Gender Dysphoria in children and young people
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Published in:
Journal of Clinical Nursing

DOI:
10.1111/jocn.16164

Published: 31/05/2022

Document Version
Peer reviewed version

Citation for published version (APA):
Summary

- In the past few years there has been a very significant rise in the number of children and young people seeking treatment for gender dysphoria.

- This area is the subject of much discussion, as evidenced in a recent court case in the UK which examined competence and capacity of young people to consent to potentially irreversible treatment.

- Clinicians involved in gaining consent to treatment for gender dysphoric young people, must understand the evidence in this area and be aware of the heavy burden of accountability placed upon them.

It is increasingly apparent that nurses must engage with discussion around sex and gender. While these concepts have become highly charged for many, those on the frontline of clinical practice are increasingly likely to require knowledge in this area. In this paper we hope to stimulate engagement with this most difficult of topics by exploring the implications for clinical staff of a recent legal case in the United Kingdom (UK) which considered the issue of consent to treatment with puberty blockers by children and young people experiencing gender dysphoria.

The UK National Health Service (NHS) (2021) defines gender dysphoria as a ‘sense of unease…because of a mismatch between [an individual’s] biological sex and their gender identity’. Gender identity in turn is defined as a ‘sense of who we are and how we see and describe ourselves’ relating to whether an individual identifies ‘as male or female’. Some people feel they have a gender identity that is different from their biological sex and the mismatch can generate ‘unease or dissatisfaction, which may be so intense, it can lead to depression and anxiety and have a harmful impact on daily life’.

The number and profile of patients who present with gender dysphoria has altered significantly in recent years. In the UK, since 2009, there has been a 25-fold rise in referrals of children and young people to the Tavistock and Portman NHS Trust’s (Tavistock) Gender Identity Development Service (GIDS) (De Graaf et al. 2018). Whilst the presenting majority demographic were adult males, with a minority of boys, patients are now disproportionately likely to be adolescent girls (De Graaf et al. 2018). Coexisting neurodevelopmental disorders, previous adverse childhood experiences, substance misuse during treatment and mental health concerns during treatment are independently associated with accessing care (Hall et al. 2021).

For some children, distress is instigated or exacerbated by the onset of puberty, where they see the mismatch between their sexed body and developing secondary sex characteristics, (e.g. the rounding of hips and menstruation for girls, and growth of the testes, scrotum and penis for boys), with their gender identity. Signs include change of appearance, behaviour, interests, discomfort, distress, low self-esteem, depression or anxiety, becoming withdrawn or socially isolated, taking unnecessary risks or neglecting themselves (NHS 2021).

One of the interventions offered to children and young people is the off-label administration of gonadotropin-releasing hormone analogues or ‘puberty blockers’. Puberty blockers act on the pituitary gland, inhibiting hormone secretion and suppressing the endogenous
production of oestrogen in girls and testosterone in boys to prevent pubertal development of secondary sex characteristics. Puberty blockers have been used on-label since the 1980s to treat precocious puberty – that is abnormal early onset puberty defined as onset occurring before the age of 8 years for girls and 9 years for boys. Their use for gender dysphoria is much more recent.

The rationale for this intervention is the belief that the suspension of normal pubertal development, using puberty blockers, would reduce distress and provide a reversible pause to development, enabling time for on-going discussion and full psychological exploration of a child’s gender identity and distress before deciding whether to take further, irreversible interventions such as cross-sex hormones. Cross-sex or ‘gender confirming’ hormones include the administration of testosterone to girls and oestrogen for boys. Effects of the cross-sex hormones include facial hair and a dropped voice for girls and enlargement of breast tissue for boys.

**Background to the case**

Approaches to the treatment of children and young people who present with gender dysphoria vary internationally. In some states in America, the medicalisation of gender dysphoric youth is fully legislated for, and in some situations, allows for surgical intervention, for example, double mastectomies for girls, irrespective of age or mental health status (SEGM 2021a).

Elsewhere the situation is different and there is a growing concern about the medicalisation of these young people. Significant concern has been expressed about the use of these drugs, their side effects and the potential for irreversible damage. This concern is exacerbated by the observation that children who report gender dysphoria also experience disproportionately high levels of comorbidities and/or co-traumas, including depression, anxiety, autism, physical and/or sexual abuse and loss by separation (Kozlowska et al 2021), that significant numbers who report gender dysphoria find that the experience subsides in late adolescence, or early adulthood (Ristoria & Steensmab 2016), and are more likely to grow up to be same sex attracted (Griffin et al. 2020). There is also evidence of growing cohort of ‘de-transitioners’—individuals who have transitioned gender, including medically transition, who subsequently come to regret that decision (Littman 2021).

Recently, Sweden has suspended medical interventions for those under eighteen who are experiencing gender dysphoria and proposed to only prescribe puberty blockers in the context of randomised control trials (SEGM 2021b). Finland also questions providing any irreversible interventions before 25 years, has banned all surgical interventions for the under 18s and emphasises psychological therapy as the first line clinical intervention. Use of puberty blockers is cautioned and reserved primarily for children and young people with no pre-existing co-morbidities (SEGM 2021c). It also queries the use of interventions with unknown effects on brain development, which could impact the ability of the child or young person to provide informed consent. Both countries stress that a clearer understanding of the cause of the rise in referrals of children and young people presenting with gender dysphoria is needed.

