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Early puberty, medicalisation and the ideology of normality



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SYNOPSIS

Healthy girls with early puberty are sometimes given gonadotropin-releasing hormone agonists (GnRHAs) to delay their pubertal development until they reach an average age of onset. Feminist research has called this treatment into question, arguing that age at puberty should be seen in terms of diversity rather than normality and abnormality. In support of this feminist position, it is argued that treatment has been justified by an ideology that medicalises healthy girls to make them “normal.” This core objective has been linked to increasing final height, reducing psychosocial difficulties, delaying sexual activity and reducing the risk of abuse. All of these auxiliary treatment objectives have been justified by being fitted to evidence rather than tested against it, and all are problematic. Side effects of GnRHAs, including reduced IQ, have not been properly addressed, the alternative of providing girls with support has been little considered, and the rights of the girls are not recognised.

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Introduction

What should be done when a girl begins puberty at a surprisingly young age? One way to address this question is to consider how family members and others in the child's circle can re-relate to her in ways that support and accommodate her early maturation. In the field of medicine, however, an opposite approach has been taken, one that puts the onus of changing on the child to ensure that she fits into a typical puberty timeframe. This change is effected by using a powerful pharmacological intervention to arrest the child's pubertal development.

Gonadotropin-releasing hormone agonists (GnRHAs) suppress the production of sex hormones. After being extensively and sometimes corruptly marketed (Department of Justice, 2001), GnRHAs are now widely prescribed in various treatments of adults. The drugs are also prescribed for children, where they are highly effective in halting puberty; sometimes they put it into reverse. Any girl with pubertal onset under the age of 8 years is categorised as having “precocious” puberty and is eligible to take GnRHAs. Girls starting puberty at an older age are also sometimes prescribed the drugs off-label. By far the most common form of this supposed medical condition occurs in girls aged 6 years and over (Herman-Giddens, Slora, Wasserman, et al., 1997). For about 90% of these girls, there is

no apparent cause (BMJ Best Practice, 2014). Once girls are placed on a GnRHa they are usually continued on it until they are aged around 11 years; a review of 30 studies found mean age at treatment discontinuation ranged from 10.6 to 11.6 years (Carel, Eugster, Rogel, et al., 2009). Eleven years is slightly above the mean age of pubertal onset for girls in most countries (Parent, Teilmann, Juul, et al., 2003).

The use of GnRHAs to delay puberty was first reported by Comite, Cutler, Rivier, et al. (1981) in a preliminary case series of 5 girls. The study identified the purposes of GnRHa treatment as increasing final height by allowing extra time to grow before bones fused, and preventing “adverse psychosocial effects” (Comite et al., 1981: 1546). The study also stated that some untreated children with precocious puberty needed contraception, with the implication that treatment guarded against early sexual activity. The advisability of GnRHa treatment was quickly challenged by MacGillivray (1982), who raised concerns over side effects, questioned the need for height treatment, and reported on the satisfactory psychological adjustment to puberty by girls given support from their parents and physician. Comite (1982) contested these reservations, others ignored them, and a research programme got underway to measure outcomes for children given GnRHa treatment. In accepting Comite's position over MacGillivray's, the field of

paediatric endocrinology was following an established path. A culture of medical intervention to restore “normality” in girl's development was already in place. Since the 1940s, tall girls had been treated with oestrogen to reduce final height (Lee & Howell, 2006). Since the 1960s, girls with early puberty had been treated with medroxyprogesterone acetate (MTA). This drug also suppresses pubertal development in girls, although it does not increase final height (Kaplowitz, 2004).

Paediatric use of GnRHs has subsequently become well established in Europe and in North America and is increasing worldwide (Thornton, Silverman, Geffner, et al., 2014), with considerable research now being carried out in new markets in Asia (e.g., Tascilar, Bilir, Akinci, et al., 2011; Wang, Liang, Liu, et al., 2014). Some doctors have warned that GnRH treatment can be over prescribed (Kaplowitz, 2004; Rosenfield, 1994; Rosenfield, Bachrach, Cherausek, et al., 2000). However, provided discretion is used, pharmacological intervention to prevent early puberty appears to be widely accepted as legitimate by the medical profession, with GnRH treatment said to be its “gold standard” (Bertelloni and Baroncelli, 2013).

