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ORIGINAL ARTICLE

Difficulties Faced by Caregivers while Transporting Children with Autism Spectrum Disorder: A Cross-Sectional Survey

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ABSTRACT

Context: Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder that typically emerges early in life, characterized by social withdrawal, communication difficulties, and repetitive behaviors. These traits can hinder children's ability to access transportation and participate in community activities, posing challenges for caregivers.

Aims: To explore transportation-related difficulties faced by caregivers of children with ASD.

Settings and Design: A methodological study conducted in two phases: questionnaire development and validation, followed by a cross-sectional caregiver survey.

Methods and Material: A 60-item questionnaire covering three domains was developed and validated by eight occupational therapy experts, yielding a Content Validity Index (CVI) of 0.93. The tool was administered to 50 caregivers of children aged 4–10 years with ASD, via interviews and phone calls. Only caregivers involved in regular transportation were included. Descriptive statistics were used to calculate percentage scores reflecting caregiver difficulties.

Results: Caregivers frequently reported temper tantrums, self-injurious behaviors, and stress during transportation. Most preferred private modes and used distraction strategies such as toys and snacks. Key concerns included lack of danger awareness, difficulty sitting near others, and social isolation.

Conclusions: The findings provide valuable insights for occupational therapists in addressing caregiver challenges and planning effective interventions to support transportation and community mobility for children with ASD.

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KEYWORDS

• Autism Spectrum Disorder • Children • Caregivers • Transportation • Behavior

Key Messages: Caregivers of children with ASD face significant transportation challenges due to behavioral issues. Understanding these difficulties can help occupational therapists design targeted interventions to enhance safety, reduce stress, and promote community mobility.

INTRODUCTION

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition typically identified between 26 and 36 months of age. It impacts brain development and is characterized by social withdrawal, communication difficulties, and repetitive behaviors, often at the expense of imaginative play[1]. The DSM-5 criteria for ASD highlight persistent deficits in social communication and interaction, restrictive and repetitive patterns of behavior, and early developmental onset of these symptoms[2].

Transportation and community mobility:

Competence in community mobility is an important component of quality of life through the life span. Community mobility can be accomplished in many ways including walking, using bicycle or a powered mobility device, riding as a passenger, driving oneself or using public transport. It is an area of occupation that affects all areas of practice and is considered an IADL. Community mobility can be a means to an occupation or an occupation in and of itself.[3]

The potential for engagement in areas of occupation and community mobility are closely linked. Community mobility is critical for accomplishment of necessary activities and enabling individuals to maintain social connectedness. Transportation problems are often cited as a primary barrier among individuals with disability.[3]

According to Reynolds *et al.* (2011), these actions including biting, hitting or eloping cause the child and family to become socially isolated. Environmental obstacles may also limit the frequency, diversity, and intensity of community interaction for children with ASD and their careers. This can lead to reduced involvement in commmunity participation. Thus, it can be difficult and risky for parents and families to participate in the community when children with ASD engage in these behaviors while being transported in a vehicle.[3]

SUBJECTS AND METHODS

This quantitative, cross-sectional survey aimed to explore the difficulties faced by caregivers while transporting children with ASD. The study was conducted in two phases:

Phase 1: Questionnaire Development and Validation

A 60-item questionnaire was developed to assess child behavior, caregiver experiences, and coping strategies during transportation. Eight pediatric occupational therapists, with either a Bachelor's degree and at least four years of experience or a Master's degree (specializing in pediatrics or developmental disability) and a minimum of two years of experience, validated the questionnaire's content.[4]

Phase 2: Data Collection

The validated questionnaire was administered to 50 caregivers of children with ASD, aged between 4 and 10 years. Data were collected through both in-person interviews and phone calls. Only caregivers who were actively involved in transporting their child with ASD were included in the study, while those caring for children with additional medical or cognitive conditions were excluded. The collected raw data were subjected to statistical analysis.

RESULTS AND DATA ANALYSIS

In the content validity phase, eight occupational therapists evaluated the relevance of each questionnaire item using a 4-point Likert scale, where scores of 3 and 4 indicated relevance, and scores of 1 and 2 indicated irrelevance.[5] Item-level Content Validity Index (I-CVI) values ranged from 0.62 to 1.0. The scale-level content validity, assessed using both the average method (S-CVI/Ave) and universal agreement (S-CVI/UA), yielded an S-CVI/Ave of 0.93, indicating strong content validity.

