

PUBERTAL CHALLENGES IN FEMALE ADOLESCENTS WITH AUTISM SPECTRUM DISORDER: MOTHER'S PERSPECTIVE



By

Adiba Tafhim Anisa

February 1, 2019

This thesis is submitted in total fulfillment of the requirements for the subject

Research 2 & 3 and partial fulfillment of the requirement for degree

Bachelor of Science in Occupational Therapy

Bangladesh Health Professions Institute (BHPI)

Faculty in Medicine,

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Statement of Authorship

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The ethical issue of the study has been strictly considered and protected. In case of dissemination of the findings of this project for future publication, research supervisor will highly concern and it will be duly acknowledged as undergraduate thesis.

Signature: _____ **Date:** _____

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List of Abbreviation

WHO	World Health organization
CRP	Centre for the Rehabilitation of the Paralysed
ASD	Autism Spectrum Disorder
IRB	Institutional Review Board
NIMH	National Institute of Mental Health
IQ	Intelligence quotient
ADL's	Activities of Daily Living
CRI	Centre for Research and Information
DLS	Deficit of Living Skills

Abstract

Autism Spectrum Disorder is a neuro-developmental disorder that is marked persistent communication deficit, restricted behavior which interferes with a person's ability to feel, think and create problem in language and performing a task in their daily-life. Person with or without ASD all have to go through a physical & mental transition called puberty. This is an extremely challenging and confusing period for person with ASD as they have to encounter a number of events. They require more times to cope with the changes that occur in their body and with the changing relation and situation. Girls with ASD especially face difficulty during menstruation because of complicated menstrual management. Besides this their change in attitude, feeling of romantic relationship, need for extra menstrual hygiene all have great impact in the life of girl with ASD and their mother. The objectives of the study is to identify the challenges that mother face during the puberty of their daughter and how are they coping with those challenges through taking interview of mothers. The researcher did a phenomenological qualitative study in which she interviewed the mother to find out the answer. After analyzing, researcher come to an understanding that mothers of girl with ASD have to deal with a number of issues in their daily life regarding the issues related to puberty.

Key words: ASD, Adolescence, Puberty & Changes

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Chapter 1: Introduction

1.1 Introduction

Autism Spectrum Disorder (ASD) is a neuro-developmental disorder which is associated with the presence of socio-communication deficit and restricted and repetitive behavior (Ousley and Cermak, 2013). According to American Psychiatric Association, Autism Spectrum Disorder is a complex developmental disorder that can cause problems with thinking, feeling, language and the ability to relate to others (Copeland, 2018). Autism is basically a developmental disorder that affects a person's communication and behavior and symptoms generally appear in the first two years of life. Because of the wide variation in symptoms and types that people experience, it is known as "spectrum" disorder (National Institute of Mental Health, 2018). According to DSM-V diagnostic criteria, persistent deficits in social communication and social interaction across multiple contexts including deficit in social-emotion, non-verbal communication, developing & maintaining relationship and restricted & repetitive pattern of behavior, interest or activities are marked (American Psychiatric Association, 2015). Approximately 1% of children throughout the world have an ASD, each with his or her own unique combination of symptoms and levels of impairment (National Institute of Health, 2015). At least 17 per 10,000 babies in Bangladesh have Autism Spectrum Disorder and the prevalence is higher in urban areas and among boys (Molla, 2018). In every 10,000 boys 24 were found to be autistic, compared to 9.8 girls in every 10,000. (Maswood, 2018).

According to Melissa Dubie, regardless of IQ level, social or physical skill all individual go through puberty and the brain doesn't stop the changes that comes through puberty. Puberty is the transitional stage when the infant turns into a toddler (Dubie, 2014). For males, enlargement of testes and scrotum is the beginning of puberty which occurs Puberty between the age of 8 and 14 and after that the penis start to grow which lead to sexual maturity ("Ford, Ptasznik, Blumberg, Clayton,& Beeching", n.d.). For girls, developing breasts, growing spurts, pubic & underarm hair, having vaginal discharge are

the signs of puberty. Menstruation begin one or two year after those changes and the average age of starting menstruation is around 12 or 13 but it may stars as early as 9 or as late as 17. (Dubie, 2014).

During adolescence, a range of social, physical, emotional and cognitive changes occurs (Cridland, 2014). Important psychosocial and social changes that occurs alongside with various physical developments (sexual and body changes) that occur during adolescence mark this period as a critical stage towards becoming an adult (Ford, Ptasznik, Blumberg, Clayton, & Beeching, n.d.). An Individual with autism spectrum disorder requires more time than his/her peers to cope with those major changes that come with puberty (Autism Awareness Australia, n.d.). Continuation of a familiar routine is necessary for individuals with an Autism Spectrum Disorder (ASD) as they have to face difficulties coping with different changes during this period .Typically, the time at which an adolescent, even without an ASD, goes through puberty can be stressful for the individual as well as for all family members (Ford, Ptasznik, Blumberg, Clayton, & Beeching,n.d.) as the period of adolescence requires a complex patterns social interaction; importance to fitting-in and conforming to social norms and exposure to a wide range of social norms(Cridland, 2014). Although, when a child has an ASD, these stressful times are compounded and may become more complex these things are more stressful, compounded and may become more complex when the family has a child with ASD (Ford, Ptasznik, Blumberg, Clayton, & Beeching, n.d.). Parents often wonder about the appropriate timing to discuss about puberty with their child. As children with ASD commonly need a longer period of time to accommodate themselves with the changes, parents need to decide the time and amount of preparation the child require to understand the changes associated with puberty based on the specific personality of the child (Ford, Ptasznik, Blumberg, Clayton,& Beeching, n.d.). Parents need to answer all the question honestly regarding puberty. This will help the child to understand that puberty is nothing about embarrassment and they will not become anxious regarding the changes during puberty (The National Autistic Society, 2011).

Adults and teenagers are often poorly informed about sexual and reproductive health as these topics are still a taboo in Bangladesh (Ainul, Bajracharya, Reichenbach, & Gilles,

2017). The situation is worst for girls as they face restriction in education and work due to unawareness, shame and inconvenience regarding menstruation (Akhter, 2018). Families of autistic children and children with other disabilities have to face immense pressure due to prejudice and ignorance about disability in our society (“Autistic Children in Bangladesh”, 2013). As a result, autistic teens likely to have less access towards information and service regarding sexual & reproductive health.

1.2 Justification

According to the World Health Organization 1 in 160 children has Autism Spectrum disorders (WHO, 2017). The prevalence of ASD ranged 0.15% in Bangladesh (Centre for research and Information, 2014). There is no exact number about how many of them are adult. But the number is no less without any doubt. These teenagers especially girls need special education and care during the period of puberty. But this topic is a very neglectable issue in our society especially in their case. As a result, their performance in ADL and quality of life may decrease and these may create extra burden on the parents. As health professional, Occupational Therapists should have a clear idea about the possible challenges and difficulties that create barriers in the level of participation in everyday life of a female teenager with ASD. This study aims to find out the challenges that the parents face during the pubertal period of their children and how they are trying to cope with these problems. This study will help to create awareness among health professionals regarding pubertal challenges. Though there are few resources regarding male puberty but there are a very few resources regarding female puberty. In Bangladesh, no research is conducted regarding this issue. As issues regarding puberty is very sensitive and with a limited resource, both professionals and parents face challenges during this period of transition of an autistic child especially in case of female. This study will help occupational therapy professional to find effective ways to deal with those challenges and to help both female teenagers with autism spectrum disorder and their parent.

1.3 Research Question: What are the experiences of mother during the puberty of female adolescents with Autism Spectrum disorder?

1.4 Study aim and specific objectives

Aim: To find out the challenges female adolescent with ASD face during puberty.

Objectives

- To find out mother's level of understanding about puberty.
- To find out the challenges faced by the mother of female adolescents with autism spectrum disorder during puberty.
- To explore the ways mothers are coping with challenges during puberty of their adolescent daughter with ASD.
- To identify mothers expectations from health professionals regarding puberty related issues issue.

1.6 Operational Definition:

Autism Spectrum Disorder:

Autism, or autism spectrum disorder, refers to a range of conditions characterized by challenges with social skills, repetitive behaviors, speech and nonverbal communication, as well as by unique strengths and differences.

Adolescence:

Adolescence typically describes the years between ages 13 and 19 and can be considered the transitional stage from childhood to adulthood. However, the physical and psychological changes that occur in adolescence can start earlier, during the preteen or "tween" years (ages 9 through 12). Adolescence can be a time of both disorientation and discovery. This transitional period can bring up issues of independence and self-identity; many adolescents and their peers face tough choices regarding school, sexuality, drugs, alcohol, and social life .

Puberty & Changes:

Puberty is the period of human development during which physical growth and sexual maturity occurs. The word puberty is derived from the Latin "pubertas", which means adulthood. Puberty is initiated by hormonal changes triggered by a part of the brain called the hypothalamus, which stimulates the pituitary gland, which in turn activates other glands as well. These changes begin about a year before any of their results are visible.

Sexual and other physical maturation that happens during puberty is a result of hormonal changes. In boys, it is difficult to know exactly when puberty is coming. There are changes that happen, but they happen gradually and over a period, rather than as a single event. Girls experience puberty as a sequence of events, but their pubertal changes usually begin before boys of the same age. Each girl is different and may progress through these changes differently. The following are average ages when puberty changes may happen:

- Beginning of puberty: 8 to 13 years
- First pubertal change: breast development
- Pubic hair development: shortly after breast development
- Hair under the arms: 12 years old
- Menstrual periods: 10 to 16.5 years old

Chapter2: Literature review

Literature review:

History & Characteristics of ASD

Autism was first discovered by American, Leo Kanner or the German, Hans Asperger who discovered the “Asperger Syndrome” in the back in the 1940’s but the presence of autism was long before that. People used to consider autism as a form of spiritual possessions, a mental illness or handicap, an emotional disorder, a communication disorder, a developmental disorder and newly added an information processing disorder, a movement disorder or a sensory or perceptual condition (Donna, 1996). Landrigan (April, 2010) stated that, autism is a biologically based disorder for which genetic factors, mutations, deletions and copy number of variants are responsible but only for a few number of cases. However, different environmental factors such as early exposure to thalidomide, misoprostol, valproic acid and external exposure to lead, ethyl alcohol etc. are also hold accountable by some indirect evidence as the cause of autism. Rachel (n.d.), explained five sub-types of autism and they are: Asperger’s Syndrome (often misdiagnosed and unskilled in social communication skill with repetitive movement & fixed pattern of behavior), Kanner’s Syndrome described by Dr. kanner in 1930s a common & classic autistic disorder (they have poor social & communication skill, low functioning, always followed a fixed pattern of routine, deeply affected by light, smell etc.), Pervasive Developmental Disorder or PDD-NOS (as similar as Kanner’s Syndrome and difference between both of the types), Rett’s Syndrome described by Dr.Rett which is a very rare type of condition only happen to girls(these girls become mentally restarted, have muscle atrophy and repetitive hand motions, requires care for rest of their life), Childhood Disintegrative disorder another rare type of disorder that strike a child suddenly at two and four years of age (the child started to forget and disinterest in language & communication skill, often do not potty train etc.). But in the current revised version of DSM (the DSM-5), all the types are combined into “autism spectrum disorder” (NIMH, March 2018).

Changing characteristics of ASD in Adolescence:

The diagnostic criteria of autism are most prominent between the age of 3 to 6 which usually have changed by adolescence and early adulthood (Carol & Jennifer,2010).Carol & Jennifer also stated that, by adolescence individual with high functioning autism shows a development in language skill and Individual with Asperger's Syndrome shows similar characteristics as individual with high functioning autism by adolescence (Gilchrist et al, 2001).They also found that, though individual with ASD may show some improvement and change in stereotype behavior but deficit in socio-communication skill continue to persist by adulthood, some may also experience a worsening of symptoms (Seltzer et al, 2005).

Gael & Hsin-Yu (2015) stated that Young adult with ASD along with an intellectual disability depend on parents and professionals for functional dependency more than those without disability. Carol & Jennifer (2010) stated that, individual with ASD who spent more time with their peer gain more adaptive skills rather than those who don't engage with peers socially (McGovern and Sigman, 2005). Gael & Hsin (2014, sep 15) also stated that Individual with ASD but without intellectual disability likely to spend more time in personal activities like watching TV, using computer etc. which help to make them independent in solitary activities.

