Perspectives of Caregivers on Pubertal Changes among Young Adolescent Girls with Cerebral Palsy: a Qualitative Analysis

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ABSTRACT

Purpose: *Girls with cerebral palsy can have limited capacity to cope with pubertal issues. It results in their parents being burdened with additional caregiving during this period. A qualitative study was undertaken among parents of girls with cerebral palsy to understand the caregivers' challenges and concerns.*

Method: *Twenty-one interviews were conducted among purposively selected parents and caregivers of young adolescent girls with cerebral palsy in a tertiary care referral hospital in South India. The interview questions were related to menstrual hygiene, behavioural changes around puberty, fear of sexual abuse, and perceptions about contraception. Transcripts were coded and, after data anonymisation, manual thematic analysis was done using an inductive approach.*

Results: *A total of 6 themes emerged, related to identification of problems, treatment-seeking patterns of the caregivers, social support and perspectives on contraception, pubertal challenges and concerns of parents for the future of their girls. Caregivers reported that puberty in girls with cerebral palsy places an additional burden on the caregivers. They were also worried about the safety of their girl children. Contraception and menstrual suppression were not considered as options. Caregivers wanted education and financial independence for their children.*

Conclusion: *Awareness of methods of managing pubertal issues, shared caregiving responsibility by the family, and customised approach for healthcare*

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interventions are of paramount importance in helping caregivers deal with the transition to puberty by girls with cerebral palsy. Family counselling and therapy can help to allay the parents' fears, worries and tensions

Key words: *menstruation, caregivers, developmental disorders, secondary sexual characteristics, contraception, growth hormone*

INTRODUCTION

Adolescence is the transitional phase which helps shape a young adult (Zacharin, 2009). Cerebral palsy (CP) is one of the leading causes of disabilities, diagnosed in 1-3 per 1000 children and associated with physical and mental disability (Parthasarathy et al., 2013). Many girls with cerebral palsy have limited capacity to cope with issues like menstrual hygiene, abdominal pain (dysmenorrhoea), heavy bleeding, irregular cycles, and infections due to restricted mobility; lack of comprehension can manifest as behavioural changes. Motor disabilities along with intellectual disability influence the self-care potential of these girls as they attain puberty.

Caregivers of girls with cerebral palsy go through various phases in coping with their children's condition: refusal to accept, shock, fear, anger, loss of the ideal child, inability to fulfil normal motherhood as per the norms of the community, and so on (Devesa et al., 2010). Caregivers' efforts to cope with the challenges of rearing girls with cerebral palsy can lead to psychological problems that require counselling (Marilee et al., 2010; Novak et al., 2012; Ogunlesi et al., 2016). Parental anxiety is enhanced due to fear of sexual abuse and pregnancy, hence they are sometimes forced to opt for permanent methods of contraception (Huang et al., 2010). Evidence suggests that there is an unmet need for reproductive health services among parents and children with neurodevelopmental disabilities (Nasrin et al., 2014). There could be higher levels of parental anxiety due to lack of information (Pelchat et al., 2009). Professional guidance and support are required for caregivers, as they play an important role in the transitional care of children with cerebral palsy (Keith, 2008).

There is a paucity of literature addressing these issues and providing context-based solutions. Although healthcare interventions are universal, there is a need to address the social dimensions of parenting when a child with neurodevelopmental disability goes through puberty. Hence, an exploratory study among parents of girls with cerebral palsy was undertaken to understand their challenges and concerns.

Objective

The primary objective of the study was to explore the concerns of caregivers regarding pubertal challenges among girls with cerebral palsy. The secondary objective was to understand the perceptions of caregivers regarding social support and the future of their girls with cerebral palsy.

METHOD

Study Design

This qualitative study is built on the constructs of 'An epidemiological study of gynaecological disorders among girls with cerebral palsy'. It follows a sequential exploratory design, Quantitative→Qualitative approach.

The study was conducted between April 2016 to April 2018. It revealed the growth, sexual maturity and patterns of onset of puberty among the study participants (Rao et al.,2019). Development of sexual characteristics commences at around 9-11 years of age among Indian girls, while girls with cerebral palsy can develop signs of precocious puberty earlier (Backeljauw et al., 2004; Agarwal & Agarwal, 2020).

