CHAPTER 4

Module Development

This chapter presents the development of the psychosocial intervention module, informed by the results and analysis from Phase 1 of the study. Phase 1 involved a comprehensive needs assessment conducted through in-depth interviews with mothers of children with ASD. The data collected from these interviews were meticulously analysed, leading to the identification of five key themes and fifteen sub-themes. Firstly, the results derived from the qualitative analysis of the interviews were outlined, highlighting the core themes that emerged from the participants’ experiences. Each theme and sub-themes are discussed in detail, providing insight into the specific challenges and needs identified through the assessment. Following the presentation of the results, we delve into a discussion that interprets these findings, exploring their implications for the development of the psychosocial intervention module. This discussion contextualizes the results within the broader framework of existing literature and identifies how the findings have shaped the design and content of the intervention. Overall, this chapter aims to bridge the gap between the needs assessment and the practical application of the intervention module, ensuring that the developed module is both relevant and effective in addressing the identified needs of mothers caring for children with ASD.

Introduction

Mothers of children with autism face unique challenges that are frequently overlooked and lack adequate support within mainstream societal structures. Despite the increasing awareness surrounding autism spectrum disorder (ASD) in recent years (Dillenburger et al., 2013), the lived experiences of these mothers continue to be characterized by a complex array of challenges (Pohl et al., 2020; Masaba et al., 2021). From navigating the intricacies of healthcare systems (Brewer, 2018; Boshoff et al., 2021) to grappling with societal stigmas and misconceptions about autism (Gill & Liamputtong, 2011; Pohl et al., 2020; Oti-Boadi et al., 2020), these mothers often find themselves isolated and overwhelmed by the demands of caring for a child with special needs (Gorlin et al., 2016; Papadopoulos, 2021). The journey of parenting a child with autism is marked by a constant need to advocate for their child's unique needs (Ryan & Cole, 2009; Boshoff et al., 2016), whether it be in educational settings, healthcare appointments, or social interactions. The relentless nature of these responsibilities can take a toll on maternal mental health and well-being, leading to feelings of exhaustion, frustration, and isolation.

To better understand these challenges, it is essential to consider the broader environmental factors influencing mothers' experiences, which is where Ecological Systems Theory becomes relevant. According to Urie Bronfenbrenner's Ecological Systems Theory, individuals are influenced by multiple layers of their environment, ranging from their immediate family dynamics (microsystem) to larger societal and cultural factors (macrosystem). This theory highlights how mothers' stress and coping mechanisms are shaped not only by their direct interactions with their children but also by their larger social environments, including healthcare systems, community support, and societal attitudes toward autism. By applying this theoretical framework, we gain a more comprehensive understanding of the multifaceted challenges mothers face and the systemic factors that contribute to their caregiving experiences (Bronfenbrenner, 1994).

The exploration of needs within the context of autism caregiving has garnered substantial attention from researchers, resulting in a considerable body of literature that offers insights into the diverse needs and experiences. A recurring theme in the literature underscores the significant role of medical professionals in the diagnostic process and subsequent support for families. Many parents lamented the lack of sufficient information provided by medical professionals during the diagnosis phase, leaving them feeling unguided and uncertain about the path forward (Whitaker, 2002; Crane et al., 2016; Aguiar & Pondé, 2020). In a study conducted by Siklos and Kerns (2006), findings highlighted the pressing need for professionals who possess specialized knowledge about autism, emphasizing the significance of expertise in guiding effective interventions and support systems.

Moreover, a prevalent trend observed across studies is the child-centred nature of parents' needs, particularly concerning children with autism exhibiting behavioural difficulties and communication challenges (Siklos & Kerns, 2006; Papageorgiou & Kalyva, 2010; Brown et al., 2012). These core symptoms often overshadow other aspects of daily life, leaving parents grappling with the immediate need for consistent (Brown et al., 2012) and accessible therapies (Wetherston et al., 2017). Parents consistently emphasized the paramount importance of therapies tailored to their child's specific needs

(Siklos & Kerns, 2006). The availability and accessibility of therapies also emerged as primary concerns, with parents expressing frustration over barriers hindering their ability to access essential services for their children. In a study by Wetherston and colleagues (2017), a staggering 68.6% of participants reported experiencing difficulty in accessing essential services for their children with autism. These challenges ranged from a scarcity of trained health professionals and treatment facilities to extensive waiting lists, compounded by the burden of long travel distances endured by parents seeking treatment.

Additionally, studies also emphasize the significance of social support or familial support, including various forms such as emotional, financial, and physical assistance, for mothers of children with autism (Siklos & Kerns, 2006; Papageorgiou & Kalyva, 2010). These studies highlight the crucial role that social support networks play in buffering the challenges faced by mothers in their caregiving roles. In a study conducted by Derguy and colleagues (2015), relational support and emotional support were identified as fundamental needs, emphasizing the significance of social and emotional resources in fostering well-being amidst the complexities of autism caregiving. Similarly, in a self-reported needs and expectations study conducted by Papageorgiou and Kalyva (2010), it was discovered that a lack of familial support resulted in mothers facing feelings of isolation and psychological distress while managing the demanding responsibilities of caregiving and financial concerns emerged as a notable stressor, further compounding the burdens faced by these families. Moreover, Siklos and Kerns (2006) in their study reported that an overwhelming 93% of parents reported a lack of adequate financial support for their child's therapies, indicating a pervasive gap in access to essential resources.

Acknowledging and validating the experiences of these mothers is a crucial step towards building a more inclusive and supportive society for families affected by the challenges in raising children with autism. By amplifying their voices and advocating for their needs, we can foster a culture of empathy, understanding, and support that empowers mothers of children with autism to navigate their journey with resilience and strength.

By delving into the complex challenges faced by mothers within this demographic, the study seeks to identify key areas requiring support and intervention.

The goal is to design a holistic psychosocial intervention module that addresses the diverse needs of mothers, encompassing aspects such as emotional support, coping strategies, access to resources, and enhancement of social support networks. Through this endeavour, the study aims to provide mothers with the necessary tools and resources to navigate the complexities of caregiving for children with ASD effectively, ultimately promoting their well-being and resilience in the face of caregiving challenges.

Methods

This study aimed to develop a multicomponent psychosocial intervention module to address the challenges faced by mothers of children with autism spectrum disorder (ASD). The research focused on understanding these needs through in-depth interviews and an extensive literature review. The study was conducted in Kamrup Metropolitan District, Assam, at community centres that work with children with autism. Using a qualitative, exploratory design, the study employed purposive sampling to select biological or adoptive mothers, who are primary caregivers of children with ASD. Data was collected via semi-structured interviews with open-ended questions covering topics such as understanding ASD, parenting experiences, stressors, coping strategies, stigma, and support systems. Ethical approval was obtained from Tezpur University Ethics Committee, and all participants provided informed consent, ensuring confidentiality and voluntary participation. Thematic analysis was used for data analysis. The process involved organizing and transcribing data, followed by initial analysis to identify key concepts and gaps. Coding and theme development were carried out in three steps: detailed examination of data, categorization into subthemes, and grouping of subthemes into central themes. This comprehensive approach provided valuable insights into the psychosocial needs of mothers, informing the development of a targeted intervention module.

Results

The interviews unveiled the narratives of mothers who encountered numerous obstacles while raising a child with autism. The age range of the interviewed mothers was from 30 to 46 years. Eight of the mothers were currently living with their spouses, while two of them were single mothers (widowed and divorced). Out of the total respondents, six of them had received formal education, while the remaining four had not pursued formal education. Among the respondents, three were homemakers, and the remaining seven were employed in either the private or governmental sectors. The detailed socio-demographic profiles of the participants and children are shown in Table 4.1.

Table 4.1

Socio Demographic Profile of Respondents

Participant No.	Age	Religion	Education	Employment Status	Socio Economic Status	Total No. of children	Total No. of children with Autism	Gender of child with Autism	Age of child with Autism
1	46	Hindu	BA Pass	Not employed	Upper Middle	1	1	Male	18
2	43	Hindu	BA Pass	Employed Nurse	Upper Middle	2	1	Female	10
3	45	Hindu	BA Pass	Teacher	Upper Middle	3	1	Male	17
4	38	Hindu	No formal education	Homemaker	Upper Lower	1	1	Male	16
5	35	Hindu	No formal education	Homemaker	Upper Lower	2	1	Female	14
6	40	Hindu	No formal education	Domestic Help	Lower	2	1	Female	12
7	30	Hindu	No formal education	Domestic Help	Lower	2	1	Male	15
8	46	Hindu	12th Pass	Teacher	Upper Lower	2	1	Female	17
9	38	Hindu	BA Pass	Private	Upper Middle	2	1	Female	12
10	31	Hindu	BA Pass	Homemaker	Upper Middle	2	1	Male	14

The analysis identified and categorized 15 subthemes, which were subsequently grouped under five central themes.

Theme 1: Knowledge about ASD

The participants commonly shared a theme of possessing varying levels of awareness about the condition and its diverse impacts on their lives as they raised a child with autism. The sub-themes encompassed mothers' own awareness of recognition of early signs and symptoms of ASD, understanding the diagnosis and emotional responses following it, awareness of needs and challenges associated with ASD and the factors influencing these aspects, Medical Practitioner's Awareness and Community Awareness, Stigma, and Discrimination Surrounding ASD.

Sub theme 1.1 Recognition of early signs and symptoms and understanding the diagnosis

The awareness of autism among most mothers in the study emerged predominantly after their children received a formal diagnosis. Notably, there were diverse approaches to this awareness. Some mothers, upon observing atypical behaviours in their children, promptly sought medical attention, demonstrating a proactive response to potential concerns. On the other hand, a contrasting perspective was found among other mothers who perceived any developmental delays in their children as normal, not initially recognizing them as potential indicators of autism. This variation in response underscores the complexity of mothers' awareness journeys, revealing distinct pathways shaped by their perceptions and interpretations of their children's behaviour.

