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Gender dysphoria in young people: The Interim Cass Review and its implications for nursing

Introduction

The aim of this editorial is to explore the implications for nurses of the initial published findings of the English 'Independent review of gender identity services for children and young people'. The Review, led by paediatrician Dr Hilary Cass, was commissioned by NHS England. Its aim is to make recommendations on clinical management and service provision to ensure that the best model(s) for safe and effective services for children and young people who experience gender incongruence or gender-related distress are commissioned. The Interim Report was published in February 2022 (Cass, 2022) and represents the work of the Review to date. This work was instigated against a backdrop of growing international concern about the recent and very rapid growth in the numbers of children and young people presenting with gender dysphoria and how best to support them. Of particular concern has been the current model for care and role of medical and surgical intervention. Whilst findings and recommendations will only relate to England, they are likely to inform international opinion and reverberate well beyond that country.

Dr Cass outlines that her "measure of success for this Review will be that this group of children and young people receive timely, appropriate and excellent care, not just from specialists but from every healthcare professional they encounter". In addition, the report is clear that "the care of this group of children and young people is everyone's business… and that [the wider clinical community should] consider their own roles in providing the best holistic support to this population."

Drawing on a broad evidence base, with input from children and their families, advocacy groups, detransitioners and clinicians, the Interim Report does not set out final recommendations, but summarises emerging and consistent themes and provides initial advice so that action to improve services and care can be taken more quickly.

Gender dysphoria is commonly understood to involve a subjective mismatch between a person's biological sex and their gender identity, or their sense of who they are in terms of whether they identify as male or female. Although the experience has been known of for decades (Joyce 2021), over the course of a few short years there has been a dramatic rise in incidence across much of the West. This has been particularly evident in the increasing number of children and young people who report feelings of dysphoria. Other changes have also been noticed in this new cohort, with predominance shifting from boys to girls and an increasing prevalence of trauma, comorbid mental health problems, attachment loss and autism. For some, this change in prevalence and demographic is evidence of more liberal and accepting societies in which young people can freely express their true selves. For others, it is an example of the impact of social contagion amongst a troubled and confused generation (Shrier, 2020).

How best to support these children and young people has become a highly charged and deeply controversial topic. There are those who argue that the gender dysphoric young person is best supported using an 'affirmative model' in which their self-declared gender is accepted without question or examination of alternative causes of distress, and where medical intervention is to be readily available to support transition. In contrast, proponents of a 'watchful waiting' approach advocate caution, arguing that the young person should be given time to explore their feelings and causes of distress in a neutral environment. They argue that medical interventions such as puberty blockers are experimental and accompanied by risk of significant and irreversible consequences including sterility, sexual dysfunction and regret, as well as lead to further irreversible interventions, such as double mastectomy. They also argue that, given time, and the appropriate psychological support, dysphoric feelings usually resolve without medical intervention, enabling children and young people to avoid medical interventions which are unnecessary and cause long term harms.

Given the emotive context – the safeguarding and well-being of children and young people – and the radical nature of the issue – the notion that a child is somehow born in the 'wrong body' and that it is both desirable and possible for them to change sex, it should not surprise us that debate has raged across social media and variously captured sections of the academic, public and political discourse in Australia, the United States, the UK, Holland, Sweden and Finland. In contrast, the

relative silence of regulatory, academic and practice leaders in nursing is profound. Clinicians and students have been left to explore the issues through social media, via the press and often through the lens of lobby groups, and self-declared 'allies'. Many individual nurses as well as nursing and health organisations are currently affiliated with lobby groups, and some have aligned themselves to political activism relating to the clinical management of dysphoric young people. For a profession in which evidence-based practice and safeguarding are central to our codes of professional conduct, this is potentially problematic.

Context and background

The Cass Review was commissioned in light of growing concerns within the United Kingdom and internationally, about rapid change to epidemiology, clinical management of children and young people who present with gender dysphoria which can lead to irreversible interventions, and quality of the evidence base.