Parents were asked open-ended questions which enabled the researchers to understand their perceptions and concerns in relation to the onset of puberty among their daughters with cerebral palsy, and the fears regarding their safety and security. The qualitative study aimed at analysing the perceptions and concerns regarding challenges which the parents foresee.

Participants

Caregivers of girls with cerebral palsy in the age group of 6-12 years, who had admitted their children to the hospital for treatment, were selected for the study. A basic proficiency in the local dialect (Kannada) was required. Participants were purposively selected following the quantitative study to ensure broad representation of various levels of cerebral palsy as per the GMFCS-ER. The nature and purpose of the study were explained, and informed consent was obtained from the participants.

The interviews were conducted in classrooms adjacent to the orthopaedic hospital wards where the girls with cerebral palsy were admitted for treatment between April 2016 and April 2018.

Study Tools

The interview guide consisted of the following domains:

1) Activities of daily life;
2) Menstrual hygiene;
3) Behavioural changes around the onset of puberty;
4) Parental fear of sexual abuse; and
5) The perceived role of contraception for the girl with cerebral palsy.

These domains were based on inputs from a review of the literature and subject experts. The interview guide was pilot-tested among 3 caregivers of girls with cerebral palsy who could speak Kannada language. Audio recording of the interviews was done during the study, using Olympus (model no – WS 812).

Data Collection

A total of 25 parents were approached for in-depth interviews. Among them, 3 parents were not willing to participate in the study. Each interview lasted for 25 - 75 minutes. The interview commenced with an explanation of the purpose and nature of the study, after which informed consent was obtained from the caregiver. Following the introduction and the rapport-building questions, the interviews proceeded with questioning across domains decided earlier. The line of questioning followed the pattern and nature of responses by the caregivers. Probing was used where necessary. Notes were taken during the interview for non-verbal responses and other relevant field information.

Data Analysis

A unique identification code was assigned to all audio-recording files. The identifiers were cleaned from the transcripts once the unique identification code was allocated. The transcripts were read repeatedly to identify frequently reported patterns, in terms of both similarities and differences. They were coded and extensively elaborated, followed by development of themes in keeping with the study objectives.

Ethics

Ethical clearance from the Institutional Ethical Committee was obtained before the study commenced.

RESULTS

Table 1 shows the characteristics of the respondents who participated in the present study. Most of the participants were mothers. Five of them were caregivers of pre-menarcheal girls with cerebral palsy. Two mothers were separated from their respective spouses because of their daughters' cerebral palsy condition. The qualitative analysis revealed 6 major themes with subthemes among each of them.

Table 1: Characteristics of the Respondents

Participant number	Cerebral Palsy level of child	Age	Gender	Education	Occupation	Relationship with Girl with Cerebral Palsy
1	1	42	Female	9th std	House-wife	Mother
2	3	36	Female	Primary	House-wife	Mother
3	4	42	Male	Primary	Electrician	Father
4	5	36	Female	Primary	House-wife	Mother
5	1	38	Female	Primary	House-wife	Mother
6	1	40	Female	Graduate in Special Education	Teacher in Special School	Mother
7	3	38	Female	Graduate in modern medicine	Doctor	Mother
8	1	Parent was unaware	Female	Illiterate	Homemaker	Mother
9	2	40	Male	Primary	Coolie	Father
10	5	32	Female	Graduate	State Govt Employee	Sister
11	3	38	Female	Primary	House-wife	Mother
12	1	Parent was unaware	Female	Primary	House-wife	Mother
13	4	32	Female	Primary	House-wife	Mother
14	4	Parent was unaware	Female	Illiterate	House-wife	Mother
15	1	33	Female	Primary	Security	Mother
16	1	34	Female	Primary	House-wife	Mother
17	1	35	Female	Primary	House-wife	Mother
18	4	45	Female	Pre-primary	Tailor	Mother
19	3	40	Female	Graduate	House-wife	Mother
20	1	36	Female	Pre-primary	Labourer	Mother
21	1	36	Female	Pre-primary	House-wife	Mother
22	1	18	Female	Pre-primary	House-wife	Sister

Theme 1

Identification of the Disability

The caregivers shared various early childhood symptoms of their wards, such as seizures, and mentioned their visits to doctors. In one case, the child visited the doctor about 7 months after onset of symptoms in Mysore. After treatment, the symptoms started to reappear almost every month. The child was taken to a hospital in a city nearby where the doctors recommended medicines to be taken for a period of 7 years.

