

Care of children and adolescents with gender dysphoria

Summary of national guidelines
December 2022

Summary

The National Board of Health and Welfare has been commissioned by the Swedish government to update the national guidelines entitled Good care of children and adolescents with gender dysphoria, published in 2015 [1]. The parts of the guidelines have been updated and published in stages. This is a summary of the final report published in December 2022, which contains the updated guidelines in its entirety, and thus replaces both previous interim reports and the guidelines from 2015.

For decision-makers

For several years, care for people with gender dysphoria has been characterised by accessibility problems and inadequate knowledge about the results of treatments. The National Board of Health and Welfare emphasises the importance of decision-makers in the health regions acting to promote improvement on both issues, and stresses that this needs to happen in the near future.

Young people suffering from gender dysphoria need to be promptly assessed and offered appropriate treatment measures, based on health care needs assessments. Good psychosocial care is essential. The patient group is heterogeneous and psychosocial care needs to clearly include young people with a non-binary gender identity. Gender-affirming treatments need to be offered when these are deemed indicated.

The 2015 guidelines stressed the importance of monitoring and evaluating the treatment interventions offered in the context of clinical work. The quality registry (gender dysphoria registry) that was planned at the time has so far not been able to meet existing needs. It is urgent that the health regions act to ensure that systematic documentation and monitoring of care at national level are realised. Longitudinal data are required to provide a coherent picture of this patient population, from referral to any diagnosis of gender dysphoria and with follow-ups of patients that are offered various treatment interventions.

The Swedish Agency for Health Technology Assessment and Assessment of Social Services (SBU) concludes that existing scientific evidence is insufficient for assessing the effects of puberty suppressing and gender-affirming hormone therapy on gender dysphoria, psychosocial health and quality of life of adolescents with gender dysphoria [2]. Knowledge gaps need to be addressed and the National Board of Health and Welfare recommends that these treatments be provided in the context of research. Here too, the health regions have a responsibility to provide support so that relevant research can begin in the near future. Research questions that need to be answered for the healthcare area are listed in the SBU's database of knowledge gaps. Priority needs to be given to studies that can answer the salient questions, as far as possible.

Caution in the use of hormonal and surgical treatment

At group level (i.e. for the group of adolescents with gender dysphoria, as a whole), the National Board of Health and Welfare currently assesses that the risks of puberty blockers and gender-affirming treatment are likely to outweigh the expected benefits of these treatments. The National Board of Health and Welfare therefore gives the following weak, negative recommendations as guidance to the healthcare system:

- Treatment with GnRH analogues, gender-affirming hormones, and mastectomy can be administered in exceptional cases.

Care must be provided on the basis of scientific evidence and proven experience and according to the principle of doing good and not harm. In revising its recommendations, the National Board of Health and Welfare has taken account of the fact that the efficacy and safety, benefits and risks of treatments are not proven [2] and that three factors have shifted the balance between benefit and risk in a negative direction:

- The uncertainty resulting from the lack of clarity about the causes, that the number of people diagnosed with gender dysphoria has continued to rise since the publication of the guidelines in 2015, particularly in the 13 to 17 age group and especially among people whose registered sex at birth is female.

- The documented prevalence among young adults of medical detransition, which is the process by which a person discontinues gender-affirming medical treatment for any reason or seeks to reverse the medical effects of completed gender-affirming treatment [3, 4]. According to the SBU, it is not possible to assess how common it is for young people to later change their perception of their gender identity or to discontinue a gender-affirming treatment [2].
- The experience-based knowledge of participating experts is less uniform than it was in 2015.

Decisions on treatment in an individual case

To guide the decision on puberty-suppressing treatment for an adolescent in Tanner Stage 3 and for gender-affirming hormone therapy, the National Board of Health and Welfare recommends the criteria whose use has been documented and monitored within the framework of the “Dutch protocol” [5-7]. The criteria include the existence of the incongruence since childhood, the stability of gender identity over time, clear distress caused by the onset of puberty, and the absence of factors that complicate the diagnostic assessment. According to the participating experts, puberty-suppressing treatment can in some cases be considered to be of great benefit even in Tanner stages 4 and 5, particularly for young people with a registered sex of male at birth whose masculinisation in later puberty makes it very difficult to pass as an adult.

The documented experience with the Dutch protocol includes only adolescents with binary gender identity, and among participating experts there is a lack of clinical experience with puberty-suppressing and gender-affirming hormone therapy for adolescents with non-binary gender identity. The National Board of Health and Welfare notes that there is a lack of knowledge to guide decisions on hormonal treatments for adolescents with non-binary gender identity, but still believes that gender dysphoria rather than gender identity should guide access to care and treatment. Urgent work that remains when updating the guidelines for adults with gender dysphoria [8] is to map the experience of assessment and gen-

der-affirming treatment for patients with non-binary gender identity in adult health care.

Other recommendations

Other recommendations include that health services should:

- Offer psychosocial support for unconditional exploration of gender identity during the diagnostic assessment. As in 2015, the National Board of Health and Welfare emphasises exploration as a prerequisite for good and safe care.
- Systematically search for signs of autism spectrum disorder (ASD) and ADHD/ADD before, or at an early stage of the assessment. In case of signs of ASD, neuropsychiatric assessment should be initiated.

The recommendations of the National Board of Health and Welfare remain as before, that the health care system should offer the following measures to adolescents with gender dysphoria:

- Sexology counselling and treatment
- Fertility preservation
- Voice and communication treatment
- Hair removal

The expected benefit to patients of the measures are considered high and the risks comparatively low. It is important that these measures are also documented for follow-up when they are offered, in order to enable increased and comprehensive knowledge regarding the patient group and care.

References

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