Within the UK, the treatment of children and young people who present with gender dysphoria has become highly politicised, fraught and often based on ideological commitment as opposed to evidence. On the one hand there are those who argue for an affirmative model of care and who support the use of puberty blockers. In contrast, others point out that there is limited evidence to support the use of these drugs for gender dysphoria, and that such medical interventions are effectively medicalising gender non-conforming youth.
who are disproportionately likely, without medical intervention, to grow up to be lesbian or gay adults

Bell V's Tavistock Judicial Review and Appeal – England and Wales

The Bell V's Tavistock Judicial Review case was brought by two claimants, Keira Bell and Mrs A. Keira Bell is a 24-year-old woman who was treated for gender dysphoria at GIDS. She was placed on puberty blockers aged 16, cross-sex hormones aged 17 and underwent a double mastectomy aged 20 years. In her early twenties she de-transitioned and reverted her identity back to her natal sex. Bell believes that the model of medical interventions offered to her harmed her and that clinicians should have conducted further psychological exploration into the other reasons for her presenting distress. Mrs A is the mother of a 15-year-old girl with autism presenting with gender dysphoria who fears that her daughter will be prescribed puberty blockers without fully understanding the implications.

In the UK, children under the age of 16 can provide informed consent to medical treatment, including against parental wishes, if clinicians judge that they have the intelligence, competence and understanding to appreciate the implications of treatment. This is medico-legally known as being ‘Gillick competent’. Centrally, the Judicial Review tested the claim that children under the age of 16 years could not provide informed consent to puberty blocking medical intervention. The High Court ruled that for a child to be able to provide informed consent, clinicians need to be satisfied that the child is able to understand, retain, and weigh up the immediate and long term physical and psychological consequences of medical interventions and impact on future adulthood.

Evidence of benefit was not established and the potential for harm was determined to be substantial. Effects of puberty blockers followed by cross-sex hormones include reduction in bone density, loss of sexual function and sterility. Effect of suppression of normal puberty on child brain development and long-term outcomes remain unknown, and the medical interventions on offer were deemed experimental. In addition, instead of providing a reversible ‘pause’ for exploration of gender identity, puberty blockers now appears to serve as a direct pathway to full medical transition as almost all (98%) of children prescribed puberty blockers progress to cross-sex hormones (Carmichael et al 2021). As such, consent to puberty blockers cannot, in effect, be separated from consent to cross-sex hormones.

The High Court ruled that children aged younger than 16 years were, depending on their age, either unable or unlikely to be able to provide informed consent for the medical interventions offered, and as such cannot be Gillick Competent in this matter. For 16- and 17-year-olds, the Court determined that there was a presumption of capacity, however, application for medical interventions could be made to the Courts for ‘best interest’ purposes. GIDS subsequently halted the referral of children and young people for puberty blockers.

The Judicial Review was subsequently appealed by the Tavistock in the UK’s High Court in June 2021 and the Judgment was published in September 2021. The Court of Appeal reversed the previous decision and supported the Appeal. It ruled that the original Judgement made a ruling on the ability of children to provide informed consent as a group based on age that it was not entitled to make. It determined that judgement as to whether a child is Gillick competent and can provide informed consent to medical interventions offered should instead be decided on an individual basis by clinicians, parents and children, and not in the Courts. Importantly, unlike in the original Judicial Review, there was no wider consideration in the Appeal Judgment on the appropriateness of medical interventions on offer. However, paragraphs 92 and 93 of the Judgement state that clinicians must be aware of their ethical duties when determining a child’s informed consent, and failure to do so could carry regulatory consequences or civil action.
Implications for clinicians

The Judgement informing regulatory or civil action for clinicians in cases of failure to ensure informed consent is particularly important for clinical practice. While reversing the original ruling it effectively puts the onus on clinical staff to determine Gillick competence and capacity. This has significant implications for those involved in the care and treatment of children and young people seeking puberty blockers.

Medical intervention must be evidence based with known and unknown outcomes, safety and effectiveness clearly communicated to all concerned, including the patient. Recent reviews by the National Institute for Health and Care Excellence on the clinical effectiveness, safety and cost-effectiveness of puberty blockers and cross-sex hormones concluded that the evidence base of impact on gender dysphoria, mental health and quality of life is of low, or very low quality (NICE 2021a & 2021b).

Importantly, to determine informed consent and the appropriateness of intervention, clinicians will need to consider the long-term medical consequences and healthcare needs that arise as a direct result of the medical interventions offered as well as impact of not providing medical interventions. A systematic review highlights that 61-98% of children and young people who present with gender dysphoria, without medical intervention, desist Ristoria and Steensmab (2016). That is, naturally stop opposite sex identification and reconcile themselves to their natal sex. Therefore, there is a substantial cohort of children and young people who, with appropriate support, could avoid medical intervention and long-term health impacts. When this is compared with the 98% of children and young people who progress from puberty blockers to cross sex hormones, there are significant questions relevant to current clinical practice in this area.

It is essential that clinicians offer patients who present with gender dysphoria usual norms of evidence based care. Children and young people have the right to high standards of individualised care that best support their developmental and healthcare needs, and long-term outcomes. Clinicians must ensure the history, needs and causes of presenting distress of the individual child is centred to their care and not influenced by political or ideological positions. This will help safeguard and ensure high standards of therapeutic care for children and young people who present with gender dysphoria, and enable the many who would naturally desist, to do so, without medical intervention and long-term harms.

Ultimately, Bell V Tavistock firmly places the responsibility to determine informed consent in the hands of clinical staff. This is a very heavy responsibility and one which must be discharged carefully and in the knowledge that registered clinical staff are accountable for both their actions and omissions.

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