Caring for the Career: Understanding the emotional and Self-Care Experience of Parents Raising Children with Special Needs

By

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A thesis submitted to BRAC Institute of Educational Development in partial fulfillment
of the requirements for the degree of
Master of Science in Early Childhood Development

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Declaration

It is hereby declared that

1. The thesis submitted is my/our own original work while completing degree at Brac University.
2. The thesis does not contain material previously published or written by a third party, except where this is appropriately cited through full and accurate referencing.
3. The thesis does not contain material which has been accepted, or submitted, for any other degree or diploma at a university or other institution.
4. I have acknowledged all main sources of help.

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Approval

The thesis titled “Caring for the carer:understanding the emotional and self care experiences of parents raising children with special needs ” submitted by Shahanara Tuly **(**ID-23255010 **)** of Thesis Fall 2025 has been accepted as satisfactory in partial fulfillment of the requirement for the degree of Master of Science in Early Childhood Development on December 2025.

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Ethics Statement

Title of Thesis Topic: Caring for the Carer: Understanding the Emotional and Self-Care Experience of Parents Raising Children with Special Need

Student name: Shahanara Tuly

1. Source of population

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2. Does the study involve (yes, or no)

a) Physical risk to the subjects

– No

b) Social risk
– No

c) Psychological risk to subjects
– No

d) discomfort to subjects
– No

e) Invasion of privacy
– No

3. Will subjects be clearly informed about (yes or no)

a) Nature and purpose of the study
-Yes

b) Procedures to be followed
-Yes

c) Physical risk
-No

d) Sensitive questions
-Yes

e) Benefits to be derived
-Yes

f) Right to refuse to participate or to withdraw from the study
-Yes

g) Confidential handling of data

-Yes

h) Compensation and/or treatment where there are risks or privacy is involved
-Yes

4. Will Signed verbal consent for be required (yes or no)

a) from study participants
-Yes
b) Will precautions be taken to protect anonymity of subjects?
-Yes

5. Check documents being submitted herewith to Committee:

a) Proposal
b) Consent Form
c) Questionnaire or interview schedule

Ethical Review Committee:
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Abstract

Parents raising special needs children often face complex emotional, psychological, and physical challenges that can deeply affect their well-being. This study explores the emotional experiences and self-care practices of these parents, emphasizing how care giving responsibilities intersect with personal identity and resilience. Using qualitative methods approach, the research highlights patterns of emotional fatigue, guilt, and social isolation, alongside emerging strengths such as adaptability, empathy, and advocacy. Findings suggest that while many parents struggle to prioritize self-care due to overwhelming demands, supportive networks and targeted interventions can significantly improve emotional health and quality of life. The study calls for healthcare professionals, educators, and policymakers to adopt a holistic framework that recognizes caregivers' needs as integral to family-centered care. Understanding the emotional landscape and self-care strategies of parents raising children with special needs not only informs best practices in support programs but also promotes sustainable care giving and family well-being.

Keywords: caregiver well-being; emotional resilience; parental self-care; special needs parenting; family support; holistic care

Dedication

This research is dedicated to parents of children with special needs in Bangladesh and across the world. In the Bangladeshi socio-cultural context, where limited resources, social stigma, and inadequate institutional support often intensify caregiving responsibilities, these parents—particularly mothers—demonstrate remarkable resilience, patience, and commitment. Their continuous efforts to nurture, protect, and advocate for their children reflect profound strength and selflessness. This work honors their lived experiences and acknowledges their indispensable role in fostering inclusion, dignity, and well-being for children with special needs.

Acknowledgement

I extend my deepest appreciation to the BRAC Institute of Educational Development (BIED), BRAC University, for offering me the opportunity, resources, and continuous support to carry out this thesis.

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Most importantly, I wish to express my heartfelt thanks to the parents who participated in this study. Their openness, time, and willingness to share their lived experiences added depth and purpose to this research, for which I remain truly grateful.

Above all my gratitude and thanks to my family and friends for their unconditional support through the journey,specially my friend Kazi Tahmina. My heartfelt gratitude for your unconditional support and encouragement that made this accomplishment possible.

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List of Acronyms

ADHD	Attention Deficit Hyperactivity Disorder
ASD	Autism Spectrum Disorder
ID	Intellectual Disability
IDD	Intellectual and Developmental Disabilities

Glossary

Term	Definition
Autism Spectrum Disorder (ASD)	A developmental condition marked by challenges in communication, social interaction, and restricted or repetitive behaviors. It varies in severity and presentation among individuals.
Caregiver Burden	The emotional, physical, and financial strain experienced by individuals providing long-term care to family members with chronic conditions or disabilities.
Caring for the Carer	A concept emphasizing the need to support caregivers' mental, physical, and emotional health to sustain effective caregiving.
Coping Mechanisms	Behavioral and psychological strategies individuals use to manage stress, adapt to challenges, and maintain emotional balance.
Developmental Disability	A group of lifelong conditions that affect physical, learning, language, or behavioral development, often beginning in early childhood.
Emotional Burden	The psychological distress—such as guilt, anxiety, and sadness—resulting from the continuous demands and emotional weight of caregiving.
Intellectual Disability (ID)	A disability involving significant limitations in intellectual functioning and adaptive behaviors, originating before adulthood.
Isolation	A sense of social and emotional detachment experienced by caregivers due to stigma, lack of understanding, or limited social opportunities.

Term	Definition
Respite Care	Temporary or short-term care provided to a dependent individual to give the primary caregiver rest and relief from continuous caregiving.
Self-Care	Intentional practices undertaken by individuals to maintain their physical, emotional, and mental well-being, such as rest, leisure, and relaxation.
Social Stigma	Negative stereotypes, prejudice, or discrimination toward individuals or families associated with disabilities, often leading to marginalization.
Support Systems	Networks of family, friends, community organizations, and professionals that provide emotional, practical, or financial assistance to caregivers.
Thematic Analysis	A qualitative research method for identifying and analyzing recurring patterns or themes within a dataset, such as interview transcripts.
Well-being	A holistic state encompassing physical, emotional, and social health, reflecting an individual's overall quality of life and life satisfaction.

Chapter I: Introduction & Background

Introduction

Parenting is a deeply rewarding yet demanding journey, requiring patience, resilience, and unwavering commitment. When a child has special needs—whether due to developmental delays, physical disabilities, chronic illnesses, or neurodivergence—these responsibilities increase in intensity and complexity (Kyzar et al., 2012). Parents in this role often become not only caregivers but also advocates, medical coordinators, educators, and emotional anchors. Such multifaceted responsibilities, while rooted in love and dedication, can exert significant pressure on their emotional, physical, and social well-being (Dabrowska & Pisula, 2010).

Globally, the identification of children with special needs has grown, owing to improved diagnosis, heightened awareness, and evolving definitions of disability (World Health Organization [WHO], 2021). In numerous areas, especially within low- and middle-income nations, parents frequently serve as the main source of support, often lacking access to professional respite services (Brehaut et al., 2009).Cultural norms may further reinforce the expectation that caregivers, especially mothers, should sacrifice personal needs for the sake of the child's welfare (Skinner & Weisner, 2007). While this selflessness reflects profound devotion,it may also result in ongoing stress, exhaustion, and a reduced quality of life (Zuna et al., 2010).

