ELSEVIER

Social Science & Medicine 61 (2005) 1629–1639

SOCIAL SCIENCE & MEDICINE

www.elsevier.com/locate/socscimed

Using hormone treatment to reduce the adult height of tall girls: Are women satisfied with the decision in later years?

Priscilla Pyett[a,*], Jo Rayner[b], Alison Venn[c], Fiona Bruinsma[b], George Werther[d], Judith Lumley[b]

[a]*Centre for the Study of Health and Society, School of Population Health, University of Melbourne, Victoria 3010, Australia*
[b]*Mother and Child Health Research, La Trobe University, 251 Faraday Street, Carlton, Victoria 3053, Australia*
[c]*Menzies Research Institute, University of Tasmania, Private Bag 23, Hobart, Tasmania 7001, Australia*
[d]*Department of Endocrinology and Diabetes and Centre for Hormone Research, Royal Children's Hospital, Parkville, Victoria 3052, Australia*

Available online 22 April 2005

Abstract

Treatment with synthetic oestrogens to reduce adult height has been available for tall girls since the 1950s. Treatment aims to reduce psychosocial problems associated with tall stature that might occur in adolescence or adulthood, but little is known about the long-term outcomes. This retrospective cohort study identified 1248 eligible women from the medical records of Australian paediatricians who assessed or treated tall girls between 1959 and 1993, and 184 women from self-referrals. They included girls who received oestrogen treatment (diethylstilbestrol or ethinyl estradiol) in adolescence (treated group) and those who had been assessed but did not receive treatment (untreated group). A total of 1243 (86.8%) women were traced and invited to participate in the study, and 67.9% of these women (396 treated and 448 untreated) agreed. This paper reports on women's satisfaction with the decision that was made to have treatment to reduce their adult height. In a postal questionnaire women were asked to comment on a range of issues including how they felt about their current height, the assessment and treatment procedures, and the decision whether or not to have treatment. While untreated women were almost unanimously glad they were not treated (99.1%), no matter how tall they became, 42.1% of the treated women expressed dissatisfaction with the decision that was made. There was no clear association between satisfaction with treatment and the women's final height. However, dissatisfaction was related to: (a) whether or not the girls had an active say in the decision-making; (b) to negative experiences of the assessment or treatment procedures; (c) to side effects experienced during the treatment period; and (d) to later side effects women believed were associated with the treatment. The study finds that qualitative analysis of comments made by treated women helps to explain their dissatisfaction with the decision to have treatment.

Keywords: Tall girls; Height; Oestrogen; Treatment satisfaction; Australia

*Corresponding author. Tel.: +61 3 8344 0885; fax: +61 3 8344 0824.
E-mail addresses: pmpyett@unimelb.edu.au (P. Pyett), J.Rayner@latrobe.edu.au (J. Rayner), Alison.Venn@utas.edu.au (A. Venn), F.Bruinsma@latrobe.edu.au (F. Bruinsma), george.werther@rch.org.au (G. Werther), J.Lumley@latrobe.edu.au (J. Lumley).

Background

Synthetic oestrogens have been used to treat tall stature in adolescent girls since the 1950s, in Europe, the USA and Australia (Barnard, Scialli, & Bobela, 2002; Normann, Trygstad, Larsen, & Dahl-Jorgensen, 1991; Prader & Zachmann, 1978; Wettenhall, 1981). The

0277-9536/$ - see front matter © 2005 Elsevier Ltd. All rights reserved.
doi:10.1016/j.socscimed.2005.03.016

rationale for treatment is based on the known property of oestrogen to fuse the epiphyses of long bones during late puberty. Therapy was deemed appropriate for psychosocial indications, if used at an age where accelerated puberty was considered acceptable, usually not before the age of 10. Reasons cited by clinicians for consideration of treatment included the potential for the girl to feel different from her peers; be teased about her height; adopt bad posture or withdraw socially; have decreased prospects of finding a male partner; experience difficulty and extra expense acquiring appropriate clothing and shoes; and be excluded from some careers, such as classical ballet (Bailey, Park, & Cowell, 1981; de Waal, Torn, de Muinck Keizer-Schramer, Aarsen, & Drop, 1995; Prader & Zachmann, 1978; Wettenhall, Cahill, & Roche, 1975). The number of girls treated for tall stature in recent years is not known but is believed to be considerably less than in the 1960s–1980s, probably because of lessening social concerns about tall stature. A recent survey of paediatric endocrinologists in the USA (Barnard et al., 2002) showed that 92 (22%) of 411 respondents had treated tall girls in the last 5 years, although most had treated fewer than five girls.

Until the early 1970s the oestrogen most commonly used in Australia was diethylstilboestrol (DES). The use of this drug was stopped because of reports that in utero exposure to DES was associated with clear cell adenocarcinoma of the vagina in the daughters of women who were treated with DES in pregnancy to prevent miscarriage (Herbst, Ulfelder, & Poskanzer, 1971). Ethinyl estradiol (EE) was subsequently introduced as the preferred treatment in Australia and elsewhere (de Waal et al., 1995; Wettenhall et al., 1975). Progestogens were used for several days each month, in addition to oestrogens, to induce cyclical menstrual bleeding. Treatment was offered to girls with estimated mature height (EMH) predictions of greater than 177 cm (or 183 cm in later years). The initial consultation included a hand and wrist X-ray to establish EMH (see Bayley & Pinneau, 1952). The most common reasons for not having treatment were that the girl's predicted height did not warrant it, or there was limited remaining growth potential at the time of assessment. For girls who underwent treatment, regular assessments of their height, weight and pubertal development occurred throughout treatment and in some cases afterwards (Wettenhall et al., 1975).