> "I knew that some kind of mental illness happens at a young age but I was not aware of this condition called autism; it wasn't after his diagnosis that I became aware of the existence of such a condition."
>
> "In the case of my son, we noticed a delay in his speech, but we thought it happens to children. We did not take it seriously until he was around two-and-a-half years old, when it became more difficult to understand him so that was when we sought medical help."

Mothers who possessed a foundational understanding of autism were able to swiftly identify signs of challenges in their children. Equipped with knowledge about the relevant specialists, these mothers took proactive steps to seek a diagnosis promptly. This proactive approach not only led to a quicker identification of the condition but also facilitated timely access to the appropriate medications and therapies needed for their children's well-being.

> “He is my second child so I have noticed certain differences as compared to my first born and I had a feeling that something was off so I told my husband that we need to take him to a specialist. We knew a family friend who is a doctor and she used her contacts and got us an appointment and even though we did not know right away that it is autism the doctor said that there are chances so we were prepared.”

Mothers who lacked prior awareness about autism faced challenges in grasping the diagnostic process and its intricacies. The unfamiliarity with the condition made it more difficult for them to navigate the steps involved in seeking a diagnosis for their children. This lack of awareness posed a hurdle in comprehending the signs and symptoms, potentially leading to delays in recognizing and addressing the needs of their children.

> “I did not think it was anything to worry about and thought once he goes to school and mingle with others, he will be fine, but the around 4 years old when the teacher told me that he needs to be in a special school because he is not like other children, I just took him out of that school and enrolled in another one. It was not until he was 7 that I went to get him checked when other people and teachers in the new school said that he is different.”

Some mothers encountered difficulty in coping after the diagnosis, struggling to come to terms with the realization that autism is a lifelong condition. The challenge of acceptance prompted them to seek opinions from various doctors in a quest for alternative perspectives. This cycle of consulting different healthcare professionals persisted, reflecting the ongoing struggle to reconcile with the permanence of the diagnosis and the search for potential solutions.

> “When the medicine doctor told us to consult a psychiatrist for our child, I got angry as I was not ready to accept something is wrong with her. I said my child is not mentally ill so I don’t need to consult a psychiatrist so I convinced my husband to consult a different doctor instead.”

However very few mothers upon receiving a diagnosis of autism for their child, promptly sought, and accessed necessary therapies and treatments without delay. Recognizing the importance of early intervention, these mothers quickly connected with therapists and other essential services, ensuring that their children received timely and appropriate support to address the challenges associated with autism.

> "The doctor had told us about the availability of these centres and we have been advised to start the therapies as soon as possible so we did a little research about the different therapy centres, asked around and admitted him as soon as we got to know about this organization."

Sub theme 1.2 Awareness of needs and challenges associated with ASD, and the accessibility of support services

Mothers who were aware of the availability of special schools or therapy centres in and around their area were able to enrol their children to these services promptly but many mothers shared that these specialized schools were not available nearby their residence. Notably, mothers residing in urban areas within the district demonstrated better access to diverse special schools and therapy centres. In contrast, those living in more remote outskirts faced challenges, lacking proximity to such schools or centres. This geographical distance posed difficulties in securing consistent treatment or therapy for their children, necessitating extensive travel. Additionally, one mother revealed that, despite financial constraints, she had to rent accommodation in the city to access essential services for her child.

> "The nearest centre for me was 180 km away from my residence, my husband had not been well and I was not able to handle him alone when travelling so initially I travelled at least twice a week for his therapy but I had to eventually stop because it was getting too hectic and too expensive so his treatment was delayed and I did my best to teach him at home. I have resumed his therapy now when he is 16 years of age and I realised that it is too late but I had no other option."

> "My husband is working in the village and we decided that it was best if we just stayed in the city as travelling all the way from the village is impossible if I want him to get regular therapy, we have been struggling financially as living here is not cheap but we are doing our best."

It was noted that mothers with higher socioeconomic status have the capacity to avail additional private therapies, supplementing those offered by special schools. Conversely, mothers facing economic constraints solely depend on the services provided by these schools, even when certain needed services are unavailable. One mother disclosed the challenge of a specific school lacking a speech therapist, which her child required urgently. However, due to financial limitations, she could not afford a private speech therapist or relocate her child, especially considering the proximity of the school to their residence.

Sub theme 1.3 Medical Practitioner's Awareness and Communication in ASD Diagnosis

This theme explores the experiences of mothers with medical practitioners throughout their entire journey, starting from their first visit to the doctor to address their child's initial issues. It encompasses Mothers' experiences with medical practitioners in terms of communication about ASD and Perceived adequacy of information provided during the diagnostic process.

Many mothers shared that when they initially consulted healthcare professionals, autism was not immediately identified. Some were recommended to wait a few more months and observe their child's behaviour to pinpoint the exact issue, while others were swiftly prescribed medications without being informed about the root cause. Consequently, a significant number of mothers reported navigating from one doctor to another because they struggled to comprehend their child's situation, and many professionals were unable to provide clarity.

> "When we took her to the doctor, we were told that these things tend to happen and we need to wait for a few more months to get any diagnosis but we weren't told about the possibility of it being autism and we were prescribed with medications."

Conversely, a small number of mothers recounted receiving an immediate diagnosis or being informed by medical practitioners about the possibility of it being autism. Additionally, several mothers mentioned that they learned about various therapies or specialized schools directly from these practitioners.

Most mothers were unprepared for the challenges they were about to face. Some believed it was just a phase, and their child would eventually recover after a year or so. This misinformation was observed to originate from the inadequate distribution of accurate information.

Regarding the information or support provided by the organizations or centres where they send their children, mothers expressed diverse opinions. Some mothers mentioned that certain centres completely exclude them from the treatment process, with their only role being to drop off and pick up their children. They believe that the education and other therapies their children are undergoing lack transparency and are not communicated to them. On the other hand, mothers from different centres reported active involvement and regular updates about their children's progress. Mothers emphasized the value of support group sessions organized by some centres for parents or guardians, stating that it is more beneficial compared to those who do not offer such sessions.

> “I shifted my son to this centre because in the previous one there was no improvement at all, I did not know what they were teaching him there and their speech therapist was replaced all the time.”

> “We do not have support group sessions in other organizations like we do in this centre. These are helpful as we see that we are not alone. I used to think I am the only one struggling but coming here I realised others have it worse.”

Mothers held the belief that healthcare professionals lacked essential knowledge about autism, causing significant delays in the treatment of their children. Due to this deficiency in understanding, mothers found themselves compelled to transition from one doctor to another in pursuit of answers.

Sub theme 1.4 Community Awareness, Stigma, and Discrimination Surrounding ASD

This theme delves into the mothers' observations regarding the overall community's comprehension of ASD. It examines their encounters with social inclusion or exclusion influenced by community awareness, the repercussions of stigma and misconceptions, and how they manage and cope with these challenges.

Many mothers conveyed a prevailing sentiment that the broader community continues to grapple with a limited understanding of autism. They emphasized that, on a personal level, their own awareness of autism only developed when they had to live through the experiences of raising their children.

Mothers shared that, at times, find themselves facing a sense of exclusion. These experiences reveal instances where their unique needs and challenges may not be fully understood or accommodated within the community. At times, there's a sense of distance in the community, indicating a lack of awareness about the complexities of raising a child with ASD. This tends to make mothers feel excluded or not entirely a part of community interactions.

> "There was a time when the neighbours were having a birthday party and we were not invited I just observed that many children were there but my son was not invited, the thing about my son is that he loves food and thus when he sees food or cake, he will grab it so maybe because of his behaviour they did not call us over but that made me feel bad as my son loves to attend parties."

However, some mothers expressed feeling embraced and supported, a specific example highlighted this positive experience. One mother, actively involved in a women's committee in her community, shared how the group consistently lends a helping hand, whether it is looking after her child during errands or offering support when she is unwell. Additionally, certain mothers mentioned that their family members, friends, or neighbours were informed about autism. With the support of these individuals, the mothers were able to seek medical attention and became aware of the existence of specialized schools and therapy centres.

> "My friends never let me scold my daughter when she misbehaves in public and I get embarrass they will instead tell me that she is just a child let her be and they would take her and care for her whenever I am occupied with some work."

> "It was because of my neighbours that I got to know the existence of special school and they even helped me get admission as I am not educated myself so I did not know the process."

The mothers predominantly shared their encounters with stigma and discrimination. Some mothers recounted instances when they took their children out in public, and due to certain behavioural issues, they received comments from people.

> "I have received comments were people say I am unable to discipline my child and my child is so naughty."

Mothers acknowledge that receiving comments from strangers and the public is unavoidable, but what saddens them even more, as shared by some, is when negative comments come from their own relatives. A few mothers mentioned that their relatives, in particular, have perceived their child as 'dangerous' to be around, leading to a tendency to actively avoid the child at all costs. Some mothers conveyed that they have faced accusations and blame for having a child with challenges, being unfairly held responsible for their child's difficulties.

When questioned about how they manage or address these stigmas and instances of discrimination, mothers revealed that initially, in the beginning, they found it challenging and often resorted to isolating themselves. They would privately shed tears without sharing their feelings with anyone, occasionally feeling as though they must have made a mistake to be in such a situation. However, over time, they have learned to adapt and live with these challenges. Some mothers mentioned that they have developed the ability to overlook people's comments and move forward. When asked if they attempted to explain the condition to others, one mother expressed that repeating the same information over and over seemed futile.

> “Earlier comments or stares from people did bother me and when we go out my husband does not get out of the car, I think it’s because he feels embarrassed but now, I do not really bother anymore I have accepted that this is how it is as for comments from relatives I just ignore.”

