

What constitutes medically professional responsibility and diligent care for children and adolescents with gender dysphoria?

PERSPECTIVES

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Children and adolescents with gender dysphoria are a vulnerable group who need good health care. However, the Norwegian Directorate of Health's guidelines do not provide adequate recommendations in accordance with the requirements for professional responsibility and diligent health care.



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Gender incongruence refers to a mismatch between a person's assigned sex at birth and their gender identity or gender expression [\(1\)](#). Other terms in use are *transgender* (where a person's gender identity is the opposite of their assigned sex at birth) and *non-binary* (where a person does not identify as male or female). Discomfort in this regard is called *gender dysphoria*. In Norway, people over the age of 16 have a statutory right to self-determination of legal gender without a medical diagnosis.

Gender incongruence is not an illness [\(2, 3\)](#), but many people with gender incongruence experience minority stress and want greater acceptance of their gender expression and identity [\(4\)](#). Not all of them seek gender-affirming treatment or surgery.

In this article, I will discuss the knowledge base for hormone therapy for gender dysphoria in children and adolescents. Diagnosis and treatment of children and adolescents with gender dysphoria differ from that of adults, and those under the age of 18 are not normally eligible for surgical intervention. Below, I use the terms *gender dysphoria* and *patients* when associated to medical treatment.

Hormone therapy for children and adolescents

Gender-affirming hormone therapy (oestrogens or androgens) has long been in use, although mostly for adults [\(5\)](#). In Norway, adolescents over the age of 16 with long-term gender dysphoria have been offered gender-affirming hormone therapy to reduce the mismatch and discomfort they feel about secondary sex characteristics and their physical appearance. The assumed benefits in terms of

psychosocial health and suicide risk have been used to justify lifelong hormone therapy with possible irreversible effects on a person's body, sexuality, fertility and metabolism.

Puberty blockers (gonadotropin-releasing hormones) have been in use in the last few decades to treat gender dysphoria, with the aim of reducing the burden of undesirable puberty development and improving the starting point for subsequent gender-affirming hormone therapy (5). According to procedures prescribed in the so-called Dutch Protocol, hormone therapy is started in Tanner stage 2 of puberty (6, 7). Puberty blockers have been considered reversible hormone therapy, but questions are now being raised about irreversible effects, including on bone health, sexuality and fertility (8).

A vulnerable and complex group

In the last decade, there has been a substantial increase in children and adolescents seeking medical treatment for gender dysphoria (9), including in Norway. The increase is particularly seen among young people who are assigned female at birth and who developed gender dysphoria at varying ages, often as teenagers. Many of them identify as non-binary. The prevalence of neurodiversity (autism spectrum disorder and ADHD) and mental illness (anxiety, depression, suicidal ideation) is higher in this group than among their peers in the majority population (10, 11).

«Many adolescents who seek treatment for gender dysphoria experience minority stress in their daily life, have a substantial symptom burden and find their gender identity a significant challenge»

Many young people who seek treatment for gender dysphoria experience minority stress in their daily life (4), have a substantial symptom burden and find their gender identity a significant challenge. This group needs stable, supportive and competent health care. Those who do not meet the criteria for hormone therapy under the Dutch Protocol (6, 7) feel largely rejected by the public health service.

Gender diversity is not in itself a psychiatric illness, and a significant proportion of young people with gender incongruence do not have a mental illness or neurodiversity (11). We do not know how many of those have gender dysphoria and require treatment. In the International Classification of Diseases from 2019 (ICD-11), gender incongruence has been moved from the chapter on mental and behavioural disorders to a new chapter on conditions related to sexual health (2).

National guidelines on gender incongruence

The Norwegian Directorate of Health publishes national clinical guidelines with 'systematically developed advice and recommendations relating to the prevention, diagnosis, treatment and/or follow-up of patients, service users or diagnosis groups' (12). Recommendations in guidelines are supposed to be founded on knowledge-based practice generated from evidence-based, experience-based and service user-based knowledge (12). Relevant evidence-based knowledge is summarised as systematic reviews developed according to scientific standards (13).

