimental? Are they made aware that the vast majority of children will desist once they reach puberty? Given that the vast majority of young people who commence puberty blockers proceed to cross-sex hormones,[15] it may be that puberty blockade 'locks' a child into a permanent state of gender incongruence.

The position of the RANZCP

At this point, the Royal Australian and New Zealand College of Psychiatrists (RANZCP) provides very little guidance for clinicians around the best ways of supporting young people with GD. While the College previously

endorsed the gender-affirming guidelines presented by the Royal Children's Hospital in its standards of care,[19] a revision in College policy (position statement 83) in September 2019 curiously saw this reference removed.[20] No explanation for this was provided. While this leaves clinicians without any official treatment guidelines, we believe that the absence of a formal college position is an accurate reflection of the lack of robust evidence on which to base treatment decisions for childhood GD. By subsuming the question of GD under its umbrella position on LGTBQ+, the College has deftly sidestepped the core controversies by remaining vague and non-committal. The position statement claims 'good outcomes' for the affirmation model, but cites only one small study with 77 participants where only 14 natal females were assessed at completion.[10]

Contrast this with the less ambiguous position statement of The Royal College of Psychiatrists in the UK[21]:

'The College believes that a watch and wait policy, which does not place any pressure on children to live or behave in accordance with their sex assigned at birth or to move rapidly to gender transition, may be an appropriate course of action when young people first present'.

The RANZCP should take note. Working with adolescents is especially fraught because the normative developmental tasks of sexual and emotional maturation can confound and influence the manifestation of psychiatric pathology, and the consequences of aggressively treating false positives for young people can be catastrophic and lifelong.[22] The enthusiastic prescription of hormones and surgery for a condition of questionable construct validity and with such a high rate of natural desistance risks, in our opinion, a plethora of unanticipated consequences and potential lawsuits.

Disclosure

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

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