Traditionally, research has focused on the needs, development, and outcomes of children with special needs, often neglecting the lived experiences of their parents (Woodgate et al., 2015). However, the well-being of caregiver is inseparable from the well-being of the child (Kuhlthau et al., 2014). Parents who are emotionally resilient and physically healthy are better equipped to provide consistent, compassionate, and effective care. Conversely, neglecting caregiver needs can create a cycle of exhaustion, frustration, and reduced caregiving capacity (Mugno et al., 2007).

Self-care, emotional resilience, and access to support systems are, therefore it is essential for parents raising children with special needs (Myers et al., 2009).Understanding their emotional experiences, the strategies they use to maintain personal well-being, and the barriers they encounter in practising self-care is vital for designing interventions that address the needs of the whole family. This study seeks to explore these dimensions, amplifying the voices of

parents whose own health and happiness are often sacrificed in the name of caregiving, and advocating for a more holistic approach to special needs care.

Statement of the Problem

Parents of children with special needs encounter distinctive and frequently demanding challenges that is beyond the scope of ordinary parenting responsibilities. Their roles frequently encompass medical management, therapy coordination, advocacy in educational settings, and providing constant emotional and physical support. While these responsibilities are undertaken with deep love and commitment, they often result in elevated stress levels, social isolation, financial strain, and physical exhaustion (Brehaut et al., 2009). Over time, the continuous demands of care-giving can hamper the parent's own health and well-being, increasing their risk for depression, anxiety, and burnout.

As a school teacher, I have observed that parents of special needs children often encounter significant psychological challenges, including depression, anxiety, and burnout. The constant demands of care-giving, coupled with social stigma and a lack of adequate support systems, make it difficult for these parents to maintain their own well-being. Many of them are unable to openly share their struggles with others due to fear of judgment, lack of understanding, or limited awareness within their communities. This unspoken burden not only affects their emotional health but may also influence their ability to provide consistent care and support for their own children.

Despite the essential role that parents play in their children's growth and everyday functioning, the majority of interventions, policies, and research continue to prioritize the child's needs , with comparatively little attention given to the parents emotional and self-care needs. This oversight is problematic because the well-being of the caregiver is strongly associated with the level of care the child receives (Kuhlthau et al., 2014).When Parents experience emotional exhaustion and neglect their own needs, their capacity to provide patient, consistent, and effective care diminishes.

In many cultural contexts, societal expectations compound the problem by idealizing self-sacrifice as an essential aspect of "good" parenting, particularly for mothers. This can foster feelings of guilt or selfishness when caregivers attempt to prioritize their own needs, leading

to further neglect of self-care (Skinner & Weisner, 2007). Without accessible support systems, including respite services, mental health resources, and social networks, parents may find themselves trapped in a cycle of depletion that negatively affects both themselves and their children.

The limited availability of focused research exploring the lived experiences of caregivers, especially in resource-limited settings, means that many of their challenges remain invisible to policymakers and service providers. Understanding the emotional realities and self-care practices of parents with special needs children is essential for developing holistic interventions that support the well-being of the whole family rather than focusing solely on the child. This study seeks to address this gap by examining the emotional and self-care experiences of these parents, thereby contributing evidence that can guide culturally relevant policies and support programs.

Purpose of the Study

This study aims to gain a true understanding of everyday life for parents who are raising children with special needs—how they feel, how they take care of themselves, and what makes this care difficult or possible. While many studies focus on the child's needs, far fewer look closely at the parents's own well-being. This research aims to fill that gap by listening to parents' personal experiences, their emotional challenges, and the ways they try to protect their health and happiness while caring for their child.

By giving space to these voices, this study hopes to show that looking after the caregiver is not a luxury, but a necessity. The findings will help guide the creation of support systems, programs, and policies that give equal importance to parents' health as to their children's development. In the long run, caring for the carer benefits the whole family, because when parents are supported, children thrive.

Significance of the study

Raising a child with special needs is a journey filled with love, patience, and dedication, but it can also bring constant demands that affect a parent's health, relationships, and daily life.

Parents often become more than just caregivers—they are therapists, advocates, teachers, and emotional supporters all at once. These responsibilities, while deeply meaningful, can also lead to exhaustion, stress, and feelings of isolation (Brehaut et al., 2009). For many parents, self-care is pushed to the side because their child's needs always feel more urgent.

This study is important because the well-being of parents directly affects the well-being of their children. When parents are emotionally and physically healthy, they can provide more patient, loving, and consistent care. However, when they are overwhelmed or burned out, it becomes harder to meet the child's needs effectively (Kuhlthau et al., 2014). Despite this, most programs, policies, and research focus mainly on helping the child, leaving the parents' own needs under-recognized and under-supported.

Another reason this research matters is the influence of cultural and social expectations. In many communities, parents—especially mothers—are expected to give everything to their child without complaint. While this devotion is admirable, it can create guilt or shame if they try to take time for themselves (Skinner & Weisner, 2007). These pressures make it even harder for parents to practice self-care, even when it is badly needed. By exploring the emotional experiences of caregivers, this study can help challenge the idea that self-care is selfish, showing instead that it is essential for strong, sustainable care-giving.

This research will also provide valuable information for policymakers, health professionals, and community organizations. By understanding what parents actually go through—their struggles, their coping strategies, and the kind of support they wish they had—services can be designed to meet their real needs. Support programs such as respite care, counselling, peer groups, and workplace flexibility could make a major difference in helping parents stay healthy while caring for their children (Myers et al., 2009).

In short, the significance of this study lies in its focus on the parent as a person whose health and happiness matter—not only for their own sake, but because their well-being shapes the future of their child. By giving voice to these parents, this research seeks to bring about more compassionate and balanced approaches to special needs care—approaches that care for the carer as much as the child.

Research Questions

This study will answer the following research questions:

1. What are the key emotional difficulties for Bangladeshi parents of children with special needs?
2. How do parents of children with special needs feel about their care-giving role?
3. What do these parents do to take care of themselves?
4. What makes it hard for them to look after their well-being?

Operational Definition

Care for the Carer: Refers to the emotional, psychological, and physical health and well-being of parents who consistently care for children with special needs. It encompasses the strategies, supports, and interventions aimed at maintaining or improving the caregiver's health and resilience.

Emotional Experience: Describes the range of feelings and emotional responses—such as stress, joy, guilt, anxiety, or fulfillment—that parents encounter in their caregiving role. This includes both positive and negative emotions experienced in day-to-day interactions and caregiving responsibilities.

Self-Care: Denotes the deliberate actions and practices that parents engage in to maintain their mental, emotional, and physical health. Examples include seeking social support, setting boundaries, engaging in leisure activities, or accessing professional help when needed.

