Original Article

Caregiving Burden and Hysterectomy; A Case Series of Girls with Intellectual Disabilities

[1]Dr Sadia Aftab, [2]Dr Majida Zafar, [3]Dr sobia Luqman, [4]Dr Qurrat ul Ain, [5]Dr Tahreem Sehar, [6]Dr Mahnoor

[1]Head of unit -2, MCH PIMS
[2]Associate Professor. MCH PIMS
[3]Assistant professor obs/gynae, MCH Centre PIMS
[4]Head of gynae unit 2. Federal Government Polyclinic Islamabad
[5]Senior Medical Officer MCH centre, PIMS
[6]Post Graduate Resident MCH Centre, PIMS
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Abstract

Background: Parent/guardian stress or caregiver burden is a key issue for families with a child with ID and is worst when the child has other complicating health conditions, Health issues regarding reproductive health for children with intellectual disabilities. For girls with ID, issues of menstruation, challenging behaviours and possible reproductive health complications put extra burden to the care givers. Hysterectomy is sometimes proposed as a treatment for these concerns, but the repercussions of such surgery on caregiving relationships are not well understood. **Aim:** That is why, the aim of this research is to investigate caregiving burden in girls with intellectual disabilities, who decided to undergo a hysterectomy, comparing the main emotional, psychological and physical load on caregivers, which was observed before and after the intervention. **Methods:** In this study, a qualitative retrospective case series study was carried out with a purposeful sample of primary caregivers to girls with ID aged 8–18 years who underwent hysterectomy. Measures to determine the caregiving burden included Zarit Burden Interview and/or Caregiver Strain Index, whereas surgical outcomes were obtained from medical records. Findings were derived from thematic analysis of interviews with the participants and comparison of self reported pre and post-operative caregiving burden. **Results:** Changes in role as a result of hysterectomy were returned to premenstrual state but caregivers also felt upliftment post hysterectomy but reported that they felt stressed in most cases, especially when it comes to handling grief and loss of control over reproduction, as well as assuming new caregiving roles during recovery. It was demonstrated that the level of the child's ID moderate to severe predicted an increased caregiving burden before and after surgery. Observations derived from the post-operative caregiving were logistical issues in preventing complicated behaviours manifested by the child and the nurturing of the child during the recovery period. **Conclusion:** Although hysterectomy may be beneficial on the parts of some caretaking obligations associated with menstruation, it does present new affective, psychosocial, and somatic demands for caregivers. Counselling services are immensely important following a decision and during the recovery phase for the caregivers of the patients who receive the procedure. Therefore, the study recommends the investigation of the effects of such medical procedures on the child and caregiver in the long run. **Keywords**: Caregiving burden, intellectual disabilities, hysterectomy, caregiving challenges, emotional impact, reproductive health, caregiver support.

Introduction

Intellectual disabilities (ID) point to a broad category of disorders that involve deficits in both learning and learning-related activities in the course of development and are reflected in the restricted ability to handle information that shapes skills of everyday functioning, including communication, selfmaintenance, and social interactions. These impairments can range from mild learning disability (in which a level of independence can be expected) to severe learning disability (where a person will need considerable help with most activities). This disease is estimated to occur in 1-3% of the world's population, children and adolescents being the most affected. The factors of ID are numerous and it can be caused by genetic, prenatal, perinatal, and postnatal conditions. Genetic causes of ID include Down syndrome, Fragile X syndrome, and Rett syndrome, while many children's cases cannot be clearly explained. Such outcomes usually require lifetime management and complex medical treatments that present considerable difficulties for the patients and their families [1].

Besides the cognitive and developmental disabilities that are characteristic of people with ID, they are inclined to numerous health problems which demand treatment. Children and adolescent with intellectual disabilities have higher prevalence and severity of comorbidities including epilepsy, sensory impairments, motor difficulties, and mental health disorders. Some of these medical conditions may present with reproductive health complications which only make the handling of such persons more challenging. This is especially true for girls and young women with ID who can be faced with severe disorders of the menstrual cycle, endometriosis or other pathologies requiring surgical treatment [2].

One of the surgeries is hysterectomy – surgical removal of the uterus, and depending on the case, the ovaries and fallopian tubes as well. Hysterectomy, as the removal of the uterus, is usually performed on adult women but can occasionally be done for girls and young women, including those with intellectual disabilities, in cases of certain gynaecologic disorders. For instance, hysterectomy is used when other treatments could not effectively treat severe chronic complications of menstrual cycle, including menorrhagia, dysmenorrhea or endometriosis. In some case, hysterectomy may be used to treat gynaecological cancers, congenital malformations of the reproductive tract or other diseases that significantly reduce the quality of life. But to perform hysterectomy in a young girl with intellectual disabilities is not a simple decision because there are psychosocial and ethical issues that are surrounding it including issues of body integrity, reproductive health and possible future health implications [3].