The national clinical guideline for healthcare services for people with gender incongruence from 2020 was drawn up as a response to the government's action plan against discrimination based on sexual orientation, gender identity and gender expression (1). The intention was to affirm the provision of health services for people with gender incongruence. The guideline sets out the overarching organisation of tasks and functions in a decentralised, differentiated and comprehensive health service provision. There is limited emphasis on clinical details, but health care for children and adolescents under the age of 18, including medical assessment and hormone therapy, is described in a separate section (pp. 27–31). Many of the recommendations are adapted from health legislation, with an emphasis on patient rights. Reference is also made to the Health Personnel Act, which states that 'health personnel shall conduct their work in accordance with the requirements for professional responsibility and diligent care that can be expected based on their qualifications, the nature of their work and the situation in general' (14). For hormone therapy, interdisciplinary assessment is required by the Norwegian National Gender Identity Clinic.

The recommendations in the guideline mainly refer to consensus-based expert recommendations and selected empirical articles of varying methodological quality (5, 15, 16). One reference that recurs in the Norwegian Directorate of Health's guidelines and similar guidelines (1, 15, 16) is the Standards of Care (SOC) by the World Professional Association for Transgender Health (WPATH). The recommendations in version 7 of this guideline (2012) were criticised for lacking a scientific basis (5), and version 8 was subsequently published in 2022 (17). In this recent version, with 114 authors, 258 pages and approximately 1400 references, a number of recommendations on assessment, diagnosis and treatment of gender dysphoria are presented, including recommendations for children and adolescents. The document bears little indication of evidence-based methodology and lacks a systematic and critical assessment of the published material's relevance, methodological quality and grading of the strength of the recommendations (12, 18).

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The Norwegian Directorate of Health's guideline does not use high-quality, systematised research-based evidence of the short and long-term effects and risks as a point of reference. On the contrary, they note that 'documentation of treatment outcomes, adverse effects and prognosis for health care for people with gender incongruence is weak, and research has therefore been given less emphasis' (1, p. 33) – a remarkable argument in a national guideline which deals with, inter alia, potentially irreversible treatment for children and adolescents.

More restrictive recommendations in Sweden

Until recently, Sweden has taken a liberal approach to hormone therapy for children and adolescents with gender dysphoria. However, there are now indications that puberty blockers can cause delayed bone mass development, with uncertain normalisation following subsequent gender-affirming hormone therapy (19, 20). This has also raised new questions about psychosocial effects and cognitive development when using puberty blockers. The National Board of Health and Welfare in Sweden therefore decided to summarise the knowledge base and commissioned a systematic literature review (8, 21). The work was carried out according to the PRISMA standard (8, 13), a scientific methodology that was developed specifically for reporting reviews evaluating the effects of interventions.

A systematic literature search in seven research databases resulted in 9934 unique hits, which were reviewed systematically for relevance and quality. Twenty-four articles were included in the analysis. Most of the studies included people who had received both puberty blockers and gender-affirming hormone therapy. One study had a control group, but none of the studies were randomised controlled. GRADE methodology was used to assess the strength of the recommendations (22). The methodological quality was low, with risk of bias assessed as moderate to high in 18 studies and low or moderate in six. The 24 studies were small and attrition rates were high. Most of them were observational studies measuring the effects before and during treatment. Various diagnostic systems were used for participant inclusion.

Treatment programme procedures were not fully described in several of the studies and the follow-up time was limited. Current practice is mainly based on the Dutch Protocol, an observational study in which 55 young people were followed for an average of seven years (6, 7) – a population that differs in many ways from the major target group of today (23, p. 36).

The conclusion of the systematic literature review was that the evidence base is insufficient for assessing the effects of hormone therapy on psychosocial health (mental health, quality of life, suicidal ideation, gender dysphoria), cognitive

function (development and brain health), bone health (bone density compared to peers) and metabolism (body mass index, lipid profile, blood pressure, growth) in children and adolescents. Based on this, the National Board of Health and Welfare in Sweden presented new guidelines for health services for children and adolescents with gender dysphoria [\(21, 23\)](#):

' ... Despite the evidence base remaining virtually unchanged since the research base was first established in 2015, the previous strong, positive recommendations on puberty-blocking and gender-affirming interventions are now considered to be weak and negative.'

The evidence base is considered insufficient to determine the effects of puberty blockers and gender-affirming hormone therapy on gender dysphoria, psychosocial health and quality of life in children and adolescents, and the risks of such interventions probably exceed the expected benefits. Hormone therapy can be given in special cases if the criteria in the Dutch Protocol are met and treatment is established as part of a clinical trial (23, p. 10).