A small number of studies of treated and untreated tall girls have compared final adult height with EMH, and have reported only short-term side effects of treatment, including menstrual irregularities, nausea, weight gain, limb pain, thrombosis, ovarian cysts, and deepened pigmentation of the nipple and aureola (Bailey et al., 1981; Bierich, 1978; Binder, Grauer, Wehner, & Ranke, 1997; de Waal et al., 1995; Drop, de Waal, & de Muinck Keizer-Schrama, 1998; Prader & Zachmann, 1978; Trygstad, 1986; Wettenhall et al., 1975). These studies rarely examined women's satisfaction with the treatment. In one study, conducted on average 10 years after treatment, 93% of women were reported as satisfied although 11% had concerns about possible long-term side effects, or felt that tallness was no longer a problem for women (de Waal et al., 1995). Wettenhall and colleagues reported that all 87 women in their study were 'glad they had been treated' (Wettenhall et al., 1975:605), and only two of the 100 women in Crawford's study regretted the decision to have treatment (Crawford, 1978). Two studies have reported small numbers of tall women who regretted that they had not been offered treatment to reduce their adult height (de Waal et al., 1995; Lecointre & Toublanc, 1997), while another found that for treated and untreated women satisfaction with their adult height was not related to the decision for or against therapy (Binder et al., 1997). Most studies of treated tall girls were carried out by the clinicians involved, and were limited by incomplete follow-up and the relatively young age of women at the time of contact.

This paper reports findings from a retrospective cohort study of girls who were assessed between 1959 and 1993 for treatment to reduce their adult height. This independent study adopted a rigorous methodology, using both qualitative and quantitative methods, to investigate longer-term health and psychosocial outcomes for treated and untreated women, The multidisciplinary study team included researchers with expertise in epidemiology, paediatric endocrinology, sociology, women's health, obstetrics and gynaecology, and adolescent psychiatry. Findings showing that treatment was associated with impaired fertility in the long-term have been reported elsewhere (Venn et al., 2004). This paper reports findings related to satisfaction with treatment. We were interested in finding out how women felt now about the decision that was made to have treatment to reduce their adult height and how this related to their final height. We were also interested in women who did not receive the treatment, either because they were not considered eligible when they were assessed or because they or their parents rejected the offer, and how the women felt about the decision in later years. Did they regret not having the treatment, and were their feelings related to their final adult height?

Within the medical literature the keyword 'satisfaction' registers thousands of reports of patient satisfaction with individual treatments, surgical methods, practitioner styles and so on, but very little around the variables involved in predicting satisfaction. The literature does suggest, however, that satisfaction increases when patients are given information, have some control in the process, have their expectations met, and when physicians consider the problem from the patient's perspective (Breen & Breen, 2003; Deluca,

1999; Lochman, Dain, & Babick, 1984; Ross, Frommelt, Hazelwood, & Chang, 1994).

A comprehensive literature search revealed very little on the significance of height for women. Research on female body image focuses on issues related to weight and facial attractiveness rather than height, and clearly indicates that women are more concerned with and more dissatisfied with their physical bodies then men are (Jackson, 1992). The broad area of gender studies largely ignores physical attributes, focusing rather on emotional and behavioural characteristics associated with femininity and masculinity (Leaper, 1995). Early studies relating to the importance of height in intimate relationships referred to the cultural norm where men are taller than women (Beigel, 1954; Gillis & Avis, 1980; Graziano, Brothen, & Berscheid, 1978). Recent reviews of the social importance of height reveal that stereotypes still exist: shorter women are regarded as more attractive and taller men as having higher social status (Biernat, 1993; Roberts & Herman, 1986; Sheppard & Starthman, 1989), although these studies pre-date the current admiration and commercialisation of the tall female fashion model.

Method

The cohort included girls who received oestrogen treatment (3 mg diethylstilbestrol daily or 150 μg EE daily) in adolescence (treated group) and those who did not (untreated group). Eligible women were identified from the medical records of Australian paediatricians who assessed or treated tall girls from 1959 to 1993, and from self-referrals. The majority of women (85%) were identified through the records of one paediatric endocrinologist. These records comprised a complete cohort of girls assessed for tall stature during his practice. Other treating doctors ($n = 50$) were identified through professional networks of paediatricians and paediatric endocrinologists, and by women who had been treated, but only three doctors were able to identify eligible participants ($n = 26$). Self-referrals included members of an Australian support group for women who were treated as girls ($n = 118$), and women who contacted the study team directly as a result of publicity ($n = 66$). Women were eligible if they had undergone a medical assessment for tall stature that included a radiological assessment to establish EMH.

Data collection

Women identified from medical records were traced with the use of electoral rolls and telephone listings. In the planning phase of the study, five focus groups were conducted with treated and untreated women to identify the range of issues that were of concern to them in relation to being tall and to undergoing assessment and treatment for tall stature. For the main data collection, all eligible women for whom a contact address had been found were invited by letter to complete a postal questionnaire and computer-assisted telephone interview (CATI). Non-respondents were followed up by a reminder letter and a telephone call. The postal questionnaire sought demographic information and details of assessment and treatment. The CATI included questions about reproductive history, general physical and mental health, and sexual history. Data were also abstracted from medical records, where possible, for women who provided written consent.

Measuring satisfaction

In the questionnaire, women were asked both open and closed questions about: overall satisfaction with the decision that was made whether or not to have treatment; who made the decision and their own role in the decision-making; experiences as tall girls and as adults; satisfaction with current height; experiences of the assessment and treatment procedures; and any side effects experienced during treatment. Questions were developed from the focus group data and from a questionnaire used in an earlier French study (Lecointre & Toublanc, 1997). Questions aimed to examine how women feel about their height and about treatment for tall stature.