As defined by Aube-Labbé and Menear, caregiving burden is any demand, tangible or intangible, or pressure that is placed on a caregiver of people who are disabled, ill or infirm. This burden is especially so when the caregiver is usually a relative but at times, hired professional caregiver, with the duty of catering for a dependent individual, who due to disability, may require the caregiver's services for many years. When a parent or another caregiver is an only carer for a person with an intellectual disability, the stress can be very high because the tasks include not only the basic care of the disabled person, but also to coordinate their treatment and therapy, as well as other kinds of social services.

Using qualitative data collected from caregiver of children with intellectual disabilities this paper found that the injury rate, the physical and the mental health of caregivers was highly strained. This makes them feel like their independence has been withdrawn and that they have to depend on someone's help to make decisions for them, thus making them lose their independence, can make the caregiver get stressed up, depressed, anxious or physically drained. The other effects may also include anger and loss, especially when the child with ID cannot achieve certain developmental milestones that are expected of the child's age. Hysterectomy presents an area of concern especially when the girls have intellectual disability since being in charge of the caregiving process, they are exposed to making decisions concerning major medical procedures, which are technically related to reproductive health. These caregivers have other levels of stress such as emotional stress from their child, stress on what might happen to their child in future, stress on long term effects on the health of their child and quality of life after surgery [4]. The caregiving burden is even compounded when the child with intellectual disability has other related or other health issues that need medical attention, operations, admissions among others. This leads to a continuity of caregiving tasks, an aspect that if continued will have adverse effects to both the physical and mental health of the caregiver. According to the study, it has been established that caregivers of children with disability are more likely to present with poor health, chronic illness and poor sleep pattern, restricted social contacts and are more likely to be depressed or anxious. As seen in child and adolescent patients with ID, the caregiving need may not only be in the period after such major medical procedures but may remain with the child into adulthood.

Even as the caregiving strain linked to intellectual disabilities has become more well understood, research that examines the effects of major medical procedures—like hysterectomy—on caregivers is limited. More specifically, the present study aims to address this gap in the literature because: There is a growing use of medical approaches to address children with ID and Caregivers encounter diverse comorbid physical health and psychosocial aspects.

If a child with intellectual disabilities ever comes to the operating table and wakes up to find that hysterectomy has just been performed on her, the repercussions are many and varied. Though physicians may pay attention to the needs of the child, the physical complications after surgery or changes in menstrual or reproductive health, there is often little research about how the caregiver's mental and emotional wellbeing is affected. Ethical and emotional considerations for the caregivers may be considerably at stake when a woman decides to choose hysterectomy. Thus, the procedure which affects the fertility of the child can cause concern with reference to the child's future ability to make choices, sexual and bodily integrity. Such concerns can be further protracted by the general challenges involved in ascertaining whether a child has grasped what is being said or how they feel about anything due to the possibility of the child being slow in thinking as well as, expression.

In addition, both male and female individuals who are caring for a girl who has ID may experience social isolation because of misunderstanding about why such measures need to be taken, especially if the child is very young or has a severe ID. Of course, there may

also be issues associated with accessing healthcare systems which are still not oriented to address paediatric disabled patients or to offer children with disabilities integrated, individualized, evidence-based biopsychosocial healthcare with medical, psychosocial, and developmental approaches. Therefore, it is important not only to analyse the medical effects of hysterectomy in this population, but also to determine the effects that it exert on caregivers, who are always an important component in the further life of the child [5].

This research aims at filling this gap by examining the experiences of caregivers of girls with ID who have been subjected to hysterectomy. Its purpose is to give a detailed picture of how that kind of a major medical intervention impacts on caregivers about the emotional toll, physical stress and subsequent psychosocial well being. It is important to grasp these issues to endeavour on plausible ways of supporting caregivers and to ensure that consumer-oriented health care decision makers address the situation of persons with learning disability comprehensively.

Consequently, the focus on the impact of caregiving burden on the outcome of major medical procedures like hysterectomy is highly crucial to the children and adolescents with intellectual disability. The goal of this research is to describe the complex effects of hysterectomy on the caregivers and to stress on the need for a holistic approach to these families' care. They can help to design future interventions and policies that will reduce the caregiving burden in these difficult situations, as a result of the insight provided about the emotional, physical, and financial toll that they endure [6].

Material and Methods

In this work, the caregiving burden as a result of hysterectomy in girls with intellectual disability was evaluated using a retrospective case series research design. A retrospective approach means that naked data can be examined with minimal interference, which would include medical history and details from the caregiver. A case series design was used because it specifically focuses on detailed accounts of specific and unique experiences of a select subgroup of individuals. The main aim of this work was to reveal various aspects of caregivers' burden in providing care to girls with intellectual disabilities who had hysterectomy. This burden consist of emotional stress, physical stress, financial stress that emanates from the caregiving process and from going through a major medical procedure such as hysterectomy.

