

Research Consortium Archive

P(ISSN): 3007-0031 E(ISSN): 3007-004X

https://rc-archive.com/index.php/Journal/about





Exploring the Lived Experiences of Children with Autism in Hospital Settings: A Qualitative Study

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Publisher: EDUCATION GENIUS SOLUTIONS

Review Type: Double Blind Peer Review

ABSTRACT

Children with Autism Spectrum Disorder (ASD) often face unique challenges in hospital environments due to heightened sensory sensitivity, communication difficulties, and changes in routine. This qualitative study explores the lived experiences of 20 children with autism (10 males and 10 females) admitted to pediatric hospital settings within the past six months. Using semi-structured interviews, data were collected and analyzed thematically. Results highlighted common emotional and sensory challenges, with gender-based differences in coping strategies and reactions. Males exhibited more behavioral rigidity and sensory defensiveness, whereas females displayed greater emotional expression and reliance on comfort objects or familiar staff. Findings suggest that hospital environments often fail to accommodate neurodiverse needs, leading to distress and withdrawal. The study emphasizes the importance of staff training, routine predictability, and sensory-adapted care protocols to support children with ASD. These recommendations can enhance patient comfort, compliance, and long-term mental health outcomes for this vulnerable population.

Keywords: Autism Spectrum Disorder, Sensory Sensitivity, Coping Strategies, Qualitative Study, Lived Experiences, Emotional Distress. **Introduction**

Disorder (ASD) Autism Spectrum constitutes a long-term neurodevelopmental disorder, which is based on the differences in communication, social interaction and restricted and repeating behaviors (American Psychiatric Association, 2013). The world has been witnessing a steady increase in the reported cases of autism and the most recent estimations show that 1 out of 100 children was reported with ASD (World Health Organization [WHO], 2023). The process of identifying, diagnosing, and supporting ASD children is usually delayed or lacks altogether in Pakistan as well as other low- to middle-income countries, and their access to mainstream services including hospitals is even more problematic (Khan et al., 2021). Hospitals are not built with accommodation in an autistic population at heart and so they tend to make a hospital experience unbearable to an autistic child as it is full of strange routines, excessive sensory stimulus, and communication barriers (James et al., 2020).

Many of the hospital stays are unfortunately characterized by clinical interventions, strangers, and loss of control, already creating anxiety in non-neurodivergent children. In people with autism, however, this experience can be enhanced by challenges in emotional control, sensitivity to senses, and the inability to communicate the needs (Tromans et al., 2021). As an example, loud monitors and bright lights, unstable schedules, inconsistent physical contact with unfamiliar caregivers may cause sensory overload and result in either meltdowns or withdrawal (Mazerolle et al., 2022). Children are also likely to lose the elements of routine

and coping on hospital visits particularly where the visit is the result of an emergency or/and inpatient treatment hence enhancing distress. Under these conditions, the possibility of the hospital personnel interpreting the self-stimulatory behavior as resistance or aggression can result in improper treatment or failure to take the real medical concern into consideration (Walsh et al., 2021).

It has also been noted that accommodations must also emphasize on environmental and interpersonal factors that may affect the children with autism in the process of hospitalization. Children with an ASD usually seek the support of familiarities, routine, and familiar caregivers when approaching new experience (Silva et al., 2023). Should their stabilizing factors be impeded as in the case of hospitalization then they may lose their coping ability. A child that normally relies more on communication other than language may fail to explain pain, fear, or no-pleasure in a crowded hospital setting. Nurses and caregivers often complain that they are poorly prepared to handle the effects of autism on different behaviors, and they lack specific guidelines to deal with the problem thus leading to bad outcomes to the child and high parental burden (MacDonald et al., 2020).

Irrespective of these issues, research is scarce on the qualitative inquiry of children with autism experiences and views of their stay at hospital. Although past studies have been inclined to revolve on the participation of parents or professionals, little inclusion of autistic children particularly those able to describe their experiences with the help of support might be applied in the healthcare policies and crafting (Ford et al., 2019). By realizing the needs, the perceptions, and the ways in which these children cope better, the hospital can design an autism-friendly environment in the hospital which will provide them with safety, communication, and well-being.

