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## Experiences of Care-Seeking Parents With Children With Autism Spectrum Disorder in India

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# Walden University

College of Health Sciences and Public Policy

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Yash Patel

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Walden University  
2026

Abstract

Experiences of Care-Seeking Parents With Children With Autism Spectrum Disorder in

India

by

Yash Patel

MPH, Chamberlain University, 2019

BS, University of Illinois at Chicago, 2018

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Public Health

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## Abstract

Autism spectrum disorder (ASD) affects approximately 18 million individuals in India, yet the factors influencing parental care-seeking behavior were not well understood. Guided by the health belief model, the purpose of this basic qualitative study was to explore how parents' perceived severity of a child's symptoms, parental beliefs about the causes of autism, and perceived mental and physical health outcomes of caregiving influence parents' intention to seek services for children age 1–10 years diagnosed with ASD in India. Data were collected using semistructured interviews with 10 mothers of autistic children. Data were analyzed using Braun and Clarke's six-step thematic analysis. Findings revealed that participants had high perceived severity of speech delay, aggression motivated early intervention, and cultural normalization of mild symptoms delayed care. Scientifically informed beliefs increased the urgency for therapy, whereas cultural beliefs, such as karma and divine will, acted as barriers. Caregiving strain often hindered service seeking, although coping strategies, such as spousal support and peer networks, facilitated engagement. This study may promote positive social change by reducing stigma, enhancing early screening, and empowering families, thereby improving outcomes for children and enhancing caregiver well-being in India.

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## Dedication

I want to dedicate this study to all parents across the world who are working with children who have developmental conditions like autism. This study aimed to develop resources to find cures and improve treatment options for children in India and other developing countries. It aimed to raise awareness that developmental conditions are not diseases. These conditions can be treated and corrected with clinical and social help and the proper guidance of physicians and health care providers.

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## Chapter 1: Introduction to the Study

A recent survey by Chakrabarti (2023) revealed that 18 million Indians, or 12.7% of the population, are on the autism spectrum. This statistic highlights the prevalence of autism in India, underscoring the need for specialized support systems for those affected. Further research by Fatima et al. (2021) from Puducherry revealed the mental health challenges faced by parents of children with neurodevelopmental disorders, particularly the heightened risk of depression and anxiety among mothers, who are often the primary caregivers. The sociodemographic conditions of these families also contribute to their mental health struggles, exacerbating their stress. Additionally, research by Limaye (2015) suggested that many families prefer to keep their children with special needs at home due to various factors, including limited availability of special education facilities, lack of awareness, distance from schools, and a general sense of pessimism. These barriers hinder access to education and services, reinforcing societal stigma and making it more crucial to promote awareness, improve accessibility, and foster inclusivity in educational and health care settings. Previous studies, such as Doda et al. (2024), on autism employed case studies that compared variables related to autism treatments. Upon further research on previously published studies, an area of limitation was found in the screening and acceptance of autism and other developmental conditions (Doda et al., 2024).

The current study addressed care-seeking parents with autistic children in developing countries such as India. I aimed to understand how parents perceive the severity of an autistic child's symptoms, their beliefs about the causes of autism, and how

their perceived caregiving mental and physical health outcomes influence their intention to seek services for their children with ASD in India. Parental early acknowledgment, acceptance, and action of an autistic child and their treatment may effect social change in India. This chapter provides an overview of the study conducted to address the research problem.

### **Background**

People with ASD often have problems with social communication, interaction, and restricted or repetitive behaviors or interests (Centers for Disease Control and Prevention [CDC], 2024). The signs of autism start developing in the first 12 months of life. Children with ASD have comorbidities, including intellectual disability, behavioral challenges, and psychiatric and medical disorders, thereby increasing the caregiving demands on parents (Lai et al., 2019). Parents are considered essential stakeholders in autism-related intervention services and are expected to be actively involved in their child's overall management, necessitating a substantial time commitment. Previous research suggested that the lengthy diagnostic process can increase family stress and delay the initiation of critical interventions, thereby affecting optimal long-term outcomes (Crane et al., 2015).

India is one of the largest countries in the world and has one of the most significant democracies (Maiorano, 2025). Indian culture has a significant influence on an individual's day-to-day lifestyle. Child developmental delays and conditions are often viewed as setbacks in a child's growth. Many parents restrict the activities of children with developmental delays and conditions (Castillo et al., 2019). Parents limit their

children's play activities, do not enroll them in school, limit their social engagement, and hide them from neighbors, among other measures (Vasquez, 2020). Many parents have a hard time accepting conditions such as autism in their children. It is challenging to educate parents that not all autism symptoms are the same from one child to another (Castillo et al., 2019). Autism has a spectrum that includes attention deficit disorder, attention deficit hyperactivity disorder, and speech delay (Vasquez, 2020). Each type of ASD condition requires specialized treatment and therapy plans to speed recovery (Uke et al., 2024).

Several studies have been completed on autistic children and their treatment in India in the last 5 years (Chakrabarti, 2023). However, few studies focused on parents who are also experiencing unknown socioeconomic variables to acknowledge developmental and neurological conditions such as autism. Many parents do not have enough education to understand that conditions such as autism exist in the world and can be treated with correct treatment and therapies (Vats et al., 2024). Quantitative studies on variables such as living environment, finances, education, geographic location, and access to care have yet to be conducted to determine whether they are related to finding care in India (Abeer et al., 2024).

The health care system in India differs based on their implementation; children cannot meet the standard screening requirement after birth (Chakrabarti, 2023). Many parents do not find a cure once they find the symptoms in their children. Most symptoms are suspected during the initial school years, which is late screening for an individual child (Vats et al., 2024). Vats et al. (2024) revealed that, based on identifying symptoms,

many families struggle with financial issues, family size, access to care, parental marital status, and parental income, among other factors.

The current study was conducted to fill the gap in the literature regarding parents' perceptions of the perceived severity of an autistic child's symptoms, their beliefs about the causes of autism, and their perceived caregiving mental and physical health outcomes. This study was essential to bring more awareness to parents to overcome the stigma of ASD. I sought to help them understand that autism is not a disease. It is a condition that can be treated with professional care, help, and support (Vats et al., 2024). I also sought to help parents understand why stressed people do not accept challenges together. Many parents go through separation while taking care of their autistic child due to challenging lifestyles, constant need for the child's care, not enough time as a couple to spend together, financial pressure, family beliefs, and differences in their opinions (Uke et al., 2024).

### **Problem Statement**

Autism screening is lacking across India, leading to many social, developmental, physical, and emotional growth delays in children and adults (Srivastava et al., 2024). The Indian Autism Center 2023 survey showed that 18 million (12.7%) of Indians are on the autism spectrum (Chakrabarti, 2023). Many risk factors associated with autism have been identified in the U.S. population, including prenatal factors such as advanced maternal age, fetal distress, and gestational respiratory infections; perinatal factors such as labor complications, preterm birth, neonatal jaundice, delayed birth cry, and birth asphyxia; and other factors such as consanguinity, maternal hormonal intervention, and

significant childhood illnesses (Vats et al., 2024). Many parents consider autism a disease and not a condition that they want to fix in their child (Samachar, 2024). The acceptance of having an autistic child often comes with feelings of shame and burden, particularly in the Indian context, where awareness about autism remains limited (Vats et al., 2024). According to Chakrabarti (2023), parents frequently report significant emotional and practical struggles in their day-to-day management of children with ASD. Not all parents are fortunate enough to find care and support for the treatment or care of their autistic children. Autism research is needed to explore parent-related factors that influence parents' intention to seek services for their children with ASD (Chakrabarti, 2023).

### **Purpose of the Study**

The purpose of this basic qualitative study was to explore how factors (parents' perceived severity of an autistic child's symptoms, their beliefs about the causes of autism, and their perceived caregiving mental and physical health outcomes) influence parents' intention to seek services for their children with ASD (age 1–10 years) in India. This study was grounded in a constructivist research paradigm, which assumed that knowledge is coconstructed through participants' experiences and interpretations within their social context.

### **Research Questions**

RQ1: What factors influence parents' intention to seek services for their children with an autism spectrum disorder (1–10 years old) in India?

RQ1a: Child-related factor: How does the perceived severity of an autistic child's symptoms affect parents' intention to seek services for their children with an autism spectrum disorder (1–10 years old) in India?

RQ1b: Parental knowledge and perception: How do the beliefs about the causes of autism affect parents' intention to seek services for their children with an autism spectrum disorder (1–10 years old) in India?

RQ1c: Parent-related factor: How do perceived caregiving mental and physical health outcomes affect parents' intention to seek services for their children with an autism spectrum disorder (1–10 years old) in India?

### **Theoretical Framework**

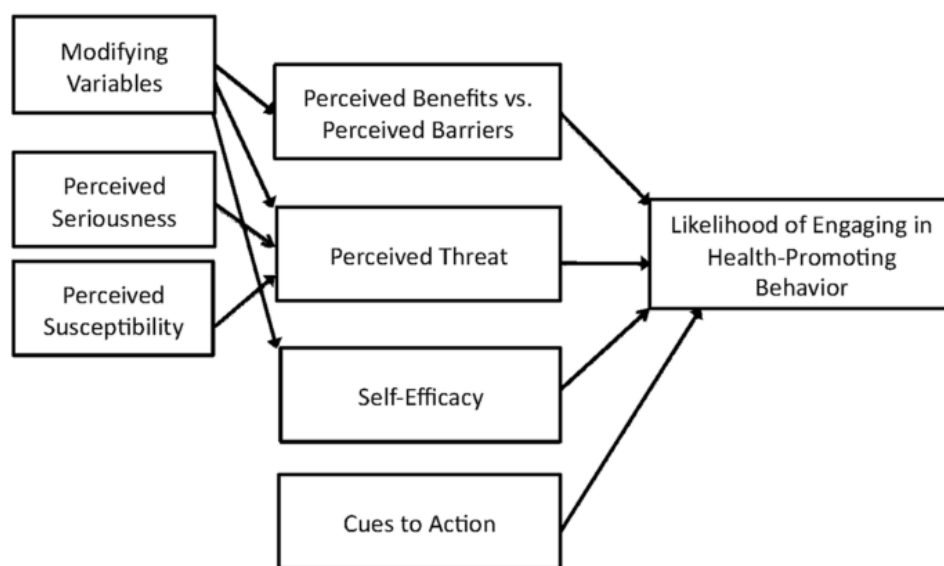
The study focused on parents seeking care for their children diagnosed with ASD, utilizing the health belief model (HBM; Hochbaum et al., 1952) framework to analyze their experiences. Through semistructured interviews, I intended to gather qualitative data, employing an inductive approach that allowed themes and patterns to emerge from the collected information rather than being preconceived by specific hypotheses (Collins & Stockton, 2018). The HBM has been widely used in health promotion, education, and behavior change interventions. The HBM is a systematic framework that I used to understand the factors influencing parents' decisions to pursue health care services for their children with ASD in India. This model's core components were used to understand how parents perceive their child's condition (perceived susceptibility), assess the seriousness of autism symptoms (perceived severity), recognize the benefits of professional interventions (perceived benefits), confront obstacles in accessing services

(perceived barriers), respond to triggers that encourage them to seek help (cues to action), and exhibit confidence in navigating care systems (self-efficacy; Kanna et al., 2020; Jones et al., 2015; see Figure 1).

### Figure 1

*Application Stages of the Health Belief Model*

## The Health Belief Model



*Note.* From “Qualitative study of knowledge, perception, behavior, and barriers associated with cardiovascular disease risk among overweight and obese Hispanic taxi drivers of South Bronx, NYC” By Kanna et al., 2020, *BMC Public Health*, 20(1).

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Zuckerman et al. (2016) examined the application of the HBM in Western countries such as the United States. Zuckerman et al. explored the social stigmas associated with awkwardness, knowledge gaps, and parental leadership in decision making that impact health-care-seeking behaviors. Zuckerman et al. noted that emotional responses such as grief and confusion often prompt action but can vary depending on

socioeconomic status, especially regarding health care access. In contrast, research by Bakare and Munir (2011), Daley (2002), and Kang et al. (2012) emphasized the profound cultural beliefs prevalent in non-Western nations such as India, Nigeria, and South Korea. These cultural beliefs contributed to the stigma surrounding ASD. These studies highlighted the importance of spiritual, communal, and mixed knowledge influences on decision making, while also pointing out emotional reactions such as shame, fear of judgment, and barriers to care as crucial elements affecting care-seeking behaviors in these cultural settings. Based on cultural reference, the key difference between Western and non-Western studies was that parents in Western studies make care-seeking decisions. In contrast, family or community-based decisions are sometimes made in non-Western studies.

Indian parents seek care for children with ASD; it is essential to move beyond biomedical frameworks and engage with perspectives from medical anthropology and disability studies that better capture the sociocultural complexities of the Indian context (Sue et al. 2015). Expectations around childhood development are deeply embedded in cultural scripts regarding education, obedience, marriageability, and productivity (Garland-Thomson, 2002). Kleinman's (1980) concept of explanatory models indicates that parents often integrate biomedical, traditional, cultural, and spiritual perspectives when interpreting autism. Farmer's (2004) framework of structural violence emphasizes how systemic inequalities, including poverty, caste, and gender, restrict access to health care services. The social model of disability transitioned the focus from individual ASD impairments to societal barriers that hinder inclusion and support (Hamraie, 2015). In

India, lack of inclusive infrastructure, inadequate schooling, and social stigma create more disabling conditions than the diagnosis itself.

### **Nature of the Study**

This study employed a basic qualitative approach to address the research questions about perceived severity, beliefs about causes, and perceived health outcomes that influence parents' intentions to seek services (Merriam and Tisdell, 2015). Semi-structured interviews were particularly appropriate for exploring these questions because they allowed in-depth exploration of parents' personal experiences, beliefs, and decision-making processes while maintaining sufficient structure to ensure cross-case comparability (DeJonckheere and Vaughn, 2019). The flexibility of semi-structured interviews allowed for follow-up probing to gather rich data on the complex factors influencing parental decision-making regarding autism services in the Indian context. The semi structured interview protocol was developed based on the three key constructs derived from the research questions: (1) perceived severity of autism symptoms, (2) beliefs about causes of autism, and (3) perceived mental and physical health outcomes. For each construct, 3-5 open-ended questions were developed based on existing literature (Srikanth et al., 2020; Vats et al., 2024) and aligned with Health Belief Model components. The protocol began with general questions about the child's diagnosis journey before progressing to more specific questions about each research construct. Each main question is accompanied by potential probing questions to encourage elaboration. The protocol was reviewed by an expert in qualitative research methods and autism spectrum disorder before pilot testing with two participants who met the inclusion

criteria. In the pilot study, two parents were interviewed to understand the initially prepared questions, and between 9 and 17 parents were recruited for individual semi structured research. Additional parents may be recruited if the saturation point is not reached. A pilot test of semi-structured interview protocols allowed the researcher to identify potential issues with their interview questions, ensuring they were clear, relevant, and appropriate for the target population (DeJonckheere and Vaughn, 2019). It ultimately led to better-quality data collection in the main study by enabling necessary adjustments to the protocol before its full implementation. The semi-structured interview protocols helped to check for clarity and comprehension, assess question flow and relevance, identify potential biases, practice interviewing skills, adapt to cultural contexts, and refine probing questions (DeJonckheere and Vaughn, 2019). The saturation point was determined based on the study by Srikanth et al. (2020). Hennink and Kaiser's (2021) study identified 23 studies. They developed a statistical tool that measured the saturation point of qualitative study interviews to be between 9 and 17 sample sizes. The inclusion criteria were parents of autistic children residing in Gujarat state, biological parents, and children actively enrolled at the Asian Neuro Child Clinic during the study period. After the interviews, the primary research data were analyzed.

The study had a separate recruitment process for pilot study participants, and data collected during the pilot study were excluded from the main study. They consisted of responses from parents regarding their experiences with their ASD child and the services in India. Primary data were collected through semi-structured interviews with the parents. The interviews were conducted in Gujarati at the clinic first by the researcher, and the

audio was recorded, transcribed, and analyzed in English. The in-person semi structured interviews were approximately one-hour-long sessions. A descriptive thematic analysis extracted themes and subthemes from each interview (Srikanth et al., 2020). After the first nine interviews, whether additional parents may be recruited (the saturation point is reached) is determined.

### **Definitions**

*Actively enrolled:* Someone currently participating in or registered in a program, course, or study. It suggested that the individual is fully involved and engaged in the activity or process (Ambrosia, 2024).

*Affect:* In this qualitative study, affect refers to the influence of a phenomenon or experience on individuals' experiences, perspectives, and behaviors rather than a cause-and-effect relationship measured numerically (Tenny et al., 2022). In this study, parents' experiences, perspectives, and behaviors played a crucial role in seeking services for autistic children.

*Asian Neuro Child Clinic:* This clinic is in Ahmedabad, India. This clinic runs diagnostic and clinical treatments for children with neurological and developmental delays, including Autism (<https://asianchildneuroclinic.com>).

*Autism spectrum disorder/autism:* A neurological and developmental disorder. It affects an individual's communication skills, learning abilities, and behavior. The disorder's symptoms appear around the first few years of life (Chakrabarti et al., 2023).

*Factor:* The elements that shape, influence, or contribute to the phenomenon under study (Tenny et al., 2022). This study explored how three factors (the perceived

severity of an autistic child's symptoms, their beliefs about the causes of Autism, and their perceived caregiving mental and physical health outcomes) influence parents' intention to seek services for their children with an autism spectrum disorder (1-10 years old) in India.

*Influence:* In this qualitative study, influence refers to the impact or effect a factor has on the ongoing process, experiences, or perspectives of participants, shaping their behaviors, attitudes, and meanings. It is a process-oriented concept rather than a static outcome, emphasizing how something changes or alters the course of action or understanding (Tenny et al., 2022). In this study, parents seeking care for autistic children had an influence based on their autism-related experiences and perspectives, shaping their behaviors, attitudes, and meanings.

*Parental knowledge and perception:* Parents' beliefs and understanding of autism. It is the parents' level of information, belief, and interpretation of Autism in the child (Asiri et al., 2023). Educational programs, resources, and support services play a crucial role in empowering parents to make informed decisions and provide the best possible care for their children.

*Parents' intention to seek services:* Parents planned or expressed a desire to actively look for and access a particular service, like healthcare, counseling, or other professional assistance, indicating their willingness to obtain that service when needed (Gelaye et al., 2024).

*Perceived caregiving mental and physical health outcomes:* The effects that caregiving, especially for individuals with neurodevelopmental disorders like autism, can

have on the caregiver's overall well-being. These mental and physical outcomes often result from the challenges and stresses associated with caregiving responsibilities (Asiri et al., 2023).

*Perceived severity of autistic children:* The severity of a child's symptoms based on observations of their behavior and communication abilities. It represents the level of autistic symptoms in children to provide appropriate treatment (Asiri et al., 2023). It is important to note that autism is a spectrum, and the severity of a child's symptoms can change over time with appropriate interventions and support.

### **Assumptions**

In this research study design, I recruited parents with children diagnosed with autism/ASD for individual semi-structured interviews at the Asian Neuro Child Clinic in Ahmedabad, India. Based on the need for primary data collection, several assumptions are made. I assumed all parents are going through similar challenges in their pre-care-seeking and during care-seeking experiences. I assumed the interviews would be conducted in person at the clinic for approximately an hour, in Gujarati, and then translated into English. I thought parents would be honest and openly talk about their life changes, challenges, and struggles with an autistic child. I assumed the clinic's location would be less busy during the interview, allowing parents to complete it in one session. I also assumed that each parent could answer all questions without reservation about the research.

### **Scope and Delimitations**

This study's intended objective was to explore how the perceived severity of an autistic child's symptoms, the beliefs about the causes of autism, and perceived caregiving mental and physical health outcomes affect parents' intention to seek services for their children with an autism spectrum disorder (1-10 years old) in India. The inclusion criteria are

- biological parents of autistic children (1–10 years old)
- residents of Gujarat state
- the child actively enrolled at the Asian Neuro Child Clinic during the study period

The exclusions included participants who did not meet the requirements mentioned above. In this qualitative study, several delimitations were noted. The researcher established delimitations to define the scope of the study. An example is

- Population selection: The population matches the inclusion requirements of this study.
- Time frame- parents who are actively seeking autism care for their autistic children.
- The theoretical framework is based on the Health Belief Model, which focuses on cognitive constructs rather than emotional and social factors (Gustavsson & Beckman, 2024).

### **Limitations**

The first limitation of the study was the potential bias in the instruments used for data collection, which could have influenced the process and results of the study (Anderson, 2010). A possible limitation of the study was recruiting parent participants with children with ASD, as potential participants may feel uncomfortable participating in a research study. Another potential challenge was the time-consuming nature of the process. An example is conducting one-on-one, semi-structured interviews at the clinic. There may be a Hawthorne effect, in which participants react differently when being observed (Anderson, 2010). In qualitative studies, there was difficulty in establishing validity and realizability biases. Semi structured interview documentation was used in journaling before the research. The documentation continued throughout the recruitment, interviewing, data analysis, and result stages. The process has strengthened the trustworthiness of the results by identifying inaccuracies and inconsistencies between participants based on the researcher's experience. A possible limitation of this qualitative study was response bias, as the data collected may have been influenced by participants' limited understanding of the topic (Anderson, 2010). Self-assessed behaviors may be biased due to social desirability or a misunderstanding of how to measure proper behavior. The study was limited to transcribing the primary data set from Gujarati to English or from Gujarati to English only.

### **Significance**

This study has insights into the challenges Indian parents face in raising their children with autism and support systems. The findings contributed to the knowledge

base, helping service providers better understand parents' needs during this critical period (Srikanth et al., 2020). It also informed public health departments and practitioners of practical ways to support families during transition. The research has the potential to bring about positive social change by providing critical information for decision-making and planning that can improve transition support services for families affected by ASD in India. Additionally, professional support for parents seeking assistance is crucial in addressing key aspects that affect their lives, such as family values, mental and physical health improvements, enhancing marital relationships in the context of caring for an autistic child, gaining a deeper understanding of the child's needs, recognizing and managing the child's behavior, and taking proactive steps to access healthcare resources and support. (Srivastava et al., 2024). Autism screening will contribute to social integration in academic settings, such as schools and kindergartens. It will potentially create more resources and training for academic professionals to acquire the skills necessary for working with autistic children. Furthermore, autism screening facilitates the development of mentorship programs that aim to promote autism awareness, accessibility, and accommodations for autistic children in India (Murthi et al., 2024).

### **Summary**

Chapter 1 explored the care-seeking parents' perceived severity of an autistic child's symptoms, their beliefs about the causes of autism, and their perceived caregiving mental and physical health outcomes. Of studies on autism over the last decade, few focus on studies that talk about the parental aspect of living with autism by children. This chapter concluded by acknowledging, accepting, and acting on the needs of autistic

children, with a focus on improving parents' accessibility to care. It aimed to spread more awareness for the parents and families to work with an autistic child and their needs.

Chapters 2 and 3 provided a more detailed literature review, accompanied by further investigation.

