

‘Mothers experiences on menstrual care management of girls with intellectual disabilities’

By
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We the undersigned certify that we have carefully read and recommended to the Faculty of
Medicine, University of Dhaka, for acceptance of this thesis entitled,

“MOTHERS EXPERIENCES ON MENSTRUAL CARE MANAGEMENT OF GIRLS WITH
INTELLECTUAL DISABILITIES”

Submitted by Masuda Akter Mamony, for the partial fulfillment of the requirements for the degree
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List of abbreviations

ADHD	: Attention Deficit Hyperactivity Disorder
APA	: American Psychiatric Association
CRP	: Center for the Rehabilitation of the Paralysed
CPPD	: Cyclic Premenstrual Pain and Discomfort
DSM-IV	: Diagnostic and Statistical manual of Mental disorders, 4 th edition
DSM-V	: Diagnostic and Statistical manual of Mental disorders, 5 th edition
GnRh	: Gonadotropin-Releasing hormone
ID	: Intellectual Disabilities
IQ	: Intelligence Quotient
LH	: Luteinizing Hormone
PMS	: Premenstrual Syndrome
PPD	: Premenstrual Pain and Discomfort
PWDs	: People/Person with Disabilities
SDGs	: Sustainable Developmental Goals
UNICEF	: United Nations International Children's Emergency Fund
WHO	: World Health Organizations

Abstract

Introduction: The menstrual cycle process is same for girls and women but the support level for managing their menstruation must be higher in girls with intellectual disabilities. They need more support for managing and developing menstrual management habit because of their cognitive limitations in understanding, learning, applying and expressing their needs due to limitations in communications. They generally they get support in education, leisure and other areas of self-care activities from professionals but in case of menstrual management their mothers are the only support giver.

Aim and objectives: The aim of the study was to explore the experience of mothers in managing their daughters with intellectual disabilities during menstruation. Study objectives includes identifying type of support, challenges faced by mothers, menstrual impacts and based on the challenges adopt some strategies and recommendations to ease mothers stress and developing menstrual management habit among girls with intellectual disabilities.

Study method: Data was collected by conducting in-depth interview sessions with six mothers of girls with intellectual disabilities and data was collected till saturation. Data were analyzed by using thematic analysis to develop themes that explore the experiences of the mothers.

Results: Researcher identified four themes containing subthemes including 1. various level of menstrual supports (sub-themes- mothers give support before starting menarche , mothers need to understand premenstrual symptoms, first onset of menstrual support by mothers , regular menstrual support noticing, reminding , Mostly mothers are the only caregiver, 2. mothers facing so much challenges (sub-themes- first menstrual reactions management causing stress, care burden causes challenges and stress for mothers, thinking about extra protection issue also cause stress for mothers), 3. achieving menarche has long term impacts both physical and psychologically (subthemes- after achieving menarche girls are growing faster, girls achieve better understanding level), 4. strategies come out from mothers that overcome challenges

and ease mothers emotional distress subthemes- mothers focus on increasing girl's independency level, Support seeking behavior by mothers, mothers focus on increasing girl's independency level, mothers give more importance on professional's recommendations).

Discussion: Although supports from professionals' might ease mother stress and give her hope about future management of menstruation, these type of supports are absent or inadequate. Mothers manage their daughters during their menstrual period by applying their own experiences.

Conclusion: Mothers facing so many challenges and mental stress but they have to manage the situation by themselves due to inadequate sharing platforms and social, religious and cultural taboo.

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Chapter 1: Introduction

1.1 Background of the study

Menstruation is normal process of a women's life that starts during puberty. For the first time it's challenge for every woman but proper guidance and education about handling this situation by mother or other family members will make them able to manage the situation independently until menopause. But the situation is different for women with disabilities because they may need support depending on the severity of their disabilities. Literatures show that menstruation process (regular menstrual cycle- amount of flow, length of cycle) for women with intellectual disabilities (ID) are the same as for women without intellectual disabilities (Memarian & Mehrpisheh, 2015).

Intellectual disability is the disability where the person may have mild to severe problem in understanding, learning new things and applying learning in handling any problem or situation (Gonzalez, Martinez & Bedolla, 2018). So, they have not same capabilities to handle the menstrual care as women without ID. That's why they may need support from caregiver usually mother for proper managing menstrual hygiene including wearing & changing pad, maintain hygiene, cleaning etc. Yaacob et al. have found in their study that mothers always think about their girl reaction about onset of menstruation and how they will manage that situation (Yaacob et al, 2012). As mothers are supporting the girl in other daily living areas like self-care activities, education and leisure activities, managing challenging and disruptive behavior so they take the menstrual care as additional burden which creates high level of stress. Mothers need to give support to their girl with intellectual disabilities in wearing and changing pad, dealing with pain and behavioral difficulties during menstruation (Gonzalez, Martinez & Bedolla, 2018).

Besides facing challenges in managing menstrual hygiene parents also fear of sexual abuse that's why some parents make decisions about hysterectomy and hormone replacement therapy (Yaacob et al, 2012; Greenwood & Wilkinson, 2013). But both hormone replacement therapy and hysterectomy is not morally recommended as hormone replacement therapy has side effect such as osteoporosis (Memarian & Mehprishes, 2015)

and as women with ID also have sexual and reproductive rights (Rugoho & Maphosa, 2017). Although laws in many countries permit hysterectomy for the girl with severe ID to protect them from pregnancy as a result of rape and reduce menstrual management burden (Memarian & Mehprishes, 2015).

In one study, some Indian and Australian some mothers make decision for hysterectomy due to facing some negative experiences such as excessive care burden because menstrual supports are count as embarrassing task by other family members and some mothers take their girl's menstruation as normal process and good for their girl so they feel the need for training and information related to menstrual care of menstruation of their girl with ID (Gonzalez, Martinez & Bedolla, 2018).

1.2. Significance of the study

In Bangladesh there is very limited study related to menstrual issue for women with disabilities and also this issue is understudied for the girl with intellectual disabilities. Some studies are conducted regarding to menstrual health management of school going girls and found that 85% students use old cloths for their menstrual management due to lack of awareness and 40% remain absent in school due to menstrual symptoms like pain, nausea, tiredness etc. (Farhin, 2018; Mahbub et al, 2017). Another study conducted in Bangladesh has found that Bangladeshi women garment workers are more vulnerable to health risk for using spare fabrics or textile waste found on the floor of the factory and 44% women complains contracting from urinary infection (Malik, 2017). Women or girls with disabilities are more vulnerable as they may need support for managing the issue for their limitations although the issue is understudies still now.

In Bangladesh usually girls with intellectual disabilities receives education from special school system where multi-professionals' occupational therapist, speech and language therapist, psychologist and special educators work together for improving their daily living skills, communication skills, academic skills and social skills. Special school girls with ID receives therapy services, vocational training, self-care skills (eating, dressing, washing

activity, cleaning, toileting, personal hygiene etc.) training, leisure participation skills through participating in individual session, group activities, live performance etc.

Although self -menstrual care is important area of self-care skills but there is limited practice related to this area. Usually mothers don't get any information or training from school and manage by applying their own knowledge. Even professionals from their school are not informed about this issue. So, this study has explored mothers' experiences and based on mothers' experiences researcher adopted some strategies and recommendations that will helpful for school authority, professionals to design specific educational and training program for mothers and their daughters with intellectual disabilities. The study findings also will draw the attention of the policy makers for addressing the issue considering mothers' experiences.

1.3. Aim and objectives of the study

The aim of the study is to explore the mothers experience in handling their girls during menstruation and the objectives are-

- a) To explain the type of supports, need to give by mothers to manage menstrual hygiene
- b) To describe the challenges of mothers in managing first menstruation and regular menstrual hygiene including their (mothers) own emotional distress
- c) To explain the impacts of menstruation on the girls with intellectual disabilities (physical, psychological).
- d) To explore strategies that can be adopted to overcome challenges and reduce mother's emotional distress

And result of the objectives indicates the need for implementing training and educational program about menstrual care girl with ID in practice of health professionals, school staff and day center.

Chapter 2: Literature review

Literature review is done by searching different literatures on Google scholar, PubMed, Google by writing research title related terms. The articles which were related to my title and research question and published within the last 5 years were more prioritized and reviewed very carefully explaining my research question related terms.

Intellectual disability is a term where the person has limitation in mental functioning that causes limitation in learning, communication, social skills and taking care of him/her. They may have limited ability in the area of age appropriate new learning and applying those learning practically (DSM-V, 2013). Sometimes their physical development is as normal but mental development become slower according to age. The group of this people also characterized by level of intellectual functioning based on the IQ, who have IQ of 70-75 or less that originates before the age of 18 counts as intellectual disabilities (Greenwood & wilkison, 2013). According to world health organization (WHO), intellectual disability is a *“state of arrested or incomplete development of mind which means that the person can have difficulties in understanding, learning and remembering new things and in applying that learning to new situation”* (WHO, 2011). It is also known as developmental disability, learning disability, mental retardation or mental handicap and intellectual disability (Gonzalez, Martinez & Bedolla, 2018).

The critical components of IQ test including verbal comprehension, working memory, perceptual reasoning, comprehensive reasoning, abstract thought, cognitive efficacy. Judgements, clinical training are required to appropriately interpret the results (DSM-V, 2013). Mild ID refers when the person has intellectual quotient (IQ) range from 50 to 70 and most of them with mild ID can lead independent life within the community with some kind of vocational and social skills training, moderate ID from IQ level 35 to 49 and this group of person need social, vocational and occupational training for leading life within community with the supervision, IQ level is 20 to 40 for severe ID and 20 to 25 for profound ID where person with severe ID also can become skilled in some self-care activities and communication but they need close supervision and the person with profound ID need private and highly support for developing basic self-care skills, communication

skills and motor development by training in a structure environment (DSM-IV, 2000 as cited in Park, 2013). On the basis of the adaptive functioning not IQ score, ID is also classified into mild, moderate severe and profound intellectual disability based on three domain analysis conceptual domain where there are difficulties in academic performances learning, reading, writing, money management and support needed in one or more areas to meet age related expectations (DSM-V, 2013).

Girls with intellectual disability also experience menarche as girls without disabilities. Among 300 students Hosain et al. found in their study that 68% girls reached menarche in age of 12-13 and only 5.705 reached menarche at the age of 9-10 years (Hossain et al, 2014). Every girl has to face this phase during their adolescent age of 10-15 years old (Jaman, Shampa & Rahman, 2010). At this time the girls face some physical changes (wider hip, growing breast and hair growth) and symptoms like abdominal cramps & pain, nausea, headache, backache, tenderness in breast, constipation and emotional & psychological changes like irritability, sadness, anxiety, fatigue, mood swing, insomnia, emotional sensitivity (House, Mahon & Cavill, 2012; Yaacob et al, 2012).