The most comprehensive scrutiny of GnRH treatment of early or precocious puberty has come from Roberts (2015). In her feminist critique, Roberts has argued that treatment is embedded in a network of interests and should not be accepted uncritically. She has suggested that given the complexities of height prediction, justifications for treatment that link early puberty to reduced height may be reductive, and she has questioned whether early puberty and psychosocial phenomena should be linked in cause and effect terms. Roberts has also argued that medical discourse characterises the range of development in children's bodies in terms of normality and abnormality rather than diversity, and that medical practise has focused on making girls more “normal,” rather than living better with this diversity. Roberts suggests that for girls with early puberty “supportive acceptance and even celebration of changing bodies would be more likely to facilitate a positive sense of embodied sexual self” than drug treatment (2015: 210).

Here I develop these criticisms of GnRH treatment of healthy girls with early puberty—using the term healthy to mean that the only physical differences between these girls and prepubertal girls of the same age are the changes of puberty. I argue that the facts about GnRH treatment, as they are presented in the medical research literature, cannot be reconciled with claims in this same literature that the drugs represent a medical advance of benefit to patients. For healthy girls with pubertal onset over 6 years, researchers have not shown that there is a need for height treatment, or that the drugs do in fact increase height, or that “adverse psychosocial effects” require pharmacological treatment. Gaps in the medical literature raise further concerns; no published research has followed up on the reported GnRH side effect of reduced IQ; there is very little discussion of the ethical issues involved in the attempt to regulate behaviour and reduce risks (and so-called risks) through use of the drugs, and very little discussion of how girls might be supported rather than medicated. To explain these facts and omissions, I argue that the justifications for treatment are founded on an ideology of normality. From the perspective of this ideology, what is normal is also perfect (Kittay, 2006). In pursuit of this idealised normality, the rights of girls treated for precocious puberty are being infringed.

Medicalisation and ideology

Justification for the treatment of precocious puberty is framed by the comprehensive medicalisation of healthy girls who happen to mature early. Medicalisation has been defined as “defining a problem in medical terms, using medical language to describe a problem, adopting a medical framework to understand a problem, or using a medical intervention to treat it” (Conrad, 1992: 211). All these forms of medicalisation are found in the literature on precocious puberty, to create an overall impression of girls enveloped by various threats to their health and well-being. This medicalisation cannot be considered as a medical advance. Rather, it is disease mongering (Jutel, 2009), an instance of unnecessary treatment of healthy people, including treating of aspects of ordinary life (Williams, Martin, & Gabe, 2011) and variations from a statistical norm (Jutel, 2009; Morrison, 2015; Smith, 2002). In contrast to unnecessary medical procedures, such as cosmetic surgery, where the fact that patients are healthy is openly admitted, in disease mongering this fact is obscured. Hence, the seriousness and prevalence of problems are exaggerated (Moynihan, Heath, & Henry, 2002), and treatment is justified by reference to some future risk, to the extent that risk itself is seen as akin to disease (Aronowitz, 2009; Gillespie, 2012; Moynihan et al., 2002).

The ideology of normality, therefore, presents particular values and interests, associated with providing healthy people with drugs to achieve an idealised norm, in terms of the universally accepted values of using medical treatment to restore or protect patients' health. To try and justify giving drugs to healthy girls in this way, evidence is fitted to confirm that there are medical (or medical-sounding) threats to their health, rather than genuinely testing whether these threats are real and significant, or questioning whether they are truly medical. This fitting of evidence characterises an ideological approach to research (Arendt, 1973; Popper, 1966, 1992). It is concerned not with critically examining its framework of assumptions, in this case assumptions about the desirability of the norm, but with using rhetorical techniques to “erase” them, that is, to make them invisible and accepted unquestioningly (Edwards, 2006: 55). It biases the presentation of facts to support a predetermined conclusion and replaces logic with teleological reasoning directed at supporting this same conclusion, even at the expense of shifting inconsistently between different ideas. In theory, this ideological approach to research is wholly different from an open minded and scientific attitude, but in practise the distinction can be much less clear cut. Although the formal methods of scientific and medical research are designed to guard against biased and illogical arguments, it is possible to manipulate them to maintain the appearance of objectivity while pursuing an ideological agenda.

“Normal” puberty: narrowing the range and targeting the mean

From the perspective of the ideology of normality, the peak age of pubertal onset is also the ideal age of onset. In pursuit of this ideal, “normal” puberty is defined in terms of an overly narrow range around the mean so that treatment is extended to include variants of normal. Further, such treatment is

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