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Early Medical Treatment of Children and Adolescents With Gender Dysphoria: An Empirical Ethical Study

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A B S T R A C T

Purpose: The Endocrine Society and the World Professional Association for Transgender Health published guidelines for the treatment of adolescents with gender dysphoria (GD). The guidelines recommend the use of gonadotropin-releasing hormone agonists in adolescence to suppress puberty. However, in actual practice, no consensus exists whether to use these early medical interventions. The aim of this study was to explicate the considerations of proponents and opponents of puberty suppression in GD to move forward the ethical debate.

Methods: Qualitative study (semi-structured interviews and open-ended questionnaires) to identify considerations of proponents and opponents of early treatment (pediatric endocrinologists, psychologists, psychiatrists, ethicists) of 17 treatment teams worldwide.

Results: Seven themes give rise to different, and even opposing, views on treatment: (1) the (non-) availability of an explanatory model for GD; (2) the nature of GD (normal variation, social construct or [mental] illness); (3) the role of physiological puberty in developing gender identity; (4) the role of comorbidity; (5) possible physical or psychological effects of (refraining from) early medical interventions; (6) child competence and decision making authority; and (7) the role of social context how GD is perceived. Strikingly, the guidelines are debated both for being too liberal and for being too limiting. Nevertheless, many treatment teams using the guidelines are exploring the possibility of lowering the current age limits.

Conclusions: As long as debate remains on these seven themes and only limited long-term data are available, there will be no consensus on treatment. Therefore, more systematic interdisciplinary and (worldwide) multicenter research is required.

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IMPLICATIONS AND CONTRIBUTION

This study shows large differences in the moral evaluation of using puberty suppression in children and adolescents with gender dysphoria. Current policies are predominantly expert opinion based because only limited long-term data are available. Nevertheless, increasing numbers of treatment teams embrace early treatment and explore lowering age limits.

Conflicts of Interest: There are no potential conflicts, real and perceived, for all named authors.

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Gender dysphoria (GD) is a condition in which individuals experience their gender identity (the psychological experience of oneself as male, female, or otherwise) as being incongruent with their phenotype (the external sex characteristics of their body) [1]. The most extreme form of GD, often called transsexualism, is accompanied by a strong wish for gender reassignment [2]. Of the individuals experiencing GD, a small number is children.

Only in a minority of prepubertal children, GD will persist and manifest as an adolescent/adult GD. The percentage of “persisters” appears to be between 10% and 27% [3–5]. Treatment for prepubertal children therefore is predominantly psychological. However, those children who still experience GD when entering puberty, almost invariably will become gender dysphoric adults [6]. These young adolescents may demand hormonal interventions such as puberty blockers (gonadotropin-releasing hormone agonists) to suppress the development of secondary sex characteristics. In recent years, the possibility of puberty suppression has generated a new but controversial dimension to the clinical management of adolescents with GD. The purpose of puberty suppression is to relieve suffering caused by the development of secondary sex characteristics, to provide time to make a balanced decision regarding the actual gender reassignment (by means of cross-sex hormones and surgery) and to make passing in the new gender role easier [7]. In the Netherlands, puberty suppression is part of the treatment protocol and as a rule possible in adolescents aged 12 years and older who are past the early stages of puberty and still suffer from persisting GD. When there are good reasons to treat an adolescent before the age of 12 years, for example, because of the height of the adolescent, treatment at a slightly younger age is acceptable.

Although an increasing number of gender clinics have adopted this Dutch strategy and international guidelines exist in which puberty suppression is mentioned as a treatment option [8,9], many professionals working with gender dysphoric youth remain critical [10,11]. Concerns have been raised about the risk of making the wrong treatment decisions and the potential adverse effects on health and on psychological and psychosexual functioning. Proponents of puberty suppression, on the other hand, emphasize the beneficial effects of puberty suppression on the adolescents’ mental health, quality of life, and of having a physical appearance that makes it possible to live unobtrusively in the desired gender role [12].

Strikingly, in this debate, proponents and opponents of puberty suppression use the same ethical principles (autonomy, beneficence, nonmaleficence) but interpret them in totally different ways. Ethical discussions are often held on the level of these ethical principles only, with moral intuitions moving between extremes; for example, puberty suppression as a blessing versus treatment as an evident danger or a definite competence of the child versus incompetence because the child is simply too young and has an immature developmental level to decide on these substantial issues. What is missing in the discussions is an exploration of underlying ideas and theories about the nature of gender (dichotome or fluid) and GD (mental illness or social construct), child welfare, and child competence. Proponents and opponents seem to have different views on these issues, often without openly stating them. It is an essential task to elucidate these underlying ideas and theories because they substantially influence the judgment on GD treatment.

Strikingly, in the literature on GD, most of the times, only proponents give arguments for their treatment position. It is difficult to find arguments against the use of puberty suppression as a treatment option as opponents rarely publish in professional journals. Therefore, to date there is no clear overview of the considerations of proponents and opponents regarding the use of early medical interventions in GD. An overview explicating considerations, which underlie the different views on puberty suppression, could be the first step toward a more consistent approach recommended by health care professionals across

different countries. The aim of our study was to explicate the considerations of proponents and opponents of puberty suppression to move forward the ethical debate.

For this purpose, we have performed an empirical ethical study to answer the following questions: (1) what are the moral intuitions (direct thoughts or opinions) of informants on puberty suppression in GD; (2) what are the (underlying) ideas, assumptions, and theories of informants about the etiology of GD, and the concepts “gender,” “child competence,” and “best interests”?; and (3) do moral intuitions, ideas, and theories of proponents of puberty suppression differ from those of opponents, and in what sense?

Methods

An empirical ethical approach was followed, using a qualitative interview and questionnaire study. The study was approved by the institutional review board of the Leiden University Medical Centre.

Fifteen professionals participating in the study were interviewed face-to-face, six by using Skype (Microsoft Corp., Redmond, WA). Some treatment teams indicated that they did not master the English language well enough for a direct interview. These teams were offered similar questions in a questionnaire by e-mail. The questionnaire was filled in by 15 professionals. The empirical data were obtained between October 2013 and August 2014.

Initial interview topics were formulated after examination of the relevant literature. In accordance with qualitative research techniques, the interview topics evolved as the interviews progressed through an iterative process to ensure that the questions captured all relevant emerging themes [13,14]. The interviews contained general topics and no close ended questions.

The informants were child and adolescent psychiatrists, psychologists, and endocrinologists from diverse treatment teams in European and North American countries. Two Dutch ethicists, who are not directly related to a treatment team, were also interviewed. The treatment teams were purposefully selected on the basis of their stance in favor or against puberty suppression in the past. Interestingly, at the time this study was initiated, puberty suppression was not part of the treatment protocol for adolescents of several treatment teams. However, during this study, puberty suppression did become part of the treatment protocol of some of these teams. When interviewing these teams, extra emphasis was placed on the arguments they used to justify these treatment changes. The 36 professionals who participated in this study worked in 10 different countries (Figure 1).

An extensive description of the analysis of the data is given in Appendix A, which can be found online.

Results

From the literature, interviews, and questionnaires, seven themes emerged that lead to different, and sometimes even opposing, views on the treatment of adolescents with GD. Representative quotations were chosen to illustrate the themes identified.

The availability or nonavailability of an explanatory model for gender dysphoria

With regard to the causes of GD, no single cause has been found so far. In the literature, genetic, hormonal, neurodevelopmental,

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