Analysis

Stata software (Stata Statistical Software, 2003) was used for all statistical analyses. Continuous data were expressed as means (SD). The differences between treated and untreated women were investigated using Pearson's χ^2-test, and χ^2 for linear trend. Statistical significance was inferred at a p value <0.05. Odds Ratio with a 95% Confidence Interval was used to measure strength of association.

Qualitative data were entered verbatim into an Access database and coded by two researchers (PP, JR). Intercoder reliability was checked twice, in 10% of the sample, and any differences were settled by consensus. Qualitative data were linked by ID number to the statistical package. Coding categories developed for a thematic analysis of the focus group data were also used for the qualitative data obtained from the questionnaire, with some additional categories.

Results

Characteristics of study participants

A cohort of 1432 eligible women (572 treated, 860 untreated) was identified: 1248 from medical records

(1222 of these from one paediatrician) and 184 from self-referrals. A total of 1243 (86.8%) women were able to be traced and invited to participate in the study, and 844 (67.9%) women (396 treated, 448 untreated) agreed.

The characteristics of study participants are shown in Table 1. The mean age of participants was 40 years (range 20–55) in the treated group and 38.4 years (range 23–54) in the untreated group. Treated and untreated participants were similar in their marital status and highest level of education achieved. Women treated with DES were similar to those treated with EE in terms of their age at the commencement of treatment, the final EMH predicted before treatment commenced, and the duration of treatment. Self-reported current height was greater in treated women (mean 179.0 cm, SD 4.0 cm) than in untreated women (mean 176.3 cm, SD 9.7 cm). Similarly, EMH was greater for treated women (mean 181.3 cm, SD 3.3) than in the untreated group (mean 174.6 cm, SD 4.3). Based on data obtained largely from their medical records, only 27.6% ($n = 121$) of the untreated women had an EMH prediction greater than 177 cm compared with 79.4% ($n = 308$) of the treated women. Eighty women (20.6%) with an EMH prediction of less than 177 cm were treated.

Medical records indicate that 60.3% ($n = 223$) of the untreated women were not treated because their EMH did not warrant it, and 23.2% ($n = 86$) had limited growth potential at the time of assessment. Nineteen girls (5.1%) were not treated because the girl or her parents did not want treatment. The mean age at which treatment commenced was 13.0 years (range 8–16.3 years SD 1.4).

Table 1
Characteristics of study participants

Characteristic	Treated group ($n = 396$)		Untreated group ($n = 448$)	
	n	%	*n*	%
Age (years)				
<25	4	1.0	6	1.3
25–34	98	24.8	120	28.8
35–44	189	47.8	262	58.5
45–54	100	25.3	51	11.4
>54	4	1.0	0	0.0
Missing	1		0	
Marital status				
Married or cohabiting	297	75.8	333	74.7
Divorced, separated or widowed	45	11.5	37	8.3
Single	50	12.8	76	17.0
Missing	4		2	
Highest education level achieved				
Did not complete secondary school	39	9.9	21	4.7
Completed secondary school	65	16.5	86	19.2
Apprenticeship/ certificate/diploma	89	22.6	96	21.5
Degree	113	28.7	154	34.5
Postgraduate	88	22.3	90	20.1
Missing	2		1	
EMH (cm)[a]				
⩽177.0	80	20.6	318	72.4
177.1–182.9	183	47.2	108	24.6
⩾183.0	125	32.2	13	3.0
Missing	8		9	
Adult height (cm)[a]				
⩽177.0	114	28.8	222	49.8
177.1–182.9	229	57.8	186	41.7
⩾183.0	53	13.4	38	8.5
Missing	0		2	

Missing data excluded from calculation of percentages.
[a]EMH from medical records. Where medical records were not available, self-reported EMH was used ($n = 110$).

Satisfaction with treatment

In the questionnaire women were asked, 'In general, are you satisfied with your current height?'. Overall most women in the study (87.8%) reported that they were satisfied with their final adult height. However, treated women (82.7%) were significantly less likely than untreated women (92.4%) to be satisfied with their current height ($p < 0.001$) (Table 2).

Women were also asked: 'On balance, are you satisfied with the decision that was made about whether or not to have treatment?' The responses offered were 'Yes' or 'No', with space for comments. We queried satisfaction with the *decision* rather than satisfaction with *treatment* because we wanted to examine satisfaction among untreated as well as treated women. Women who were not eligible for treatment at the time of their assessment and those who grew taller than their EMH might regret that treatment had not been offered to them. Furthermore, treatment was a lengthy process (average 26 months duration) and women may have had different feelings about different aspects of it; the outcome of treatment (adult height) was not known for many years; there is uncertainty about the accuracy of EMH predictions; and women may still have concerns about unknown long-term consequences of the treatment. Questions were included to cover these issues.

Thirty-four women (16 untreated, 18 treated) did not answer the question about satisfaction with the treatment decision, and were therefore excluded from results reported here. Of the 810 women who did answer the question, 432 were untreated and 378 were treated. While almost half of the treated women (42.1%)

Table 2
Satisfaction with adult height and treatment decision

	Treated group ($n = 396$)		Untreated group ($n = 448$)	
	n	%	*n*	%
Satisfaction with current height				
Not satisfied and unsure	68	17.3	34	7.6
Satisfied	325	82.7	412	92.4
Missing	3		2	
Satisfaction with treatment decision				
Not satisfied	159	42.1	4	0.9
Satisfied	219	57.9	428	99.1
Missing	18		16	

Missing data excluded from calculation of percentages.

reported dissatisfaction with the decision to have treatment, only four untreated women regretted the decision not to have treatment (Table 2), and three of these women had EMH predictions of less than 177 cm so it is unlikely that treatment would have been recommended for them.