Parents Raising Children with Special Needs: Refers to mothers, fathers, or primary guardians responsible for the upbringing and daily care of children who have developmental, intellectual, or physical disabilities that require additional attention and support beyond typical parenting demands.

Chapter II: Literature Review

Parents raising special needs children—for example those with developmental disabilities, chronic illnesses, or neurodivergent conditions—face many challenges that go beyond everyday parenting. Caring for a child in these circumstances can be physically exhausting, emotionally overwhelming, and sometimes socially isolating. These pressures can affect a parent's mental health, relationships, and overall quality of life. Studies in different fields show that caregiving can be both deeply meaningful and deeply challenging, offering moments of love and pride alongside periods of stress, worry, and fatigue.

Emotional Experiences of Parents of Children with Special Needs

Parental stress and psychological distress are well-documented phenomena in this population. Studies consistently experience higher levels of stress than parents of typically developing children largely due to the unpredictability of care needs, financial strain, and social stigma (Hayes & Watson, 2013). Mothers often report higher stress than fathers, which is linked to traditional caregiving expectations and maternal role intensification (Dabrowska & Pisula, 2010).

Emotional burden is compounded by the persistent advocacy required for their child's needs, navigating complex healthcare and education systems, and managing others' lack of understanding (McConnell & Savage, 2015). Parents may also experience ambiguous loss—grieving the difference between their expected and actual parenting journey (Boss, 2010).

However, not all emotional outcomes are negative. Some parents report increased resilience, empathy, and personal growth (Bayat, 2007). This phenomenon, often framed as post-traumatic growth, suggests that caregiving can foster new strengths alongside ongoing stress.

Self-Care Practices in Caregiving Contexts

Self-care is defined as deliberate activities undertaken to Support overall physical, mental, and emotional health (Godfrey et al., 2011) For parents of CSN, self-care is often deprioritised due to time constraints, financial limitations, and guilt over taking time away from caregiving (Fereday et al., 2009). Lack of self-care is linked to caregiver burnout, depression, and decreased capacity to adequately address the needs of their child.(Raina et al., 2005).

Physical self-care (e.g., adequate sleep, exercise, medical check-ups) is frequently disrupted by irregular schedules and nighttime care demands. Psychological self-care—such as therapy, mindfulness, or support group participation—can provide emotional regulation but requires accessible services and social support. Social self-care, including maintaining friendships and leisure activities, is protective against isolation, yet often declines due to stigma or exhaustion (Green, 2007).

Social Support and Coping Strategies

The buffering effect of social support is well-established in caregiving literature (Cohen & Wills, 1985). Family networks, peer support groups, and community organisations can reduce stress and promote self-care engagement. Effective coping strategies—problem-focused (seeking solutions) and emotion-focused (acceptance, reframing)—are associated with better psychological adjustment (Lazarus & Folkman, 1984).

However, cultural expectations influence how parents seek and receive support. In collectivist societies, caregiving is often framed as a familial duty, potentially reducing parents' willingness to seek outside help (Kyzar et al., 2012). Conversely, in individualist contexts, systemic support structures may be more formalised but less personal.

Gaps in the Literature

Many studies have looked at the stress, anxiety, and coping strategies of parents of children with special needs, but few have studied how emotional well-being relates to self-care. Most of this research also focuses mainly on mothers., leaving the experiences of fathers and other types of caregivers less understood. There is also a lack of studies that listen closely to parents' own stories, especially in non-Western and low-resource settings. In addition, we need more research on whether planned self-care programs can truly help parents feel better and cope more effectively in their daily lives.

Conclusion

Research shows that caring for a child with special needs greatly affects a parent's emotional health, often creating a struggle between meeting caregiving demands and looking after themselves. Parents show strength and adaptability, but when they neglect their own needs, stress can grow and make caregiving harder. Future research should look at caregiver support in a more complete way, including emotional, physical, and social self-care, while also considering culture, social expectations, and the different challenges families face in various situations.

Chapter III: Methodology

Research Approach and Design

A qualitative approach was used in this study to examine how parents of children with special needs handle their emotional well-being and self-care.It was suitable as it captured real-life experiences and the personal meaning parents attach to their caregiving roles (Creswell & Poth, 2018).Through in-depth interviews(IDI)Data had been collected , observations, field notes and audio recording to provide a well-rounded understanding of how parents cope with stress and make time for self-care.

Research Site

The study took place in selected inclusive education centers and in the homes of participating families in Dhaka city. They are from Vashantek, Kafrul, Mirpur and Dhaka Cantonment. These locations were chosen because I as school teacher work in Dhaka Cantonment area. Besides,some were my students' parents, the students who had special needs and connected with families from diverse socioeconomic backgrounds. By conducting interviews in both schools and homes, the research will capture a fuller picture of parents' emotional and self-care experiences in their daily care-giving contexts. The study also looked at the support systems available to these families, including professional services, community networks, and informal care within the home.

Research Participants

This study involved parents of special needs children, including developmental, intellectual, physical, or behavioural disabilities. A deliberate sampling approach was used to identify and select participants. with direct and sustained care-giving experience. Participants had recruited through inclusive education centers and parent support groups to ensure that they have relevant insights to share. To capture a diversity of perspectives, the sample consist of both mothers and fathers representing diverse socioeconomic and cultural backgrounds. as well as they are belong to different ages. 10 participants took part in individual interviews, each lasting 45 to 60 minutes.

Sampling Procedure/Participants Selection Procedure

Creswell (2012) describes a population as the complete set of individuals, objects, or events that a researcher seeks to understand, from which a sample is drawn and about which generalizations are made based on shared characteristics. In the present study, ten participants were involved, with the final number determined once data saturation was achieved—when no new insights emerged from the interviews. A purposive sampling strategy was adopted to intentionally recruit parents of children with special needs, including those with autism, ADHD, and various developmental or physical disabilities. This approach ensured that participants could provide rich, relevant, and diverse perspectives grounded in their lived experiences. Participants were selected for their direct caregiving experience and willingness to share their perspectives. By informing consent had gained from all participants.

Data Collection Tool

The data collection instruments were carefully developed to align directly with the study's research questions. The tools included an In-Depth Interview (IDI) Guide for parents and a short demographic questionnaire (to gather background information such as age, relationship to the child, diagnosis, and care-giving duration). Field notes (to record non-verbal expressions, contextual details, and researcher observations)

Data Collection Method and Procedure

Interview Approach

Data for this study were gathered through semi-structured, in-depth interviews. These interviews were conducted either face-to-face or via secure video conferencing platform,, depending on each participant's comfort, preference, and accessibility. This flexible approach allowed participants to choose a setting where they felt most at ease, while ensuring that discussions stayed aligned with the study's key research objectives. Open-ended questions guided the conversation, encouraging participants to share their personal experiences and perspectives in their own words.

Interview Process

Each interview lasted approximately 45 to 60 minutes. With participants' informed consent, all sessions were audio-recorded to preserve the accuracy of their responses and to facilitate a detailed analysis later on. The conversational nature of the interviews helped build rapport between the researcher and participants, making it easier to explore sensitive or complex topics with empathy and understanding.

