

Hysterectomy in the Intellectually Disabled Girl - From the Perspective of Indian Mothers

Mehnaz Abdulla¹, Annie Rajaratnam²

How to cite this article:

Mehnaz Abdulla, Annie Rajaratnam. Hysterectomy in the Intellectually Disabled Girl - From the Perspective of Indian Mothers. Indian J Obstet Gynecol. 2019;7(1):49-53.

Abstract

Introduction: The practice of hysterectomy in intellectually disabled individuals has raised a lot of controversy in both the medical fraternity and the general public. The request comes from the primary caregivers mostly parents in view of not being able to maintain menstrual hygiene and the fear of unwanted pregnancy. *Materials & Methods:* Twelve Indian mothers of daughters with intellectual disability were interviewed to study their perception regarding the hysterectomy for menstrual suppression. *Results:* Six mothers had considered hysterectomy due to difficulties related to menstrual cycle whereas another six had not thought about it and were either undecided or did not think it was appropriate. *Conclusions:* Half of the study population perceived hysterectomy as an option for menstrual cessation. This highlights that service providers should offer appropriate reproductive health education to primary caregivers about various options available for menstrual manipulation. Treatment policies should be clearly defined with the scope for tailoring individual needs.

Keywords: Hysterectomy; intellectually disabled; Indian mothers; perspective.

Introduction

In adolescents with disabilities, the onset of menarche can cause

significant disruption to their lives as well as the lives of their caregivers. In those who are Intellectually Disabled (ID), the inability to communicate and comprehend makes it even more difficult to manage in terms of maintaining menstrual hygiene. Factors such as thyroid disorders in trisomy 21, altered prolactin levels due to use of mood stabilising drugs and Poly Cystic Ovarian Disease (PCOD) in those with seizure disorders predispose them to menstrual irregularities [1,2].

Other factors that may complicate care of these individuals during menstruation include increased neurologic problems eg. seizures, and the presence of orthopaedic disorders such as deformities, contractures, and spasticity [3]. A seldom acknowledged fact is that there is a lack of knowledge on part of parents or clinicians regarding appropriate gynaecological care [3]. In our country, adolescent gynaecology has still not been explored optimally [4]. The gynaecological issues of adolescents with ID are rarely addressed.

In the recent past, there has been a lot of controversy in the western countries regarding the practice of hysterectomy in females with ID as a method of menstrual cessation and protection against

¹Final Year Post graduate ²Associate Professor, Department of Obstetrics & Gynaecology, Yenepoya Medical College, Mangalore, Karnataka 575018, India.

Corresponding Author:
Annie Rajaratnam,

Associate Professor, Department of Obstetrics & Gynaecology, Yenepoya Medical College, Mangalore, Karnataka 575018, India.

E-mail: annierajaratnam@yahoo.com

Received on 22.12.2018

Accepted on 14.01.2019

unwanted pregnancy. An example is the case of Ashley X in which the parents of a severely disabled young girl opted for estrogen therapy, hysterectomy and breast bud removal with the intent to reduce her projected adult height and discomfort associated with menstruation. Even though the aim was to improve her quality of life and to ensure better care by her parents, this had evoked a mixed response in both the medical fraternity and general population [5]. The Ashley treatment is the name given to a series of medical and surgical procedures that inhibit both somatic growth and sexual development in profound intellectually impaired patients which is one that is being currently debated in terms of ethical consideration [6].

The purpose of this qualitative study was to inquire regarding the perception of parents of ID girls with regards to hysterectomy as a means of menstrual suppression.

Materials & Methods

Interviews were conducted among mothers of ID girls residing in and around Mangaluru regarding their perception towards hysterectomy in their daughters for menstrual suppression. The study population included mothers of girls with Down's syndrome, cerebral palsy with intellectual disability and low functioning autism. A semi-structured questionnaire was used to guide the interviews with the mothers. The questions investigated the perception of the mother towards hysterectomy.

Schools catering to ID population situated in Mangaluru were identified and details regarding the study were communicated to the heads of the institute, who in turn notified the parents regarding the same. The parents who consented to participate were interviewed. A total of 35 ID individuals who had attained menarche were identified. The interview of mothers of such individuals was conducted. One was excluded as she was aged 34 years and had already undergone hysterectomy for heavy menstrual bleeding with fibroid uterus. Twelve were excluded as they were aged above 19 years. Ten participants were accompanied by their primary caregivers who were employees of a residential school for the ID. Consequently, 12 mothers who were the primary caregivers were interviewed.