United nations define adolescent as the second decade of life between 10-19 years (UNICEF, 2011 as cited in Samuels, Jones & Hamad, 2017) and during this time boys and girls achieve some changes such as start of menstruation for girls, breast development for girls, hair growth, deepening voice and transition from childhood to adult hood. Jones and Hamad also mention that adolescence is a pivotal time where some changes occur and specially girls have to pass this time with experiencing lot of life changing experiences such as social isolation, bullying by peers, lack of supportive adults and sexual and others violence such as domestic violence (Jones & Hamad, 2017). Adolescent face multiple disadvantages due to age, gender, disability, poverty that create inequality in accessing health information, services and supplies to support them through puberty and girls with disabilities have very limited support in case of menstrual management (Jones et al, 2020).

Tan et al. described the menstrual cycle in their study that menstrual cycle lasts for an average 28 days (Tan et al, 2020) and there are no differences in length of cycle, menstrual flow of girls with and without intellectual disabilities (Memarian & Mehrpisheh, 2015).

Katalinic et al. mentioned that children with ID show pre-menstrual symptoms such as restlessness, hyperactivity, aggressiveness, crying, cramp, weight gain, even seven days before of bleeding seizures can happen which are troublesome for mothers (Katalinic et al, 2012). Yaacob et al have found in their study that half of the parents remain tensed about their daughter's first reaction on the onset of menarche and handling those situations (Yaacob et al, 2012). One qualitative study conducted in India have found that most of the mother prefer to keep the issue secret and skip the necessity of menstrual management training as they like to manage this in their own way but some mothers also state that repeatedly practice the usage, disposal of sanitary napkin by their mother and elder sister some women with ID are independent in their menstrual hygiene (Gonzalez, Martinez & Bedolla, 2018). Mothers have tendency to hide the menstrual issue and stop talking about this issue openly due to social stigma and these can cause fear and anxiety among girls also (Jones et al, 2020).

Menstrual cycle creates additional stress for the family for some behavioral problems such as self-injurious behavior, crying and distracting behavior around the cycle and also can creates some medical problems such as polycystic ovarian syndrome, epileptic disorder, irregular in menstruation which can cause economic burden also (Thapa & Shivakami, 2019). Steward et al. found that during menstruation girls' others associate conditions such as epilepsy can be exaggerated and seizures can be increased during this time.

In one Taiwan study most of the mother take the menstrual management issue as their fate and cope with the issue manage this issue in their own strategic way without discussing this issue with others professionals and strategies are influences by mother's own menstrual management strategies. They use napkin, pad and change this depending on the flow of blood and need to clean underwear frequently and in the night sometime blood piers and unclean cloths and bed which creates extra working load for the mother (Chou & Lu, 2012).

Parents think that although the menstrual hygiene can be managed by support but in future how their daughter can manage this if mothers are not available (Yaacob et al, 2018).

Thapa and Shivakami stated that in India and Nepal girl with menstruation forced to keep in 'menstrual hut' or cowshed for separating the girl from the family and they also stated that not only in Nepal or India in most communities throughout the world menstrual issue is considered as social, religious and culturally restricted issue for ritually unclean (Thapa & Shivakami, 2019) that's why mother is only responsible for managing this issue without involving the others family members (Chou & Lu, 2012). Walia et al. stated in their study that still now there is various misconception and restriction about menstruation among Indian and they count the menstruation as dirty or unclean things even adolescence girls develop negative concept about their physiological phenomena and they have very limited scientific knowledge about menstruation and puberty (Walia et al, 2015). Steward et al found in their study that there is social taboo related to menstruation such as dirty things, things of fear or be ashamed or embarrassed, so to accept it as natural, normal and healthy part of growing young girls need to know the biological information about menstrual cycle, anatomy of the vagina or uterus and causes of happening menstruation (Steward et al, 2010).

Besides managing menstrual hygiene parents or caregiver feel the extra care burden and fear of sexual abuse to their daughter as some girls with ID can't express and maintain their needs, violence. That's why some parents or caregiver make decisions to permanently remove the uterus or other contraceptive methods for avoiding this kind of burdens (Gonzalez, Martinez & Bedolla, 2018; Thapa & Shivakami, 2019). Parents take this decision without taking permission from their daughter with ID as they think their daughter is to naïve to understand which causing the sexual and reproductive right violence of the women with ID (Gonzalez, Martinez & Bedolla, 2018; Thapa & Shivakami, 2019, Rughoho & Mephosa, 2017). In Zimbabwe women with disabilities are forced to sterilization and administration of lifelong contraceptive without their consent (Rughoho & Mephosa, 2017) and society people even family of the people with disabilities have negative attitudes about their sexual and reproductive life (Rughoho & Mephosa, 2015 as

cited in Rughoho & Mephosa, 2017). The United Nations Convention on the Rights of Persons with Disabilities (UNCRP), international law which elaborates the rights of PWDs along with equal access to sexual and reproductive rights for the PWDs (Rughoho & Mephosa, 2017).

Menarche signals the body is now ready for reproductive life or pregnancy (Tracky, Grover & Macgibbon, 2016) for that reason parents become conscious about the risk of sexual abuse & unwanted of their daughter after menarche (Memarian & Mehrprisheh, 2015). In quantitative study of Malaysia have found that majority of the parents fell the risk of sexual abuse of their child and think that irresponsible person can take advantage from their daughter (Yaacob et al, 2018). Another study found that the women with disabilities are seem too weak by abuser so they are more prone to sexual abuse (Rughoho & Mephosa, 2007 cited as Rughoho & Mephosa, 2017).

Literatures shows that although the girl with ID have problem in level of understanding depending on their severity of intellectual skills but all have an ability to learn menstrual management skills and self-protection skills by giving proper training and education regarding to menstrual management, basic reproductive physiology, dealing sexual harassment, aware about good touch, bad touch model, aware about their bodies, puberty, communication about intimacy and sexuality, gender differences based on their level of understanding (Yaacob et al, 2018; Memarian & Mehrprisheh, 2015, Greenwood & wilkison, 2013; Field et al, 2013). Girls with mild intellectual problem have more independency level in managing menstruation, where moderate IDs need supervision support in performing self-care during menstruation and girls with severe or profound ID completely dependent on mothers (Joshi & Joshi, 2015 as cited in Ariyanti & Royanto, 2017).

There is risk of sexual harassment of girls with ID if they need assistance from others for cleaning their bodies so self-care skills training during their menstruation is very important issue and training method depends on the individual unique characteristics (Ariyanti & Royanto, 2017). There is lack of primary research and guidelines on sexual health care to

girls with ID although women with ID have high risk for abuse including sexual abuse. People with ID known as disparity group and their sexual care is very neglect area (Greenwood & Wilkinson, 2013). Adolescent face multiple disadvantages due to age, gender, disability, poverty that create inequality in accessing health information, services and supplies to support them through puberty and girls with disabilities have very limited support in case of menstrual management (Jones et al. 2020).

Wilbur et al found that menstrual restrictions add additional challenges for careers and there is inadequate menstrual hygiene information, training and support such as one participant told that she needed one year to understand the process and experience and one told that teacher sent her daughter from the school to home at the onset of menarche instead giving support (Wilbur et al, 2021). Women with ID feel embarrassing to share and openly discuss about sexual issue so create positive environment like providing adequate information about sexual health and longer appointment needed where everyone can feel comfort to share and discuss openly (Greenwood & Wilkinson, 2013). Group training is more effective rather than training through booklet because mothers have greater understanding and awareness about sexual health care of adolescent girls with intellectual disabilities through group training (Goli, Noroozi & Salehi, 2021).

Wilbur et al. mentioned that based on the SDGs aim 'no one leaves behind' there should be give attention to minority group as women with disability to develop disability inclusive menstrual hygiene management guidelines for making progress within last nine years of the SDGs (Wilbur et al, 2021).

Chapter 3: Methodology

3.1. Theoretical Framework

3.1.1. Hormonal impacts

Menstrual cycle is repetitive process which is controlled by changing level of some hormones in the women body and these hormones are responsible for changing mood during menstrual cycle (Schwartz, Romanis, Meiyappan, Souzal & Einstein, 2012). The menstrual cycle consists of three Phases-Menstrual phase (day 1-5), Follicular Phase (Day 6 to 14, with ovulation occurring at day 14) Luteal Phase (Day 15 to 28) (Levay & Valente, 2006 as cited in Motivation and emotion book, 2015). Gonadotropin-Releasing hormone (GnRh) stimulates Follicle stimulating hormone for maturing follicle where premenstrual symptoms ease with GnRH. Increasing estrogen hormones is associate with high anxiety, irritability which usually occurs just prior to menstruation and progesterone hormone is associated with ease the premenstrual symptoms (Integrative Psychiatry, 2015 as cited in Motivation and emotion book, 2015). Premenstrual syndrome (PMS) describe in the international classification of disease that it is the cyclic recurrent of some symptoms such as distressing physical, emotional and behavioral symptoms which influence women health, behavioral and functional performance and about 30% to 50% of menstruating women experience moderately severe PMS 4% to 14% experience severe PMS during menstrual cycle (Taylor, 2005). These premenstrual disorders are the major challenges and fear of the caregiver of/mother specially girl with disability (Yaacob et al, 2012). Psychological symptoms (Fatigue, difficulty in concentration, irritability, sad, hopeless, anger etc.) may occur before one week of menstruation and symptoms ease during the initial week of menses (Taylor, 2005). Tailor also mentioned that Cyclic Perimenstrual Pain and Discomfort (CPPD) are the pain and discomfort during menstrual cycle and it affects 70% menstruating girl or women.

3.1.2. Cultural and religious beliefs

Menstruation is as biological event as well as social and cultural events. Menstruation and its management are related to female issue. It is perceived socially as natural smelly and bloody. It is socially expected that girl will keep this issue secret and hide from boys and male and culturally also there is many taboo around this issue like girl with menstruation considered as impure and impurity will transfer upon others. Although menstruation is assign of women fertility but girl with menstruation have to feel secrecy, shame, embarrassment, fear and stigma due to surrounding environment (Danielson, 2017). In case of girl with disabilities the caregivers or Mothers also influenced by these factors- culture of society, beliefs, values that's why they feel comfort to give support to their girl in managing menstruation in their own way without sharing with others even involving family members also (Gonzalez, Martinez & Bedolla, 2018).