Concerning gender, literature indicates that there are also significant disparities in the manner in which a male and female child on the autism spectrum encounter and respond to sensory or emotional stressful factors (Lai et al., 2021). As an example, girls with autism can show better skills with regards to masking or attachment toward certain objects or persons, whereas boys are more prone to externalizing the distress through avoidance or routine reliance. Such gender distinctions are particularly instrumental in the case of a hospital setting, where a standard, automatic approach at care can miss such distinctions and, in turn, cause greater discomfort.

More than that, the cultural context plays a significant role in perception and the approach to the concept of autism in any healthcare system. In some of the South-Asian cultures, such as Pakistan, the perception of stigma associated with neurodevelopmental disorders is seen as a factor that causes late diagnosis and treatment. It is because of this delay that there is not much preparation that is being done regarding some experiences

like hospitalization where the children ought to be able to adjust to new surrounding quite fast. The convergence of neurodiversity, health care, and cultural expectations in these contexts has necessitated the need to address it using culturally relevant practices that value the lived experiences of autistic children and their families (Nisa et al., 2023).

This research uses a phenomenological qualitative study to find out the lived experiences of children with autism of both gender when in a hospital setup. Under this strategy, detailed descriptions can be provided where the emotional, sensory, and relational aspects of hospitalization by the child can be described. Through semi-structured interviews involving visual assistance and support of caregivers, the researchers will identify the key themes that may help to describe the peculiarities of stress experienced by these children, sociological benefits, and support that they require. The sample consists of male and female children with the age between 6 and 12 that were in the pediatric hospitals during the last six months.

The following goals are informed by the assumption that healthcare facilities should be more embracive, patient, and sensitive to the senses and emotional realities of autistic children. This study will help the healthcare providers of the pediatric field, hospital management, and policymakers seeking to conduct autism-friendly practices to gain a useful body of evidence.

Through the thematic analysis of the stories of autistic children, the research finds the variance in male and female children traversing the hospital space. It also considers the significance of routine, seeing to it that the staff members are approached in an empathetic manner and the familiar senses. Finally, based on the data, structural improvements to pediatric healthcare settings are the suggested research findings, such as the training of staff on autism, incorporation of sensory-sensitive environments, and establishing communication options.

Conclusively, even though healthcare in a clinical setting keeps on enhancing the outcomes of pediatric healthcare cases, there has been strong urgency in humanizing such encounters to vulnerable populations. Heightened sensory and emotional needs of children with autism pose specific obstacles to them in hospitals. Placing their lived experiences at the center does not only contribute to the inclusive healthcare policy, but it also guarantees that hospitals can be healing rather than traumatic spaces. The paper can therefore be seen as a cry to change the clinical perception of autism to attach more of an empathetic perspective to it that is based largely on lived experience.

Literature Review

Autism Spectrum Disorder (ASD) is neurodevelopmental disorder characterized by impairment in social communications, sensory perception and limited, repetitive behaviors. Special sensory and behavioral responsiveness of the autistic children is a complicated situation, especially when it comes to the hospital setting, which is commonly overstimulating and unfamiliar (Taneja et al., 2020). An abundance of literature has suggested that research is needed on how the hospital environment affects the psychological, emotional, and physiological health of children with autism (Benham & Gibbs, 2021). The following literature review disseminates information from significant recent analyses on the topics of emotional regulation, sensory processing, interaction of the hospital staff, parental engagement, and environmental design with consideration of gender-based ideas in case it is indicated.

Emotional and Psychological Challenges in Hospital Environments

Unpredictability, change of schedules and not knowing what to expect may especially bother children with ASD on hospital premises. Research has always supported the argument that emotional dysregulation is a major issue in children with autism under hospital admission. Koller and Nicholas (2022) note that children with ASD tend to have higher anxiety rates that are stimulated by medical procedures, blood draws, physical examination, and invasive monitoring. They managed to recognize an increased level of cortisol and which included increased emotional outbursts in autism children hospitalized regarding neurotypical peers.