A similar process to that in Sweden is underway in the United Kingdom [\(24\)](#). In 2023, the Danish Health Authority will initiate a revision of the Guide on Healthcare related to Gender Identity [\(25\)](#). Targeted research is also underway in other countries with a view to strengthening the knowledge base for the treatment of children and adolescents with gender dysphoria [\(26\)](#).

Non-pharmacological treatment

Not all children with gender incongruence experience gender dysphoria. A considerable proportion of children who develop gender incongruence at a young age find their way back to a gender identity that matches their sex at birth [\(27\)](#). There is little empirical research on the stability of gender identity and on predictors of the persistence of gender incongruence [\(8\)](#). There is broad agreement that hormone therapy should not be given to prepubescent children [\(1, 15–17\)](#), but increasingly younger children are being given hormone blockers because the age for the Tanner 2 stage of puberty is falling. It is uncertain what proportion of these proceed with gender-affirming hormone therapy, and what proportion of these subsequently terminate the therapy [\(8\)](#).

«Regardless of whether a person's gender incongruence persists or not, there may be a need for long-term psychosocial support»

There is international consensus that conversion therapy (an intervention that seeks to change a person's gender identity) is a violation of professional ethics. Regardless of whether a person's gender incongruence persists or not, there may be a need for long-term psychosocial support. Relevant experience-based recommendations for assessment and follow-up are found in Standards of Care version 8 and in the new Swedish guidelines [\(17, 23\)](#). Here the emphasis is on evaluating psychiatric comorbidity and neurodiversity, which require additional attention. The Swedish guidelines highlight the importance of support for 'an unconditional exploration of gender identity', which is also

described in a qualitative interview study with experienced Norwegian psychologists (28). Standards of Care version 8 has a focus on continuity, accessibility and interdisciplinary collaboration with expertise in developmental psychology, culture and diversity (17), as a basis for negotiating follow-up strategies that enable children and adolescents to live in accordance with their gender identity in their daily life.

Non-binary gender identity

Until recently, gender incongruence has been perceived as a binary phenomenon, where a person's gender identity is the opposite of their sex assigned at birth. Medical interventions were referred to as gender reassignment, and the terms *born in the wrong body*, *transsexuality* and *transgender* have been used. More and more people, however, are identifying outside the binary categories of gender, where neither male nor female are recognised as a relevant alternative. The prevalence of non-binary gender identity is uncertain and culture-dependent, but it probably includes an increasing proportion of people with gender incongruence, especially adolescents. Little is known about the stability and persistence of a non-binary gender identity.

«Self-determined legal gender can be a reversible contribution to preventing irreversible medical treatment»

People who identify as non-binary are a heterogeneous and vulnerable group who appear to be exposed to even more social pressure and mental illness than people with binary gender incongruence (29). Wishes and needs for treatment vary. For some, the most important thing is to be respected in terms of name, pronouns and formalities, and self-determined legal gender can be a reversible contribution to preventing irreversible medical treatment. Many young people who identify as non-binary experience rejection from the health service.

The evidence base for hormone therapy and/or surgery for this group is almost non-existent (23), but in Standards of Care version 8, individually customised medical interventions in the form of low-dose hormone therapy (oestrogen/testosterone) and/or body adjustment surgery are still recommended (mastectomy) (17). The National Board of Health and Welfare in Sweden states that there is a need to explore the prerequisites for offering adolescents who identify as non-binary hormone therapy in a clinical trial (23). Both guidelines strongly emphasise the importance of competent psychosocial assessment and support in an open and safe environment for adolescents who identify as non-binary. One prerequisite for appropriate health care is that the patient's experiences and preferences are acknowledged and form a basis for growth and development (28).

Informed consent – unrealistic?

Informed consent is considered essential for all medical practice, including hormone therapy for children and adolescents with gender dysphoria (1, 15–17). However, the conclusion of the Swedish literature review breeds doubt about whether informed consent is at all possible. Patients and their families must be informed of the possible short and long-term effects and risks when treating children and adolescents in a life phase characterised by physical, psychological and cognitive development. This requires their doctor to have sufficient knowledge of the subject.