Theme 2: Sources of Support Systems

This theme focuses on the diverse origins of support, encompassing primary sources of support derived from immediate family members such as parents, spouses, or siblings; secondary sources of support drawn from extended family members, friends, neighbours, or other parents of children with disabilities; and tertiary sources of support obtained from various organizations, schools, the community, and more. Additionally, it explores the various types of support systems available to mothers, including social, emotional, physical, and financial support. The focus is on the level of accessibility and availability of these support systems. Overall, the sub-themes are grouped into informal support systems and formal support systems.

Sub-theme 2.1: Informal Support Systems

In some cases, mothers moved away from their maternal homes in the village after marriage, making it challenging to receive support or help from their parents or other family members as they live far away. So, for them, their primary support system consists of their husbands, but they expressed that they receive little to no assistance in caregiving for the child. Nevertheless, a few mothers acknowledged that they would find it difficult to handle the burden alone without the help of their spouses.

> “His family was in Guwahati and my family was in Nalbari. The three of us were in Bongaigaon for my husband's work, so they were all very far away. It was somehow okay when my husband was there, but ever since he passed away, it has just been the two of us, and it is very difficult for me to manage everything.”

> “Our family members are in the village on the Nagaon side. Here, we are staying in rented accommodation, so we do not get that kind of immediate help. My husband and I take care of everything. It would have been really challenging if my husband was not supportive.”

Other mothers mentioned that they find comfort in being able to depend on their family members for both physical assistance and support. They expressed gratitude for having relatives who are willing to lend a helping hand with various tasks.

> “My sister lives upstairs so she helps out whenever I am in need especially since it’s just the two of us, I can really depend on her.”

> “I do not have that kind of burden I can depend on my daughters and they help out and makes things easier for me.”

> “When my mother was admitted in a hospital and I had to be there with her, my sister and other relatives willingly took care of him and fed him and bathe him, I am so grateful for that.”

> “My in laws are extremely helpful and since they live nearby, I can rely on them when it comes to taking care of my child. They know about his condition and they all love him so much.”

When asked about the accessibility of emotional support, the responses were diverse. Most of the emotional support came from secondary sources. Some mothers expressed turning to their friends to vent their frustrations, while others confided in their own mothers. For some, emotional support came from other mothers who have children with the same condition, as they believed only those in similar situations could truly empathize. However, a few mothers felt that they had shared too much and, at times, refrained from burdening their loved ones with their ongoing challenges.

> “Whatever it may be, even small insignificant things, I would call my mother up and tell her. She would always listen to me in fact she would be worried if I failed to call her in a day.”
>
> “For me, no matter how supportive your family members are, they cannot always understand you, I feel only mothers going through the same situation would be able to understand me so I do not hesitate to share my feelings and emotions in support group sessions, it really helps me out to also listen to others when they share.”
>
> “At times I feel like I have been sharing too much or too many times and I feel they must be tired of me already. so, I sometimes keep to myself and do not want to trouble them with my problems.”

Another mother mentioned that even though her family is geographically distant and unable to provide physical assistance, they do offer financial help when the need arises. Other types of social support involved receiving information from relatives or well-wishers who assisted them in finding doctors, special schools, therapy centres, and other resources.

Sub-theme 2.2: Formal Support Systems

It was observed that mothers predominantly received formal support from tertiary sources, that is, from the organization that runs these specialized schools for their children, from therapy centres, and from hospitals. They expressed that the availability of these specialized schools significantly assisted in managing their child's condition, without which it would have been challenging to cope on their own. One mother shared:

> “When my daughter was about 4 years old, we admitted her to a special school where she underwent speech therapy and physiotherapy. She made significant progress there, learning essential skills such as washing her hands after eating and proper eating habits. The therapist suggested I attend weekly therapy sessions to observe and learn how to continue teaching her at home.”
>
> “I am thankful that there is a school bus in which I do not have to go and drop him or pick him up every day as I have to also go to work.”

Some mothers emphasized the value of support group sessions conducted in these centres for parents, finding them extremely beneficial in providing information on better child care and offering a space to share their feelings and frustrations.

> "When other mothers share their problems and how they manage them, it personally assists me in viewing situations from various angles. It provides me with insights into handling specific issues and equips me with valuable information on problem-solving."

Some mothers also mentioned that, in addition to the support provided by specialized schools, they also opt for additional therapy sessions with private therapists. This additional therapy has proven to be beneficial in enhancing their ability to manage their child's condition more effectively.

> "I've actually enrolled him in CRC near GMC for occupational therapy and speech therapy on Mondays and Thursdays, from 10 to 12. On Saturdays, he attends play therapy. Additionally, we have a therapist who visits our home three times a day to teach him specific exercises or yoga. I make sure to keep him occupied because if he stays at home all day, he tends to become lethargic and sleep throughout the day."

Furthermore, some mothers who are members of women's groups within their community find assistance from their fellow group members when required. This support can be in the form of looking after the child when the mother is busy with work or providing financial help when needed.

Theme 3: Stressors: Emotional and Physiological Challenges

This theme centres on the collective stress experienced by mothers, encompassing emotional and physiological stress. Emotional stress involves the mental strain resulting from emotional responses to challenging situations, triggered by feelings of anxiety, fear, sadness, anger, or frustration. On the other hand, physiological stress refers to the strain experienced by the body due to physical demands or external factors arising from activities, environmental conditions, or challenging physical circumstances. Although emotional and physical stress can occur independently, they are interconnected and can influence each other.

Sub-theme 3.1: Emotional Distress

At first, a number of mothers discussed how they were in a state of complete denial regarding their child's condition, finding it difficult to accept it. This denial had a negative impact on their mental well-being, as they expressed experiencing not only persistent fear and grief but feelings of guilt and self-blame.

> “Not accepting the diagnosis was one of the many regrets I had because if I had acknowledged it sooner, I could have searched for or provided treatment and support for my child earlier.”

The majority of mothers conveyed that they are consistently burdened by worry and anxiety concerning their child's welfare, particularly their future and the challenges they might confront if something were to happen to the mothers, preventing them from providing care for their child any longer. One mother particularly shared that,

> “As a mother, I am aware that I am the sole caregiver for him. I understand him completely, knowing what triggers his emotions of anger or sadness. I am concerned about what will happen to him if something happens to me; I doubt anyone else could care for him as deeply as I do. I worry about this constantly.”

Certain mothers described a profound sense of helplessness when they couldn't promptly enrol or send their child to specialized schools or therapy centres following a diagnosis. The primary reason was the unavailability of such facilities in their local area. One mother shared that they made the decision to relocate to the city for their child's treatment and therapy. However, the unexpected death of her husband resulted in significant financial challenges, which compelled them to return to their hometown. Living in the city had proven to be financially burdensome due to expenses like rent, food, and the cost of treatment. This situation led to a persistent sense of guilt for not being able to provide the basic necessities her child required.

> “When my husband passed away unexpectedly, we started facing financial problem especially with all the expenses in the city – rent, food, and treatments. And I can't help but feel guilty that I can't give my child what he really needs."

Some mothers, whose children have been undergoing consistent therapy sessions and who diligently work with their children on daily tasks like brushing teeth or dressing themselves, express that they notice improvement over the course of a week or so. However, on some days, these children suddenly seem to struggle with tasks they had previously improved in. This cyclical pattern of progress and regression can be disheartening for the mothers. It erodes their hope and leads to a sense of grief as they grapple with the disappointment of unfulfilled expectations and dreams, they had for their children.

> "When you witness them making progress, and then out of nowhere, you wake up one day to see them regress back to square one, needing to relearn everything they have already learnt before. Like for example, he already learnt how to brush his own teeth and then he just did not know anymore, and we had to teach him all over and this has been happening with other things too, it's just disheartening. There are moments when I just feel like giving up and question the purpose of it all."

Assuming the role of the primary caregiver for their child and providing continuous care has resulted in isolation for some mothers. They find themselves without the time or opportunity for self-care, unable to engage in activities they enjoy or socialize with friends. As a result, they often feel isolated and, in some cases, express feelings of frustration.

> "I do not have the time at all. I am either always occupied in caring for my child or other household work. I literally have to do everything. I would be too tired to do anything else by the end of the day so I just sleep."

> "I long to have a day for myself or go to the spa and relax but even if I do get the chance to go out, I would always be wondering about my daughter and worried about her all the time she is not with me."

Most mothers who only have one child express their desire to have another child; in fact, some of them experience pressure from family members to do so in the hope that the second child will not have autism. However, most of them are hesitant because raising a child with autism is already difficult, so they do not want to take a chance. They grapple with the dilemma of whether to take the risk of having another child. This emotional turmoil places a heavy emotional burden on them, causing significant stress.

In general, mothers conveyed that the absence of emotional support from their loved ones is a major contributor to their overall stress. Additionally, continually having to cope with comments from relatives regarding their child's condition, as well as facing stigma and discrimination, is emotionally exhausting.

Sub-theme 3.2: Physiological Stress

In this scenario, mothers experience physiological stress primarily due to the overwhelming burden of caregiving responsibilities, stemming from a lack of substantial support from primary and secondary sources. One mother expressed this by sharing:

> “I will be completely honest about this but I do not get any physical help from my husband when it comes to looking after our son. I handle everything on my own - from assisting him with bathing and using the toilet to cleaning up after him. As he has grown older, it's only gotten tougher for me.”

> “Managing both my son and younger daughter has been tough, especially since she is still a baby. My son's behaviour can also be quite challenging at times, making it exhausting for me to handle them both.”

When inquired about experiencing financial difficulties, certain mothers mentioned their ability to depend on relatives or friends for financial assistance in case of an emergency. Nonetheless, the majority of mothers explicitly convey encountering financial strain, especially concerning the considerable costs linked to therapies and treatments. While some mothers acknowledged the need to work extra to meet their child's necessities, they did not characterize it as a burden.

> “We've had some financial struggles, so we have had to cut back on certain things and make sacrifices. But I wouldn't call it a burden; we're still managing to get by and survive.”

