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Proper guidelines are needed for young people with gender incongruence

PERSPECTIVES

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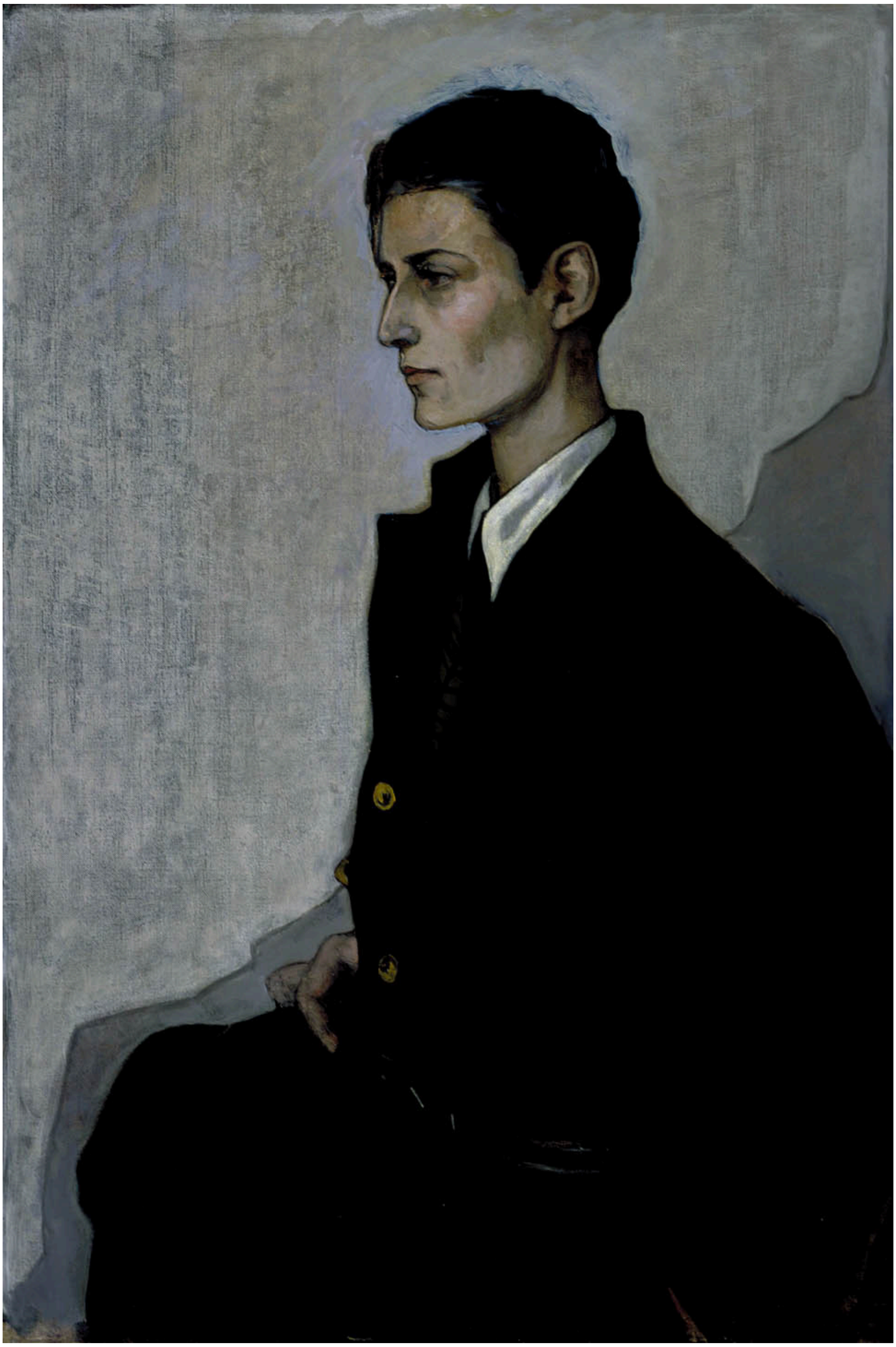
'Gender-affirming' medical treatment for children and young people with gender incongruence is associated with considerable uncertainty and serious risk. Existing guidelines fail to provide sufficient protection against potentially harmful interventions and lack the necessary support for prudent, conservative approaches in primary care.