Untreated women's satisfaction with the decision

Comments offered by women to explain why they were satisfied with the decision not to have treatment were often expressed strongly and included feeling positive about their height, having concerns about adverse side effects they or their children might have experienced as well as a preference for letting nature take its course.

As already noted, the untreated women are not as tall as those who were treated, their EMH predictions were not as great, and far fewer of these women were recommended for treatment. They would have had fewer assessments and could not experience side effects of treatment. The question of their height being a potential problem may have been discussed for a shorter period in their life. These confounding factors, in addition to their overwhelming satisfaction with the decision, limit the usefulness of any further comparisons with the treated women in relation to their feelings about the decision. The rest of this paper analyses treated women only.

Treated women's satisfaction with the decision

Over half (57.9%, $n = 219$) of the treated women who participated in this study were glad they received treatment to reduce their adult height (Table 2). Over a third of these women (39.7%, $n = 87$) offered comments to explain their satisfaction; the most common reason (48/87) was being pleased they were not taller:

> I'm glad I didn't grow to 6′1″ as I found 5′10″ too tall as it is.

> I am very happy about my choice and I'm glad I am NOT 6ft 5 inches. (*emphasis in original*)

Some women were extremely positive (12/87):

> Yes—extremely happy. I have a very tall daughter who I would consider treating should she desire.

One woman commented on her 'soaring self-confidence' following treatment; others wished they had started treatment earlier (in the belief that they could have been even shorter). Three women expressed gratitude to their parents or the doctor, one saying:

> I am grateful to my doctor every day that I am 6′ and not 6′5″.

However, many of those who commented (53/87) qualified their satisfaction with various doubts and concerns. Some (12/87) expressed concerns about future adverse effects of the treatment on their own or their children's health:

> I am pleased I am not 6ft. However, I am very concerned about the effect the treatment may have on my 3 daughters

> I haven't had children yet, so I hope the treatment has not affected my fertility or [chances of] having normal children.

Some women (12/87) expressed disappointment at having no say in the decision, almost always recognising that it was done 'in a spirit of caring', and sometimes acknowledging that times have changed:

> I am happy with my current height and believe my parents thought it was in my best interest to proceed with the treatment. As an adult I do not however agree that such interference is warranted.

> Society attitudes in late 60s—attitude to new 'medical miracles'—parental desire for what's best = treatment.

Women also expressed uncertainty about the level of success of the treatment (6/87):

> I was pleased to be having the treatment, but disappointed to still reach the height I did.

> Yes, I am happy with my height. [Although] at times I feel too tall, overall I am relieved not to [be] 6′ 7″.

Others (12/87) had non-specific regrets about the assessment or treatment procedures, or were just unsure:

> I would have to say that I only just tip the scales in favour of 'yes', I found this a very hard call.

> I guess I'm happy—I can't imagine things differently now.

The qualified satisfaction expressed by so many of these women illustrates some of the difficulties inherent in asking women to comment on a treatment that was provided to them as children or adolescents: looking back to a time when they may have had little or no say over decisions made for them; being unable to imagine life—and particularly their height—other than as they have experienced it; and disentangling concerns about side effects (that they may have experienced or read about) from their satisfaction with a perceived reduction in their adult height. Nevertheless, it is important to recognise the concerns expressed by these women and to try to understand the reasons for the dissatisfaction expressed by the other 42.1% of treated women in this study.

Explaining dissatisfaction with treatment

Statistical analysis revealed significant associations between dissatisfaction with the treatment decision and several key variables, although not all that might have been predicted (Table 3). The majority of treated women who were dissatisfied with the treatment decision offered comments to describe their feelings (76.7%, $n = 122$) and these go some way toward explaining the patterns identified in the quantitative data.

Table 3
Satisfaction with treatment decision among treated women

	Not Satisfied $n = 159$		Satisfied $n = 219$		Odds Ratio	
	n	%	*n*	%	OR	95%CI
Height groups						
⩽177 cm	52	50.5	51	49.5	1.0	Ref
177.1–182.9 cm	86	38.6	137	61.4	1.6	1.0–2.6
⩾183 cm	21	40.4	31	59.6	1.5	0.8–3.0
Difference between current height and recalled EMH						
⩾10 cm less than recalled EMH	33	35.1	61	64.9	1.0	Ref
6–9.9 cm less than recalled EMH	32	34.0	62	66.0	1.0	0.6–1.9
1–5.9 cm less than recalled EMH	51	49.5	52	50.5	0.5	0.3–1.0
<1 cm less, or taller than recalled EMH	21	51.2	20	48.8	0.5	0.2–1.1
Missing	22		24			
Reported number of adverse side effects experienced during treatment						
0	21	25.0	63	75.0	1.0	Ref
1	16	27.1	43	72.9	0.9	0.4–1.9
2	19	31.1	42	68.9	0.7	0.4–1.5
3	26	44.8	32	55.2	0.4	0.2–0.9
4	18	52.9	16	47.1	0.3	0.1–0.7
5	16	66.7	8	33.3	0.2	0.1–0.5
>5	43	74.1	15	25.9	0.1	0.0–0.3
Experienced infertility[a]						
No	84	36.5	146	63.5	1.0	Ref
Yes	67	54.0	57	46.0	0.5	0.3–0.8
Missing	8		16			
Active say in treatment decision						
No	94	60.3	62	39.7	0.2	0.2–0.4
Yes	55	26.7	151	73.3	1.0	Ref
Missing	10		6			
Negative memory of assessment or treatment procedures						
No	55	25.5	161	74.5	1.0	Ref
Yes	104	64.2	58	35.8	0.2	0.1–0.3

Missing data excluded from calculation of percentages and OR.
[a]Infertility defined as ever having tried without success for 12 months or more to get pregnant.