Gemma (2014) stated that, for young adult with ASD transition to adulthood can be very difficult (Giarelli and Fisher 2013; Roncaglia 2013), and transition support can be also problematic (Beresford, Moran, Sloper, Cusworth, Mitchell, Spiers, Weston, and Beecham 2013; Reid 2007; Allard 2009; Griffith, Totsika, Nash, and Hastings 2012). Young adult with high functioning ASD requires little support during transition to adulthood (Barnard 2001; Beresford and others, 2013) but for others with ASD outcome in quality of life, independence, employment, relationships etc. tends to be poor(Orsmond, Shattuck, Cooper, Sterzing, and Anderson 2013; Howlin, Goode, Hutton, and Rutter 2004; Barneveld, Swaab, Fagel, van Engeland, and 5 de Sonnevile 2014; Taylor and Seltzer 2011; Tobin, Drager, and Richardson 2014; Kamio, Inada, and Koyama 2013).

Adolescence & Puberty:

Adolescence is a complex period that depends on an individual's experience of physical, emotional and cognitive maturation with some other changes while puberty is the borderline between childhood & adolescence. But puberty alone can't describe the complexity of adolescence (UNICEF, 2011). According to WHO (n.d) "Adolescence is a period of life with specific health and developmental needs and rights. It is also a time to develop knowledge and skills, learn to manage emotions and relationships, and acquire attributes and abilities that will be important for enjoying the adolescent years and assuming adult roles". Elizabeth and Lorah (n.d.) stated that puberty is the developmental process that provides stimulation for all the physical changes & putative psychological changes that occurs during the developmental period. On the other hand, adolescence is a wider term that includes both puberty & other social, emotional, wider psychological changes that occurs during the transitional period of becoming an adult. For girls, breast development & first menstrual periods and in case of boys broadened shoulders with deepened voices are the marked and prominent stage of adolescence. Alongside with these, they develop emotionally, develop a sense of self, start to think abstractly, engage socially with peers and experience new behaviors that come along the transitional period (American Psychological Association,2002).10 to 14 is early adolescence where physical changes generally commence which begins with a growth spurt, development of sex organs followed by secondary sexual characteristics. These changes are often become the source of anxiety or excitement or pride for the individual who is going through the transmission. Late adolescence is the later part of teenage between the age of 15-19 where all the physical changes already occurs but the body is still developing, brains develop to skill to think analytically & reflectively, individual becomes confident about own identity and the ability to evaluate a risk & taking constructive decision occurs (UNICEF,2011).According to American Psychological Association (2002), puberty started at the age of 10 to 12 & completed at the age of 17 to 19 in girls and in boys it started at the age of 12 to 14 & completed at 20 (Hofmann & Greydanus,1997).Girls may experience puberty 12-18 months earlier than boys; usually girl's experience first period at the age of 12 while boys experience first ejaculation at the age of 13.Sometimes girl's may experience the first menarche as early as 8 years old (UNICEF,2011).

Puberty & complexity faced by female adolescents with ASD:

All individual experience puberty regardless of their mental or physical state (Melissa, n.d.) and this time of puberty is a stressful time for the family members & for the individual with or without ASD (Elizabeth, Gabrilla, Megan, Samantha & Sara, n.d.). This time may be more difficult for parents of pre-teens & teens with ASD (Autism speaks, n.d.) because changes associated with puberty can be difficult (Center on Secondary Education for Students with ASD, 2016) & parents often become confused about when to discuss those changes with their child (Elizabeth, Gabrilla, Megan, Samantha & Sara, n.d.). Any changes for children with autism are difficult. So, when they undergo through massive changes during puberty especially when girls experience the beginning of menstruation, they may become frightful (Chantal, 2011). Whiteny(2016) stated that, females with ASD reported to experience irregular cycles, dysmenorrhea, heavy flow, menorrhagia, severe acne, mood and behavioral change, hirsutism at a higher rate compared to their peers with developmental disorder(Burke et al,2010; Ingudomnukul et al.,2007; Pohl et al.,2014). Mothers of the female with ASD shared that they often experience difficulties due to complicated management of menses (carrying or changing hygiene ported to product), unexpected cycles that leads to behavioral problems, interference in the performance of daily activities due to painful period which makes them unable to cope with the situationan. The effect of menstruation is poorly described as female with ASD is largely ignored in research (Kirkoyski, Enicott & Fitzggerald, 2013; Lai et al, 2013; Shefcyk, 2015; Werling & Geschwind, 2013). Sarah et al (2016) stated that young women who can manage their own feminine care are more independent & have greater privacy (Demetral et al.,1983) than females with developmental delays that depends on their family members or carer. So, females with developmental delays need o learn feminine care before the average age of menarche. All females with ASD need to be prepared for menarche from a very younger age, so that they can learn the skills because all female with ASD will experience menarche regardless their condition. Elizabeth et al (2013) found in their research that, puberty especially the onset of menstruation is the most concern issues among mothers but most of the mothers whose daughters had already experience menarche described that their

daughter is managing the situation in a very well way because of their logical & factual attitudes and willingness to discuss the issues of period.

Personal hygiene & social-interaction skills:

Hygiene and its impact on the female with ASD and the challenges they face to meet the demand of the increased hygiene routine is another discussed topic by the mothers. So, most of the mother said that they continued a “hand’s-on” role with their daughter from childhood.

Adults with Autism Spectrum Disorder may refuse to engage in personal hygiene due to sensory issues and lack of social awareness may also have an impact while decision making regarding personal hygiene activities. Issues regarding hygiene become more extensive with age as these are very important to portrait an acceptable self-image for adults with ASD in front of their peer (Miachel, 2014). Dean et al (2014) stated that, Individual with ASD are less socially integrated than their regular peers as they spend less time in socialization (Kasari et al., 2011) and they lack in social experience as they have fewer opportunity to practice & develop age appropriate social skills. Which results in a widen gap between typically developing children & children with ASD (Rotheram-Fuller et al., 2010). According to Elizabeth et al (n.d.), there are some characteristics like maintaining eye contact, initiating interactions and interfering the interest of others and difficulty of these characteristics may hinders the development of meaningful personal relationships (Dodd,2005). Elizabeth et al (2013) narrated that, girls with ASD may have relatively strong social skills including pretend play (Attwood 2012,2013;Solomon et al 2012), communication (Nichols et al., 2009),social imitation (Baron-Cohen et al,2011; Hsiao et al,2013; Rivet and Matson 20110,ability to focus (Nichols et al,2009) and additionally fewer behavioral problems compared to male with ASD(William et al,2012) which lead to the delayed diagnosis of their condition. Sometimes it may be delayed until their transition towards adulthood occur (Begeer et al., 2013; Bolick, 2011; Willey, 2003) Marlina et al., (2017), social & communication development follows a different trajectory in girls which may impact the autism of presentation in girls (Koenig & tsatsanis, 2005) and the findings of their research indicate difficulty in initiating and sustaining conversation while communicating. Elizabeth et al (2013) also stated that

during adolescence, significant social impairment more evident due to the increased complexity of social relationship (Bauminger et al., 2008; Carrington et al., 2003).

Developing & sustaining friendship with peer:

Parents of the daughter with ASD express their worry about the difficulties their daughter face while developing & sustaining friendship over the years especially with typical developing peer and also mention about the fear of their daughter of social rejection while initiating friendship and also mention their concern about bullying behavior (Marilena et al., 2017). Elizabeth et al (2013) also stated that, adolescent female relationship requires more complex skills in comparison to male adolescent relationships. That's why female adult with ASD need more time to process & respond to information (Nichols et al., 2009) to keep-pace with their peers and as a result it make them more disadvantaged while maintaining & developing friendship than male adolescents with ASD (Hsiao et al., 2013; McLennan et al., 1993; Nichols et al., 2009; Rivet and Matson, 2011b). Dean et al (2014) explained that, girls with ASD appears to be less preferred as a friend and they are not being rejected but may be they are being overlooked or ignored which makes them socially & emotionally at risk (Rose and Roudolph, 2006).

Personal relationships & sexual issues:

Elizabeth et al (n.d.) narrated that Individual with ASD have trouble to identify someone's else feelings (Nichols, Moravcik & Tetenbaum, 2009) which makes it difficult for them to develop romantic relationship (Attwood, 2009). Moreover, individual with ASD may have limitation in social skill, communication skill and in communicating emotions which affect their ability of lasting a romantic relationship for a long time (Attwood, 2009). Even though it's difficult but it's not impossible for them to develop a romantic relationship. Elizabeth et al (2013) explained that, increasing sexual issues and romantic relationships was another topic discussed by many mothers. Most of the mother said that their daughter shows less interest in romantic relationship and often face challenges due to misunderstanding & confusion of different issues like flirting, personal boundaries etc. They also think that boys with ASD may have a higher sexual urge compared to girls with ASD and they are concerned that their daughter may be exploited

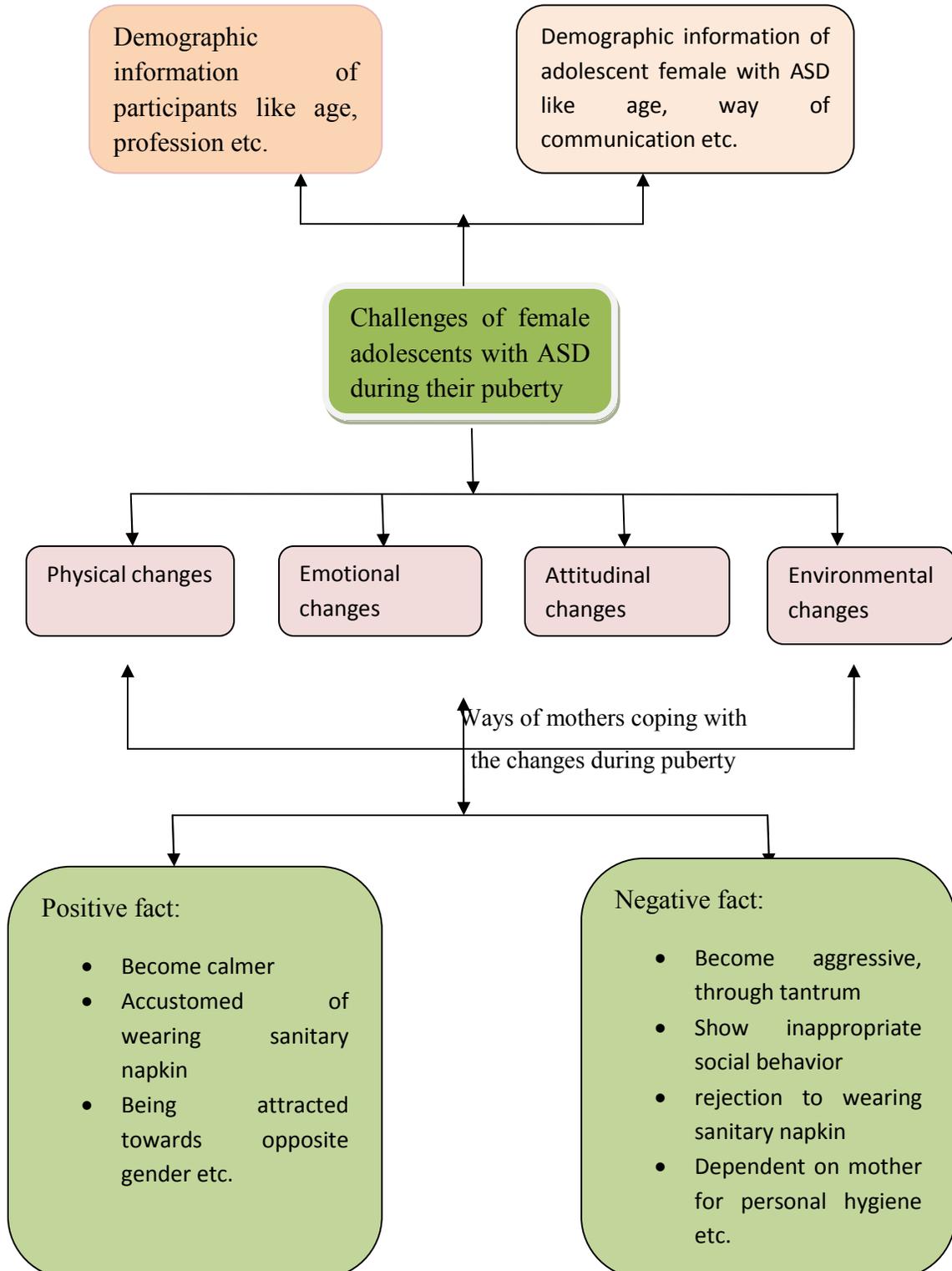
by others due to overly trusting. According to Merilena et al (2017), providing sexual education to their intellectual disable daughter is a concerning issue for mothers because their daughters do not understand menstruation, birth control, puberty etc. and, they have no idea how they will provide education about intimate, sexual and romantic relationship to their daughters. They also express their worry about that after getting the knowledge their daughters may want to experience an intimate relationship and they may become victim of sexual exploitation.