## Chapter 2: Literature Review

Chapter 2 provides a literature review to support the current qualitative study. The research problem this study addressed was that family decision making is shaped by traditional gender roles, with mothers primarily responsible for caregiving. However, their perspectives are underrepresented in research (Gulati et al., 2019). These perspectives are shaped by a prioritization of faith-based practices over conventional medical treatment, rural–urban disparities that further restrict access to services, and the inability to afford private care, causing delays in seeking care for autistic children in India. The purpose of the current study was to explore how factors such as parents’ perceptions of the severity of their autistic child’s symptoms, their beliefs about the causes of autism, and perceived caregiving mental and physical health outcomes affect parents’ intention to seek services for children with ASD age 1–10 in India.

Some factors that influence parents’ intention to seek services for their children with ASD are awareness of ASD, parents’ education, cultural beliefs, and access to health care (Raju et al., 2023). Because of these factors, many lower income household children face challenges such as late screening and diagnosis that limit early intervention services for ASD (Elkhatib Smidt et al., 2020). It is not only the caretakers who pose a barrier; a study assessing the perceived availability of services in autism centers revealed that many centers lack essential services, including home care and outreach programs, integrative educational programs, and occupational therapy, with limited access to outside referrals (Babatin et al., 2016).

Factors include specific ASD intervention types and effects of diagnostic experiences, particularly in cultures where societal judgment or discrimination are a concern. As a result of cultural norms, parents may hesitate to seek professional help due to fears of being socially rejected or marginalized (Narayana et al., 2020). The current study addressed the gap between care-seeking parents of ASD children to help parents recognize and acknowledge the severity of an autistic child's symptoms, their beliefs about the causes of autism, and their perceived caregiving mental and physical health outcomes in India. Chapter 2 presents a literature review of topics related to this research topic. Chapter 2 includes the literature search strategy, the theoretical framework, and a comprehensive review of the key variables and factors associated with ASD.

### **Literature Search Strategy**

I used databases such as MEDLINE/PubMed, Scopus, CINAHL, APA PsycInfo, SocIndex, ScienceDirect, Academic Search Complete, Social Sciences Citation Index, Education Source, Directory of Open Access Journals, and several others to find peer-reviewed articles published between 2016 and 2025. The primary search keywords were *autism/ASD/autism spectrum disorder, child/children, parents, and India*. The initial search yielded around 250 articles. To refine the results, I used an advanced search focusing on epidemiology journals, which narrowed the list to 16 articles (see Table 1).

**Table 1***Literature Search Strategies*

Database	Search term	Result
Walden University Library	Autism/ASD/autism spectrum disorder, child/children, parents, and India from 2016-2025	250
Google Scholar	Autism, children, parents, and India from 2016-2025	152

**Theoretical Framework**

The Health Belief Model (HBM; Hochbaum et al., 1952) provides the theoretical framework for this study. It is used in public health, where it helps promote public health promotion models and interventions, such as preventive behaviors like vaccinations and screenings, as well as risk behaviors and contraceptive behaviors. The HBM explained how individuals' perceptions of severity, benefits, and barriers influence health-related decisions. HBM theorized that people will act to prevent illness if they regard themselves as susceptible to a condition described as "perceived susceptibility." "Perceived severity" arises if they believe it would have potentially serious consequences. "Perceived benefits" referred to whether they think that a particular course of action available to them would reduce the susceptibility or severity or lead to other positive outcomes. Finally, if they perceive negative attributes related to the health action, this is known as "perceived barriers" (Jones et al., 2015).

The strengths of HBM in the qualitative study included identifying health behavior triggers, providing a comprehensive view of health behavior, its applicability to various health issues, a focus on perceptions, and customization to specific populations

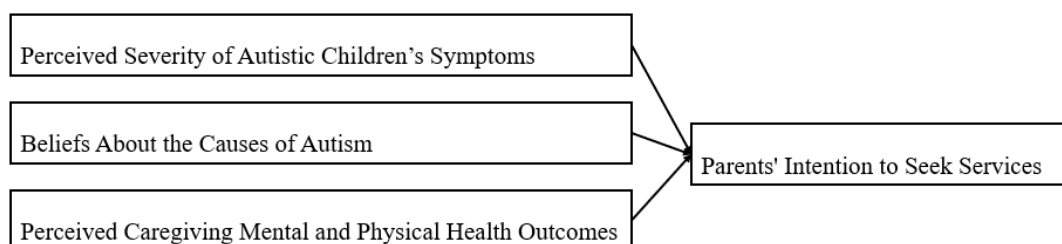
(Champion et al., 2008). The HBM framework explains various cognitive and emotional factors that influence healthcare decisions. It helped enhance self-efficacy and tailor health interventions to uncover different social, cultural, and economic contexts, thereby shaping health-related behaviors. Especially in qualitative studies, HBM has explored barriers such as cost, inconvenience, and fear. The HBM model's strengths align with the care-seeking parents' lived experience in India.

The HBM model's qualitative limitations include rationality, lack of attention to social media, cultural limitations, limited focus on emotion and psychological factors, and assumptions of active decision-making in a qualitative study. In the current study context, parents may not seek care for their children with ASD despite understanding the benefits because of emotional fear, guilt, or denial. It overrode their decision-making capacity. The health belief model cannot fully capture this complexity. It can limit the ability to explain parental delays in seeking care for their children with ASD.

This study explored how parents' perceptions of the severity of an autistic child's symptoms, the causes of autism, and caregiving mental and physical health outcomes influence their decisions to seek services for their children with an autism spectrum disorder (1-10 years old) in India (see Figure 2).

## Figure 2

### *Studied Constructs and Their Relationships*



### **Perceived Severity of Autistic Children's Symptoms**

The literature reveals significant tensions and contradictions that shape the understanding and measurement of ASD severity. Waizbard-Bartov et al. (2023) argued that the severity of symptoms should not be viewed solely through the core diagnosis, but rather as a multidimensional construct shaped by co-occurring conditions, adaptive functioning, and environmental factors. This perspective contrasts with Al Dera's (2017), who used the Autism Treatment Evaluation Checklist (ATEC) to link parental risk factors such as maternal depression, advanced maternal age, and BMI to higher severity scores, suggesting a more linear and individual-focused understanding of ASD severity. These perspectives reflect a deeper tension between clinical quantifications of severity and how parents and practitioners may perceive it in everyday life. Moreover, Narzisi et al. (2024) highlighted that although social skills interventions show moderate efficacy for children with Level 1 ASD, the lack of consistent outcome predictors implies that perceived severity may not directly correspond to actual intervention responsiveness. This

disconnect raises questions about the reliability of existing severity labels in capturing the actual support needs and functional challenges of autistic youth.

Additionally, the term “profound autism” developed by Waizbard-Bartov et al. (2023) aimed to clarify support needs but may reinforce categorical thinking that oversimplifies individual differences. Collectively, these studies concluded that ASD is not a fixed clinical disorder, but a fluid and context-dependent concept influenced by diagnostic frameworks, access to care, parental experiences, and the adequacy of cultural support. Thus, when discussing the perceived severity of a child in India with ASD, the level of severity is challenging to define.

### **Beliefs About the Causes of Autism**

Parents’ beliefs about the causes of autism significantly influence their care-seeking behaviors, with cultural interpretations shaping their treatment choices. Studies, such as those by Zuckerman et al. (2016), Vats et al. (2024), and Chaidez et al. (2018), showed that cultural beliefs, such as karma or divine will in India, or environmental factors and vaccines in other contexts, can lead parents to seek alternative or traditional treatments over evidence-based medical care. This creates tension between traditional and biomedical perspectives, where well-meaning but misinformed cultural beliefs may delay diagnosis or result in the pursuit of ineffective treatments. Furthermore, cultural context studies, such as those by Asiri et al. (2023), have highlighted a significant knowledge gap in Saudi Arabia. The study shows that parents may hold positive attitudes toward autism but lack a deep understanding, contributing to misconceptions and delays in seeking the appropriate care. Cultural stigma, as noted by both Vats et al. (2024) and

Asiri et al. (2023), also plays a key role, as many parents hesitate to disclose an ASD diagnosis in their children for fear of discrimination from the communities or relatives, further delaying intervention. Thus, there is a need for culturally sensitive approaches to address parental beliefs and knowledge gaps, guiding families toward timely and effective autism care.

### **Perceived Caregiving Mental and Physical Health Outcomes**

In India, particularly in rural regions, parental physical and medical health plays a critical role in shaping awareness, perceptions, and responses to ASD. Narayana et al. (2020) recognized that in Indian rural communities, limited awareness of ASD among parents results from poor access to medical resources, insufficient training for healthcare providers, and underlying challenges in parental health literacy. As a result, these factors often delay early detection, leading to a missed window for timely ASD intervention for their children. While caregivers' physical and mental health are rarely the central focus of studies of Indian childhood ASD, they are essential in determining whether families recognize or pursue the need for developmental assessments. This also resonated in broader global findings, such as those by Asiri et al. (2023), where even among educated parents in Saudi Arabia, misperceptions and stigma about ASD diagnosis were common issues. Such barriers are magnified in India, where healthcare disparities are more pronounced.

Furthermore, the psychological readiness of parents, influenced by chronic stress and untreated health conditions, can influence their openness to seek help, as seen in the study by Onyeukwu and Donahue (2023), which links maladaptive personality traits and

mental health stigma to avoidance of treatment. In India, where parental health services often focus narrowly on maternal or childcare, a more holistic approach is needed, one that addresses the physical and mental health of caregivers, improves health education, and integrates ASD awareness into routine community health initiatives. This factor highlights a critical tension; while improving child outcomes requires early ASD detection in India, doing so without supporting the well-being and medical literacy of parents' risks perpetuating cycles of delay, denial, and disengagement from care.

### **Parents' Intention to Seek Services**

Based on the HBM, it is assumed that parents' desire to actively seek and access a particular service, such as healthcare, counseling, or other professional assistance, is influenced by their perceptions and beliefs (Gelaye et al., 2024).

## **Literature Review Related to Key Variables and/or Concepts**

### **Children With an Autism Spectrum Disorder**

ASD is a neurological and developmental condition with increasing prevalence, particularly in India, where diagnosis and healthcare access remain significant challenges. Studies and reports (Bhatia et al., 2019; Tiwari et al., 2021; Weiss et al., 2017) showed that ASD is linked to altered brain activities and influenced by genetic mutations. Children with ASD respond to light, sound, and texture delays sensitively (Tomchek and Dunn, 2017). In the United States, higher socioeconomic status (SES) areas show a higher prevalence of ASD (Durkin et al., 2017). However, in developing countries like India, limited access to healthcare and low awareness result in poor compliance with

health screenings and vaccinations, underscoring the need for greater awareness and improved intervention services (Akhtar and Akhtar, 2023).

In India, the ASD prevalence is 1 in 100 children (Bhatia et al., 2019). Studies like Tiwari et al. (2021) found prevalence rates of 1 in 125 children in the 2-6 age group and 1 in 80 in the 6-9 age group in Northern and Western India. Arun and Chavan (2021) reported a prevalence rate of 2.25 per 1,000 children in Chandigarh, covering urban, rural, and slum areas. The data suggests that the rising recognition of ASD in India is contrasted by barriers such as underreporting, limited healthcare access, and varying cultural perceptions, affecting diagnosis.

In India, the Indian Scale for Assessment of Autism (ISAA), the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), and other tailored tools are used for autism screening. ISAA diagnoses, classifies, and enables disability certification for ASD and is considered valid across India. The validity and effectiveness of this scale depend on region-specific factors and cultural appropriateness in India. Cultural values and language differences across regions, such as Gujarat, may also affect the applicability and effectiveness of autism screening tools.

### **Services for Children With ASD**

The services for children with ASD are educational, diagnostic, and therapeutic. Educational services encompass understanding families' perspectives, fostering empathy, and refining the quality of education policies and practices. Baglama and Demirok's (2016) study showed that an autistic child's mother expresses those concerns with insufficient educational support and services. Diagnosis services include healthcare

access and the viability of primary care providers. Cantor et al.'s (2021) survey showed that approximately 50.3% of outpatient mental health treatments for children with ASD. Lindly et al.'s (2018) data showed that 29% of children with ASD experience healthcare access problems in finding primary care providers. Therapeutic services include applied behavioral analysis (ABA) and cognitive, speech, and visual therapies for children with ASD (Sinha et al., 2018), and specialized services are limited only to urban centers (Basu et al., 2020).

In India, there are challenges to accessing services for Children with ASD, for example, distance to diagnostic centers and costs of assessments (Reddy et al., 2020). Specialized diagnostic professionals and services are limited to geographic sites (Patel et al., 2017). Many mainstream schools lack the necessary resources (Ghosh, 2017) and have limited reach to government schemes and financial support (Rao and Nayar, 2021). In urban areas, support groups help with emotional support and advocacy, while awareness campaigns by NGOs aim to reduce stigma and promote inclusion (Reddy et al., 2020; Thakur and Singh, 2019).

Telehealth is one of the new initiatives that aligns with broader health initiatives aimed at improving accessibility and reducing healthcare service disparities (Cantor et al., 2021). The gaps in existing studies highlighted the need for more culturally sensitive educational policies, widespread awareness campaigns, and accessible services for children throughout India. Most existing studies lack accounts of the lived experiences of care-seeking parents.

## **Role of Parents and Caregivers in Supporting Autistic Children**

Parents and caregivers play a significant role in the social, emotional, and cognitive development of children with ASD. A 2017 study by Dawson et al. found that parents trained in behavioral techniques can effectively reinforce therapeutic skills at home, improving social communication and adaptive behavior. Caregivers also provide crucial emotional and psychological support, helping children manage social difficulties, sensory sensitivities, and emotional regulation. Perry et al. (2020) emphasized that caregivers' emotional stability and responsiveness are vital for fostering positive outcomes in children with ASD. The limitation is the neglect of family context and heterogeneity in the intervention model. Furthermore, parents often advocate for their children's cognitive needs in educational settings, ensuring they receive the proper accommodations and support. Lukens and Linscheid (2018) demonstrated that parent training improves caregivers' understanding of ASD and equips them with strategies to address challenging behaviors and promote positive behaviors, albeit with limited reporting fidelity.

In India, parents and caregivers play a critical and multifaceted role in supporting the development, well-being, and inclusion of children with ASD (Vats et al., 2024). Due to India's unique socio-cultural, economic, and healthcare challenges, these roles can vary significantly from those in other parts of the world. With limited awareness of ASD in India, parents are often the first to identify early signs of developmental delays or behavioral issues, such as speech delays, social withdrawal, and repetitive behaviors (Narayana et al., 2020). Despite facing financial, geographical, and cultural barriers,

parents actively seek diagnostic evaluations for their children (Patel et al., 2017).

Additionally, the stigma surrounding disabilities, including autism, often adds emotional stress for families. Parents and caregivers frequently encounter societal misconceptions and advocate for their children's rights to education, social inclusion, and acceptance (Sharma et al., 2018). They also navigate bureaucratic obstacles to secure the appropriate educational support, striving for better resources in mainstream and special schools (Ghosh, 2017).

Parent training programs are increasingly available in urban areas, helping parents learn autism-specific behavioral strategies. However, in rural areas and smaller towns, many parents assume responsibility for implementing therapeutic interventions at home due to the limited availability of professional services. There is conceptual tension between global frameworks and local realities. In countries like India, cultural stigma in healthcare infrastructure often limits awareness, which differs significantly from the international framework. The global study pattern shows the growing recognition of parental and caregiver importance in ASD childcare.

### **Factors That Influence Parents' Intention to Seek Care for Children With ASD**

The health belief model allows analyses of factors that influence parents' decisions to seek services for children with ASD, including individual, family, societal, and systemic elements. These factors often vary across cultures, regions, and socioeconomic groups but share common themes of awareness, accessibility, and support.

## **Modifying Factors: Demographic, Socioeconomic, Geographic, and Cultural Factors**

Socioeconomic factors play a significant role, as the cost of diagnosis and therapy can be prohibitive, especially for low-income families. Even in urban areas, financial limitations can restrict access to quality care (Sinha et al., 2018). The cultural stigma surrounding autism in some societies, such as India, can create feelings of shame, making parents hesitant to seek help (Narayana et al., 2020), while traditional family views may also conflict with professional treatment (Vats et al., 2024). Access to healthcare services is another major factor. Families in urban areas generally have easier access to specialists. In contrast, rural families face difficulties due to a lack of trained professionals, long waiting times, and inadequate support (Basu et al., 2020). Support from family, friends, and advocacy groups can also significantly influence parents' decisions to seek help, providing both emotional and practical guidance (Thakur and Singh, 2019).

In India, parents of autistic children face multiple challenges, including a lack of knowledge and skills for caregiving, social stigma, and difficulties in accessing healthcare and legal support (Junnarkar et al., 2022). Social stigma arises from misinformation about autism, leading to discrimination, social devaluation, and parental isolation, which impacts mental health (Gupta and Arriaga, 2014). Additionally, parents struggle with securing adequate educational and financial support, managing hyperactive behavior, and communicating with their children (Nkonyane et al., 2021). In this current study, semi structured interviews were designed to address the parents' understanding of

autism, struggles with cultural norms in India, and parental experiences living with children with ASD based on the limitations of Gupta and Arriaga's (2014) and Nkonyane et al. (2021) studies.

This shows the conceptual tension between cultural or traditional beliefs and the modern medical understanding of autism. It creates conflicts for care-seeking parents who want to seek effective treatment yet face pressure from cultural norms to discourage them. The global study pattern shows consistency in financial burden and gender roles in providing care worldwide, with cultural taboos and weak infrastructure specific to non-Western countries. It creates more opportunities to explore the severity of an autistic child's symptoms.

### **Perceived Severity of an Autistic Child's Symptoms**

Autism screening is crucial to early childhood development and identifying autism symptoms. Pediatricians monitor a child's growth during the first few years at intervals of 3, 6, 9, and 12 months, followed by additional check-ups at 2 years and beyond. The American Academy of Pediatrics recommends autism screening at 18 and 24 months (Clinical Screening for ASD, 2024). Early detection allows better management of ASD, improving a child's developmental outcomes (Chantaraseno et al., 2024). For example, a lack of response to one's name or not engaging in social games can appear as early as 9 months. It helps pediatricians identify red flags and refer children for further evaluation and intervention. Table 2 represents the symptoms with standard milestones in children compared to children with ASD and delays in key milestones.

**Table 2***Key Milestones and Autistic Symptoms by Age*

Age	Typical milestone	Autistic symptom
0–12 months	Smiles, babbles, responds to name	Limited eye contact, little social interaction
12–24 months	Uses simple words, engages in basic play	Delayed speech, lack of pretend play
2–3 years	Forms short sentences, enjoys group play	Difficulty with communication, prefers to play alone
3–5 years	Plays with others and understands emotions	Limited social interest may repeat actions or phrases

ASD symptoms are not only related clinically but also in contexts of cultural, societal, and geographical factors, especially in India. Gupta and Singhal (2004) mentioned that in India, developing ASD symptoms related to personality traits, divine punishment, and past karma are part of cultural stigma. It prevents parents from seeking medical attention and challenges early diagnosis. Sinha et al. (2018) highlighted geographical disparities, noting that urban areas generally have better access to diagnosis and interventions. Families in urban areas have a better understanding of ASD symptoms, particularly those with higher education (Doda et al., 2024; Reddy et al., 2020). India is a diverse country with multiple languages that create barriers between parents and healthcare providers to form effective communication during care-seeking and screening of their children with ASD. The included studies showed the need for more culturally sensitive, accessible, and consistent autism screening and diagnosis practices in underserved areas in India.

Addressing children's ASD symptoms related to cultural misconceptions, improving awareness, particularly in rural areas, and bridging resource gaps due to diagnosis delays will further impact ASD developmental outcomes (Patel et al., 2017). The conceptual tension highlights the interplay between clinical objectivity and cultural subjectivity. It represents the gap between medical recommendations for early interventions and the perceived symptoms by families, resulting in delays in diagnosis. That leads to a better understanding of the beliefs about the cause of autism.

### **Beliefs About the Causes of Autism**

Autism is a neuro and developmental disorder. Its lived experiences are shaped by social, cultural, and economic factors, and they vary in different countries based on the perspective of diagnosis and care. Traditional medical frameworks consider autism as a neurodevelopmental disorder that causes deficits in social communication and repetitive behaviors. Critical disability studies argue that disability, like autism, is shaped by social, economic, and political factors that create barriers to inclusion and equality (Oliver, 1996). The lived experience of autism can be varied across individuals and is shaped by diverse family dynamics, cultural norms, economic contexts, and access to resources (Silvers, 2018). In a culture like India, where family is the primary source of care and support, cultural interpretation of autistic disabilities can be a mark of stigmatization, empowerment, exclusion, and broader social attitudes (Simplican, 2015).

Especially in countries like India, cultural and familial factors play a significant role in the care and perceptions of ASD in children. Simplican (2015) discussed that in India, autism is seen through the lenses of stigmatization, empowerment, and exclusion in

the context of culture and society. It shows that cultural values can hinder the acceptance of ASD in children by their families. Parental knowledge and awareness impact the willingness and ability to find care for their children with ASD (Vats et al., 2024). Even highly educated parents lack awareness about autism and have difficulty understanding the variation of ASD. It can lead to misdiagnosis, delayed interventions, and inconsistencies in finding care for ASD in their children.

Autism misconceptions are widespread, and education alone is not enough to change parents' beliefs. Castillo et al. (2019) found that people living in the USA believed spiritual forces, negative thinking, stress, and diet were significant causes of autism. Srivastava et al. (2024) discussed that people in India believed in myths like the idea that vaccinations cause autism. These beliefs help dispel care-seeking behavior in parents through better education. Vats et al. (2024) discussed that in India, urbanization and the decline of joint families have affected traditional child-rearing and the support systems available for families raising children with autism.

In global study patterns, autism is often studied in Western countries; however, contexts like the USA may not reflect the same experiences in non-Western countries like India. Cultural differences in understanding, perceiving, and maintaining ASD can lead to biases. Lack of cross-cultural studies generalized the targeted population, such as children with ASD, across the world. Limitations such as the complexity of autism, cultural variability and generalizability, parental and societal knowledge gaps, stigma, barriers and benefits, self-reported data in previously conducted research, intervention of diversity, and efficacy play essential roles in beliefs about causes of ASD.

### **Perceived Caregiving Mental and Physical Health Outcomes**

Care-seeking parents with a child with autism experience immense strain in families, leading to marital challenges, emotional burdens, especially in mothers, and physical exhaustion, leading to broader family and therapeutic impacts. As a parent of children with ASD, most fathers often struggle with acceptance, resulting in emotional distance from their partner and, in extreme cases, abandonment. Baker et al. (2021) found that fathers who experience depression and anxiety may feel isolated or misunderstood in the caregiving process. Mothers often face frustrations due to a lack of time or space. They are unable to manage their emotions because they cannot leave their children alone. Smith and Green's (2019) study highlighted that mothers often play the leading role as caregivers and are frequently the primary point of contact with healthcare providers. They suffer more severe health outcomes compared to fathers, such as high blood pressure, sleep disturbances, a weakened immune system due to stress, and other mental health issues (Kaufman and Feldman, 2020). Kang et al. (2012) found that family beliefs encourage overprotectiveness in a collectivist culture like India. Both parents' emotional and physical toll leads to self-blaming for their child's condition with ASD and neglect of their health.