Satisfaction with height

We expected that satisfaction with treatment would relate to the women's adult height and whether the treatment was effective in reducing their predicted height. Since the untreated women were not as tall, nor were they predicted to be as tall, as the women who were treated, it is hardly surprisingly that treated women were significantly less likely than untreated women to be satisfied with their current height (Table 2). However, there was no significant association between satisfaction with *height* and satisfaction with the *treatment decision*. What about height itself? For the analysis, participants were divided into three height groups: 177 cm was the usual cut-off point for treatment; and 183 cm is a symbolic marker of tall women as over 6ft. Women in the middle height group (177.1–182.9 cm) were significantly more likely to be satisfied with the treatment decision ($p = 0.040$) than women in the shortest group, but there was no significant difference between the shortest and the tallest groups (Table 3). Across all three height groups, women's comments were about side effects, future health concerns, lack of height reduction, or general regrets about the assessment or treatment.

Women were asked to recall their EMH before treatment. The difference between their remembered EMH and their self-reported current height was calculated (46 women did not remember and were coded as missing data). Women who reported little or no difference between their current height and remembered EMH, or who were taller than their remembered EMH, were least likely to be satisfied with the treatment decision ($p = 0.01$ for trend) (Table 3). This suggests that satisfaction with the treatment decision has some relationship to the perceived effectiveness of the treatment. Comments from women who were dissatisfied with the treatment decision (23/122) clearly reflect their disappointment with treatment effectiveness:

> I am horrified that I was put at such a risk for 1 inch of height.
>
> Because I still grew to 5′11 and 3/4″ not the 5′10″ he predicted so it wasn't worth the effort.

Dissatisfaction with the prescribed treatment

Given the publicity about adverse effects of DES when used to prevent miscarriage, and media reports of concerns that had been expressed by treated tall women, we were interested to know if the type of treatment women received affected their satisfaction. No significant association was found between treatment type and satisfaction with the treatment decision.

Adverse short-term side effects of oestrogen treatment for tall stature have been widely reported, although often dismissed as minor or temporary (Bailey et al., 1981; Binder et al., 1997; Boleyn, 2001; de Waal et al., 1995; Drop et al., 1998; Duck, 2001; Jackson, 2000; Jennings, 1997; Morris, 2000; Prader & Zachmann, 1978; Trygstad, 1986; Wettenhall et al., 1975; Whelan, 2000). Participants reported a range of side effects experienced during treatment, and analysis revealed that satisfaction with the treatment decision was significantly reduced with more side effects experienced (Table 3). Women who reported they had three or more adverse side effects whilst on the treatment were significantly less likely to be satisfied with the treatment decision (χ^2 for trend 45.865, $p < 0.001$). Improved skin was reported by 61 women (15.4%) as a positive side effect of treatment but was not significantly associated with satisfaction with the treatment decision and was not included in the summary measure. The most frequently reported side effects included: problematic weight gain, increased nipple pigmentation, heavy periods, irregular periods, mood swings, increased vaginal secretions, depression, nausea, and calf cramps. Each of these was independently associated with dissatisfaction.

One in four of the dissatisfied women who provided comments (32/122) mentioned side effects that they experienced during the treatment period:

> I did not want the treatment. I did not worry about my height. The repercussions for my health were terrible.
>
> I think it put a lot of physical and emotional pressure on me as an adolescent—fifteen-day periods.

Almost as many (25/122) expressed concerns about future adverse effects, or side effects that have occurred since treatment, often commenting that the small reduction in height was not worth the risks involved, and that insufficient information was provided at the time:

> Concern regarding long-term effects, especially in regard to infertility and cancer risks.
>
> I have had extremely painful periods all my life, endometriosis, difficulty falling pregnant (had IVF)—1 child. THE TREATMENT MADE ME SICK. (*emphasis in original*)
>
> No—it wasn't a fully informed decision. We weren't told what the long-term consequences of the treatments were.

Women who had tried unsuccessfully to get pregnant for 12 months or more were significantly more likely to be dissatisfied with the decision to have treatment for tall stature ($p = 0.001$) (Table 3). Most of the dissatisfied treated women who had experienced infertility commented on their dissatisfaction (82.1%, 55/67), mainly expressing concerns about side effects experienced or feared (31/55):

> I wish I had not had the treatment as it worries me that I took drugs, especially as I had to take more to start a family with IVF.

> I feel very strongly about medical intervention and the long-term effects it has. Given the choice now I would not even consider it.

They were also more likely than women who had not experienced infertility to comment on the uncertain effect of height reduction (11/55):

> We were not told that it wasn't a proven treatment. I don't remember any risks OR side effects being discussed and I don't think it actually reduced my height at all.

Having an active say in the decision

An issue that arose in the focus groups was a feeling of discontent with having had little or no control over the decision to have treatment to reduce their adult height. In the questionnaire, women were asked if they felt they had an active say in this decision, and were invited to provide comments. Women who felt they did not have an active say were significantly more likely to be dissatisfied with the decision than women who felt they did ($p = <0.001$) (Table 3).

While some of the comments made by these women related to not having a say (10/70), almost a third were about side effects they had experienced (18/70). Others were concerns about future adverse effects (10/70), the uncertain effect of the treatment in reducing their height (10/70) and a preference to let nature take its course (10/70):

> I had a say but was very lacking in understanding. I would ensure counselling was offered to uncover issues—this was needed more!

> The choice was to go ahead because you were made to feel that it was highly necessary because being tall wasn't appropriate.