A total of 50 caregivers of children with Autism spectrum disorder participated in the

study. Data were collected through interviews and telecommunication methods. The final questionnaire included 60 items across three domains. Following administration, the responses were analyzed statistically, and percentage scores were calculated to reflect the extent of transportation-related difficulties faced by caregivers of children with ASD.[6]

Table 1: Demographic Data of Caregivers and Children

S. no	Variables		Values (Percentage)
1.	Gender of the child (Male/Female %)		74/26
2.	Gender of the caregiver (Male/Female %)		8/92
3.	Caregiver relationship	Father	6%
		Mother	88%
		Grandfather	4%
		Grandmother	2%
4.	Mode of transportation	Two-wheeler	66%
		Car	8%
		Bus	10%
		Auto	14%
		Cab	2%

Table 2: Percentage Distribution of Child Behavior – Domain 1

Questions	Responses (%)	Questions	Responses (%)
Social Relationship and Recirocity		**Emotional Responses**	
Eye contact	Never & seldom (40)	Appropriate emotional response	Seldom (46)
Social smile	Seldom (42)	Exaggerated emotional response	Frequently (40)
Aloofness	Never (32)	Engaging in self-stimulating emotions	Frequently (42)
Reaching out to other person	Always (48)	Reaction to fear of danger	Never (36)
Reaction to environmental cues	Seldom (44)	Excited or agitated during transportation	Frequently (42)
Taking turn in social interactions	Never (40)		
Lack of tolerance for deviation of routine	Frequently (34)		
Resists any type of change	Frequently (34)		
Behavior Pattern		**Sensory Aspects**	
Repetitive and stereotypical behavior	Occasionally (93)	React emotionally or aggressively to touch	Never (48)
Engage in inanimate objects	Frequently (46)	Difficulty in standing or sitting close to other people	Never (38)
Elopement	Frequently (44)	Scratch out a spot that has been touched	Never (58)
Aggressive behavior	Occasionally & frequently (30)	Becomes anxious or distressed when feet leave the ground	Seldom (38)
Temper tantrums	Frequently (64)	Fear of falling or heights	Never (34)
Self-injurious behavior	Never (60)	Seek all kinds of movement	Frequently (36)
		Respond negatively to unexpected or loud noises	Never & frequently (30)

Table 3: Caregiver Questionnaire Responses – Domain 2 (Percentage)

Questions	Response (%)
Public transportation	Seldom (46)
Private transportation	Always (60)
Driving by self	Always(38)
Felt nervous while transporting	Always & never (32)
Felt stressed	Frequently(48)
Felt that cannot handle the child	Frequently(42)
Felt upset about your child's behavior	Frequently(62)
Felt that things are going on your way	Frequently(52)
Felt frustrated when transporting	Occasionally(34)
Felt anger when transporting	Frequently(58)
Felt helpless when transporting	Frequently(34)
Your child's social relationship is limiting your transportation	Frequently(32)
Felt that your child's emotional responses are limiting your transportation	Frequently(32)
Felt that your child's behavioral pattern is limiting your transportation	Frequently (30)
Felt that your child's sensory aspect is limiting your transportation	Frequently(34)
Felt that your child's behavior is limiting your community participation	Frequently(36)
Felt upset about things that have happened unexpectedly	Frequently(44)
Show elopement while transportation	Frequently(46)
Show aggression while transporting the child	Occasionally(30)
Felt that your child doesn't have the fear of danger	Seldom (30)
Felt that your child is behaving different from other children while transportation	Frequently(42)
Thought that your youngster lacks the ability to tolerate sitting while travelling	Frequently(28)
Worried that your kid won't be able to manage their bladder while travelling	Seldom(24)
Felt that your child gets exaggerated to horn sound while transporting	Frequently (30)

Table 4: Percentage of Calming Strategies Reported By Caregivers – Domain 3

Questions	Response
Do you instruct your child before you are transporting?	Frequently (40)
In these circumstances, do you avoid the child?	Never(46)
When confronted with such circumstances, do you engage in fights?	Never (60)
Have such circumstances made you feel ashamed?	Never (50)
Have you ever reacted unreasonably in such circumstances?	Never (36)
Do you give the child their favorite toy to calm them?	Never (64)
Do you feed the child their favorite snack to help them relax?	Never (60)
Do you divert the child's attention from that situation?	Frequently (64)
Do you give any verbal instructions to the child?	Occasionally (38)
Do you give any feedback if the child obeys you?	Frequently(46)

DISCUSSION

Autism Spectrum Disorder (ASD) is a complex neurodevelopmental condition characterized by persistent challenges in social communication and interaction across various contexts.[1] These behavioral difficulties often lead caregivers to limit transportation and community participation for children with ASD.[3] Given the individualized nature of ASD, it is essential to explore caregivers' perceptions of stereotypical behaviors and their experiences while transporting their children. Furthermore, identifying specific behaviors that impede social involvement can help inform targeted interventions.

Phase 1: Questionnaire Development and Validation

This study employed a two-phase design. Phase 1 focused on the development and validation of a questionnaire to explore caregivers' experiences while transporting children with Autism Spectrum Disorder (ASD).[7] The tool comprised three domains: the child's transport-related behaviors, caregiver responses, and calming strategies used during transportation. A panel of eight experts evaluated the content validity.[4] Item-Level Content Validity Index (I-CVI) was 0.93, indicating excellent relevance across items.[7] Scale-Level CVI using the average method (S-CVI/AV) revealed that six items were only fairly relevant, while the remaining items demonstrated good validity. Universal agreement among experts (S-CVI/

UA) was achieved for 54 out of 60 items, yielding a 63% agreement rate. The high CVI values confirmed that the questionnaire had strong content validity and was appropriate for capturing caregiver perspectives on transportation-related challenges in children with ASD.