Baker et al. (2021) suggested that emotional distancing is observed in both the father's and mother's sides due to different approaches to care seeking for their child with ASD. Early intervention, such as couples therapy sessions, better health education about ASD in their children, their understanding and severity of ASD, and cultural factors, helps them to focus on their marital and family values as parents, yet as a couple. These

mental and physical outcomes, in turn, disrupt ASD children 's therapy and overall development. Diverse experiences of parents raising children with ASD need better support structures, therapies, and interventions that address care-seeking parents' needs alongside children with ASD (Baker et al., 2021; Kaufman and Feldman,2020; Smith and Green, 2019).

The conceptual tension lies between parental self-care and child-focused caregiving. There are conflicts between ideal good parenting and the reality of long-term caregiver sustainability. The global study pattern shows caregivers' well-being, capacity, burden, health support, and significant emotional and physician strains worldwide. With health outcomes, parental barriers, and benefits, finding care for children with ASD is challenging.

### **Perceived Benefits and Barriers**

Cultural beliefs are the most significant barrier in India. Apart from that, Bakar et al. (2019), Chakraborty et al. (2020), and Reddy et al. (2021) noticed barriers that care-seeking parents of children with ASD experience like a financial burden, high treatment costs, limited health insurance, low governmental support, transportation and cultural beliefs, poor awareness of laws, and complex healthcare application process in India. High treatment costs and not covered by limited or inadequate insurance coverage significantly delay or restrict access to ASD treatments, affecting children's well-being and development (Mazurek et al., 2023). The Rights of Persons with Disabilities Act of 2016 recognizes autism as a certifiable disability. However, enforcement gaps persist, with limited awareness of government schemes, insufficient social facilities, and complex

financial aid application processes (Chakraborty et al., 2020; Reddy et al., 2021). Furthermore, the complex application process for governmental financial aid and services, transportation issues, and lack of flexible appointments and therapy sessions create barriers to seeking help, especially in rural India. One of the most underrated barriers is lifestyle changes in prominent families, such as dietary adjustments or restrictions on high-sugar foods, which challenge care-seeking parents to balance their family responsibilities.

Kuzmina and Krivoshei (2024) and Vats et al. (2024) studies noticed some benefits that help care-seeking parents treat their children with ASD such as tailored ASD care plans, social media support, better parental education and understanding of ASD. In Indian private clinics help care seeking parents with customized health care plans to improve ASD children's needs, quality of life, illustration that not all children progress at the same pace or time window (Vats et al., 2024). Bakar et al. (2019) noted that care-seeking parents' use of technology helps them join online social media groups that share similar interests and resources based on their geographical locations. It provides care-seeking parents a space to connect, share experiences, exchange advice, ease the emotional burden, and feel less isolated when surrounded by other care-seeking parents from the community. As part of the technology access benefit, Kuzmina and Krivoshei (2024) highlighted that early screenings lead to better access to interventions, helping care-seeking parents tailor their support strategies in India.

Despite governmental challenges with better enforcement of policies, improved awareness of ASD in the community, and implementations of schemes in accessing

financial aid for care-seeking parents with children with ASD, healthcare professionals play crucial roles in holistically managing children with ASD and highlighting the need for parental self-efficacy to gain more and quicker benefits to seek care for their children with ASD. The conceptual tension lies between care seeking parents' accessibility and the effectiveness of autism care in their children. The global studies pattern shows that care-seeking parents rely equally on informal networks such as social media and negatively fragmented support systems worldwide. Self-efficacy guides care-seeking parents in making necessary changes in their lifestyle to create more benefits for their children with ASD.

### **Perceived Self-Efficacy**

Parents of children with ASD experience lower self-efficacy, leading to negative impacts on care-seeking roles. It leads to higher levels of mental and physical health conditions, such as stress, anxiety, and depression. Low self-efficacy in care-seeking parents hinders their ability to access ASD-related services and resources for their children.

In India, studies and research highlight the importance of enhancing parental self-efficacy through effective intervention plans for their children, such as innovative approaches like assistive technology (Chiswick et al., 2024). Care-seeking parents feel ineffective with increased psychological burdens, stress caused by perceived inadequacy, and reduced ability to engage positively with their child (Kou et al., 2019; Febrianti and Hildayani, 2024). Overwhelmed parents feel helpless, which prevents them from seeking help and may prevent them from pursuing resources and support for their child with

ASD. It may result in poorer outcomes for children seeking ASD. In India, the assistive technologies used by IIT and NID institutions reduce communication barriers, but also contribute to stress and frustration for children and their care-seeking parents.

Addressing parental self-efficacy via targeted interventions can improve parental health and the ability to advocate for access to services for their ASD children (Weiss et al., 2015). Especially for Indian parents, targeting self-efficacy can address unique cultural and systemic barriers, leading to better health outcomes for parents (Kanwal and Asad, 2018; Mohammed et al., 2024). Moreover, assistive technology enhances the communication of children with ASD. It improves parents' sense of competence by reducing their stress and burnout levels, ultimately leading to better care-seeking outcomes (Chiswick et al., 2024).

Existing studies have shown that conceptual tensions between individual responsibilities placed on parents hinder their ability due to systemic and structural limitations. Global study patterns show that low self-efficacy is a recurring theme amongst the care-seeking parents of children with ASD. However, Western countries have better interventions to support parents than non-Western countries. It also reflects the need for a global policy-driven, culturally sensitive support system. Low self-efficacy is interrelated with a cue to parental action for their children with ASD. It explores the parental understanding and relationships with their children with ASD.

### **Cue to Action**

Parental cues to action are key factors for initiating and sustaining behavior change and health interventions for children with ASD, especially in India, where

culturally responsive and resource-sensitive strategies are needed. Actions such as parent-mediated interventions, including culturally adapted communication tools and materials, responsive models like VQURA, and addressing the individual needs of children and families by improving parent-child interactions, as well as visual and narrative tools like cue cards, help trigger awareness and reinforcement of positive behavior in children with ASD. Lafleur et al. (2024) found that autistic children use visual cues, such as eye, cognitive, and verbal movements, as well as arrows, to direct attention, enhance memory, and reinforce behavior. In contrast, Christopher and Shakila (2012) used story-based cue cards with preschoolers in India, showing improvement in memory, attention, and eye contact. Kalorath et al. (2022) and Suman et al. (2024) demonstrated that value-based and family-adapted interventions improved multiple developmental domains.

These tools, such as visual cards or cues, support habits and facilitate independent decision-making in children by providing consistent visual prompts (Lafleur et al., 2024). These tool narratives are tailored to the needs of children with ASD to make it easier for parents to engage and reinforce learning outside of school or the clinic. These approaches help change family dynamics and support the uniqueness of each ASD child's development profile, as well as address resource limitations in India (Kalorath et al., 2022; Suman et al., 2024).

For parents, visual storytelling and cue-based interventions benefit non-verbal or minimally verbal children by reducing cognitive load and increasing engagement. It will also empower parents to create emotional and environmental support for the behavior change. It is encouraged to sustain responsive interventions by parents for long-term

benefits for their children with ASD. The conceptual tension highlights the gap between the potential effectiveness of parent-mediated interventions and the practical barriers to their implementation. As a result, in a global pattern, parental involvement is increased with family-centered and culturally responsive interventions. This study aims to ensure an understanding of caregiving parents' knowledge gaps in seeking care for their children with ASD.

### **Gaps in Literature: Factors That Influence Parents' Intention to Seek Services for Their Children With Autism Spectrum Disorder**

In India, there is a gap in several lesser-explored cultural, structural, emotional, and informational factors that significantly influence parents' decisions to seek care for children with ASD. It includes stigma and social acceptance of ASD in children, extended family influence, health literacy and information access, emotional and psychological factors, awareness of services and policies, peer and community influence, and financial concerns. Narayana et al. (2020) showed that fear of social rejection delays help-seeking. Vats et al. (2024) described traditional beliefs of elders as a barrier, as well as guilt and stress, as deterrents. Patel et al. (2017) identified gaps in rural information access, and Sinha et al. (2018) highlighted the economic trade-offs.

The key conceptual tension lies between structural and cultural explanations for parents' parenting-seeking behaviors. The study's evidence showed culturally that families in India avoid formal ASD diagnoses to protect the family reputation and avoid discrimination from the community, and involve multiple generations in decision-making that complicates traditional vs. modern beliefs (Narayana et al., 2020; Patel et al., 2017).

In terms of structural concepts, there are information gaps between rural and urban areas in India; parents may not pursue care options due to gaps in knowledge of support systems and subsidies (Basu et al., 2020; Rao and Nayar, 2021). In communities, positive or negative stories of children with ASD shape parents' beliefs about care outcomes. Emotionally, care-seeking parents often deny or are guilty of many reasons for postponing confronting a diagnosis (Vats et al., 2024).

These multiple studies showed cultural layers of barriers to accessing ASD services, family structures, mental and physical health of care-seeking parents, the need for improvement at the policy outreach level, community-based interventions, and financial support structures to encourage more equitable care-seeking. These changes will improve outcomes for children with ASD and provide support for the care-seeking parents. Existing studies showed a consistent global pattern of underutilization of ASD services, limited mental health literacy, financial barriers, and lack of culturally sensitive outreach, like existing Indian literature related to ASD in children. In this study, these gaps will narrow their focus to ASD severity perceptions, beliefs about causes, and caregiving burdens that influence parents' intentions to seek care for their ASD children.

### **Summary and Conclusions**

Chapter 2 concluded the literature review on children with autism and their parents seeking care in India. A comprehensive review highlights the availability of resources for treating autism in India compared to the USA (Chakrabarti, 2023). Known factors that influence parents' intention to seek services for their children with ASD are awareness of ASD, parents' education, cultural beliefs, and access to healthcare (Raju et

al., 2023). There are unknown factors like specific ASD intervention types, effects of diagnostic experiences, and particularly in cultures where societal judgment or discrimination is a concern. With cultural norms, parents may hesitate to seek professional help due to fears of being socially rejected or marginalized (Narayana et al., 2020).

While this study maintained its focus on the Indian context, understanding parental care-seeking behaviors for children with autism in India contributes to global scholarly conversations about how cultural interpretations of disability shape healthcare decision-making. Davenport et al. (2018) argue that cross-cultural examination of autism care reveals important insights into the intersection of culture, healthcare systems, and family dynamics that transcend national boundaries. Ramaswamy et al.'s (2018) study presented an improvement in autism healthcare through training healthcare professionals on cultural factors and engagement with families, as well as appropriate interventions for children with ASD.

This chapter addressed the gap in key aspects of the literature on children with ASD, the roles of parents and caregivers, parental beliefs, mental and physical health, knowledge and perceptions of ASD, and how the perceived severity of symptoms influences parents' care-seeking behavior. Chapter 3 provides an in-depth discussion of the interview guide, target population, researcher's role, ethical considerations, instrumentation, and ensuring trustworthiness in the study.

### Chapter 3: Research Method

The purpose of this basic qualitative study was to explore how the perceived severity of an autistic child's symptoms, parental beliefs about the causes of autism, or their perceived caregiving mental and physical health outcomes influence parents' intention to seek services for their children with ASD age 1–10 years in India. Chapter 3 focuses on the methodological aspects of this study, including the research questions, methods, role of the researcher, participant selection choices and logic, instrumentation, pilot study, recruitment process, data collection, data analysis plan, issues of trustworthiness, and ethical procedures.

#### **Research Design and Rationale**

This qualitative study addressed the following research questions:

RQ1: What factors influence parents' intention to seek services for their children with an autism spectrum disorder (1–10 years old) in India?

RQ1a: Child-related factor: How does the perceived severity of an autistic child's symptoms affect parents' intention to seek services for their children with an autism spectrum disorder (1–10 years old) in India?

RQ1b: Parental knowledge and perception: How do the beliefs about the causes of autism affect parents' intention to seek services for their children with an autism spectrum disorder (1–10 years old) in India?

RQ1c: Parent-related factor: How do perceived caregiving mental and physical health outcomes affect parents' intention to seek services for their children with an autism spectrum disorder (1–10 years old) in India?

A semistructured interview protocol was developed and pilot tested to explore how three HBM constructs (perceived severity of an autistic child's symptoms, the beliefs about the causes of autism, and perceived caregiving mental and physical health outcomes) influenced parents' intention to seek services for their children with ASD 1–10 years old in India. The research design was a basic qualitative approach, and the data analysis followed Saldana's (2015) descriptive coding process, utilizing both first- and second-cycle coding.

A basic qualitative study with thematic analysis was an appropriate choice for the lived experiences of care-seeking parents living with children with ASD in India. The design allowed me to explore parents' caregiving journey without being bound to a specific theoretical tradition. Thematic analysis helped me identify patterns across narratives, contexts, meanings, sensitivities, and emotions. The combinations of methods and analysis enhanced the understanding of parents' coping strategies, cultural influences, support systems, challenges, and policies around ASD in India.

### **Role of the Researcher**

As the primary investigator conducting the interviews, I recognized my position as a researcher and an individual with professional experience in health care settings serving children with developmental disorders in India. This dual position presented advantages and potential biases that needed to be addressed to ensure the data's trustworthiness. My professional background as a clinical health care professional provided me with a contextual understanding of health care systems in India and clinical knowledge about ASD. This knowledge facilitated rapport building with participants and

enabled more nuanced interview probing. However, this experience created preconceptions about parental experiences that could have influenced data collection and analysis.

I employed reflexivity to manage potential biases throughout the research process by maintaining a detailed research journal, documenting my reactions, assumptions, and decision-making processes. Before collecting data, I explicitly documented my preconceptions about factors influencing parents' service-seeking behaviors. During interviews, I practiced active listening and used primarily open-ended questions to ensure that participants' perspectives, rather than my assumptions, guided the conversation.

I had no prior relationship with any potential participants at the Asian Neuro Child Clinic, which helped minimize power differentials that could influence data collection. However, I recognized that my position as a researcher affiliated with Walden University may create perceived power imbalances. To address this, I emphasized my role as a learner, seeking to understand participants' experiences, conducted interviews in participants' preferred language (Gujarati), dressed in culturally appropriate attire, and engaged in informal conversation before beginning formal interviews to establish rapport.

## **Methodology**

### **Participant Selection Logic**

Gujarat state is a diverse state in India where people share different cultural values within the state (Anchal, 2022). Many families from diverse backgrounds across India live in the city of Ahmedabad. The population in Ahmedabad is a mixture of urban and rural communities, as it is one of the largest cities connected with many rural areas in

Gujarat state (Anchal, 2022). This allowed us to recruit participants from various backgrounds and cultures to share their experience as care-seeking parents with an autistic child in India. It helped to cover different cultural values, norms, challenges, and available resources while raising a child with autism.

Semi-structured, face-to-face interviews were conducted with 12-15 parents (Hennink and Kaiser 2021), each lasting at least 30 minutes. Interviews were conducted until data and theoretical saturation were reached; that is, (a) no new codes emerged in three consecutive interviews, (b) all research questions were thoroughly addressed with rich data, and (c) sufficient variation in experiences was captured. This approach recognized that predetermined numerical targets may be insufficient for ensuring qualitative rigor, particularly when exploring complex phenomena such as parental decision-making processes in culturally specific contexts (Guest et al., 2020).

Both purposive and snowball sampling were utilized. Initial participants were recruited voluntarily through flyers at the Asian Neuro Child Clinic in Ahmedabad, Gujarat, India. The inclusion criteria included: 1) biological parents of autistic children, 2) residents of Gujarat state, and 3) the child is enrolled at the Asian Neuro Child Clinic during the study period. The eligibility was confirmed during the consent process (before the interview). After the interview, the participants were encouraged to share the study flyer with other potential participants.

### **Instrumentation**

Semi-structured interview protocols were developed to explore how the perceived severity of an autistic child's symptoms, the beliefs about the causes of Autism, and

perceived caregiving mental and physical health outcomes influence parents' intention to seek services for their children with an autism spectrum disorder (1-10 years old) in India. First, key topics and potential interview questions related to each research question were developed through literature research and consultation with experts (e.g., committee members, clinic staff, etc.). Then, they validated and refined through the pilot test. The final study semi-interview guide was administered in person in Gujarati (the local language), and it contained a series of open-ended questions followed by secondary questions. Each interview was audio recorded. All audiotape recordings were transcribed after the interviews, first in Gujarati and then translated into English. The raw data (transcript, field notes, journal, etc.) were analyzed (code, categories, and themes developed).

### **Procedures for Pilot Study**

The pilot study (pilot study consent form, recruitment flyer, and interview protocol) was covered under the same IRB approval number as the main study. Two participants were recruited voluntarily through flyers at the Asian Neuro Child Clinic in Ahmedabad, Gujarat, India. The inclusion criteria are identical to those from the main study; they must be: 1) biological parents of autistic children, 2) residents of Gujarat state, and 3) the child is enrolled at the Asian Neuro Child Clinic during the study period. The eligibility was confirmed during the consent process (before the interview). After the interview, the pilot study participants were encouraged to share the study flyer with other potential participants. They were also informed that their responses would not be part of the main study; however, they were used to improve the interview guide/protocol (by

adding or modifying open-ended and/or follow-up questions). Each pilot study interview also helped the researcher audio record their response and test their interviewing skills.

### **Procedures for Recruitment, Participation, and Data Collection**

Potential participants were recruited voluntarily through flyers at the Asian Neuro Child Clinic in Ahmedabad, Gujarat, India. This clinic was chosen because it serves children with neurological and developmental delays. Once potential participants show an interest in the study (via email or a phone call), they received additional information about this qualitative study. The interview (date/time, location) was scheduled (via phone or email). The consent form was reviewed and signed before the interview.

I planned to recruit and interview 12-15 participants over the 4- to 6-week timeline. However, the recruitment continued until the content and theoretical saturation were reached. Each interview lasted approximately 30 minutes. It was audio-recorded. Participants and I communicated in Gujarati. Participants could stop the interview at any time, refuse to answer questions, and withdraw entirely from the study. At the end of each interview, participants were thanked for their participation and provided with information on disseminating the final study results. After each interview, the responses were transcribed and then translated into English. Codes, categories, and themes were developed to inform the content of the following interview.

**Table 3***Procedures for Recruitment, Participation, and Data Collection*

Recruitment			Data collection instrument: Semi-Structured interview			
Location	Sample	Mode	Location	Frequency	Duration	Recording
Asian Neuro Child Clinic in Ahmedabad, Gujarat, India	12-15 parents	Flyer	Asian Neuro Child Clinic in Ahmedabad, Gujarat, India	One interview per participant (not follow-up interviews)	Approximately 30 minutes per interview	Audio-recording
Timeframe			Summer -fall 2025			

**Data Analysis Plan**

Qualitative study data analysis involved gathering information and knowledge through a process that required the researcher to employ a range of skills, focusing on details. At the same time, it is essential to maintain a comprehensive view of the overall research project (Sullivan, 2011). The data analysis plan commenced in the summer and fall of 2025. In this study, responses from each interview were audio-recorded in Gujarati. It created more accessibility for analyzing the dataset. After each interview, the responses were transcribed and then translated into English. Codes, categories, and themes were developed to inform the content of the following interviews and to evaluate progress toward content and theoretical saturation (Paul and Bandyopadhyay, 2018). Thematic analysis is one of the most effective methods for determining the meaning of the research and answering the original research questions. Thematic analysis provides flexibility and freedom, making it a widely used qualitative research tool (Majumdar, 2019). In thematic analysis, I initially coded to identify key ideas, followed by themes by

grouping codes, reviewing, and refining themes to accurately reflect the data using NVivo qualitative analysis software (Campbell et al., 2021). Thematic analysis was conducted in three phases, as outlined in Table 4. The collected data protected the participant's credibility, transferability, dependability, and confirmability, thereby maintaining a high standard of qualitative research (Faria-Schützer et al., 2021).

**Table 4**

*Data Analysis Plan*

Research Questions	RQ1: What factors influence parents' intention to seek services for their children with an autism spectrum disorder (1-10 years old) in India?	RQ 1a: Child-related factor: How does the perceived severity of an autistic child's symptoms affect parents' intention to seek services for their children with an autism spectrum disorder (1-10 years old) in India?	RQ 1b: Parental knowledge and perception: How do the beliefs about the causes of Autism affect parents' intention to seek services for their children with an autism spectrum disorder (1-10 years old) in India?	RQ 1c: Parent-related factor: How do perceived caregiving mental and physical health outcomes affect parents' intention to seek services for their children with an autism spectrum disorder (1-10 years old) in India?
<b>Analysis</b>				
Timeframe	Summer -fall 2025			
Method	Thematic analysis <ul style="list-style-type: none"> <li>• First phase: Thematic analysis after each interview to inform you about the content of the following interview</li> <li>• Second phase: Thematic analysis after 12-15 interviews to determine the extent to which content and theoretical saturation have been reached</li> <li>• Third phase: Thematic analysis after each interview until the content and theoretical saturation are reached</li> </ul>			
Software	NVivo -qualitative data analysis software			

The dissertation findings were made available to parents to help them understand the overall challenges that care-seeking parents face in Indian society, including cultural, religious, economic, and social norms, so they can learn, adopt, and share more resources as care-seeking parents of an autistic child in India. In addition, this dissertation aims to draw attention to the challenges faced by care-seeking parents and to inform policymakers, government agencies, and healthcare professionals (including researchers, clinicians, and therapists) in India, enabling them to address these challenges and review the lived experiences of parents to create more effective outcomes and service plans.

### **Issues of Trustworthiness**

#### **Credibility**

Credibility, also known as internal validity, ensures that the qualitative study results are authentic, trustworthy, and accurately represent the participants' perspectives. For example, prolonged engagement in a qualitative study involves spending sufficient time with participants to build rapport, understand their context, and capture a rich, in-depth understanding of the phenomenon being studied (Hammarberg et al., 2016). This also allowed participants to understand the setting and the process, helping to determine whether the findings might transfer to other contexts or populations (Denzin, 2017). This study introduced participants to the recruitment flyer, consent form, and interview protocols. It helped them with the study participants' expectations and the credibility of their input to complete this study. The study chair validated the study data and methodological approach through the peer debriefing process. Steps such as triangulation for data cross-checking and interpretation, persistent observation with a chair, member

(methodologist) checking, and reflexivity to confirm the validity of biases involved, are employed to validate this qualitative study.

### **Transferability**

Transferability enables readers to assess whether the findings can be applied to other similar situations, based on the detailed context and descriptions provided by the researcher. The researcher should provide detailed descriptions of the research context, participants, and setting, allowing readers to assess whether the findings can be applied to their contexts (Yin, 2018). In this study, my documentation of each step ensured that the study design could be replicated in similar contexts or for similar phenomena, thereby enhancing the potential for transferability across multiple settings (Yin, 2018).

### **Dependability**

Dependability in qualitative research refers to the stability and consistency of the data over time, similar to reliability in quantitative research. It emphasizes whether the findings of a study are consistent and can be repeated or verified in similar contexts. Keeping detailed records of the research process, including decisions made during data collection, analysis, and interpretation, is helpful (Birt et al., 2016). This allows readers to trace the derivation of the findings. For example, at Walden University, doctoral students work with the Chair and methodologist to verify the consistency and stability of their collected data. In this process, doctoral students work with the chair and methodologist to develop a clear research design, keep comprehensive records of all steps in the study, including raw data such as interview transcripts, field notes, memos, and reflections, and conduct peer examinations of each chapter. In the next step, IRB approval is required to

continue participant interviews based on the developed interview guide, process, and notes. Furthermore, returning to participants to ensure that the interpretations and findings accurately represent their perspectives helps the consistency and stability of the qualitative study (Birt et al., 2016).