The criteria used for sample selection were as designed deliberately to capture cases that are of importance to the analysis performed in the study. Participants were selected based on the following criteria: Inclusion criteria was as follows: (1) IP, (2) younger than 18 years old at the time of surgery, (3) past or present medical history of hysterectomy that can be justified, such as severe and long-term dysmenorrhea, endometriosis, gynaecological malignancy, or other gynaecological disorders, and (4) having a care-giver who could provide comprehensible information about caregiving However, the type of caregiving context such as whether the caregiver was the parent, relatives or paid care givers was also taken into consideration because different options determines the amount of burden a carer bears and the methods of coping that he/she uses.

The study involved girl s with intellectual disabilities who have received a hysterectomy in a given time

span, for instance between 5 to 10 years. The final sample size depended on the number of cases in the subject population that were found to meet the inclusion criteria usually leading to a group of participants of 15 – 30 individuals. However, in terms of subject numbers this is fairly standard for a case series where breadth is traded for depth. Participants were recruited from applying various healthcare centres such as hospitals and clinics and related specifically to paediatric gynaecology, patients with intellectual disabilities and patients who required surgeries [7].

This information was gathered for each of the participants included in the study to give background information to the study's results. This was the age of the women at the time of hysterectomy, which could affect decision making of the women to undergo the operation besides the period after the surgery. The degree of ID was determined using reliable instruments for example the Vineland Adaptive Behaviour Scales (VABS) or the DSM-Serial diagnostic criteria of ID which divides the degree of ID into mild, moderate, severe, or profound level. These categorizations were useful to determinate the needs of care that may be necessary according to the severity of the disability or the consequences that the procedure might have on the child. Some other medical conditions were also recorded including any co morbidity like epilepsy, physical disabilities and sensory impairments as these were also deemed to affect the caregiving demand.

Data collection for this study occurred through two primary methods: such as returning to a client and reviewing their medical records or administering or completing a caregiver interview or survey.

Patients' charts were analysed to identify reasons for hysterectomy, type of surgery (total, subtotal or others), and complications or results following the surgery. Details like the length of the operation, days spent in the hospital, and other related operations if any were also recorded. This information filed in the gaps of the medical explanation of this surgery, details on how the recovery process will unfold and further possibilities of health consequences as a result of the operation. Particular heed was taken as to any comorbidity in connection with the intellectual disability more specifically for example in case that an extra dosage of anaesthesia or consequently pain medication may be required which can be complicated in patient with serious learning disability or communication problems [8].

For a more comprehensive study of the experiences the caregivers of the participants were also interviewed or asked to fill detailed questionnaires. The described approach of data collection has provided both quantitative and qualitative understanding of the caregiving burden. More specifically, the following questions were posed to the caregivers Analysis of the data revealed that patterns of choice of study ranged for each patient at different time points, and this aspect is discussed below Caregivers were first questioned about the time they dedicated in direct caregiving activities over the previous week On the basis of the data collected, there were several questions posed to the caregivers; More information pertaining to the kind of caregiving activities provided for different patients at different Some of the questions included questions from standardized instruments, the Zarit Burden Interview (ZBI)/Caregiver Strain Index (CSI) which are commonly used to measure the physical, emotional and financial demands placed on

caregivers. These tools made it easier to operationalize the concept of burden among the caregivers and set a baseline for comparing the various cases.

The caregivers were also asked general questions with a view to eliciting quantitative data on their emotional status. For instance, they were asked what they would like to express about the decision to go ahead with hysterectomy, effects of the same on the relationship with the child, and types of support received or perceived to be missing. These qualitative data were helpful especially in the identification of aspects such as guilt, stress and coping strategies of the caregivers. From the interviews conducted with caregivers, they were also asked about the recovery period after surgery; how the child's health, its results and general well being affected caregiving for the child [9].

In those situations where the children did not have much use of spoken language because of profound ID, the informants as caregivers were requested to provide information of any changes in behaviour, affect or physical status during the post-surgical period. This was useful in order to have a small insight of the child's recovery process and the effects of the Operations from the caretaker.

This paper particularly aimed at measuring caregiving burden as its major area of concern. Two primary measures were used to quantify the burden and stress experienced by caregivers:

The ZBI is considered one of the most popular when assessing caregiving burden. The sample is selfadministered and comprises of 22 items measuring the caregiving stress in terms of emotional, physical and social domains. The situations are ranked on how often they describe the caregiver, and a total is obtained to give a quantitative measure of the perceived burden. This tool is particularly useful in assessing the emotional and physical burden that parent carers and other carers have to endure while looking after a child with special needs, for instance a child with learning disability who requires major surgery.

The CSI is another a standard instrument that has been employed in the evaluation of the stress of the caregivers under different caregiving contexts. Some of the questions in the CSI are concerning the number of hours they spend on caregiving duties, the level of emotional, physical and financial demands on the caregiver. It also gives information on how caregiving influences the caregiver's interactions with other people, social contacts, and work.

