

# Maternal attitude towards delaying puberty in girls with and without a disability: a questionnaire-based study from the United Arab Emirates

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## ABSTRACT

**Background** Parental anxiety about the impact of puberty/menses, particularly in girls with severe disability leads to seeking therapeutic pubertal suppression. We aim to explore maternal attitudes and reasons for seeking pubertal suppression.

**Methods** Mothers of girls receiving gonadotropin-releasing hormone analogue therapy in Mafraq hospital, Abu Dhabi were enrolled in the study. A semistructured interview was conducted to ascertain possible reasons for delaying puberty. The study group was divided into girls with a disability with central precocious puberty (CPP) or normal puberty and girls without a disability presenting with CPP.

**Results** 42 mother–daughter pairs were enrolled and divided into two groups; group A: 15 girls with CPP with no disability; group B: 27 girls with disability (10 had CPP (group B1) and 17 had normal pubertal timing (group B2)). Mothers in group A aimed to delay puberty, while in group B, 13 (48%) mothers desired to halt puberty and 7 (26%) requested permanent surgical intervention. Fear of short stature (15, 100%), inability to cope psychologically (10, 67%) and fear of peer rejection (9, 60%) were the main concerns in group A. In group B, mothers were concerned about menstrual hygiene management (25, 92.5%), fear of child abuse or unwanted pregnancy (15, 55%) and fear of inability to express pain/discomfort with menstruation (8, 30%).

**Conclusion** Mothers of girls with a disability commonly seek medical help to delay/halt puberty due to concerns about menstrual hygiene. Short final height was the main concern for girls without a disability. Culture and religion play an important role in puberty management in girls with a disability.

## INTRODUCTION

Childhood disability has a major impact on the affected child and families. A Census report from the USA showed that there are over 5 million children under 18 years having disabilities.<sup>1</sup> The endocrine system is highly affected by disability with effects on the hypothalamic pituitary function, bone health, pubertal timing, sexual function and

## What is already known on this topic?

- Puberty suppression may be sought for girls with a disability for improving quality of life.
- Gonadotropin-releasing hormone analogue therapy is an option for pubertal suppression in girls with and without a disability.
- Surgical intervention for permanent suppression of menstruation is occasionally considered by families of girls with a disability.

## What this study hopes to add?

- Mothers of girls with and without a disability have different reasons for seeking advice on puberty suppression.
- Cultural and religious issues may influence the attitude of mothers on puberty suppression.
- Concerns about menstrual hygiene and fear of short adult height were the most common reasons for seeking puberty suppression in girls in the United Arab Emirates with and without disability, respectively.

fertility. Accordingly, assessment of pubertal changes should be an essential component of the multidisciplinary care for children with disability.<sup>2</sup> In this group of children, puberty poses various challenges particularly in relation to management of menstruation. It is reported that 50% of families of girls with disabilities seek medical advice in relation to menstruation management.<sup>3</sup>

Children with neurological impairment have a higher risk of central precocious puberty (CPP). Girls with cerebral palsy undergo puberty earlier but reach menarche slightly later than the general population.<sup>4</sup> Families of adolescents with disabilities can present for counselling before or after menarche.<sup>5</sup>

Maternal attitudes towards their daughters' early puberty is influenced by the maturity and the cognitive ability of the girl. While physical care issues related to puberty can be prominent in girls with a disability, other factors might be of more concerns in girls with normal mental development. There is a high level of parental anxiety regarding the impact of menses, particularly in girls with severe disability.<sup>3</sup> Increase in linear growth is a major component of puberty and it is well known that untreated CPP is detrimental to adult height. Parental concerns about growth may be different in children with and without a disability. Parents and caregivers occasionally approach healthcare professionals requesting permanent surgical measures to abolish puberty, which raises ethical dilemmas if the patient is not able to participate fully in consent.<sup>6</sup>

Treating girls with CPP can alleviate psychological distress and delay menstruation.<sup>7</sup> Use of gonadotropin-releasing hormone analogue (GnRHa) therapy to treat CPP is proven to be safe and effective.<sup>8</sup> Advancing puberty and onset of menstruation can raise clinical dilemmas associated with hormonal intervention either to delay onset of menstruation or to reduce the menstrual flow. Although various non-hormonal and hormonal interventions are available for such a purpose, each modality of treatment has advantages and disadvantages. It is of paramount importance to individualise the treatment decisions considering each child's circumstances.<sup>4,9</sup> It is recommended that menstrual suppression therapy should not commence until menarche is achieved.<sup>10,11</sup> However, in certain circumstances, delaying puberty and menstrual suppression can reduce morbidity and improve quality of life both for the girls and for their caregivers.<sup>12</sup>

In the United Arab Emirate and some other Arab and Asian countries, mothers are the main carers of girls with a disability and are more commonly involved in hospital visits and treatment decisions than fathers (personal observation). In our region, pubertal changes in a girl with disabilities can pose significant issues when male family members and helpers are involved in personal care. This stems from both cultural and religious reasons and may contribute to reasons for seeking help to delay or suppress puberty (personal observation).