3.1.3. Impacts of Social learning theory on menstrual reaction

Social learning theory plays role in developing premenstrual symptoms and negative experience during menstrual cycle. One study found that as menstruation is socially accepted to show negative symptoms during this period so women also show negative symptoms and in social learning theory people learn by observing others that means same things or in same situation what other people do (Woods, Mitchell & Lentz, 1995 as cited in Motivation and emotion book, 2015). Emotional changes occur during menstrual cycle as it is socially also expecting that women with menstruation will show emotional changes during this time. For example, if a girl see that her mother shows some emotional changes and negative feeling prior and during this time then the girl also will show the same behavior learned through observing her mother (Janes, 2008). In case of girls with intellectual disabilities mother also manage their girl's menstrual issue from their own experience without discussing the issue with health professionals although facing various challenges (Yaacob et al, 2012). In China Society mothers have the only responsibilities in managing this issue for their daughter who need support so they have to learn or adjust to this society as society also expect that good mother must care to their daughter during menstruation (Chou & Lu, 2012). Social learning explains human learn from observing within society that guide their behavior (Janes, 2008).

3.1.4. Impact on cognitive theory on menstruation

Cognitive theory is also important in explaining causes of premenstrual reactions. Based on this theory both physical symptoms and meaning of these symptoms causes emotional distress. Therefore, when someone feels the body function is out of her control (e.g. menstruation) then she reacts by showing irritate sadness and angriness which causes psychological and physical upset but also develop coping mechanism by overeating or mood swing (Blake et al, 1998 as cited in Motivation and emotion book, 2015). In case of girl with intellectual disabilities as they have wide ranges of cognitive problem like in conceptual knowledge, memory, reasoning, language), social (empathy, social judgment, interpersonal communication, relationships) and practical (personal care, self - management, time and money management, recreation, managing school task) understanding and skills so they need supports, education and resources for adapting daily life (Trackey, 2016). Trackey also found girl with ID take longer time to learn the steps of maintaining menstrual hygiene as they very slow in understanding and memory but the girl who are able in maintaining toilet hygiene will able to be independent in maintaining menstrual hygiene also.

3.1.5. Mothers stress

The main challenges of handling people with disabilities are burden of care e.g. supports needed, medical cost for preventing harm and inclusion barriers e.g. accessing opportunities, social stigma that leads the people with disabilities and family members feeling stress (Bunning, Newton & Hartley, 2017).

3.2 Study Design

The aim of the study was to explore the experiences of the mother in managing menstrual hygiene of the girl with intellectual disabilities so the study adopted qualitative research approach because research has tried to develop theory and some recommendations regarding to the aim of the study with phenomenological study design as researcher has tried to explore the mothers' lived experiences or feelings or perceptions in that particular situation.

3.3 Sampling technique and sample size

Researcher purposefully selected cases which were information rich and matched with inclusion criteria and six mothers of girls with intellectual disabilities were interviewed and data were collected till saturation.

3.4 Data collection tool

The open ended questionnaire was developed by reviewing different literatures and then conducted a pilot study using 2 participants to see the acceptability of the questionnaire against culture, individual understanding. After test researcher made some modifications to the questionnaire and these 2 participant's data were not analyzed.

3.5 Study setting

Study setting were Wiiliam Marie Taylor School, Savar and Alokito Shishu Special school, Mohammadpur and Center for the Rehabilitation of the Paralysed (CRP), Savar in Bangladesh but in case of collecting data research collected data only from two special school and needed to skip the rehabilitation unit because girl with intellectual disabilities take therapy session in special school were not available in the rehabilitation unit and non-school going girls with ID were not available during data collection time.

3.6 Data collection method

Researcher confirmed the diagnosis as intellectual disability by checking documents of clinical assessment of that particular girls with ID. Clinical assessment was conducted combine by different professionals (OT, SLT, Psychologist, Special educators) and clinical assessment criteria are mostly matched with DSM-V criteria of adaptive deficits in the area of conceptual, social and practical domains for identifying mild, moderate, severe and profound ID. The study selected girls with ID who had mild to severe ID and who already achieved monarchy phase considering adolescence age 10-19 years old (UNICEF, 2011 as cited in Samuels, jones & Hamad, 2017) and need support during their menstrual period.

Researcher concerned the participants about purpose of the interview and also concerned about confidentiality issue. After taking consent from the participant's researcher used open ended questionnaire for researcher for conducting face to face interview to the participants. As the research topic was sensitive issue so researcher collected data by individual face to face interview maintaining higher privacy. Each interview session took around 15-20 minutes. Researcher conducted informal discussion with the mothers of school going girl with ID by social talk to build rapport so that they became feel free to share the issue openly. Researcher only recorded answer of qualitative part of the questionnaire by taking consent formally and took answer of demographic part without recording for maintaining confidentiality. Due to unavailability of the ID girls in the rehabilitation unit and pandemic situation researcher only collected data from school going girls with ID and data was collected till saturation of the information.

3.7 Data analysis procedure

After collecting data researcher had made script hearing recording and ensured translation, back translation of the script for the question of acceptability. Researcher used thematic analysis to identify pattern in the data that are interesting and important to address the research question. Researcher performed thematic analysis by becoming familiar with the data, generating initial coding of the data, searching for theme and reviewing the theme, defining the theme and finally writing up for generating theory. Researcher presented result by using quotation box, flow chart and table.

3.8 Inclusion Criteria

- Mothers of daughters with ID
- Girls with mild to profound intellectual disability
- Adolescence age groups: 10-19 years who already achieved menarche phase

3.9 Exclusion Criteria

- Girls with ID with severe physical disabilities and cerebral palsy
- Mother who has hearing, speech disability and mental illness

3.10 Ethical considerations

After getting ethical approval from the Institutional Review Board (IRB), researcher planned to conduct study and after taking formal approval from school authority researcher started to collect data from mothers who present at school. Researcher gave detailed explanation of the purpose of the data collection and the consent form was readout to the participants and all participants were informed about their volunteer participation. All sensitive issues asked to the participants very carefully and ensure them that information would be used only for academic purposes and not for any other purposes. One of mother of a girl with ID rejected to participate so researcher softly rejects this.

3.11 Study limitations

- Researcher has used more clues and facilitation during data collection as participants have tendency to feel shy to share secret issue.so sometimes biased information has been collected.
- Time consuming data collection as researcher needed to conduct informal discussion for building rapport with participants.
- Although researcher planned to collect data from mothers of school and non-school going ID but researcher only collected data from mothers of school going ID due to unavailability of the ID girls in the rehabilitation center and pandemic situation.

Chapter 4: Findings

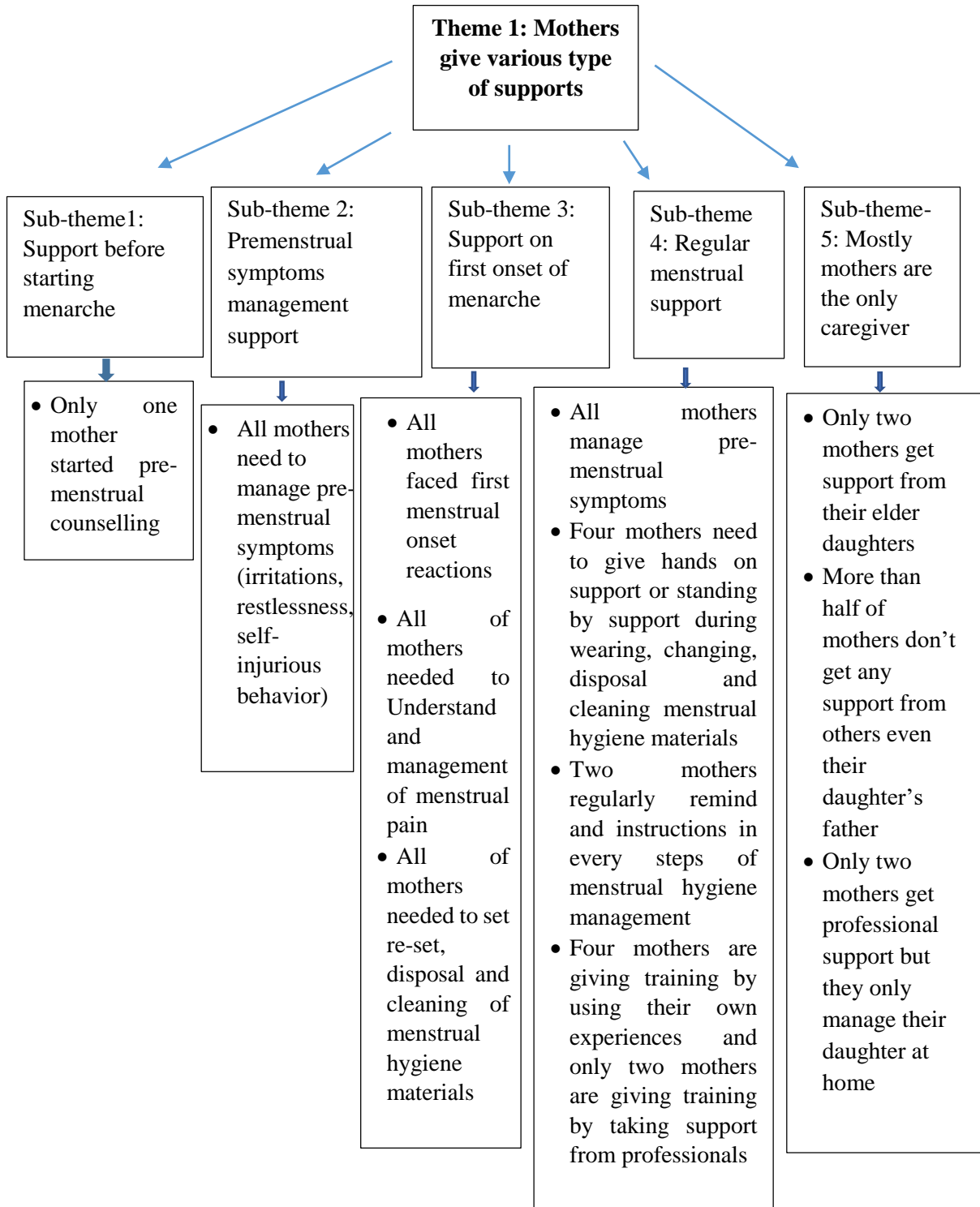
Characteristics of the 6 mothers interviewed and their daughter

Participants are six mothers of girls with ID and the mean age of the participants 45 years old. All of mothers are educated and all are housewife living in the urban area at present. Only two mothers have daughters over menarche age. Their daughters' mean age is 16 years old and mean age of onset of menstruation is 12.16 years old. Among six girls with ID two of them having moderate intellectual disabilities and three of them have Severe ID and only one girl identified as profound ID. Of total six girls four of them are receiving vocational training, one girl is receiving education at grade 5 and other on play level academic performances.