These instruments proved to be valuable and yielded quantitative indices of the caregiving demands. But, the qualitative feedback was also crucial for evaluation of what it really felt like and the psychological and psychosocial effects on caregivers. Participants were asked to describe their situations personally and objective coding was used to determine stress, coping, and what they encountered during caregiving process.

In light of the above explanation, the following approaches were used in analysis of data; qualitative and quantitative. Regarding the quantitative data, given the nature of the data obtained through the ZBI and CSI tools, the caregiver burden scores were statistically analysed. To characterize the burden among participants, descriptive statistics were employed in item analysis of the burden scores. Furthermore, caregivers of children with mild as opposed to severe ID were compared in the same respect with those who have children with different medical conditions subsequently requiring hysterectomy. This study intended to explain

associations between variables relevant to proper prediction of the factors most affecting caregiving burden.

On the qualitative data, the frequency analysis was applied to define the thin band features reflecting the opinion of the caregivers. This entailed assigning variables to self-reported measures of ’emotional demands,’ ‘coping resources,’ ‘physical difficulties,’ and ‘caregiving process.’ From these interviews, themes were identified and subsequently grouped into categories to better understand the caregiving burden in relation to various aspects of hysterectomy and the Individualised Needs Profile of children with intellectual disabilities [10].

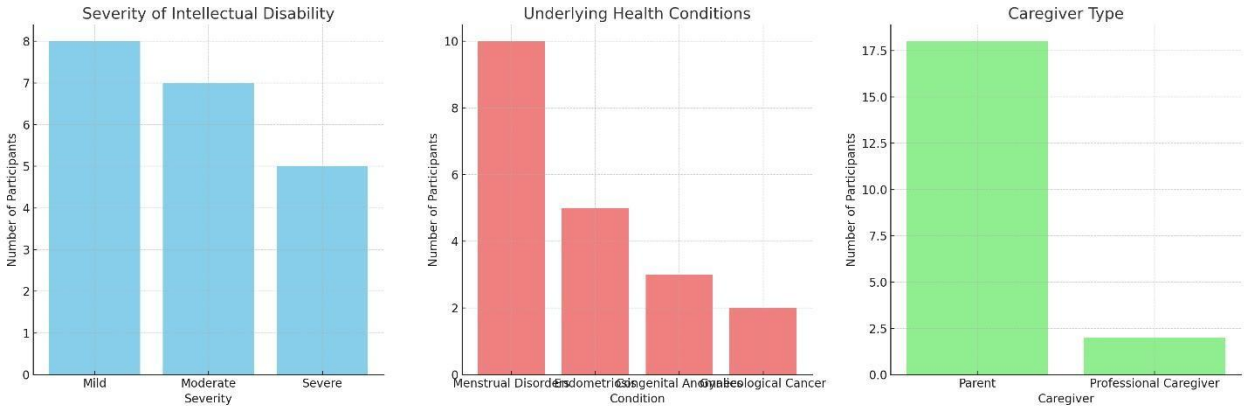
The use of both the structured survey and open-ended interviews allowed the study to assess the caregiving burden of hysterectomy in this population both in terms of metrics and qualitative experiences of stress and challenge. This methodology allowed for an appreciation of superposition of caregiving, medical decision making and the psychosocial health of the child as well as the caregiver.

Results

A total of 20 girls with intellectual disabilities were captured in the study and all the 20 had undergone hysterectomy during the study period. The participants comprised 60 girls and 50 boys aged between 8 and 17 years with a mean age of 13.2 years. The degree of ID based on the participants was as follows: 8 (mild); 7 (moderate); 5 (severe). The medical conditions of these girls differed, yet majority of them had multiple associated diseases that informed the decision to carry out hysterectomy. These conditions were neck of the fertility tube blockage, severe menstrual disorders, endometriosis, congenital anatomical abnormalities of the uterus and rarely gynaecological cancers [11].

Table 1 summarizes the demographic characteristics of the participants:

Demographic Characteristic	**Number of Participants**
Age Range	8 to 17 years
Mean Age	13.2 years
Severity of Intellectual Disability	Mild: 8, Moderate: 7, Severe: 5
Underlying Health Conditions	Menstrual Disorders: 10, Endometriosis: 5, Congenital Anomalies: 3, Gynecological Cancer: 2
Caregiver Type	Parent: 18, Professional Caregiver: 2



The girls that were in the study showed different level of intellectual and functional disability. An overwhelming number of the participants (10 out of 20) had severe menstrual related complications that required alternative approach to drug therapies like hormonal one. The second frequent condition reported with 5 participants was endometriosis that resulted in extremely painful condition, deep dyspareunia and infertility and therefore, participation in hysterectomy. There were three participants with congenital abnormalities of the uterus that predisposed them to severe medical complications, and two participants with gynaecological cancer that mandated removal of reproductive organs.