Experience of the mothers of female adolescents with ASD:

Navot, Jorgenson & Webb (2017) sated that, while raising a daughter with ASD mothers shared a mixed feeling regarding diagnosis, significant challenges that their daughter experience during puberty and showed concern about sexual & romantic relationship that emerge with age. Elizabeth et al (2013), mothers shared a thought that they are more involved with their daughter with ASD rather than the mothers with a typically developing daughter because they must help their daughter from school activities to facilitating hygiene. Navot, Jorgenson & Webb again stated that mothers described a feeling of guilt about the late diagnosis of their daughter which affects their ability to understand their daughter's need and described their struggle while reshaping their expectations to form a special relationship with their daughter. They also expressed that they often felt helpless while trying to understand their daughter and after the diagnosis of their daughter they got a better chance of understanding their daughter.

Chapter 3: Methodology

3.1 Conceptual Framework



3.2 Study Design:

To identify the pubertal challenges of female teens and pre-teens with ASD, researcher used qualitative research design. The researcher used qualitative study to fulfill the objective of the study because qualitative study can address the situation of particular event and how the approaches or techniques are influenced through the user (Patton & Cochran, 2002). The nature of qualitative research is exploratory through which the researcher gain insights into another person's view's, opinion, feeling and beliefs within their own natural setting (Ohman, 2005). Qualitative research helps to identify client's thought, ideas, feelings, attitudes & perception through exploring depth information (Hissong et al., 2014). So, researcher used qualitative study to gain an insight of the view, opinion, feelings, attitudes & perception of the mother of teens and pre-teens with ASD through exploring the information they provided.

3.3 Study population

The study population was Mother of female adult with autism spectrum disorder.

3.4 Study setting

This study was conducted in schools that are working with children with different disabilities and autism based schools. The names of the schools are: Proyash School, Autism Welfare Foundation, school for gifted children, Anodoshala school. The researcher conducted interview and collected data in a separate room which was quiet so that participants can comfortably share their experiences and information.

3.5 Study period:

The period of this study was from August, 2018 to April 2019. However, the researcher got time to collect data from 1st December to 30th January, 2019.

3.6 Sample size

The main of the study was to explore the challenges of female with ASD faces during puberty through the perception of their mother. The researcher used purposive sampling as it meets the inclusion criteria. According to Cook (n.d), Purposive sampling is often recommended for qualitative study as strategy of choice (Lincoln & Guba, 1985; Taylor & Bogdan , 1984).When the researcher judgmentally select participants (French et al., 2001) then purposive sampling is used. According to Patton & Cochran (2002), in purposive sampling the sample size is very small and there is not necessary representative of the vast population in qualitative research study. 12 participants were selected who meet the inclusion criteria. There is no accurate sample size for qualitative research and scholars often argue that data saturation is the most important factor in deciding the sample size as saturation is the point at which no new or relevant data is found through data collection (Dowrkin, 2012).

3.7 Inclusion criteria

Participants who were included matched the following criteria:

- Only the mothers of female adolescent with ASD
- Age range of the female adolescent must be between 10-19.

Exclusion criteria:

- Mothers who are not the main caregiver of female adolescent with ASD.
- Mother of female adolescent without ASD
- Age<10, Age>19.

3.8 Sampling Technique:

The researcher used purposive sampling technique to identify the challenges face by female adolescents during their puberty.

3.9 Data collection tools/ materials

Audio recorder was used to record interview of the participants for judgment and it is the most appropriate method for recording interview.

- Paper and pen were used to write down the observation note or any other information that was obvious needed to research study.
- Self-developed semi-structured questions
- Consent form
- Information sheet
- Clip board
- Audio recorder

3.10 Data collection methods

All data of this research was collected through face-to-face interview by using a self-developed semi-structured question. In this study, the researcher has explored the experience each mother that they are facing in their day to day life. In-depth interview has conducted in this study to collect data thoroughly from the participants. With in-depth interview participants would be given freedom to explain their feelings and experience or perception in their own words. This interview procedure would provide the opportunities to observe the facial expression of participants and would help there searcher to determine their understanding of the questions. The question was written in Bengali so it would be easily under stable for all participants. The researcher started from the initial stage of the data collection procedure. At first, the researcher would verbally present the details of the study such as, aim, objectives and purpose of the study then explain the rights, roles, benefits and importance of the written consent form in a descriptive way and arranged the interview in a suitable place. Before starting the interview, the researcher asked the participants about the place of interview. When the participant agreed with the researcher and they felt comfort with the place, then the researcher started to interview. During the interview, a recorder was used to record the conversations and discussion between the participants and interviewer. Recorder, paper and pens also used during interview for writing the additional information from the participants.

3.11 Data management and analysis

The researcher selected Qualitative Content Analysis (QCA) method for analyzing data. QCA follows the three steps (coding, categorizing and generating theme) to present the result of the study.

3.12 Quality control & quality assurance

All data collection should be appropriately done with the concern of respective supervisor along with follow all instructions. It must be ensuring that, the methods which have been using there that are validated fit for the purpose before use the text.

From the beginning of data collection, the researcher completed a pilot study with 3 participants for the survey question, and face- to -face interviews conducted to ensure whether participants were understanding the questions and whether question were covering all criteria. It is important to carry out a field test before collecting the final data because it helps the researcher to refine the data collection plan and to justify the reliability and validity of the questionnaire fit with Bangladeshi context. This field test was performed to identify any missing are in the question. Then the researcher got chance to rearrange the questions to make it more understandable, clear and enough for the participants and the study.

3.13 Ethical considerations

The researcher has maintained some ethical considerations like:

- The researcher gained permission from the ethical committee to conduct the research.
- Ethical consideration ensured by means of an informed consent letter.
- Every personal data (e.g. name, address) recorded and kept confidential.
- All sources cited and acknowledged appropriately.
- All participants were informed about the aim of the study.
- A written consent form which has written in Bengali (Appendix 3) used to take the permission of each participants of the study.
- The researcher had ensured that all participants were informed about their rights

and reserves and about the aim and objectives of the study.

- All rights of the participants would be reserved and researcher was accountable to the participant to answer any type of study related question.
- Confidentiality of personal information strictly maintained. The information gathered from the participants anonymously.
- Researchers ensured the confidentiality and abide by the rules of the organization

Summary of data analysis and result:

Table: 1

Objectives	Question no.	Categories	Themes
To find out mother's level of understanding about puberty.	2	Mothers understand the various physical, attitudinal and emotional changes during puberty.	Mothers have a good knowledge about various changes during puberty
To find the challenges faced by mothers during the puberty of their adolescent daughter with ASD.	4, 5, 7, 8, 9, 10, 12, 14, 15, 16, 18, 19, 23	<p>Mothers face challenges due to the lack of understanding of their daughter about their own physical transition.</p> <p>Mothers observed attitudinal and emotional changes like aggressiveness, calmness, attraction towards opposite gender in their daughter along with physical changes.</p>	Maximum mothers mainly face challenges due to the various emotional and attitudinal changes in their daughter during puberty.

<p>To explore the ways mother coping with puberty related challenges of their adolescent daughter with ASD.</p>	<p>7, 9, 10, 12, 16, 17, 23, 25</p>	<p>Mothers deal with their daughter's personal grooming and personal hygiene related issues for example helping to remove pubic hair, cleaning private parts after toileting etc.</p> <p>Mothers provide education to their daughter about appropriate social behavior, personal relationship and personal security to their daughter and use different strategies to control when their daughter become excited.</p>	<p>Mothers use different ways like accustomed of wearing sanitary napkin, giving education etc. to cope with various emotional & attitudinal changes during puberty.</p>
<p>To identify mother's expectation from health professional.</p>	<p>27</p>	<p>Mothers have various expectation from health professionals</p>	<p>Maximum mothers reported parental training about different pubertal issues.</p>

Chapter 4: Result & Discussion

Common practice of reporting in qualitative research studies is writing result and discussion in same chapter (Stephenson & Wiles, 2000). Result has been analyzed from data which is being collected from the participants understanding and practical experience and discussion helps to present the study in a more clear way (Hissong et al., 2014). These understanding and practical experience emerge from mother's perception and the challenges they face in their daily life during puberty of their daughter with autism. In discussion section, the researcher adds explanation of the work and presents the result of study and findings. Here the investigator presented the findings and discussion with necessary literature support and result part is described as detailed as possible to justify the findings of the study.

The objectives of the study was to find out those challenges, their ways of coping with those challenges through interviewing them in order to explore their understanding and expectation regarding this issue.

The first objective was to find out mother's level of understanding about puberty. Question no. 2 is used for this objective and 1 category is developed.

Category 1: Mothers understand the various physical, attitudinal and emotional changes during puberty.

Under this category the following theme emerged:

Theme 1: Mothers have a good knowledge about various changes during puberty

Second objective was to explore the changes faced by mothers during the puberty of their adolescent daughter with ASD. Under this objectives question number 3, 5, 7, 8, 9, 10, 12, 14, 15, 16, 18, 19, 23 are used and following 2 categories emerged.

Category 2: Mothers face challenges due to the lack of understanding of their daughter about their own physical transition.

Category 3: Mothers observed attitudinal and emotional changes in their daughter along with physical changes.

Under these two categories the following theme emerged:

Theme 2: Maximum mothers mainly faces challenges due to various challenges due to emotional and attitudinal changes in their daughter during puberty.

The third objective was to search out the ways mother coping with those changes that occurs during the puberty of their adolescent daughter with ASD. Question no. 7, 9, 10, 12, 16, 17, 23, 25 are used to develop the following two categories.

Category 4: Mothers deal with their daughter's personal grooming and personal hygiene related issues.

Category 5: Mothers provide education to their daughter about appropriate social behavior, romantic relationship and personal security to their daughter and use different strategies to control when their daughter become excited.

Under category 4 & 5 the following theme has emerged:

Theme 3: Mothers use different ways like accustomed of wearing sanitary napkin, giving education etc. to cope with various challenges due to emotional & attitudinal changes during puberty.

Objective 4 was about the expectations of mothers from teacher and health professionals and question no. 27 is used and 1 category developed.

Category 6: Mothers have various expectations from health professionals.

Under category 6 the following theme has developed:

Theme 4: Maximum mothers reported a parental training about different pubertal issues.

In this section participant's opinions are presented through coding under each category and according to which theme is selected. The findings are presented through tables and below each of the table collected data is presented. "√" is used for the columns where participant agree with the opinion and "P" is used for participants. Description of each theme according to each categories and theme has been given in next page.

4.1: Table no: 2

Theme 1: Mothers have a good knowledge about various changes during puberty

Coding	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	P11	P12
Physical, mental and hormonal changes	√		√	√		√				√	√	√
Becomes shy, sensitive, wants to appear beautiful in front of others	√		√		√			√				
A gap create between parents and child			√	√		√		√	√			
Becomes introvert or extrovert.	√		√	√		√		√				√
Reacts quickly on any matter, argue on everything.			√		√					√		

According to Erickson (2016), Puberty is a daily experience, a series of steps of becoming adult in which a person has to re-acquaint with the developing body and changing hormones cope and navigate with new and challenging social environment and develop new cognitive skills.