Commenting specifically on their role in the decision, many women who felt they had no say expressed anger or resentment (28/66):

> My parents and the doctor NEVER asked me if I wanted to have treatment. The doctor did NOT ask me or my parents to make the decision he just prescribed the tablets. When he did this I was very upset and was crying, and it was obvious that I did not want to have the treatment. (*emphasis in original*)

> I didn't want to, I wanted to be tall for basketball. I was ridiculed by Dr […] when I said this. Dad wasn't for it either—divorced parents.

Others said they were too young to have a say (28/66). Many believed they were 'co-operative' children who just did what they were told, while others felt they were not in a position to challenge their parents' decision:

> They certainly discussed it with me but I think at that age I certainly was not able to make an 'adult decision'. I was too young to realise what it all meant.

> Not an active say—I think I more or less went along with the decision which was heavily made by the doctor persuading my parents and myself that it was the 'right' decision and basically there [was] little other choice if I was to be a 'normal' woman.

Some women commented on the way the visit to the doctor problematised the issue of their height for them:

> I went along with it as I was frightened I would be lots taller than the norm and because I had to see a doctor that [meant] there must be something wrong with me.

An embarrassing procedure

Many women in the focus groups recalled the assessment procedures with significant discomfort. Women remembered being alone with the (male) doctor, although usually with the door open, and being weighed, measured and photographed either naked or in their underpants. An examination of their pubertal development (breasts and pubic hair) was undertaken at the initial assessment, at the commencement of treatment and during subsequent visits, in order to assign a Tanner score (Tanner, 1962) and to monitor changes effected by the treatment. The questionnaire asked a series of nine questions to elicit women's recollections of the assessment procedures. However, in recognition of the potential for memories to be inaccurate, we focus here on women's feelings about the procedure. Using a closed-ended question with 12 statements, both negative and positive, that were drawn from the focus group data, and providing additional space for comments, we asked women to describe their 'overall experience' of the assessment and treatment procedures for tall stature. We developed a summary measure of 'negative experiences of the assessment procedure' if women described it as 'intrusive', 'scary', 'distressing', or 'painful'. Women who reported negative experiences of assessment and treatment were significantly less likely to be satisfied with the decision to have treatment ($p<0.0001$) than women who reported no negative memories (other than embarrassment) (Table 3).

Women who were dissatisfied with the treatment decision and reported negative experiences of the assessment procedures offered a range of comments, often expressing strong feelings, whether in relation to the assessment experience itself (7/80), the side effects already experienced (17/80), the uncertain outcome (12/80), or their lack of a say in the decision (10/80):

I feel violated by what happened to me.

I think it was a gross invasion. I feel my body was stolen from me.

Absolutely dissatisfied due to nature of massive side effects at time of treatment, nature of treatment and reasons for it!

It was entirely unnecessary and had negligible effect.

Did not want to take part in it.

Some women's comments reflected the view that they were not ill and should not have been subjected to any medical intervention (14/80):

I would like to be who I am. Tallness is not a medical condition that requires treatment.

It wasn't ever impressed on me or on my family that I wasn't ill, I was treated for an emotional self-esteem problem with serious physiological treatment.

All my life I've felt like a freak and kept it [the treatment] a secret. I was ashamed I had to be 'made right'.

As we have already seen, for every reason offered to explain their dissatisfaction with the treatment decision there were women who expressed their feelings strongly. This was especially the case amongst the tallest women, those who had less height reduction, those who felt they had no say in the decision, and those who reported more than three adverse side effects, but most of all amongst women who had negative memories of the assessment procedures.

Discussion

The findings reported in this paper relate to women's perceptions, feelings and memories. A key finding is that while there were mixed feelings about the decision among the treated women, the vast majority of untreated women (99.1%) were satisfied with the decision not to have treatment. Although the two groups were similar in many respects, selection bias due to non-response may have occurred. The response rate in the treated group was higher (77%) than in the untreated group (62%) and may have been greater in those with concerns about the effect of treatment and its perceived side effects, and those with distressing memories of the assessment procedure. Nevertheless, girls who were not offered treatment to reduce their adult height, whether the assessment occurred too late or they were not predicted to grow 'too tall', or because they or their parents decided against it, did not regret the decision *no matter how tall they became*. By contrast, 42.1% of the treated women who participated in this study did regret the decision that was made to have treatment. If we add the women who reported that they were satisfied with the decision but who qualified their satisfaction with numerous concerns, over half (56%) of the treated women were less than satisfied. The results of a sensitivity analysis performed suggest that selective participation in either the treated or untreated groups is unlikely to have explained the observed effect on satisfaction. For example, the difference remains significant ($p<0.001$) even assuming that all treated women who did not participate were satisfied, while satisfaction among untreated women who did not participate was the same as among untreated women who did participate.

Women who were satisfied with the decision to have treatment were grateful for having their adult height reduced, even if they feel they had no say in the decision, have experienced side effects they attribute to the treatment, or have distressing memories of the assessment or treatment procedures. However, for many women, a visit to the doctor for a medical opinion about their height had led to feelings that there was 'something wrong', and this had added to, rather than reduced, any discomfort they felt about being tall. For treated women who were dissatisfied with the decision to have treatment a number of factors were found to be statistically significant and were supported by the comments women made. Dissatisfaction is clearly related to side effects experienced by women during and after the treatment, and to concerns for their own or their children's future health, including problems already experienced trying to get pregnant. Dissatisfaction is also related to a perceived lack of height reduction; to not having an active say in the decision; and to having memories of distressing experiences of intrusive examinations at a sensitive stage of development.

