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Mothers' experiences: A missing puzzle piece in caring for children with autism spectrum disorder

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To the Editor

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by impairments in social relationships, communication, and restricted and repetitive behavioral patterns [1]. In recent years, epidemiological studies have shown a rapid increase in the prevalence of ASD. According to the report from the Center for Disease Control and Prevention in the United States, the prevalence was estimated to be 1 in 59 individuals in 2014 and 1 in 54 individuals in 2016 among 8-year-old children [2].

ASD is a complex developmental condition that is accompanied by persistent challenges in social interaction, speech, and nonverbal communication, significantly affecting mother-child interactions [3]. One of the most significant concerns for mothers of these children is how to care for them. The exact cause of this disorder remains largely unknown, and lack of awareness about autism often leads to delayed recognition of the child's difficulties by families [4]. As a result, the golden time for early intervention may be missed, and life in society becomes more challenging for both these children and their caregivers. Additionally, these children require care and support from their families and community institutions from birth throughout their growth and development, making caregiving a stressful process for mothers. Therefore, caring for these children necessitates the adoption of specialized caregiving and parenting approaches [5, 6].

The literature review indicates that the majority of studies conducted in the field of caring for children with autism have primarily been quantitative studies with a traditional intervention approach, focusing on the effectiveness of cognitive-behavioral therapy, play therapy, storytelling therapy, supportive counseling, psychotherapy, and teaching coping skills [7-9]. While quantitative research methods have their benefits in many areas, they alone cannot provide a comprehensive examination of the deep dimensions of the phenomenon from the perspective of individuals' first-hand experiences [10].

On the other hand, mothers of children with ASD have diverse and unique experiences that cannot be fully captured by common quantitative research, making qualitative research highly valuable for a deep understanding and exploration of these real experiences [5]. Additionally, families with lifelong ASD require long-term intervention, education, and support. However, factors such as limited treatment and rehabilitation centers, a lack of credible family education, and limited support from mental health service providers have increased the pressure on caring for children with autism [11]. Given the unique characteristics of children with ASD and the critical role of mothers in their resilience and care, and considering that a significant portion of mothers' lives is dedicated to caregiving, their experiences are the best source of information for providing care for these children. There is a growing sense of the need for studies focused on designing and implementing a simple, cost-effective, and efficient care pro-
gram based on mothers' experiences, which can alleviate caregiver fatigue and enhance families' ability to cope with the condition [5].

A deep understanding of mothers' experiences in living with a child with autism can provide insight into the psychological well-being of mothers, their needs, and their challenges. This understanding can be valuable for all institutions and organizations involved, including counselors and policymakers in the field of family services and welfare organizations, in developing comprehensive and practical programs for the care of children with ASD. Therefore, developing interventions that align with mothers' experiences and are culturally appropriate can be highly effective.

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