Phase 2: Data Collection

The validated questionnaire was administered using a cross-sectional design through face-to-face and telephonic interviews with caregivers of children with ASD who met the selection criteria.[8] Data were collected, scored, and analyzed statistically. Among the 50 children, 74% were male and 26% female. Caregivers comprised 8% males and 92% females, with 88% being mothers, 6% fathers, 4% grandfathers, and 2% grandmothers. Regarding transportation modes, 66% used two-wheelers, 14% buses, 10% autos, 8% cars, and 2% cabs (*Table 2*). This phase aimed to better understand caregivers' transportation challenges.

Domain 1: Questionnaire on Child's Behavior

This domain assessed four areas: social relationship and reciprocity, emotional responses, behavior patterns, and sensory aspects.

Social Relationship and Reciprocity: Among caregivers, 48% always felt that their child never reach out others incase of danger, 44% seldomly react to environmental changes, 40% reported that their child never maintain eye-contact and wait for their turn. Only 34% frequently lack tolerance to any type of change or change in routine and 32% never remains aloof.

Emotional Response: About 46% observed seldom appropriate emotional responses, and 42% reported frequent self-stimulating emotions. Meanwhile, 36% noted no fear of danger, and 40% reported exaggerated emotional reactions.

Behavior Patterns: Tantrums were frequently reported by 64%, while 60% said their child never self-harmed. Additionally, 46% observed frequent play with inanimate objects. Less frequently reported behaviors included elopement (44%) and stereotypy (30%).

Sensory Aspects: Fifty-eight percent never reacted to touch, and 48% had no emotional response to it. Thirty-eight percent rarely showed anxiety, while 36% frequently sought excessive movement. Only 30% always reacted to loud noises.

These findings highlight the emotional, behavioral, and sensory challenges experienced by children with ASD and their impact on caregivers during transportation (*Table 3*).[9]

Domain 2: Questionnaire for the Caregivers

This domain explored caregivers' emotional responses and transportation-related challenges. About 62% frequently felt upset, 60% preferred private transport, and 58% reported anger during transport. Additionally, 52% felt plans often failed, and 48% experienced frequent stress. Forty-six percent seldom preferred public transport, and the same percentage observed frequent elopement attempts. Feelings of helplessness (34%), frustration (34%), and limited community participation (36%) were also noted.[6] Around 30–34% reported challenges related to sensory issues, behavior patterns, aggression, and sitting tolerance. These findings reflect the varied and intense emotional and logistical challenges caregivers face when transporting children with ASD (*Table 4*).[10]

Domain 3: Strategies used by Caregivers to Calm the Child

As shown in *Table 5* and Graph 1, 64% of caregivers never used their child's favorite toy for calming but often redirected attention instead. Similarly, 60% avoided conflicts and did not use favorite snacks for soothing. Half of the respondents reported never feeling ashamed, while 46% avoided their child during transport. About 46% frequently used obedience feedback, and 40% gave transportation instructions. Additionally, 38% occasionally provided verbal cues, and 36% admitted to reacting unreasonably in some situations.[11]

The findings of the current study align with those obtained in a prior study focused on parents and their experiences with safety measures while transporting children with autism.[11] The results of the study indicated that caregivers tend to restrict their travel distances when their child exhibits maladaptive behaviours, which, in turn, limits their social involvement and engagement. Notably, 95% of caregivers reported that their children displayed sensory modulation behaviours, while 58% reported incidents of

attempted elopement. The study participants also mentioned that they have not received sufficient information or education concerning car safety, with some expressing concerns about the accessibility of available resources. These factors may lead to a reduction in the distance travelled during transportation and caregivers restraining community and occupational participation due to their child's behaviour, which can potentially result in social isolation.

Similarly, in the present study, caregivers reported witnessing sensory modulation behaviours, elopement incidents, limitations in social participation, and restricted travel distances. Additionally, caregivers noted the various challenges they face and highlighted specific strategies they employ to calm their child.

The developed questionnaire is a valuable tool for occupational therapists to assess a child's behavior during transportation, caregiver challenges, and community participation impact. It also identifies strategies caregivers use to manage behaviors. Incorporating transportation-related questions into assessments provides a comprehensive view of the child's functioning. Thus, occupational therapists must collaborate with caregivers to develop behavior management strategies and teach coping skills, promoting safer and more inclusive transport experiences.

The study had limitations, including a small sample size, gender imbalance, and geographic restriction. Additionally, children with comorbid conditions were not included. Future research should expand the questionnaire to cover more sensory and travel-related factors and explore effective intervention strategies to address behavioral and safety concerns during transportation.

CONCLUSION

This study developed a validated questionnaire to assess transportation challenges faced by caregivers of children with ASD. It highlights key behavioral concerns like isolation, lack of danger awareness, and poor sitting tolerance. Caregivers often experience distress, prefer private transport, and use calming strategies. The findings support occupational therapists in understanding behaviors, caregiver difficulties, and effective management strategies during transportation.

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