It may seem logical that the quality of life of patients with gender dysphoria who are at an increased risk of suicide improves following gender-affirming or body adjustment therapy. This raises important questions about the potential risk of withholding such treatment. However, these treatment strategies have not been subjected to the scrutiny that is otherwise considered mandatory in the health service in Norway, and there is insufficient evidence that the treatment reduces the risk of suicide, gender dysphoria and mental health problems (23).

Many people were surprised when the Swedish health authorities declared that the efficacy and safety of hormone therapy, which was introduced several decades ago, is unknown (23). Healthcare personnel – including myself – who have relied on their own experience and the World Professional Association for Transgender Health's recommendations (17) probably felt they were on solid professional ground, not least because the Norwegian Directorate of Health's guidelines from 2020 confirms such practice (1). In 2022, the National Board of Health and Welfare in Sweden stated that it is primarily the assessment of the evidence base that has changed in light of current assumptions about evidence-based practice (23). The risk of potentially irreversible interventions for children and adolescents is weighed more heavily than the possible effect, which lacks robust research documentation and critical assessment.

Several of the studies included in the Swedish systematic review are also found in the reference list for Standards of Care version 8. The methodological quality of the two literature reviews differs significantly in terms of the strategy for sources, searches, samples and evaluating references, and, not least, the systematic review and grading of the strength of the recommendations. Several sections in Standards of Care version 8 give the impression that the recommendations are drawn up first and then supported with a selection of references; a strategy that does not meet contemporary methodological standards and is often referred to as cherry-picking. The UK health authorities also base their ongoing review of this issue on methodological principles for evidence-based practice (24).

Revised guidelines – new challenges?

In Norway, the health service must ensure that the patient rights of children and adolescents with gender incongruence are met (1). The Norwegian Directorate of Health's guidelines may have been interpreted as establishing a legal right to hormonal or surgical interventions for people with gender incongruence. However, health services for children and young people with gender dysphoria must meet the law's requirement for clinically justified and compassionate health care (14). The guidelines state: 'Service user involvement in a medical context does not entail a right to self-determined treatment choice or degree of urgency' (1, p. 4).

Patient participation cannot overrule responsible treatment strategies. How then can we ensure that the service provision is professionally responsible and is perceived as diligent by a particularly vulnerable patient group?

«Patient participation cannot overrule responsible treatment strategies»

The Swedish systematic literature review reveals a need for a revision of the Norwegian Directorate of Health's guidelines for treating gender incongruence (8). To start with, the issue of hormone therapy for children and adolescents with gender dysphoria must be put on the agenda. When revising the guideline, a clearer distinction should be made between recommendations for clinical practice and issues related to the organisation of the health service. There are also numerous challenges related to evidence-based treatment practices for gender dysphoria in adults and to medical treatment for non-binary gender incongruence at all ages.

Key dilemmas must be clarified if the Norwegian health authorities are to recommend treatment practices that follow the Swedish pattern. One example is the further management of hormone therapy that has already been started, with professionally responsible procedures that can reassure patients, parents and therapists. If hormone therapy is only to be offered to children and adolescents with gender dysphoria in special cases as part of a clinical trial or as experimental treatment, the design and execution of the studies must be quality assured, preferably as part of a Nordic cooperation. The source data entered in patient registers must comply with the criteria for prospective register-based studies, and not only function as a quality register. They must also include data on gender identity persistence and on treatment that is terminated. Systematic reviews are necessary to assess effects, but they do not provide all the knowledge that is needed. There is also a need for qualitative studies of the experiences of patients and practitioners.

What now?

The non-pharmaceutical service provision for children and adolescents with gender dysphoria needs to be strengthened considerably. Thorough assessment, psychosocial support for the unconditional exploration of gender identity and long-term follow-up must be provided in order to reassure patients and parents, regardless of whether gender incongruence persists or not. Diagnostic clarification of gender dysphoria in children and adolescents requires robust interdisciplinary expertise and coordination, and is therefore centralised at a national level in other countries. In Norway, GPs can be an important resource for the ongoing follow-up of children, young people and their families, but only if specialised services take responsibility and have the capacity for evaluation, guidance and stable professional support.

A public health effort for a society that is open to gender diversity is at least as important as good health services (3). If people are allowed to be who they are to a greater extent, within or beyond established gender categories, minority stress and the need for medical treatment can be reduced.

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