Concerns about Delayed Milestones

Growth was observed to be slow among girls with cerebral palsy in comparison to their peers without disabilities. One of the caregivers revealed that her daughter started to sit only at 2 years of age. The parents bought her a 3-wheeler walker, which the child used to push around and walk a little.

In another case, the caregiver revealed that the child was advised continuous physiotherapy for six months. She was born prematurely with a weight of just 650 grams, and the parents had little hope of her survival.

About experiences with physiotherapy, one of the parents stated:

"In our town, physiotherapy sessions are conducted but clients experience a lot of pain, and hence we brought the child to Manipal hospital" (42-year-old father of a 6-year-old girl with cerebral palsy).

The caregiver further revealed that the child's growth was slow even after 1 year of age, and it was then considered a problem.

Concerns about IQ and Memory

The caregivers shared that compared to their peers, girls with cerebral palsy have low intelligence and are poor in studies; however they do remember what they watch on television and in cinema theatres. At home, they remember every word spoken but have issues with regard to grasping the lessons at school. One caregiver revealed that her daughter understands things after they are repeated twice or thrice.

Difficulty in Walking and Related Implications

One parent revealed that the child was kept in the Intensive Care Unit for about 60 days after she was born. As the child grew, there was weakness in her leg and it was bent. After she started going to school, she complained of pain in her legs.

The 36-year-old mother of a daughter with cerebral palsy explained:

"The child does everything with her legs, eating, playing games on mobile. She sweeps and mops the floor (with her legs), *plays with toys, everything with legs. No power in hands at all."*

Theme II

Treatment-seeking for Menstrual Issues

The treatment-seeking behaviour of the participating parents reveals that they sought immediate resolution of their children's problems. They would not take the child for treatment to the same doctor if there was no improvement. After repeated visits to doctors and hospitals, parents expressed frustration and helplessness and some burnt their child's clinical records**.** Most of them had spent lots of money, taken loans ('*saala*') for their children's treatment and they said they could see only minor improvements after all the cycling and other exercises to which the children were subjected.

A 32-year-old caregiver, sibling of a girl with cerebral palsy, said that there was some improvement in the functioning of her sister's legs:

"Just 3 years only. Previously mummy used to bring her for physiotherapy. It seems they said there are no hopes. So they stopped coming."

The dependency of the children was a big worry for the caregivers. The ultimate aim of seeking treatment was to make the children independent in their daily activities.

Theme III

Caregivers' Perceptions on Pubertal Challenges

The study revealed that caregivers had observed the physical changes in girls with cerebral palsy such as breast development, hair growth in the armpit and pubic areas, and onset of menstruation. A few caregivers shared that young adolescents reported pain in the breasts if touched while bathing. Some reported that the adolescents had irregular menstrual cycles, fortnightly or monthly, white discharge and itching in the private parts.

"Sudden development of the breasts, large in size, embarrassed my child and she became very conscious of her appearance after that" (36-year-old mother of a young adolescent with cerebral palsy).

Most of the caregivers reported that their girls suffered painful periods with heavy bleeding during the first three days, followed by a gradual decline on the 4th and 5th days. Some of them complained of clots during menstruation, symptoms of persistent backache, abdominal pain, and leg pain. None of the caregivers had sought any professional advice for these symptoms. One respondent shared that her child's abdominal pain was severe on the first day but would subside after that and did not require medication.

Use of Pads during Menstruation

Majority of the caregivers reported the use of cloth pads rather than sanitary napkins, for different reasons. They believed that cloth pads were useful during heavy bleeding, were more absorbent than sanitary pads, and are cheaper and easily available at home. It is easy to clean cloth pads and change the cloth every alternate month. Since these adolescents sit for longer hours, staining of undergarments and seats occur; so the caregivers cut up saris and used big pieces of cloth beneath the undergarments to avoid staining. Cloth pads are used on the first three days when the bleeding is heavy, followed by the use of sanitary pads. Interestingly, one mother reported that since the men at home would not go out to buy sanitary pads, they use cloth pads even if sanitary pads are recommended by the doctor. They reported that they had to do everything by themselves to take care of their daughters.