What is more is that, the problem of emotion regulation is characteristic of the children with autism and it is rooted in the inability to demonstrate the distress in a socially acceptable manner. It is possible that, as Jorgensen et al. (2021) pointed out, most of the children with autism can find verbal and behavioral ways to demonstrate fear, hiding, aggression, or shutdown which will not allow the medical staff to assess the situation and treat it properly. This emphasizes the necessity of training the personnel to understand nonconventional signals of emotional distress.

The recent literature has also found the differences due to gender in emotional response. During distress, female children with autism show more internalizing behaviors (e.g., withdrawal, tearfulness) whereas, male children usually show externalizing reactions (e.g., aggression, tantrums) (Dean et al., 2020). These results cluster with the thematic analysis of the present investigation, in which female participants expressed greater amount of emotional attachment and separation anxiety, and males exhibited fear-related avoidance attitudes.

Sensory Overload and Hospital-Induced Sensitivities

One of the difficulties most frequently reported in children with ASD during the stay in hospitals is the issue of sensation. The surrounding in the hospital with the tough lighting, abrupt sounds, strange textures, and the interaction with constantly changing people can rapidly unravel and become too much to handle even to autistic children. Literature, including that by Donnelly et al. (2023), indicates that sensory hypersensitivity plays an essential role in

dictating the stress in hospital experiences of autistic people. In their study of observational research, they have also pointed out that many children with autism can get angry because of ambient noise (e.g. monitor beeping, shoes clicking in hallways) and fluorescent lighting.

A similar study by Hughes et al. (2020) studied sensory modulation rooms in children hospitals. The authors discovered that ASD children experienced substantial decreases in anxiety and enhanced the level of cooperation with the medical staff when using a low-stimulation environment whose safety to sense falls within the sensory domain. These findings are also confirmed in the current study whereby both males and females indicated distress associated with sensory overload, e.g. avoidance of a sounding machine or of intense light.

Interestingly, the female autistic children in the hospital settings could report more sensory coping behavior like humming or attachment to some comfort items (Lai et al., 2020). Such gender disparity confirms a stronger argument that additional individualized sensory accommodations of ASD patients in pediatric care can benefit more.

Coping Mechanisms and Adaptive Behaviors

The ability to cope with several behaviors is quite different in children with autism and, in many cases, it depends on the level of communication skills, cognitive level and sensitivity to different kinds of stimulus. The study carried out by Beighton and Wills (2021) revealed that repetitive behavior (e.g., hand-flapping, rocking), or adherence to a particular routine is the type of self-regulation most commonly used by autistic children. This can be confirmed by the following observations in the present study: the participants (males) resorted to self-stimulatory behavior or followed stereotypic patterns, whereas the participants (female) clung on to emotion-related items, or the people that take care of them.

The literature also establishes a pattern of routines and visual signs to be very useful when it comes to managing anxiety during the process of hospitalization. Specifically, Slattery and George (2021) mentioned that autistic children could learn more about hospital events and prepare to attend them with visual timelines, picture boards, and storybooks that described medical procedures, which helped them avoid emotional and behavioral disturbances. The adaptive tools have the potential to encourage autonomy, especially among the verbal-impaired children.

In addition to that, Lydon et al. (2023) study showed that coping strategies need gender-specific focus when planning intervention strategies. Another example is girls with ASD who had a greater tendency to camouflage signs of distress and pretend to behave normally, and such behaviors may obscure the need to offer them assistance. This is an example of how female autistic patients can be underassessed in terms of distress, and that more

specialised, gender-specific care-giving strategies are needed.

Staff Interaction and Communication Challenges

Communication between people of a hospital and a child with autism is essential yet very missing. Employees have expressed little confidence and training in handling children with autism (Petrou & Bolarinwa, 2020). The issues of communication are not only based on the problems of language impairments but also the incapability of the staff to detect nonverbal communication and behavioral patterns.