Apart from that, balancing the demands of work and caregiving responsibilities can be quite challenging. Single mothers or mothers who lack their spouses' assistance in caring for their child often find themselves juggling multiple roles, including caregiver, advocate, and potentially breadwinner, which can become quite overwhelming. A single divorced mother shared,

> “You see, I just dropped them off here, and now I'm heading off to college. Luckily, my dad will be available to pick them up today; otherwise, I'd have to rush back to get them, take them home, feed them, and then rush back to college. This has sometimes affected my performance at work, as some colleagues have complained that I'm not as focused or take too many breaks. But they don't understand my situation; as a single mom, I bear all the responsibility for taking care of them.”

This stress can have adverse effects on a mother's physical health. Providing care for a child with autism frequently involves intensive, time-consuming interventions and therapies. Often, mothers become so dedicated to addressing their child's needs that they inadvertently neglect their own well-being. The constant caregiving can lead to both physical and emotional exhaustion.

Theme 4: Coping Responses or Behaviour

This theme delves into the array of approaches that mothers employ when confronted with stressful situations. It was noted that the coping strategies adopted by mothers tend to lean more toward the emotion-focused aspect. Emotion-focused coping revolves around managing and regulating emotional responses to stressful situations; this encompasses expression of emotions, acceptance and mindfulness, a shift in perspective, seeking divine trust in coping with uncertainty and avoidance or distraction.

Sub-theme 4.1: Emotional Outreach: Seeking Support through Expression

Mothers of children with autism express their emotions through various means, such as verbalizing feelings of frustration, sadness, or anger. They seek solace and understanding by reaching out to friends, family, or support groups for emotional support. These coping strategies help mothers navigate the complex emotions that arise from raising a child with autism.

Mothers expressed that when they confide in their friends and family about their emotions and thoughts, it brings them a deep sense of comfort. This open communication allows their loved ones to offer empathy, showing that they understand and share in the mothers' feelings, which in turn strengthens the support network and helps alleviate emotional burdens.

> "… I can rely especially on my younger sister, she has always been there for me and I tell her almost everything I go through, she has been a constant help for both of us"
>
> "…when it comes to sharing about my problems then it's my mom I go to, she will always know what to say to make me feel better."
>
> ".. whenever I get the chance, I would call my friend up and vent to her."

Some mothers who participate in the organization's support group sessions find solace in sharing their emotions and feelings within the group. They feel that doing so brings them a sense of relief, as there are certain aspects of their experiences they hesitate to discuss with their family and friends. They believe that only fellow parents or mothers facing similar challenges can truly comprehend their situation and offer genuine empathy.

> "…my family does not always understand what I'm going through, these mothers here would be the only ones who would know what I'm talking about."

> "I would not hesitate to pour my heart out because I know they won't judge me as they are probably going through the same thing."

> "I have in fact learn many things about certain tips and tricks to deal with my child during his outbursts by attending these support groups sessions."

These mothers discover a unique source of support in support group sessions. They believe that fellow group members who share similar experiences are more likely to understand their struggles and provide empathy, which they may not always find in their immediate social circles. Sharing their feelings in this setting offers a sense of relief, as it provides a safe space for discussing deeply personal and challenging aspects of their lives.

Sub-theme 4.2: Acceptance and adapting to challenges

When dealing with a situation that is beyond their control, some mothers say that the only way is to come to terms with the fact that some things may not be changeable, no matter how much one might wish otherwise, and this means accepting the uncertainty and focusing on the here and now. By adopting this approach, they find it easier to adapt to challenges and maintain focus on future goals.

Many mothers have admitted to harbouring regrets about potentially not pursuing early treatment or adopting more proactive measures in the past. However, they have since learned to forgive themselves for these perceived shortcomings and redirect their attention to the present moment. Rather than dwelling on past regrets, they have embraced the importance of focusing on the present and providing guidance to their child in whatever capacity they can manage.

> "…if I had accepted it from the very first, I would have started treatment early but there is no point thinking about it, I focus on trying to give the best now…we have enrolled in many therapy sessions for her and she has improved so that is what matters now."

> "It was definitely tough knowing there is no such thing as a cure but over time I have learnt to accept it and embrace it."

> "…seeing as to how much he has improved from before; it gives me hope."

A few other mothers believed that they had reached a point in their lives where they had opted to disregard and, in some way, adapt to specific challenges. They have overcome situations that used to trouble them, and these issues no longer affect them as they once did.

> "Earlier, when other people used to stare at my child and give me looks when my child acts unusually or behaves aggressively, I used to feel embarrassed, but now I have gotten used to it, and it does not bother me anymore when people stare."

> "My child has certain behavioural issues, so in the beginning we had a hard time dealing with all that, and we were all stressed at home, which affected our well-being as a family. But now we have learned how to deal with it somehow, and we are getting used to it."

They have recognized that, even in the face of adversity, they can still make plans and set goals for the future. This can include planning for the well-being of their child or preparing for potential challenges that may lie ahead.

> "I am only looking for different ways to try out in order to help my child, I have been researching on other therapy available that would help my son's problems."

> "… now, I am only looking ahead, planning for his future."

Sub-theme 4.3: Shift in perspectives and positive self-talk

These themes highlight the transformative power of shifting perspectives in coping with the challenges of raising a child with autism. They underscore the importance of resilience-building and fostering optimism as essential components of effective coping strategies.

In order to reduce emotional distress, one tends to change the way they think and feel about a situation. In this case, some mothers shared how going through these struggles and challenges has actually helped them in their personal growth. One mother in particular shared,

> "Before having my child, I was the kind of person who usually stayed at home and hardly went out, and even if I did go out, someone else would always accompany me because I felt scared to go by myself. But the situation has changed so much that now I am doing all the things by myself, like taking him to the hospital for treatment or therapies. I have learned so many things in the process, like how to talk with people and how to travel on my own, which was never possible earlier."

Another mother expressed that the difficulties she encountered in raising her child with autism have empowered her to become self-reliant. She has overcome these obstacles and developed the valuable ability to be independent and less dependent on others, which is a significant change from her prior reliance on external support. Not only did she become more self-sufficient, but facing and overcoming these obstacles has also cultivated a remarkable sense of resilience within her.

This mother's experience reflects a common theme in coping with adversity, where individuals not only adapt to challenging circumstances but also develop a newfound sense of self-reliance and inner strength. By facing difficulties head-on and finding ways to overcome them, she has not only become more self-sufficient but has also built resilience—the capacity to bounce back and thrive in the face of adversity.

In another scenario of shifting perspectives, it was noticed that offering self-praise and practicing positive self-talk also intends to change one's outlook and self-perception into a more optimistic and self-encouraging one. This shift often leads to a decrease in negative emotional responses for some mothers.

> “Other people who have seen my workload often tell me that they wonder how I am able to keep up with everything, but because I have learned how to multitask, I can manage pretty well even with all the struggles, and for that, I am really proud of myself.”
>
> “… I am a working woman, but I am still able to care for my child, who has special needs, and provide for my family…I don’t think other people would be able to go through what I am going through at the moment.”

These strategies are often used to counteract negative self-perceptions and promote a more optimistic and self-compassionate outlook, ultimately helping to manage and regulate emotions in a healthier way. They are part of the toolkit for emotion-focused coping that focuses on managing and improving emotional well-being.

Sub-theme 4.4: Seeking Divine Trust in coping with Uncertainty

These themes underscore the role of faith and spirituality in providing comfort and guidance for mothers navigating the challenges of raising a child with autism. They reflect a deep-seated trust in the notion of a predetermined destiny and the belief that challenges are part of a larger, divine plan.

This theme highlights the tendency of mothers to turn to their faith or spiritual beliefs for support, comfort, and guidance during times of stress or adversity. It reflects the belief that spiritual practices provide solace and reassurance amidst life's challenges.

> "If anything happens to me, I don't know who will be able to care for her as much as I do. I am just leaving everything to God."
>
> "It was God's will so God will show the way…"

When inquired about their future plans when it comes to both themselves and their children, many mothers believed that their life's path is predetermined and certain challenges in life are inevitable and part of their destiny, so as a result, they have entrusted the future to a higher power, accepting the idea that whatever unfolds will do so according to plan.

> "... even though at times we questioned why this has happened to us, it is after all in our destiny, so there is nothing to complain about anymore, and we have accepted what God has given to us. "
>
> "When I planned to have a second child, my family was worried if I should take any chances, but I was not worried at all; I have entrusted it to God."

Sub-theme 4.5: Distraction or Avoidance

Distraction or avoidance is typically seen as a short-term tactic to provide temporary relief when one is faced with a stressful situation that cannot be changed, and tackling that situation would only result in extreme emotional distress. Some mothers shared that their other way of coping during a stressful event is by resorting themselves to some sort of diversion that involves activities like watching television or engrossing themselves through social media engagement.

Some mothers also shared that avoidance is another way of dealing with an unwanted situation. Some mothers described instances where they either repressed their feelings or emotions to prevent any kind of conflict or physically distance themselves from individuals who they believe could provoke uncomfortable circumstances.

> "There was a time when I was arguing with my husband, and in order to prevent it from going too far, I just left my home for a while and went to my neighbour's place."
>
> "There are relatives who keep commenting on how my child is not speaking yet, even at 4 years old, and even after explaining to them about the condition, they keep commenting, so I have totally avoided meeting them."

Theme 5: Impact of Children's Challenging Temperaments on Maternal Well-being

Since autism is a highly heterogeneous condition and its symptoms, severity, and development can vary significantly from person to person, their caregivers too experience a wide range of challenges that can be influenced by different factors. This central theme delves into the repercussions of challenging temperaments on caregivers within two primary domains: behavioural challenges and communication difficulties exhibited by the child, both of which profoundly affect the overall well-being of mothers.