Maximum participant reported puberty as a period of physical and mental transition when they become sensitive, nothing can be imposed on them and a gap creates between parents & child.

A participant said *“I think that during this period they go through a mental transition. They become sensitive. They think that no one is trying to understand them”*.

4.2. Table no: 3

Theme 2: Maximum mothers mainly face various challenges due to emotional and attitudinal changes in their daughter during puberty.

Coding	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	P11	P12
Lack of understanding of adolescents with ASD about own physical transition		√		√	√		√	√	√		√	√
Lack of knowledge of adolescents with ASD about private parts	√	√		√	√		√	√	√		√	√
Becomes restless, stubborn, aggressive, shows problematic behavior		√			√	√	√	√		√	√	√
Becomes restless, irritated or hyper like throw things, during menstruation or showed problematic behavior only during first menstruation.	√	√		√	√		√		√	√	√	√
Rejection to wear sanitary napkin due to hypersensitivity	√									√		
Excessive feeling of attraction towards opposite gender, presence of romantic feeling or private part touching tendency which sometimes lead to awkward situation	√		√		√	√	√				√	

According to maximum mother their daughter doesn't have any understanding about the transition their going through. This is too much complex for them to understand.

One participant said *"I think she doesn't understand the changes she is going through. But her teacher says she does. For me, she doesn't understand anything"*.

Another participant said *“No, she doesn’t understand her transition. She doesn’t have the maturity level”*

A number of changes come along with puberty and pre-teens with autism spectrum disorder may find it extremely difficult to understand these changes. It is also difficult for parents to explain those changes to their child. (Puberty & Adolescence Resource, n.d.)

Around 12 participants gave interview and result has been derived by analyzing their understanding. Maximum mother described a change in attitude and behavior in their daughter either positive or negative. Some mothers said that their daughter becomes calmer and stable as she is growing. Again some noticed no change in attitude in their daughter. While some mothers said that their daughter condition is deteriorating as her puberty begins.

Teenagers with autism spectrum disorder can go through a more frequent or sever mood changes than other typically developing teens. Problem behavior- like tantrums, violence or aggression might start or get worse and he/ she might get cranky, scream, fidget, giggle or cry. This may occur as they might have difficulty to cope with the sudden changes or they may have trouble in concentrating (raisingchildren.net.au, 2017).

Like one participant said *“my daughter cries sometimes but why I don’t know”*

Another participant said about her daughter *“normally she remains calm but sometimes she becomes damn crazy. I don’t know why? What’s the reason? Is she hurting anywhere?”*

Due to sudden change in behavior mother sometimes become puzzled and couldn’t find out a way to deal with their daughter.

Some participants notices irritability, hyperactivity, restlessness during especially the in the day before period. Mothers said that they don’t know the reason behind this and they think that it might be due to stomach ache or they feel unwell during that time.

According to one participant *“She becomes excited, keeps moving in her room, indicates in her belly”*.

The 1st period may be a little bit difficult for girl with autism spectrum disorder. Some mother said that their daughter rejected to wear pad during her 1st period.

The onset of menses is often challenging for developmentally-disabled women who may experience menstruation in a more negative and different way including frequent report

of dysmenorrhoea, menorrhagia, mood and behavioral changes and menstrual related hygiene issues (Steward, Crane, Roy , Remington & Pellicano, 2018)..

According to Erickson (2016), Females with ASD reportedly experience menstrual related symptoms like heavy flow, irregular cycle, dysmenorrhea, mood & behavioral changes etc. at a greater rate compare to their peers without ASD ((Burke et al., 2010; Ingudomnukul et al., 2007; Pohl et al., 2014) and mother of ASD shares that it is often very difficult to their daughter to carry out complicated management of menses like carrying or changing hygiene product and painful priod often interrupt in their performance of daily life.

Again some mother said their daughter doesn't show ay behavioral or attitudinal change.

One participant said *“No, I haven't notice anything like that.”*

Menstruation is often seen as a particularly difficult and distressing event specially for women with disabilities because their pre-existing challenges like hypersensitivities, difficulty in regulating emotions and behavior become more exacerbated before, during and after menses (Steward, Crane, Roy , Remington & Pellicano, 2018).

Out of 12 participants 8 participants stated that their daughters either feel attracted towards boys which is sometimes very difficult to control or show inappropriate sexual behaviors like touching private parts or apply spit on breast.

According to Realmubo and Ruble (1999), inappropriate sexual behavior includes touching private parts in public, removing clothes in public, touching the opposite sex inappropriately, and presenting other behaviors such as discussing inappropriate subjects, looking up shorts or down shirts, and touching parents inappropriately

Sexual and romantic experiences and feelings may create extra challenge for teenagers with ASD because they often find it hard to understand the feeling of intimacy, attraction and affection. As a result it's become hard for them to express their feelings and they often ended up doing inappropriate or risky things or getting into unhealthy relationships (raisingchildren.net.au, 2017).

A participant reported *“if she sees any boys, she immediately will go near to him, wants to touch him or talk to him. It is too hard to stop her from doing so. She is too much attracted towards boys”*

4.3. Table no: 4

Theme: Maximum participant use different ways like accustomed of wearing sanitary napkin, setting examples, giving education etc. to cope with various challenges due to emotional & attitudinal changes of their daughter during puberty.

Coding	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	P11	P12
Accustomed daughter of wearing sanitary napkin, tight jeans etc.				√	√							
Mother practically showed and prompted the whole procedure during her own period	√		√		√					√		√
Give complete assistance to maintain menstrual hygiene	√	√	√	√	√		√		√	√	√	√
Mothers applied razor to another part of the body, practically showed the whole procedure			√				√					
Let their daughter to do brushing or bathing alone	√						√				√	
Trained from childhood to make independent in toilet hygiene	√		√			√		√			√	√
Give partial or complete assistance for toilet hygiene	√	√		√	√		√		√	√	√	
Give partial or complete assistance for personal hygiene except toilet hygiene.	√	√	√	√	√		√	√	√	√	√	√
Mother scold, force or beat to diverting her from being attracted towards opposite gender.			√		√		√					

Coding	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	P11	P12
Give examples or divert attention to another topic						√						
Forbid to touch private part				√	√				√			
Gives practical examples to make understand about personal security			√			√		√	√			
Mother doesn't have proper knowledge or idea, or doesn't think that their daughter has the ability to understand complicated issues like romantic relationship, personal space, personal security	√	√		√	√	√		√	√	√	√	√
Try to control their daughter with affection, by giving favorite things, give time to be calmer, take consultation from a doctor etc.	√	√	√		√	√	√	√		√		√
Mother fights or hit when her daughter becomes excited.				√							√	

Some participants stated that they make their daughter accustomed of wearing pad 2 years before her period so that when the time come she can adjust with the change. Some participant practically showed their daughter the total procedure of pad wearing, changing pad and maintaining hygiene during their menstruation. This helps their daughter a lot to adjust with the situation. One participant stated that *“When her menstruation started, her teachers needed to help her in her first day. But she didn't require any help from second day”*

In a study of Steward, Crane, Roy , Remington and pellicano (2018), most teen with ASD first obtained information either through their parents or through school and some from their friends or others like medical professionals or internet. It is essential to teach them

that it's a part of their growth, about menstrual hygiene products and need to prepare them early.

Some participants stated that they were worried about the possible chance of rejection to wear sanitary napkin, touching blood or throwing away the pad. But when they provided practical knowledge to their daughter regarding menstruation and made them accustomed of wearing pad, they easily adjusted with the situation.

Despite giving the practical knowledge, one participant stated that her daughter is still struggling to wear sanitary napkin. Another participant stated that she is thinking of giving education regarding menstruation to her daughter. But in case of maintaining hygiene during menstruation or taking managements like wearing or changing the sanitary napkin, maximum mothers still needs to provide complete assistance to their daughter.

Maximum participants reported that their daughter reported that their daughter either completely or partially dependent on them for bathing, brushing or for removing pubic hair.

Among individual with ASD, 42% faced difficulties while maintaining personal hygiene but 58% were independent at bathing and & 75% at toileting (Linda & Helena, 2007)

One participant stated that in at first her daughter was afraid of razor. So she applied it in her own body and also other parts of her daughter's body to make her understood that the razor is harmless and more ever it were necessary to remove her pubic hair. After that she co-operates her during the task. Another mother stated that she did it in front of her daughter so that she can learn the procedure.

Teenagers with ASD learn better by doing rather than watching or listening and tools like visual schedules, social stories with picture or video modeling are good ways to help them to learn personal hygiene skills (rainigchildren.net.au, 2017).

About bathing, a participant stated that she sometimes let her daughter to bath alone so that she can learn.

Some other participants stated that they provided training to their daughters in childhood about personal hygiene.

Many participants said that they forcefully try to divert them by scolding or beating when their daughters smile towards a random guy or wants to talk or get close with a guy.

A participant reported that her daughter smiles at any guy and it doesn't matter whether it's a rickshaw puller or day laborer or any random guy. She said "Whenever I see her smiling toward any boy, I immediately ask her why she smiles, scold her and say her that it's a very bad thing."

Another participant said *"She becomes crazy to get married. To divert her I immediately change the topic by saying we will marry her off after she completes her study"*

The main problem is maximum participant don't know how to deal with such kind of situation.

Teenagers with ASD may or may not develop romantic feelings like other teenagers and it is a bit challenging for them. Parents may help them by explaining what is attraction, how one feel when they are attracted and how one will behave when they are not interested (raisingchildren.net.au.2017).

Some participants who noticed private part touching tendency in their daughter stated that the immediately tell them to stop and then their daughter stop the behavior but again show it later.

Some other participants said that they don't think the habit of private part touching tendency is not due to any sexual issue but more than sensory issue.

According to maximum participants their daughters don't have the ability to understand the knowledge they will provide regarding this issue.

One participant said "I am trying my best to make her understand but she does not understand at all. I have to come up with new ideas"

Limited sexual knowledge and less opportunity to have romantic and sexual experience often combine with the core feature of ASD and leads to problematic sexual behavior like hypersexual and paraphilic behaviors or sexual offending (Schottle, Briken, tuscher & Turner, 2017).

Mothers often don't understand how they will teach their daughter about personal security as it's a very vital and complex issue.

One participant said *"I am trying but she does not understand that she shouldn't go near to strangers. I am still struggling to make her understand. I still have to puts a lots of effort in it by using various ways."*

Maximum participants expressed that their daughter will not understand even if they try because they have a very low IQ or the issue is itself very much complex for them to understand. Inability to identify inappropriate behavior (Zeitlin, McNally, & Cassidy, 1993) Inability to detect violation (Deprince, 2005) increased the risk of victimization of person with ASD.

Some participants share that they try to control their daughter with affection when they get hyper or excited. According to a participant *“If I scold or hit her, it will worse her situation. So, I try to solve it by showing affection to her.”*

Another participant said that whenever her daughter gets angry or excited she gives her time to be calmer. Giving favorite things is another way reported by participants because their daughter often gets angry when they don't get their favorite things.

Another participant said *“She doesn't listen to me even if I try. So, I have to hit her to make her calmer”*.

4.4. Table no. 5

Theme: Maximum participants expressed a demand for parental training, counseling or education about different pubertal issues.

Coding	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	P11	P12
Counseling, training or education program for parents on puberty	√	√		√	√	√	√	√	√	√	√	√
No expectation			√									

Maximum participants expect and demand for either for a counseling or training or for an education program on preparation for puberty, ways of dealing with sexual or personal security related issues.

According to one participant “We need to be trained before beginning of puberty because maximum of us don’t how to deal with the changes during puberty of our daughter”.

Some parents stated that it would be good if their daughters are trained on menstrual relate issues.

Like one participant said, “I wish if my daughter can wear her sanitary napkin by herself. If I am not with her than she can eat by herself but no one going to help her to maintain menstruation related hygiene except me.

Chapter 5: Conclusion

5.1 Limitation

According to Simon (2011), Limitation is the potential weakness of a study and they are normally out of control of researcher. Though researcher tried her best to conduct the study in a systemic way but there are some limitations of the study. Those limitations are given below:

- Puberty is a series of issue. Though researcher tried her best to cover all the issue , she might miss out some issues.
- As researcher conducted this study within a short period of time, it was not possible for her to maintain the nature of in-depth interview.