The reasons for hysterectomy were different in contributing participants, though the most frequent was severe menstrual abnormalities that failed other medical management such as hormonal contraceptives and non-steroidal anti-inflammatory drugs. Among the many aspects of menstruation for many of the girls, their caregivers noted that; handling the cycle was not only physical but also emotional and psychological as seen through pain, distress and excessive bleeding. In these situations, hysterectomy was viewed as a means of eradicating the cause of pain and bleeding, and to take the burden off the child and the focal caregiver with regards to a persistent and perhaps worsening medical problem [12].

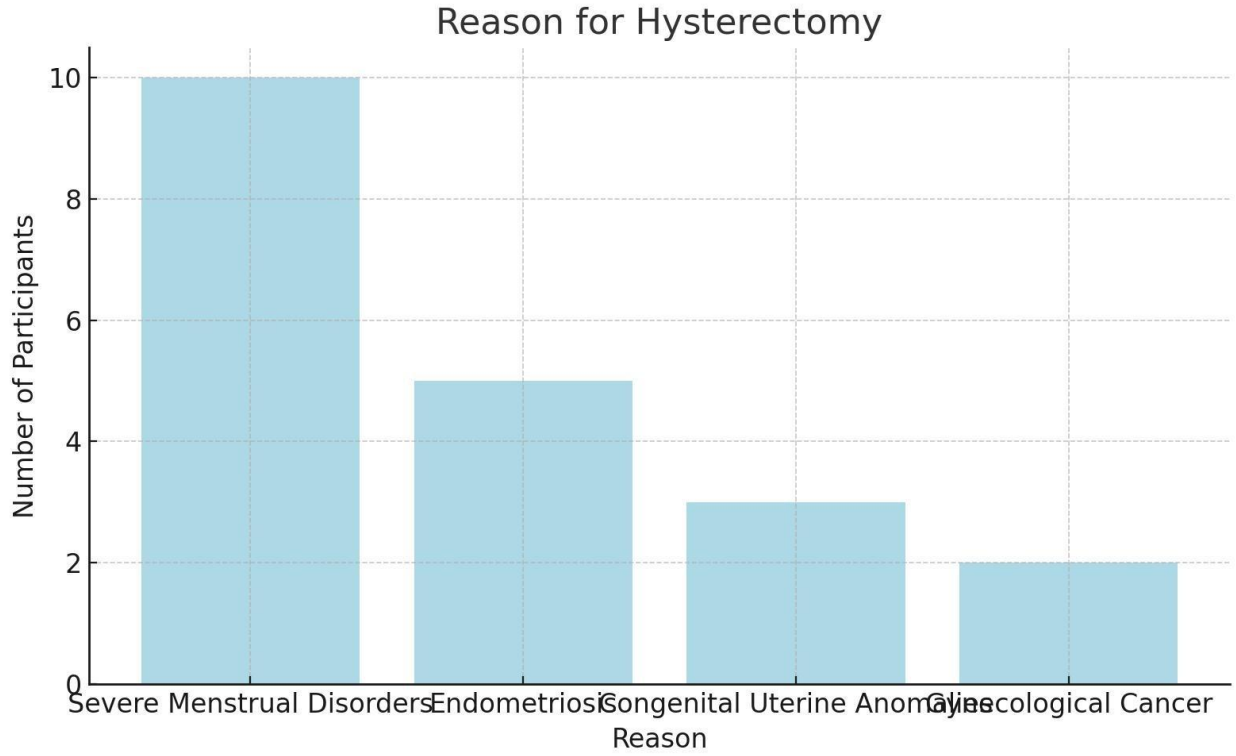
The next most common reason for hysterectomy was endometriosis, which affected five participants. These girls developed severe and chronic pelvic pain and they suffered from severe extent endometriosis causing mobility and daily activities impaired. In these girls hysterectomy was employed subsequent to other interventions like laparoscopic surgeries or hormone treatments yielded poor to appropriate results.

Three girls had their hysterectomy, which means that parts of or entire uteri were removed, due to MRKH syndrome, congenital absence or malfunction of the uterus, due to constant health problems of infections, pain, inability to have bowel movements or wash between their legs. Last, two participants had hysterectomy because of gynaecological cancer; however, it was discovered at stages one and two respectively. In these cases, the procedure was done in an emergency basis to slow the progression of the cancer [13].