Mothers	Mothers (participants)						Daughters with ID			
	Age	Education	Occupation	Area of living	No. of Family members	No. of daughter over menarche	Severity of ID	Age	Onset of Menstruation	School grade
P1	41	S.S.C	Housewife	Urban	4	0	Moderate	19	11	Vocational
P2	38	S.S.C	H.wife	Urban	4	0	Moderate	16	14	Class 5
P3	42	Graduate	H.wife	Urban	4	0	Severe	17	15	vocational
P4	45	SSC	H.wife	Urban	5	1	Severe	19	12	Vocational
P5	49	Post graduate	H.wife	Urban	3	0	Profound	13.5	11	Vocational
P6	55	SSC	H.wife	Urban	7	3	Severe	10.5	10	Play

Table: Demographic information of the participants and their daughters with ID

Theme 1: Mothers give various type of supports



Flowchart1: Concept map for various type of supports in managing menstruation

Sub-theme 1.1: Mother give Support before starting menarche

The study findings show that only one mother started counselling about menstruation before starting menarche of her daughter based on the recommendations from professionals from a special school. Beside therapist, psychologist, and special educators from her daughter's special school mother educate her daughter about menstruation, menstrual behavior and menstrual hygiene materials.

Mother (5) said, *'In her school she is achieving counselling, training by flashcard which is pad, how to set up on panty, how much time she needs to keep this and change this. I also give training by flash card about at home''*.

Sub-theme 1.2: Mothers need to understand premenstrual symptoms

And some mothers always notice their daughter's reactions or premenstrual symptoms (irritations, restlessness, self-injurious or other behaviors etc.) as their daughter unable to express their onset of menstruation. One mother told that before starting menstruation her daughter become very restlessness and irritated and after observing these behaviors mothers becomes sure that her daughter will get menstruation.

Mother (5) said, *'now every month some days before starting menstruation my daughter remains restlessness, doesn't want to sit on chair at school and home and when menstruation occurs then everything become ok''*.

Sub-theme 1.3: First onset of menstrual support by mothers

After having menstruation for the first time All of mothers needed to explain their daughters about menstruation using the example of themselves, their elder daughter, close friends, relatives.

Mother (2) said, *'I notice blood spot on her cloth and explained the reason of this using the example of her elder sister, I told, your sister also has this, your sister also wear pad, panty so you have to wear these''*.

Among six mothers four mothers told that as their daughters have limited ability to express and have poor understanding level so mothers need to give stand by support and hands on support such as identifying onset of menstrual flow, setting, disposal & cleaning of

menstrual hygiene materials and used clothes such as upper and lower half dresses, bedsheets etc. during onset of first menstruation. Some mothers told that their daughters had tendency to put-off the materials and frequently go washroom so mothers need to notice and give support again and again.

Mother (6) said, ” *She doesn't want to keep pad, she feels uneasy and has tendency to put off the pad, so we have to give full support* ”

Sub-theme 1.4: Regular menstrual support including noticing, reminding

Four of mothers told that they need to notice pre-menstrual symptoms and based on this they need to notice if their daughters have menstruation or blood spot on the lower half dress because their daughter are unable to tell or remain conscious about having menstrual flow.

All of mothers told that they need to give support in managing menstrual hygiene of their daughters and at the beginning of the menstruation few months they needed to give full support in menstrual care of their daughter. After passing few months or year mothers become used to give support and their daughters also learn partially to help mothers as mothers are giving training to their own way.

Mother (3) said, ” *She doesn't understand that her menstruation has started, she makes dirty her clothes then we have to tell her to take materials. She didn't wear and change it herself; we have to set and put-off pad for 3 months and then she can set and put-off materials herself with instruction. I and My elder daughter have taught her.* ”

Mother (1) said, ” *At the beginning I give full support but now as I am teaching her how to manage without help, I taught her that her brother and father on the same bed so she has to tell me about starting of menstruation so now she can tell and can set materials with my instruction.* ”

Three mothers give maximum support to their daughters in managing menstruation such as -identify onset of menstruation, set pad with panty or pampers, change pad in time, disposal of used pad (wrap pad with paper, keep the used pad in the dustbin), clean bloody

panty and other clothes (lower half dress, bed cover), hygiene during toilet time. Mothers need to give full support because they are still giving training to their daughters.

Mother (3) said, *'' We are trying to give training so that she can do this without help, she doesn't want to keep pad, she feels uneasy and has tendency to put off the pad. We need to give full support''*.

Mother (2) said, *'' I need to go with her in bathroom, putout the pad and again I need to set the pad on the panty, in absence me she can't set''*.

Some mothers told that their daughters don't understand the onset of the bleeding so mothers need to identify this and remind and instruct her to wear materials, change and disposal of used pad, wash panty and other clothes and maintain hygiene after using washroom. Mothers have to give instruction in every steps of the menstrual hygiene.

Mother (1) said, *'' Need to remind her during her toilet time, every time need to instruct to wrap the used pad with paper and throw into the dustbin otherwise, she forgets''*.

Another mother (2) said, *'' I have taught her that if she has menstruation I become happy then when she has menstruation she runs and tells that she has menstruation then I have to instruct her to take panty, set pad on the panty and wear this, then she does this.*

Sub-theme 1.5: Mostly mothers are the only caregiver

Mothers have tendency to hide this issue from others even from family members, two of mothers who have daughters over menarche age, share this issue with their elder daughter so that she and her elder daughter can support and train her daughter with ID during her menstrual care.

Mother (3) said, *'' I and my elder daughter have taught her as she couldn't understand, my elder daughter is so helpful she helps her a lot''*.

More than half of the mothers manage and train their daughter's menstruation without any help from others even they don't share the issue with any professionals and manage and train their daughter by using their own experience. More than half of the mothers don't get any support related to menstrual care management because they think that mothers are only responsible for training and, managing this.

Mother (1) said, *'' I only support her, she goes to school, does therapy, no one helps her about this''*.

Mother (2) said, *'' From school we don't get any training for managing this, who will give this? Only I have to give this, I train my daughter in my own way, who will support? In case of other issue such as cooking, feeding, washing clothes anyone can help but for this issue who will care or support except mother, who will take responsibilities''*.

Mother (4) said, *'' She has tendency to change pad every after few minutes, sometimes she wants to change every after few minutes''*.

Two mothers told that they have shared this issue with the special educators in their daughters' special school and they are giving training to their daughter how to manage menstruation independently by giving hands on training, training by using flash card etc. So, based on their instruction the mothers also giving training to their daughters and they hope that their daughters will able to manage independently.

Mother (5) said, *''In her school she is achieving counselling, training by flashcard which is pad, how to set up on panty, how much time she needs to keep this and change this, I also give training by flash card about at home''*.

Mother (6) said, *'' School teachers are also giving support; they also give hands on training during staying at school and counselling along us''*.

Theme 2: Mothers facing so much challenges causing emotional distress

Sub-theme 2.1: First menstrual reactions management causing stress

This study finding shows that all of mothers' worry about their daughters first onset of menstruation that what will happen, how their daughters will react, how they will manage menstrual care, can they manage themselves. Every mother doesn't face the same reaction of their daughter during their 1st onset of menstruation. Some mother's daughters understood the onset of menstruation and told their mothers by telling 'what is this, what is happening, I have bleeding, I have peed and some were not able to tell their mothers and mothers understood by noticing blood spot on their dress, sign of restless.

Mother (3) said, *''My daughter was crying and told that what is this, what is this''*



Fig : Reactions showed by the girls with ID during onset of menarche

Half of mothers told that during 1st menstrual onset their daughter didn't want to wear materials (pad with panty) and had tendency to put-off the materials then they explain the reason of wearing by using the example of her mother, elder daughter, friends, cousins. Mother (1) said, *'I told that it is also happening to all female and your younger sister (cousin) also wear pampers during this time''*.

Mother (2) said, 'I set pad and panty, she felt disturb, then I told her that you have to wear this during this time. I and others wear this, all women, your friends wear this, this way I made sense to her''.

Two mothers told that during their daughter's first onset of menstruation they were absent at home for emergency work. During this time, they asked help from their relatives and next-door female neighbors. They thought that this is secret issue and need to hide from the male persons even from their daughter's father.

Mother (4) said, 'I wasn't at home; I was in Dhaka for having emergency work. I kept my daughter to her father. Then my next-door neighbors phoned me and told that my daughter was telling everyone that she had bleeding, then she(neighbors) set materials ''.

More than half of the mothers told that their daughters experienced pain, vomiting during first onset and regular onset of menstruation. The daughters who could speak they told their mothers that they had pain and the daughters who are not able to speak, mothers understood that by noticing their daughter's behaviors like pressing abdomen by hands, crying, restless. Then mothers handled these behaviors by explaining the reason of pain, coping strategies, giving medicine, ensuring sleep.

Mother (3) said' ''she tells, Ammu, I have pain on my belly then I tell her it will be ok and sometimes I give medicine ''.

Mother (5) said, ''When she feels pain she sits with pressing abdomen as she doesn't express by telling so she lies or sits with pressing abdomen by hands. I give Napa only, I don't give other medicine, sometimes I give hot pack''

Mother (6) said, 'I give her Napa or tell her, you have to cope with this, your mother also had this, it will be ok. I try to keep her sleep during this time''.

Sub-theme 2.2: Care burden causes challenges and stress for mothers

Most of the time mothers are the main caregiver of their daughter everyday activities including self-care and academic activities. Although others family members partially help in managing self-care and academic activities but during menstrual time mothers are the only caregiver in giving menstrual care. Most of mothers think that as the menstrual issue

is very secret issue so they have to manage it. They are teaching and managing their daughter in their own way even they hide this issue from others family members and relatives also. Some mothers always keep eyes to their daughter because their daughters can tell or show anyone as they don't understand.

Mother (1) said, *'' There is no way or options, only I am teaching her for managing this''*

Mother (2) said, *'' Only I have to give support, as her father in male, when her father remains in one room, we go on another room, except me there is no one for helping her, there is no one without mother''*

Mother (4) said, *'' I feel shamed when she tells everyone that she has menstruation, she tells this to her nephew that 'brother I have menstruation 'then it embarrasses me''*.

More than half of the mothers feel stressed and tensed that in absence of them who will manage their daughter during this time. In case of going outside during this time some mothers feel very tensed as their daughters may need support any time and some mothers leave their daughters in relative house but feel tensed about their daughters are their daughters getting proper support or not.