### **Confirmability**

Confirmability refers to the degree to which the findings of a study are shaped by the participants and the data rather than by the researcher's biases, motivations, or perspectives (Fetters, Curry, and Creswell, 2013). Researchers must ensure that the data support their interpretations and conclusions, and that others can verify these. This was achieved by providing clear evidence of how the findings were derived from the data and minimizing the researcher's subjectivity (Fetters, Curry, and Creswell, 2013). For example, transparent documentation helped researchers recognize their biases before data collection, during interviews, and during raw data collection via notes and documentation.

### **Ethical Procedures**

The Interview process followed Walden University IRB guidelines to maintain ethical values. Participants were introduced to the process and asked to sign consent and interview protocol forms. Participants were informed about their volunteer participation, the choice to withdraw at any time, and the option to skip questions. Furthermore, the interview introduction includes transferability, honesty, and adherence to the process of not harming participants and following Walden University's IRB regulations. Ethical concerns, such as privacy, will be addressed by protecting participants' autonomy and

identity throughout the recruitment and data collection process. Participants' names were de-identified to protect individual confidentiality—for example, the participants were given a unique participant ID. As the researcher, I ensure the recruitment of participants, data collection, analysis, and interpretation. The collected data is electronically password-protected and encrypted. Data access is shared between the researcher and the committee to maintain data transparency and facilitate the completion of the dissertation process. Based on the inclusion criteria, if a participant decides to discontinue or withdraw, the collected data will be destroyed five years after the study's completion.

### **Summary**

This chapter has a detailed description of research methods, participant selection logic, the role of the researcher, pilot and primary studies, procedures for recruitment and participation, data collection, data analysis plan, and ethical procedures. The chapter provides in-depth knowledge of participants' trustworthiness, confidentiality, and transparency. Ethical procedure and IRB guidelines were discussed in a manner to protect the qualitative study of experiences of care-seeking parents with children with autism spectrum disorder in India. After IRB approval, Chapter 4 presents the data analysis of the collected datasets, followed by Chapter 5, which discusses the interpretation of the data findings, limitations, recommendations, and implications.

## Chapter 4: Results

The purpose of this basic qualitative study was to explore how factors (parents' perceived severity of an autistic child's symptoms, their beliefs about the causes of autism, and their perceived caregiving mental and physical health outcomes) influence parents' intention to seek services for their children with ASD 1–10 years old in India. This chapter outlines the recruitment process for the pilot study, the main study, the settings, and the demographic characteristics of the participants. The rest of Chapter 4 focuses on the data collection steps and analysis methods, with transparency regarding the recruitment and interview process of care-seeking parents living with autistic children in India.

### **Research Questions**

RQ1: What factors influence parents' intention to seek services for their children with an autism spectrum disorder (1–10 years old) in India?

RQ1a: Child-related factor: How does the perceived severity of an autistic child's symptoms affect parents' intention to seek services for their children with an autism spectrum disorder (1–10 years old) in India?

RQ1b: Parental knowledge and perception: How do the beliefs about the causes of autism affect parents' intention to seek services for their children with an autism spectrum disorder (1–10 years old) in India?

RQ1c: Parent-related factor: How do perceived caregiving mental and physical health outcomes affect parents' intention to seek services for their children with an autism spectrum disorder (1–10 years old) in India?

### **Pilot Study**

The recruitment process was smooth because of direct in-person access to parents of autistic children at the clinic. Parents of autistic children come to the clinic for the therapy sessions, which run between 1 and 2 hours. Therapy sessions include sensory, cognition, speech, and various other therapies based on the individual plans of the autistic child. Parents bring their child to the clinic and have them attend sessions with a therapist who trains them in various skills during the therapy sessions. Prior to the sessions, parents wait in the lobby area of the lounge, where I had the opportunity to recruit them individually. This circumstance provided me with direct access to explain to participants the purpose, procedures, and details of the current study, including volunteer participation, the right to withdraw at any time, and confidentiality of study data.

Recruitment for the pilot study began by posting flyers on the clinic's information board and in other areas of the clinic. I also found parents who come for the therapy sessions with their autistic children at the clinic with the help of the receptionist. I spoke individually with each parent at the clinic while they were waiting for their child's therapy session. I shared the pilot study flyers for volunteer participation in both English and Gujarati. Once they expressed interest in joining the study, I provided them with pilot consent forms to review and sign before scheduling their interview.

There were two pilot study interviews, each audio recorded separately within a week. The collected data were transcribed into English, and the pilot data were shared with the chair and members for feedback and suggestions to analyze the effectiveness of the questions in understanding the care-seeking behavior of parents living with autistic

children in India. The interview consistency helped to understand the effectiveness of each main question with suggested probes to address the research questions. The collected data from two interviews helped to avoid repeating the same ideas, facilitate smooth transitions from main questions to probes, and maintain the flow of the interviews. No additional changes were made to the interview guidelines. After refining the interview protocol through the pilot study, the next step was to establish the setting for the main data collection to ensure privacy and consistency.

### **Setting**

After completing the IRB study # 08-05-25-1028387 process at Walden University, data collection commenced at the Asian Neuro Child Clinic in Ahmedabad, Gujarat, India. Dr. Naik, a pediatric neurology consultant, runs this clinic. She provides diagnosis, treatment, and therapy for children who have neurodevelopmental disorders. I completed the recruitment of the participants and semi-structured interviews at this clinic in person. Dr. Naik and her staff have provided a private interview room to conduct the interview process, ensuring the privacy and confidentiality of the participant's data. They did not participate in recruitment, data collection, or data analysis.

### **Demographics**

The participants for this study were the biological parents of autistic children living in Ahmedabad, Gujarat, India. All participants' children sought care at the Asian Child Neuro Clinic. Recruitment began with two participants for the pilot study, followed by the main research, which included 10 participants who completed interviews. All 10 participants were mothers of autistic children, resulting in 100% female participation

among parents. This was not intentional; most children attended clinic visits with their mothers, resulting in an all-female participant group.

The gender ratio of autistic children was 60% boys and 40% girls. Participants' ages ranged from 29 to 42 years, with a median age of 35. Their education levels varied from high school to a master's degree: 60% held at least one graduate-level degree, 30% had a double graduate-level degree, and 10% were high school graduates. All participants were married and had between one and two children. These demographic details are summarized in Table 5.

**Table 5***Demographics of Participants*

Participant	Age	Relationship to the ASD child	Education	Number of children	Marital status	Gender of the child	Town
P1	38	Mother	Graduate	1	Married	Girl	Ahmedabad
P2	29	Mother	M.Com	1	Married	Boy	Ahmedabad
P3	42	Mother	Fashion Designer	2	Married	Boy	Ahmedabad
P4	33	Mother	B.Sc.	2	Married	Girl	Ahmedabad
P5	31	Mother	BBA	1	Married	Boy	Ahmedabad
P6	34	Mother	Graduate	1	Married	Boy	Ahmedabad
P7	39	Mother	B.A. B.Ed.	1	Married	Boy	Ahmedabad
P8	36	Mother	High School	2	Married	Girl	Ahmedabad
P9	42	Mother	Masters	2	Married	Girl	Ahmedabad
P10	30	Mother	Engineer	1	Married	Boy	Ahmedabad

**Data Collection**

Data collection was completed at the Asian Child Neuro Clinic in Ahmedabad, India. The participants who matched the inclusion criteria of this study were recruited. I recruited the parents of the autistic child. Each parent received recruitment flyers and consent forms about the study in English and Gujarati. Once participants decided to join the study, they read and signed a consent form for their participation as volunteers before

the interview. Ten participants from the main study completed semi-structured in-person interviews at the clinic.

I used a private interview room at the clinic to complete the semi-structured interview process in person. It helped to maintain participants' privacy and confidentiality. Each interview lasted 30 minutes to one hour. Each interview answer was recorded in an app called "Audio Recorder." This app allowed the recording of the responses in local languages to be later transcribed into English. The interviews were scheduled between the participants and me at mutually agreed-upon dates and times. Throughout each participant's interview, I observed no significant distractions that could have hindered data collection. Each participant responded comprehensively to questions, fully engaging in the research process.

After each interview, the thematic analysis method was used to code the data in NVivo qualitative software. Furthermore, I developed themes and categories as more interviews were completed. After each interview, I conducted initial data analysis. For the first 3–4 interviews, I only developed codes. After interview 5, I began developing themes and categories. This process helped to refine clarity, improve flow, and enhance the depth of the interviews. It helped to capture richer and more relevant data while maintaining consistency with the research questions. Here is Table 6, which shows the changes to the data collection instrument after each interview.

**Table 6***Changes to The Data Collection Instrument After Each Interview*

Interview number	Change made	Reason for change
1	Asked for additional information about physical health	To capture health outcome coping mechanisms
2	Created an example to understand the question related to society/cultural observation	To collect richer context about society and cultural context
3	Asked a question by breaking it down to a simple form	To ensure coverage of the probe questions in relation to the main question.
4	Asked participant to provide an example when they only said “yes or no.”	To collect a complete answer for the Individual question
5	Rephrase the question when the participant did not understand the question: “Are there any specific reasons that can cause autism in a child?”	To collect relevant context
6	Reassurance about the confidentiality to speak with no judgement	To provide credibility for the study
7	Asked to provide more details about the child comparison	To support the main research question context
8	Focused on her beliefs about nontraditional medicine	To create the depth of the context.
9	Minor wording adjustment	Data saturation approaching
10	No change	Data saturation approached

Once I have completed 10 interviews, data saturation occurs when I have gathered enough data to draw meaningful conclusions (Braun and Clarke, 2021). Further data collection yields diminishing returns, as it does not provide new information or insights that were not already available. The collected data will be stored electronically for a period of 5 years. Once the interviews were transcribed, the next phase involved organizing and analyzing the data using thematic methods.

## Data Analysis

The data analysis process followed Braun and Clarke's (2006) six-step thematic analysis framework. It was organized into five stages: coding, category development, theme development, conceptual mapping, and saturation check. This systematic approach ensured transparency and rigor throughout the study.

The first stage, coding, began after each interview was transcribed and de-identified. Transcripts were imported into NVivo, where initial codes were created to capture meaningful units of data related to the research questions. NVivo was used to generate code frequency reports and visualizations. For example, after the third interview, NVivo reports showed that "speech delay" appeared in 80% of transcripts, signaling its importance as an emerging pattern.

Next, category development involved grouping related codes into broader categories using Excel. A code-to-category mapping table was created to organize codes under categories aligned with the research questions. For instance, codes such as "speech delay," "lack of eye contact," and "social withdrawal" were grouped under the category "Social Communication Challenges." Excel also supported frequency matrices, which allowed for the comparison of category prevalence across participants, providing a clear view of recurring issues.

The third stage, theme development, synthesized categories into higher-level themes that addressed the research questions. NVivo facilitated this process through coding comparison queries and reviews. At the same time, Excel was used to build theme development matrices linking categories to research questions. Themes such as "Social

Communication and Interaction Difficulties,” “Misinformed or Culturally Influenced Beliefs,” and “Mental Health Outcomes” emerged from this iterative process.

In the fourth stage, conceptual mapping, relationships among themes and research questions were visualized using PowerPoint and Excel. These conceptual maps illustrated how factors such as perceived severity, cultural beliefs, and caregiving strain interacted to influence care-seeking behavior. For example, one map illustrated the connection between high perceived severity and increased service-seeking, in contrast to cultural fatalism, which can lead to delayed action.

Finally, a saturation check was conducted after ten interviews when no new codes or themes emerged. NVivo coding frequency reports and Excel matrices confirmed that data saturation had been reached, ensuring the completeness of the analysis. All outputs, including NVivo coding reports and Excel mapping tables, were documented and are available for committee review.

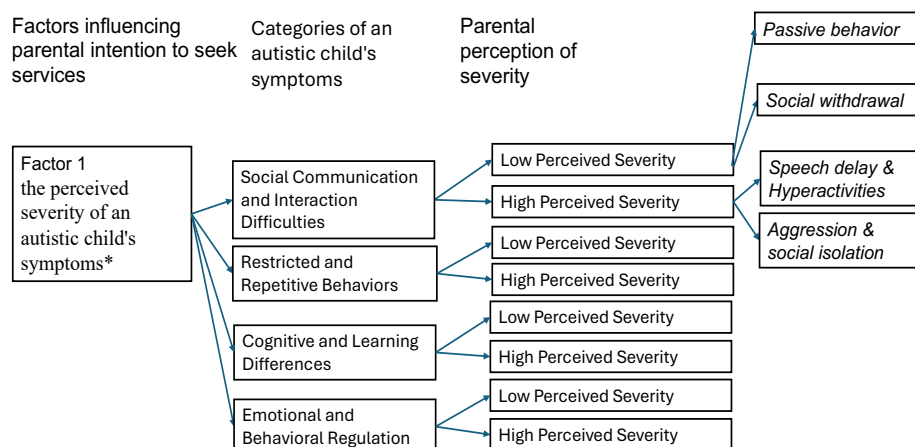
The main research question and its sub-questions are interconnected, forming a cohesive framework for understanding parental decision-making. Each factor, including the perceived severity of the child’s symptoms, parental beliefs about autism’s causes, and caregiving mental and physical health outcomes, was systematically analyzed to generate categories and themes that explain how these factors influence parents’ intentions to seek services for children with autism spectrum disorder (ages 1–10) in India. Figures 3 through 6 illustrate this progression: starting with initial coding of interview data (Figure 3), grouping codes into categories aligned with research questions (Figure 4), synthesizing categories into higher-level themes (Figure 5), and finally

conceptual mapping to show the relationships among themes and Health Belief Model constructs (Figure 6). This iterative process ensured that themes were not only descriptive but also explanatory, revealing how high versus low perceived severity, scientifically informed versus culturally influenced beliefs, and positive versus negative caregiving outcomes collectively shape care-seeking behaviors.

### Figure 3

#### *Child-Related Factor: The Perceived Severity of an Autistic Child's Symptoms*

RQ1: What factors influence parents' intention to seek services for their children with an autism spectrum disorder (1-10 years old) in India?

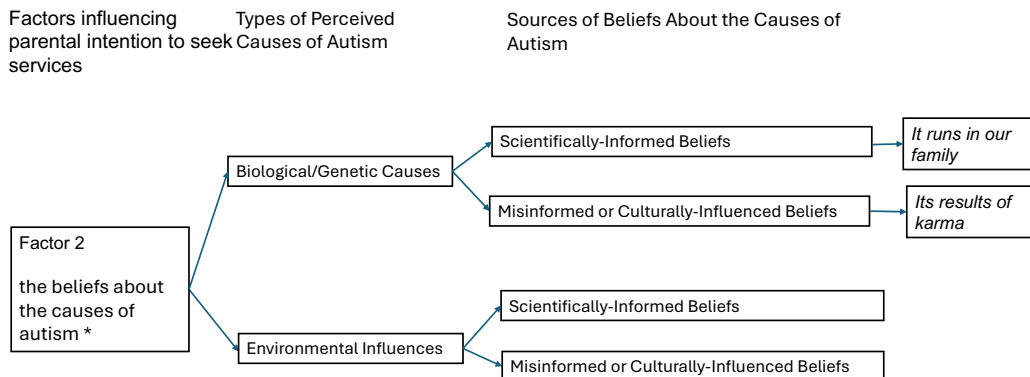


\* Note: Factor one is aligned with RQ 1a: Child-related factor: How does the perceived severity of an autistic child's symptoms affect parents' intention to seek services for their children with an autism spectrum disorder (1-10 years old) in India?

**Figure 4**

*Parental Knowledge and Perception: The Beliefs About Causes of Autism*

RQ1: What factors influence parents' intention to seek services for their children with an autism spectrum disorder (1-10 years old) in India?

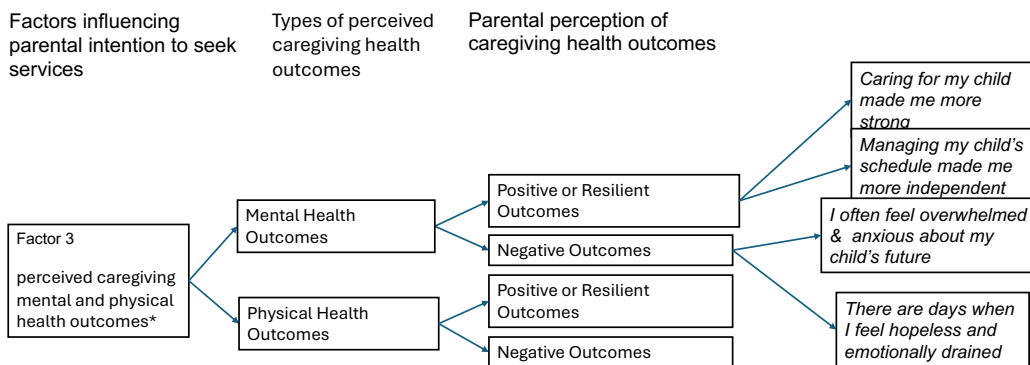


\* Factor two is aligned with RQ 1b: Parental knowledge and perception: How do the beliefs about the causes of autism affect parents' intention to seek services for their children with an autism spectrum disorder (1-10 years old) in India?

**Figure 5**

*Parent-Related Factors: Perceived Caregiving Outcomes of Mental and Physical Health*

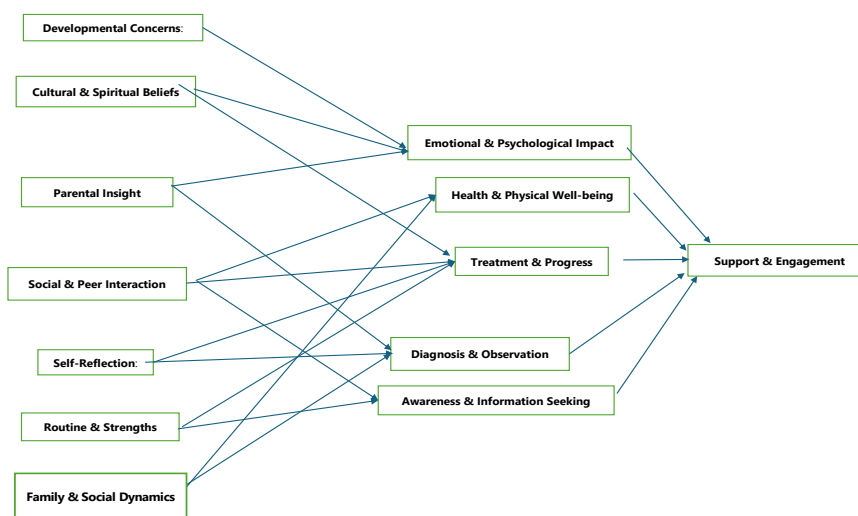
RQ1: What factors influence parents' intention to seek services for their children with an autism spectrum disorder (1-10 years old) in India?



\* Factor three is aligned with RQ 1c: Parent-related factor: How do perceived caregiving mental and physical health outcomes affect parents' intention to seek services for their children with an autism spectrum disorder (1-10 years old) in India?

**Figure 6**

*Mapping of The Factors: How They Affect Parents' Intention to Seek Services for Their Children*



### **Evidence of Trustworthiness**

Credibility was established through several strategies designed to ensure that the findings accurately represented participants' experiences. Prolonged engagement was achieved by conducting all interviews in person at the clinic, which allowed time to build rapport and observe contextual cues. Dissertation chair checking was implemented by sharing summary interpretations with participants after transcription to confirm accuracy through regular consultations, providing external review of coding and theme development. A rich, thick description of the setting, recruitment process, and participant demographics was included to contextualize the findings. Additionally, an audit trail was

maintained through NVivo coding reports and Excel mapping tables, which were documented and submitted for review by the committee.

Transferability was addressed by providing detailed descriptions of the research setting, participant demographics, and the cultural context that influenced care-seeking behavior. The study setting, the Asian Neuro Child Clinic in Ahmedabad, India, was described in detail, along with participant characteristics such as age, education, family structure, and caregiving context. Although the sample was limited to mothers from one clinic, the inclusion of diverse educational backgrounds and caregiving experiences offers insights relevant to similar urban Indian contexts. These descriptions enable readers to determine whether the findings apply to other settings.

Dependability was ensured through systematic documentation of all research steps, including recruitment, data collection, transcription, coding, and thematic analysis. An audit trail was maintained in NVivo and Excel to record methodological decisions, coding iterations, and theme development. A code-recode strategy was applied by revisiting initial codes after several interviews to check consistency. The interview guide was iteratively refined based on early interviews to improve clarity and depth, as documented in the instrument-change table. To strengthen dependability, a second coder will review a subset of transcripts (20–30%) to compare coding consistency, resolve discrepancies through consensus, and refine the codebook. These measures demonstrate that the study could be replicated under similar conditions and yield comparable findings.

Confirmability was achieved by ensuring that findings were grounded in participants' narratives rather than in the researcher's bias. A reflexive journal was

maintained throughout data collection and analysis to record assumptions, decisions, and reflections. NVivo outputs and Excel matrices provided transparency in how codes evolved into categories and themes. Peer review through continuous feedback from the dissertation chair helped validate interpretations and reduce subjectivity. These strategies confirm that the conclusions are data-driven and not shaped by personal perspectives.

## **Results**

### **Research Question 1**

What factors influence parents' intention to seek services for their children with an autism spectrum disorder (1-10 years old) in India? This section explains the factors that influence parents' decisions to seek services for children (ages 1–10) diagnosed with autism in India. The factors are grouped into four categories. Three of these categories align with the key constructs from research questions 1a, 1b, and 1c (perceived severity of the child's autistic symptoms, parental beliefs about the causes of autism, and perceived mental and physical health outcomes associated with caregiving). The fourth category includes other factors mentioned by participants that were not part of the research questions 1a–1c.

#### ***Perceived Severity of An Autistic Child's Symptoms***

To examine how parents' perceptions of symptom severity influence their intention to seek services, autistic child symptoms were grouped into four categories: social communication and interaction difficulties, restricted and repetitive behaviors, cognitive and learning differences, and emotional and behavioral regulation. These categories are based on the DSM-5 diagnostic criteria (American Psychiatric Association,

2013). Each category was further divided into low and high parental perception of severity, as the Health Belief Model suggests that perceived severity, whether mild or severe, affects whether parents take preventive or corrective action (Champion and Skinner, 2008; Jones et al., 2015). Table 7 shows that parents most often viewed social communication difficulties and restricted behaviors as highly severe, prompting early service-seeking. For example, one parent noted, "*He cannot ask if he needs anything... He cannot ask me in a sentence*" (P2). In contrast, cognitive and learning differences were frequently perceived as less severe, often normalized by cultural beliefs such as, "*As our family says, some children take longer to talk or walk*" (P5) (Gupta and Singhal, 2004).