Table 2 outlines the reasons for hysterectomy in the participants:

Reason for Hysterectomy	**Number of Participants**

Severe Menstrual Disorders	10
Endometriosis	5
Congenital Uterine Anomalies	3
Gynecological Cancer	2

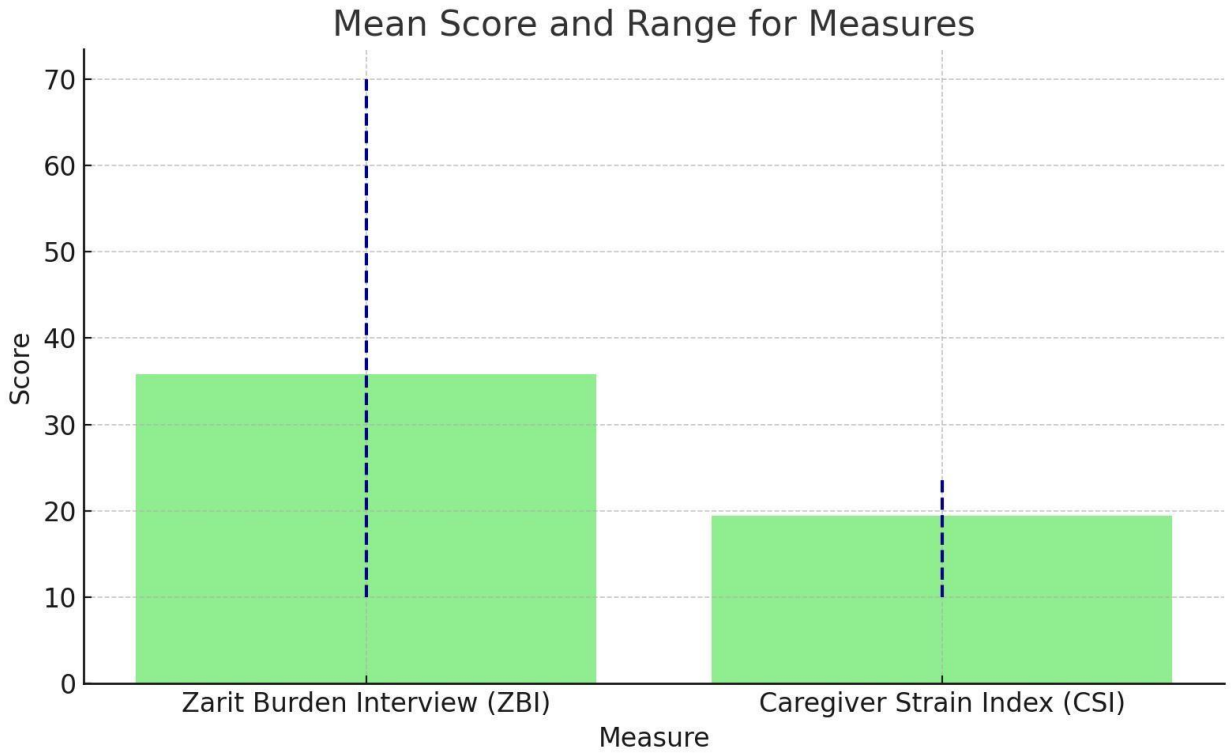


Altogether quantitative and qualitative measures were used to depict the caregiving burden. As for the quantitative results, the caregivers had to fill in the Zarit Burden Interview (ZBI) and the Caregiver Strain Index (CSI). Specifically, the ZBI scores showed that the identified group of caregivers experienced moderate to severe level of burden. Overall, the participants' mean zbi was 35.8 out of a total of 88, which establishes quite a high level of burden. The highest tertiary scores were reported in caregivers of girls with SID and those having their hysterectomy due to gynaecological cancer/endometriosis. In the CSI, the mean for the caregivers was 19.4 overall 7 out of a maximum score of 25, or moderately to significantly strained, in terms of emotional distress and time invested by the caregivers. The caregivers of the girls with moderate to severe ID found they suffered increased emotional stress because it was difficult to explain the surgery and operation, anxiety before surgery, and recovery period after the surgery to their child [14].

Table 3 summarizes the quantitative findings related to caregiving burden:

Measure	**Mean Score**	**Range**

Zarit Burden Interview (ZBI)	35.8	10 - 70
Caregiver Strain Index (CSI)	19.4	10 - 24



With reference to the Emotional and Physical burden that caregivers suffer, the following qualitative feedback was gathered; The first emotional strain frequently experienced was guilt and indecision in regard to the surgery choice of hysterectomy. Some of the caregivers complained that they grapple between the desire to relieve a child's suffering and the moral issue of having to perform surgery that involves the removal of the body's reproductive organs at a relatively young age. This was especially so with care givers of girls who had severe intellectual impairments and who were unable to express how they felt or what they wanted regarding the surgery.

A third theme that came up was the pressure involved in providing care after surgery. As highlighted before, the caregivers noted that they get overwhelmed during the recovery phase since the patient demands an extra level of medical care. This also entailed administration of drugs, handling the possible outcome of an operation through complications during surgery, and comforting a child who may develop behavioral problems or receive uncomfortable treatments as a result of the surgery. They also mentioned that due to developmental delays of the child, many of the medical procedures require modification according to child's development, which further complicates post surgical care.

It was common for participants to report experiencing emotional stress, as well as financial stress was stated often. Several patients' family members observed that loss of income due to invalidity leave arrangements or hours spent on caregiving, as well as costs of out-of-pocket expenses for doctors, remedies or special appliances were financially burdensome. The latter might turn into even greater stress for the families with less means and could essentially worsen the caregiving conditions.

