The psychological burden of short stature: evidence against

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Abstract

Short stature, per se, is clearly not a disease, but is commonly perceived to be associated with social and psychological disadvantage. The assumption, widely held by pediatricians that short children are likely to be significantly affected by their stature, has been founded largely on older, poorly designed clinic-based studies and laboratory investigations of beliefs about the association between stature and individual characteristics. In contrast, data from more recent and better designed clinic- and community-based studies show that, in terms of psychosocial functioning, individuals with short stature are largely indistinguishable from their peers, whether in childhood, adolescence or adulthood. Parents and children alike should be reassured by these findings. In the absence of clear pathology, physical or psychological, GH therapy for the short but otherwise normal child raises ethical concerns about so-called ‘cosmetic endocrinology’.

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Introduction

Short stature (SS) may result from an idiopathic deficiency in growth hormone (GH) or be a feature of a more complex syndrome or chronic disease, but it is usually found to be an isolated physical characteristic in an otherwise healthy child, i.e. ‘idiopathic’ or short normal stature (1).

Prior to the advent of biosynthetic or recombinant GH in 1985, limited supplies meant that only those children with classic GH deficiency (GHD) were considered for treatment. Since the introduction of GH, the criteria for diagnosing GHD have become less stringent, but the identification of children most likely to benefit from treatment is still far from clear (2). First, biochemical tests for GHD are unreliable and secondly, the distribution of GH secretion appears to be continuous, tall children secreting more GH than short (3). Thus the notion of GH ‘insufficiency’ has arisen, leading, inevitably, to a somewhat grey area at the lower end of the continuum (4).

As a result, even short normal children are now considered potential targets for growth-promoting therapy. According to a recent report, some 40% of children on GH appear not to be GH deficient and, in the USA, idiopathic SS (ISS) alone accounts for about one-third of all children on GH (5, 6). Although there may be metabolic benefits of GH therapy in a few syndromes, such as Prader–Willi (7), the primary goal of treatment is usually an accelerated short-term growth rate and a greater final height. The rationale behind this goal is that SS constitutes a psychosocial burden (8). This belief is widespread. In a recent survey, 56% of physicians felt that height impaired emotional well-being in children below the 3rd centile (9). Thirty-two percent of these same physicians also believed that quality of life in non-GHD SS could be improved by an increase in height. There is little compelling evidence, however, for either.

SS in the pediatric clinic

It is the impression of many clinicians that individuals with marked SS are severely disadvantaged by their height (9–13). However, most studies dealing with the psychological adaptation of such children have been based on clinic referrals, including a variety of medical conditions (14). Many studies reported in the literature were conducted at a time when GH therapy was severely restricted and thus the patients involved tended to be those most severely affected by their condition.

Social problems reported in the clinic setting have included anxiety, introversion, stigmatization and juvenilization (14). Treating the child according to height age rather than chronological age may condition him or her to behave in a socially immature manner and to seek out younger children or adults (15). Alternatively, children with SS may be (or may be seen as) physically weaker than their peers, leading to parental overprotection, in itself a potent predictor of victimization by peers in the general school population (16–19). At the other
extreme, the short individual may try to overcompensate for SS by seeking peer approval as the group mascot or clown, or by being overly assertive and belligerent (20).

Most reports on short children’s school performance have likewise been based on clinic-referred samples (21). Clinical syndromes featuring SS are often associated with academic underachievement, despite average intelligence, but are probably due to specific neurocognitive deficits associated with the particular syndrome (14). Importantly, in clinic-referred populations, academic achievement is largely unrelated to height and not remedied by GH therapy, even among those with well-recognized syndromes (22, 23). Nor, to date, have any short- or long-term psychological benefits of GH therapy been demonstrated in those with short normal stature (i.e. ISS) (24, 25).

It is sometimes assumed that delayed puberty, often associated with SS, will compound any psychological problems (26). It has even been suggested that the benefits of advancing puberty might outweigh the potential risk of attenuated adult height (27). The evidence, however, is inconclusive (28–31). One follow-up study of constitutional growth delay revealed that many subjects remained unemployed and economically dependent on their parents as young adults, but that the level of educational attainment had not been seriously affected (32). Others have reported no significant psychological dysfunction in the adults traced (33–35).

More recent clinical research, avoiding many of the methodological flaws associated with earlier studies, is now questioning long-held beliefs regarding the presumed disability of SS (21, 36). Skuse et al. (37) reported no significant differences in peer acceptance, self-perception or social competence between clinic-referred children and their classmates. In a large, consecutively referred sample, Sandberg et al. (38) identified only minor difficulties of behavioural adaptation, mainly in boys. A Dutch study (39) reported similar findings in untreated young adults. Although three-quarters reported a negative experience attributed to their SS, quality of life remained unimpaired.