Demographic Information

Before the interviews, participants completed a brief demographic questionnaire that gathered key background information, including their age, profession, relationship to the child, and the child's specific diagnosis. This information showed important contextual insight for interpreting and understanding the qualitative data.

Field Notes and Observations

In addition to the audio recordings, the researcher maintained detailed field notes during and immediately after each interview. These notes captured non-verbal cues, contextual details, and personal reflections about the interaction. Such observations enriched the understanding of participants' responses and added depth to the overall analysis.

Data Management and Analysis

All interviews were carefully transcribed verbatim to preserve the authenticity and accuracy of participants' voices. A thematic analysis approach was then applied to systematically identify meaningful patterns and overarching themes that captured the depth and complexity of participants' experiences. The analysis was followed Braun and Clarke's (2006) six-step framework: (1) becoming familiar with the data by reading and re-reading the transcripts, (2) generating initial codes, (3) searching for potential themes, (4) reviewing and refining themes, (5) defining and naming themes, and (6) producing the final report. Both the interview transcripts and field notes will be analysed to capture verbal and non-verbal insights. The demographic questionnaire data will be summarised using descriptive statistics to provide context for the qualitative findings. NVivo software was used to organise and code the data systematically.

Validity & Reliability

Ensuring Reliability

In qualitative research, reliability refers to the consistency and dependability of the data collection and analysis process. To enhance reliability in this study, the researcher used a semi-structured interview guide to ensure that all participants were asked similar core questions, while still allowing room for individual expression. This balance between structure and flexibility helped maintain consistency across interviews without limiting the depth or authenticity of participants' responses.

All interviews were audio-recorded and later transcribed verbatim to preserve the accuracy of participants' words. The researcher also kept reflective notes throughout the data collection process to track emerging themes and potential biases. These steps helped ensure that interpretations were grounded in participants' actual experiences rather than the researcher's assumptions.

Establishing Validity

Validity in this study was achieved through multiple strategies aimed at capturing the authenticity and richness of participants' lived experiences. First, **member checking** was employed: participants were invited to review and confirm key interpretations or summaries of their interviews to ensure that their perspectives were represented accurately.

Second, **triangulation** was used by comparing insights from interview transcripts, field notes, and demographic data. This cross-verification strengthened the credibility of the findings by showing consistency across different data sources.

Third, the researcher kept a comprehensive audit trail that recorded each stage of data collection and analysis. This transparent documentation enabled others to trace the researcher's decisions and assess the study's methodological rigor.

Lastly, reflexivity played an important role throughout the study. The researcher continuously reflected on their own background, assumptions, and potential influence on the research process. This practice helped maintain openness and authenticity in interpreting participants' stories.

Ethical Issues

This study involved parents sharing personal and often emotional experiences, great care was taken to ensure that their rights, comfort, and privacy were respected at every stage. The study followed the ethical guidelines of the Institutional Review Board (IRB), and approval was gained before any data were collected. Participation was completely voluntary, and each participant was given clear information about why the study was being conducted, what their involvement would look like, and their freedom to quit at any point.

Their consent was taken before beginning each interview. To protect participants' identities, all information was anonymised using pseudonyms, and no details that could reveal who they were were included in transcripts or reports. All audio recordings, transcripts, and demographic forms were stored securely stored on devices secured with a password and accessible solely by the researcher.

Since some of the topics discussed could be sensitive or emotional, the study also made an effort to create a supportive and respectful environment. Participants were reminded that they could pause, skip any question, or stop the interview whenever they felt the need. These steps

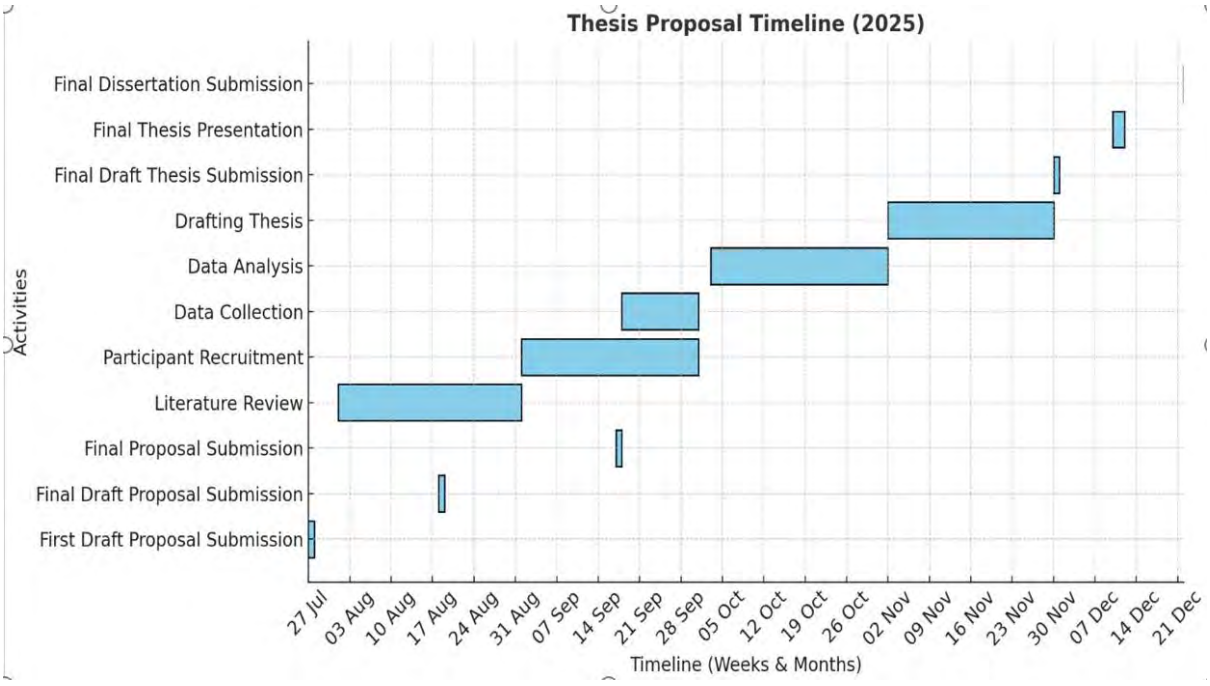
helped ensure that the study was carried out with compassion, dignity, and full respect for the individuals who generously shared their experiences.

Timeline of the Study

The study was conducted over several months following a clearly defined and systematic research process. In the early stage, the research topic was identified, relevant literature was reviewed, and the research proposal was prepared during July and August. The proposal was then presented at an Advanced Seminar and approved by BRAC University.

Following approval, the development of data collection instruments was completed in August. Data collection activities were carried out in September. During October, the collected data were organized, transcribed, and examined using thematic analysis procedures.

In the final phase, the research report was drafted and refined based on the Supervisor's feedback throughout November. The fully edited and finalized thesis was submitted in December.