Current service provision in England comprises a single gender identity specialist service (GIDS) based at the Tavistock and Portman NHS Foundation Trust, with satellite bases in Leeds and Bristol. There has been recent and significant increase in numbers, change of demographic and increase in complexity of case-mix of children and young people presenting, from approximately 50 referrals per annum in 2009, mainly boys, to 2,500 per annum in 2020, now mainly adolescent girls. Within the current presenting cohort, there is an over representation of children and young people likely to grow up to be same-sex attracted, (Griffin et al 2021) those with neuro-diversities, co-morbidities and/or co-traumas (Koslowska et al 2021) and those who are looked-after (Mathews et al. 2019). The increase in number and complexity has outstripped capacity at GIDS, leaving children and young people in need and distress.

Historically, GIDs provided assessment and support to children. If puberty blockers were prescribed, this occurred when children reached pubertal development Tanner stage 5, at around age 15 years. In 1998, a new 'Dutch Protocol' introduced puberty blockers at Tanner stage 2, an earlier and predominantly younger stage of pubertal development. GIDS introduced the Dutch Protocol in 2011 as part of the 'Early Intervention Study' research protocol, and adopted it as routine clinical practice in

2014. However, unlike within the Dutch Protocol, GIDS did not incorporate the stricter requirements for psychological intervention, particularly if children presented with psychiatric or autistic related co-morbidities. Results of GIDS Early Intervention Study 5. were published in December 2021, and indicated that 98% of those prescribed puberty blockers also went onto receive cross-sex hormones, such as testosterone for girls and oestrogen for boys, which can result in irreversible bodily changes.

Interim findings

The review states that the service at GIDS has not been subject to some of the usual norms of clinical governance, research and evidence base expected, particularly when initiating new or innovative interventions for children. For example, although puberty blockers and cross sex hormones can lead to profound outcomes for children, including sterility, loss of sexual function, reduced bone density and with unknown impacts on cognitive development, the report highlights that use of such interventions occurred without audit, adequate clinical documentation or exploration for differential diagnoses and other co-existing causes of presenting distress. There was a lack of consistency of clinical approach and a culture in which an affirmative, non-exploratory approach of other causes of presenting distress predominate. Clinicians often felt pressure to pursue an affirmation approach, which is at odds of standard neutral psychotherapeutic explorative care, the norm for other clinical presentations. Linked to this, the report describes 'diagnostic overshadowing' in which once gender incongruence or related distress is identified, and children placed on the GIDS waiting list, there is no intervening engagement and support for children and young people by other healthcare services, including for the many other potential causes of presenting distress.

The wider culture environment in which the Review sits is acknowledged in the report and the polarisation of views regarding the management and treatment for these children, particularly in line with the potential irreversible nature of medical interventions. As such, the report urges for respectful and open dialogue to enable improvements in care. Similarly, the report makes specific reference to the role of social transition, e.g. change of name, pronouns and use of opposite-sex facilities,

commonly supported by parents, schools, society and advocacy groups, that it is not a neutral intervention, and links the extent of social transition to the desire of individual children and parents for an affirmative medical approach. In addition, 'doing nothing' for these children is also deemed not a neutral act.

A primary focus of the Review is to establish whether puberty blockers provide, as suggested by advocates, a valuable pause for children and young people which allows them to examine their options, or whether they 'effectively lock in' children and young people down a medical pathway to cross sex hormones and irreversible interventions. The interim report did not provide definitive advice on the use of puberty blockers and cross sex hormones, citing gaps and poor quality of current evidence base regarding the clinical effectiveness, cost effectiveness, safety and impact of these interventions on gender related distress and mental health, both nationally and internationally. Whilst there has been research into the short-term mental health outcomes and physical side effects of puberty blockers, there has been very limited research on the sexual, cognitive or broader developmental outcomes for children and young people of puberty blockers and cross-sex hormones, including over the long term. Of particular concern is a poor understanding of the changing epidemiology of gender distress, with a surge in predominantly girls presenting with gender dysphoria, and the 'very limited' availability of follow up data regarding children and young people receiving hormone treatment.

