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TMJ Blogs

Controversies in the treatment of children with gender dysphoria

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Over the years, the lay press has maintained an interest in the treatment of children with so-called gender dysphoria (GD). This reached a peak in a series of articles in the Weekend Australian of 18-19 February 2023. The issue included 3 detailed articles (pp 1, 11, 24) plus an editorial, on the courses of historic treatment available for gender reassignment in children under the age of 16 at the Tavistock Clinic (London) and Westmead Hospital (Sydney). The articles followed publication of a book describing the history and fate of the Tavistock Clinic by Hannah Barnes,[1] a senior journalist at the BBC, and of a recent academic paper[2] from Westmead Hospital Sydney, the University of Sydney and Harvard Medical School. The paper is based on a "naturalistic" follow-up study of 79 patients aged under 16 years referred to the Department of Psychological Medicine at the hospital for assessment of gender dysphoria and possible "gender affirming" treatment. Both these publications cast doubt on the historical "one size fits all" approach to this group of highly vulnerable patients. In this model, children are offered puberty blockers using gonadotrophin releasing hormone (GnRH) agonists, and may progress at a later age to drug-induced gender reassignment and, on attainment of adulthood, to surgery. The individuals must consent at each stage but there is doubt as to the ability of those under 16 to understand the complex issues they face, that is, there is doubt as to their capacity to give informed consent. The percentage of patients who proceed to gender reassignment from puberty blockade is moderate at best but the precise proportion is uncertain.

Surprisingly, none of the Weekend Australian articles mentioned detailed judgements made by the Family Court in Australia and the Supreme and District courts in the UK that are highly relevant, but potentially leave undetermined the answers to the many questions that arise. For example: Can children under 16 give valid informed consent for puberty blockers, given the immaturity of brain development? Has the use of drugs in gender dysphoria in children been shown to be effective in clinical trials, the gold standard of evidence in drug therapy? Both the Barnes book and the Elkado study suggests otherwise. If NO, is the use of drugs in controversial medical circumstances without trial evidence ethical? The Australian National Statement on Ethical Conduct in Human Research[3] is silent on this issue, being focused on the ethical conduct of *research*. Thus the questionable practice of experimental drug therapy on an on-going basis in the absence of an adequate research base is under-recognised. Though examined in court judgements, the usual conclusion is that the matter is for hospital authorities and the medical profession to resolve. Is the off-label use of the drugs such as puberty blockers with potential serious side-effects in children lawful? Drugs are often and justifiably used off-label in many areas but this case is difficult to justify. Do the possible likely adverse effects of the treatments on future fertility and sexual health receive the weight they deserve? Is the psychiatric formulation that assigns primary status to gender dysphoria and secondary status to other coexisting psychiatric conditions such as autism reliable? When two distinct psychological conditions co-exist, which is the cart and which is the horse? What is the relationship between gender dysphoria and sexuality?

The Westmead study[2] followed the authors' recognition that the evidence base for the treatment model in 2014 was "sparse". As may be expected from an uncontrolled observational study with progressive selection criteria, several outcomes are possible. The authors reviewed the outcomes in 79 of 108 young patients who had diagnostic assessment and agreed to participate, out of 128 patients who had screening assessment including puberty staging and were referred to the Psychological Medicine team, out of 484 referred to the Gender Service between December 2013 and November 2018. Thus the 79 patients were a minority of the total (16%) and may not have been representative. The reviews were conducted between November 2022 and January 2023. The length of follow-up ranged from 4 to 9 years; the mean is not stated. Sixty-six of 79 met the DSM-5 criteria for GD initially, but 2 of 13 were deemed subsequently to have the condition. One patient who had precocious puberty was excluded. Of the resulting 67 patients, 49 (73%) had been started on puberty blockers and of these 38 progressed to receiving cross-

sex hormones. However, this group also included 11 who tracked to stage 2 directly plus two who did so but did not meet the DSM-5 criteria, with a total of 51 patients, including 20 under the age of 16 years. The authors suggest that since access to cross-sex hormones in NSW is restricted to patients over 16, they were provided by "unregulated sources". Of the 51, 3 desisted from further medical treatment and only 6 (12%) had progressed to stage 3 (surgery), though 5 were considering surgery at the point of follow-up. These numbers may have been affected by background changes in NSW legislation that occurred during 2017.

The authors also report on side effects of GnRH agonists, which included low bone density (undefined), hot flushes, weight gain, anxiety, and discomfort at the site of injection.

Interpretation of these data is difficult but the provision of cross-sex hormones from presumed unregulated sources in 39% of patients at stage 2 who were under 16 is truly alarming. The authors of the article clearly have great insight into the needs of their patients and appear to offer exemplary levels of support. They are nevertheless concerned that an unstated proportion of the patients come to regret their previous decions to enter the treatment pathway and argue in favour of continuing psychiatric assessment. They also caution that treatment may be started in patients too young to fully understand their situation and to give informed consent, and that the effect of puberty blockers may not be fully reversible.

Unfortunately the answers to the question raised here and in the above paper (and many others) remain uncertain, but the duty to protect children is absolute. We have reservations over the management of gender distress in children under 16 on the grounds of potential net harm and suggest that a major judicial review of the area is required to resolve the complex issues arising.

References

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