**Table 7**

*Factor 1: The Perceived Severity of an Autistic Child's Symptoms\**

Category of symptoms	Parental perception of severity	An autistic child's symptoms	Participant and parent quote
Social Communication and Interaction Difficulties	Low	Mild routine support	P4: "Her typical day involves waking up in the morning... After that, she goes to school and then returns in the afternoon."
	Low	Passive behavior manageable	P6: "She has no behavioral issues. She has significantly fewer behavior issues."
	Low	Social withdrawal	P10: "She was not socially active. She was not making eye contact with other people. When we used to call her name, she used not to pay attention, she used not to reply."
	High	Speech delay and hyperactivity	P2: "Starting with when he turned 4, I started getting panic... About okay, now it is super late for him not to speak."
	High	Aggression and isolation	P5: "She also had social awkwardness and no social awareness. She used to hate going out with us."
	High	Speech delay and aggression	P8: "My girl has everything okay except speech delay. So, there was one of the first symptoms that I noticed in her."
Restricted and Repetitive Behaviors	Low	Uncertainty about the condition	P2: "Starting with when he turned 4, I started getting panic... About okay, now it is super late for him not to speak."
	Low	Focused on one toy	P3: "He used to play with that toy constantly and not look at the things around him."
	Low	Difficulty identifying the speaker	P4: "She could not tell whether she was addressing me or someone else."
	High	Eye squinting and toe walking	P5: "He used to squint his eyes. He used to not walk with his entire foot on the floor... He used to walk in circles."

Category of symptoms	Parental perception of severity	An autistic child's symptoms	Participant and parent quote
Cognitive and Learning Differences	High	Lack of eye contact and hyperactivity	P7: "Also, the eye contact was lacking. He was unable to socialize with the people. He was trying to flip his hand around, getting hyper here and there."
	High	No eye contact and delayed speech	P9: "She was not socially active. She was not making eye contact with other people. When we used to call her name, she used not to pay attention."
	Low	Belief in natural delay	P5: "As our family says, some children take longer to talk, and sometimes take longer to walk."
	Low	The family said it was too early for sentences	P8: "I ask around the family how long it takes for the child to speak. However, then all my family members said it is too early for her to speak complete sentences and words."
	Low	Compared to a cousin	P4: "My sister-in-law's son also had a similar issue when he used to speak late, so they also pointed out that she might have a sign of autism."
	High	Developmental delay	P1: "My mother-in-law noticed and mentioned that my child has delays in development compared to children in the neighborhood."
	High	Lack of socialization during COVID	P3: "We used to take him to the garden during COVID. That time, all socializing events had stopped."
	High	Recommended help	P7: "My in-laws and parents also suggested that some children speak late. However, they also recommended that I go and seek help."
Emotional and Behavioral Regulation	Low	Mental health challenges	P4: "It was very unexpected. My child was very normal suddenly... I felt very, very, very isolated."
	Low	Felt overwhelmed but stayed strong	P6: "It was very overwhelming for me at the same time. To process and adopt into my lifestyle."

Category of symptoms	Parental perception of severity	An autistic child's symptoms	Participant and parent quote
	Low	Pain from comparison	P9: "Having said that, when I used to see my child with other children who are normal... that also affects you."
	High	Emotional breakdown	P1: "I locked myself in that room with my child, and I cried a lot; I kept crying until evening."
	High	Shock and isolation	P2: "As a mother, I felt very shocked at that time. I used to cry for many days when I found out that my child had autism."
	High	Self-blame and frustration	P5: "I felt terrified. I also cried a lot. I blame myself a little bit, too, because I must be very careful about my child."

\* *Note.* Factor one is aligned with RQ 1a: Child-related factor: How does the perceived severity of an autistic child's symptoms affect parents' intention to seek services for their children with an autism spectrum disorder (1-10 years old) in India? \*\*P4 refers to Participant 4.

### ***Perceived Causes of Autism***

To explore how parental beliefs about the causes of autism influence service-seeking behavior, these beliefs were grouped into two categories: (a) scientifically informed beliefs and (b) misinformed or culturally influenced beliefs. This division was necessary because, according to the Health Belief Model, the nature of parental beliefs, whether grounded in science or shaped by cultural misconceptions, can affect the likelihood of taking preventive or corrective action (Champion and Skinner, 2008; Jones et al., 2015). Table 8 shows that scientifically informed beliefs, such as attributing autism to genetic factors or prenatal stress, often increased parents' intention to seek professional help. For example, one parent stated, "*I think that autism does occur because of the stress*

during pregnancy” (P2). In contrast, culturally influenced beliefs, such as karma or black magic, tended to delay intervention, as reflected in the quote, “Autism is something that has been evil magic... somebody has put a curse on you” (P2) (Gupta and Singhal, 2004).

**Table 8**

*Factor 2: The Perceived Causes of Autism\**

Belief category	Example cause	Parent quote
Scientifically Informed Beliefs	Genetic Factors	P6 – “I believe my child’s autism is due to genetics because it runs in our family.”
	Environmental Influences	P2- “I think exposure to certain chemicals during pregnancy caused my child’s autism.”
	Prenatal and Birth Complications	P3 – “Complications during birth might have led to my child’s autism.”
Misinformed or Culturally Influenced Beliefs	Spiritual/Karmic Reasons	P5- “We believe it is a result of karma or spiritual imbalance.”
	Vaccination	P3- “My child developed autism after receiving vaccinations.”
	Parental Behavior	P4- “Maybe it is because of how we raised him.”
	Diet and Nutrition	P8- “Poor maternal nutrition might be the reason.”

\* *Note.* Factor 2 is aligned with RQ1b: Parental knowledge and perception: How do the beliefs about the causes of autism affect parents’ intention to seek services for their children with an autism spectrum disorder (1-10 years old) in India?

### ***Perceived Mental and Physical Health Outcomes of Caregiving***

To analyze how caregiving outcomes influence parents’ intention to seek services, outcomes were divided into two main categories: mental health and physical health. Each

category was further subdivided into positive and negative outcomes, as the Health Belief Model suggests that the perceived direction of an outcome, whether beneficial or harmful, can affect the likelihood of taking preventive or corrective action (Champion and Skinner, 2008; Jones et al., 2015). This differentiation was necessary because positive outcomes, such as increased emotional strength or improved health awareness, may encourage sustained engagement with services. In contrast, negative outcomes, such as stress, anxiety, fatigue, and chronic pain, can either motivate urgent intervention or create barriers to care. Table 9 shows that mental health outcomes were most commonly negative, with stress and anxiety frequently reported, for example, “I often feel overwhelmed and anxious about my child’s future” [P2].

In contrast, positive mental health outcomes like emotional resilience were less frequent: “Caring for my child has made me more patient and emotionally strong” [P1]. Similarly, physical health outcomes were predominantly negative, including fatigue and sleep disturbances: “I am constantly tired and do not get enough sleep” [P4]. In contrast, only a few parents mentioned positive outcomes, such as improved health awareness: “I have become more conscious about my health so that I can better care for my child” [P1] (Gupta and Singhal, 2004).

**Table 9**

*Factor 3: Perceived Mental and Physical Health Outcomes of Caregiving\**

Outcome Type	Outcome Category	Example Outcome	Parent Quote
Mental Health	Positive/Resilient	Increased emotional strength	P1 – “Caring for my child has made me more patient and emotionally strong.”
Physical Health	Positive/Resilient	Improved health awareness	P1- “I have become more conscious about my health so that I can better care for my child.”
Mental Health	Negative	Stress and anxiety	P2 –”I often feel overwhelmed and anxious about my child’s future.”
		Depression	P3 – “There are days when I feel hopeless and emotionally drained.”
Physical Health	Negative	Fatigue and exhaustion	P4 – “I am constantly tired and do not get enough sleep.”
		Chronic health issues	P5- “My back pain has worsened since I started lifting and chasing after my child daily.”

\* *Note.* Factor 3 is aligned with RQ 1c: Parent-related factor: How do perceived caregiving mental and physical health outcomes affect parents’ intention to seek services for their children with an autism spectrum disorder (1-10 years old) in India?

### ***Other Factors***

To capture additional influences on parents' intention to seek services, factors beyond symptom severity and beliefs were grouped into three categories: family support, social interaction, and social challenges. This categorization aligns with the Health Belief Model, where family support and social interaction act as perceived benefits and cues to action, while social stigma and exclusion represent perceived barriers (Champion and Skinner, 2008; Jones et al., 2015). Table 10 shows that strong family support, such as spousal encouragement, often increased parents' confidence in seeking services: "My husband says... 'She is our child. We do not have to worry about what others say about her. We will do everything for her she needs'" (P2). Conversely, social stigma and exclusion frequently delayed intervention, as reflected in the quote, "Society always looks down on children with autism... Sometimes it also makes you feel about your child. Do not bring him outside in public" (P3) (Gupta and Singhal, 2004).

**Table 10***Other Factors Influencing on Care-Seeking Parents*

Category	HBM construct	Factor	Quote
Family Support	Perceived Benefits and Self-Efficacy	Spouse Support	P2 - “My husband says... ‘She is our child. We do not have to worry about what others say about her. We will do everything for her that she needs.’”
		Family Structure	P1- “In my support system, I have my in-laws, my husband, my elder child, and my parents.”
		Parental Acceptance	P4- “Acceptance as a parent, yes, that my child is this, this, this... Other than that, we were very proactive from day one.”
Social Interaction	Cues to Action	Social Communication	P8- “She likes to interact with them, and although she has a speech delay, she loves having those socializing activities.”
Social Challenges	Perceived Barriers	Social Stigma	P3- “Society always looks down on children with autism, especially in the village areas... Sometimes it also makes you feel about your child. Do not bring him outside in public.”
		Social Exclusion	P5- “Sadly, children are playing in our neighborhood... They tried to look down on her because she has a statistical condition... They always try to corner her.”
		Social Misunderstanding	P7- “People used to criticize me but did not understand what to do with my child in a public setting.”

**RQ1a: Child-Related Factor**

How does the perceived severity of an autistic child’s symptoms affect parents’ intention to seek services for their children with an autism spectrum disorder (ages 1–10) in India? This section presents findings on how the perceived severity of an autistic

child's symptoms, classified into four categories (social communication and interaction difficulties, restricted and repetitive behaviors, cognitive and learning differences, and emotional and behavioral regulation), influences parents' decisions to seek services for children aged 1–10 diagnosed with autism in India.

### ***Social Communication and Interaction Difficulties***

Parents' perceptions of the severity of social communication and interaction difficulties significantly influenced their intention to seek professional services. When these difficulties were perceived as severe, parents demonstrated a heightened sense of urgency to obtain intervention, recognizing the need for specialized support. For instance, in table 11 one participant stated, "He cannot ask if he needs anything... He cannot ask me in a sentence" (P2), illustrating how an inability to express basic needs prompted early engagement with services. Conversely, when parents considered these difficulties to be mild or manageable, their intention to seek professional assistance often diminished, reflecting a belief that such challenges could be addressed without external intervention.

Social communication and interaction difficulties were identified through behavioral observations and family reports across all interviews. These challenges encompassed behaviors such as stubbornness, hyperactivity, reduced socialization, and limited engagement in daily activities. In table 12, such behaviors represent early indicators of autism that typically emerge before or during treatment. Beyond communication-related concerns, parents also noted repetitive behaviors, which further shaped their decisions regarding service-seeking.

**Table 11***Illustrative Quotes from Parents on Social Communication and Interaction Difficulties*

Symptom	Parental perception of severity	Service-seeking behavior	Parental quote
Inability to express basic needs	High	Prompted early intervention	“He cannot ask if he needs anything... He cannot ask me in a sentence.” (P2)
Speech delay and hyperactivity	High	Recognition of frustration and aggression led to seeking help	“Due to her speech delay... she becomes very hyper and angry... tries to hit her head.” (P8)
No response to verbal cues	High	Raised concerns, prompting professional support	“He did not use to pinpoint... It was difficult sometimes to understand what he wanted.” (P10)
Limited verbal communication	High	Viewed as abnormal, led to service-seeking	“He cannot talk in complete sentences... He sometimes starts throwing things around.” (P5)
Lack of social engagement	High	Behavioral rigidity prompted intervention	“He is very stubborn... whenever he wants to ask something, he cannot put it into a sentence.” (P3)
Difficulty adapting to new people	Low	Managed at home, delayed professional help	“If she has a different teacher for the day... she gets confused and wants the same teacher.” (P4)
Passive or withdrawn behavior	Low	Initially perceived as manageable, delayed service-seeking	“He just used to sit in the corner alone, doing nothing... we used to think he was learning something.” (P10)

**Table 12**

*Perceived Seriousness (Social Communication and Interaction Difficulties) × Parents' Intention to Seek Services*

Symptom severity	Intention: Low	Intention: High
Difficulties: Low	Difficulty adapting to new people – Managed at home, delayed help (P4) Passive or withdrawn behavior – Initially perceived as manageable (P10)	None observed – Low severity rarely led to high intention  Inability to express basic needs – Prompted early intervention (P2) Speech delay and hyperactivity – Led to urgent help (P8)
Difficulties: High	Shock and denial initially delayed help despite severe symptoms (P2)	No response to verbal cues – Raised concerns (P10) Limited verbal communication – Viewed as abnormal (P5) Lack of social engagement – Behavioral rigidity prompted intervention (P3)

### ***Restricted and Repetitive Behaviors***

Parents reported a range of restricted and repetitive behaviors that influenced their decisions to seek services. Behaviors perceived as highly severe, such as eye squinting, toe walking, lack of eye contact, and hand-flipping, prompted early evaluations. In table 13, one parent shared, "He used to squint his eyes... walk in circles" (P5), while another noted, "The eye contact was lacking... He was trying to flip his hand around" (P7). Safety concerns also accelerated intervention when parents observed hyperactivity and nighttime wandering: "He used to run in the middle of the night... sometimes he hurt

himself” (P6). These high-severity symptoms consistently led to high intention to seek services.

In contrast, behaviors perceived as mild, such as repetitive play with a single toy, ignoring one’s surroundings, or difficulty identifying the speaker, were often normalized and managed at home. One parent explained, “He used to play with that toy constantly and not look at the things around him” (P3). Others delayed help due to uncertainty: “I was still in a dilemma··· I waited for 2 to 3 months” (P2). Table 14 confirms this trend: high-severity behaviors almost always resulted in early intervention, while low-severity behaviors rarely did. In some cases, initial shock and denial temporarily delayed seeking help despite severe symptoms, illustrating how perception and emotional response influence decision-making. Building on these findings, the following section explores cognitive and learning differences, which emerged as another critical dimension influencing parental decisions to seek services.

**Table 13***Illustrative Quotes from Parents on Restricted and Repetitive Behaviors*

Symptom	Parental perception of severity	Service-seeking behavior	Parental quote
Eye squinting and toe walking	High	Prompted early evaluation due to unusual motor behaviors	“He used to squint his eyes. He used to not walk with his entire foot on the floor. He used to walk in circles.” (P5)
Lack of eye contact and hand-flipping	High	Raised concern, led to developmental support	“The eye contact was lacking. He could not socialize with people. He was trying to flip his hand around, getting hyper here and there.” (P7)
No response to name and delayed speech	High	Motivated parents to seek help	“She was not socially active. She was not making eye contact. When we used to call her by her name, she did not pay attention or reply. Her speech is also a little bit delayed.” (P9)
Hyperactivity and nighttime wandering	High	Safety concerns increased the urgency for intervention	“He used to run in the middle of the night, so sometimes he hurt himself because you could see objects or stuff in the house.” (P6)
Repetitive play and ignoring surroundings	Low	Initially perceived as manageable, delayed service-seeking	“He used to play with that toy constantly and not look at the things around him. What is going on?” (P3)
Difficulty identifying the speaker	Low	Managed at home, delayed professional help	“She could not tell whether she was addressing me or someone else.” (P4)
Uncertainty about the condition	Low	Waiting period before seeking help	“I was still in a dilemma whether my child had a normal condition... I waited for 2 to 3 months to see if his speech had improved, but then, with time, I did not find any results.” (P2)

**Table 14***Restricted and Repetitive Behaviors × Parents' Intention to Seek Services*

Symptom severity	Intention: Low	Intention: High
Low Severity	<ul style="list-style-type: none"> <li>• Repetitive play, ignored surroundings – Initially perceived as manageable (P3)</li> <li>• Difficulty identifying speaker Managed at home, delayed help (P4)</li> <li>• Uncertainty about condition Waiting period before seeking help (P2)</li> </ul>	None observed – Low severity rarely led to high intention
High Severity	<ul style="list-style-type: none"> <li>• Initial shock and denial delayed help despite severe symptoms (P6)</li> </ul>	<ul style="list-style-type: none"> <li>• Eye squinting and toe walking – Prompted early evaluation (P5)</li> <li>• Lack of eye contact and hand-flipping – Led to developmental support (P7)</li> <li>• No response to name and delayed speech – Motivated parents to seek help (P9)</li> <li>• Hyperactivity and nighttime wandering – Safety concerns increased urgency (P6)</li> </ul>

***Cognitive and Learning Differences***

Across all ten interviews, cognitive and learning differences emerged as a critical factor influencing parental decision-making. These differences were often identified through family observations in joint family settings, where comparisons with peers or siblings highlighted developmental delays. For example, developmental delay compared to neighborhood children was perceived as highly severe. It prompted early evaluation: "My mother-in-law noticed delays compared to children in the neighborhood" (P1). Similarly, speech delay noted by family members increased urgency for professional

intervention: "Other family members pointed out that he cannot speak as many words as he should" (P2). High-severity symptoms, such as lack of socialization during COVID or recommendations from in-laws, consistently led to timely service-seeking (P3, P7).

In contrast, low-severity perceptions often delayed intervention. Cultural normalization of delays, such as the belief that "some children take longer to talk or walk" (P5), reduced urgency to seek services. Likewise, advice to wait for natural improvement resulted in postponed help: "All my family members said it is too early for her to speak complete sentences... So, we waited for a couple more months" (P8). Table 16 confirms this trend: high-severity symptoms almost always resulted in high intention to seek services, while low-severity symptoms rarely did. In some cases, initial hesitation due to cultural beliefs temporarily delayed help despite severe symptoms, illustrating the complex interplay between perception, family influence, and action. Collectively, these findings underscore that the perceived severity of cognitive and learning differences, shaped by family observations and cultural norms, plays a pivotal role in determining whether parents pursue early intervention or delay professional care.

**Table 15***Illustrative Quotes from Parents on Cognitive and Learning Differences*

Symptom	Parental perception of severity	Service-seeking behavior	Parental quote
Developmental delay compared to peers	High	Prompted early evaluation due to family observation	“My mother-in-law noticed and mentioned that my child has delays in development compared to children in the neighborhood.” (P1)
Speech delay noted by family	High	Increased urgency for professional evaluation	“Other family members also might have pointed out that he cannot speak as many words as he should, and some issues do not seem normal.” (P2)
Lack of socialization during COVID	High	Motivated parents to seek help	“My in-laws pointed out that he is not socializing with other children or family... symptoms decreased due to decreased playtime with his elder sister.” (P3)
Late speech compared to cousin	High	Led to early suspicion and consideration of autism services	“My sister-in-law’s son also had a similar issue when he used to speak late, so they also pointed out that she might have a sign of autism.” (P4)
Belief in natural delay	Low	Reduced urgency to seek services	“As our family says, some children take longer to talk, and the cultural take longer to walk.” (P5)
Recommendation to seek help	High	Encouraged timely service-seeking	“My in-laws and parents also suggested that some children speak late. But then they also recommended that I go and seek help.” (P7)
Waiting based on family advice	Low	Delayed service-seeking despite signs of speech delay	“All my family members said it is too early for her to speak complete sentences and words. So, we waited for a couple more months.” (P8)

**Table 16***Cognitive and Learning Differences × Parents' Intention to Seek Services*

Symptom severity	Intention: Low	Intention: High
Low Severity	<ul style="list-style-type: none"> <li>• Belief in natural delay – Reduced urgency (P5)</li> <li>• Waiting based on family advice – Delayed help (P8)</li> </ul>	None observed – Low severity rarely led to high intention
High Severity	<ul style="list-style-type: none"> <li>• Initial hesitation due to cultural normalization (P4)</li> </ul>	<ul style="list-style-type: none"> <li>• Developmental delay compared to peers – Prompted early evaluation (P1)</li> <li>• Speech delay noted by family – Increased urgency (P2)</li> <li>• Lack of socialization during COVID – Motivated help-seeking (P3)</li> <li>• Recommendation to seek help – Encouraged timely intervention (P7)</li> </ul>

***Emotional and Behavioral Regulation***

Parents' emotional and behavioral responses played a significant role in shaping service-seeking decisions. High-severity reactions such as emotional breakdown, shock, and fear of worsening symptoms often triggered urgent intervention. For instance, one mother shared, "I locked myself in a room and cried all day" (P1), while another expressed, "I thought it was going to get worse over time" (P10). These intense emotions created a strong sense of urgency to seek professional help. Conversely, low-severity responses, such as uncertainty in motherhood or pain from comparison, tended to delay action: "I cried a lot and isolated myself... I thought I would make her okay" (P8). Table 18 reinforces this trend: parents experiencing severe emotional strain generally moved toward early intervention, while those with milder reactions often postponed seeking

services. This pattern highlights how emotional regulation, whether marked by denial, guilt, or acceptance, can act as either a barrier or a motivator in the care-seeking process.

**Table 17***Illustrative Quotes from Parents on Emotional and Behavioral Regulation*

Symptom	Parental perception of severity	Service-seeking behavior	Parental quote
Emotional breakdown and isolation	High	Prompted realization of the need for external support	“I locked myself in that room with my child, and I cried a lot; I kept crying until evening till my husband came back home from work around 6 pm. My in-laws tried to ask me what was happening, but I did not feel like answering anyone.” (P1)
Shock and denial	High	Initially delayed service-seeking due to disbelief	“As a mother, I felt very shocked then. I used to cry for many days when I found out that my child had autism, and I used to not talk to anybody. This was very unexpected for me.” (P2)
Loss of confidence	High	Emotional exhaustion hindered early intervention efforts	“It is not easy when you discover your child is not normal. It took a couple of months to adjust to the news... After my child’s birth, all that creativity of mind has been gone. I have completely lost my confidence.” (P3)
Mental health strain	High	Increased awareness of the need for support	“Mentally, it does affect me a lot to wonder when this situation will end. In the beginning... I went through a lot of mental health challenges as a mother.” (P4)
Self-blame and guilt	High	Contributed to the delayed seeking of services	“I sit and think about what would have happened if my child had been normal... I always blame myself first in this condition. I do often cry. I get very frustrated.” (P5)
Overwhelm and exhaustion	High	Emotional burnout prompted eventual service-seeking	“It is tough for me... your mental capacity is very drained, exhausted, and overwhelmed... You feel like you just want to give up on everything.” (P6)
Uncertainty in motherhood	Low	Lack of preparedness delayed initial help-seeking	“I do not know much about motherhood. How to carry my son around. It was very, very shocking.” (P7)

Symptom	Parental perception of severity	Service-seeking behavior	Parental quote
Isolation and denial	Low	Emotional withdrawal delayed acceptance and service-seeking	“It was tough for me to digest. I cried a lot and isolated myself. I used to not talk to people. I used to think that I would make her okay. I was wrong before anybody else registered or learns about her condition.” (P8)
Pain from comparison	Low	Led to hesitation in seeking help	“When I used to see my child with other children who are normal... that also affects you.” (P9)
Fear of worsening condition	High	Motivated parents to seek services to prevent further decline	“That was a tough day. I still remember. And I honestly felt that I did not know taking him out of that spectrum would be that easy. I thought it was going to get worse over time.” (P10)

**Table 18***Emotional and Behavioral Regulation × Parents' Intention to Seek Services*

Symptom severity	Intention: Low	Intention: High
Low Severity	<ul style="list-style-type: none"> <li>• Uncertainty in motherhood – Lack of preparedness delayed help (P7)</li> <li>• Isolation and denial – Emotional withdrawal, delayed acceptance (P8)</li> <li>• Pain from comparison – Hesitation in seeking help (P9)</li> </ul>	None observed – Low severity rarely led to high intention
High Severity	<ul style="list-style-type: none"> <li>• Shock and denial – Initially delayed service-seeking (P2)</li> <li>• Self-blame and guilt – Contributed to delay (P5)</li> </ul>	<ul style="list-style-type: none"> <li>• Emotional breakdown and isolation – Prompted realization of need for support (P1)</li> <li>• Loss of confidence – Emotional exhaustion hindered early efforts but led to eventual help (P3)</li> <li>• Fear of worsening condition – Motivated parents to seek services (P10)</li> </ul>

**RQ1b: Parental Knowledge and Perception**

How do the beliefs about the causes of autism affect parents' intention to seek services for their children with an autism spectrum disorder (1-10 years old) in India?