5.2 Conclusion

Puberty is the period of transition in which every person goes through some physical and mental changes and these changes sometimes become very difficult to accept as the individual has to deal with a number of social, environmental, mental and physical demands. This period of transition can be more difficult and confusing for an individual with ASD especially females. Because in person with ASD have deficit across multiple areas including communication, sensory, behavior, socialization etc. This deficit can be worsening during puberty and due to their communication deficit they couldn't understand and properly deal with the changes that come along with puberty. In girls, the event of menstruation can be even more difficult because of mood swing, behavioral change and complicated period management.

In Bangladeshi contest mothers have to take full care and assistance to a individual with ASD. So, when a pre-teen with ASD reaches her puberty or preparing to reach puberty, mothers have to deal with the challenges that come along with puberty. The findings of the study shows that, mothers have to deal with a range of behavioral, emotional and attitudinal change when their daughter reaches puberty. The timing of menstruation is more challenging for mothers because they have to help their daughter in

maintaining the complicated procedures of wearing to changing sanitary napkin, cleaning their genital area etc. Issues like feeling of romanticism or attraction towards opposite gender makes the situation more difficult for them.

Thought mothers along with the help of health professional and teachers try to cope up with those changes and challenges but more focus should be given on this issue. Mothers need to be prepared early for the puberty of their daughter to ease their difficulty and so that they can have ideas about how they can deal with those changes.

5.3 Recommendation

There is little organization that works with adult female with ASD. So, parents often don't receive adequate help from health professionals. As health professional occupational therapist should give more focus in this issue. Occupational therapist should train mothers and teacher of different special schools about puberty and the possible changes during that time. More research should be conducted to find out ways to make this transition less difficult and confusing for parent and Individual with ASD. Female with ASD need to be trained about menstrual related issues. Parents counseling should also be provided so that they can have a better understanding of this issues.

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Appendix

Appendix-i

IRB Approval Letter for Conducting the Study

October 04, 2018
The Chairman
Institutional Review Board (IRB)
Bangladesh Health Professions Institute (BHPI)
CRP- Chapain, Savar, Dhaka- 1343, Bangladesh

Subject: Application for review and ethical approval

Sir,

With due respect, I would like to draw your kind attention that I am a student of 4th year B. Sc. in Occupational Therapy course at Bangladesh Health Professions Institute. For the requirement of my course curriculum I have to conduct a research project session. My research title is **Pubertal Challenges in Female Adolescents with Autism Spectrum disorder: Parental Perspective** that will be supervised by SK. Moniruzzaman, Assistant Professor, Department of Occupational Therapy, BHPI, CRP. The purpose of the study is to find out the difficulties and challenges faced by the mother of female adolescents with autism spectrum disorder during puberty. Self-developed questions will be used by face to face interview. That will take about 45-60 minutes. Related information will be collected from the participant. The study will not because of any harm to the participant. Data collectors will receive informed consents from all participants as written record. Any kind of collecting data will be kept confidential.

Therefore, I look forward to having your kind approval of the research proposal and data collection. I also assure you that I will maintain all the requirements for study.

Sincerely yours,
Adiba Tafhima Anisa
Session: 2014-2015
Student ID: 122140151
4th Year Student of B. Sc in Occupational Therapy,
BHPI, CRP, Savar, Dhaka- 1343, Bangladesh
Signature: *Adiba Tafhima Anisa*

Recommendation from the thesis supervisor:
SK. Moniruzzaman
Assistant Professor
Dept. of Occupational Therapy,
BHPI, CRP- Chapain, Savar, Dhaka- 1343
Signature: *SK. Moniruzzaman*
15/10/2018

Appendix-ii

Permission letter for data collection



বাংলাদেশ হেল্থ প্রফেশনস ইনস্টিটিউট (বিএইচপিআই)
BANGLADESH HEALTH PROFESSIONS INSTITUTE (BHPI)
(The Academic Institute of CRP)
CRP-Chapain, Savar, Dhaka, Tel: 7745164-5, 7741404, Fax: 7745069
BHPI-Mirpur Campus, Plot-A/5, Block-A, Section-14, Mirpur, Dhaka-1206. Tel: 8020178, 8053662-3, Fax: 8053661

তারিখ : ২৩.০১.২০১৯

প্রতি
অধ্যক্ষ
বিউটিফুল মাইন্ড
উত্তরা, ঢাকা।

বিষয় : রিসার্চ প্রজেক্ট (dissertation) এর জন্য আপনার প্রতিষ্ঠান সফর ও তথ্য সংগ্রহ প্রসঙ্গে।

জনাব,
আপনার সদয় অবগতির জন্য জানাচ্ছি যে, পঞ্চাশতন্ত্রস্তরের পূর্ণবাসন কেন্দ্রে-সিআরপি'র শিক্ষা প্রতিষ্ঠান বাংলাদেশ হেল্থ প্রফেশনস ইনস্টিটিউট (বিএইচপিআই) ঢাকা বিশ্ববিদ্যালয় অনুমোদিত বিএসসি ইন অকুপেশনাল থেরাপি কোর্স পরিচালনা করে আসছে।

উক্ত কোর্সের ছাত্রছাত্রীদের কোর্স কারিকুলামের অংশ হিসাবে বিভিন্ন বিষয়ের উপর রিসার্চ ও কোর্সওয়ার্ক করা বাধ্যতামূলক।

বিএইচপিআই'র ঐর্ঘ বর্ষ বিএসসি ইন অকুপেশনাল থেরাপি কোর্সের ছাত্রী আদিবা আফহিম আনিসা তত্ত্ব রিসার্চ সমন্বিত কাজের জন্য আপাতী ২৯.০১.২০১৯ তারিখ থেকে ১৫.০২.২০১৯ তারিখ পর্যন্ত সময়ে আপনার প্রতিষ্ঠানে সফর করতে আগ্রহী।

তাই তাকে আপনার প্রতিষ্ঠান সফর ও তথ্য সংগ্রহে সার্বিক সহযোগিতা প্রদানের জন্য অনুরোধ করছি।

ধন্যবাদান্তে

Su. mm
23/01/2019

শেখ মনিরুজ্জামান
বিভাগীয় প্রধান
অকুপেশনাল থেরাপি, বিএইচপিআই



Appendix-ii



বাংলাদেশ হেল্থ প্রফেশনস ইনস্টিটিউট (বিএইচপিআই)
BANGLADESH HEALTH PROFESSIONS INSTITUTE (BHPI)
(The Academic Institute of CRP)
CRP-Chapain, Savar, Dhaka, Tel: 7745464-5, 7741404, Fax: 7745069
BHPI-Mirpur Campus, Plot-A/7, Block-A, Section-14, Mirpur, Dhaka-1206. Tel: 8029178, 8053662-3, Fax: 8053661

তারিখঃ ২৩.০১.২০১৯

প্রতি
অধ্যক্ষ
আনন্দশালা
জাহাঙ্গীরনগর বিশ্ববিদ্যালয়, ঢাকা।

বিষয়ঃ রিসার্চ প্রজেক্ট (dissertation) এর জন্য আপনার প্রতিষ্ঠান সম্বর ও তথ্য সংগ্রহ প্রসঙ্গে।

জনাব,
আপনার সদয় অবগতির জন্য জানাচ্ছি যে, পঞ্চাষাভ্যন্তরের পূর্ববাসন কেন্দ্রে-সিআরপি'র শিক্ষা প্রতিষ্ঠান বাংলাদেশ হেল্থ প্রফেশনস ইনস্টিটিউট (বিএইচপিআই) ঢাকা বিশ্ববিদ্যালয় অনুমোদিত বিএসসি ইন অকুপেশনাল থেরাপি কোর্স পরিচালনা করে আসছে।

উক্ত কোর্সের ছাত্রছাত্রীদের কোর্স কারিকুলামের অংশ হিসাবে বিভিন্ন বিষয়ের উপর রিসার্চ ও কোর্সওয়ার্ক করা বাধ্যতামূলক।

বিএইচপিআই'র ৫র্থ বর্ষ বিএসসি ইন অকুপেশনাল থেরাপি কোর্সের ছাত্রী আদিবা তাফহিম আনিসা তার রিসার্চ সমন্বিত কাজের জন্য আগামী ২৯.০১.২০১৯ তারিখ থেকে ১৫.০২.২০১৯ তারিখ পর্যন্ত সময়ে আপনার প্রতিষ্ঠানে সম্বর করতে আহ্বায়।

তাই তাকে আপনার প্রতিষ্ঠান সম্বর ও তথ্য সংগ্রহে সার্বিক সহযোগিতা প্রদানের জন্য অনুরোধ করছি।

ধন্যবাদান্তে

Su. Mridha
23/01/2019

শেখ মনিরুজ্জামান
বিজ্ঞানীয় প্রধান
অকুপেশনাল থেরাপি, বিএইচপিআই



Appendix-ii



বাংলাদেশ হেল্থ প্রফেশনস ইনস্টিটিউট (বিএইচপিআই)
BANGLADESH HEALTH PROFESSIONS INSTITUTE (BHPI)
(The Academic Institute of CRP)

CRP-Chapain, Savar, Dhaka, Tel: 7745464-5, 7741404, Fax: 7745069
BHPI-Mirpur Campus, Plot-A/5, Block-A, Section-14, Mirpur, Dhaka-1206. Tel: 8020178, 8053662-3, Fax: 8053661

তারিখ : ২৪.১১.২০১৮

প্রতি
অধ্যক্ষ
স্কুল ফর গিফটেড চিলড্রেন
লালমাটি, ঢাকা।

বিষয় : রিসার্চ প্রজেক্ট (dissertation) এর জন্য আপনার প্রতিষ্ঠান সফর ও তথ্য সংগ্রহ প্রসঙ্গে।

জনাব,

আপনার সদয় অবগতির জন্য জানাচ্ছি যে, পক্ষাঘাতগ্রস্তদের পুনর্বাসন কেন্দ্রে-সিআরপি'র শিক্ষা প্রতিষ্ঠান বাংলাদেশ হেল্থ প্রফেশনস ইনস্টিটিউট (বিএইচপিআই) ঢাকা বিশ্ববিদ্যালয় অনুমোদিত বিএসসি ইন অকুপেশনাল থেরাপি কোর্স পরিচালনা করে আসছে।

উক্ত কোর্সের ছাত্রছাত্রীদের কোর্স কারিকুলামের অংশ হিসাবে বিভিন্ন বিষয়ের উপর রিসার্চ ও কোর্সওয়ার্ক করা বাধ্যতামূলক।

বিএইচপিআই'র ৪র্থ বর্ষ বিএসসি ইন অকুপেশনাল থেরাপি কোর্সের ছাত্রী আদিবা তাফহিম আনিসা তার রিসার্চ সংক্রান্ত কাজের জন্য আগামী ০১.১২.২০১৮ তারিখ থেকে ৩১.০১.২০১৯ তারিখ পর্যন্ত সময়ে আপনার প্রতিষ্ঠানে সফর করতে আশ্রয়ী।

তাই তাকে আপনার প্রতিষ্ঠান সফরে সার্বিক সহযোগিতা প্রদানের জন্য অনুরোধ করছি।

ধন্যবাদান্তে

Su. Mondol
24.11.2018

শেখ মনিরুজ্জামান
বিভাগীয় প্রধান
অকুপেশনাল থেরাপি, বিএইচপিআই।



Appendix-ii


বাংলাদেশ হেল্থ প্রফেশনস ইনস্টিটিউট (বিএইচপিআই)
BANGLADESH HEALTH PROFESSIONS INSTITUTE (BHPI)
(The Academic Institute of CRP)
CRP-Chapain, Savar, Dhaka, Tel: 7745464-5, 7741404, Fax: 7745069
BHPI-Mirpur Campus, Plot-A/5, Block-A, Section-14, Mirpur, Dhaka-1206. Tel: 8020178,8053662-3, Fax: 8053661

তারিখ : ৩০.১০.২০১৮

প্রতি
অধ্যক্ষ
প্রয়াস
ঢাকা সেনানিবাস, ঢাকা।

বিষয় : রিসার্চ প্রজেক্ট (dissertation) এর জন্য আপনার প্রতিষ্ঠান সফর ও তথ্য সংগ্রহ প্রসঙ্গে।