Peter (A Young English Girl), 1923–24, Romaine Brooks (1874–1970). Smithsonian American Art Museum, in public ownership

As general practitioners (GPs) and community medicine specialists, we have observed with concern the growing number of children and young people presenting with gender incongruence. The need for a more nuanced medical discourse on this issue has long been recognised, but it has taken time to gather courage. The public discourse has been characterised by ideology, polarisation and considerable conflict, which has hindered efforts to engage in a balanced, evidence-based professional discussion on the subject.

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Many children and young people with gender incongruence request medical intervention during their first primary care appointment. However, both our clinical experience and the current evidence base indicate that these interventions lack robust empirical support and entail considerable health risks. For those of us in primary care, who are often the first point of contact, the guidelines are ambiguous and decision-making support is insufficient.

Primum non nocere

The treatment of children and young people with gender incongruence, including the use of hormone blockers to delay puberty, continues to be marked by significant disagreement among healthcare personnel and the wider medical communities (1–4). To outside observers, this disagreement could be perceived as a clash between ideological positions and legitimate medical concerns. While patients' experiences and feedback are undoubtedly valuable, we believe that medical decisions must first and foremost be based on thorough clinical and ethical evaluations of the available evidence, where potential risks are carefully weighed against documented benefits before new treatment approaches are implemented.

History provides numerous examples of the serious consequences that can result from disregarding this fundamental principle. A rigorous, evidence-based approach is particularly crucial when treating minors, and when the treatment in question is controversial due to concerns about severe side effects and uncertainty regarding long-term outcomes. Given the lack of professional consensus and the significant concerns about treatment safety and efficacy, it is essential that we, as doctors, uphold our responsibility to act as the patient's medical advocate.

In this role, we must not forget the most important principle of the Hippocratic Oath: *Primum non nocere* – first, do no harm. This also means that, based on assessments of justification, we may at times need to withhold certain treatments requested by patients or patient organisations. In such cases, it is pertinent to note that, under Section 4 of Norway's Health Personnel Act, doctors have the right to refuse involvement in treatments they deem medically indefensible.

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Effect and safety

Some studies, including those discussed in a previous article in the Journal of the Norwegian Medical Association (1), emphasise positive patient experiences and highlight the importance of relatively short-term outcomes. However, it is important to recognise that puberty blockers, in addition to the subsequent treatment with exogenous sex hormones (which the majority of those receiving puberty blockers eventually undergo (5, 6)), must still be considered experimental. There is currently insufficient clinical evidence of lasting health benefits, in terms of empirical data (7, 8) and systematic evaluations of study quality (9, 10). Existing studies are often characterised by methodological challenges such as considerable variation in study design, low scientific quality due to high dropout rates, relatively short follow-up periods, heterogeneous study populations and insufficient sample sizes to draw definitive conclusions (7–10).

Furthermore, hormone-modulating therapy can cause serious adverse effects such as infertility (11, 12), irreversible damage to the genital organs (13, 14), osteoporosis (15), dyslipidaemia, elevated haematocrit and an increased risk of cardiovascular complications (thrombosis, infarction and sudden death) (16–19). Patients who subsequently undergo surgery face additional risks of complications, including infections, haemorrhage, impaired wound healing and surgical side effects such as scar contractures, fistula formation, necrosis, urinary incontinence and voiding dysfunction, accompanied by psychosocial problems and chronic pain (20–23). Surgical removal of the native genitalia generally results in permanent sterility (24).

Although gender incongruence is no longer classified as a mental disorder, experience and research indicate that many of these children and young people also have mental health problems, and the high prevalence of psychiatric comorbidity is a major concern (25, 26). However, mental health is not always thoroughly evaluated before irreversible treatment interventions are initiated. In some cases, this can impair a patient's overall health, which several of us have encountered.

There are few longitudinal studies in this field. In a well-known Swedish study that followed 324 adults for up to 30 years (with an average follow-up of 10 years) after gender reassignment via hormone therapy and surgery, suicide rates remained high in the follow-up period (27). The overall rate was 19 times higher than that of age-matched controls, and 40 times higher among individuals who had transitioned from female to male.

A subsequent Swedish registry study (28) found evidence that surgical interventions, but not hormone therapy, improved mental health in individuals with gender incongruence. In response to criticism from the medical community, the editor-in-chief of the American Journal of Psychiatry (29), which published the study, prompted an independent statistical review. This review refuted the main conclusion of the original study. In a subsequent reanalysis, the authors compared two equal-sized groups with gender incongruence: one that had undergone surgery and one that had not (30). No significant long-term differences in mental health were found, and overall, the findings did not support the notion that 'gender-affirming' interventions have a documented positive long-term effect on mental health.