Understanding the maternal attitude and concerns towards puberty enables healthcare professionals to provide appropriate and culture-sensitive solutions. Highlighting specific issues in a population helps to improve quality of life and maternal satisfaction through provision of appropriate measures.

### Aims of the study

We aimed to explore maternal attitudes towards their daughters' puberty. We also planned to explore the reasons for seeking medical help to delay puberty in girls with and without a disability who presented with normal or precocious puberty.

## PATIENTS AND METHODS

The study was undertaken at the Paediatric Endocrinology department of Mafraq Hospital. A list of girls receiving GnRHa therapy for delaying puberty between 2013 and 2016 was compiled from the clinic database. This list was cross-checked with the hospital pharmacy electronic records for dispensing of GnRHa. All girls in the database were approached to enrol in the study. Mothers of girls on GnRHa therapy were approached to participate in the study during one of their daughters' scheduled visits for GnRHa injection. The study was explained to the mothers and information sheets were given. Mothers who agreed to participate in the study gave a verbal consent and had their daughters enrolled. The study was approved by Mafraq hospital Research and Ethics committee.

The mothers had a semistructured interview by a clinical psychologist (MA) in a one-to-one setting. A questionnaire was designed to include possible reasons for intervening in puberty. The multiple choice of reasons was derived from a literature search on the subject and reflected study team own observation and cultural background of the cohort. The questionnaire was completed during the interview (online supplementary appendix). The mothers were asked to suggest other reasons for seeking pubertal suppression if their reason was not included in the list.

Medical information was collected from the electronic medical record by the study team including: detailed underlying medical condition for girls with a disability, cause of CPP (if established), age at puberty presentation, the initial signs of puberty, and the results of the initial biochemistry and radiology tests.

No formal power calculation was performed. The intention was to approach all eligible patients and enrol all who consent. All girls receiving GnRHa therapy for puberty were eligible for enrolment and they were subdivided into the following groups for analysis:

- ▶ Group A: girls with CPP without a disability.
- ▶ Group B: girls with a disability—subdivided into group B1 with CPP and group B2 with normal puberty.

## RESULTS

A total of 46 girls receiving GnRHa therapy were identified in the medical and hospital pharmacy records. Forty-two mothers consented to the study and their daughters were enrolled. All the families were Muslim, 19 were Emirati, 18 from other Arab countries and 5 were Indian or Pakistani. Fifteen of the girls had no disability (group A). All presented with CPP and were diagnosed with idiopathic CPP after performing full investigations including brain MRI scans. Twenty-seven of the girls had a degree of physical/intellectual disability (group B) with the following underlying causes: cerebral palsy, spina bifida, Arnold-Chiari malformation, hydrocephalus with a shunt, microcephaly, hemimegalencephaly, Biotin deficiency, Rett's syndrome, cerebral dysgenesis, ataxia, intractable seizure and idiopathic developmental delay

**Table 1** Characteristics of study population

Variable	Girls with a disability group B		
	Girls with CPP and no disability group A	CPP group B1	Normal puberty group B2
Number	15	10	17
Mean (range) of age at enrolment (years)	9.6 (7.0–13.0)	9.2 (5.0–11.1)	10.1 (10.3–14)
Mean (range) of age at onset of puberty (years)	6.3 (5.5–7.8)	6.5 (3.0–7.6)	11 (9.5–13.0)
Mean (range) duration of treatment (years)	2.2 (0.2–5.4)	2.6 (1.9–5)	0.9 (0.3–3.1)
Number of mothers intending to delay puberty	15 (100%)	8 (80%)	6 (35%)
Number of mothers intending to stop puberty	0	2 (20%)	11 (55%)
Number of mothers who would consider surgical intervention to stop puberty	0	2 (20%)	5 (29%)

with seizures. Of these 27 girls, 10 had CPP (group B1) and 17 had normal puberty (group B2).