Practice of Menstrual Hygiene

For the majority of the adolescents, the caregivers took charge during their periods. Knowing the importance of hygiene, they cleaned the private parts of adolescents periodically during menstruation. Girls with cerebral palsy accept the help of the caregiver initially but learn to be independent as they grow up. The caregivers changed the pads depending on the requirement. For a few, it was changed once a day. The adolescents did not give trouble during cleaning or changing the pads. A young adolescent shared with the caregiver that she felt cursed for having been born as a woman.

One mother specifically pointed out that she takes the adolescent outdoors so that she feels happy during this “critical phase”. She mentioned that the adolescent becomes more irritable when at home. Parents shared that it was difficult to identify the mood of their child during menstruation, as they are sometimes irritated with parents for not understanding what they want and tend to get short-tempered.

Responses towards the Opposite Sex

Caregivers had observed changes in the girls’ behaviour, such as attraction to the opposite sex, anticipation of marriage proposals, and feelings of shyness to communicate with males, including relatives, especially in answering their questions and stating their names. They express and share everything only with mothers or female caregivers. One respondent said that before she matured, her daughter used to behave like a child but was now like a grown-up woman.

Theme IV

Social Support

Most parents did not take their daughters with cerebral palsy to social gatherings for fear of discrimination. Some of the caregivers reported that their daughters themselves hesitated to go out with their parents. Mothers preferred to stay at home with their children while fathers attended the functions. Some of them said that their relatives question them about the adolescents’ health and they prefer to avoid questions that put them in an embarrassing position. The adolescents shared with the caregivers that they do not like people staring at them during social gatherings.

A few caregivers took their daughters to all functions, without feeling any apprehension or hesitation. They were not bothered about what other people think about them. Some parents also said that they enjoy taking their daughters with cerebral palsy on motorcycle rides.

Support of Parents, Relatives and the Community

Caregivers become tired of constantly caring for their adolescents. They have to do household work, and feel very disturbed by arguments at home regarding physical exercises. While some of them reported that neighbours helped them out, a few acknowledged that some Non-Governmental Organisations were also helpful. They had been helped in paying the school fees. Some caregivers shared that distant relatives always keep in touch with their children.

"Right from when she was young, we have showered her with a lot of love. My uncle and everyone will be calling her regularly; she is in touch with everyone, with cousins. She remembers everybody's birthday. For everyone's birthday, hers is the first wish. At 12 am, she wishes them"(32-year-old sister of an adolescent with cerebral palsy).

Theme V

Key Perspectives on Contraception

Caregivers were aware of the different contraceptive methods but had never thought of using any precautionary measures for their daughters with cerebral palsy. Two mothers reported that their family members had suggested uterus removal for their daughters with cerebral palsy as they did not think they would be in a position to start a family and therefore menstruation would be an extra burden. However the parents were not willing to follow this advice even though it meant taking extra care during menstruation. Caregivers believed that menstruation is normal and good for health, while surgical removal of the uterus would lead to obesity or other side effects in adolescents. Some of the caregivers acknowledged that menstrual suppression would come as great relief, both to their child and for them. The majority of the caregivers were aware of contraceptives but some mothers said they were scared of intra-uterine device insertion for themselves and had opted for sterilisation after the birth of their second child.

Theme VI

Future Concerns and Worries of the Caregivers

a) Marriage

Most parents were very worried about the future as they wondered who would marry their daughters with disabilities. They said that getting an arranged match for their girls – a custom which is still very common in this part of the world – would be tough at present. After marriage, mothers worry about possible pregnancy and delivery of their daughters. A few caregivers also said that financial issues are a cause of concern. They indicated that girls should be economically and socially independent before they marry.

b) Education

The caregivers thought that proper academic education for their daughters would help them in securing jobs and make them financially independent. Education was prioritised even if there were financial constraints.

"*How much ever she wants to learn, whichever school she wants to go* (I will send her). *Her brother is going to a private school. She should not feel bad*" (42-year-old father of a child with cerebral palsy).

c) Security

Parents were worried about the safety of their daughters with cerebral palsy and did not like to leave them alone. A mother revealed that she is more worried since her daughter has attained physical maturity and she hoped that her child would not be abused by any unknown person when left alone. In addition, she mentioned that she has her limitations in guarding and protecting her child throughout her life. These insecurities were not shared by others, including husbands.