In the recent past, there has been some positive outcome in training programs focused on increasing the levels of competence in healthcare professionals to handle autism. As an example, Fleming et al. (2021) saw the results of applying a training module to pediatric nurses and revealed the improved interactions with patients, a decrease in the distress they experience, and parental satisfaction increased. Nevertheless, in the literature, one can also find systemic obstacles that hinder the scale introduction of such programs including time limitations, understaffing, and institutional support (Bailey & Moloney, 2022).

This issue is also clarified by thematic data of this study. In the former, male participants exhibited aversion to direct eye contact whereas female participants strongly preferred some of the staff based on perception of gentleness or familiarity. They are minute details necessary to bring about a positive patient-staff relationship and highlight the necessity of individual interaction plans.

Role of Parental Involvement and Caregiver Mediation

Having parents around influences the process of being in a hospital greatly in the case of an autistic child. The longitudinal analysis performed by Tang et al. (2022) and other studies indicate that children whose parents were actively engaged throughout the time spent in hospital had fewer incidents of distress and improved emotional outcomes. Caregivers not only provide emotional support but also act as interpreters and advocates for the child's needs.

The importance of care giver contribution can be especially felt with children who are unable to express themselves using words. In such cases, parents tend to intervene to clarify the triggers, likes or preferences and coping skills of their kid. The current scene agrees with this position and the caregivers were used to help the interview so that the child voice could speak properly.

However, not every hospital supports active parental involvement especially when procedures are to be performed or when a child is to be admitted. Such neglect might worsen the distress, particularly among children with high attachment needs that are usually observed in female respondents in this research. The institutions thus ought to revise the policies, so as to integrate the caregivers into the entire process of pediatric services of

autistic children.

Environmental Design and Autism-Friendly Spaces

Negative patient experiences can be seen in most hospitals where the infrastructure is not really friendly to individuals with autism. The clinic study by Richardson et al. (2020) stressed that the majority of pediatric wards fail to consider the distinctive sensory and behavioral requirements of autistic patients. The review also suggested the introduction of quiet zones, sensory-safe rooms, personalized spaces, and visual signage as a way of alleviating levels of anxiety.

Recent action has shown that making the changes as regards the environment can have the potential to enhance the experiences of children with ASD substantially. As an example, Maxwell et al. (2022) tested an autism-friendly ward model: dimmable light sources, noise dampeners, and a schedule-driven manner of organizing care management. The researchers discovered impressive reductions in patient anxiety and greater satisfaction of the staff with patient contact.

The present study corroborates these findings. Scheduling regular routine, repeat nurses, and silence were the elements which were reported by the participants to make them feel more comfortable. This implies that environmental redesigning does not only act as an advantage but also a requirement in the effective care of hospitalized autistic children.

Methodology

Objectives

Following were the research objectives of the current research

- 1. To explore the sensory and emotional experiences of autistic children while they are in the hospital.
- 2. To examine how autistic children cope with stressors associated with hospitals.
- 3. To Identify the impact of hospital settings and staff interactions on the well-being of autistice children.

Research Questions

Following are the research questions

- 1. What emotional and sensory experiences do children with autism have during hospital stays?
- 2. How do autistic children view interactions with medical workers and the environment?
- 3. What coping strategies do children with autism use in hospital settings?

Sample

The sample consisted of 20 children diagnosed with Autism Spectrum Disorder (ASD), 10 males and 10 females, aged 6 to 12 years. Participants were chosen from pediatric hospitals in Islamabad and Rawalpindi. All children had been hospitalized to hospitals within the previous six months. A purposive sampling technique was used to identify participants who could provide detailed information about the lived experiences of children with

ASD in hospital settings. The inclusion criteria were that children have a documented ASD diagnosis and can engage in interviews with the help of visual aids or caregivers.

Research Design

In order to better understand the hospital experiences of children with autism spectrum disorder, this study used a qualitative exploratory research approach. Based on a phenomenological approach, the design sought to document participants' subjective realities and lived experiences in clinical settings. A more thorough examination of the emotional, behavioural, and sensory difficulties that children with ASD encounter while in the hospital was made possible by this design.