The mean (range) age of group A at enrolment was 9.6 years.<sup>7–13</sup> All had CPP with a mean (range) age at presentation of 6.3 years (5.5–7.8) and were on GnRHa for a period of 2.2 years (0.2–5.4). Of the 27 girls with a disability, those with CPP (group B1) had a mean (range) age at presentation of 6.5 years (3.0–7.6) with GnRHa treatment for 2.6 years (1.9–5.0). For group B2, the mean (range) age at the start of puberty was 11 years (9.5–13.0) with GnRHa treatment for a mean of 0.9 years (0.3–3.1).

From the interview, all mothers of the group A girls intended to delay their puberty, while 13 (48%) of the group B mothers expressed the wish to stop the puberty. While none of the group A mothers considered surgical intervention for stopping puberty, 7 mothers in group B (26%) would consider surgical intervention (hysterectomy) to prevent puberty permanently (table 1).

Fear of short adult height was the main reason identified by mothers in group A for delaying puberty, while none of the mothers in group B had height as a concern. Inability to cope with puberty psychologically was given as a reason by 10 (67%) mothers in group A, but cited less frequently in mothers in group B. Nine (60%) of group A mothers feared peer rejection for their daughters which was not the case in group B. Concern about hygiene management during menstruation was the main concern which was shared by 25 (92.5%) mothers in group B while it was raised by only 4 (27%) group A mothers. Fear of abnormal sexual and emotional behaviour was raised in both groups. However, it was more highly rated by mothers in group B as a reason to delay puberty compared with group A. Over half of mothers in group B feared sexual abuse or unwanted pregnancy in their daughters while it was not a major concern in mothers in group A. Inability to express menstrual pain and possible aggravation of convulsions or chest pain due to wheelchair strapping on the developing breast were all expressed as pertinent concerns by mothers in group B while none were applicable to group A. Around 25 (95%) mothers in group B feared

difficulty in maintaining hygiene during menstruation. Fear of their daughter's inability to express pre-/menstrual pain was expressed by 8 (30%) mothers and 5 (18.5%) of them were concerned about increased convulsion frequency with the progression of puberty. Seven (26%) mothers in group B expressed concern about the difficulty of seeking male family member help if their daughter had progressive signs of puberty, due to cultural and religious reasons (table 2).

**Table 2** Reasons for seeking puberty suppression by mothers. Numbers in italic under percentage indicates the order of frequency of the choice

Reason for delaying /stopping puberty	Number	
	Girls without a disability Group A n=15	Girls with a disability Group B n=27
Fear of short adult height	15 (100%) 1	0
Inability to cope with puberty changes psychologically	10 (67%) 2	5 (18.5%) 6
Fear of peer rejection	9 (60%) 3	0
Difficulty in maintaining hygiene during menstruation	4 (27%) 4	25 (92.5%) 1
Fear of abnormal sexual or emotional behaviour	3 (20%) 5	11 (41%) 3
Fear of child abuse or unwanted pregnancy	2 (13%) 6	15 (55.5%) 2
Menstrual pain that cannot be properly expressed	N/A	8 (30%) 4
Difficulty of seeking male family member help	N/A	7 (26%) 5
Effect on convulsion frequency	N/A	5 (18.5%) 6
Chest pain from pressure of wheelchair harness on breasts	N/A	3 (11%) 7



## DISCUSSION

Parents of girls with early puberty are reported to be worried, embarrassed and concerned about their daughters' inability to cope with early sexual development and possible peer rejection.<sup>7</sup> It is reported that girls who mature earlier than their peers find pubertal adjustment more challenging. Those girls appear to go through various psychological difficulties and can experience detrimental sequelae.<sup>13</sup> Stice *et al* reported that girls who had CPP were at 1.9 times greater risk for depression.<sup>14</sup> In our cohort, two-thirds of the mothers of girls without a disability expressed concern that their daughters might not be able to cope with puberty changes psychologically and might face peer rejection. This concern, however, was infrequent in mothers of girls with a disability. Concerns about how their daughters would cope with the physical changes of puberty were more prevalent in girls with a disability. These concerns included painful breast development and menstrual pain which they might not be able to fully express. In girls who wear a harness in a wheelchair, breast development in puberty can cause discomfort due to chest tenderness with the harness impinging on the developing breast tissue.<sup>15</sup> If the girl is unable to express the pain, this might not be recognised by families and may just manifest as irritability.

There is a high level of parental anxiety regarding the impact of menses, particularly when disability is severe.<sup>3</sup> The anxiety may relate to the impact on the child's medical condition such as on the frequency of convulsions or it may relate to the consequences of puberty. The latter mainly includes hygiene issues for girls with a disability, menstrual irregularities, premenstrual symptoms, cyclical pain (which might not be properly expressed), unwanted sexual contact or pregnancy.<sup>16 17</sup> These issues collectively were more often raised by mothers of girls with a disability in our cohort.