It is important to take into account the social climate and attitudes of the time when this treatment was first offered, and to consider the motivation of the clinicians and the girls' parents. Some social difficulties were no doubt experienced by some tall women, particularly in the earlier period covered by this treatment, and in the decades preceding it. Social and practical difficulties would have been experienced by some of the girls' mothers, many of whom were themselves tall. As indicated by our focus groups, some of the girls would themselves have already experienced difficulties with clothing, and discomfort related to standing out at school, since all of the girls were already tall for their age when the assessment occurred. Parents seeking a medical opinion concerning their daughters, and the treating clinicians, were no doubt trying to alleviate anticipated psychosocial discomfort for these tall girls. However, neither the clinicians nor the parents could have foreseen that women would become on average taller in the years ahead, nor that tall women would become more socially acceptable and even be admired as models and sports-

women. Furthermore, women's position in society and career options have also changed significantly since 1959 (although not much since 1993 when the last of the girls in this study were recommended this treatment).

Nevertheless, although the treatment was offered for 'psychosocial indications', there were no formal psychological assessments carried out on the girls in this study nor on others reported in the literature (de Waal et al., 1996). Some of these 'indications' were little more than assumptions about feminine norms and the importance of physical appearance to a girl's future career and marriage prospects. The paucity of literature on the psychological effects of tallness and its treatment has been noted in the literature (Binder et al., 1997; Lecointre & Toublanc, 1997), although adverse psychological reactions to the sudden development of puberty were reported in 1978 (Prader & Zachmann, 1978).

Of particular concern are the 'intrusive', 'scary', 'painful' and 'distressing' memories many of the women have of the assessment procedure that they feel was imposed on them as girls as young as 10, 11 or 12, and sometimes carried out subsequently at intervals through their adolescent years. While the examinations may have been carried out by doctors believing this was medically appropriate, these examinations of the young women's development through puberty have had a lasting effect on many of the women in this study.

Although the treatment was offered to tall girls in order to reduce their adult height, not much of women's dissatisfaction with the treatment appears to be explained by their actual height. The overwhelming majority of both treated and untreated women say they are satisfied with their current height irrespective of how tall they became. Some dissatisfaction with the treatment decision was related to the amount they believed their height had (or had not) been reduced by the treatment.

There had been no long-term follow-up of this treatment at the time the girls in this study were treated and yet they were reassured that they could expect minimal side effects. This study has found that women's dissatisfaction is strongly related to side effects they recall during the treatment. These included problematic weight gain, increased nipple pigmentation, heavy and irregular periods and increased vaginal secretions. For these adolescent girls, these side effects were clearly not experienced as 'minor'. Women also expressed concerns about later side effects they believe to be related to the treatment, and about possible future adverse health outcomes for themselves or their children. While these could partly be attributed to the adverse publicity surrounding DES, there was no relationship between satisfaction with the treatment decision and the type of treatment women received. Hence, it is more likely that concerns about side effects are related to a generalised preference not to 'interfere with' nature that was expressed by many women. Although it is not clear whether the health problems reported by women can be attributed to the treatment, the women's concerns are justified by the scarcity of longer-term follow-up research (de Waal et al., 1995; Wettenhall, 1981). Furthermore, this study has identified higher rates of infertility and a longer time taken to conceive amongst the treated women (Venn et al., 2004).

While we acknowledge that reasonable care was probably taken to counsel families and to seek the girl's views about her height and the proposed treatment, in the long-term many women feel that they were not involved in the decision. This may be partly retrospective regret but indicates that these women feel some resentment about an intervention that they feel was imposed on them as children and which has left them with bad memories, undesirable consequences, or uncertainty about their future health. At the time when treatment was first offered, children probably had less power socially. Adults were more inclined to make decisions without consulting children. As recently as 1997, a French study noted that it is often the mothers of tall girls, rather than the adolescent girls themselves, who seek treatment to reduce the girls' height (Lecointre & Toublanc, 1997).

For the women in this study, their final adult height bears little relationship to how they feel about the decision that was made when they were children, whether or not they would undergo a treatment that was intended to reduce their height. These children were offered a medical solution to a perceived social problem. While we recognise that times have changed, our findings raise concerns about prescribing hormone treatment or any other medical interventions for young girls, however tall, in order to reduce their adult height. It is also important to think about other therapeutic interventions being suggested today that are purportedly aimed at 'improving' girls' or boys' future social chances, but which may instead have a negative impact on their adult lives.

Acknowledgements

This study was carried out at Mother and Child Health Research (formerly the Centre for the Study of Mothers' and Children's Health), La Trobe University and supported by funding from the National Health & Medical Research Council of Australia. We thank the women who participated in the study and the physicians who provided access to their medical records. We also thank members of the study's reference group for their advice, Ms Lyn Watson for statistical advice, Ms Penelope Jones and Ms Michelle Kingston for research assistance, and Dr Meredith Temple-Smith for her thoughtful comments on an earlier version of the paper.

References

Bailey, J. D., Park, E., & Cowell, C. (1981). Estrogen treatment of girls with constitutional tall stature. *Pediatric Clinics of North America*, *28*(2), 501–512.

Barnard, N. D., Scialli, A. R., & Bobela, S. (2002). The current use of estrogen for growth-suppressant therapy in adolescent girls. *Journal of Pediatric Adolescent Gynecology*, *15*, 23–26.

Bayley, N., & Pinneau, S. R. (1952). Tables for predicting adult height from skeletal age: Revised for use with the Greulich–Pyle hand standards. *Journal of Pediatrics*, *40*, 423–441.

Beigel, H. G. (1954). Body height in mate selection. *Journal of Social Psychology*, *39*, 257–268.

Bierich, J. R. (1978). Estrogen treatment of girls with constitutional tall stature. *Pediatrics (Supplement)*, *62*(6), 1196–1201.

Biernat, M. (1993). Gender and height: Developmental patterns in knowledge and use of an accurate stereotype. *Sex Roles: A Journal of Research*, *29*, 691–714.