Limitations of the Study

Like many qualitative studies, this research does not aim to generalize its findings to all parents of children with special needs. The participants were intentionally selected for their unique experiences, which provided deep, meaningful insights rather than broad statistical representation. While this focused approach allowed for a closer look at the emotional and practical realities of caregiving, it also means that the findings reflect the voices of a small group rather than a wide population.

The sensitive nature of the topic also brings certain challenges. Talking about personal struggles, emotions, and family life can be difficult, and some participants may have chosen to share only what felt safe or socially acceptable. Feelings of guilt, stigma, or a desire to present themselves positively could have influenced how openly they discussed certain experiences.

Even with these limitations, the study offers valuable, real-world perspectives that shed light on the day-to-day realities faced by parents of children with special needs. These stories highlight both the challenges and the resilience within families, offering insights that can help shape more compassionate research, informed policies, and meaningful support systems in the future.

Chapter IV: Results/Findings

Introduction

This chapter outlines the key findings from a qualitative investigation into the lived experiences of parents caring for children with developmental and intellectual disabilities. The analysis is based on detailed interviews conducted with both fathers and mothers,highlighting their emotional journeys, daily challenges, coping strategies, and the social factors shaping their caregiving experiences. Through thematic analysis, several interrelated themes were identified, reflecting the emotional, psychological, social, and practical perspectives of caregiving.

Theme1.Emotional Burden and Isolation

Parents of children with developmental and intellectual disabilities experience a profound sense of emotional burden and isolation as they navigate the daily realities of caregiving. Many described feelings of guilt, helplessness. anxiety, and loneliness, intensified by the constant comparison between their children and others. Emotional responses to diagnosis were often marked by grief, shock, and devastation, gradually evolving into chronic worry about their child's future and social acceptance. Mothers, in particular, expressed the strain of balancing caregiving responsibilities with their own well-being and other family roles.

Participant A(Labonno), *"The main emotional challenge is that my child is not like other child. In every stage of life I understand that by the society. Though they show me sympathy towards me, I feel discomfort-able."*(IDI-1,08.09.25)

Participant C(Adiba), *"Sometimes I feel helpless and guilty. It breaks my heart when he wants to say something but cannot. I worry about his future—how he will manage, who will understand him, and whether society will accept him."* (IDI-3,08.09.25)

Fathers similarly revealed deep emotional struggles, describing ongoing tension between maintaining hope and confronting reality.

Participant B(Ferdousi) expressed, *"The biggest emotional challenge is balancing hope and reality. I often worry about his future—how he will cope when we are no longer around."*(IDI-2,09.09.25)

Echoing this concern,participant I (Haque) shared, *"The most painful challenge is accepting that our daughter's journey will be different from what we once imagined. We constantly worry about her future—how she will cope, study, make friends, or live independently."* (IDI-09,12.09.25)

These narratives collectively reveal that the emotional toll of caregiving extends beyond physical exhaustion, encompassing social isolation, anticipatory grief, and persistent anxiety about the child's future. The lack of societal understanding and genuine support further

intensifies parents' feelings of being emotionally burdened and alone in their caregiving journey.

Theme2.Impact on Daily Life and Family Relationships

The theme *"Impact on Daily Life and Family Relationships"* highlights how the intensive caregiving demands of raising a child with developmental or intellectual disabilities deeply influence parents' everyday routines, personal lives, and family dynamics. Parents described how their schedules, priorities, and emotional energy are almost entirely shaped by their children's needs, often resulting in physical exhaustion, emotional fatigue, and strained family relationships. Many mothers reported that caregiving responsibilities consumed nearly all of their time and attention, leaving little space for self-care or nurturing other family bonds.

Participant A(Labonno)explained, *"My child wants 100% attention. It hurts me. It hampers my personal life, social life."* (IDI-1,08.09.25)

Participant B(Ferdousi) echoed this strain, sharing, *"I become exhausted by take care of her. I can not care my husband, my other family members or even myself. For that often my husband quarrel with me."* (IDI-1,08.09.25)

These reflections illustrate how the demands of constant caregiving can lead to tension within marital relationships and feelings of guilt for neglecting other family members.

Fathers also described the pervasive influence of caregiving on their daily lives, emphasizing the mental and emotional toll of balancing work, family, and caregiving roles.

Participant G (Ragib) shared, *"My daily routine revolves around ensuring Safwan's comfort and progress... it can be mentally tiring after a long day at the office."* (IDI-7,11.09.25)

Similarly, paticipant G (Mahfidur) reflected, *"Our daily routine requires constant adjustment... At times, I feel guilty for not being able to spend enough time with him due to my job."*(IDI-8,11.09.25)

The sense of ongoing adaptation was echoed participant I (Haque), who noted, *"Our daily routine revolves around Nuhai's needs. Therapy sessions, speech exercises, and structured*

play are a big part of our schedule. As both of us are doctors, balancing professional duties with caregiving is extremely demanding."(IDI-09,12.09.25)

Likewise, participant J (Saleh) described the relentlessness of their routines, saying, *"Every day requires extra patience and planning. From helping him get ready for school to assisting with physical therapy, our schedule revolves around his needs."*(IDI-10,15.09.25)

Collectively, these accounts reveal that caregiving responsibilities profoundly reshape family structures and interpersonal relationships, often creating emotional distance between partners and limiting time for personal or social engagement. The findings demonstrate that caregiving is not confined to a set of daily tasks—it becomes a way of life that continuously tests parents' emotional resilience, marital harmony, and overall family well-being.

Theme 3.Social Stigma and Barriers

The theme *"Social Stigma and Barriers"* highlights the pervasive influence of societal attitudes, cultural misconceptions, and judgmental behaviors that parents of children with developmental and intellectual disabilities encounter in their daily lives. Participants consistently described experiences of being stigmatized, misunderstood, or socially excluded, which contributed to emotional pain and withdrawal from community engagement. Mothers, in particular, reported that staring, gossip, and insensitive remarks from others reinforced their feelings of shame and discomfort.

Participant B shared (Ferdousi), *"People weirdly behaved with me sometimes. Nowadays, I just avoid all social functions and invitation."*(IDI-2,08,.09.25)

Similarly,participant F(Sornali) expressed, *"Sometimes I feel emotional when people stare or make insensitive comments. As a mother, it hurts deeply."*(IDI-6,10.09.25)

Fathers also discussed the challenges of navigating social stigma and public misunderstanding.

Participant G (Ragib) stated, *"Social attitudes are a big challenge. Many people don't understand intellectual disability; they often think such children can be 'fixed' with strict discipline or prayers alone."*(IDI-11,15.09.25)

Participant H (Mahfidur) added, *"Many people in our society think ADHD is simply a lack of discipline or bad parenting... we often hesitate to talk openly about his condition."* Likewise, MD. (IDI-08,15.09.25)

Participant I(Haque) explained,*"Cultural attitudes toward autism are often judgmental. Even among educated circles, people tend to label children like Nuhai as 'slow' or 'abnormal.'"*(IDI-09,15.09.25)

Participant J (Saleh)echoed this sentiment, saying, *"In our society, physical disability is often viewed with sympathy rather than understanding. Many people look at Aman with pity or curiosity, which hurts us as parents."*(IDI-10,15.09.25)

These accounts reveal how cultural misconceptions and negative labeling create significant barriers for parents, discouraging them from seeking help and fostering a sense of social alienation. The stigma attached to disability often leads to self-isolation and silence, where parents withdraw from social activities to protect themselves and their children from judgment. This theme underscores how societal attitudes not only marginalize families but also perpetuate the emotional burden of caregiving by restricting acceptance, inclusion, and open dialogue about disability.