Mother (3) said, *'' When visiting outside I feel very tensed what can happen that's why I take extra pad and other things''*.

Mother (5) said, *'' Sometimes I need to go outside then I have to keep her to another person then I feel very stress that how she is managing, is the person giving proper support''*.

Some mothers felt stressed at the starting of first menstruation of their daughter but now they are used to supporting their daughters.

Mother (2) said, *'' I am used to doing this now, I am not feeling stressed in giving support to her but I feel tensed that absence of me who will take care of my daughter''*.

Some mothers told that their daughters remain very much disturbing during this time which causes extra stress for mothers. Such as their daughters have tendency to crying, frequently going to washroom, putting off pad, peeing on the bed, making dirty clothes. So, during this time mothers need to extra care such as frequently instruct their daughter, remind their daughters, frequently set pad with panty, clean dirty clothes, maintain hygiene etc.

Mother (6) said, *'' During this time the more she goes washroom I or her elder sister need to help her, she doesn't want to keep pad, she feels uneasy and has tendency to put off the pad, she has tendency to pee in the night time so during this time she it becomes difficult; I need to change and clean bed sheet''*.

All of mothers told that their daughter need support during their menstrual care otherwise their daughters can't manage independently, although their elder daughter sometimes help and teach their daughters but mothers need to give support step by step otherwise their daughters forget or cannot properly manage. That's why mothers feel depressed by thinking about their daughter's future management support of menstruation.

Mother (1) said, *'' How will she manage in absence of me, who will take care of her? I become depressed about her as a mother (tears on eyes), who will lead her?''*

Mother (5) said, *'' In future how she will manage or understand this, taking this issue in my mind I feel much tensed and very upset''*.

Mothers who have elder daughter think that their elder may support in future but also prioritize their daughter independency as their elder daughters also will have family.

Mother (3) said, *'' sometimes she understands sometime not, sometimes she can manage, sometimes not, she can't do step by step so she needs support whole life, in absence of me my daughter will support*

Mother (6) said, *'' I feel tension that as a mother and her elder sister we are giving support but after 2-8 years if she gets older, she has to manage herself if she can't then what will happen''*.

Sub-theme 2.3: Thinking about extra protection issue also cause stress for mothers

All of mothers need to become very conscious about their daughter's menstrual care and they use sanitary napkin, pampers for managing menstrual flow and avoid clothes and change those pad in right time to prevent menstrual infection.

All of mothers are very much alert about their daughter 's safety issue because now their daughters are growing older so they take extra care about her. As their daughters have poor understanding level and unable to express clearly so anyone can take advantage by showing

abusive behaviors. All of mothers always try to keep their daughter with her and don't allow to let her go alone anywhere. Half of the mothers told that when they visit outside or relatives' home, they always keep their daughter with them and if they unable to take their daughters with them then they keep their daughter at home by locking the door outside and sometimes they keep their daughter near to close relatives or neighbors.

Mother (1) said, " After having menstruation she has grown up so anyone can do bad things, *outside people can take opportunity, may do any abusive behavior with my daughter and If we keep her home alone then lock the door from outside because anyone can enter house then we feel safe*".

Mother (2) said, " Now I worry about her always, she doesn't understand that she is growing up and doesn't need to become very close to the father or uncles, who knows who have bad intensions, if they touch her badly then she can't say, that's why I always keep eyes to her".

Mother (3) said, " She is growing up, now she is adult, I worry about her future now because she can't do anything without support, I don't think about her marry because now she is alone it's better, giving marry will create extra problems".

Mother (4) said, " As she can't tell so men can take opportunities (bad intension), so if they do bad things she will not say, I always keep eyes to her, When I go outside, I keep her to my nephew and sister because they keep her safe like me".

Theme 3: Achieving menarche has long term impacts both physical and psychologically

Sub-theme 3.1: After achieving menarche girls are growing faster

All of mothers told that after menstruation their daughters growing faster physically that make them more conscious about her safety from any abusive occurrences so mothers always need to keep eyes on their daughters.

Mother (2) said, " As she is growing up so everywhere I take her with me, if I couldn't take her then I leave her in the room by locking the door outside".

Some mothers have noticed some unexpected impact after having menarche phase such as gaining weight, irregular menstruation, increasing white discharge that creating itching on

vaginal area, masturbation tendency. And only one mother sought medical help for her daughter's menstrual related problem.

Mother (5) said, *'After having menstruation she tries to press the vaginal areas, when she has white discharge onset of menstruation, she frequently itches that area, want to keep finger directly on that areas'*.

Some mothers told that menstruation don't interfere their daughter's participation in school activities but their daughters are forbidden to avoid heavy therapeutic work.

Mother (2) said, *'She goes to school, attain program during this time. I need to tell the supporting staff on the school for the help of changing tissue when she goes bathroom'*.

Sub-theme 3.2: Girls achieve better understanding level

Five mothers out of six mothers have told that they have noticed some changes after achieving menarche phase. Some mothers have told that their daughters understand better after having menstruation. Their daughters now understand that having menstruation is a good sign and after recovery of this period they can show happiness.

Mother (1) said, *'She understands better than previous, she becomes happy after this and tells 'Ammu, I am ok now', she becomes happy that she doesn't need to wear pad now'*.

Mother (3) told *'Now she understands that as her menstrual flow has stopped so she can now say prayers, then she copies our prayer positions'*.

Two mothers told that before having menstruation their daughter was so much disturbing, restless, tendency to hit themselves but after achieving menarche phase their daughter have become calm than before.

Mother (4) said, *'I think she achieves some behavioral changes, before onset of menstruation she was so much disturbing, restless but after having menstruation she is now better than before'*.

Mother (5) Said, *'Before having menstruation she was so much hyperactive, had to sit here and there, lying tendency, hit herself by hands but after having menstruation she has become calm than before'*.

Two mothers told that their girls have tendency to tell someone that she has bleeding so they avoid to visit outside or if visit outside then mothers always remain with their daughters.

Theme 4: Strategies come out from mothers that overcome challenges and ease mothers emotional distress

Sub-theme 4.1: Mothers focus on increasing girl's independency level

Every mother is worrying about their daughter's future support in managing menstrual care of their daughter so they give importance on training to their daughters in managing their menstrual hygiene so that their daughters can independently manage this. Some mothers are giving training their daughter by using their own experiences/techniques because they think as the menstruation issue is secret so they only have to manage it which indicated the need of mother's education and counselling.

Sub-theme 4.2: Support seeking behavior by mothers

Two mothers feel ease as their elder sister help them to manage their daughter during this time. So, some mothers seek support from the family members which eases their emotional stress and challenges. One mother wants to get support from school for training their daughters about this issue as her daughter obeys teacher's command.

Mother (4) said, *'If I get support from school then I will become happy but I didn't get any support from school about this issue, she tries to obey or follow the command of the school teacher so if they train her about this such as not tell anyone then she may follow this''*.

Sub-theme 4.3: Mothers who get support become so hopeful

Two mothers are getting support from school in managing their daughter's menstruation. They are giving training to their daughters how to independently manage menstrual hygiene and self-safety according to therapist's recommendations from the school and they become hopeful that one day their daughter can manage menstrual hygiene independently. Mother (6) said, *'She will able to manage this issue independently, she will able to understand the matter, independently manage herself such as put on, changing, cleaning.''*

Sub-theme 4.4: Mothers give more importance on professional's recommendations

Two mothers are training their daughters based on the recommendations from school about good touch bad touch, gender identification, self-protection techniques such as when someone shows bad touches then protect themselves by crying, pocking, telling directly to mother.

Mother (5) told, *'' School teacher and I are giving her bad touch, good touch training, self-protecting techniques, gender identification so that she can safe herself''*.

Mother (6) told, *'' Based on therapist recommendations school and I are giving training on gender identification, good touch bad touch, protection techniques by crying, telling mother''*.

Mother (5) told, *'' She has tendency to hug anyone, if any boy or men call her using gestures then she wants to go, so I want she will able to differentiate gender completely, she is learning good touch bad touch from school, if she can protect herself then I will be stress-free''*.

All of mothers think that if their daughter can express, manage menstruation and protect themselves without any support then mothers will become happy otherwise they think in absence of them who will support during their menstrual hygiene.

Chapter 5: Discussion

All participants from this study are highly educated and living in the urban area with economic solvency and their experiences are very similar. Menstrual management experiences will vary in case of mothers who are illiterate or less educated, living under poverty and living in the very rural area where sometimes lack of proper sanitation, water supply and lack of hygiene materials or unable to buy hygiene materials.

Onset of menstruation is the sign of going through puberty. Although girls with disabilities have same experience of menstrual cycle like girls without disabilities but mothers' experiences and their daughter's self-management during this is different. Generally, mothers or elder sisters or close relatives introduces first onset of menstruation of girls without disabilities and then they can manage themselves without any help. But in case of having disabilities mothers have to face so many challenges for managing their daughter's menstrual hygiene during this time. Mothers have to give support in every step of managing their daughter's menstruation. Similar study conducted in Taiwan also found that All of mothers had to give complete assistance during menstruation of their daughters with intellectual disabilities (Chou & Lu, 2012). Type of support depends on the type and severity of disabilities, the more severity of disability the more support needs to give.

In case of girls with intellectual disabilities mother's menstrual management experiences during this time is very challenging also as the girl with intellectual disabilities have cognitive problems like poor memory, difficulty in learning new things, poor problem-solving skills, low understanding level etc. So, mothers have to give support their daughters in everyday life activities such as self-care, academic and leisure activities. Although other family members give support in others daily living activities but during their daughter's menstrual management only mothers are responsible and mothers are mentally prepared that as they are mother, they will only manage and train their daughters during this time from their own experiences. Similar findings show that mothers perceive menstrual management assistance is the motherhood task so when they leave their child at home for performing job, familial duties they become worried, anxious and scared (Power et al, 2020).

Mothers have tendency to keep secret this issue from others male family members. Even some mothers don't share this issue with any professionals of their daughters' school. This finding is consisted with the study of Malaysia that, due to social taboos, cultural and religious beliefs parents refuse to ask help from professionals (Nurkhairulnisa et al, 2018). Two mothers have shared the matter with professionals of their daughter's special school and they are giving training based on the expert recommendations and school teacher also giving training as part of their self-care activity. Similar things happen in Australia where mothers receive support from the local health department, school staff and books (Park, 2013 as cited in Thapa & Shivakami, 2017). Although the menstrual management is the part of important self-care activities training but this issue is skipped in most of the special school and they only give emphasis on self-dressing, social communications, problem solving skills, cultural participations etc. Some mothers feel the need of support from the school but due to unavailability of opportunity they don't share the matter with the professionals in the school.

