Policy Change Regarding Hormonal Treatment of Minors with Gender Dysphoria at Tema Barn - Astrid Lindgren Children's Hospital.

Background

The hormonal treatment of children and adolescents with gender dysphoria may consist of puberty-blocking treatment initiated at the onset of puberty, and cross-sex hormones initiated at the age of 16. These treatments are controversial and have recently become subject to increased attention and scrutiny both nationally and internationally. In December 2019, the SBU (*Swedish Agency for Health Technology Assessment and Assessment of Social Services*) published an overview of the knowledge base which showed a lack of evidence for both the long-term consequences of the treatments, and the reasons for the large influx of patients in recent years. These treatments are potentially fraught with extensive and irreversible adverse consequences such as cardiovascular disease, osteoporosis, infertility, increased cancer risk, and thrombosis. This makes it challenging to assess the risk / benefit for the individual patient, and even more challenging for the minors and their guardians to be in a position of an informed stance regarding these treatments.

A highly publicized court case in Great Britain shed light on this issue and in a recent ruling (December 1st, 2020), established overarching problems associated with puberty-blocking treatment. Further, the ruling specifically establishes that it is highly unlikely, if at all possible, for an individual under the age of 16 to give informed consent to this treatment. For individuals between the age of 16 and 18, the court considers it advisable to request court approval before starting hormonal treatment, since the treatment should be considered experimental. As a result of this ruling, the NHS (National Health Service) put an end to initiating hormonal treatments in new cases of individuals under 16, while recommending a thorough review of ongoing, actively treated cases. For patients between ages 16 and 18, it is recommended that the treating physician receives court approval before cross-sex hormones are initiated.

Executive Decisions

- In light of the above, and based on the precautionary principle, which should always be applied, it has been decided that hormonal treatments (i.e., puberty blocking and cross-sex hormones) will not be initiated in gender dysphoric patients under the age of 16.
- For patients between ages 16 and 18, it has been decided that treatment may only occur within the clinical trial settings approved by the EPM (*Ethical Review Agency/Swedish Institutional Review Board*). The patient must receive comprehensive information about potential risks of the treatment, and a careful assessment of the patient's maturity level must be conducted to determine if the patient is capable of evaluating, and consenting to, the treatment.

- These changes do not affect the continued psychological and psychiatric care within BUP (Public child and adolescent psychiatry) for patients under 18 years of age.
- These changes apply from April 1, 2021.

For patients currently treated with puberty blockade or cross-sex hormones, a careful individual assessment to determine whether treatment should be stopped or continued must be performed by the treating provider. During this assessment, it is important to present appropriate information about the uncertainty in the state of evidence regarding long-term effects and potential risks of the treatment, in order to make it possible for patients and guardians to make as well-informed decisions as possible about consenting to a potential continued treatment. The young patients' degree of maturity and ability to consent, as well as other indications should factor into these decisions.