Precautions taken for Safety of the Children

The caregivers did not communicate with their daughters about safety issues. They felt that the children lacked the maturity to understand their fears. Parents were afraid that their daughters could be easy victims of rape because of their disabilities. A mother explained that she would lock her daughter in the house when nobody was at home. A few caregivers shared that they lived in joint families and consequently managed to take care of their daughters very well. A few of them said that villages are safer than urban areas.

DISCUSSION

In the present study, parents identified early symptoms of developmental delays in their children as well as abnormal features compared to other children, and shared that they searched for medical treatment. They exhibited a strong treatment-seeking pattern and were willing to opt for surgical treatment of their children in order to make them independent. This finding differed from a study done by Iversen et al. (2009) which reported that caregivers felt helpless and vulnerable as their children could not express their concerns to them due to their disability (Susan et al., 2021).

The current study revealed that there is a significant change in the lives of parents when a child with cerebral palsy is born. All their activities revolve around that child and they do not expect constant support from other sources for caregiving activities. These children are very dependent on their caregivers for physical help in their daily routine. It is however interesting to note that caregivers indicated that their daughters strive hard to be independent. This may be of considerable help in carrying out their daily chores.

Studies have revealed that caregivers of children with cerebral palsy experience high levels of stress and physical tiredness, anxiety and inability to complete daily tasks due to lack of time as a result of the caregiving process for their children with disability (Zuurmond et al., 2015). In the current study, parents have reported physical stress in managing their children as they grow older. Many families were economically weak, and would invest their finances in their child's health rather than spending on themselves (Ramita et al., 2016; Vivek et al., 2018).

Experience of discrimination and isolation during social functions, and avoidance of such functions by parents, are major problems in normalising the lives of these families. This is a social challenge faced by caregivers, along with limitations that they may experience in building and maintaining social relations in their communities.

With respect to menstruation, some of the parents reported that their daughters suffered with heavy bleeding during their menstrual cycles but none of them had sought treatment for this problem. A study by Zacharin et al. (2009) conducted in Melbourne revealed that there was a high level of anxiety among caregivers and more than 50% of them sought menstrual advice even before their daughters attained menarche. However, studies have also emphasised the lack of knowledge of menstrual control among caregivers and that there is an acute need to educate these families and provide them with the necessary information (Grover, 2002; Albanese & Hopper, 2007).

Parents reported that menstruation was good for their child's health and they would not think of uterus removal. In a study by Dizon et al. (2005), a few families of girls with neurodevelopmental delay had opted for hysterectomy and sterilisation for menstrual management. However another study by Grover (2002) advised gynaecologists against giving in to the demands of the parents of such children and to opt for more conservative methods. Caregivers reported educating their girl child to be aware of strangers trying to get close to them or touching them in public places. This was observed more often in families when the girls were around pubertal age.

Limitations

The study was conducted only among Kannada-speaking participants. Interviews were conducted in the hospital setting, which could have influenced the responses of the caregivers.

CONCLUSION

There are several dimensions which have emerged from this qualitative study. Understanding parental concerns will help in facilitating a meaningful approach towards the challenges that they face. Parents' awareness of their children's early symptoms, deformities, low IQ, etc., is important in evolving a user-friendly treatment strategy. One of the important issues which should influence such strategy and interventions is the critical period of menarche. Behavioural changes in girls with cerebral palsy, who experience both shyness and attraction towards the opposite sex, deserve to be handled with care and support. While caregivers indicated that the pattern and onset of pubertal changes was normal, they found that dealing with their daughters' menstruation was challenging and an added burden in the task of caregiving. Economic factors also play a role in maintaining support systems. For instance, limited monetary resources and family support were some of the reasons behind inadequate menstrual hygiene practices. Discrimination and avoidance of social functions are also issues that need attention in shaping programmes and interventions directed at girls with cerebral palsy.

Recommendations

Awareness of better methods for management of pubertal issues, shared caregiving responsibility by family members, and a customised approach for healthcare interventions are needed to help caregivers deal with the transition to puberty among girls with cerebral palsy. Family counselling and therapy can help parents to deal with their fears, worries and tensions. It will also help in reinforcing their roles of supporting each other.

Conflicts of interest:

The authors of the study hereby declare no conflict of interest.

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