Procedure

Semi-structured interviews were used for data gathering, and they were held in a calm, sensory-friendly setting inside hospitals. Picture cards, emotion charts, and visual aids were employed to meet the communication needs of kids with ASD. Caregivers supported the child's comfort during the session and helped understand responses in situations when verbal communication was limited.

Each interview lasted between 20 and 30 minutes, depending on the child's attention span and engagement. Ethical guidelines were rigorously followed, including obtaining informed consent from parents or guardians and agreement from children when needed. All interviews were audio-recorded with permission and then transcribed for analysis.

The data were examined using thematic analysis, which followed Braun and Clarke's (2006) six-step methodology. Themes and subthemes were identified inductively to reflect the children's shared patterns and distinct experiences during their hospital stays. **Demographic Table**

Variable	Category	Male (n=10)	Female (n=10)
Age Group	6-8 years	4	5
	9-12 years	6	5
Diagnosis Age	2-4 years	7	6
	5-7 years	3	4
Hospital Visits	1-3 times	6	7
	4-6 times	4	3

Table 1 summarizes the sample's demographic characteristics (N = 20), which were evenly split between male and female autistic children aged 6 to 12 years. The majority of individuals were diagnosed between the ages of 2-4 and had one to three hospital visits. There were somewhat more girls in the lower age group (6-8), and more men in the older age group (9-12). The table gives context to understanding the heterogeneity in hospital experiences based on age and visit frequency.

Table 2: Thematic Analysis: Male Children with Autism

Primary Theme	Sub-Theme	Verbatim
Emotional	Fear	f "They put a needle in. I hid
Reactions	Procedures	under the bed."
Sensory Overload	Noise Sensitivity	"I screamed when the beeping started."
Coping Strategies	Self-stimulatory Behavior	"I tap my fingers a lot. It makes me calm."
Environmental Adaptation	Preference for Routines	"I liked it when breakfast came at the same time."
Social Discomfort	Avoidance of Eye Contact	e "I don't like when the doctor looks at me."

Table 2 summarizes the important themes observed in interviews with male autistic children. The children regularly expressed emotional reactions, such as anxiety of medical procedures and a strong dislike of hospital sounds. Sensory overload was frequently reported, with coping strategies such as finger-tapping or a preference for structured routines. There was also evidence of social discomfort, particularly during interactions with hospital staff. These themes emphasize the need for controlled, low-stimulation surroundings for male autistic individuals.

Table 3: Thematic Analysis: Female Children with Autism

Primary Theme	Sub-Theme	Verbatim
Emotional Reactions	Separation Anxiety	I cried when mom went outside the room.
Sensory Overload	Light Sensitivity	The light hurts my eyes. I close them and hum.
Coping Strategies	Attachment to Personal Objects	I hold my pink bear and sing to it.
Communication Challenges	Difficulty Expressing Pain	I didn't know how to tell nurse my tummy hurt.
Environmental Adaptation	Comfort from Familiar Staff	I liked the nurse who wore blue. She was quiet like me.

Table 3 summarizes the topic trends seen in interviews with female children with autism. The girls reported experiencing more relational distress, such as separation anxiety, as well as increased sensitivity to environmental stimuli such as light. Soft toy attachment and a preference for known healthcare staff were among the unique coping techniques. Communication challenges in conveying physical pain were prevalent, highlighting the need for alternate pain-assessment instruments designed for nonverbal children. These themes focus on the emotional and relational needs of female children with autism in hospitals.

Thematic analysis identified shared patterns among male and

female autistic children throughout hospital stays. Both groups experienced sensory overload and emotional discomfort, but males displayed greater avoidance and routine-seeking behaviour, whilst females demonstrated stronger emotional connection and nonverbal coping methods. These findings highlight the need of providing autism-sensitive healthcare facilities.