Theme 4.Lack of Social Support

Lack of Social Support captures parents' experiences of insufficient emotional, practical, and institutional assistance, which intensified their caregiving stress and sense of isolation. Mothers overwhelmingly reported that they received little to no help from family members, leaving them to manage all caregiving responsibilities on their own.

Participant A(Labonno), *"To be honest I do not get any support from my family. As a mother, I have to deal with the child solely."*(IDI-1,08.09.25)

The absence of family involvement compounded their exhaustion and feelings of being overwhelmed, especially when balancing household duties, employment, and their child's therapeutic needs.

All parents noted that while some support from organizations, friends, or professionals was occasionally available, it was often inconsistent or inadequate. Two parents described that during periods of crisis—such as the COVID-19 pandemic—the lack of accessible services and understanding further deepened their emotional strain. The scarcity of reliable social networks meant that emotional exhaustion and burnout were common, particularly among mothers who were primary caregivers. Parents emphasized that consistent emotional and practical support could help them better cope with stress, maintain hope, and prevent isolation.

Collectively, this theme highlights how the absence of a robust support system exacerbates the challenges faced by caregivers, leaving them vulnerable to fatigue, depression, and emotional withdrawal. Conversely, where emotional or community support was present, parents reported greater resilience and optimism. These findings underline the critical need for structured social and institutional support systems that address the psychological and practical needs of caregivers, fostering inclusion and emotional well-being.

Theme 5.Barriers to Self-Care and Coping strategies

Parents face multiple challenges in maintaining their own well-being while caring for children with developmental and intellectual disabilities. Parents described being caught between intense caregiving responsibilities, professional duties, and family roles, leaving little time or energy for personal care. Time constraints, guilt, financial strain, and limited access to professional or respite services emerged as major obstacles to self-care. Mothers, in particular, expressed that their own needs were consistently deprioritized in favor of their child's comfort and safety.

Participant J (Sornali) shared, *"I often feel guilty taking time for myself, as I always think about her comfort and safety."*(IDI-6,10.09.25)

Participant A(Labonno) explained, *"The main obstacle is lack of time. Household work, child's responsibility, job responsibility and doing MSC for all these I need time. Lack of time I can't do self care."*(IDI-1,08.09.25)

Despite these limitations, some mothers identified adaptive coping mechanisms that helped them recover emotionally and sustain their caregiving roles. These included prayer, relaxation, shopping, listening to music, and finding short moments of solitude.

Participant A(Labonno) reflected, *"When I become exhausted, usually apply some technique. I take time, heal myself in different way. I do shopping, the things I like. I think time is the best healer."* (IDI-1,08.09.25)

These self-initiated strategies served as important emotional outlets, offering brief relief from daily pressures.Fathers also acknowledged similar struggles, often emphasizing the difficulty of balancing employment demands with caregiving responsibilities.

Participant G(Ragib) explained, *"Time and mental pressure are the main obstacles. My office responsibilities are heavy, and after returning home, most of my energy goes into helping Sawan and supporting my wife."*(IDI-7,15.09.25)

Participant H (Mahfidur) shared a similar approach to coping, noting, *"I try to stay calm through prayer and reflection... The main obstacle is time... Sometimes I feel guilty taking time for myself."* (IDI-8,15.09.25)

Participant G (Ragib) also highlighted the role of shared coping within marriage, adding, *"I try to keep myself emotionally balanced through prayer and reflection... My wife and I also encourage each other to take breaks when needed."*(IDI-7,15.09.25)

Collectively, these accounts reveal that time scarcity, guilt, and financial pressures severely limit opportunities for self-care, even though parents recognize its importance for their mental and physical health. Most coping strategies are informal and self-directed, relying heavily on faith, reflection, and emotional resilience rather than structured external support. These findings align with previous research emphasizing that while adaptive coping methods—such as mindfulness, prayer, and short leisure activities—can mitigate stress, systemic barriers and social expectations continue to hinder caregivers' ability to prioritize their own well-being. This theme underscores the urgent need for targeted support interventions, including respite care, counseling, and awareness programs that promote self-care as an essential component of sustainable caregiving.

Theme 6. Hope, Acceptance, and Redefining Meaning

Despite uncertainty and exhaustion, parents expressed enduring hope for their children's future. They envisioned a world where their children would be accepted and included — in schools, workplaces, and society at large.

Acceptance, for many, was a gradual emotional achievement. Participant D (Shefali) stated, *"At first, I only saw his limitations. Now, I see his joy, his kindness — that's who he really is."*(IDI-4,09.09.25). Participant C(Adiba) reflected, *"He may not be like other children, but he's perfect in his own way. I've learned to celebrate every small step."*(IDI-4,09.09.25).

Through acceptance, parents found new meaning in their caregiving role. They began to redefine success not by societal standards but by personal growth — both their child's and their own. This transformation marked a shift from surviving to thriving, driven by love, hope, and an evolving sense of purpose.

Summary

Together, these six themes portray a multidimensional picture of caregiving — one that encompasses emotional hardship, social isolation, and fatigue, but also resilience, faith, and deep love. Parents' experiences reveal that self-care and emotional well-being are not separate from caregiving but are integral to it.Their journeys illustrate that caring for a child with special needs is both a challenge and a profound opportunity for personal growth, emotional strength, and redefined meaning in life.

Discussion

1. Emotional Adaptation and the Journey toward Acceptance

Agreeing with Lazarus and Folkman's (1984) Stress and Coping Theory, the findings suggest that parents undergo an evolving process of emotional adaptation, moving from shock and denial toward gradual acceptance and meaning-making. Initial reactions to diagnosis often reflected grief and helplessness, aligning with earlier studies that compare parental responses to bereavement (Gray, 2002).

However, over time, parents in this study demonstrated strong emotional adjustment, shifting their focus from "fixing" the child to understanding and supporting them. This transformation was not linear but cyclical, reflecting periods of despair followed by renewed hope. Such emotional fluidity underscores caregiving as an ongoing psychological negotiation rather than a fixed state of acceptance.

2. The Social Weight of Stigma and Isolation

A pervasive theme in this study was the emotional burden of social stigma. Parents described feeling judged, pitied, or blamed by others — a finding that echoes research from similar sociocultural contexts (Islam et al., 2020). The Family Systems Theory posits that family well-being is shaped by its interactions with the social environment; thus, when societal acceptance is absent, emotional distress intensifies.