In every steps of the menstrual management from onset to end, mothers have to give support and faces some challenges. Management of first onset of menstruation and their daughter's reaction during this time is so much difficult than regular menstrual management. Because when first menstruation started their daughters got frightened, had tendency to reject wearing menstrual hygiene materials (pad, panty). Mothers needed to again and again explain their daughters about menstrual flow and give stand by support or instruction which causes extra stress for mothers. Chou and Lu have found similar findings and they state that mothers need to repeatedly support their daughters in setting, changing and disposal of pad or diapers as their daughters have tendency to reject wearing and putting-off pad (Chou & Lu, 2012).

Menstrual pain management, hygiene management and others behavioral (crying, restless, sleepless, tendency to put-off menstrual hygiene materials, tendency to go washroom frequently) management all led to stress for mothers for managing first and regular onset of menstruation. One Malaysian study also found in their study that 59% parents

complain that their daughters with ID experienced abdominal discomfort during their menses and abdominal cramps is the most severe symptoms among the girl with intellectual disabilities (Yaacob et al, 2012).

Although management of first few months of menstrual onset is very much challenging but after couples of months' mothers become used to do or give support during their daughter's period. This finding is consisted with the Chou and Lu's study, they found that by repeatedly doing same things over a couples of years' mothers become used to coping with menstrual support to their daughters (Chou & Lu, 2012). Mothers who have elder daughter also give support during this time which reduce mother's stress but mothers always worry by thinking her daughter's future management of menstruation in absence of mothers because their daughters can't manage their menstrual hygiene independently like others house hold chores. Mothers thinks that there is someone who can give support in case of her other daily activities but in case of menstruation who will manage.

Menstrual management support depends on the level of understanding or IQ level of the girl with intellectual disabilities. The girls who have moderate ID have better understanding about menstrual management. At the starting of menarche, they need maximum support but after couple of months they need minimal support during menstrual hygiene management because they have forgetting tendency and each time mothers need to remind, instruct their daughters in wearing, changing materials, cleaning used clothes, disposal of the materials etc. But the girls who have severe and profound ID need moderate to maximum support throughout the life which causes mental stress for the mothers by thinking their daughter's future management of their menstrual hygiene. Similar findings from one study also suggests that girls with mild intellectual problem have more independency level in managing menstruation, where moderate IDs need supervision support in performing self-care during menstruation and girls with severe or profound ID completely dependent on mothers (Joshi & Joshi, 2015 as cited in Ariyanti & Royanto, 2017).

Menstruation issue is still now very secret issue and there are many taboos in the society about this. Although menstruation issue is a normal physiological issue of female and sign of reproductive age but findings shows that mothers hide this issue from other family members, relatives even from their daughter's father. Mothers again and again forbid their daughters to hide this issue from any person especially male persons. Mothers feel very embrace when their daughters share with anyone. Steward et al also found in their study that there is social taboo related to menstruation such as dirty things, things of fear or be ashamed or embarrassed (Steyward et al, 2020).

Study findings shows that there are some physical, psychological and behavioral changes after achieving menarche phase such as becoming adult through hair growth, breast development, gaining weight, irregular menstruation, understanding better, becoming calm than before, reducing restlessness etc. But there are some changes which creates embracing conditions for the mothers and family like frequent touching vaginal areas, masturbation tendency. Mothers become worried about these embracing behaviors of their daughters. Current study shows that their daughters are physically growing fast and their understanding level is increased after having menstruation and they can show sign of happiness. Similar finding suggests that the girls with ID can cope with their physical changes e.g.- breast development, hair growth and monthly menstrual flow (Cummins, Pellicano & Crane, 2020).

Only one mother consulted with doctors about her daughter's menstrual problem for one time and when same problems occur in further time she didn't consult with doctors for economic burden. This finding is similar to the result of a study conducted in Malaysia that very few parents or guardians seek medical help due to some factors and family low income is one of them (Nurkhairulnisa et al, 2018).

As the onset of menarche is the sign of reproductive age so mothers start to take extra care of her daughter. As their daughters are unable to express or tell and have poor understanding level so anyone can take advantage showing abusive behaviors so they always ensure their daughters protection by keeping their daughters with them always and

if they go outside without their daughters then they leave their daughters at home by locking the door. Everywhere mothers keep eyes to their daughters and mothers always feel stress and tensed about their daughter's safety issue and to avoid any bad incidence they always ensure their daughter's safety. The finding is almost similar with a study of Ireland that as person with ID have poor understanding level and poor knowledge about their rights so they are more prone to sexual abuse and most of the offenders are known to victim as they may from close relatives or family members or careers (Walsh et al, 2001). They feel very tensed and depressed when they think about their daughter's future protection in absence of them even, they can't think about their daughter's marriage as it will create further problems such as child bearing. But other study suggests that women with ID also have sexual and reproductive rights as women without disability (Rugoho & Maphosa, 2017).

Mothers give emphasis on giving training to their daughter so that their daughters can manage menstrual care independently in absence of them (mothers). Independent management of menstruation by their daughter with ID will decrease mother's tension and mental stress. Besides having menarche their daughters are achieving some physical changes which indicates they are becoming adult so mothers always feel stressed thinking their daughter's safety. As their daughters have low understanding level so mothers always worry about their safety and give importance on increasing their daughter's understanding level. Sometimes mothers also feel the need of help from professionals of their daughters' special school for increasing their daughter's understanding level about menstrual management and self-safety issue. On the other hand, in contrary some studies findings show that due to fear of extra care burden and sexual abuse parents or guardians take decision to permanently remove uterus, sterilization or other contraceptive method (Gonzalez, Martinez & Bedolla, 2018; Nurkhairulnisa et al, 2018; Thapa & Shivakami, 2019).

Mothers who are getting support from special school are very much hopeful than they are not getting support from school. Similar. findings from Ghana also shows although support

from professionals reduce parents stress and create hope for the mothers about their children but these type of support is very much limited (Badu, 2016).

Chapter 6: Conclusion and Recommendations

6.1. Conclusion

The onset time of menarche phase of girls with intellectual disabilities is same as like as girls without disabilities. But girls with ID face some challenges during managing menstrual care due to poor cognitive skills, poor understanding level, poor learning abilities and poor communication skills. They need support from mothers/caregiver for managing their menstrual care in every month. Although mothers feel the need of support from others but they manage their daughters by taking stress and as a fate of their life.

Mothers are the primary and main caregiver of girls with ID. As child with ID have low IQ or intellectual problems so they need support in every day daily activities. Onset of menstruation for girls with ID creates extra stress for mothers as mothers are the only caregiver sometime. Mothers need to manage menstrual first onset reactions (Fear, pain, angriness, restless, rejection of wearing hygiene materials, frequent use of washroom) of their daughters, need to give regular menstrual support-identifying onset of menstruation, wearing and changing hygiene materials, cleaning used clothes, disposal of used materials etc. Considering this secret issue mothers and sometimes elder sisters only give support during this time. Each month during onset of first menstruation mothers remind their daughters about menstrual care otherwise their daughters forget even can't identify the onset of menstruation so mothers need to always conscious about this and give continuous support during this time. Mothers feel very much tension as their daughters can't manage menstrual hygiene without support so in absence of mothers what will happened.

Not only mothers think about their daughter's future management of menstruation but also they think about their daughter's extra safety and care as their daughters now growing old and any strangers can show abusive behaviors.

As girls with ID have low understanding level depending on their IQ level so they need minimal to maximum support in managing menstrual hygiene. And as mothers are only responsible for managing this, they feel very much mental stress by thinking their daughter's future management. Mother's wrong perception (she is only responsible), lack

of support from others are main causes for increasing stress of the mothers. Family members, relatives can support as well as different professionals can also give support for reducing mental stress of the mothers. Professionals can conduct counselling, education, therapy session with the parents about the self-menstrual management by their daughters, future independent management, protection strategies from abusive behaviors etc. that can reduce parent's physical and mental stress.

6.2. Recommendations

After exploring the experience of mother about handling their daughters during menstruation researcher has found some gaps and made some strategies and recommendations for reducing this gap. Researcher found every mother face so much challenges during handling their daughters with ID at the time of their menstruation and feels lack of support during this time which increases mother's mental stress.

➤ **For the mothers:**

- ✓ Mothers can start pre-menstrual counselling by introducing their daughters with menstrual flow as normal issue, hygiene materials, put-on and disposal of materials and overall cleaning when their daughters reach to the age of 10 years by using social stories, visual strips. This may prevent sudden frightened (crying, restlessness, sleeplessness) and disturbing reactions (reject to use hygiene materials, put-off the materials).
- ✓ Mothers need to always focus on their daughter's independency in managing menstrual hygiene rather than increasing dependency by giving hands on support and should seek help from professionals.

➤ **For family members:**

- ✓ Beside mothers always remind and instruct the girls with ID what to do next, how to do during her menstrual management and this will helpful for her to develop menstrual management habit.

➤ **For Professionals:**

- ✓ Professionals may develop specific education and training guideline about self-management techniques of menstruation, sexual abuse and frank discussion about self-protection techniques by training to good touch bad

touch model, gender identification, increasing communication skills related to express abuse related information etc.

- ✓ As girls with ID have poor communication, memory and understanding level so therapist can work with increasing communication, cognitive skills and problem-solving skills related to menstrual hygiene issue.

➤ **For policy makers:**

- ✓ As menstrual care is related to better health and wellbeing of the girls with and without disability so some contents such as proper menstrual care, hygiene maintenance, causes of relevant risks (infections, abusive incidences) and preventions strategies (proper hygiene, self-protection, bad touch-good touch concept) must be included by the policy maker in the secondary level academic book.
 - ✓ As menstrual hygiene is related to menstrual hygiene materials so these materials should be cost effective and policy maker can fix the reasonable cost of these materials by coronation with different menstrual hygiene materials making companies.
 - ✓ Education and training guide book about menstrual hygiene management, sexual education by parents to their girls with disabilities should be developed and make compulsory to each inclusive and special school.
- Further qualitative study should conduct to explore the mother's experiences who are living in the rural areas and living under poverty that will introduce the more challenges and these will helpful to develop holistic education and training guide.
- Further qualitative and quantitative study with large sample should conduct to identify experiences and perception of mothers about education and counselling session related to menstrual care of their daughters with ID.