Discussion

The results of this qualitative study highlight the complex and diverse lived experiences of children with Autism Spectrum Disorder (ASD) in hospital settings. Children with autism. regardless of gender, face significant emotional and sensory challenges while hospitalized. However, male and female individuals differed in their experiences and coping strategies with these stresses. These findings are consistent with and expand prior empirical research on autism and healthcare access, underlining the importance of autism-sensitive hospital facilities.

Emotional Reactions and Separation Anxiety

Children with autism showed increased emotional discomfort during hospital stays, as predicted by the study's primary aim. Male participants indicated worry and anxiety regarding medical treatments, but female participants frequently reported separation anxiety from caregivers. These findings are consistent with those of Brentnall et al. (2022), who reported that unfamiliar routines and unpredictable procedures frequently cause anxiety in children with ASD during hospital admissions. Female participants in this study reported that their fear was frequently exacerbated by an emotional reliance on their mothers, which is consistent with gender-based emotional expression patterns identified by McGuire et al. (2021), who discovered that girls with autism are more likely to experience attachment-related distress in medical settings.

Sensory Overload and Environmental Stressors

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Coping Mechanisms and Emotional Regulation

In response to the second research question, this study discovered many coping mechanisms utilized by children with autism. Male children frequently engaged in self-stimulatory behaviours such as tapping, rocking, or hiding, whereas female youngsters sought solace in personal items such as plush animals or familiar tunes. Su et al. (2022) defined these behaviours as part of a larger spectrum of autism-related self-regulatory processes, emphasizing the necessity of identifying such coping behaviours as crucial self-regulation techniques in overstimulating contexts rather than disruptive ones. Furthermore, these findings support the work of Hull et al. (2020), who hypothesized that girls with ASD frequently engage in more camouflaging behaviours to manage stress, making their distress less visible to healthcare providers.

Communication Barriers and Nonverbal Expression

One of the most powerful themes among female participants was the difficulty of expressing pain or distress. This is consistent with the third purpose and reflects ongoing issues in healthcare communication for children with ASD. Female participants, in particular, struggled to articulate their needs, a finding echoed by Nicoll et al. (2021), who discovered that girls with ASD may exhibit less externalizing behaviours, but feel severe interior pain that often goes undetected. These communication difficulties can result in misdiagnosis or ineffective pain management, emphasizing the critical need for healthcare personnel to be trained in understanding nonverbal signs and alternate communication modalities.

The Importance of Routine and Familiarity

Both groups emphasized regularity and routine. Male participants indicated satisfaction with daily activities that followed a regimented schedule, but female participants found comfort in contacts with familiar or kind staff personnel. This underscores the critical role that predictability plays in the emotional well-being of children with ASD, as proven in a research by Smith et al. (2021), who found that structured surroundings dramatically reduced stress and behavioural problems in autistic children during hospitalization. Female children's preference for quiet, calm personnel reinforces the significance of customized care, which aligns with neurodiversity-informed care concepts (Crane et al., 2020).

Implications for Practice

The findings of this study have various ramifications for hospital operations and the larger area of pediatric healthcare. First, the discovery of gender-based disparities in emotional expression and coping techniques highlights the importance of personalized treatment approaches. Health professionals must be trained to recognize and accommodate both verbal and nonverbal expressions of distress in children with autism. Second, developing sensory-friendly hospital facilities, such as adjustable lighting, noise cancellation systems, or designated quiet zones, can significantly enhance these children's hospital experiences. Third, involving caregivers and incorporating familiar routines or objects into the child's hospital stay can help reduce anxiety and foster trust, according to Marsack-Topolewski et al. (2023) and McGuire et al.

(2021).

Limitations and Recommendations for Future Research

Despite its important findings, the study has some drawbacks. The sample size was small (n = 20), which limited generalizability. Furthermore, because the data was gathered with caregiver assistance, there may have been some impact on the children's replies. Future research should involve longitudinal follow-ups to investigate how recurrent hospitalizations change children's coping methods over time. Including healthcare providers' perspectives would provide a more complete picture of care delivery challenges and successes.

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