SS in the community

Not all children with SS are referred for specialist evaluation. It would thus be a mistake to assume that the psychosocial or educational experiences of those who are referred will apply to the general population. Those seeking help are likely to have greater problems of psychosocial adaptation than those who do not. Parental perceptions are also potentially biased and any behavioural or emotional problems in the child may well be interpreted as stature related, even where this is not the case (4).

The Wessex Growth Study (40), a prospective cohort study, was unique for having recruited an unselected population of very short, but otherwise healthy children, from the age of 5 years (40). Children with known organic disease were excluded, the age range lay within a tight band, a wide range of socio-economic classes was represented, and the study incorporated case-matched controls of average stature. Results showed no evidence of serious psychosocial or academic disadvantage, before, during or, indeed, after puberty, in these youngsters (41–43). Although mean intelligence quotient (IQ) values between groups was significantly different this, again, was of no clinical import. Height, on its own, explained only 2% of the variance in IQ, emphasizing the need always to look beyond P values and consider the effect size. The Wessex data merely confirmed other reports that socio-economic factors, rather than stature, best predict psychosocial and academic outcome (44, 45). As others have found, although short children would have preferred to be taller, and reported more bullying than taller peers, neither appeared to impact on school performance or self-esteem (35, 46). Such findings suggest that the stigmatized individual is able to call upon self-protective cognitive mechanisms that serve to leave the self-esteem intact (38). As Illich (47) has claimed, one aspect of good health is to be successful in coping with reality.

Two subsequent studies lend support to the Wessex data. Kranzler et al. (48) compared three groups of children: those referred with normal SS, a non-referred short group and case controls of average stature. The referred group appeared to have significantly more behavioural problems than the non-referred short group, which was indistinguishable from the average-stature control group. Busschbach et al. (49) compared adults with ISS, who had originally presented to a pediatric clinic, with equally short adults sampled from the population. The former clearly had poorer coping skills and claimed that the social disadvantages of SS dominated their social interactions. The latter showed no impairment in their quality of life. Thus it would seem that the discrepancy between earlier and more recent research can be explained by participant selection bias. These data strongly support the notion that behavioural and social difficulties are likely to be attributed to SS, even where these are largely unrelated (4).

Parents and physicians alike can be reassured that, for most, SS is unlikely to be a burden, now or in the future (50, 51).

Ethical considerations

In the absence of clear pathology, physical or psychological, GH therapy for short but otherwise normal children raises issues as to the ethics of so-called ‘cosmetic’ or ‘plastic endocrinology’ (52, 53). Discussions range from whether such children deserve treatment, whether they should be entitled to treatment and
whether SS is a medical or a social condition. At the heart of the controversy lies the fact that SS is neither life-threatening nor, in itself, a disease, in spite of attempts to demonstrate otherwise (50, 54, 55).

One argument in support of GH therapy is based on the notion that medicine is primarily concerned with the relief of suffering, regardless of the aetiology of the condition (56). Why offer GH to the child who is GH deficient but not to another, who may be equally short, when one of the goals – to improve psychosocial functioning – might be the same (57)? According to this argument, the primary purpose of treatment is not to correct the cause but to mitigate the handicap or disability of SS (58), but this presupposes that SS does indeed lead to suffering or, at the very least, social disadvantage.

Even if it could be established that the short adult is at a social disadvantage, it is debatable whether the role of medicine is to make everyone equal competitors in life (59). There are further issues for parents to consider. Commercial pressures play a significant role, not least whenever investigators are funded to discover new indications for a drug (60). Indeed, the cynic might argue that shortness became a disease only when a treatment became available (55). Routine growth screening may be of value if it facilitates the detection of previously undetected pathology, although most short children thus identified will have no obvious pathology (61). Care must be taken to reassure them that they are indeed healthy and normal. There is a danger that demands for treatment may be motivated less by concern for the children than by the aspirations of their parents who may wish to give their children a perceived advantage in life (62). They should bear in mind, however, that where the SS is familial, treatment will not prevent SS from recurring in subsequent generations.

Any attempt by the parent to modify their child’s appearance may signal tacit disapproval and a concern that they are unacceptable as they are (63). There is also a danger that the short child who has unrealistic expectations as to the benefits of treatment may be frustrated and disappointed by what is perceived as ‘treatment failure’ (64). The outcome of GH treatment, where there is no GHD, is neither predictable nor very dramatic in terms of centimetres gained (65, 66). A further consideration is the long-term safety of recombinant human GH, yet to be established (67).

Finally, there is an argument for not spending limited resources on so-called ‘cosmetic endocrinology’ when there may be cheaper, non-invasive options (68, 69).

As Brook (70) suggests, it is much more important for a short child to acquire coping skills than to buy inches through pharmaceutical means. The widespread use of GH, as a first line of treatment, risks perpetuating a climate of opinion where SS is unacceptable, both to parents and society, and is likely to lead to a spiralling demand for therapy.

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