In Bangladeshi society, where disability is often misunderstood or moralized, parents reported both social withdrawal and emotional exhaustion. However, small circles of empathy—supportive friends, teachers, or therapists—acted as social buffers, validating Bronfenbrenner's Ecological Systems Theory, which highlights the protective influence of positive micro systems even amid broader stigma.

3. Self-Care as a Neglected Necessity

The findings clearly reveal that self-care remains one of the most neglected aspects of caregiving. Parents, particularly mothers, described the caregiving role as "24 hours," with little time left for rest or personal healing. The emotional guilt attached to self-care—feeling selfish for taking a break—was strikingly consistent across participants.

This aligns with global caregiving research, which identifies role engulfment and caregiver burnout as common outcomes when personal boundaries blur (Hayes & Watson, 2013). Despite these challenges, small coping activities—prayer, journaling, music, or brief solitude—offered emotional regulation and renewed strength. Such findings highlight the need

for structured self-care awareness and accessible respite services for parents of special needs children in Bangladesh.

4. Family Relationships: Strain, Sacrifice, and Solidarity

Family relationships were deeply affected by caregiving responsibilities. The study found that spousal relationships often revolved solely around the child's needs, reducing emotional intimacy. Yet, many couples reported that shared caregiving struggles also deepened their mutual understanding and teamwork. This duality aligns with Walsh's Family Resilience Framework (2003), which emphasizes that adversity can either fragment or fortify family bonds depending on communication and shared meaning.

Sibling dynamics were another subtle yet significant concern, with parents expressing guilt for not spending enough time with other children. The findings suggest that emotional strain within families is not merely logistical but existential—families constantly renegotiate identity, responsibility, and togetherness within a caregiving context.

5. Faith and Spiritual Meaning-Making

Faith emerged as a powerful emotional anchor. Almost every parent referred to prayer, belief in divine purpose, or religious acceptance as key coping mechanisms. This aligns with Pargament's Theory of Religious Coping (1997), which suggests that spirituality provides meaning, comfort, and a sense of control during uncontrollable circumstances.

Parents viewed their caregiving role as a spiritual duty, often saying, *"Allah chose me for this child."* Such belief systems fostered psychological resilience, helping parents reframe caregiving from a burden into a divine responsibility. While faith sometimes limited engagement with formal mental health services (due to reliance on spiritual coping), it largely functioned as an emotional stabilizer and meaning-maker in their daily struggles.

6. Redefining Hope, Progress, and Parenthood

Perhaps the most powerful transformation revealed by this study was the redefinition of success and parenthood. Parents shifted their focus from societal expectations to personal growth—celebrating small milestones, cherishing unique strengths, and valuing emotional connection over achievement.

This echoes Posttraumatic Growth Theory (Tedeschi & Calhoun, 1996), where individuals facing adversity experience deep personal development and altered life perspectives. Parents learned to see progress in new words spoken, new gestures made, or moments of calm after distress. Such micro-successes became emotional lifelines, reinforcing the belief that caregiving, though difficult, brings profound lessons in empathy and strength.

7. The Need for Systemic and Policy-Level Support

Across all interviews, parents emphasized the lack of institutional support—limited therapy centres, untrained teachers, and minimal government involvement. These findings highlight an urgent need for systemic reform. Emotional well-being cannot thrive in isolation; it requires inclusive schools, affordable therapy, public awareness, and social safety nets.

In contexts like Bangladesh, where disability is still stigmatized, emotional health interventions for caregivers must combine community-based support groups, faith-sensitive counselling, and public education campaigns that normalize difference and inclusion.

Summary of Discussion

In summary, this study reaffirms that caregiving for a child with special needs is not merely a set of physical or logistical duties—it is an emotional, social, and spiritual journey. Parents traverse cycles of pain and peace, exhaustion and resilience, alienation and acceptance.

Their emotional wellness is shaped not only by internal coping but also by external realities—social stigma, family support, and institutional accessibility. Self-care, though recognized as essential, remains constrained by guilt, cultural expectations, and lack of resources. Yet, faith, love, and hope serve as protective shields, transforming caregiving into a profound act of endurance and meaning.

Recommendations

Based on the findings, several key recommendations are proposed for parents, practitioners, policymakers, and researchers:

1.For Parents and Families Prioritize self-care:

Parents should be encouraged to engage in small, meaningful acts of rest, reflection, and recreation without guilt. Self-care is not selfish—it sustains care-giving capacity.

Build peer support networks: Sharing experiences with other parents facing similar challenges can reduce isolation, normalize emotions, and foster mutual understanding.

Seek shared responsibility: Involving all family members—including spouses and siblings—can distribute emotional and practical care-giving burdens more evenly.

2. For Practitioners and Educators

Integrate emotional support in intervention programs: Counselors, therapists, and educators should include parental well-being as a component of child-centered interventions.

Offer culturally sensitive counseling: Professionals should respect parents' religious and cultural coping mechanisms while gently introducing evidence-based emotional care practices.

Provide parent training: Practical workshops on stress management, communication, and behavioral strategies can strengthen confidence and emotional resilience

3. For Policymakers

Develop inclusive and accessible support systems: Establish community-based resource centers offering affordable therapies, respite care, and emotional counseling for families.

Promote public awareness campaigns: Reducing stigma through education and media can foster social empathy and inclusion for both children and their parents.

Collaborate across sectors: Health, education, and social welfare ministries should coordinate to create integrated services that address the holistic needs of special needs families.

4. For Future Research

Further studies could explore fathers' emotional experiences, the role of extended families, and longitudinal changes in caregiver resilience.

Comparative research across urban and rural settings may reveal how environment and access shape emotional well-being. Incorporating mixed-method designs can enrich understanding by combining quantitative measures of stress and qualitative narratives of coping.

Conclusion

This study explored the emotional and self-care experiences of parents raising children with special needs, revealing the profound complexity of their caregiving journeys. Through in-depth interviews, parents shared stories that illuminated both their struggles and their strength—narratives woven with exhaustion, guilt, love, and hope.

The findings demonstrate that caregiving is not only a practical responsibility but also an ongoing emotional negotiation shaped by personal resilience, social support, and faith. While parents often experience isolation and emotional fatigue, they also cultivate deep acceptance and spiritual meaning that sustain them through daily challenges.

Ultimately, this research emphasizes that supporting children with special needs must include caring for their caregivers. Parents' emotional well-being directly influences their capacity to provide compassionate, consistent care. Recognizing and empowering parents as "co-survivors" of the caregiving journey is essential for holistic family well-being and social inclusion.

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Appendix A.

Research Tools

Research Title: Caring for the Carer: Understanding the Emotional and Self-Care Experience of Parents Raising Children with Special Needs

Research Question:

1. What are the key emotional difficulties for Bangladeshi parents of children with special needs?
2. How do parents of children with special needs feel about their care-giving role?
3. What do these parents do to take care of themselves?