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Annexure

Annex-1: List of glossaries

Attention Deficits Hyperactivity Disorder (ADHD): Neurodevelopmental psychiatric disorder with impaired level of inattention, hyperactivity and impulsivity that causing limitation in academic and functional performances (DSM-V, 2013).

Cyclic Perimenstrual Pain and Discomfort (CPPD): Pelvic pain, cramping associated with menstruation that may lead to discomfort during menstrual period.

Intellectual disability (ID): Definition: Refers to impairment in adaptive behavior that manifest during developmental years and less than 18 years old with sub-average intellectual functioning based on the IQ. Inability to learning with behavioral and developmental disorders (DSM-V, 2013).

Types of ID: According to DSM-V, On the basis of the adaptive functioning ID is classified into mild, moderate severe and profound intellectual disability based on three domain analysis conceptual domain.

Mild ID: where there are difficulties in academic performances learning, reading, writing, money management and support needed in one or more areas to meet age related expectations. In adults there is impaired function in planning, abstract thinking, short term memory, functional use of academic skills. In social domain Person with ID may not have age appropriate behavior or emotions, limited understanding risks in social situation and sometimes individual may have manipulated by others. In practical domain individual may have good skills in self-caring but have some difficulties in grocery shopping, transportation, home and child caring, money management and they may need support in health care decisions and legal decisions. They can involve in job that don't emphasis on conceptual skills.

Moderate ID: In moderate intellectual disabilities conceptual domains demonstrate the individual's conceptual skills markedly impaired and they need support in all areas of academic skills and level is on elementary level during adulthood and their pre-schooling languages and pre-academic skills developed slowly. Others need to take the responsibilities of the individuals for completing conceptual tasks. In social domain individual have ability in making social relationship with friends and family and sometimes they may have romantic relationship in adulthood, judgment and decision making abilities are limited and caregiver must give support in life decisions and social and communicative support needed in work setting for success. In practical domain individual need time training to become independent in self-care skills like eating, dressing, elimination, hygiene as an adult through extended period of teaching and time is needed to learn these skills. Individual need ongoing support and reminder for successfully performing household ask in adulthood. They may involve in employment which need minimal conceptual and communication skills and need support from co-worker, supervisors.

Severe ID: Conceptual skills are very limited and have little understanding on written language concept involving numbers, quantity, time. Caregiver need to give extensive support throughout

The life. Individual's speech may be single word or phrases and they can understand simple speech and gestural communication. Only able to maintain relationships with family and familiar others. Individual requires support in all activities of daily living including dressing, bathing, meal preparation and personal hygiene and requires supervision at all times. Maladaptive behavior such as self-injurious behavior may be present.

Profound ID: Conceptual skills involves physical world rather than symbolic. Individual can understand matching and sorting concept rather than functional uses and impaired co-occurring motor and sensory function may prevent of using object functionally. Individual have very much limitation in understanding symbolic communication or gestures and h/she just may understand some simple instruction and gestures. Individual maintain relationship with family members, caregivers and some familiar persons using gestures and cues.

Individual depends on others for all activities of daily living and only may assist in some work at home such as carrying dish to the table. H/she involve in vocational activities with high level of ongoing support. Recreational activities such as listening music, watching television, going for walk may be performed by the individual. Co-occurring sensory and motor impairment may hinder participation. Maladaptive behavior such as self-injurious behavior may present (DSM-V, 2013).

Intelligence Quotient (IQ): Standardized test for level of intelligence, the critical components of IQ test including verbal comprehension, working memory, perceptual reasoning, comprehensive reasoning, abstract thought, cognitive efficacy. Judgements, clinical training are required to appropriately interpret the results. IQ ranges 50-70 indicates mild ID, 35-49 moderate ID and 20-40 severe ID and 20-25 profound ID (DSM-IV, 2000 as cited in Park, 2013).

Menstrual cycle:

Menstrual cycle lasts for an average 28 days, can be divided into two phases follicular and luteal, follicular phase begins with 1st day of menstruation and lasts until ovulation which occurs around days 14 and during this phase while menses occurs estrogen concentration remain low and stable and rise quickly after cessation of menstruation on the other hand progesterone remain low throughout the follicular phase. When ovulation occurs due to luteinizing hormone (LH) and then luteal phases starts, during this phase progesterone concentration remain high and estrogen concentration remain on moderate. At the end of this phase both estrogen and progesterone concentration fall and menstruation occurs with starting a new cycle (Tan et al. 2020).

Premenstrual Syndrome (PMS):

Wide variety of sign and symptoms include mood swing, irritability, tender breast, depression before immediate starting of menstruation.

Annex-2: Two case studies for better understanding

Annex 2.1. Case study 1

Sifa (nickname) is a 19 years old girl who diagnosed as girl with intellectual disability. She has one younger brother who is 6 years old. She is a student of a special school and reads in class five. At the age of 11 years old she has achieved menarche. Her mother is 41 years old and a house wife in spite having post-graduation degree. She told that she faced lots of challenges for her daughter because her daughter had delay in walking, speaking and learning and still facing problems of teaching her daughter in every new thing. The biggest challenge was managing her daughter during her menstruation. She was tensed about her onset of her first menstruation and how she will manage.

When her daughter's first menstruation started, she got frightened and told "what is this, why this is happening". Then her mother explained the reason of menstruation by telling her that as they women they have to face this issue. She didn't want to wear the materials like panty with pad then her mother needed to use example of her cousins who achieved menarche that they also wear this and then she wore the materials with the help of her mother. At the beginning she also had lower abdominal pain and vomiting so her mother had to give medicine for that.

Now at present it has become easy to handle the girls during this time because at the beginning she needed full support for managing menstrual such as wearing and changing materials, cleaning, maintaining hygiene. Now she can wear, change materials, clean clothes without help but every month she needs verbal instructions otherwise she forgets to wear and change materials such as need to remind her during her toilet time and every time for setting pad, disposal of used pad by wrapping the pad with paper and throw to the dustbin. Sometimes her mother needs to set the pad in panty and instruct her to wash the panty otherwise she forgets.

During her period time she goes to school, does therapy, performs dance. Her mother doesn't tell any professionals in the school about her daughters' menstruation because she

thinks that this the secret issue and only the responsibility of the mother to manage this. As there is no way so she is training to her daughter in her own way and she believes that one day her daughter will be able to manage this without support. Although she feels much stressed because she has to support her daughter in every steps so in absence of her who will support her, what will happen. Her mother feels the need of helping hands who will give support in absence of her.

Her mother also feels stresses by thinking her future as her daughter is now adult and any bad things can happen such as sexual abuse or other abusive behaviors. So, now her mother takes extra care of her such as doesn't let her go alone, keep her with her mother always and if her mother goes outside, she tries to take her with her or lock the door outside. Because her daughter doesn't understand and can open the door if anyone knock the door so considering safety issue, she locks the door outside.

Annex 2.2. Case study 2

Saima (nickname) is a younger daughter of 'S' begum. She was diagnosed as down syndrome with profound intellectual problems. She has 3 elder sisters and 3 elder brothers. Her mother is a housewife and 55 years old women. Her mother and one elder sister are the caregivers of her. She goes to a special school and there she takes therapy and training on performing activities of daily living without support and learning activities by special educators.

As Saima's understanding level is very poor that's why according to therapist's recommendations her mother and special educators started counselling on the matter of menstruation, menstrual materials before onset of the menarche. When she achieves menstruation at the age of her 11 years old she shown reaction by telling that she had peed and then she wore pad with panty without any hesitation and her expression was like that she knows this.

During this time, she is very much disturbing because during first day of menstruation she uses 12-15 pads and when she enters bathroom, she put-off the pad.in this time every day

in the night time she peed on the bed. When experiencing pain in this time she become very disturbing then her mother tells her to bear this and tells that same things happens also in case of her mother. Sometimes her mother gives her medicine for the pain.

She needs full support during her menstrual period, every time her mother needs to set the materials, change the materials, clean the used panty and clothes. As she has peeing tendency during night time so this time it becomes very difficult because mother needs to change and wash the bloody bed clothes and her daughter's clothes. She remains disturbing in the first and 2nd night, 1st day she destroys 12-15 pads because when she goes bathroom, she put off the pad, tendency to go washroom. The more she goes washroom her mother or sometimes her elder sister needs to help her otherwise she putts off the pad. During her a school time special educator give hands on training on managing menstrual hygiene independently beside giving counselling. In home mother also giving training on managing menstrual care independently according to teachers' recommendations.

Her mother feels very stresses about her because she needs full support and remain very disturbing during this time. Mother told that she and her elder daughter are now giving support but after 2-8 years if she can't manage this without support then what will happen. After achieving menarche phase now, she tries to frequently press the secret area, want to keep finger directly to that area so her mother and teachers need to frequently instruct to stop that. When she has whit discharge before onset of menstruation, she has frequent tendency to itch that secret area and sometimes these creates very embracing situation for the mother.

Mother expects that if she understands the matter and manage the issue such as understand onset of menstruation, set, change materials, disposal of used materials, cleaning herself independently then her mother will happy. Her mother and school teachers are giving training on menstrual care and hygiene independently and mother hopes that her daughter will be able to manage menstrual care independently.

After achieving menarche phase mother also giving extra care to her. Based on the Therapist recommendations from the school she and school teachers are giving training on gender identification, good touch bad touch by flash card, protection techniques by crying, telling directly to mothers for preventing any bad incidence.

Annex-3: Questionnaire for qualitative data collection (English and Bangla)

Demographic information

Participant's information:

Name: _____ Age: _____ Education: _____
Occupation: _____
No. of family member: _____ No. of daughter under & over menarche age: _____
Living address: _____

Participant's Daughter's information:

Name: _____ Age: _____ Onset age of menarche: _____
School going: Yes/no _____ Grade: _____ Type of school: _____

Qualitative information

1. What are your experiences in handling menstrual hygiene in your daughter?

Sub questions:

- I.** How was your daughter first reaction towards her first menstruation?
- II.** Do you yourself have lot of pain or other menstrual symptoms? Then what happened to your girl, how you handle?
- III.** what type of materials they use and how many times a day they change?
- IV.** If the daughters change or need support? Then what kind of support they need during managing her menstrual hygiene at home and school?
- V.** Do you need support from other family member? If yes, what type of support and if no why?
- VI.** Does she go to school during this time? what type of support are getting from school?
- VII.** What are the challenges are you facing during maintaining her menstrual hygiene?
- VIII.** What kind of emotional stress are you feeling during managing your daughter's menstruation or thinking about her future management support?
- IX.** What type of changes have you observed after having menstruation, how you handle?

- X. Do you feel any education or menstrual management skills training needed for your daughter for her future? Yes/no why?