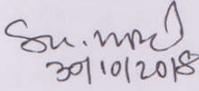
জনাব,
আপনার সদয় অবগতির জন্য জানাচ্ছি যে, পক্ষাঘাতগ্রস্তদের পুনর্বাসন কেন্দ্রে-সিআরপি'র শিক্ষা প্রতিষ্ঠান বাংলাদেশ হেল্থ প্রফেশনস ইনস্টিটিউট (বিএইচপিআই) ঢাকা বিশ্ববিদ্যালয় অনুমোদিত বিএসসি ইন অকুপেশনাল থেরাপি কোর্স পরিচালনা করে আসছে।

উক্ত কোর্সের ছাত্রছাত্রীদের কোর্স কারিকুলামের অংশ হিসাবে বিভিন্ন বিষয়ের উপর রিসার্চ ও কোর্সওয়ার্ক করা বাধ্যতামূলক।

বিএইচপিআই'র ৪র্থ বর্ষ বিএসসি ইন অকুপেশনাল থেরাপি কোর্সের ছাত্রী আদিবা তাফহিম আনিসা তার রিসার্চ সংক্রান্ত কাজের জন্য আগামী ০১.১১.২০১৮ তারিখ থেকে ৩১.০১.২০১৯ তারিখ পর্যন্ত সময়ে আপনার প্রতিষ্ঠানে সফর করতে আহ্বান।

তাই তাকে আপনার প্রতিষ্ঠান সফরে সার্বিক সহযোগিতা প্রদানের জন্য অনুরোধ করছি।

ধন্যবাদান্তে


শেখ মনিরুজ্জামান
বিভাগীয় প্রধান
অকুপেশনাল থেরাপি, বিএইচপিআই।



Appendix-iii-A



বাংলাদেশ হেল্থ প্রফেশনস ইনস্টিটিউট (বিএইচপিআই)

অকুপেশনাল থেরাপি বিভাগ

সিআরপি-চাপাইন, সাভার, ঢাকা-১৩৪৩. টেলি: ০২-৭৭৪৫৪৬৪-৫, ৭৭৪১৪০৪, ফ্যাক্স: ০২-৭৭৪৫০৬

কোডনং:

অংশগ্রহণকারীদের তথ্য এবং সম্মতিপত্র

গবেষণার বিষয়: “বয়স্কিকালীন সময়ে একজন অটিজম আক্রান্ত মেয়ের সম্ভাব্য চ্যালেন্জসমূহ: মায়ের এর দৃষ্টিকোণ”।

গবেষক: আদিবা তাফহীম আনিসা, বি.এস.সি ইন অকুপেশনাল থেরাপি (৪র্থ বর্ষ), সেশন: ২০১৪-২০১৫ ইং, বাংলাদেশ হেল্থ প্রফেশনস ইনস্টিটিউট (বিএইচপিআই), সাভার, ঢাকা- ১৩৪৩

তত্ত্বাবধায়ক: এস.কে মনিরুজ্জামান, সহকারী অধ্যাপক, অকুপেশনাল থেরাপি বিভাগ, বাংলাদেশ হেল্থ প্রফেশনস ইনস্টিটিউট।

গবেষণার স্থান: প্রয়াশ (ঢাকা), অটিজম ওয়েলফেয়ার ফাউন্ডেশন

পর্ব ১ তথ্যপত্র:

ভূমিকা:

আমি আদিবা তাফহীম আনিসা, ঢাকা বিশ্ববিদ্যালয়ে চিকিৎসা অনুষদের অধীনে বাংলাদেশ হেল্থ প্রফেশনস ইনস্টিটিউটে বি.এস.সি.ইন অকুপেশনাল থেরাপি বিভাগে ৪র্থ বর্ষের ছাত্রী হিসেবে স্নাতক শিক্ষাকার্যক্রম (২০১৪-২০১৫ ইং) সেশনে অধ্যয়নরত আছি। বিএইচপিআই থেকে অকুপেশনাল থেরাপি বি.এস.সি শিক্ষাকার্যক্রমটি সম্পন্ন করার জন্য একটি গবেষণা প্রকল্প পরিচালনা করা বাধ্যতামূলক। এই গবেষণা প্রকল্পটি অকুপেশনাল থেরাপি বিভাগের সহকারী অধ্যাপক এস. কে মনিরুজ্জামান এর তত্ত্বাবধায়নে সম্পন্ন করা হবে। এই অংশগ্রহণকারী তথ্য পত্রের মাধ্যমে গবেষণার প্রকল্পটির উদ্দেশ্য, উপাত্ত সংগ্রহের প্রণালী ও গবেষণাটির সাথে সংশ্লিষ্ট বিষয় কিভাবে রক্ষিত হবে তা বিস্তারিত ভাবে আপনার কাছে উপস্থাপন করা হবে। যদি এই গবেষণায় অংশগ্রহণ করতে আপনি ইচ্ছুক থাকেন, সেক্ষেত্রে এই গবেষণার সম্পৃক্ত বিষয়সম্পর্কে স্বচ্ছ ধারণা থাকলে সিদ্ধান্ত গ্রহণ সহজতর হবে। অবশ্য এখন আপনার অংশগ্রহণ আমাদের নিশ্চিত করতে হবেনা। যে কোন সিদ্ধান্ত গ্রহণের পূর্বে, যদি চান তাহলে আপনার আত্মীয়-স্বজন, বন্ধু অথবা আস্থাজন

যেকারো সাথে এই ব্যাপারে আলোচনা করে নিতে পারেন। অপরপক্ষে, অংশগ্রহনকারী তথ্যপত্রটি পড়ে, যদি কোন বিষয়বস্তু বুঝতে সমস্যা হয় অথবা যদি কোন কিছুর সম্পর্কে আরো বেশি জানার প্রয়োজন হয়, তবে নির্দিধায় প্রশ্ন করতে পারেন।

গবেষণার প্রেক্ষাপট ও উদ্দেশ্য:

এই গবেষণাতে বারো বছরের উপরের অটিজম আক্রান্ত মেয়ের মায়েদের অন্তর্ভুক্ত হবার জন্য আমন্ত্রণ জানানো হবে। এর অংশ হিসাবে, আপনাকেও উক্ত গবেষণা প্রকল্পে অংশগ্রহনের জন্য আমন্ত্রণ জানানো হলো। কারণ, একজন মা হিসেবে বয়সস্কিকালে আপনার মেয়ে যে সমস্যা ও চ্যালেঞ্জ সমূহের মুখোমুখি হয় তা আপনি খুব ভালোভাবে উপলব্ধি করতে পারেন। এই গবেষণার মূল উদ্দেশ্য হচ্ছে একজন অটিজম আক্রান্ত মেয়ের বয়সস্কিকালের সম্ভাব্য সমস্যা ও চ্যালেঞ্জ সমূহ খুঁজে বের করা যার মুখোমুখী আপনার এবং আপনার মত অন্য মায়েদের হতে হয়। এই গবেষণাটি এই সকল সমস্যা এবং তাদের সমাধান খুঁজে বের করতে সাহায্য করবে। আপনার কার্যকারী অংশগ্রহণ গবেষণার উদ্দেশ্য পূরণে সহায়তা করবে বলে আমরা আশাবাদী।

এই গবেষণা কর্মটিতে অংশগ্রহনের সাথে সম্পৃক্ত বিষয় সমূহ কি সে সম্পর্কে জানা যাক:

আপনার থেকে অনুমতিপত্রে স্বাক্ষর নেবার আগে, এই অংশগ্রহনকারী তথ্যপত্রের মাধ্যমে গবেষণা প্রকল্পটির পরিচালনা করার তথ্যসমূহ বিস্তারিত ভাবে আপনার কাছে উপস্থাপন করা হবে। আপনি যদি এই গবেষণায় অংশগ্রহন করতে চান, তাহলে সম্মতিপত্রে আপনাকে স্বাক্ষর করতে হবে। আপনি অংশগ্রহন নিশ্চিত করলে, আপনার সংরক্ষনের জন্য সম্মতিপত্রটির একটি অনুলিপি দিয়ে দেয়া হবে। পরবর্তীতে গবেষক কর্তৃক গঠিত তথ্য-উপাত্তসংগ্রহের একটি দলের প্রতিনিধি আপনার কাছে যাবে। আপনার থেকে চেয়ে নেওয়া যে কোন একটি নির্দিষ্ট সময়ে একটি প্রশ্নপত্রের মাধ্যমে তথ্য সংগ্রহ করা হবে। এই গবেষণার প্রকল্পে আপনার অংশগ্রহণইচ্ছিক। যদি আপনি সম্মতি প্রদান না করেন তবে আপনাকে অংশগ্রহন করতে হবে না। আপনি সম্মতি প্রদান করা স্বত্ত্বেও যে কোন সময় গবেষককে কোন ব্যাখ্যা প্রদান করা ছাড়াই নিজের অংশগ্রহন প্রত্যাহার করতে পারবেন। গবেষণা প্রকল্পটিতে অংশগ্রহন করা কিংবা না করা অথবা পরবর্তীতে অংশগ্রহন প্রত্যাহার করার সিদ্ধান্তের সাথে আপনার সম্মতনের বর্তমান চিকিৎসা কোন ভাবে প্রভাবিত হবে না।

অংশগ্রহনের সুবিধা ও ঝুঁকি সমূহ কি ?

গবেষণা প্রকল্পটিতে অংশগ্রহনের জন্য আপনি সরাসরি কোন সুবিধা পাবেননা এবং গবেষণা প্রকল্পটি চলাকালীন সময়ে আপনার কিছু ব্যক্তিগত প্রশ্নের উত্তর দিতে হতে পারে যার কারণে আপনি অত্যন্ত অপ্রস্তুত বোধ করতে পারেন। তবে আমরা আশাবাদী যে, গবেষণার মাধ্যমে প্রাপ্ত উপাত্ত পরবর্তীতে চিকিৎসা কার্যক্রমকে আরো গতিশীল করতে সাহায্য করবে। এখানে সংশ্লিষ্ট গবেষণায় অংশগ্রহনে কোন ধরনের বাড়তি ঝুঁকি, বিপত্তি অথবা অস্বস্তি নেই বলে আশা করা যাচ্ছে।

তথ্যের গোপনীয় তা কি নিশ্চিত থাকবে?

এই সম্মতি পত্রে স্বাক্ষর করার মধ্য দিয়ে, আপনি এই গবেষণা প্রকল্পে অধ্যয়নরত গবেষণা কর্মীকে আপনার ব্যক্তিগত তথ্য সংগ্রহ ও ব্যবহার করার অনুমতি দিয়েছেন। এই গবেষণা প্রকল্পের জন্য সংগৃহীত যেকোন তথ্য, যা আপনাকে সনাক্ত করতে পারে তা গোপনীয় থাকবে। আপনার সম্পর্কে সংগৃহীত তথ্যসমূহ সাংকেতিক উপায়ে উল্লেখ থাকবে। শুধুমাত্র এর সাথে সরাসরি সংশ্লিষ্ট গবেষক ও তার তত্ত্বাবধায়ক এই তথ্যসমূহে প্রবেশাধিকার পাবেন। সাংকেতিক উপায়ে চিহ্নিত উপাত্ত সমূহ পরবর্তী উপাত্ত বিশ্লেষণের কাজে ব্যবহৃত হবে। তথ্যপত্র গুলো তালাবদ্ধ ড্রয়ারে রাখা হবে। বিএইচপিআই এর অকুপেশনাল থেরাপি বিভাগে ও গবেষকের ব্যক্তিগত ল্যাপটপে উপাত্ত সমূহের ইলেকট্রনিক ভার্সন সংগৃহীত থাকবে।

প্রত্যাশা করা হচ্ছে যে, এই গবেষণা প্রকল্পের ফলাফল বিভিন্ন ফোরামে প্রকাশিত এবং উপস্থাপিত হবে। যে কোন ধরনের প্রকাশনা ও উপস্থাপনার ক্ষেত্রে তথ্যসমূহ এমন ভাবে সরবরাহ করা হবে, যেন আপনার সম্মতি ছাড়া আপনাকে কোনভাবেই সনাক্ত করা না যায়। তথ্য-উপাত্ত প্রাথমিকভাবে কাগজপত্র সংগ্রহ করা হবে।

গবেষণা সম্পর্কে জানতে কোথায় যোগাযোগ করতে হবে?