Less severely disabled children may experience a deterioration in their behaviour and demonstrate socially inappropriate sexual behaviour such as public masturbation at an early age, raising family concern about the risk of sexual contact.<sup>15</sup> Abnormal sexual behaviour was an issue of concern in a far greater proportion of mothers of girls with a disability in our study.

Increase in linear growth is a major component of puberty. It is well known that untreated children with CPP have an initial growth spurt then shorter adult height. All mothers of girls in group A raised growth as the main issue when medical advice for puberty delay was sought. Interestingly, none of the mothers with girls with a disability felt that short adult height was an issue. While final adult height might not be a concern for families with disabled children, rapid growth associated with puberty does have an impact on the family and the child with a disability. It raises issues of needing to change medical equipment, such as the provision of an adequately sized wheelchair, progression of scoliosis bracing or altering the size for chest braces or ankle-foot orthoses.<sup>15</sup>

Parent and caregivers may occasionally approach healthcare professionals requesting permanent surgical measures to abolish puberty, which raises ethical dilemmas if the patient is not able to participate fully in consent.<sup>6</sup> All mothers in group A wanted to delay rather than stop puberty. However, 13 (48%) of group B mothers chose stopping of puberty. Surgical intervention (hysterectomy) was a measure that was considered by 7 mothers out of 13. The choice of delaying or stopping puberty did not seem to depend on the daughters' degree of disability. However, further subanalysis was not feasible due to the relatively small number of participants. Concerns about potential treatment side effects, inconvenience or expense may contribute to why a family may consider more permanent surgical methods to avoid menstruation. Two mothers in group B chose surgical intervention with hysterectomy fearing long-term side effects of medical treatment. Use of GnRHa to treat central PP is proven to be safe and effective.<sup>8</sup> However, these medications are relatively expensive when compared with other treatments that can be used to delay or abolish menstruation, and GnRHa are very rarely covered by medical insurance policies. In addition, it is an injectable form of medication which is often a traumatic experience and can cause sterile abscesses. In our cohort, one girl developed an abscess at the site injection which subsided and did not recur on further injections. Treatment with GnRHa requires attention to dosage and interval of injection to avoid intermittent bleeding. The initial injection had a stimulatory effect and two girls had vaginal bleeding after commencing treatment. Another girl had intermittent bleeding during the first 9 months of treatment that subsequently subsided. Overall, GnRHa was found to be an acceptable form of treatment in our group particularly with the low frequency of injection by using the depot form. However, it can be a challenge to persuade the mothers to stop the medicine after the treatment period is completed to avoid long-term side effects, especially the effect of GnRHa on bone mineral density. Although final height data suggest that the reduction in bone mineral density on treatment is reversed by the time final height is attained and peak bone density is unaffected,<sup>17</sup> it is recommended to avoid the long-term use of puberty antagonists.<sup>11</sup>

In our region where mothers may be assisted by male family members and male helpers when undertaking care such as bathing, transferring and lifting their daughter with disability, there are significant issues and difficulties in utilising male help as their daughter matures. Involving a male helper in these daily routines involves physical exposure of the growing girl which might not be acceptable to the mother or the male helper. This stems from both cultural and religious reasons and might be a reason for seeking help to delay or abolish puberty (personal observation). In our cohort, over a quarter of mothers interviewed expressed this issue as a major concern.

Our study shows that early pubertal changes in girls with a disability are associated with major concerns. Mothers of girls with a disability seek medical help to delay puberty due to various reasons, particularly, fear of the difficulty in maintaining hygiene during menstruation. In comparison, short adult height is the main concern expressed by mothers of girls with CPP without a disability. Culture and religion have an impact on the decision-making of delaying puberty and some families would consider surgical measures to stop puberty in girls with a disability.

Limitations of our study include the use of a quantitative questionnaire methodology in a relatively small sample size, and it would be valuable to further explore the differences in a larger cohort. Another limitation is that we explored maternal attitudes through a retrospective study of girls already on treatment and the answers given may be subject to recall bias. It may be more pertinent to explore these questions prospectively. The maternal attitudes highlighted in this study reflect the social, religious and cultural norms of this geographical region and further studies in other populations would be needed to be able to generalise the results more widely.

**Contributors** AD: designed the study, applied for ethical approval and wrote the manuscript. MA: designed the questionnaire and interviewed the study participants. AAZ and ZS: collected patients' data and collated the results. SA, HAS and NAQ: clinicians who recruited the study subjects. SE: revised the study proposal, advised on the questionnaire design and revised the manuscript.

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