2. What you are thinking about her extra care and protection?

Sub questions:

- I. Do you feel any mental stress about her extra care and protection issue, if yes why are you feeling that kind of stress?
- II. Do you feel any risk of complications like infections, sexual abuse? If yes, why?
- III. What type of actions have you taken to avoid these risks like hormone replacement therapy or hysterectomy of any other things?

Questionnaire for qualitative data collection (Bangla)

জনতাত্ত্বিক তথ্য

অংশগ্রহণকারীর তথ্যঃ

নামঃ বয়সঃ শিক্ষাঃ পেশাঃ

পরিবারে সদস্য সংখ্যাঃ ঋতু শুরু ও শুরু হয় নি এমন কন্যার সংখ্যাঃ বয়সঃ

বসবাসের ঠিকানাঃ

অংশগ্রহণকারীর মেয়ের তথ্যঃ

নামঃ বয়সঃ ঋতু শুরুর বয়সঃ স্কুলে যায় কিনা, হ্যাঁ/না

গ্রেডঃ স্কুলের ধরনঃ

গুণগত তথ্য

প্রশ্ন ক। ঋতুকালীন সময়ে আপনার মেয়ের ব্যবস্থাপনায় আপনার অভিজ্ঞতা কেমন?

উপপ্রশ্ন সমূহঃ

১। প্রথম ঋতু শুরু হলে আপনার মেয়ের প্রতিক্রিয়া কেমন ছিল/থাকে?

২। ঋতুর সময় আপনার কি ব্যথা হয়? আপনার মেয়ের ক্ষেত্রে হলে কিভাবে সামলান?

৩। আপনার মেয়ের ঋতুকালীন ব্যবস্থাপনায় কি ধরনের উপকরণ ব্যবহার করেন?

৪। আপনার মেয়ে কি নিজে নিজে উপকরণ পরতে ও বদলাতে পারে? এ সময়ে আপনার কি কি ধরনের সাহায্য সহযোগিতা করতে হয় বাসায় ও স্কুলে?

৫। শুধু কি আপনিই সাহায্য করেন নাকি পরিবারের অন্য কেউ সাহায্য করে? কিভাবে সাহায্য করে?

৬। এসময়ে কি আপনার মেয়ে স্কুলে যায়? স্কুল থেকে কি কোন সাহায্য করে? কিভাবে সাহায্য করে?

৭। ঋতুকালীন সময়ে আপনার মেয়েকে সাহায্য সহযোগিতা করতে গিয়ে কি কি চ্যালেঞ্জ এর মুখোমুখি হন?

৮। এ সময়ে আপনার মেয়েকে সাহায্য করতে গিয়ে বা তার ভবিষ্যত ব্যবস্থাপনার কথা ভেবে আপনি কেমন মানসিক চাপ অনুভব করেন?

৯। ঋতু পরবর্তী কোন পরিবর্তন আপনার মেয়ের মধ্যে লক্ষ্য করেছেন? কি কি ধরনের পরিবর্তন যেমনঃ শারীরিক, মানসিক পরিবর্তন?

১০। এ সময়ে আপনার/আপনার মেয়ের কোন সাহায্য, তথ্য, প্রশিক্ষণ দরকার যেটা আপনার মানসিক চাপ কমাতে, আপনি কি মনে করে?

প্রশ্ন খ। আপনার মেয়ের বাড়তি খেয়াল ও সুরক্ষার ক্ষেত্রে কি ভাবছেন?

উপপ্রশ্ন সমূহঃ

- ১। আপনার মেয়ের বাড়তি খেলাল ও সুরক্ষার কথা ভেবে আপনি কেমন চাপ অনুভব করেন?
- ২। আপনার মেয়ের ঋতু পরবর্তী জটিলতা যেমন সংক্রমণ, যৌন হয়রানি ও যৌন নির্যাতন এর ঝুঁকি আছে কি না আপনি কি মনে করেন?
- ৩। এসব ঝুঁকি থেকে উত্তরণের জন্য কি কি পছন্দ অবলম্বন করেছেন?

Annex-4: Information Sheet (English)

I am the student of M.Sc. in Rehabilitation science at Bangladesh Health Professions Institute (BHPI), the academic institute of Center for the Rehabilitation of the Paralyzed (CRP) under the medicine faculty of University of Dhaka. I would like to inform that for our part of academic research I am going to do a research on the topic of ‘**Mothers experience on menstrual care of girls with intellectual disabilities**’. The purpose of the study is to find out the challenges are you facing during handling your daughter menstruation and how you are taking care after menarche which help the researcher to make some recommendation based on your experiences. These recommendations will helpful for the health professionals and other professionals to address this issue or include this issue to their practice also.

So, your valuable information will helpful for understanding your experiences. All information will be kept very confidential and information will be used only for my research purpose. For understanding your every speech and expression I need to record your information. You have full right to reject participation any time or you can skip any sensitive points on the questionnaire if you don’t want to share. From this study you are not directly benefited or get any gift.

Sign of Researcher

Information Sheet (Bangla)

তথ্য পত্র

আমি বাংলাদেশ হেলথ প্রফেশনাল ইনস্টিটিউট (বি এইচ পি আই), সি আর পি -র একাডেমিক ইনস্টিটিউট ও ঢাকা বিশ্ববিদ্যালয়ের মেডিসিন অনুষদের আওতায় মাস্টার্স ইন রিহেবিলিটেশন সায়েন্স এর ছাত্রী। আপনাকে জানাচ্ছি যে, আমাদের শেখার অংশ হিসেবে শেষ বর্ষে একটি গবেষণা করতে হয় ও আমার গবেষণার বিষয় হচ্ছে 'বুদ্ধি প্রতিবন্ধী মেয়েদের ঋতুকালীন ব্যবস্থাপনায় মেয়েদের অভিজ্ঞতা'। আমার গবেষণার উদ্দেশ্য হচ্ছে আপনারা আপনাদের মেয়েদের ঋতুকালীন ব্যবস্থাপনায় ও যত্নে কী ধরনের জটিলতার মুখোমুখি হচ্ছেন এবং এ সময়টাতে কীভাবে যত্ন নিচ্ছেন এই তথ্যগুলো বের করে গবেষক কিছু প্রস্তাবনা তৈরি করবেন। এই প্রস্তাবনাগুলো হেলথ প্রফেশনালস ও অন্যান্য প্রফেশনালসদের এই সমস্যা সমাধান ও কিছু বিষয় তাদের রেগুলার প্র্যাকটিস এ অন্তর্ভুক্ত করতে পারবেন।

সুতরাং, গবেষণায় আপনার অংশগ্রহণ ও আপনার মূল্যবান তথ্য আপনার অভিজ্ঞতা জানতে খুবই প্রয়োজন। আপনার পরিচয় ও তথ্য সম্পূর্ণ গোপন রাখা হবে এবং শুধুমাত্র আমার গবেষণার কাজে ব্যবহার করবো। আপনার প্রত্যেকটি কথা ও মুখভঙ্গি বুঝার জন্য আপনার কথা রেকর্ড করতে হবে।

গবেষণায় আপনার অংশগ্রহণ সম্পূর্ণ ঐচ্ছিক ও আপনি অংশগ্রহণ এড়াতে পারেন অথবা প্রশ্নপত্রের যে কোনো পয়েন্টস এড়াতে পারেন। এই গবেষণা থেকে আপনি কোন সুবিধা/গিফট পাবেন না।

গবেষকের স্বাক্ষর

Annex-5: Consent Form (English)

I am

I have read/ have being informed clearly about the study purpose. All information related to study has been given. As all information will be kept confidential and used for only her research purpose so I agree to participate in this study.

.....

.....

Signature of the participants

Sign of the Researcher

Consent Form (Bangla)

সম্মতিপত্র

আমি গবেষণা ও তার উদ্দেশ্য সম্পর্কে সুস্পষ্টভাবে আমি অবহিত হয়েছি। গবেষণা সম্পর্কিত সকল তথ্য পেয়েছি। যেহেতু গবেষণায় বলা সকল তথ্য গবেষণার কাজ ছাড়া অন্য কাজে ব্যবহার হবে না ও গোপন রাখা হবে সুতরাং আমি গবেষণায় অংশগ্রহণ করতে রাজী আছি।

অংশগ্রহণকারীর স্বাক্ষর

গবেষকের স্বাক্ষর

Annex-5: scan copy of Institutional Review Board (IRB) permission letter and permission letter for data collection

Annex-5.1: IRB Approved letter

বাংলাদেশ হেল্থ প্রফেশন্স ইনস্টিটিউট (বিএইচপিআই)
Bangladesh Health Professions Institute (BHPI)
(The Academic Institute of CRP)

Ref: CRP-BHPI/IRB/02/2020/1390

Date: 24th February 2020

To:
Masuda Akter
M.Sc. in Rehabilitation Science (MRS)
Session: 2018-2019, Student 181180106
BHPI, CRP-Savar, Dhaka-1343, Bangladesh

Subject: Approval of thesis proposal "Parents/caregiver experience on menstrual and post menstrual care of girls with intellectual disabilities" by ethics committee.

Dear Masuda Akter,
Congratulations.
The Institutional Review Board (IRB) of BHPI has reviewed and discussed your application to conduct the above mentioned thesis, with yourself, as the Principal Investigator". The Following documents have been reviewed and approved:

S.N.	Name of Documents
1.	Thesis Proposal
2.	Questionnaire (English and Bangla version)
3.	Information sheet & consent form.

The study involves use open ended questionnaire by face to face interview for exploring the experience of parents or caregiver handling the girls with intellectual disability during their menstrual cycle and that may take 10-15 minutes. Since, there is no likelihood of any harm to the participants in the study; the members of the Ethics Committee have approved the study to be conducted in the present form at the meeting held at 2pm-5pm on 18th February, 2019 at BHPI.

The institutional Ethics committee expects to be informed about the progress of the study, any changes occurring in the course of the study, any revision in the protocol and patient information or informed consent and ask to be provided a copy of the final report. This Ethics committee is working accordance to Nuremberg Code 1947, World Medical Association Declaration of Helsinki, 1964 - 2013 and other applicable regulation.

Best regards,

Muhammad Millat Hossain
Assistant Professor, Dept. of Rehabilitation Science
Member Secretary, Institutional Review Board (IRB)
BHPI, CRP, Savar, Dhaka-1343, Bangladesh

CRP-Chapain, Savar, Dhaka-1343, Tel : 7745464-5, 7741404
E-mail : principal-bhpi@crp-bangladesh.org, Web: bhpi.edu.bd, www.crp-bangladesh.org

Annex-5.2: Data collection permission letter