গবেষণা প্রকল্পটির বিষয়ে যোগাযোগ করতে চাইলে অথবা গবেষণা প্রকল্পটির সম্পর্কে কোন প্রশ্ন থাকলে, এখন অথবা পরবর্তীতে যে কোন সময়ে তা জিজ্ঞাসা করা যাবে। সেক্ষেত্রে আপনি গবেষকের সাথে উল্লেখিত ০১৯১২০২৮৬৪৬ (আদিবা তাফহীম) নাম্বারে যোগাযোগ করতে পারেন। এই গবেষণা প্রকল্পটি বাংলাদেশ হেল্থ প্রফেশন্স ইনস্টিটিউট, সাভারের প্রাতিষ্ঠানিক নৈতিকতা পরিষদ (সিআরপি- বিএইচপিআই/আই আর বি/১০/১৮/১২৩৬) থেকে পর্যালোচিত ও অনুমোদিত হয়েছে। এই গবেষণা প্রকল্প পরিচালনা প্রসঙ্গে যে কোন উদ্দিগ্ন, অথবা অভিযোগকারী ব্যক্তি প্রাতিষ্ঠানিক নৈতিকতা পরিষদের সাথে এই নাম্বারে (৭৭৪৫৪৬৪-৫) যোগাযোগ করবেন।

গবেষণা থেকে নিজেকে প্রত্যাহার করা যাবে কি?

আপনি সম্মতি প্রদান করা স্বত্বেও যে কোন সময় গবেষককে কোন ব্যাখ্যা প্রদান করা ছাড়াই নিজের অংশগ্রহণ প্রত্যাহার করতে পারবেন। বাতিল করার পর তথ্যসমূহ কি ব্যবহার করা যাবে কি যাবেনা তার অনুমতি অংশগ্রহণকারীর প্রত্যাহার পত্রে (শুধুমাত্র স্বেচ্ছায় প্রত্যাহারকারীর জন্য প্রযোজ্য) উল্লেখ করা থাকবে।

অংশগ্রহণকারীর প্রত্যাহারপত্র

(শুধুমাত্র স্বেচ্ছায় প্রত্যাহারকারীর জন্য প্রযোজ্য)

অংশগ্রহণকারীর নাম:

প্রত্যাহার	করার	কারণ:
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পূর্ববর্তী তথ্য ব্যবহারের অনুমতি থাকবে কিনা?

হ্যাঁ/না

অংশগ্রহণকারীর নাম:

অংশগ্রহণকারীর স্বাক্ষর:

তারিখ:

*নিরক্ষর হয় যদি

অংশগ্রহণকারীর আঙ্গুলের ছাপ

স্বাক্ষীর নাম:

স্বাক্ষীর স্বাক্ষর:

তারিখ:

সম্মতি পত্র ০২ :পর্ব

“বয়স্কিকালীনসময়ে একজন অটিজম আক্রান্ত মেয়ের সম্ভাব্য চ্যালেন্জসমূহ :অভিভাবক এর দৃষ্টিকোণ”

-শীর্ষক গবেষণায় অংশগ্রহনের জন্য আমাকে আমন্ত্রন জানানো হয়েছে। আমি পূর্বলিখিত তথ্য পত্রটি পড়েছি বা এটা আমাকে পড়ে শোনানো হয়েছে। এই বিষয়ে আমার প্রশ্ন জিজ্ঞাসা করার সুযোগছিল এবং যে কোন প্রশ্নের আমি সন্তুষ্টজনক উত্তর পেয়েছি। এই গবেষণায় একজন অংশগ্রহনকারী হবার জন্য আমি স্বেচ্ছায় সম্মতি দিচ্ছি।

অংশগ্রহনকারীর নাম:

অংশগ্রহনকারীরস্বাক্ষর:

তারিখ :.....

গবেষক ও সম্মতি কারীর বিবৃতি:

আমি অংশগ্রহনকারী কে অংশগ্রহনকারীর তথ্যপত্রটি পড়ে শুনিয়েছি এবং আমার সর্বোচ্চ সামর্থ্য অনুযায়ী নিশ্চিত করেছি যে, অংশগ্রহনকারীর বোধগম্য হয়েছে যে, নিম্নোক্ত বিষয় সমূহ করা হবে।

- ১) সকল তথ্য গবেষণার কাজে ব্যবহৃত হবে।
- ২) তথ্য সমূহ সম্পূর্ণভাবে গোপনীয় করা হবে।
- ৩) অংশগ্রহনকারীর নাম ও পরিচয় প্রকাশ করা হবেনা।

আমি নিশ্চিত করেছি যে, এই বিষয় সম্পর্কে অংশগ্রহনকারীকে প্রশ্ন জিজ্ঞাসা করার সুযোগ দেয়া হয়েছে এবং অংশগ্রহনকারী যে সকল প্রশ্ন জিজ্ঞাসা আমার সর্বোচ্চ সামর্থ্য অনুযায়ী, সেগুলোর সঠিক উত্তর প্রদান করা সম্ভব হয়েছে। আমি নিশ্চিত করেছি যে, কোন ব্যক্তিকে সম্মতি দান করতে বাধ্য করা হয়নি। তিনি অবাধে অথবা স্বেচ্ছায় সম্মতি দিয়েছেন।

অংশগ্রহনকারীকে অংশগ্রহনকারীর তথ্য ও সম্মতিপত্রের একটি অনুলিপি দেওয়া হয়েছে।

গবেষকের নাম:

গবেষকের স্বাক্ষর:

তারিখ:

Appendix: iii-B



Bangladesh Health Professions institute (BHPI)

Department of Occupational Therapy

CRP-Chapai, Savar, Dhaka-1343, Telephone: 02-77414044

Title: Pubertal Challenges in Female Adolescents with Autism Spectrum disorder: Mother's Perspective.

Investigator: Adiba Tafhim Anisa, Student of B.Sc. in Occupational Therapy, Bangladesh Health Professions Institute (BHPI), CRP- Savar, Dhaka- 1343

Place: Some Autism based organizations of Dhaka.

Part I: Information Sheet Introduction

I am Adiba Tafhim Anisa, B.Sc. in Occupational Therapy student of Bangladesh Health Professions Institute (BHPI), have to conduct a thesis as a part of this Bachelor course, under thesis supervisor SK. Moniruzzaman. You are going to have details information about the study purpose, data collection process, ethical issues. You do not have to decide today whether or not you will participate in the research. Before you decide, you can talk to anyone you feel comfortable with about the research. If this consent form contains some words that you do not understand, please ask me to stop. I will take time to explain.

Background and Purpose of the study:

You are being invited to be a part of this research because as a mother you have better understanding about the challenges and problems during the pubertal period of your daughter. The purpose of my study is to find out those challenges faced by you and other mothers of adolescent daughters. This study will be helpful to have a better understanding about those possible challenges and some possible solutions to cope with those challenges.

Research related information:

The research related information will be discussed with you throughout the information sheet before taking your signature on consent form. After that participants will be asked to complete a self-administrative question which may need 45-60 minutes. In this questionnaire there will be questions on socio-demographic factors (for example: Age, sex, experience). It will also contain some specific questions related to puberty. Particularly, in this research we have selected mothers of some female pre-teens and teens with Autism Spectrum Disorder for the study.

The information recorded is confidential and your identity will not be disclosed.

Risks and benefits:

We are asking to share some personal and confidential information, and you may feel uncomfortable talking about some of the topics. You do not need to take part in the discussion interview/survey if you don't wish to do so, and that is also okay. On the other hand, you may not have any direct benefit by participating in this research, but your valuable participation is likely to help us to find out the possible challenges during puberty faced by female adolescents with Autism Spectrum Disorder.

Confidentiality

Information about you will not be shared to anyone outside of the research team. The information that we collect from this research project will be kept private. Only the researchers will know about your information's and we will lock that information up with a lock and key. It will not be shared with or given to anyone except Sk. Moniruzzaman, study supervisor.

Sharing the Results

Nothing that you tell us today will be shared with anybody outside the research team, and nothing will be attributed to you by name. The knowledge that we get from this research will be shared with you before it is made widely available to the public. There will also be small presentation, and these will be announced. Following the presentations, we will publish the results so that other interested people may learn from the research.

Who to Contact

If you have any questions, you can ask me now or later. If you wish to ask questions later, you may contact any of the following: Adiba Taffim Anisa, Bachelor science in Occupational Therapy, Department of Occupational Therapy, Cell phone- 01912028646. This proposal has been reviewed and approved by Institutional Review Board (IRB), Bangladesh Health Professions Institute (BHPI), CRP-Savar, Dhaka-1343, Bangladesh, which is a committee whose task it is to make sure that research participants are protected from harm. If you wish to find about more about the IRB, contact Bangladesh Health Professions Institute (BHPI), CRP-Savar, Dhaka-1343, Bangladesh. You can ask me any more questions about any part of the research study, if you wish to. Do you have any questions?

Can you withdraw from this study:

You can cancel any information collected for this research project at any time. After the cancellation, we expect permission from the information whether it can be used or not.

Withdrawal	Form
Participants	Name:
Reason of Withdraw:
Participants	Signature:
Day/Month/Year:

Part II: Certificate of Consent Statement by Participants

I have been invited to participate in research titled Pubertal Challenges in Female Adolescents with Autism Spectrum disorder: Parental Perspective. I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have been asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study.

Name of Participant _____

Signature of Participant _____

Date

Statement by the researcher taking consent

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands that the following will be done:

1. The information only will be used for the study
2. All information will be kept confidential
3. The identity of the participant will not revealed.

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily. A copy of this ICF has been provided to the participant.

Name of Researcher taking the consent _____

Signature of Researcher taking the consent _____

Date:

Appendix- iv-A



বাংলাদেশহেলথপ্রেশনসইন্সটিটিউট (বিএইচপিআই)

অকুপেশনালথেরাপিবিভাগ

সিআরপি-চাপাইন, সাভার, ঢাকা-১৩৪৩, টেলিঃ ০২-৭৭৪১৪০৪৪

বাংলপ্রশ্নাবলী

১. “অটিজম” সম্পর্কে আপনি কতটুকু জানেন ?
২. বয়ঃসন্ধিকাল বলতে আপনি কি বুঝেন ? এ সময় কি ধরনের শারীরিক বা আচরণগত পরিবর্তন হয় বলে আপনি মনে করেন ?
৩. আপনার মেয়ে কি তার শরীরের প্রত্যেকটি অঙ্গ-প্রত্যঙ্গ, যেমনঃ তার নিজের হাত-পা বিশেষ করে তার গোপনাঙ্গ সঠিকভাবে চিনতে পারে ? আপনি কি ভাবে তার শরীরের প্রত্যেকটি অঙ্গ-প্রত্যঙ্গ সঠিকভাবে চিনতে শিখিয়েছেন ?
৪. আপনার মেয়ের শারীরিক পরিবর্তন যেমনঃ স্তনের আকার পরিবর্তন, গোপনাঙ্গে লোম বৃদ্ধি ইত্যাদি আপনি কবে থেকে বুঝতে পেরেছেন ? কীভাবে বুঝতে পেরেছেন ?
৫. শারীরিক পরিবর্তনের পাশাপাশি আপনার মেয়ের মধ্যে কোন আচরণগত পরিবর্তন যেমনঃ হঠাৎ অতিরিক্ত চূপ বা উত্তেজিত হয়ে যাওয়া ইত্যাদি লক্ষ্য করেছেন ?
৬. আপনার মেয়ে কি তার শারীরিক পরিবর্তন বুঝতে পারে? কতটুকু বুঝতে পারে ?
৭. আপনার মেয়ের ঋতু :স্রাব কবে থেকে শুরু হয়েছে? তার প্রথম ঋতু :স্রাবের সময় আপনি কি ধরনের সমস্যার সম্মুখীন হয়েছেন ?
৮. ঋতু:স্রাবের সময় আপনার মেয়ের মধ্যে কোন আচরণগত পরিবর্তন যেমনঃ চিৎকার করা, কান্না করা ,উত্তেজিত হয়ে যাওয়া ইত্যাদি কি আপনি লক্ষ্য করেছেন ?
৯. আপনার মেয়ে কি ঋতু:স্রাবের সময় প্রয়োজনীয় ব্যবস্থা যেমনঃ স্যানিটারি ন্যাপকিন ব্যবহার ইত্যাদি গ্রহণ করতে বা পরিচ্ছন্নতা বজায় রাখতে পারে ? এই ব্যাপারে আপনি তাকে কিভাবে বা কতটুকু সাহায্য করেন ?
১০. আপনার মেয়ে কি তার নিজস্ব শারীরিক পরিচ্ছন্নতা যেমন নিয়মিত দাতব্রাশ ,গোসল করা বিশেষত ব্যক্তিগত অঙ্গের পরিচ্ছন্নতা বজায় রাখতে পারে ? কতটুকু পারে বা আপনার তাকে কতটুকু সাহায্য করতে হয় ?
১১. আপনার মেয়ে কি তার ব্যক্তিগত কাজগুলো যেমনঃ নিজের কাপড় ভাজকরা, নিজের প্লেট ধোয়া ইত্যাদি নিজে নিজে করতে পারে? কতটুকু পারে বা আপনার তাকে কতটুকু সাহায্য করতে হয় ?