Sub-theme 5.1 Children's Behavioural Challenges

Mothers expressed that it gets stressful when their child goes through a phase of meltdowns or tantrums in which some children would engage in aggressive behaviour by not only hitting other people but end up hurting themselves as well. They shared that dealing with these episodes is not only emotionally draining but also physically exhausting. This is because these meltdowns and tantrums tend to be prolonged, requiring constant supervision and the provision of support.

> "We noticed that she gets angry very fast and that anger increased with her age. It becomes a problem because when she gets angry, she will start biting either herself or anyone near her or she will start pulling her own hair."

> "He tends to bite me or he will beat me up so I get scared since I am alone so when he gets really violent, I call him in a room and lock him for some time maybe for half an hour till his anger calms down."

Mothers expressed that their children's unpredictable outbursts triggered by unforeseen factors often left them feeling frustrated as they tried to understand and address these challenging behaviors. A few mothers disclosed their inability to bring their children to family gatherings or community programs or even take them out shopping, even though professionals have advised them to encourage social interactions with other people and other children.

> "It's just difficult when we have to take him out because of his certain behaviour especially when he sees food he wants to grab and eat wherever and whenever, sometimes we feel embarrassed."

The majority of mothers conveyed that their children's behavioral issues become more demanding as they grow older. They mentioned that it was easier to handle their meltdowns when they were younger, but as they age, their stubbornness and anger appear to intensify, making them increasingly challenging to handle. Some mothers, whose children still rely on them for everyday tasks, expressed feelings of physical exhaustion and anxiety when contemplating the future. They worry that as their children continue to age, caregiving responsibilities will become more burdensome, as they are predominantly the primary caregivers.

> "When he was still small it was somehow easier to control him, you can lead him and hold him but as he is growing it has been difficult for me to do that though he understands certain things when I scold him or constantly keep telling him to do things but he is very stubborn and as days pass, he is becoming more stubborn than before. My husband goes out for work and come late so I have to take care of him and household work so sometimes it is difficult."

Sub-theme 5.2 Children's Communication Difficulties

Many mothers expressed their concerns about the challenges they face in raising children who have difficulty verbally communicating their needs, desires, or emotions. This lack of effective communication from their children often serves as a significant source of stress and frustration.

> "It actually gets frustrating when I do not understand him especially when he is throwing a tantrum and I would try to do anything to get him to stop but I do not understand what he wants."

> "At times I feel I can deal with other challenges that comes with this but I just wish I am able to communicate with my child to be able to understand better about his needs."

Some mothers mentioned that although they have become adept at interpreting their children's gestures to some extent when they need something, there are times when they are not able to accurately understand, which is when it becomes particularly stressful. Mothers described the profound emotional toll they experience as they witness their child's communication struggles and feel helpless in their inability to assist them. This, they noted, often results in misunderstandings as well. It was observed that although tending to a child with autism can be challenging, it can also yield profound satisfaction. Many mothers expressed that they experience happiness and a sense of fulfilment when they witness their children's growth and enhancements.

> "I am overjoyed when she calls me 'maa,' I have been waiting to hear that for so long now…"
>
> "My son now understands that he has to point to things that he needs so that is a great progress for me."

Understanding the needs of mothers of children with autism is not only essential but also urgent in developing targeted interventions and support systems. By recognizing the specific challenges they face and the barriers they encounter, we can begin to tailor interventions that address their unique needs comprehensively. From access to specialized healthcare services to respite care options and emotional support networks, developing these tailored interventions can significantly alleviate the burden these mothers bear on a daily basis.

Discussion

Knowledge and awareness about ASD

In the realm of parenting, the experiences of mothers raising children with autism unfold as a complex narrative marked by varying levels of awareness, interactions with healthcare professionals, and the community's understanding. As we embark on an exploration of these maternal journeys, three central themes come to light: Parental Awareness, Medical Practitioner's Awareness, and General Public Awareness. Each theme sheds light on specific challenges and adaptive strategies. Yet, collectively, they intricately connect, forming a comprehensive narrative that not only captures individual trials but also reveals the resilience of mothers navigating this profound chapter of their lives.

The findings from this study revealed significant insights. The theme of parental awareness is richly explored, shedding light on the diverse levels of understanding among mothers raising children with autism. Similar to that of Poslawsky et al. (2014), a noteworthy finding in this study is the emergence of awareness predominantly after the formal diagnosis, indicating a delayed recognition for many mothers. This finding is similar to the findings of a study by Yaacob et al. (2021) where nearly half of the parents in study only heard of autism after their child was diagnosed with it. In our study, the diversity in responses is striking, with some mothers exhibiting a proactive response by seeking medical attention upon observing atypical behaviours, while, others tend to view developmental delays as normal, a phenomenon also observed by Yaacob et al. (2021) in their research. They reported that conditions such as speech delay are commonplace in some families, leading parents to be less concerned. The immediacy with which some mothers seek medical assistance may be influenced by various factors, including the presence of robust social support, either from family, friends, or the community at large (Rutgers et al., 2007; Poslawsky et al., 2014). Hence, having a foundational understanding of the condition proves to be a pivotal role in facilitating timely access to necessary interventions, including medications and therapies. Many researches (AlAlmaei Asiri et al., 2023; Ayub et al., 2017; Rodríguez et al., 2012) also underscores the significance of promptly identifying signs and symptoms to initiate swift treatment or intervention.

Additionally, the storyline highlights the challenges faced by some mothers after receiving an autism diagnosis for their children. The difficulty in accepting autism as a lifelong condition may stem from a lack of familiarity with its characteristics and challenges, leading to a state of denial among some parents (Dzubay, 2011; Aguiar & Pondé, 2020). The persisting stigma and misconceptions surrounding autism contribute to the reluctance of some parents to acknowledge the diagnosis, fuelled by concerns about societal judgment and negative attitudes (Turnock et al., 2022; Alshaigi et al., 2020). Upon learning about their child's autism diagnosis, parents may grapple with a sense of grief and loss, particularly as they adjust their expectations and dreams for their child (Dzubay, 2011; Norton & Drew, 1994). Worries about the child's future, encompassing education, socialization, and independence, add to the emotional burden (Legg et al., 2023). The uncertainty surrounding how their child will navigate these aspects of life poses a significant challenge. Moreover, there is a fear among parents that the autism diagnosis may result in social isolation for both the child and the family. This apprehension is rooted in concerns about the potential difficulties their child may encounter in forming relationships and participating in community activities (Midence & O’neill, 1999).

Financial constraints further complicated the situation, mothers with higher socioeconomic status had the capacity to avail additional private therapies, supplementing those offered by special school. Economic constraints compelled some mothers to depend solely on services provided by schools, even when specific needed services were unavailable. This section underscores the intersectionality of socioeconomic factors, geographical location, and the availability of support services, shaping the experiences of mothers raising children with autism (Yaacob et al., 2021; Neik et al., 2014)

Our findings also highlight how a considerable majority of mothers, have reported a lack of clarity in the diagnostic process when seeking guidance from medical practitioners. This finding aligns with the results of a study conducted by Aguiar & Pondé (2020), where parents had to shift between various doctors because none of them could provide satisfactory explanations or clarity. This absence of clear and comprehensive information has resulted in significant confusion for these mothers. The ambiguity surrounding the diagnosis has left many with unanswered questions, contributing to a sense of uncertainty and frustration (Dzubay, 2011). The findings also show how mothers who have received clear and comprehensive information from medical practitioners have experienced a more expedited path to obtaining treatment and accessing various therapeutic interventions for their children with autism. The clarity provided by healthcare professionals has empowered these mothers with valuable insights into available therapies, enabling them to make informed decisions promptly. This underscores the crucial role that medical practitioners play in guiding and supporting families affected by autism (Midence & O'neill, 1999). When healthcare professionals possess a thorough understanding of autism, its characteristics, and the range of available therapies, they can effectively communicate this information to parents. This, in turn, facilitates quicker decision-making, implementation of appropriate interventions, and ultimately enhances the overall well-being and developmental outcomes for children with autism. This assertion aligns with a publication by the World Health Organization (WHO) from 2013, acknowledging that a significant obstacle to enhancing global access to services is the insufficient knowledge and skills among healthcare professionals in identifying and managing autism and other developmental conditions.

Furthermore, the findings revealed that mothers who have availed themselves of support services, such as participation in support group sessions facilitated by relevant organizations, often express the positive impact these services have on their experiences. These mothers frequently articulate how the support received contributes significantly to their well-being and coping mechanisms. Engaging in support group sessions provides a platform for sharing experiences, insights, and challenges with others facing similar situations (Mc Cabe, 2008). Mothers commonly highlight that these support services create a sense of community and understanding, fostering a supportive environment where they can exchange valuable information and emotional support (Aithal et al., 2023). Additionally, mothers may express that participating in these sessions equip them with practical strategies for navigating the complexities associated with raising a child with autism. As mentioned by Dzubay (2011), many studies (Altiere & Von Kluge, 2009; Mancil, Boyd & Bedesem, 2009; Pottie & Ingram, 2008) suggested that a strong social support network demonstrated a greater ability to cope and adapt to new and challenging situations.

Mothers conveyed a prevailing sentiment that the broader community has a limited understanding of autism. Their personal awareness of autism developed through the lived experiences of raising their children, highlighting a gap in community knowledge. Mothers shared instances where they felt a sense of exclusion within the community due to the unique needs and challenges associated with raising a child with ASD. There is a perceived lack of understanding or accommodation within the community, creating a distance and making mothers feel excluded from community interactions (Gray, 1993; Martin, 2012). The societal misconceptions and lack of awareness surrounding autism contribute to instances where these mothers and their children encounter judgment or prejudice. Regrettably, even within their own families, mothers may face challenges as some relatives may harbour outdated beliefs or misconceptions about autism. This can result in strained relationships, with mothers feeling unsupported or misunderstood by those closest to them. Comparable results were observed in the research conducted by Currie & Szabo (2020), where parents encountered a lack of understanding from their family and friends regarding the difficulties they were undergoing. They felt that only individuals facing similar challenges could truly comprehend their situation, as others seemed unable to grasp it.