This section presents findings on how beliefs about the causes of autism, grouped into two categories (scientifically informed beliefs and misinformed or culturally informed beliefs), influence parents' decisions to seek services for children aged 1–10 diagnosed with autism in India.

***Scientifically Informed Beliefs***

Parental knowledge and perception, shaped by scientifically informed beliefs, significantly influenced parents' intention to seek professional services. Beliefs

attributing autism to modifiable factors such as prenatal stress and environmental isolation consistently increased urgency for intervention. For example, parents who linked autism to stress during pregnancy (P2) or social isolation during COVID-19 (P7, P8) actively pursued therapies, viewing them as corrective measures to restore developmental progress. Similarly, beliefs about screen time exposure produced mixed effects. When parents assumed the issue could be resolved by simply reducing screen time (P10), their motivation for professional help was low; however, when screen time was perceived as causing lasting developmental harm (P1, P3, P5, P6, P7, P8, P10), parents demonstrated high intention to seek services, often combining therapy with reduced digital exposure. Genetic explanations showed in table 19 and 20 nuanced influence; some parents delayed intervention, believing genetics was irreversible, while others sought therapy to manage symptoms despite genetic predisposition. Overall, scientifically informed beliefs linked to manageable causes (such as prenatal stress, social isolation, and harmful screen time) increased service-seeking behavior. In contrast, beliefs framing autism as immutable (pure genetics) or self-correcting (“just reduce screen time”) tended to reduce urgency. No belief in this sample was neutral; each either heightened or lowered parents’ motivation to pursue care.

**Table 19**

*Illustrative Quotes from Parents on Scientifically Informed Beliefs About Causes of Autism*

Belief category	Parent quote	Interpretation (service-seeking behavior)	Impact on intention
Genetic Factors	P1: "By birth, an autistic child takes longer to recover or improve compared to my child's type."	Parents who view autism as biologically determined may seek therapy to manage symptoms, but some delay care, believing genetics is irreversible.	Mixed (Increase or Decrease)
Prenatal Stress	P2: "I think that Autism does occur because of the stress during pregnancy."	Parents associate autism with prenatal stress and tend to seek developmental support proactively.	Increase
Environmental Isolation (COVID-19)	P7: "During the COVID time... there was a lot of isolation and restriction on public and socializing activities."	Recognition of environmental factors motivates parents to pursue therapies that restore social engagement.	Increase
Screen Time / Parental Negligence	P10: "Mild autism is totally because of screen time and parents' negligence... if the parent is aware and plays with their kids instead of introducing TV, it can be avoided."	If parents believe that reducing screen time alone will fix the issue, the urgency for therapy decreases; if they see lasting harm, their intention increases.	Mixed (Increase or Decrease)
Radiation / Media Exposure	P6: "My child used to have a phone when eating... Having too much exposure to Disney may have caused a logical condition and the radiation of electronic devices during pregnancy."	Some parents believe radiation damage is irreversible, reducing motivation; others seek therapy alongside reducing exposure.	Mixed (Increase or Decrease)
Early Childhood Isolation	P8: "Children get very isolated... they do not get enough attention from the	Perceived lack of stimulation leads parents to seek therapies	Increase

Belief category	Parent quote	Interpretation (service-seeking behavior)	Impact on intention
	parents because parents are busy with their respective roles.”	that enhance interaction and development.	

**Table 20**

*Scientifically Informed Beliefs About Causes of Autism x Parents’ Intention to Seek Services*

Category	Intention: Low	Intention: High
Scientifically Informed Beliefs About Causes of Autism	<ul style="list-style-type: none"> <li>• Genetic factors</li> <li>• Screen time / parental negligence</li> <li>• Radiation/media exposure</li> </ul>	<ul style="list-style-type: none"> <li>• Parental stress</li> <li>• Environmental isolation(covid-19)</li> <li>• Early childhood isolation/lack of stimulation</li> </ul>

***Misinformed or Culturally Influenced Beliefs***

Participants reported a range of misinformed or culturally influenced beliefs that shaped their care-seeking decisions. Many parents (P2, P3, P4, P6, P7, P8, P9, and P10) engaged in temple visits, prayers, fasting, and offerings, reflecting reliance on spiritual remedies. In table 21, beliefs such as karma and divine will (P5, P8) often decreased the urgency to seek professional help, as parents viewed autism as fate rather than a treatable condition. Similarly, attributing autism to black magic or the evil eye (P2) and prioritizing religious rituals (P3) or fasting and prayer (P4) delayed engagement with evidence-based care. Community influence also reinforced these patterns; for example, P10 described advice from neighbors and cab drivers to “go to Bhagawan” instead of pursuing therapy. These beliefs consistently lowered intention to seek services, as shown

in Table 22. However, exceptions emerged: P7 demonstrated a dual belief system, combining spiritual practices with medical therapy, which increased intention to seek services. P6 reflected a mixed effect, where external pressure led to spiritual remedies but did not entirely prevent professional intervention. Overall, these findings suggest that most culturally influenced beliefs acted as barriers, while integrated approaches occasionally facilitated care-seeking behavior.

**Table 21**

*Illustrative Quotes from Parents on Misinformed or culturally Informed Beliefs About Causes of Autism*

Belief category	Parent quote	Interpretation (service-seeking behavior)	Impact on intention
Spiritual/Karmic Beliefs	“Becoming a parent is such a blessing from God... if God has given me or put me in this situation...” (P5)	Belief in divine will or karma may reduce urgency to seek medical services, relying on spiritual acceptance.	Decrease
Black Magic / Evil Eye	“Autism is something that has been evil magic... somebody has put a curse on you...” (P2)	Attribution to supernatural causes may delay service-seeking and shift focus to spiritual remedies.	Decrease
Religious Rituals and Temple Visits	“I have been to every single temple... offered many offerings to the gods...” (P3)	Reliance on rituals may substitute or delay engagement with professional services.	Decrease
Fasting and Prayer	“I am a religious person... I have been fasting a lot. I have been doing all the prayers.” (P4)	Spiritual practices are prioritized over clinical interventions, especially in early stages.	Decrease
Cultural Fatalism	“Being a religious person... I tried to believe in God and Karma...” (P8)	Acceptance of autism as fate may reduce motivation to seek timely services.	Decrease
Community Influence	“Two to three cab drivers told me: ‘Do not waste your money, do not waste your time. Go to Bhagawan.’” (P10)	Advice from community members reinforces spiritual approaches and discourages professional help.	Decrease
Dual Belief System	“We are very religious... we tried to do everything in our capacity alongside the therapist.” (P7)	The integration of spiritual beliefs with medical treatment can support service-seeking when done in a balanced manner.	Increase

Belief category	Parent quote	Interpretation (service-seeking behavior)	Impact on intention
Helpless Parenting Under Influence	“Many people have come to us and recommended things we might not even believe in... but under influence...” (P6)	External pressure often leads parents to seek spiritual remedies in conjunction with, or as an alternative to, professional care.	Mixed (Increase/Decrease)

**Table 22**

*Misinformed or Culturally Informed Beliefs About Causes of Autism x Parents’ Intention to Seek Services*

Category	Intention: Low	Intention: High
Misinformed or Culturally Informed Beliefs About Causes of Autism	Spiritual/karmic beliefs Black magic/ evil eye Religious rituals and temple visits Fasting and prayer Cultural fatalism Community influence	Dual belief system

### **RQ1c: Parent-Related Factor**

How do perceived caregiving mental and physical health outcomes affect parents’ intention to seek services for their children with an autism spectrum disorder (1-10 years old) in India?

#### ***Mental Health Outcomes***

Beyond beliefs, caregiving experiences introduced significant mental health challenges that shaped parents’ engagement with autism services. Interviews revealed both negative and positive outcomes, each influencing care-seeking intention differently.

Negative outcomes such as chronic stress and anxiety (P2), depression and identity loss (P3), and self-blame and guilt (P5) often decreased intention to seek services, as emotional exhaustion and feelings of failure created internal barriers. Similarly, cultural fatalism and isolation (P9) as well as emotional burnout (P6) hindered proactive engagement. However, severe anxiety about the child's future (P2) acted as a motivator, increasing urgency for intervention, a notable exception among negative outcomes.

Conversely, positive outcomes consistently increased intention to seek services. Emotional resilience (P1), acceptance of the caregiving role (P4), and strong spousal support (P7) fostered confidence and sustained engagement. Coping strategies such as using social media for relaxation (P2), creative outlets like music and dance (P3), nature-based breaks (P6), and peer support at the clinic (P8) reinforced emotional strength and encouraged ongoing care-seeking. These findings, summarized in Tables 23 and 24, highlight that while most negative mental health outcomes act as barriers, positive outcomes and effective coping mechanisms serve as powerful facilitators of service engagement.

**Table 23***Illustrative Quotes from Parents on Mental Health Outcomes of Caregiving and Coping*

Outcome type	Participant and parent quote	Interpretation (mental health outcome and coping behavior)	Impact on intention
Positive	P1: "Caring for my child has made me more patient and emotionally strong."	Demonstrates emotional resilience; likely to continue seeking services with a proactive mindset.	Increase
Positive	P4: "At this point, I have made peace with my mind... I must give all 365 days of my life to make my daughter better."	Acceptance of a long-term caregiving role supports sustained service engagement despite emotional strain.	Increase
Positive	P7: "My husband has a very healthy relationship with me... I have been very blessed and have not experienced any [mental health issues] after accepting my child having autism."	Strong spousal and family support buffers stress, enabling consistent service-seeking.	Increase
Positive	P8: "I do not give up. I believe that if I do better, my child will do better... It is my daily routine that I must go through."	High intrinsic motivation and routine adaptation foster long-term engagement with services.	Increase
Positive (Coping)	P2: "I use Instagram and other social media... That gives me downtime and makes me feel relaxed and better."	Digital coping tools help manage anxiety, supporting emotional regulation and sustained caregiving.	Increase
Positive (Coping)	P3: "Whenever I feel overwhelmed, I just dance in my house... It is a very therapeutic activity for me."	Creative expression serves as a personal therapy, helping to manage emotional exhaustion.	Increase
Positive (Coping)	P6: "We try to go outside... to the park... it helps us escape the hectic lifestyle and get short breaks."	Nature-based coping offers emotional relief and prevents burnout, thereby facilitating continued service-seeking.	Increase
Positive (Coping)	P8: "Talking to other parents helps me feel better... we have a therapeutic system amongst the parents."	Peer support reduces isolation and reinforces emotional resilience, encouraging ongoing care-seeking behaviors.	Increase

Outcome type	Participant and parent quote	Interpretation (mental health outcome and coping behavior)	Impact on intention
Negative	P2: "It is a constant fear, constant anxiety... If I am not there in the future, who will look after my child?"	Persistent anxiety about the future increases emotional burden, potentially intensifying the urgency for services.	Increase
Negative	P3: "After my child's birth, all that creativity of mind has been gone... I have completely lost my confidence."	Identity loss and emotional depletion may hinder proactive engagement with services.	Decrease
Negative	P5: "I always blame myself first... I do often cry. I get very frustrated... I do not know what the actual meaning of depression is, but... I have been experiencing that."	Self-blame and depressive symptoms may delay service-seeking and reduce caregiver efficacy.	Decrease
Negative	P6: "Your mental capacity is very drained, exhausted, and overwhelmed... You feel like you just want to give up on everything."	Emotional burnout without sufficient coping mechanisms may lead to disengagement from services.	Decrease
Negative	P9: "I feel sometimes isolated and blame myself... I believe in karma... it affects people mentally."	Cultural beliefs and emotional isolation may create internal barriers to seeking timely care.	Decrease
Negative	P10: "I had to quit my job... I cannot even think of having another child... the pressure and mental toll it takes, it is not easy."	A high caregiving burden and the loss of personal goals contribute to emotional fatigue, which can lead to long-term disengagement.	Decrease

**Table 24***Mental Health Outcomes X Parents' Intention to Seek Services*

Outcome type	Intention: Low	Intention: High
Mental Health Outcome: Positive	None observed – All positive outcomes (emotional resilience, acceptance, spousal support, intrinsic motivation, coping strategies) consistently increased intention.	Emotional resilience (P1), acceptance of caregiving role (P4), spousal support (P7), intrinsic motivation (P8), coping strategies like social media, creative outlets, nature breaks, and peer support (P2, P3, P6, P8) → Increase intention
Mental Health Outcome: Negative	Depression and identity loss (P3), self-blame and guilt (P5), emotional burnout (P6), cultural fatalism and isolation (P9), loss of personal goals (P10) → Decrease intention	Severe anxiety about child's future (P2) → Increase intention (fear acts as a motivator for urgent intervention)

***Physical Health Outcome***

Analysis of physical health outcomes revealed a clear imbalance: negative outcomes were far more prevalent than positive ones, with most participants reporting fatigue, body aches, sleep disturbances, weight fluctuations, and chronic pain. These adverse effects often acted as perceived barriers, reducing parents' energy and capacity to pursue services. For example, P4 and P9 described constant body aches and fatigue, while P2 and P10 reported disrupted sleep cycles due to nighttime caregiving. Weight fluctuations linked to stress and post-pregnancy changes were noted in P2 and P5, and other stress-related symptoms such as thyroid issues (P7) and early-onset health concerns (P1) further compounded physical strain. These patterns suggest that physical exhaustion, without effective coping mechanisms, consistently decreases the intention to seek services.

In contrast, although less frequent, positive coping strategies had a strong influence on increasing intention. Spousal support (P6), weekend breaks and family outings (P7, P8), and short naps or peer support (P8, P9) helped parents manage physical stress and sustain engagement with therapy. These findings align with the Health Belief Model. When coping strategies enhance self-efficacy, they offset perceived barriers and encourage proactive care-seeking. Notably, from table 25 and 26 mixed cases emerged where severe physical strain coexisted with strong coping (e.g., P6, P7, P8), resulting in partial mitigation of barriers and a higher likelihood of continued service use.

**Table 25**

*Illustrative Quotes from Parents on Physical Health Outcomes and Coping Strategies of Caregiving*

Outcome type	Participant and parent quote	Interpretation (physical health outcome and coping behavior)	Impact on intention
Negative	P1: "I must think of my child first... I started spotting a black circle on my legs... early female health problems."	High physical stress and early-onset health issues; coping through reflection/peer support.	Decrease
Negative	P2: "I used to be skinny, but now I have gained so much weight... The sleep cycle is very disturbed."	Weight gain and sleep disruption reflect stress-related decline; limited coping.	Decrease
Negative	P4: "I get fatigued easily and tired... I must move with her everywhere... body aches a lot."	Physical exhaustion from caregiving; minimal coping beyond rest.	Decrease
Negative	P5: "I must run between places... severe weight loss... sleep cycle disturbed."	High physical demands and disrupted routines; lacks effective coping mechanisms.	Decrease
Negative	P6: "Physically, it is very exhausting... carry at least 10 kilos... very challenging."	An intense daily burden, <b>but</b> spousal support helps mitigate stress.	Mixed
Negative	P7: "Thyroid... weight gain, sweating, tired easily... appearance aged."	Chronic condition exacerbated by caregiving; relief via weekend breaks/family time.	Mixed
Negative	P8: "Lack of sleep... always between things... physically exhausting."	Overwhelmed by multitasking, family outings provide temporary relief.	Mixed
Negative	P9: "Constant body ache and fatigue... hectic schedule... sleep cycle disturbed."	Persistent fatigue: short naps/family dinners offer limited coping.	Decrease
Negative	P10: "Always... pain, fatigue... sleep cycle messed up... body aches."	Continuous physical exhaustion; struggles to find time for rest.	Decrease

**Table 26***Physical Health Outcomes X Parents' Intention to Seek Service*

Outcome type	Intention: Low	Intention: High
Physical Health Outcome: Positive	None observed – All positive coping strategies (spousal support, weekend breaks, peer support) consistently increased intention.	Spousal support (P6), weekend breaks and family time (P7, P8), short naps and peer support (P8, P9) → Increased intention to seek services.
Physical Health Outcome: Negative	Chronic fatigue and body aches without coping (P1, P2, P4, P5, P9, P10) → Decreased intention due to physical strain acting as a barrier.	Mixed cases where coping mitigated strain: P6 (spousal support), P7 and P8 (weekend breaks/outings) → Increased intention despite physical stress.

Key trends and comparisons suggest that negative outcomes dominated the sample and were more influential than positive ones in shaping parents' intentions to seek services. Positive coping strategies consistently increased intention, even when physical strain was high, demonstrating their role as strong facilitators of this behavior. Compared to mental health outcomes, physical health strain acted as a more persistent barrier. However, coping mechanisms had similar enabling effects across both domains. Patterns mirrored those observed in belief systems: scientifically informed beliefs generally increased intention, while culturally influenced beliefs often decreased it. In this context, physical coping strategies functioned as scientifically informed factors, promoting engagement.

In contrast, unmanaged physical strain was similar to cultural barriers that hindered timely care-seeking. Exceptions were severe anxiety about the child's future (a mental health factor). Sometimes, increased urgency for intervention was observed,

whereas physical strain rarely did so unless paired with strong coping mechanisms. This underscores that mental health outcomes can occasionally motivate action. In contrast, physical health outcomes mostly hinder it unless mitigated by support systems.

### **Summary**

This chapter synthesized the factors influencing parents' intention to seek services for children with autism spectrum disorder in India, focusing on symptom severity, parental beliefs, and caregiving outcomes. Across these domains, clear patterns and exceptions emerged. Symptom severity was the most consistent driver of early intervention: parents who perceived high severity in social communication difficulties, restricted behaviors, or cognitive delays acted quickly, while those who normalized mild symptoms often delayed care. This trend reinforces the Health Belief Model's principle that perceived severity strongly motivates preventive action.

Belief systems revealed a sharp contrast. Scientifically informed beliefs, such as attributing autism to prenatal stress, environmental isolation, or lack of stimulation, consistently increased intention to seek services. In contrast, culturally influenced beliefs, including karma, divine will, and black magic, frequently decreased urgency, diverting parents toward spiritual remedies. Exceptions occurred when parents adopted a dual belief system, combining religious practices with therapy, which facilitated care-seeking. No belief was neutral; each either heightened or lowered motivation.

Caregiving outcomes introduced complex dynamics. Mental health strain marked by anxiety, depression, and emotional exhaustion often acted as a barrier. However, severe anxiety about the child's future occasionally motivated urgent intervention.

Physical health strain, including fatigue, body aches, and sleep disturbances, was even more persistent as a barrier to progress. Compared to mental health outcomes, physical strain rarely motivates action unless paired with strong coping mechanisms. Positive coping strategies such as spousal support, weekend breaks, and peer networks consistently increased intention, even when physical strain was high, demonstrating their role as powerful facilitators.

Overall, negative outcomes dominated the sample and had a more significant influence than positive ones in shaping intention. Positive coping mirrored the effect of scientifically informed beliefs by promoting engagement. At the same time, unmanaged physical strain resembled cultural barriers that hindered timely care-seeking. Exceptions included cases where, severe anxiety or integrated belief systems increased urgency despite other barriers. These findings highlight the interplay of psychological, cultural, and contextual factors in parental decision-making and underscore the need for culturally sensitive interventions, caregiver support systems, and awareness campaigns to bridge gaps in autism care in India. Chapter 5, as the upcoming chapter will discuss, provides recommendations and outlines the limitations of the study.

## Chapter 5: Discussion, Conclusions, and Recommendations

The purpose of this basic qualitative study was to explore how factors (parents' perceived severity of an autistic child's symptoms, their beliefs about the causes of autism, and their perceived caregiving mental and physical health outcomes) influence parents' intention to seek services for their children with ASD 1–10 years old in India. Bakar et al. (2019) and Bajaj et al. (2020) suggested that factors influencing parents' care-seeking behavior in India include delayed diagnosis, limited awareness among parents, cultural misconceptions, inadequate emotional support, and restricted access to professional care. The current study was completed to fill the gap in the literature focusing on factors that influence care-seeking parents living with a child with autism in India. This research aimed to answer the following research questions:

RQ1: What factors influence parents' intention to seek services for their children with an autism spectrum disorder (1–10 years old) in India?

RQ1a: Child-related factor: How does the perceived severity of an autistic child's symptoms affect parents' intention to seek services for their children with an autism spectrum disorder (1–10 years old) in India?

RQ1b: Parental knowledge and perception: How do the beliefs about the causes of autism affect parents' intention to seek services for their children with an autism spectrum disorder (1–10 years old) in India?

RQ1c: Parent-related factor: How do perceived caregiving mental and physical health outcomes affect parents' intention to seek services for their children with an autism spectrum disorder (1–10 years old) in India?

I collected primary data by conducting a pilot study, followed by a main study, to answer the research questions. The pilot study aimed to evaluate the effectiveness of the semistructured interview protocol and open-ended questions in addressing the research questions. After the pilot interviews were conducted, 10 participants were recruited to complete the main study. The semistructured interviews were completed in a one-on-one office setting at the clinic in Ahmedabad, India. The interview transcripts were translated from Gujarati to English, and the data were coded in NVivo software to complete the analysis.

### **Interpretation of the Findings**

In Chapter 5, I interpret the findings presented in Chapter 4, connecting them to the research questions and the theoretical framework, the HBM. The study explored how the perceived severity of an autistic child's symptoms, parental beliefs about the causes of autism, and the perceived caregiving mental and physical health outcomes influence parents' intention to seek services for their children with ASD in India.

#### **Research Question 1: Factors Influencing Parents' Intention to Seek Services for Their Children With an Autism Spectrum Disorder**

The following subsections compare the study's findings with those of previous research. For each factor category, the discussion begins with factors that align with prior studies, followed by factors unique to this study, and finally, factors previously identified in the literature but not mentioned here.