To address these shortcomings the Review's research programme will review and synthesise the current evidence base related to this changing epidemiology and the current medical and psychological management of gender-related distress in children and young people. To support a quantitative analysis of follow up data the UK Health Secretary has, after the publication of the Interim Review, announced changes to the Gender Recognition Act (2004) allowing previously confidential data from 9000 records of patients who accessed hormone therapy from 2009 to 2020 to be included in an analysis of intermediate and long-term outcomes of this intervention. It is hoped that filling the gaps in the existing evidence base will support informed decision-making and service commissioning and design.

Current interim recommendations include the closure of the national GIDS at the Tavistock clinic. In its place multi-regional centres will be set up, with staff training, competency mapping and collaboration with local services to ensure the provision of full clinical, psychological and social support for children and young people in early stages of gender-related distress. This includes national coordination of regional centres to ensure shared standards of operation, multi-disciplinary team management, and standardised data collection and audit to inform epidemiology, assessment and treatment. There is to be clear criteria for referral and requirement for formal diagnosis pre hormone treatment which addresses the child or young person's physical, mental, developmental and psychosocial wellbeing. This includes medical responsibility for exploring differential diagnosis, and full documentation of informed consent including clear communication to children and parents of likely outcomes, side effects and uncertainties of outcomes of medical interventions over the long term.

Implications for nursing

The closure of an internationally renowned centre is a deeply significant event which clearly indicates major concerns about the affirmative-only model of care conducted at the Tavistock and its approach to the prescription of puberty blockers. If nursing is a safety critical profession, then this is one of our greatest challenges and our profession's current discomfort with robust and critical discussion around gender dysphoria in children and young people is no longer tenable. Cass has made clear that this is everyone's business - our profession must begin to engage. In our view, and in keeping with our Code, this engagement must be based on evidence — Sackett's (2000) triad of research evidence, patient perspective and clinical expertise would be an excellent starting point. Unless we do so, we risk creating a generation of nurses whose understanding of this area is driven by lobby groups and based not on evidence, but on hearsay, activism, anecdote and ideology. These discussions need to take place in clinical practice and in university classrooms and offices.

They should focus on specific areas. First, we need to consider the evidence which indicates a rapid growth in the numbers of children and young people presenting with gender dysphoria. We should be curious about why this has occurred. We should

also explore the possible reasons for the over-representation of our most vulnerable children and young people, those with coexisting mental health problems and adverse life experiences, in this group. Exploration of the risks and benefits to different approaches to interventions must take place to ensure health and developmental outcomes are supported, and unnecessary medicalisation can be avoided. Here, it is especially important to acknowledge that known outcomes of medical interventions such as reduced bone density, sterility and loss of sexual function will have profound impacts on children and young people into adulthood, based on a scarcity of evidence, with little known about the other long-term outcomes of interventions for this specific and emerging population. Where long term outcomes have been examined, they report on a significantly different demographic. As well as the absence of evidence, our discussions also need to consider the quality of the evidence which is available. As registered nurses, whose practice is to be rooted within the evidence base, we are accountable for our actions and omissions - where interventions involve profound and irreversible change, we need to especially clear about this.

We know that discussion will feel daunting for many and that there are good reasons for this (Patrick, 2022). Our leaders in practice, in the academy, and in the world of academic publishing have an important role to play here. They can, if they choose, help to create an environment in which the exchange of ideas on this subject is normalised – we cannot develop our understanding and explore differences of position and the evidence base if each time we disagree we are accused of bigotry or hatred. Nor will we move forward unless we approach the topic in good faith and with a willingness to consider that we might be wrong. The health and well-being of a generation of children and young people is at risk – we cannot sacrifice this for the sake of ideology or for the personal comfort that comes from silence.

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