Initially, mothers raising children with autism often face overwhelming challenges, including societal stigma and familial misunderstandings. Navigating the unique demands of caring for a child with autism can be emotionally taxing, leading to feelings of isolation and frustration. Over time, many mothers undergo a transformative journey. By gaining a deeper understanding of their child's needs, accessing support services, and connecting with like-minded communities, a positive shift occurs. Mothers learn to adapt to the challenges they face, developing resilience and finding effective coping mechanisms (Kiibler-Ross & Kessler, 2005). In a research study conducted by

Milshtein et al. (2009), it was found that parents who successfully achieve resolution concerning their child's ASD can effectively progress in blending their past and present lives. Parents who have resolved the challenges associated with their child's condition can set aside concerns about causation, embrace their child's capabilities and limitations, and focus on the positive aspects of the situation, all while recognizing the challenges they encounter.

Sources of Support Systems

In caring of children with autism, the presence and effectiveness of support systems play a crucial role (Lu et al., 2015; Zhao et al., 2021). They are integral for the well-being of both the child and the caregiver. These supports are obtained from different sources which ranges from close family members to the expansive network of community resources. For mothers dealing with the challenges of autism, the support landscape is complex and diverse (Bi et al., 2022).

The results of our recent needs assessment shed light on this complex network of support, outlining clear categories that define where support comes from and what kinds of help are accessible. Our focus lies in examining primary, secondary, and tertiary support systems, each providing a distinct mix of aid and empathy. Leading the discussion are primary sources, such as immediate family members—parents, spouses, and siblings—whose presence underpins maternal strength. Beyond family ties and connections, lie the secondary sources, extending the circle of support to include the broader community. These encompass extended family members, friends, neighbors, and other parents of children with disabilities, whose shared journeys foster solidarity and mutual understanding. Meanwhile, tertiary support arises from organizations, schools, and community initiatives, offering a structured approach to providing assistance.

Furthermore, our investigation explores the different dimensions of support, recognizing its broader scope that involves social, emotional, physical, and financial aspects. Herein lies the essence of our discussion: the accessibility and availability of these diverse support systems, which significantly influence the maternal caregiving experience for children with autism. As we delve into this discourse, we identify a distinction between informal and formal support systems, each offering its own strengths and limitations. Informal support refers to the help caregivers get from their family and social circle, such as friends and neighbors. This form of support, deeply rooted in personal relationships and communal bonds, thrives on intimacy and empathy. On the other hand, formal support, coordinated through organized channels and professional interventions, provides structure and expertise (Juin, 2019). In sum, our exploration of support systems for mothers of children with autism encapsulates a journey marked by resilience, reciprocity, and resourcefulness. By delving into the intricacies of these support networks, we attempt to shed light on the pathways to empowerment and well-being in the face of these challenges.

Informal Sources of Support

First and foremost, our findings emphasize on the importance of spousal support, particularly in the context of caregiving for children with special needs. Family support, especially from parents who are typically the primary caregivers, forms the foundation of assistance for these children (Sharief, 2014). In cases where one parent assumes the primary caregiving role, the other spouse becomes paramount in providing essential support. Thus, the significance of spousal support cannot be understated—it is crucial for the well-being of both the primary caregiver and the child with special needs. When mothers primarily depend on their spouses for support (Konstantareas & Homatidis, 1989), especially in the absence of assistance from other family members due to various reasons, the absence of help from husbands can present considerable challenges in caring for their children. Many mothers who have relied on their partners' assistance express the difficulty they would face in managing their responsibilities alone. In the study by Brobst and colleagues (2009), mothers of children with ASD who had behavioural issues indicated receiving lower levels of support from their spouses. This emphasizes the reliance on spousal support, as those who have received it cannot fathom managing the responsibilities solo. It invites reflection on the immense challenges faced by mothers who navigate caregiving entirely on their own.

In a study by Desiningrum and colleagues (2021), participants universally express a longing for such support, recognizing its ability to alleviate parenting challenges and reduce stress. They highlight the importance of the husband's social support in complementing the father's role in the child's daily life and fostering harmony within the household. This support contributes to marital satisfaction and overall family well-being, while also promoting optimistic attitudes about the future. Many other studies have also talked about the importance of spousal support or in this case the importance of the support received from the husband. Some fathers adjust their work schedules to provide assistance, leading to a more balanced household dynamic with positive implications for the family and the child (Aguiar & Pondé, 2019) while another study shows that fathers' support plays a crucial role in shielding mothers of autistic children, particularly those facing more severe behavioral challenges, from experiencing symptoms of depression and anxiety (Machado Junior et al., 2016). While spousal support undeniably forms the cornerstone of assistance for many mothers of children with special needs, it is essential to recognize that the network of support extends beyond the immediate family unit. In addition to the invaluable role that husbands play in caregiving, there is a broader spectrum of familial support that profoundly impacts these mothers' journeys. For instance, many mothers find solace in the collective support provided by other family members. Whether it is the reassurance of parents, the helping hand of siblings, or the empathy of extended relatives, these familial bonds serve as pillars of strength and resilience (Ekas et al., 2010).

Our study findings highlight the critical significance of familial support for mothers of children with special needs. Mothers actively seek both physical and emotional support from their family members, expressing relief at the accessibility of such assistance and its stress-alleviating effects. The absence of this support is perceived as a significant challenge and burden for those lacking it. A study conducted by Bristol (1984), similarly observed that mothers in low-stress groups reported higher levels of perceived support. This study identified spouses, mothers' relatives, and other parents of children with disabilities as the most vital sources of support associated with reduced stress levels among all mothers. Those who perceived greater support also reported fewer depressive symptoms and more satisfying marriages. Numerous similar studies (Gray & Holden, 1992; Luther et al., 2005; Ekas, 2010; Johnson & Simpson, 2013; Safe et al., 2012) have underscored the crucial role of familial support in mitigating stress levels among mothers, highlighting how the absence of such support, whether physical or emotional, contributes to heightened stress levels.

However, the findings also revealed that mothers sometimes hesitate to seek support from others due to concerns about burdening them with their problems. Mothers of children with autism may hesitate to seek support from others due to various concerns, including fear of burdening others with their problems (Gray, 2002). This hesitation could stem from several factors. Firstly, within the family, a lack of understanding or awareness about autism may result in misconceptions or stigma surrounding the condition (Huws & Jones, 2010) leading mothers to feel reluctant to discuss their child's challenges openly. Secondly, there might be apprehension about judgment or criticism from family members regarding parenting abilities (Papadopoulos, 2021) or the child's behaviour, causing mothers to worry about being perceived as incapable. Additionally, mothers may feel pressure to appear strong and resilient, fearing that sharing their struggles could make them appear vulnerable or burdensome to their relatives. Cultural or societal factors may also contribute, with some cultures emphasizing privacy and discouraging seeking external support for personal or family issues, further complicating the decision to seek help.

Formal Sources of Support

From the findings of our study, we observed that formal support from tertiary sources, such as specialized schools, therapy centres, and hospitals, plays a crucial role in assisting mothers of children with special needs in managing their child's condition. These specialized institutions provide valuable resources and services that are essential for the well-being of both the child and the mother. Similar results were observed in a study conducted by Luong and colleagues (2009), where parents identified the school as their primary source of support. They viewed the school as the primary provider of therapies and structured programs, and school hours also allowed parents to manage other tasks, offering some respite. The availability of specialized schools, in particular, is highlighted as significantly aiding mothers in coping with the challenges associated with their child's condition (Renty & Roeyers, 2006). This could be due to the fact that special schools can provide more targeted support and tailored approaches to address the challenges associated with ASD (McDonald et al., 2019).

In addition to the presence of specialized schools and institutions, it was seen that the support group sessions conducted in these centres offer mothers a platform to access information on better childcare practices and to share their experiences and frustrations with other parents facing similar challenges. This highlights the importance of peer support and information-sharing in helping mothers navigate the complexities of caregiving for children with special needs (Douma et al., 2006). In a study conducted by Krauss and colleagues (1993), it was found that the level of engagement of mothers in parent support groups correlated with substantial increases in perceived support from fellow group members. Likewise, Clifford and Minnes (2013) discovered that parents who were actively engaged in parent support groups tended to employ more adaptive coping mechanisms compared to those who had never participated in parent support groups. Additionally, as Clifford (2011) suggests, research investigating the effects of support groups on participants' psychological well-being consistently demonstrates that active participation in these groups is associated with decreased negative mood and improved coping abilities (Beaudoin & Tao, 2007; Kerr & McIntosh, 2000).

Furthermore, the findings of our study also highlighted the significance of additional therapy sessions with private therapists, beyond those provided by the specialized schools attended by the children. This option is perceived as beneficial in improving mothers' capacity to effectively manage their child's condition. It emphasizes the importance of personalized interventions tailored to address the unique needs of both the child and the family (Kasari et al., 2018; Brodzeller et al., 2018). But while personalized interventions are undeniably beneficial for enhancing the management of a child's condition, the limited access to such resources for families with lower socioeconomic status exacerbates existing inequalities in healthcare. This highlights the urgent need for policies and initiatives aimed at improving access to specialized services for all families, regardless of their financial means. By addressing these disparities, society can better ensure that all children, regardless of socioeconomic background, have equal opportunities to receive the support and care they need for optimal development and well-being. Moreover, the study also emphasizes on the assistance provided by women's groups within the community which demonstrates the significance of social networks in providing practical help and emotional support to mothers when needed. This highlights the importance of community-based support systems in complementing formal services and addressing the diverse needs of mothers caring for children with special needs (Lazarus, 1999; Thuy et al., 2021).