Regret after treatment

In addition to the precarious balance between treatment risks and the evidence supporting long-term outcomes, the reported incidence of regret following medical gender transition is also concerning. (31, 32). This regret is believed to be underreported in the literature due to high dropout rates in follow-up studies. The risk of regret is assumed to be particularly high among minors, as adolescents are still in the process of forming their identity and sexuality, and can therefore experience doubt (33, 34). Furthermore, many young people with gender incongruence are not mature enough to fully grasp the consequences of irreversible interventions, which complicates the process of obtaining valid informed consent (31, 32).

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Patients who undergo medical gender transition at a young age can encounter challenges related to intimacy and starting a family later in life (32, 34–36). Many still want biological children and traditional forms of sexual intimacy within relationships (35, 37, 38), which can be difficult to achieve for those who have undergone irreversible medical interventions resulting in a loss of reproductive function or fertility.

Are the guidelines justifiable?

In 2020, Finnish health authorities concluded that the evidence base for 'gender-affirming' medical treatment for minors is insufficient (39). As a result, Finland now only permits conservative interventions, primarily psychotherapy and psychosocial support. Medical interventions can only be provided within the framework of research studies to patients with early-onset symptoms and no psychiatric comorbidities (40).

In 2022, Sweden reached a similar conclusion and introduced restrictions due to inadequate documentation and concerns related to adverse effects on both mental and physical health (41, 42). In England and Wales, all use of puberty blockers for minors has been discontinued, and the use of hormone therapy has been severely restricted (43, 44).

While Finland, Sweden, England and Wales have moved away from 'gender-affirming' therapy for minors and now prioritise mental health interventions as the sole form of care permitted outside research settings (40, 42, 44), Norway has not followed suit. The Norwegian Directorate of Health's 2020 guidelines place an emphasis on patient involvement and decentralised health care, but they are unclear regarding the prioritisation of psychological support over medical treatment as the first-line approach (45). This is despite the fact that, in 2023, the Norwegian Healthcare Investigation Board (Ukom) explicitly recommended stricter practices and limitations on hormone-modulating therapy in children and young people (46).

Consequences of inadequate guidelines

It is concerning that Norwegian guidelines still do not explicitly restrict medical gender transition for minors. Particularly problematic is that the Norwegian Electronic Medical Handbook (NEL), used by most general practitioners (GPs), lists irreversible medical interventions without clearly communicating the weak evidence base and significant safety concerns. There is also a lack of evidence-based tools to support conservative treatment approaches, including psychoeducational and therapeutic interventions aimed at improving patients' emotional regulation, identity formation and social functioning, thus undermining the foundation for responsible and evidence-based decision-making in the health service.

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This creates several mutually reinforcing consequences: GPs lose the ability to offer balanced, informed and evidence-based guidance, and they lack the tools to implement appropriate conservative treatment. Referrals to the specialist health service are increasing, including for patients who request interventions with no medical basis. The threshold for initiating irreversible and high-risk procedures appears to be too low in some instances, partly due to inadequate guidelines. The school health service and the Educational and Psychological Counselling Service (PPT) also lack a sufficient knowledge base to provide nuanced and responsible advice to pupils, schools and families.

The lack of a medical basis in primary care also affects education. According to the LK20 curriculum, schools are required to teach gender, identity and sexuality from a young age, but many teachers lack the necessary medical and psychological understanding of gender incongruence. This risks promoting an oversimplified view of gender as a consequence-free choice and portraying treatment of gender incongruence as safe, straightforward and reversible.

In 2023, Ukom reported a marked increase in referrals for gender incongruence, particularly among teenage girls who identify as boys (46). Many have no prior history of gender dysphoria but develop symptoms during puberty. While the causes are complex, it is reasonable to consider whether school curricula and media influence, in the absence of a robust evidence-based framework, may be playing a role in this development.

Still an experimental treatment

Given the uncertain long-term outcomes and the risk of serious side effects, 'gender-affirming' medical treatment for minors must still be considered experimental.

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This highlights the need for a more restrictive clinical approach and clearer guidelines that emphasise the principle of *primum non nocere*. GPs and other healthcare personnel need tools that support the view that responsible care should primarily consist of psychoeducation, psychotherapy and social support, both to serve the best interests of the patient and to uphold standards of care within the health service.

The views expressed in this article represent the authors' professional judgements and personal opinions.

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