Results

The demographic characteristics of the mothers and their children are depicted in (Table 1). Eight

of the mothers were in their 30s whereas the remaining 4 were in their early 40s. Nine were married and living with their spouses, 3 were single mothers. The education levels varied, the highest being graduate degree. Most of the mothers were unemployed, even those educated elected to stay at home to provide adequate care to their daughters. Two of the single mothers were self-employed (one was a tailor, the other had a small farm) 1 was a teacher and living in a joint family. Two of the mothers suffered from chronic joint and back pain. They attributed it to the many years of carrying their growing daughters who were immobile for their activities of daily living such as bathing, toilet use, transfers from a wheelchair to bed and vice versa. The ages of the daughters ranged from 12-18 years, all having attained menarche. The medical conditions included severe and profound ID, Down's syndrome with profound ID, hydrocephalus with meningomyelocele and low functioning autism.

Attitude towards hysterectomy

Hysterectomy for menstrual cessation had been thought about or even been discussed with or advised by family/ health care workers in 6 participants. Three of these mothers had approached healthcare workers and 2 were advised to wait until their daughters were around 19-20 years. No medical, ethical or legal reasons were given for the deferment. One was advised alternate methods, and they opted for a Levonorgestrel-releasing intrauterine system (LNG-IUS) for her 16-year-old daughter with Down's syndrome with profound ID. Two mothers had discussions with their spouse and other family members, and the consensus was to opt for a hysterectomy, but they were reluctant to consult a doctor for the same, both being not sure at what age it could be done. One was advised by relatives to seek hysterectomy for her 18 year old with severe ID but her religious convictions prevented her from doing so. One mother preferred hysterectomy for her 18-year-old with low functioning autism but was afraid of any surgical complications as her daughter had a single kidney. The other 6 mothers had not thought about hysterectomy.

When the question was raised, there was a mixed response. Three of them told that they did not want to subject their daughter to a major surgical procedure and its complications. They were worried about the pain and the fact that their daughters would not be able to communicate regarding it. Two mothers told it was something they needed to think more

about and discuss with their spouse as the thought had not occurred to them till then. One mother said that she could maintain adequate hygiene during her 18-year-old daughter's irregular but scanty menses and hence did not require a hysterectomy. Her daughter had low functioning autism.

Purpose of hysterectomy

All 6 mothers who thought about hysterectomy did so because of difficulty in maintaining hygiene during menstruation or due to severe premenstrual symptoms. None of them gave the prevention of unwanted pregnancy as the primary aim of hysterectomy in their daughters. The mother of a 15-year-old with low functioning autism said, "I had a difficult time initially as soon as she started menstruation as she was refusing to use sanitary napkins and would throw them off as soon as I put it for her. Later she got used to it but keeps asking to change it even when it is just stained. I have to keep an eye when she goes to the toilet as she tends to throw it down the commode."

Another mother with a 16-year-old low functioning autism said, "I notice that few days before her periods are due, she becomes extremely aggressive, and without any provocation, she becomes physically aggressive towards me. As she is growing bigger, it is being more difficult to handle her during these meltdowns and prevent her from hurting herself."

The mother of a 16-year-old with hydrocephalus and meningomyelocele with ID had difficulty

changing frequently due to heavy menstrual bleeding and uses adult diaper during her menstruation, even though it is difficult for her to afford.

Another mother who has a 12-year-old with low functioning autism says, "As my daughter is not able to communicate the onset of menses, she invariably starts bleeding in her underclothes. If the onset is at night, the bed sheets are also stained. Sometimes she removes her pad without my knowledge and bleeds on the floor which is quite uncomfortable for other relatives if they are around."

Knowledge regarding other methods of menstrual cessation

Eleven of the 12 mothers were not aware of other methods of menstrual suppression. One mother had discussed with a doctor and was given the option of LNG IUS which was inserted. At the time of interview 5 months had passed since the insertion and since her daughter was still menstruating she was not sure if she was satisfied as she was told it would induce amenorrhea even though she was explained that it would take some time for complete cessation of menses. Her daughter was 16 years old with Down's syndrome with profound ID.

Discussion

Twelve mothers were interviewed in this study about their attitude regarding hysterectomy for their ID daughters and their knowledge regarding

Table 1: Demographic details of mother and their child.

Mothers	Age (yrs)	Marital Status	Education Level	Occupation	Health Condition	Daughters with ID	
						Age (yrs)	Condition
1	36	Married	High School	Unemployed	Joint pains and low backache	16	Hydrocephalus and lumbar meningomyelocele
2	33	Married	Graduate	Unemployed	None	12	Low Functioning Autism
3	37	Married	High school	Unemployed	None	13	Hydrocephalus and lumbar meningocoele
4	36	Widowed	High school	Teacher	None	18	Severe ID
5	35	Married	Graduate	Unemployed	None	14	Low functioning autism
6	40	Married	Graduate	Unemployed	None	18	Severe ID
7	47	Widowed	Lower primary	Self-employed	Joint pains	18	Low functioning autism
8	35	Separated	High school	Self-employed	None	15	Low functioning autism
9	36	Married	Higher secondary	Unemployed	None	16	Cerebral palsy
10	40	Married	Lower primary	Unemployed	None	18	Cerebral palsy
11	41	Married	High school	Unemployed	None	16	Downs syndrome with profound ID
12	37	Married	High school	Unemployed	None	18	Severe ID

alternate methods of menstrual suppression. The response was mixed, with half the mothers already have thought about and discussed regarding opting for hysterectomy while for the other half the thought had not come across their minds at all.