To conclude, both informal and formal sources of support are equally vital for mothers of children with autism. Informal support, such as assistance from family, friends, and participation in parent support groups, provides a sense of understanding, empathy, and shared experiences. Meanwhile, formal support, including specialized schools, therapy programs, and professional assistance, offers structured interventions and targeted strategies tailored to address the unique needs of children with autism. By embracing both informal and formal avenues of support, mothers can access a diverse range of resources and guidance to effectively navigate the complexities of raising a child with autism.

Stressors: Emotional and Physiological Challenges

Emotional stress arises from the mental strain caused by emotional reactions to difficult circumstances, often triggered by feelings such as anxiety, fear, sadness, anger, or frustration (Schmidt et al., 2010). On the contrary, physiological stress encompasses the strain experienced by the body due to physical demands or external factors stemming from activities, environmental conditions, or challenging physical situations (Pattini et al., 2019). While emotional and physical stress can manifest independently, they are interrelated and can impact each other mutually (Al Majali et al., 2020).

Numerous studies have substantiated the assertion that due to the distinctive caregiving demands associated with autism and its characteristics, mothers of children with autism experience higher levels of stress and mental health problems compared to mothers of children with other developmental disorders (Estes et al., 2009; Blacher & McIntyre, 2006; Eisenhower et al., 2005; Pisula, 2007; Benson, 2006; Hastings & Beck, 2004). There are various factors that contribute to the stress and the findings of our study emphasizes on the emotional and physiological stressors. Our study has highlighted a spectrum of challenges, ranging from denial and anxiety to financial strain and social isolation.

It was seen that in the initial state, mothers experienced a state of denial upon learning about their child's autism diagnosis. This discovery shares similarities with research conducted by Gordillo and colleagues (2020), which found that Latina mothers harboured doubts and scepticism about the autism diagnosis for their children. Similarly, in a study conducted by Russel and Norwich (2012), mothers appeared to face a dilemma. On one hand, they wished for their child to be seen as "normal" by society, aligning with societal expectations for typical development. On the other hand, they acknowledged the distinct differences or challenges posed by their child's condition, leading to an internal conflict between these competing desires.

This denial often gives rise to persistent feelings of fear, grief, guilt, and self-blame (Ryan & Runswick-Cole, 2008). The inability to accept the reality of their child's condition exacerbates emotional stress, making it challenging for mothers to cope effectively (Darling, 1979, as cited in Ryan & Runswick-Cole, 2008). Mothers may initially stay in denial and refuse to accept an autism diagnosis for a multitude of reasons. The sudden revelation of a lifelong condition may be difficult to comprehend (Lilley, 2011), leading to initial disbelief and denial as a coping mechanism. Since Autism is a complex neurodevelopmental disorder with a wide range of symptoms and outcomes (Thapar et al., 2017), mothers may fear what the diagnosis means for their child's future (Dale et al., 2006), including their ability to lead a fulfilling life, establish relationships, and achieve independence (Aguiar & Pondé, 2020). The fear of the unknown can contribute to denial as a way to avoid confronting these uncertainties. Moreover, there is still a significant amount of stigma surrounding autism (Gray, 2002; Saleh et al., 2020), perpetuated by misconceptions and stereotypes. Mothers may resist accepting the diagnosis due to concerns about how their child will be perceived by others and the potential for negative social consequences. This fear of judgment and stigma can further fuel denial.

Moreover, mothers often feel a deep sense of responsibility for their child's well-being and development. Upon receiving an autism diagnosis, they may experience feelings of guilt, questioning whether they did something wrong or failed to recognize early signs of the condition (Courcy & des Rivières, 2017; Kang et al., 2016). This overwhelming sense of responsibility and guilt can make it challenging to accept the reality of the diagnosis. Apart from that, cultural beliefs, and family expectations (Ravindran & Myers, 2012) can influence how mothers perceive and respond to an autism diagnosis. In some cultures, there may be a stigma associated with disability (Werner et al., 2012) or a lack of awareness about autism, leading to resistance in accepting the diagnosis. Additionally, familial pressures to conform to societal norms and expectations may influence mothers to deny the reality of their child's condition.

Another prevalent theme among mothers in our study is the constant worry and anxiety regarding their child's future. The uncertainty of what lies ahead creates a constant source of concern, as mothers grapple with questions about their child's long-term prospects and quality of life (Marsack-Topolewski & Graves, 2020). They fear the challenges their child may face as they navigate through different life stages and transitions. Moreover, there is a profound sense of worry about the child's well-being if something were to happen to the mother, such as illness or incapacitation (Bilgin & Kucuk, 2010). This concern stems from the central role mothers often play in their child's life and care, leading to heightened anxiety about who will provide support and guidance in their absence (Hall & Graff, 2010). The cumulative weight of these worries intensifies the emotional burden experienced by mothers, amplifying feelings of helplessness and uncertainty about the future.

Additionally, the results of our study also indicated that mothers expressed feelings of guilt due to their inability to afford essential treatments, such as therapies, for their child due to financial constraints. The sense of guilt experienced by mothers for not being able to provide the necessary care and resources for her child highlights the emotional toll of caregiving responsibilities. The findings of Sawyer and colleagues' (2010) study highlight the significant time commitment demanded of mothers caring for children with chronic disabilities like autism. This caregiving responsibility places immense pressure on these mothers, significantly impacting their mental well-being. Subsequent studies have echoed similar sentiments, underscoring the profound effect of this role on the psychological health of mothers raising children with autism. It was also seen that mothers who diligently engage in therapy sessions and daily tasks with their children often observe a cyclical pattern of progress and regression. While improvements may be noted initially, setbacks and regression can occur unexpectedly, leading to feelings of disappointment and grief. This cycle erodes hope and exacerbates emotional stress, as mothers grapple with unfulfilled expectations and dreams for their children's development. Similarly, a study conducted to explore the experiences of mothers raising autistic children found that upon receiving the diagnosis, many mothers expressed a sense of shattered expectations and lost dreams (Win & Nyunt, 2019). These mothers appeared to embark on a journey of seeking new perspectives and undergoing a delicate process of acceptance (Nicholas et al., 2016).

The role of primary caregiver often results in isolation for mothers, leaving them with limited time for self-care or socialization. In a study conducted by Hall and Graff (2010), mothers discussed their preference to remain at home due to their child's behavioural challenges. Despite expressing a desire for personal time and the opportunity to contribute to society, these mothers find themselves unable to do so. The absence of understanding and emotional support from loved ones frequently drives these mothers to withdraw from friends and family (Phelps et al., 2009; Safe et al., 2012; Lutz et al., 2012). Feeling misunderstood and unsupported, they may choose to isolate themselves, finding solace in their own company rather than facing the judgment or lack of empathy from those around them. This further compounds feelings of loneliness and frustration.

Additionally, the need to continually cope with comments from relatives about their child's condition and societal stigma adds to the emotional exhaustion experienced by mothers, contributing to overall stress levels and more isolation (Lutz et al., 2012).

Many mothers express a desire to have another child, yet they grapple with the emotional turmoil of whether to take the risk, considering the likelihood of autism recurrence. Similar findings have emerged across various studies, indicating that mothers often hesitate to have a second child due to the fear of autism recurrence (Kimura et al., 2010; Hall & Graff, 2010). Additionally, some express concern that even if the subsequent child does not have autism, they may still bear the burden of caregiving for their sibling with autism (Kimura et al., 2010). This dual apprehension underscores the profound impact of raising a child with autism on family planning decisions and highlights the complex emotional considerations involved in expanding the family. The findings also indicate that mothers experience a significant physical burden in caregiving as their child with autism grows older. It becomes increasingly challenging for them to assist their child independently with tasks such as bathing or toileting, especially in the absence of physical assistance from others. Furthermore, mothers highlighted the additional difficulty of managing their child's challenging behaviours, particularly during tantrums or outbursts. These episodes can be physically exhausting for mothers, further adding to the demanding nature of their caregiving responsibilities. The constant demands of caregiving, coupled with the emotional toll of managing a child's needs, contribute to heightened physiological stress responses in mothers. The interplay between physical and emotional stressors creates a feedback loop, where each exacerbates the other, leading to a cycle of escalating strain on maternal mental and physical health. Recognizing the interconnected nature of emotional and physical stress underscores the importance of holistic approaches to maternal well-being. Interventions aimed at reducing stress and promoting resilience must address both emotional and physical dimensions of health.

Coping Responses

A notable observation in the coping responses of mothers of children with autism in our study is the prevalence of emotion-focused coping strategies. Emotion-focused coping involves the management and regulation of emotional responses to stressors (Ben-Zur, 2020), with mothers often relying on these strategies to navigate the challenges they encounter. Findings revealed that many mothers find solace in expressing their feelings of frustration, sadness, or anger. By verbalizing their emotions, they can process and release pent-up tension, allowing for a sense of emotional relief. Mothers were observed to actively seek this form of assistance from their close ones and family members. Family members are recognized as a significant pillar of support for parents. Multiple studies (Hutton & Caron, 2005; Lin et al., 2008; Marshall & Long, 2010) also examined the significance of familial support as a crucial element of the support network. Additionally, it was observed that support groups have a beneficial influence on the lives of mothers, serving as an additional means of coping. In these groups, mothers can unload their burdens and discuss issues they may feel uncomfortable sharing with their families. Comparable research (Leggett, 2015; Mandell & Salzer, 2007; Sharma et al., 2022) has highlighted the significance of support groups, emphasizing how mothers perceive them as second families where they find empathy and guidance without fear of judgment.