### *Perceived Severity of an Autistic Child's Symptoms*

The findings of this study corroborate the existing literature from both Indian and international contexts, as mentioned in Table 27, which consistently identifies perceived severity as a critical determinant of parental help-seeking behavior. High-severity indicators such as pronounced speech delays, lack of eye contact, and marked social withdrawal were reported by participants as primary triggers for initiating professional intervention. These dimensions align with patterns documented in Indian studies (Gulati et al., 2019; Narayana et al., 2020) and global research (Crane et al., 2016), where symptom salience has a strong influence on parental decision-making. The persistence of these findings across various methodologies, including surveys, structured interviews, and observational studies, suggests that perceived severity operates as a universal construct, transcending sociocultural boundaries. This convergence may be attributed to the functional implications of these symptoms on communication and social integration, which are universally valued developmental milestones.

Distinct from prior research, this study identified context-specific perceptions of severity that have not been widely documented in earlier Indian or global studies. Notably, participants emphasized “severity spikes,” such as aggression during public outings, meltdowns in social settings, and nocturnal wandering, as immediate catalysts for seeking care. These situational markers differ from generalized severity indicators commonly reported in previous literature. The emergence of these perceptions may be explained by the methodological approach employed in this study, which involved semi-structured interviews with open-ended probes, facilitating the articulation of nuanced,

lived experiences. Furthermore, the sociocultural context of India, characterized by collectivist norms and heightened sensitivity to public behavior, likely amplifies the perceived urgency when symptoms manifest in socially visible environments (Smith and Green, 2019). The homogeneity of the sample may also have contributed to this emphasis, as all mothers may have been influenced by the gendered caregiving roles and associated social scrutiny prevalent in Indian society.

Certain perceptions documented in prior studies were absent from participant narratives in this research. For instance, Western literature frequently cites pediatric milestone screening and standardized developmental checklists as pivotal cues for early intervention (Clinical Screening for ASD, 2024). Similarly, Indian studies have noted the role of routine pediatric consultations in shaping parental recognition of severity. The omission of these factors in the present study may reflect systemic disparities in preventive pediatric care within the Indian healthcare infrastructure, as well as reliance on informal family observations rather than structured clinical assessments. This gap highlights the need to strengthen early screening protocols and integrate culturally sensitive awareness strategies to bridge the gap between clinical recommendations and parental practices.

**Table 27***Factors Influencing Parental Intention to Seek Services: Autistic Child's Symptoms**Comparison with Previous Research*

Autistic child's symptom	Perceived severity	Example from the study	Similar to previous research	Unique to the study	Previously identified factors not mentioned by participants
Social Communication and Interaction Difficulties	High	Speech delay, inability to express needs, aggression during frustration (e.g., "He cannot talk in complete sentences... starts throwing things around")	Matches Indian and global findings (Gulati et al., 2019; Crane et al., 2016)	Severity spikes (public meltdowns) as immediate triggers	Pediatric milestone screening as a cue to action (Mazurek et al., 2023)
	Low	Passive behavior, mild withdrawal, manageable routines (e.g., "He just used to sit in the corner alone, doing nothing")	Mild symptoms were normalized by families in prior Indian studies	Parents assumed the child was "learning something" without intervention	Early pediatric screening is emphasized in Western studies
Restricted and Repetitive Behaviors	High	Toe-walking, eye squinting, hyperactivity, nighttime wandering (e.g., "He used to run in the middle of the night... sometimes he hurt himself")	Prior work notes repetitive behaviors as severity markers (Waizbard-Bartov et al., 2023)	Safety concerns linked to repetitive behaviors	Sensory sensitivities (Tomchek and Dunn, 2017)

Autistic child's symptom	Perceived severity	Example from the study	Similar to previous research	Unique to the study	Previously identified factors not mentioned by participants
Cognitive and Learning Differences	Low	Repetitive play, ignoring surroundings (e.g., "He used to play with that toy constantly and not look at the things around him")	Matches the global literature on repetitive play as mild severity	Parents delayed help-seeking, assuming the child was "focused."	Prior studies highlight sensory integration issues
	High	Developmental delays compared to peers, lack of socialization (e.g., "My mother-in-law noticed developmental delays compared to neighborhood children")	Indian research confirms delayed speech as a severity indicator (Srikanth et al., 2020)	Family comparisons in joint families as a diagnostic cue	School feedback as a primary cue (Ghosh, 2017)
	Low	Belief that "some children take longer to talk or walk."	Cultural normalization of delays documented in Indian studies	Delay attributed to family anecdotes (e.g., cousin spoke late)	Western studies emphasize standardized milestone charts
Emotional and Behavioral Regulation	High	Aggression, self-harm, emotional breakdowns (e.g., "She becomes very hyper and angry... tries to hit her head")	Emotional distress as a severity marker appears globally (Smith and Green, 2019)	Maternal emotional collapse and help-isolation documented	Grief stages influencing help-seeking (Pac, 2023)

Autistic child's symptom	Perceived severity	Example from the study	Similar to previous research	Unique to the study	Previously identified factors not mentioned by participants
	Low	Mild frustration, occasional distress (e.g., "Mentally, it does affect me a lot... but I try to stay strong")	Matches prior findings on coping with mild emotional strain	Parents relied on resilience and hope rather than services	Western literature notes early counseling referrals

### ***Beliefs About the Causes of Autism***

The findings of this study align with prior research in India and globally mentioned in Table 28, which consistently identifies parental beliefs about autism's causes as a significant determinant of care-seeking behavior. Similar to previous studies (Daley, 2002; Gupta and Singhal, 2004; Chaidez et al., 2018), parents in this study attributed autism to scientifically informed factors, including prenatal stress, genetic predisposition, and environmental influences. These beliefs often increased urgency for intervention when perceived as modifiable, e.g., stress during pregnancy or social isolation during COVID-19, echoing patterns observed in qualitative studies from India and quantitative surveys in Western contexts. Conversely, misinformed beliefs such as attributing autism to karma, divine will, or black magic were also documented in earlier Indian research and African studies (Bakare et al., 2011), where cultural stigma and spiritual interpretations delayed professional help. The persistence of these belief patterns across diverse methodologies and cultural settings suggests that parental decision-making

is shaped by deeply ingrained sociocultural norms, regardless of whether studies employ interviews or structured questionnaires.

Distinct from prior literature, this study uncovered unique beliefs that have not been widely reported in earlier Indian or global research. Notably, several participants linked autism to excessive screen time, describing conditions such as “visual autism,” and perceived radiation from electronic devices as a contributing factor. These beliefs reflect the influence of modern technology and parental guilt in urban Indian households, where digital exposure is a daily occurrence. Additionally, the dual belief system observed in this study, where parents combined medical therapy with religious rituals, adds nuance to existing findings. While previous research acknowledges spiritual reliance, the simultaneous pursuit of evidence-based care and cultural practices appears specific to this context. These unique perceptions may stem from the study’s qualitative design, which allowed open-ended probing, and participant characteristics, such as all respondents being mothers in joint or nuclear families, whose caregiving roles amplify exposure to both traditional norms and modern parenting challenges.

Certain beliefs documented in prior studies were absent from participant narratives in this research. For example, Western literature frequently cites dietary factors, sensory integration issues, and maternal neglect theories as perceived causes of autism (Mazurek et al., 2023; McLay et al., 2020), yet no participants mention these. Similarly, pediatric milestone screening and early counseling referrals, often highlighted as cues to action in global studies, did not emerge in this sample. The omission of these perceptions may reflect systemic gaps in preventive pediatric care in India and limited

awareness of developmental screening protocols among parents. Cultural reliance on family observations rather than clinical assessments likely contributed to this absence, underscoring the need for stronger public health messaging and early intervention programs tailored to local contexts.

**Table 28**

*Factors Influencing Parental Intention to Seek Services: Beliefs About the Causes of Autism—Comparison With Previous Research*

Belief about the causes of autism	Perceived severity	Similar to previous research	Unique factor in the study	Previously identified factor not mentioned by participants
Scientifically Informed Beliefs	Biological /Genetic causes	Genetic predisposition viewed as irreversible → delayed help (Daley, 2002; McLay et al., 2020)	Parents believed autism is “by birth” and cannot be changed; some delayed therapy	Pediatric milestone screening as a cue to action: dietary factors (Mazurek et al., 2023)
	Neurodevelopmental differences Evidence-based environmental influences	Prenatal stress and birth complications linked to autism (Daley, 2002; Chaidez et al., 2018)	COVID-19 isolation perceived as worsening severity → urgent therapy; screen time seen as causing “visual autism.”	Sensory integration issues emphasized in Western studies (Tomchek and Dunn, 2017)
	Other evidence-based causes	Evidence-based environmental factors like toxins and complications during pregnancy (McLay et al., 2020)	Screen time normalized as “manageable” → parents delay therapy; belief that reducing screen time alone will fix autism lowered urgency	Early pediatric counseling referrals noted in Western studies

Misinformed or Culturally Influenced Beliefs	Spiritual or religious explanations	Karma, divine will, and spiritual explanations (Gupta and Singhal, 2004; Daley, 2002; Sharma et al., 2018).	Dual belief systems: therapy + rituals (P7). Fasting and temple visits are prioritized over therapy (P3, P4) and black magic beliefs (P2).	Cultural fatalism is documented globally, but its association with severity has not been explored in prior studies (Bakare et al., 2011).
	Parenting or socialization factors	Maternal blame and early neglect theories (McLay et al., 2020)	Belief that autism is temporary and will resolve naturally; some linked severity to “lack of play” rather than a neurological condition	Parenting style and maternal behavior are the primary causes
	Non-evidence-based environmental causes	Vaccination myths (Srivastava et al., 2024; Castillo et al., 2019).	Community influence discouraging therapy (“Go to Bhagawan”) (P10). Helpless parenting under cultural pressure (P6).	Parenting style and maternal behavior are the primary causes (McLay et al., 2020). Diet-related misconceptions (Mazurek et al., 2023).
	Other non-evidence-based causes	Early childhood neglect theories and maternal blame (McLay et al., 2020).	Belief that autism is temporary and will resolve naturally (P8). Some parents linked severity to “lack of play” rather than a neurological condition.	Media exposure and radiation myths have been noted in prior global studies (Kou et al., 2019).

### ***Perceived Caregiving Mental and Physical Health Outcomes***

The findings of this study corroborate existing literature from India and global contexts mentioned in Table 29, which consistently identifies caregiving as a source of significant mental and physical strain for parents of children with autism. Similar to prior research (Fatima et al., 2021; Kaufman and Feldman, 2020), participants reported high levels of stress, anxiety, and depressive symptoms, often accompanied by physical exhaustion, sleep disturbances, and chronic pain. These outcomes mirror patterns documented in qualitative studies from India and quantitative surveys in Western countries, suggesting that caregiving burdens transcend cultural boundaries. Positive coping strategies, such as emotional resilience and acceptance, also align with previous findings (Kanwal and Asad, 2018; Weiss et al., 2015), which have shown that hope and adaptability are associated with sustained engagement in care. The recurrence of these themes across diverse methodologies reinforces their universality, highlighting the interplay between caregiving intensity and parental well-being.

From prior studies, this research identified coping mechanisms that reflect the influence of modern technology and urban lifestyles in India. Participants frequently mentioned using social media platforms (e.g., Instagram, YouTube) and creative outlets, such as music and dance, as therapeutic strategies for managing their mental health. These approaches are rarely documented in earlier Indian literature. Additionally, weekend outings and short naps emerged as practical coping techniques for managing physical strain, alongside spousal assistance in domestic chores. Another unique observation was the cultural framing of physical symptoms, such as early-onset health

issues (thyroid problems, black circles on legs), which participants explicitly linked to caregiving stress. These findings may have emerged due to the study's qualitative design, which allowed for open-ended exploration, and the homogeneity of the sample, comprising all mothers whose gendered caregiving roles amplify both emotional and physical burdens.

The factors reported in previous research were absent from participant narratives in this study. For instance, formal counseling and structured therapy for caregivers, commonly recommended in Western contexts (Fatima et al., 2021), were not mentioned, possibly reflecting limited availability or awareness of such services in India. Similarly, ergonomic interventions and physiotherapy support, noted in global studies (Junnarkar et al., 2022), did not appear in participant responses, suggesting systemic gaps in caregiver-focused health programs. Fathers' mental health strain and marital conflict, documented in studies like Baker et al. (2021), were also missing, likely due to the all-female sample. These omissions highlight the need for comprehensive caregiver support systems that address both physical and psychological well-being in culturally sensitive and relevant ways.

**Table 29**

*Factors Influencing Parental Intention to Seek Services: Perceived Caregiving Mental and Physical Health Outcomes Comparison with Previous Research*

Perceived caregiving mental and physical health outcomes	Parental perception of caregiving health outcomes	Similar to previous research	Unique factor to this study	Previously identified factor not mentioned by the participants
Mental Health	Positive or Resilient	Prior studies have confirmed resilience and hope as effective coping strategies (Kanwal and Asad, 2018; Weiss et al., 2015). Use of social media and creative outlets (Instagram, dance) as coping mechanisms; peer support	Use of social media and creative outlets (Instagram, dance) as coping mechanisms; peer support at the clinic	Formal counseling and structured therapy for caregivers (Fatima et al., 2021)
	Negative	Matches Indian and global findings on maternal stress and depression (Fatima et al., 2021; Kaufman and Feldman, 2020)	Cultural fatalism linked to karma and guilt; identity loss after childbirth	Fathers' mental health strain and marital conflict (Baker et al., 2021)
Physical Health	Positive or Resilient	Limited evidence in prior research; some studies note lifestyle adaptation (Nkonyane et al., 2021)	Weekend outings, short naps, spousal assistance in domestic chores	Formal respite care and physical wellness programs for caregivers (Reddy et al., 2020)
	Negative	Consistent with previous research on caregiver physical strain (Srikanth et	Early-onset health issues (thyroid, black circles on legs) linked to	Ergonomic interventions and physiotherapy support for caregivers

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al., 2020; Kaufman and Feldman, 2020)	caregiving stress	(Junnarkar et al., 2022)
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### ***Other Factors***

The findings of this study align with prior research in India and globally, as mentioned in Table 30, which consistently identifies family support, social interaction, and social challenges as critical determinants of parental help-seeking behavior. Similar to previous studies (Gulati et al., 2019; Gupta and Singhal, 2004; Bakar et al., 2019), spousal encouragement and extended family involvement were reported as significant facilitators of care-seeking. Parents who received emotional reassurance from their husbands or in-laws were more proactive in pursuing therapy, echoing patterns documented in collectivist cultures where family plays a central role in decision-making. Social stigma and exclusion also emerged as significant barriers, consistent with findings from Indian and African contexts (Bakare et al., 2011; Sharma et al., 2018), where fear of judgment and discrimination often delays intervention. Peer support networks, such as informal parent groups, were noted as beneficial, reinforcing global evidence that social connectedness reduces isolation and promotes engagement with services (Thakur and Singh, 2019).

Distinct from prior literature, this study identified unique social dynamics that shaped parental decision-making. Advice from neighbors and community members to “go to Bhagawan” instead of seeking therapy reflects a culturally specific barrier rooted in spiritual fatalism and communal influence. Additionally, the emergence of WhatsApp-based parent networks and informal therapeutic systems among caregivers at clinics

highlights the role of digital platforms in urban Indian contexts. This adaptation has been rarely documented in earlier studies. Another unique observation was the emotional pain expressed by mothers when comparing their child to peers during neighborhood play, which intensified feelings of stigma and isolation. These findings may have emerged due to the qualitative design and the homogeneity of the sample, which consisted of all mothers whose caregiving roles and social visibility amplify their sensitivity to community judgment and reliance on informal support systems.

Some factors reported in previous research were absent from participant narratives in this study. For example, workplace discrimination and legal advocacy issues, frequently cited in Western literature (Junnarkar et al., 2022), did not appear, likely because all participants were homemakers who had already left employment. Similarly, structured parent ambassador programs and formal advocacy campaigns, noted in global studies (Daley, 2002; Davenport et al., 2018), were not mentioned, suggesting limited availability or awareness of such initiatives in India. School-based bullying and teacher bias, documented in international research (Murthi et al., 2024), were also absent, possibly because the children in this sample were younger and primarily engaged in therapy rather than formal schooling. These omissions underscore systemic gaps in institutional support and highlight the need for culturally tailored interventions that extend beyond clinical settings to address stigma and promote inclusion.

**Table 30**

*Factors Influencing Parental Intention to Seek Services: Other Factors Comparison with Previous Research*

Other factor	Type	Similar to previous research	Unique factor to this study	Previously identified factor not mentioned by the participants
Family Support	Spouse Support	Spousal encouragement improves coping and service-seeking (Bakar et al., 2019; Gulati et al., 2019)	Strong emotional reassurance from husbands (“We will do everything for her”) as a motivator for early intervention	Fathers’ active participation in therapy sessions (Baker et al., 2021)
	Family Structure	Extended family involvement documented in Indian studies (Patel and Kleinman, 2017; Gupta and Singhal, 2004)	Joint family observations triggering early suspicion of autism symptoms	Grandparent-led advocacy and decision-making noted in rural contexts (Narayana et al., 2020)
	Parental Acceptance	Acceptance is linked to proactive care-seeking globally (Kanwal and Asad, 2018; Weiss et al., 2015)	Mothers expressing strong determination and daily commitment to therapy despite emotional strain	Formal counseling programs to support acceptance (Fatima et al., 2021)
Social Interaction	Social Communication	Peer support and parent networks reduce isolation (Bakar et al., 2019; Thakur and Singh, 2019)	Informal therapeutic systems among parents at clinics: reliance on WhatsApp groups for emotional support	Structured parent ambassador programs and advocacy campaigns (Daley, 2002; Davenport et al., 2018)

Other factor	Type	Similar to previous research	Unique factor to this study	Previously identified factor not mentioned by the participants
Social Challenges	Social Stigma	Stigma is documented as a significant barrier in India and globally (Gupta and Singhal, 2004; Bakare et al., 2011)	Advice from neighbors to avoid therapy and “go to Bhagawan”; fear of public judgment during meltdowns	Workplace discrimination and legal advocacy issues noted in Western studies (Junnarkar et al., 2022)
	Social Exclusion	Exclusion from playgroups and schools was noted in prior research (Ghosh, 2017; Sharma et al., 2018)	Neighborhood children actively isolating autistic peers; mothers reporting emotional pain from comparisons	School-based bullying and teacher bias are documented in global literature (Murthi et al., 2024)
	Social Misunderstanding	Cultural misconceptions about autism are widely reported (Daley, 2002; Castillo et al., 2019)	Criticism from relatives and community for “poor parenting”; pressure to follow rituals instead of therapy	Misinterpretation of autism as a mental illness in rural India (Narayana et al., 2020)

### RQ1a: Child-Related Factor

How does the perceived severity of an autistic child’s symptoms affect parents’ intention to seek services for their children with an autism spectrum disorder (1-10 years old) in India? According to Table 31, the findings of this study strongly align with prior research, which emphasizes the role of symptom severity in influencing parental decisions to seek autism-related services. Parents consistently reported an urgent need for intervention when communication challenges were pronounced, such as severe speech

delays or the inability to express basic needs. These observations align with the conclusions of Smith (2021) and Lopez et al. (2020), who identified social communication difficulties as a primary driver of early service-seeking behavior. Similarly, the influence of overall symptom severity on parental urgency reflects patterns documented by Thompson (2023) and Alsulaiman et al (2021), reinforcing the Health Belief Model's assertion that perceived severity is a critical determinant of health-seeking behavior. Restricted and repetitive behaviors also showed partial alignment with Johnson and Kim (2022), who noted that these behaviors often prompt parental concern. However, the strength of this association varies across contexts.

Distinct from earlier studies, this research revealed nuanced parental interpretations of severity that have not been widely documented. While previous literature often treats severity as a uniform construct, participants in this study described "situational severity spikes," such as meltdowns in public spaces or nocturnal wandering, as immediate catalysts for seeking care. These context-specific triggers reflect cultural sensitivities to socially visible behaviors, which may amplify perceived urgency in collectivist settings. Additionally, parents expressed mixed views on restricted and repetitive behaviors, with some linking these symptoms to service-seeking and others minimizing their significance, a finding that diverges from Davis (2020), who reported no perceived connection. Sensory processing challenges were downplayed mainly by participants, contrasting with Carter (2019), who found these issues to be strong motivators for intervention. These unique findings highlight the significance of cultural and situational factors in influencing parental perceptions of severity.

Several factors commonly highlighted in prior research were absent from participant narratives in this study. For example, Western literature frequently cites pediatric milestone screening and standardized developmental checklists as pivotal cues for early intervention (Mazurek et al., 2023). However, none of the participants mentioned that these tools influenced their decisions. Similarly, early counseling referrals and structured guidance from healthcare providers, often emphasized in studies such as Ahmed and Lee (2020), did not emerge in this sample. The omission of these factors may reflect systemic gaps in preventive pediatric care within the Indian healthcare infrastructure and a reliance on informal family observations rather than formal clinical assessments. This gap highlights the need for culturally tailored awareness campaigns and accessible screening protocols to bridge the disconnect between clinical recommendations and parental practices.

**Table 31**

*Perceived Severity of Social Communication and Interaction Difficulties and Parents' Intention to Seek Services for Children with Autism Spectrum Disorder: Comparison With Previous Research*

Factor category	Current study finding	Consistent with previous research	Inconsistent with previous research
Social Communication and Interaction Difficulties	Parents shared stories of feeling an urgent need to seek services when communication challenges were severe	Similar themes reported by Smith (2021) and Lopez et al. (2020)	Contrasts with Brown and Patel (2019), who noted that severity had minimal influence
Restricted and Repetitive Behaviors	Participants expressed mixed views; some linked severity to service-seeking, others did not	Aligns with Johnson and Kim (2022)	Differs from Davis (2020), who found no perceived connection
Sensory Processing Challenges	Parents often minimized sensory issues, stating that these did not strongly influence decisions	Matches findings by Green et al. (2021)	Opposes Carter (2019), who reported a strong influence
Overall Symptom Severity	A dominant theme was that overall severity shaped parents' sense of urgency for intervention	Supported by Thompson (2023) and Alsulaiman et al. (2021)	Inconsistent with Ahmed and Lee (2020), who reported that severity was not a significant factor

### **RQ1b: Parental Knowledge and Perception**

How do the beliefs about the causes of autism affect parents' intention to seek services for their children with an autism spectrum disorder (1-10 years old) in India? In Table 32, the findings of this study align with prior research, which demonstrates that parental beliefs about autism significantly influence care-seeking behavior. Scientifically informed beliefs, such as prenatal stress, birth complications, and environmental

isolation, were associated with higher urgency for intervention, consistent with studies by Daley (2002) and Chaidez et al. (2018). These findings support the Health Belief Model, which posits that perceived controllability of a condition increases the likelihood of action (Jones et al., 2015). Similarly, misinformed or culturally influenced beliefs, including karma, divine will, and black magic, acted as barriers to timely care, echoing patterns documented in Gupta and Singhal (2004) and Bakare et al. (2011). Both sets of beliefs demonstrate the strong interplay between cultural context and health-seeking decisions, reinforcing the need for culturally sensitive interventions.