১২. আপনার মেয়ে কি প্রকাশ্য যেমনঃ গল্পকরা, কারো সাথে কথা বলে ইত্যাদি এবং ব্যক্তিগত আচরণ যেমনঃ ব্যক্তিগত অঙ্গস্পর্শ করা, বাথরুম করা ইত্যাদি এর মধ্যকার পার্থক্য বুঝতে পারে? সে কি প্রকাশ্য যেমনঃ স্কুল, খেলার মাঠ ইত্যাদি এবং ব্যক্তিগত জায়গা যেমনঃ বেডরুম, বাথরুম ইত্যাদি এর মধ্যকার পার্থক্য বুঝতে পারে ?
১৩. আপনার মেয়ে কি তার কাপরের যেমন জামা, পায়জামা, বক্ষবন্ধনী ইত্যাদি এর সঠিক ব্যবহার জানে ? সে কি তার কাপড় সঠিক ভাবে বজায় রাখতে জানে ?
১৪. আপনার মেয়ে তার সমবয়সী অন্য মেয়েদের প্রতি কেমন আচরণ করে থাকে ?
১৫. আপনার মেয়ে বিপরিত লিঙ্গের প্রতি কেমন আচরণ যেমন বেশি বেশি মিশতে চাওয়া, ধরতে চাওয়া ইত্যাদি পোষণ করে ? ভবিষ্যতে এমন কোন ব্যবহার প্রদর্শন করলে আপনি কি করবেন ?
১৬. আপনার মেয়ে কি যৌন উত্তেজক কোন ব্যবহার প্রদর্শন করে ? করলে আপনি কিভাবে তা প্রশমন করেন অথবা ভবিষ্যতে এমন কোন ব্যবহার প্রদর্শন করলে আপনি কি করবেন ?
১৭. আপনার মেয়ে কে আপনি যৌনতা এবং প্রজনন বিষয়ক কোন জ্ঞান কি প্রদান করেছেন ? কতটুকু জ্ঞান প্রদান করেছেন এবং কিভাবে ?
১৮. আপনার মেয়ে কি তার সমবয়সী অন্য ছেলে-মেয়ে দের কাছ থেকে কখনো বিরূপ আচরণ যেমন তাকে নিয়ে হাসি-ঠাট্টা বা তাকে মারা ইত্যাদি এর শিকার হয়েছে বা হচ্ছে ?
১৯. আপনার পরিবারের অন্যান্য সদস্যরা আপনার এবং আপনার মেয়ের প্রতি কতটুকু সহানুভূতিশীল এবং সহযোগীতাপূর্ণ ?
২০. আপনার সাথে আপনার মেয়ের সম্পর্ক কতটুকু বন্ধত্বপূর্ণ ?
২১. আপনার মেয়ে কে কি আপনি পর্যাণ্ড পুষ্টিকর খাবার যেমন দুধ, ডিম, ফল, সবজি ইত্যাদি খেতে দেন ?
২২. আপনার মেয়ে কি কোন ধরনের খেলাধুলাতে অংশ গ্রহণ করে এবং অবসর সময়ে কি করে ?
২৩. আপনার মেয়ে কি ভালো যেমন হাত ধরা, মার জড়িয়ে ধরা ইত্যাদি এবং খারাপস্পর্শ যেমন জোরকরে চুমু দেওয়া, ব্যক্তিগত অঙ্গে স্পর্শ ইত্যাদি এর মধ্যকার পার্থক্য বুঝতে পারে এবং কতটুকু বুঝতে পারে ?
২৪. আপনার মেয়ে কি যেকোন ধরনের ধারালো বা ক্ষতিকর বস্তু যেমন আগুন, ছুরি ইত্যাদি এর ব্যবহার বা এগুলো থেকে নিরাপদ দূরত্ব বজায় রাখতে পারে? এই ব্যাপারে আপনি তাকে কি ভাবে বুঝতে সাহায্য করেন ?
২৫. আপনার মেয়ে যখন উত্তেজিত হয়ে যায় যেমন নিজে কে আঘাত বা অন্যকে আঘাত করে তখন আপনি কি করেন ?
২৬. আপনি কি আপনার মেয়ের বয়ঃসন্ধি কালের পরিবর্তন এবং সমস্যা গুলোর ব্যাপারে তার শিক্ষক বা তার চিকিৎসকদের সাথে বিস্তারিত ভাবে কোন আলোচনা করেছেন ? এই ব্যাপারে তারা কতটুকু সহযোগীতাপূর্ণ ?
২৭. শিক্ষক বা তার চিকিৎসকদের কাছ থেকে এই ব্যাপারে আপনি কতটুকু এবং কেমন সাহায্য আশা করেন ?

Appendix-iv-B



Bangladesh Health Professions institute (BHPI)

Department of Occupational Therapy

CRP-Chapai, Savar, Dhaka-1343, Telephone: 02-77414044

English Question

1. How much do you know about “Autism”?
2. What do you mean by “Puberty”? What kind of physical & behavioral changes occur during this time according to you?
3. Does your daughter can identify every parts of her body for example her hand-foot especially her private parts accurately? How did you teach her to identify her body parts accurately?
4. From when did you begin to understand the physical changes like development of her breast, growth of pubic hair etc. of your daughter? How did you understand?
5. In addition to physical changes, have you noticed any behavioral changes like suddenly being quiet or excited etc. in your daughter?
6. Does your daughter understand her physical changes? How much does she understand?
7. From when did your daughter’s menstrual period start? What type of challenges and problems you faced during her menstrual cycle?
8. Do you notice any behavioral changes in your daughter during her menstrual cycle like screaming, crying, being excited etc.?
9. Can your daughter take all the necessary measures like using sanitary napkin or changing or maintaining cleanliness during her menstruation? How much do you help her in this regard?
10. Can your daughter maintain her physical cleanliness like regularly brushing, bathing etc. specially cleanliness of her private parts by herself? how much do you have to help her?
11. Can she do her personal tasks by herself? How much she can perform by herself or how much do you have to help her?
12. Does your daughter understand the difference between public behaviors (like gossiping, talking with someone etc.) and private behavior (like touching private parts, doing pee or poop etc.)? Does she understand the difference between public place (like school, play-ground etc.) and private place (like bedroom, bathroom etc.)?

13. Do your daughter know the appropriate use of her clothes like appropriate use of pajama, bra etc.? Can she maintain her clothes properly?
14. What's the attitude your daughter shows towards the girls of same age?
15. What are her attitudes towards opposite sex like wanting to talk more, wanting to touch etc.?
16. Does your daughter show any sexual attitude? If she does how you manage it or if she shows this type of behavior in future what you will do?
17. Did you provide any knowledge about sex and reproduction to your daughter? How much knowledge did you provide and in which way did you provide?
18. Did your daughter experience or still experiencing any kind of mocking or abusing from teenagers or children of her age?
19. How much your others family member is helpful and sympathetic towards you and your daughter?
20. How much friendly are you with your daughter?
21. Are you giving your daughter proper nutritional foods like milk, fish, vegetables, fruits etc.?
22. Does your daughter participate in any kind of play or game and what she does during her leisure period?
23. Do your daughter understand the difference between good touch (like holding hand, mother's hug etc.) and bad touch (like forceful kissing, touching private parts etc.) and how much does she understand?
24. Does your daughter understand the use or keep a safe distance from harmful or sharp objects like fire or knife? How you have helped her in this regard?
25. When your daughter becomes excite like hurting herself or others, how you handle her?
26. Have you ever consulted about the pubertal changes and problems of your daughter with her teacher or health professionals? How much helpful they are in this regard?
27. How much and what kind of help you expect from her teachers and health professionals in this regard?

Appendix- v



বাংলাদেশ হেলথ প্রেশনাল ইন্সটিটিউট (বিএইচপিআই)

অকুপেশনাল থেরাপি বিভাগ

সিআরপি-চাপাইন, সাভার, ঢাকা-১৩৪৩, টেলিঃ ০২-৭৭৪১৪০৪৪

জনসংখ্যা ও আর্থসামাজিক বিষয়ক তাত্ত্বিক তথ্য

অংশগ্রহণকারীর নামঃ

তথ্য সংগ্রহের তারিখঃ

বয়সঃ

পেশাঃ

ঠিকানাঃ

মোবাইল নংঃ

শিক্ষাগত যোগ্যতাঃ

স্বামীর নামঃ

শিক্ষাগত যোগ্যতাঃ

পেশাঃ

বসবাসরত এলাকার ধরনঃ

মাসিক পারিবারিক আয়ঃ

অটিজম আক্রান্ত মেয়ের তথ্য

নামঃ

বয়সঃ

জন্মতারিখঃ

সহোদর সংখ্যাঃ

স্কুলের নামঃ

শ্রেণীর নামঃ

প্রতিষ্ঠানের নামঃ

প্রথম রোগ নির্ণয় এর তারিখঃ

যোগাযোগ এর মাধ্যমঃ

১. কথা/বাকশক্তি

২. শব্দ

৩. চোখের সাহায্যে, চেহারার অভিব্যক্তি, অঙ্গভঙ্গি এবং/অথবা ইশারা এর মাধ্যমে (যেমনঃ শরীরের অঙ্গ বা লাঠি দ্বারা

৪. প্রতীকি চিহ্ন বা সংকেত

৫. ভয়েস আউটপুট ডিভিইস বা স্পীচ-জেনারোটং ডিভিইস

৬. অন্যান্য

রজঃচক্র শুরু হওয়ার তারিখঃ

অন্য কোন সংযুক্ত ব্যাধিঃ

Appendix-6

Overall Information of participants

Participant serial	Age	Educational background	Profession
Participant 1	35	Graduation completed	Housewife
Participant 2	40	Post-graduation completed	Housewife
Participant 3	40	Higher-secondary completed	Housewife
Participant 4	30	Post-graduation completed	Housewife
Participant 5	45	Post-graduation completed	Free-lancer
Participant 5	55	Post-graduation completed	Housewife
Participant 6	35	Post-graduation completed	Housewife
Participant 7	35	Graduation completed	Housewife
Participant 8	45	Graduation completed	Housewife
Participant 9	45	Post-graduation completed	Job
Participant 10	42	Graduation completed	Job
Participant 11	45	Graduation completed	Housewife
Participant 12	29	Graduation completed	Housewife

Information of Girl with ASD

Code Serial	Age	Age diagnosis	of Way of communication	of Age of starting menstrual cycle
C 1	13	3	Speech	12
C2	14	3	Gesture, body language	14
C3	14	5/6	Speech	13
C4	12	3	Speech	11
C5	18	2.5	Speech	13
C6	19	5/6	Speech	9
C7	14	1.5	Facial expression, gesture	11
C8	12	2.5	Speech	N/A
C9	13	3.5	Speech	13
C10	15	1.5	Speech	12
C11	17	3	Gesture	8
C12	13	2.5	Speech	11