Furthermore, it was seen that some mothers gravitate towards adopting acceptance and mindfulness as integral coping mechanisms, recognizing the power of embracing the present moment and acknowledging the uncertainties inherent in their circumstances. In essence, acceptance involves acknowledging the reality of their situation without judgment or resistance ("Acceptance: Definition, Benefits & Techniques," 2023), allowing mothers to come to terms with the unique challenges they face as caregivers of children with autism. This process of acceptance fosters a sense of peace and equanimity, freeing them from the burden of constantly striving to change or control aspects of their lives beyond their influence (Da Paz et al., 2018). Numerous studies (Bögels & Restifo 2014; Ridderinkhof et al., 2018) advocate for the practice of mindful parenting, suggesting that it enables parents to engage with their children in a receptive, nonjudgmental manner, considering their viewpoints and responding calmly rather than instinctively reacting. They tend to develop the capacity to respond to challenging situations with greater clarity and discernment, rather than reacting impulsively out of fear or anxiety. This heightened level of self-awareness allows them to cultivate resilience in the face of adversity, drawing upon their inner reservoirs of strength and wisdom to navigate the complexities of autism parenting with grace and resilience (Cachia et al., 2016; Rojas-Torres et al., 2021; Neff & Faso, 2015; Lilly & Tungol, 2015).

Another common coping strategy found in our study involves a profound shift in perspective, where mothers undergo a transformative journey of self-discovery and empowerment. In this process, they develop a newfound sense of self-reliance and inner strength, bolstered by the practice of positive self-talk and optimism. By facing difficulties head-on and reframing challenges as opportunities for growth, they build resilience, adaptability, and a steadfast sense of optimism that empowers them to navigate the complexities of raising a child with autism (Twoy et al., 2007). Research (Katrak & Sunkarapalli, 2021; Maheshwari & Jutta, 2020) suggests a symbiotic connection between Optimism and Parental Resilience, indicating an interdependent relationship. Individuals with higher levels of Optimism tend to demonstrate greater Resilience, highlighting their close intertwining. This implies that optimism and resilience serve as mutually beneficial coping mechanisms, complementing each other. Likewise, in addressing the challenges associated to parenting a child with autism and other neurodevelopmental disorders, numerous studies have emphasized the crucial importance of resilience and optimistic outlook. These studies emphasize the potential benefits of enhancing these coping mechanisms to support other parents facing similar challenges (Ekas & Rafferty, 2020; Kotera et al., 2021; Santoso & D OT, 2022; Ghanouni & Eves, 2023; Zhao & Fu, 2022).

For numerous mothers navigating the complex journey of raising a child with autism, faith and spirituality emerge as vital pillars of support in coping with the innumerable stressors and uncertainties that accompany their role (Karaca & Konuk Şener, 2021). Grounded in their beliefs, these mothers find solace and strength by relinquishing control over their future and placing their trust in a higher power. This act of surrendering to the notion of a predetermined destiny offers a sense of comfort and reassurance amid the tumultuous waves of adversity. Similar results have been obtained by other studies (Tarakeshwar & Pargament, 2001; Davis III, 2016; McWhirter & McIntyre, 2021; Luther et al., 2005) wherein faith provides a sanctuary of hope and healing in times of distress, serving as a source of strength and resilience when confronted with overwhelming challenges. By embracing their spiritual beliefs, mothers find refuge in the knowledge that they are never alone in their struggles, drawing upon the infinite reservoir of divine love and support to sustain them through the darkest of times.

While emotion-focused coping strategies are prevalent among mothers navigating the challenges of raising a child with autism, it is also common for some to turn to avoidance or distraction as short-term methods of alleviating stress (Piazza et al.,2014). In moments of overwhelming pressure or emotional turmoil, these mothers may find themselves seeking temporary relief by diverting their attention away from the source of their distress (Wang et al., 2011). Avoidance tactics often manifest as a deliberate effort to distance oneself from triggering situations or individuals that evoke feelings of discomfort or anxiety (Penley et al., 2002; Holahan et al., 2005). Mothers may withdraw from social interactions, avoid discussions about their child's diagnosis, or steer clear of environments triggering painful memories or caregiving reminders. By distancing themselves physically or emotionally from stressors, they aim to protect against any emotional strain. While prevailing literature (Lai et al., 2015; Taylor & Stanton, 2007; Pisula & Kossakowska, 2010) often characterizes avoidant coping as maladaptive and unhealthy in the long term, our study reveals intricate perspectives from mothers who have firsthand experience navigating the complexities of autism parenting. Contrary to prevailing notions, mothers in our study expressed that avoidant coping, particularly in the form of distraction, can serve as a helpful and adaptive strategy in certain contexts. When faced with overwhelming stressors or situations beyond their control, mothers found solace in temporarily diverting their attention away from the source of their distress. In these instances, distraction provided a respite from the intensity of their emotions and allowed them to regain a sense of composure. However, it is important to emphasize that the beneficial effects of avoidant coping are contingent upon its careful and judicious use. While distraction may offer temporary relief from stress, over-reliance on this coping strategy or persistent avoidance of confronting stressful situations may ultimately impede long-term adaptation and emotional well-being (Twoy et al., 2007). Therefore, mothers must strike a delicate balance between utilizing distraction as a coping mechanism when necessary and actively engaging with stressors in a constructive and proactive manner.

To conclude, one of the crucial benefits of emotion-focused coping is its emphasis on addressing the emotional aspects of stressors, focusing on regulating emotions, seeking support, and finding meaning in difficult situations. By encouraging mothers to recognize and express their emotions in healthy ways, we can create a supportive environment that fosters emotional well-being and strengthens family relationships. When mothers feel empowered to manage their emotions effectively, they are better equipped to deal with the challenges they face and promote positive outcomes for both themselves and their families.

Impact of Children's Challenging Temperaments on Maternal Well-being

Given the wide spectrum of autism, its symptoms, severity, and progression vary greatly among individuals, resulting in caregivers facing a diverse array of challenges. These challenges are influenced by various factors. The primary focus here revolves around the impact of difficult temperaments on caregivers, particularly in two key areas: the child's behavioural challenges and communication struggles. These aspects significantly impact the overall well-being of mothers.

Our findings uncovered that mothers encounter significant challenges stemming from their child's behavioural issues, particularly when the child exhibits aggressive behaviours that pose a risk of self-harm or harm to others. These situations become especially daunting when the outbursts occur suddenly and without warning, lasting for prolonged periods. Managing such incidents, especially in public settings, proves to be exceptionally difficult for mothers. Additionally, mothers expressed that these behavioural challenges tend to intensify as their children grow older. While handling outbursts may have been relatively easier when the children were younger, it has become increasingly challenging with their growth and development. Several other studies have similarly highlighted that the primary source of stress for caregivers of children with ASD stems from the behavioural issues and symptoms associated with the condition (Phetrasuwan & Miles, 2009; Tobing & Glenwick, 2006; Johnson & Simpson, 2013; Benson and Kersh 2011; Kersh et al. 2006; Lecavalier et al. 2006; Griffith et al., 2010). These studies emphasize the significant impact of managing the behavioural challenges inherent in ASD on the well-being of caregivers. Moreover, mothers also expressed of often facing challenges in accurately interpreting their children's gestures and communication attempts. This inability to fully understand their child's needs can lead to heightened stress and frustration for both the mother and the child. Communication difficulties can often result in misunderstandings between mothers and their children with autism. These misunderstandings may further contribute to stress and tension within the family dynamic (Siklos & Kerns, 2006; Papageorgiou & Kalyva). While caring for a child with autism can be challenging, it can also bring moments of happiness and fulfilment for mothers. Witnessing their children's growth and improvements, despite the difficulties, can provide mothers with a sense of satisfaction and joy. Overall, these points underscore the complex and multifaceted nature of the caregiving experience for mothers of children with autism, highlighting both the challenges and rewards inherent in the role.

Conclusions

In conclusion, this study has delved into the complex experiences of mothers navigating the challenges associated with raising children on the autism spectrum. The complexities surrounding the diagnostic process, coupled with the emotional responses and varied coping strategies, illuminate the resilience and adaptability exhibited by these mothers. Importantly, our findings contribute to the existing literature by shedding light on the need for heightened cultural sensitivity, long-term mental health support, and more comprehensive community understanding. As we consider the practical implications, it becomes evident that healthcare professionals play a pivotal role in the early identification of autism. The study suggests the necessity of targeted interventions to enhance healthcare practitioners' knowledge, thereby reducing delays in diagnosis and ensuring timely access to crucial support services. Furthermore, the observed variations in the accessibility of specialized schools and therapy centres highlight the importance of equitable distribution of resources, particularly for mothers residing in remote areas.

Moreover, our study highlights the diverse coping responses employed by mothers in navigating the challenges of raising children with autism. From seeking emotional support to embracing acceptance and mindfulness, mothers demonstrate remarkable resilience and adaptability in the face of adversity. While some coping strategies may be more effective than others, each reflects mothers' unwavering dedication to their child's well-being. By understanding and supporting mothers in their coping journey, we can enhance their resilience and promote positive outcomes for both mothers and their children with autism. In essence, this study advances our comprehension of the challenges faced by mothers, offering a foundation for targeted interventions and policy improvements. Through a collective commitment to fostering awareness, understanding, and inclusivity, we aspire to cultivate a society that supports and empowers not only mothers but every individual on the autism spectrum.

Outcome:

The study has resulted in the creation of a Psychosocial Intervention Module tailored for mothers of children with autism (Refer Appendix 10). This module covers various components including the enhancement of knowledge, stress management techniques, fostering helpful coping mechanisms, strengthening support systems, and addressing other relevant needs.

Although the results revealed a range of significant themes through thematic analysis, the primary focus of the intervention was to address the immediate psychosocial needs of these mothers, hence, certain themes such as stigma and discrimination from others, and the impact of medical practitioners' awareness on mothers' lives—whether positive or negative—emerged prominently. However, it was not feasible to incorporate all identified themes into the intervention module. This limitation was due to the specific scope and objectives of the intervention, which prioritized direct and actionable support strategies for the mothers' psychosocial well-being. Addressing issues like societal stigma and the broader systemic awareness among medical professionals requires a more comprehensive approach, extending beyond the immediate psychosocial interventions. Consequently, while these themes are undeniably important, they were acknowledged as areas for future research and broader policy advocacy, ensuring that the module remained focused, practical, and implementable within the given constraints.