In the Indian scenario, as in western countries, the opinion is divided regarding whether it is ethically right to perform a hysterectomy in ID girls / women due to the difficulty in maintaining menstrual hygiene and prevent unwanted pregnancy. In a paper reviewing the practices in different countries, in the Indian experience, the study of Sheth and Malpani et al. were quoted [7] in which they argued for the option of hysterectomy, stating that specialist reproductive health services were not economically feasible and hence it would be an effective means of managing menstrual hygiene. However, after certain events such as the hysterectomies that were done on 11 inmates of a government-run institute for ID [8] in the year 1994 a public uproar that followed it, certain guidelines were suggested in an article published in the Indian Journal of Medical Ethics [9].

It was recommended that hysterectomy be limited to women with profound ID and after a thorough study by a panel which should include at least one qualified psychiatrist, one clinical psychologist and a social worker with experience in the problems faced by the ID. There was however, no mention regarding the minimum age. If the hysterectomy was requested due to the inability to maintain hygiene, it should be evident to an external observer that there is inadequate hygiene in spite of adequate care and facilities.

In case there are conditions such as uterine fibroids or endometriosis, then the decision for hysterectomy by a qualified gynaecologist cannot be challenged. The prevention of unwanted pregnancy cannot be an indication as prevention of rape is the legal responsibility of the guardian. Moreover, removal of the uterus does not protect from sexual abuse.

In most western countries before deciding on a drastic measure such as hysterectomy, the case requires to be presented before the court of law for deliberation. In 2010, the family court in Brisbane authorised the hysterectomy of an 11-year-old girl with Rett's syndrome. It was requested by the parents on the opinion of three gynaecologists, on the basis that her epileptic attacks worsened during menstruation [7].

In the United Kingdom, surgical options are only considered for patient benefit and not in view of

difficulties faced by the caregiver. The requests for permanent surgical procedures are approved only in exceptional circumstances [10].

The American College of Obstetricians and Gynecologists (ACOG) committee opinion on menstrual manipulation for adolescents with disabilities mirrors the opinion of the United Kingdom. Parents requesting hysterectomy should be educated regarding the other medical options available [11].

Conclusion

There is, without doubt, a need for defined policies and services especially aimed at the reproductive health of individuals with intellectual disabilities. With these policies as guidelines, adjustments have to be made to match the need of the individuals, their abilities and consider the presence of other medical conditions. The parents / guardians should be made aware of other non or less invasive options such as the use of Depo-Medroxyprogesterone Acetate (DMPA), implants and progesterone releasing Intrauterine Devices. Endometrial ablation can also be considered before hysterectomy. Such undertakings will enable them to make an informed decision regarding the best plan of management for their daughter and is likely to be supported by society as a whole.

References

1. Prasher V. Down syndrome and thyroid disorders: A review. *Down Syndrome Research and Practice*. 1999;6(1):25-42.
2. Herzog AG, Schachter SC. Valproate and the polycystic ovarian syndrome: Final thoughts. *Epilepsia*. 2001;42(3):311-5.
3. Greydanus DE, Omar HA. Sexuality issues and gynecologic care of adolescents with developmental disabilities. *Pediatric Clinics*. 2008;55(6):1315-35.
4. Sebanti G, Rekha D, Sibani S. A profile of adolescent girls with gynaecological problems. *J Obstet Gynecol India*. 2005;55(4):353-5.
5. Edwards SD. The case of Ashley X. *Clinical Ethics*. 2011;6(1):39-44.
6. Freitag L, Liaschenko J. Holding Ashley (X): Bestowing Identity through Caregiving in Profound Intellectual Disability. *The Journal of clinical ethics*. 2017;28(3):189-96.
7. Roy A, Roy A, Roy M. The human rights of women with intellectual disability. *Journal of the Royal Society of Medicine*. 2012;105(9):384-9.

8. Nandan G. Women in India forced to have hysterectomies. *BMJ. British Medical Journal*. 1994; 308(6928):558.
 9. TEAM, Editorial. Suggested guidelines for hysterectomy in mentally handicapped women. *Indian Journal of Medical Ethics*, [S.l.], 2016 Nov;2(2):1. Available at: <<http://ijme.in/articles/suggested-guidelines-for-hysterectomy-in-mentally-handicapped-women/>>. Date accessed: 18 Jun. 2018.
 10. Jeffery E, Kayani S, Garden A. Management of menstrual problems in adolescents with learning and physical disabilities. *The Obstetrician & Gynaecologist*. 2013; 15(2):106-12.
 11. ACOG Committee Opinion, Number 448, December 2009, Reaffirmed 2.
-