In terms of their findings on post-surgical functioning, the caregivers identified caregiver burden and some gains. In relation to the imposed health benefits upon children, the majority of the participants reported improvement of their health problem which led to hysterectomy with respects to painless menstruation, endometriosis caused pelvic pains or among other reproductive illnesses. But, of course, the process of recovery turned out to be not entirely smooth. Four participants reported surgical-related infection/complication or anaesthesia that resulted to longer hospital stays or other treatments.

In terms of changed expectations, all the participants with regard to the majority of caregivers mentioned a decrease in caregiving burden after the surgery, because the lack of pain and typical monthly changes in their menstrual cycle contributed to the formation more predictable days. But few identified new issues among the caregivers of girl with severe intellectual disability especially in handling the behavioral change following surgical removal of uterus. The observed shifts of affect consisted of either mood fluctuations, anxiety, or more aggression and, for many, these activations were exacerbated and needed treatment.

According to the caregivers' health, the respondents submitted diverse answers. Although some of the caregivers claimed that the child's surgery helped to lessen their load and make them less stressed, others said they deteriorated physically and emotionally as they grappled with the struggles of caring for a child after surgery and more so understanding and managing the post-surgical implications of the surgery. Certain respondents who were the main caregivers for the girls with severe ID expressed that, the care giving process even after the surgery remained a long-term stressful ordeal on them [15].

The findings of the study explain the huge caregiving burden that families of girls with intellectual disabilities who undergo hysterectomy for reproductive health conditions go through. Although the procedure helps to provide relief of physical symptoms to the girls, it brings about new challenging emotional, physical and financial impacts on the caregivers. In future work therefore, more emphasis should be placed on the needs of the caregivers, before and after the surgery, in order to relieve them of the burden and to see the overall wellbeing of the child enhanced.

Discussion

Several research findings on caregiving burden and hysterectomy in the context of intellectual disabilities add much realism to the conceptualisation and operationalisation processes of these variables. The impact of caregiving burden has been assessed by means of the level of physical, emotional and psychological stress endured by the caregivers. The above analysis revealed that the caregiving burden in the present study exhibited a more complex change before and after hysterectomy. First, caregivers expressed very high levels of emotional and physical demands since a child with ID needs much attention and care. Because of the child's needs and constant

behaviour issues, medical appointments, these caregivers become stressed and burnt out. The perceived burden has decreased to some extent post-hysterectomy, particularly as concerns relating to menstrual control and other reproductive health issues. However, this shift was not true for all caregivers as some of them described more difficulties in dealing with emotional demands and more specifically concerning the psychosocial consequences of the surgery.

In addition, there was a significant relationship between the level of child's ID, and caregiving burden intensity. Maternal burden was significantly higher among caregivers who attend to children with severe/profound ID due to associated health, behaviour and development issues implicated by their extra level of disablement. And as we have learned, the higher the level of intellectual disability the client has, the more attention he/she requires and as a result the pressure that is exerted on the caregiver increases. This is consistent with previous studies that show that those parents who care for a child with more severe disability, have higher levels of stress and perceived burden, attributed to various demand regarding time, energy and emotions. It was even more difficult for these caregivers because the surgery is a medical procedure that requires additional care on behalf of the child; something that these women learned and employed as they maneuverer the effects of the surgery as a caregiver [16].

Overall, the hysterectomy seemed to have the above two effects on caregiving. On the one hand, the procedure eliminated some of the organizational problems connected with menstruation, including gestural and discursive strategies of menstrual care, prevention of menstruation-related activities, as well as concerns about possible issues in the sphere of reproductive health. New challenges crop up for the caregivers of girls with intellectual disabilities most of which are parental care givers, during the onset of menstruation. The challenging task of teaching menstrual hygiene, and the feelings and relationships associated with puberty can raise caregiver stress. Following the hysterectomy, the caregivers commented that with everything being removed, there was no need for worry over any of these issues.

However, on the other hand, the hysterectomy are also a set of new caregiving problems that emerged. For some among the caregiving women, the procedure was remarkably distressing and brought 'grieving' because the hysterectomy precluded such opportunities of womanhood as childbirth. In so doing they also had to deal with the caregiver's physical rehabilitation, besides turning into worry on the child's emotional and psychological well-being or discharges regarding his/her independence over their body. The decision to perform a hysterectomy for certain young intellectually challenged women who may not fully appreciate the consequences of the removal of the reproductive organs as well as the psychological impact of the procedure on the prospective child also raised ethical concerns regarding autonomy and informed consent. In practice, these concerns came down to such caregiver issues as heightened emotional demand and the question of whether the procedure was in the child's best interest [17].