Binder, G., Grauer, M. L., Wehner, A. V., & Ranke, M. B. (1997). Outcome in tall stature. Final height and psychological aspects in 220 patients with and without treatment. *European Journal of Pediatrics*, *156*, 905–910.

Boleyn, A. (2001). Stolen childhoods: The experiment that turned girls into women. *Marie Claire* (pp. 40–48).

Breen, A., & Breen, R. (2003). Back pain and satisfaction with chiropractic treatment: What role does the physical outcome play? *Clinical Journal of Pain*, *19*(4), 263–268.

Crawford, J. D. (1978). Treatment of tall girls with estrogen. *Pediatrics (Supplement)*, *62*(6), 1189–1195.

de Waal, W. J., Torn, M., de Muinck Keizer-Schramer, S. M. P. F., Aarsen, R. S. R., & Drop, S. L. S. (1995). Long-term sequelae of sex steroid treatment in the management of constitutionally tall stature. *Archives of Disease in Childhood*, *73*, 311–315.

de Waal, W. J., Janssen, A., van Bussbach, J. J., de Muinck Keizer-Schrama, S. M. P. F., Aaresen, R. S. R., Slijper, F. M. E., & Drop, S. L. S. (1996). Psychological aspects in constiutionally tall stature. In W. J. de Waal (Ed.), *Influencing the extremes of growth: Too tall—too short* (pp. 172–193). Rotterdam: Division of Endocrinology, Erasmus University.

Deluca, R. S. (1999). Diminished control and unmet expectations: Testing a theory of adjustment after caesarean delivery (childbirth satisfaction). *Dissertation-Abstracts-International*, *60*(6-B), 3015.

Drop, S. L., de Waal, W. J., & de Muinck Keizer-Schrama, S. M. P. F. (1998). Sex steroid treatment of constitutionally tall stature. *Endocrine Reviews*, *5*(5), 540–558.

Duck, S. (2001). A high price to pay for being too tall. *Progress Leader* (p. 8). Melbourne.

Gillis, J. S., & Avis, W. E. (1980). The male-taller norm in mate selection. *Personality and Social Psychology Bulletin*, *6*(3), 396–401.

Graziano, W. G., Brothen, T., & Berscheid, E. (1978). Height and attraction: Do men and women see eye-to-eye? *Journal of Personality*, *46*, 128–145.

Herbst, A. L., Ulfelder, H., & Poskanzer, D. (1971). Adenocarcinoma of the vagina: Association of maternal stilbestrol therapy and tumor appearance in young women. *New England Journal of Medicine*, *284*(16), 878–881.

Jackson, A. (2000). When being tall had its shortcomings. *The Age* (p. 12). Melbourne.

Jackson, L. A. (1992). *Physical appearance and gender: Sociobiological and sociocultural perspectives*. Albany: University of New York Press.

Jennings, G. (1997). Tall girls. *Afternoon with Gael Jennings*. Australia: ABC Radio.

Leaper, C. (1995). The use of masculine and feminine to describe women's and men's behavior. *The Journal of Social Psychology*, *135*(3), 359–370.

Lecointre, C., & Toublanc, J. E. (1997). Psychological indications for treatment of tall stature in adolescent girls. *Journal of Pediatric Endocrinology & Metabolism*, *10*, 529–531.

Lochman, J. E., Dain, R. N., & Babick, K. (1984). Interactive effects of cognitive sets, interviewing styles and subjective expectancies on perceived satisfaction. *Family Practice Research Journal*, *4*(2), 110–121.

Morris, A. (2000). Bad Medicine, *The Big Issue* (pp. 17–19). Melbourne.

Normann, E. K., Trygstad, O., Larsen, S., & Dahl-Jorgensen, K. (1991). Height reduction in 539 tall girls treated with three different dosages of ethinyloestradiol. *Archives of Disease in Childhood*, *66*, 1275–1278.

Prader, A., & Zachmann, M. (1978). Treatment of excessively tall girls and boys with sex hormones. *Pediatrics*, *62*(6), 1202–1210.

Roberts, J. V., & Herman, C. P. (1986). The psychology of height: An empirical review. *The Ontario Symposium*, *3*, 113–140.

Ross, C. K., Frommelt, G., Hazelwood, L., & Chang, R. W. (1994). The role of expectations in patients' satisfaction with medical care. In P. D. Cooper (Ed.), *Health care marketing: A foundation for managed quality* (pp. 55–69). Gaithersburg, MD: Aspen Publishers.

Sheppard, J. A., & Starthman, A. J. (1989). Attractiveness and height: The role of stature in dating preference, frequency of dating, and perceptions of attractiveness. *Personality and Social Psychology Bulletin*, *15*(4), 617–627.

Stata Statistical Software [program] (2003). Release version 8.0. College Station TX: Stata Corporation.

Tanner, J. M. (1962). *Growth at adolescence*. Oxford: Blackwell Scientific.

Trygstad, O. (1986). Oestrogen treatment of adolescent girls: Short term side effects. *Acta Endocrinologica Supplementum*, *279*, 170–173.

Venn, A., Bruinsma, F., Werther, G., Pyett, P., Baird, D., Jones, P., Rayner, J., & Lumley, J. (2004). Oestrogen treatment to reduce the adult height of tall girls: Long-term effects on fertility. *The Lancet*, *364*, 1513–1518.

Wettenhall, H. N. B. (1981). The tall child. In C. S. D. Brook (Ed.), *Clinical paediatric endocrinology* (pp. 134–140). Oxford: Blackwell Scientific.

Wettenhall, H. N. B., Cahill, C., & Roche, A. F. (1975). Tall girls: A survey of 15 years of management and treatment. *Journal of Pediatrics*, *86*, 602–610.

Whelan, J. (2000). Growth stunt. *The Sydney Morning Herald* (p. 39). Sydney.