4.What makes it hard for them to look after their well-being

Demographic information:

1) Your gender:

2) Your age:

3) Your educational background:

4) Your current profession:

5) Your approximate monthly income:

6) Your child's age:

7) Your child's gender:

Survey Questions

1) Please tell me about your child and his/her special needs.

2) What are the main emotional challenges you face as a parent?

3) How do these challenges impact your daily life?

4) What kinds of support (family, community, formal services) do you currently experience?

5) How do cultural or social attitudes impact how you feel or behave as a caregiver?

6)Please describe the self-care activities or coping mechanisms you use to manage caregiving demands.

7) What are the obstacles to implementing self-care?

8) How would you assess the effectiveness of support systems in place?

9)What would help you better manage your own emotional wellness?

10) Is there anything else you wish to share about your experience as a parent?

Appendix B: Sample Transcript 1

Participant A , Labonno Rahman

(IDI-1, Date-8-9-25)

Tool 1: In-Depth Interview (IDI) Guideline (for Parents of special needs)

Demographics:

1) Your gender: Female

2) Your age: 42

3) Your educational background: MBA

4) Your current profession:Teacher

5) Your approximate monthly income: 50,000

6) Your child's age: 7 years 5 months

7) Your child's gender: Male

8)Types of speciality:ASD

Name of the Interviewer: Shahanara Tuly

1)Please tell me about your child and his/her special needs.

He used to be an ASD child before. Now he is normalizing. Academically he is very good. The problem is socializing to others. He does not understand when and how he can talk or mix with people.

2)What are the main emotional challenges you face as a parent?

The main emotional challenge is that my child is not like other child. In every stage of life I understand that by the society. Though they show me sympathy towards me, I feel discomfort-able .

3) How do these challenges impact your daily life?

It impacts a lot in my life. My child wants 100% attention.It hurts me. It hampers my personal life, social life.

4)What kinds of support (family, community, formal services) do you currently experience?

To be honest Ido not get any support from my family.As a mother , I have to deal with the child solely.Rather than socially I got help from different people and organization.

5) How do cultural or social attitudes impact how you feel or behave as a caregiver?

No, it does not impact anymore on me. Already I have overcome the stage. I become a mature Mom through this journey.

I believe that Allah has made my child like this. So, I have changed myself.

6) Please describe the self-care activities or coping mechanisms you use to manage caregiving demands.

When I become exhausted,usually apply some technique. I take time, heal myself in different way.Ido shopping,the things I like.I think Time is the best healer.

7) What are the obstacles to implementing self-care?

The main obstacle is lack of time. Household work, child's responsibility,job responsibility and doing MSC for all these I need time. Lack of time I can't do self care.

8) How would you assess the effectiveness of support systems in place?

Alhamdulillah, positively people or organization help me.I am with it.

9) What would help you better manage your own emotional wellness?

If I get any support from my family to do household chores.Also, If someone can help me to handle my son ,I would feel relax in a sense.

10.Is there anything else you wish to share about your experience as a parent?

Yes. I believe about the parents of special needs child that Allah thinks us capable for handling this type of child.With the time everyone will be adjustable with the situation they have.

Appendix B: Sample Transcript 2

Participant B ,Ferdousy Mojumder (IDI-2, Date-8-9-25)

Tool 1: In-Depth Interview (IDI) Guideline (for Parents of special needs)

Demographics:

1) Your gender: Female

2) Your age: 46

3) Your educational background: B.A.

4) Your current profession:Home Maker

5) Your approximate monthly income: N/A

6) Your child's age: 5 years 4 months

7) Your child's gender:Female

8)Types of speciality:ASD

Name of the Interviewer: Shahanara Tuly

1)Please tell me about your child and his/her special needs.

My daughter has diagnosed ASD. She is hyper active.She can not do anything by herself.She is restless .She had curved legs before. Now after lots of struggle she can walks.

2)What are the main emotional challenges you face as a parent?

Emotional challenges I face that is misunderstanding by my husband. Nobody understand me. All through the day I work a lot, but no praise from my family or husband.

3)How do these challenges impact your daily life?

The impact I face that is in our conjugal life. I become exhausted by taking care of her. I can not care my husband, my other family members or even myself. For that often my husband quarrel with me.

4)What kinds of support (family, community, formal services) do you currently experience.

I get sometimes support from my husband. But other family members are not helpful.Regarding Society and formal service;I get financial support from Bangladesh government.

5)How do cultural or social attitudes impact how you feel or behave as a parent?

I feel barrier in all stage like social barrier , familial barrier. People weirdly behaved with me sometimes. Nowadays, I just avoid all social functions and invitation.

6)Please describe the self-care activities or coping mechanisms you use to manage care-giving demands.

I try to make myself relax by watching face book,listening music,enjoying poetry,doing prayer etc.

7) What are the obstacles to implementing self-care?

Family and society. As a mother of ASD child they think I do not need any self care. My duty is only to take of my child.

8) How would you assess the effectiveness of support systems in place?

Without financial support the effectiveness of support system to us is not enough.

9) **What would help you better manage your own emotional wellness?**

More counseling options for parents, better communication support for my child, and a small parent support group in my area would help.

10) Is there anything else you wish to share about your experience as a parent?

I always pray to Allah for my daughter recovery. If any miracle happen and she become sound and healthy.People say I will be in Jannah afterlife if I take care my daughter.I do not want that.I am worried for her future what will be happen after our death.

He used to be an ASD child before. Now he is normalizing. Academically he is very good. The problem is socializing to others. He does not understand when and how he can talk or mix with people.

1) What are the main emotional challenges you face as a parent?

The main emotional challenge is that my child is not like other child. In every stage of life I understand that by the society. Though they show me sympathy towards me, I feel discomfort-able .

3) How do these challenges impact your daily life?

It impacts a lot in my life. My child wants 100% attention.It hurts me. It hampers my personal life, social life.

4)What kinds of support (family, community, formal services) do you currently experience?

To be honest Ido not get any support from my family.As a mother , I have to deal with the child solely.Rather than socially I got help from different people and organization.

5) How do cultural or social attitudes impact how you feel or behave as a caregiver?

No, it does not impact anymore on me. Already I have overcome the stage. I become a mature Mom through this journey.

I believe that Allah has made my child like this. So, I have changed myself.

6) **Please describe the self-care activities or coping mechanisms you use to manage caregiving demands.**

When I become exhausted,usually apply some technique. I take time, heal myself in different way.Ido shopping,the things I like.I think Time is the best healer.

7)What are the obstacles to implementing self-care?

The main obstacle is lack of time. Household work, child's responsibility,job responsibility and doing MSC for all these I need time. Lack of time I can't do self care.

8)How would you assess the effectiveness of support systems in place?

Alhamdulillah, positively people or organization help me.I am with it.

9)What would help you better manage your own emotional wellness?

If I get any support from my family to do household chores.Also, If someone can help me to handle my son ,I would feel relax in a sense.

10)Is there anything else you wish to share about your experience as a parent?

Yes. I believe about the parents of special needs child that Allah thinks us capable for handling this type of child.With the time everyone will be adjustable with the situation they have.