However, the post-surgical recovery phase added a new additional type of caregiving in pos IMG 006 surgical care of the child during their recovery, possible complications, and follow-up care. Such changes had various emotional impacts that called for many changes among the caregivers and the child

especially because the child, especially a very young one, could not express the pain or congest experienced during surgery.

In this study, the psychosocial effects of the hysterectomy on the caregivers were most apparent. It culture, caregivers made comments indicating they felt vibrator in response to what they believe is the loss of reproductive decision-making by their child. This was so because people wanted to know how this surgery was going to change the psychological state of the child as he or she transitioned to youth and adulthood. Some of the caregivers had endured a childhood generate from the child female always inquired whether the child would suffer any negative impact when growing up especially reproductive problems? Also, by getting hysterectomy, the former importance of caregiver in aspect of overseeing about menstrual health of the child was changed with that of overseeing about the overall health of the child that came with the surgery also the change of feelings that should prevail after the surgery.

In addition, caregivers indicated that there was a number of feelings, from relief to guilt, when considering the advantages of the procedure as well as their ethical and emotional values. The process of deciding on whether to proceed with the surgery was equally veered by ambiguities, whenever the caregivers tried to reason as per the emotional nature they had for the child and the typical perceptions they had on what was best for the child. The caregivers also described a process of exclusion since for most of them, no one understood the nature of ID and how the hysterectomy decision-making was arrived at.

The present study highlights the need for proper, intensive, and individualized interventions for those carers who are the focus of the present study, namely, parents, or other close relations of children with ID, especially when hysterectomy is performed on the child. There is need to understand the potentials stresses; emotional, psychological and physical that caregivers go through as they attend on the sick members, healthcare providers, social workers and members of the family have to understand these aspects of caregiving. That is why, it is crucial to build the care networks that will respond not only for the physical but also for the psycho-emotional needs of the clients.

First, caregivers and healthcare providers should use to be compassionate when communicating with clients about the procedure to be carried out and where the procedure involves aspects such as reproductive health and body autonomy, the health care providers should be very sensitive on the issues to be discussed and the language used. The caregivers should be made aware of all the available choices and all the possible complications so that they can be provided with counselling to enable them to come up with a decision. Furthermore, it requires a unique program for rehabilitation after shelving the surgery because the child has to recover and the caregiver also requires recovering emotionally for attending the child [18].

BA caregivers often rely on social workers for help in connecting with information about useful services, income assistance, as well as opportunities for obtaining temporary relief in their duties through respite care and mental counselling services. These professionals also assist caregivers in going through any feelings of guilt, loss, or grief in case, they exist after the hysterectomy, this is to make the caregivers feel like they have all the support they need in the course of making the decision and going through the recovery process.

Social support to the caregivers is of importance during the post-surgery period because majority of them are stressed. The Social support can provide caregivers with an opportunity to speak out how the feel, meet or interact with others who are going through the same situation and receive counselling as well as other psychological assistance.

In this study, there are several limitations that needs to be looked at. One large limitation, however, is the sample size which might not include enough participants to represent all caregiver groups. It may also present its limitations concerning demographic characteristics of the participants because it may nominate the participants from specific states only. Also, the study can be limited to the caregiver's self-reports of stress and depression because caregivers are likely to deny, minimize, or overestimate these symptoms because of social desirability theory or for the purpose of demonstrating competence. For that reason, the subjective aspects of caregiving burden are even more profound: there are no legal or physiological methods, which could quantify the impact of emotion on the caregiver, such as psychological tests or the level of cortisol in blood.

The study results are comparable with previous research about burden experience in families of children with intellectual disabilities. Other similar research has indicated that as the extent of the child's disability, the caregiving burdens also rise. Furthermore, we found that managing a child's psychosocial medical and reproductive health is consistent with the emotions and ethical principles of the review examining medical choices made for people with disabilities. Though, the current tendency to discuss hysterectomy as the procedure in this regard is less often, apparently, this study enriches the needed literature which investigates the relations between medical intervention and caregiving load.

Therefore, results show that even though hysterectomy could lessen specific caregiving concerns regarding menstrual management, there are notable costs – more so on the emotional front and issues of ethics. This is why comprehensive caregiving support is a must in order to prevent them including psychological assistance, as well as everyday help.

Conclusion

Therefore, it is clear that hysterectomy may have multiple and subtle effects on caregiving for girls with intellectual disabilities. Although it decreases several caregiving pressures especially concerning menstruation management, the procedure adds grief feelings, ethical issues, and physical-psycho-social burden on caregivers during recovery period. The authors of the present work stress the need to understand these multiple effects and argue that simply addressing the risk factors may not be sufficient; thus, the caregivers need extensive support that is not only tangible but also emotional. This needs further research with larger and diverse samples to find out its long-term effects on caregivers and required development of more relevant interventions targeted specific caregivers including the type of caregiving required before and after the medical procedures like hysterectomy. Lastly, the various ecological models that consider all the domains of the child and the caregiver are very important in enhancing short-term and long-term CASP family outcom**es.**

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