Unlike earlier studies, this research identified distinct belief patterns that have not been widely reported. A notable finding was the concept of “visual autism,” where parents attributed symptoms to excessive screen time. This belief produced mixed responses; some parents sought therapy urgently, while others assumed reducing screen exposure would suffice. Such interpretations diverge from Western literature, which rarely associates screen time with autism causation (Tomchek and Dunn, 2017). Another unique observation was the dual belief system, where parents combined medical therapy with religious rituals, sustaining engagement despite cultural norms. This hybrid approach reflects a pragmatic adaptation within collectivist societies. It adds nuance to the existing literature, which typically frames spiritual practices as barriers rather than complementary strategies.

Several factors commonly highlighted in prior research were absent from participant narratives in this study. For example, Western literature frequently cites vaccination myths and dietary misconceptions as influential in shaping parental decisions

(Mazurek et al., 2023; Castillo et al., 2019); yet, participants in this sample did not report holding these beliefs. Similarly, structured pediatric counseling and early developmental screening, often emphasized as cues to action in global studies, did not emerge in this context. The absence of these factors may reflect differences in information dissemination and healthcare infrastructure in India, where informal networks and cultural narratives dominate decision-making. These gaps underscore the need for targeted awareness campaigns and systematic screening programs to bridge disparities between evidence-based practices and culturally embedded beliefs.

**Table 32**

*Factors Influencing Parental Intention to Seek Services: Beliefs About the Causes of Autism Comparison with Previous Research*

Belief category	Current study finding	Consistent with previous research	Inconsistent with previous research
Scientifically Informed Beliefs	Parents attributed autism to factors such as genetics, prenatal stress, birth complications, environmental isolation (COVID-19), and screen time. Urgency for seeking services was higher when causes were perceived as modifiable (e.g., stress, isolation) and lower when viewed as immutable (e.g., genetics). Screen time was uniquely described as “visual autism,” with mixed responses; some parents sought therapy, others believed reducing exposure was sufficient.	Aligns with Daley (2002), Chaidez et al. (2018), and Tomchek and Dunn (2017), who noted that scientifically informed beliefs often increase care-seeking when perceived as controllable.	Diverges from Western literature, where genetic attribution rarely reduces urgency; unique emphasis on screen time and “visual autism” is not widely documented globally.
Misinformed or Culturally Influenced Beliefs	Parents reported beliefs rooted in karma, divine will, black magic, and community influence. Many engaged in rituals, fasting, and temple visits before considering therapy. Community advice often discouraged clinical care. A distinctive finding was the dual belief system, where parents combined medical treatment with religious practices, sustaining engagement despite cultural norms.	Consistent with Gupta and Singhal (2004) and Bakare et al. (2019), which documented spiritual and supernatural explanations as barriers to timely intervention.	Contrasts with Western studies, where spiritual practices rarely substitute for clinical care; a hybrid approach (therapy + rituals) is rarely addressed in prior research.

**RQ1c: Parent-Related Factor**

How do perceived caregiving mental and physical health outcomes affect parents' intention to seek services for their children with an autism spectrum disorder (1-10 years old) in India? Table 33: The findings of this study align with prior research, emphasizing the significant impact of caregiving health outcomes on parental decisions to seek autism-related services. Mental health challenges such as chronic stress, anxiety, and depression were consistently reported as barriers to proactive care-seeking, corroborating studies by Fatima et al. (2021) and Kaufman and Feldman (2020), which documented high emotional strain among caregivers of children with neurodevelopmental disorders. Similarly, physical health burdens, including fatigue, body aches, and sleep disturbances, were identified as limiting factors, consistent with the findings of Srikanth et al. (2020) and Kaufman and Feldman (2020). These parallels reinforce the Health Belief Model's construct of perceived barriers, demonstrating that both psychological and physical strain can significantly hinder health-seeking behaviors.

From earlier studies, this research revealed unique coping strategies that shaped parental engagement with autism services. While prior literature often emphasizes formal counseling and structured mental health interventions (Fatima et al., 2021), participants in this study relied heavily on informal coping mechanisms such as social media use, music, and peer support networks. These strategies not only mitigated emotional strain but also sustained motivation for therapy, highlighting adaptive behaviors within resource-constrained settings. Similarly, physical health challenges were managed through lifestyle adjustments, including weekend outings, short naps, and spousal assistance

approaches, which are rarely documented in global studies that prioritize formal respite care and physiotherapy (Reddy et al., 2020; Junnarkar et al., 2022). These findings highlight the cultural and contextual nuances that influence caregiver resilience in India.

Several factors commonly highlighted in prior research were absent from participant narratives in this study. For instance, Western literature frequently cites structured caregiver wellness programs, ergonomic interventions, and formal respite services as essential supports for reducing physical strain (Junnarkar et al., 2022; Reddy et al., 2020); however, these were not mentioned by the participants. Similarly, professional mental health counseling, often recommended in global contexts to address caregiver burnout (Fatima et al., 2021), did not emerge as a coping strategy in this sample. The absence of these factors may reflect systemic gaps in caregiver-focused health infrastructure in India and a reliance on informal, culturally embedded coping mechanisms. These omissions highlight the need for integrated caregiver support programs that combine professional services with culturally relevant strategies to improve both mental and physical well-being.

**Table 33**

*Factors Influencing Parental Intention to Seek Services: Perceived Caregiving Mental and Physical Health Outcomes Comparison with Previous Research*

Factor category	Current study finding	Consistent with previous research	Inconsistent with previous research
Mental Health Outcomes	Parents reported chronic stress, anxiety, depression, and identity as significant barriers to care-seeking. Cultural fatalism and guilt amplified these challenges. Conversely, emotional resilience, acceptance, and coping strategies, such as social media use, music, and peer support, increased the intention to seek services.	Aligns with Fatima et al. (2021) and Kaufman and Feldman (2020) on caregiver stress and emotional burden, as well as Weiss et al. (2015) and Kanwal and Asad (2018) on the enhancement of proactive care-seeking through resilience and social support.	Diverges from Western literature emphasizing formal counseling and structured mental health interventions as primary coping mechanisms (Fatima et al., 2021).
Physical Health Outcomes	Fatigue, body aches, sleep disturbances, and early-onset health issues reduced parents' capacity to seek services. Informal coping strategies such as weekend outings, short naps, and spousal assistance helped mitigate physical strain and sustain engagement with therapy.	Matches Srikanth et al. (2020) and Kaufman and Feldman (2020) on physical strain as a barrier; Nkonyane et al. (2021) noted lifestyle adaptation as a coping mechanism.	Contrasts with global studies emphasizing formal respite care, ergonomic interventions, and physiotherapy support for caregivers (Reddy et al., 2020; Junnarkar et al., 2022).

The findings presented in Table 34 underscore the critical role of perceived severity in shaping parental decisions to seek autism-related services. Consistent with prior research, high-severity symptoms such as speech delays, lack of eye contact, and aggressive behaviors were strong motivators for early intervention (Gulati et al., 2019; Crane et al., 2016). This pattern aligns with the Health Belief Model, which posits that perceived severity significantly influences health-seeking behaviors (Jones et al., 2015). However, this study identified unique situational triggers, such as public meltdowns and nocturnal wandering, that intensified the urgency for care, reflecting cultural sensitivities to socially visible behaviors. Conversely, low-severity symptoms were often normalized within family contexts, delaying care-seeking, a trend also documented in Indian literature where developmental delays are frequently perceived as benign (Gupta and Singhal, 2004). Unlike Western studies emphasizing pediatric milestone screening as a cue to action (Mazurek et al., 2023), participants in this study relied primarily on family observations, highlighting systemic gaps in early screening protocols in India.

Parental beliefs about autism emerged as a second major determinant of care-seeking behavior. Scientifically informed beliefs such as prenatal stress and environmental isolation were associated with proactive engagement, consistent with findings by Daley (2002) and Chaidez et al. (2018). In contrast, culturally influenced beliefs, including karma, divine will, and black magic, acted as barriers, echoing patterns observed in non-Western contexts (Bakare et al., 2011; Gupta and Singhal, 2004). A distinctive feature of this study was the emergence of dual belief systems, wherein parents combined biomedical interventions with religious rituals, reflecting the complex

interplay between cultural norms and evidence-based care. Additionally, unique perceptions such as “visual autism” attributed to excessive screen time were reported, illustrating the influence of modern parenting practices in urban India. These findings diverge from Western literature, which emphasizes professional intervention regardless of environmental factors (Tomchek and Dunn, 2017).

Caregiving outcomes introduced another layer of complexity in parental decision-making. Negative mental health outcomes, including chronic stress, depression, and identity loss, often acted as barriers to care-seeking, corroborating findings by Fatima et al. (2021) and Kaufman and Feldman (2020). Cultural fatalism and guilt further compounded these challenges; a nuance rarely explored in Western research. Conversely, positive coping strategies such as emotional resilience, spousal support, and peer networks facilitated proactive engagement, aligning with Weiss et al. (2015). Unique to this study was the use of digital coping tools (e.g., Instagram, YouTube) and creative outlets (e.g., dance, music), reflecting adaptive strategies in urban Indian households. Physical health strain, manifested as fatigue, body aches, and early-onset conditions, further hindered service uptake, echoing the findings of Srikanth et al. (2020). However, informal coping mechanisms such as weekend outings and short naps mitigated these barriers, contrasting with Western recommendations for structured respite care and physiotherapy (Junnarkar et al., 2022).

In summary, Tables 31-33 reveal both convergence and divergence between this study and prior research. While symptom severity and scientifically informed beliefs consistently predicted care-seeking across contexts, culturally embedded misconceptions

and systemic gaps in early screening remain unique challenges in India. The emergence of technology-related beliefs and highlighting strategies underscores the evolving nature of parental experiences, indicating that future interventions must integrate digital education and culturally sensitive counseling to address these needs effectively. Unlike Western studies that emphasize formal caregiver support programs, this study revealed a reliance on informal networks and personal coping mechanisms, highlighting a critical gap in institutions. Developing findings reinforce the need for holistic, culturally responsive models that address not only child-related factors but also the well-being of parents and caregivers to improve autism care outcomes in India (Daley, 2002; Weiss et al., 2015; Fatima et al., 2021).

### **Integration With the Health Belief Model**

The findings strongly support the application of the Health Belief Model in understanding parental care-seeking behaviors. Each of the six HBM constructs perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, and self-efficacy was reflected in the participants' narratives.

- Perceived severity: High symptom severity prompted action.
- Perceived benefits: Parents who believed in the effectiveness of therapy were more likely to seek services consistent with Champion and Skinner's (2008) findings.
- Perceived barriers, including emotional: Distress, cultural stigma, and logistical challenges (e.g., cost, access), hindered care-seeking, echoing findings by Gustavsson and Beckman (2024).

- Cues to action: Family observations, school feedback, and media exposure often trigger service-seeking behavior, aligning with findings of Kanna et al. (2020).
- Self-efficacy: Parents with higher confidence in managing their child's condition were more proactive, as supported by Weiss et al. (2015).

### **Limitations of the Study**

This study has several limitations that should be acknowledged. First, the participant sample consisted of a non-random group of 10 individuals from Ahmedabad city, which restricts the generalizability of findings to the broader Indian population. Additionally, all participants were mothers of children with autism, providing 100% maternal perspectives and excluding insights from fathers or other caregivers. Race and ethnicity data were not collected, further limiting the ability to analyze cultural variations across India, as recruitment was confined to a single clinic in Ahmedabad. Another limitation relates to potential bias in the instruments used, which may have influenced both the process and the results of the study. Response bias was also possible, as participants' understanding of autism and related concepts varied. The interviews were audio-recorded for 9 out of 10 participants (90%), first in Gujarati and then transcribed into English. Self-transcription by the researcher introduced the possibility of interpretation bias.

Furthermore, in some cases, participants had their child present during the interview, which may have distracted them and affected the completeness of their responses. Finally, qualitative research inherently faces challenges in establishing validity

and reliability. While steps such as journaling, triangulation, and peer review were taken to strengthen the trustworthiness of the findings, these limitations should be considered when interpreting them.

### **Recommendations**

Chapter 4 results highlighted the factors that influence care-seeking parents' experiences living with a child with Autism in India. A few recommendations are presented below to guide further research and practice in this study's direction.

#### **Increase Fathers' and Other Caregivers' Involvement**

In this research study, all participants were female, with 100% participation by females and 0% by males. In India, fatherhood is considered a responsibility to provide for the family, including comfort, food, and privileges, with the female typically staying at home as a housewife. During this study, nearly 50% participant mentioned quitting their jobs or letting their previous professional career go due to their autistic child and their daily needs. Future studies should intentionally include fathers, grandparents, and other caregivers to capture a broader spectrum of caregiving experiences and gendered roles in autism care (Gulati et al., 2019). This could help identify support needs specific to different family members, the impact of caregiving on marital relationships and family dynamics, and how other family members contribute to or hinder care-seeking decisions.

#### **Expand the Geographic Scope Beyond Gujarat State**

The participant recruitment and data collection were completed at the Asian Child Neuro Clinic in Ahmedabad, Gujarat. However, a couple of participants relocated to Gujarat due to professional commitments or personal needs. Future research should

explore similar experiences across other Indian states and rural regions to understand regional disparities in autism awareness, service access, and cultural perceptions (Narayana et al., 2020; Reddy et al., 2020). Comparative studies between urban and rural populations could reveal unique challenges, inform region-specific interventions, and help understand disparities in access to autism services. Cultural variations across Indian states that influence beliefs about autism and care-seeking behavior.

### **Investigate How Cultural and Spiritual Beliefs Shape Understanding and Care-Seeking for Autism**

The study highlighted the influence of spiritual and cultural beliefs on care-seeking behavior. Future qualitative and mixed-methods research should delve deeper into how these beliefs shape parental decision-making and how culturally sensitive education can bridge the gap between traditional and biomedical models (Daley, 2002; Vats et al., 2024). Explore how spiritual and traditional beliefs shape parental decisions.

### **Assess the Long Term Mental and Physical Health Trajectories of Caregivers**

Given the significant mental and physical health challenges reported by participants, longitudinal research is needed to track how these outcomes evolve, particularly concerning the child's developmental milestones, service access, and caregiving intensity. Such studies could assess the long-term impact of caregiving on parental well-being and identify effective coping strategies (Fatima et al., 2021; Kaufman and Feldman, 2020). The current study revealed high levels of emotional exhaustion, anxiety, depression, and physical strain among mothers of children with autism.

### **Study the Role of Peer Networks, Informal Support Systems, and Parent-to-Parent Advocacy.**

To enhance emotional resilience and care-seeking behavior among parents of children with autism in India, future programs should promote peer support networks and caregiver advocacy. This study found that parents benefit from connecting with others who share similar experiences, which helps reduce stress and encourages proactive caregiving. Prior studies also support the effectiveness of parent ambassador programs and storytelling in reducing stigma and fostering empathy (Bakar et al., 2019; Daley, 2002; Vats et al., 2024). Leveraging social media platforms can further expand outreach and build inclusive support communities.

#### **Implications**

This research filled the gap in understanding the lived experiences of parents living with children with autism spectrum disorder (ASD) in India. The study provided much-needed insight into parents lived experiences, focusing on child-related factors, parent-related factors, and parental knowledge and health outcomes in India.

#### **Positive Social Change**

The study highlights the transformative potential of empowering parents through culturally sensitive education, community support, and inclusive healthcare systems. Documenting the emotional, physical, and social challenges faced by parents, especially mothers, brings visibility to a marginalized group whose voices are often underrepresented in autism research. The research underscores the need to shift societal perceptions of autism from a stigmatized condition to a treatable neurodevelopmental

disorder. This reframing can reduce shame, increase acceptance, and foster inclusive environments in schools, clinics, and communities. The study also encourages the development of peer support networks and parent-led advocacy, which can reduce isolation and promote collective action for autism awareness.

### **Implications for Theory and Method**

The study reinforces the relevance of the Health Belief Model (HBM) as a theoretical framework for understanding parental decision-making in non-Western contexts. Each HBM construct, perceived severity, perceived benefits, perceived barriers, cues to action, and self-efficacy, was reflected in the participants' narratives. For example, parents who perceived high severity in their child's symptoms (e.g., speech delay, aggression) were more likely to seek services, cultural beliefs and emotional strain acted as barriers to care, family observations and peer interactions served as cues to action, and self-efficacy was linked to proactive care-seeking and coping strategies. Methodologically, semi-structured interviews and thematic analysis provided rich, contextual insights into the caregiving journey. This approach enabled the inductive exploration of culturally embedded beliefs and behaviors, thereby validating the use of qualitative methods in public health research.

### **Recommendations for Practice**

Based on the findings, several practical recommendations emerge for healthcare providers, educators, and policymakers. The influence of spiritual and cultural beliefs on parental decision-making highlights the need for culturally responsive care models. Healthcare professionals should be trained to understand and respectfully address these

beliefs while guiding families toward evidence-based interventions (Daley, 2002; Vats et al., 2024). Integrating traditional values with modern care approaches may improve trust and service uptake.

### ***Integrated Mental and Physical Health Support for Caregivers***

The emotional and physical toll on parents, especially mothers, was a recurring theme. Mental health services, caregiver support groups, and respite care should be integrated into autism care programs to provide comprehensive support for individuals with autism and their caregivers. These services can help reduce caregiver burnout and improve the overall well-being of families (Fatima et al., 2021; Kaufman and Feldman, 2020).

### ***Early Screening and Awareness Campaigns***

Many parents delayed seeking care due to a lack of awareness or normalization of symptoms. Public health campaigns should focus on early signs of autism, the importance of early intervention, and the availability of services. These campaigns should be multilingual and tailored to local cultural contexts to maximize reach and impact (Chakrabarti et al., 2023; Gupta and Singhal, 2004).

### ***Strengthening Community-Based Services***

The study underscores the importance of accessible, community-based diagnostic and therapeutic services. Clinics like the Asian Neuro Child Clinic serve as vital hubs for care. Expanding such models across rural and underserved areas can bridge the service gap and reduce geographic disparities (Reddy et al., 2020; Rao and Nayar, 2021).

### ***Community-Based Service Expansion***

Clinics like the Asian Neuro Child Clinic serve as vital hubs. Expanding similar models across rural and underserved areas can reduce geographic disparities in autism care.

### ***Parent Empowerment Through Education and Technology***

Structured parent training programs and digital platforms (e.g., WhatsApp groups, YouTube channels) can enhance parental self-efficacy and reduce caregiver burnout.

### ***Policy Advocacy and Implementation***

Strengthening the enforcement of autism-related policies, such as the Rights of Persons with Disabilities Act, and increasing awareness of available government schemes can improve service access for families.

## **Summary**

This study examined the factors influencing Indian parents' decisions to seek services for their children with autism spectrum disorder (ASD), using the Health Belief Model (HBM) as a theoretical lens. The findings revealed that perceived symptom severity, parental beliefs about autism's causes, and the mental and physical health outcomes of caregiving significantly shaped care-seeking behavior. Parents who recognized severe symptoms such as speech delays or aggression were more likely to pursue professional help. In contrast, cultural normalization of developmental delays often led to delayed intervention. Beliefs ranged from scientific explanations to spiritual interpretations, with the latter sometimes hindering timely care. Emotional exhaustion, anxiety, and physical strain were common among caregivers. However, many

demonstrated resilience through peer support, spousal involvement, and personal coping strategies.

The study contributed to a deeper understanding of autism caregiving in India and highlights the need for culturally sensitive, inclusive, and accessible care systems. It advocated for expanding research beyond Gujarat, involving fathers and other caregivers, and bridging traditional beliefs with scientific knowledge. Practical recommendations include early screening campaigns, integrated mental health support, and community-based services tailored to local contexts. By amplifying caregiver voices and reframing autism as a treatable neurodevelopmental condition, this research promotes positive social change and calls for empathetic, evidence-based interventions that respect cultural diversity and empower families across India.

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## Appendix A: Interview Protocol Guide

### Opening the Interview:

Thank you for participating in this research study. My name is Yash Patel, and I am a Walden University research student. As mentioned in the consent form, your participation supports the need for more information about the care-seeking parents' experience living with a child with autism spectrum disorder (ASD) in India. The interview time is approximately 30 minutes to one hour. You may stop the interview at any time and for any reason. There will be open-ended questions followed by additional questions that may arise during this interview. You will only participate in one-on-one interviews to maintain confidentiality. Your responses are entirely confidential. The Walden University Institutional Review Board has approved all informed consent procedures. Personal information generated from the interview data will be redacted or destroyed. Do you have any questions before we begin?

Demographic questions:

Age:

Relationship status to the ASD Child:

Highest level of education:

Number of children:

Marital status:

Town or suburb:

“I am going to start the interview with a question about your living experiences as a parent with an ASD child.”

## Interview Questions

### **1. How did you find out your child has autism?**

- What signs did you notice?
- How did you feel when you found out?

### **2. What is a typical day like for you and your child?**

- What differences have you noticed compared to other kids their age?
- Are there specific behaviors or challenges that stand out?
- What activities does your child enjoy?
  - Are there routines that help your child feel comfortable?
- How do these traits affect your child's daily life?
- How do other family members understand your child's traits?

### **3. How has your child's autism affected your family life?**

- How do other family members interact with your child?
- What support systems do you have?

### **4. What challenges have you faced as a parent of a child with autism?**

- How have you overcome these challenges?
- Can you share a moment when you felt proud of your child?

### **5. Why did you decide to seek professional help for your child?**

- Did you face any problems from society or family members when getting help?
- How has the support you received made a difference?
- What advice would you give to other parents considering seeking help?

**6. What do you think are the potential causes of autism in children? Can you give me examples?**

- How do your beliefs about autism affect your decision to get help?

**7. How has your mental health been affected by caring for your child with autism?**

- Have you ever felt stressed, overwhelmed, anxious, worried, sad, depressed, or isolated? Can you tell me more about it?
- How do you cope with these feelings?
  - Are there any routines or practices that help you manage your mental health? Can you tell me more about them?

**8. How has your physical health been affected by caring for your child with autism?**

- Have you ever been physically exhausted, could not sleep, could not eat, or been overeating, experienced pain, or been injured? Can you tell me more about it?
- How did you cope with these physical challenges?
  - Are there any routines or practices that help you manage your physical health? Can you tell me more about them?

**9. How has being a parent of a child with autism changed you?**

- What have you learned from this experience?
- How do you take care of your own well-being?

**10. What are your hopes and dreams for your child's future?**

- What steps are you taking to help your child achieve these goals?
- How do you envision your child's life in the coming years?

**11. Is there anything else you'd like to share about your journey?**

- Any advice or insights for other parents?
- Any special moments or stories you'd like to tell?

#### Closing Question

I have learned so much about your experience as a care-seeking parent living with ASD in India. Is there anything else you want to share before we end the interview?

#### Closing Script for the Interview

Thank you for the detailed information that you shared regarding this topic. Your efforts will provide much-needed information regarding the care-seeking parents' experience living with children with ASD in India. If you remember something regarding the topic you believe is essential, please contact me via [yash.patel@waldenu.edu](mailto:yash.patel@waldenu.edu) or WhatsApp at +1(714)3515859. I will contact you once the data is completed to verify the accurate results. Once the study is completed, I will share the results. As a reminder, all collected personal information will be destroyed.