

# Perception and Awareness About Autism Self-Care Management Related Strategies in Parents of Autistic Children - A Quantitative Study

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## ABSTRACT

**BACKGROUND:** Autism Spectrum Disorder (ASD) is a complex neurodevelopmental condition characterized by impaired social communication, restricted interests, and repetitive behaviours. Caring for children with ASD often imposes substantial emotional, physical, and psychological demands on parents. Effective self-care strategies are essential to help parents cope with these challenges and maintain their well-being. Understanding parents' awareness and perceptions of self-care management can guide the development of tailored support systems that enhance family functioning and the child's developmental outcomes.

**METHODOLOGY:** A quantitative, descriptive survey was conducted among 104 parents of children with ASD. Data were collected using a structured questionnaire assessing demographic variables and five dimensions of self-care: physical, emotional, psychological, spiritual, and professional. Data analysis included frequencies, percentages, standard deviations, ANOVA, and Pearson correlation using SPSS to examine associations between awareness levels and demographic factors.

**RESULTS:** Parents face multifaceted challenges affecting all self-care domains, including time constraints, work stress, sleep deprivation, and financial pressures. Caregiving responsibilities managing behaviours, fostering social skills, and maintaining emotional stability further limit engagement in self-care activities. Many parents reported minimal participation in therapy, leisure, stress reduction, boundary-setting, and spiritual practices, highlighting gaps in holistic coping strategies.

**CONCLUSIONS:** Addressing barriers through counselling, stress management programs, flexible work policies, and social support can enhance parental well-being, enable more effective caregiving and promote positive outcomes for children with ASD.

**Keywords:** Autism Spectrum Disorder, Self-Care Management Strategies, Parental Awareness, Caregiver Stress, Quantitative Study

## INTRODUCTION

Autism Spectrum Disorder [ASD], commonly referred to as autism, is a complex neurodevelopmental condition

characterized by impairments in social communication and interaction, restricted interests, and increased repetitive behaviours, as defined by the Diagnostic

and Statistical Manual of Mental Disorders, DSM-V. [1] Globally, ASD affects a significant number of children, and in India, recent estimates suggest that approximately 1 in 65 children between the ages of two and nine are diagnosed with the disorder. [2] India is home to over 2 million children with ASD, representing more than 25% of the global incidence. [3]

ASD is often accompanied by multiple comorbidities, which may include seizures, sleep disturbances, psychiatric disorders, cognitive impairments, sensory processing abnormalities, and delayed language development. Understanding the etiology of ASD remains a major focus of research, as identifying causal factors can aid in diagnosis, guide management strategies, inform prognostic expectations, and facilitate the prediction and prevention of associated medical conditions. [4,5] The manifestation of ASD can be categorized based on the onset pattern: early-onset or regressive. Early-onset ASD typically presents within the first year of life, with noticeable delays or deficiencies in social and language development. In contrast, regressive ASD is characterized by typical early development followed by the loss of previously acquired motor, social, or communication skills, usually between the second and third years of life. [6]

The presence of a child with ASD in a family significantly impacts parental and familial functioning. Children with ASD may present challenges such as stress, difficulties in communication, and social interactions that exert a profound effect on parents and caregivers. [7] Although the precise etiology of ASD is not fully established, research has identified genetic and environmental factors as primary contributors, with genetics being the more influential determinant as demonstrated in studies involving twins, relatives, and rare syndromes. [8]

Parents of children with ASD experience substantial stress due to the complex and ongoing demands of caregiving. These pressures negatively influence their quality

of life. Challenges associated with raising a child with ASD encompass reduced parenting effectiveness, heightened stress levels, increased risk of mental and physical health issues, and considerable financial and time burdens. The caregiving burden begins with the stress of receiving the initial diagnosis and continues with ongoing responsibilities such as managing daily care, organizing medical treatments and therapies, addressing behavioural difficulties, and balancing work obligations, all of which can lead to physical and emotional exhaustion. [9,10]

The absence of a definitive cure for ASD necessitates lifelong care, which often results in cumulative stress among parents. Studies have shown that caregivers of children with ASD are at increased risk of depression, cardiovascular disease, and other chronic illnesses compared to parents of typically developing children. The time-intensive nature of caregiving also limits parents' ability to engage in self-care and health-promoting activities such as regular medical check-ups, exercise, and proper nutrition. [10]

Quality of life, as defined by the World Health Organization [WHO], encompasses six domains: physical health, psychological well-being, level of independence, social relationships, environmental factors, and spirituality. [11] Parents of children with ASD may experience reduced QOL across all domains due to heightened stress and caregiving burdens. Research indicates that compared to parents of neurotypical children, caregivers of children with ASD demonstrate poorer physical, psychological, and social health, as well as diminished spiritual well-being. [9]

The psychological stress experienced by parents is compounded by the challenges inherent in managing the child's unique needs, including communication deficits, social skill limitations, and behavioural difficulties. [11] The cumulative stresses associated with caregiving often force families to reorganize their daily routines, relationships, and life goals, resulting in

further disruption and psychological strain.<sup>[12]</sup> Parents adopt various coping mechanisms in response to these stressors, which may include adaptive strategies such as seeking social support or cognitive reframing, and maladaptive strategies such as avoidance or disengagement.<sup>[9,12]</sup>

Financial challenges further exacerbate the burden on parents. Caregiving responsibilities often coincide with work-related obligations, and the cost of interventions and treatments frequently exceeds household income. Balancing financial demands with caregiving responsibilities contributes to poorer mental health and life satisfaction among parents of children with ASD. Stepwise regression analyses have identified financial hardship, lack of caregiver acknowledgment, and health concerns as significant predictors of reduced well-being in this population. Moreover, the demands of caregiving can negatively affect work productivity, with women particularly impacted, leading to additional social and financial strain.<sup>[13]</sup>

Studies have documented that mothers of children with ASD experience higher levels of anxiety, heavier caregiving loads, poorer sleep quality, and reduced health-related quality of life in domains such as energy, emotional functioning, and social engagement, compared to mothers of typically developing children.<sup>[9,12]</sup> Despite research highlighting the substantial caregiver burden, many studies have primarily focused on child outcomes, developmental profiles, and societal stigma, rather than on parents' perceptions and lived experiences. In India, empirical data on the impact of ASD on families, particularly regarding caregivers' awareness and utilization of self-care strategies, remains limited.<sup>[14]</sup>

A lack of community awareness regarding ASD has been associated with heightened parental stress, increased stigma, and limited support for families, all of which can delay diagnosis and intervention.<sup>[15]</sup> Recent scoping reviews have highlighted that parents of children diagnosed with ASD in

India experience significant anxiety, fear, and uncertainty following diagnosis.<sup>[16]</sup> The caregiving burden extends beyond emotional stress to encompass physical and social challenges, with parents often experiencing loneliness, fatigue, and insufficient support, which adversely affects family functioning and parental well-being.<sup>[10,13]</sup> Chronic stress can contribute to caregiver burnout, characterized by emotional detachment, exhaustion, and decreased caregiving efficacy.<sup>[14]</sup>

Despite these risks, parents often undervalue self-care, which includes behaviours aimed at maintaining physical, emotional, and mental health, such as adequate rest, exercise, social engagement, and stress management activities.<sup>[17]</sup> Societal expectations, time constraints, financial limitations, and feelings of guilt frequently prevent caregivers from engaging in meaningful self-care practices. In underprivileged and developing communities, such as many regions of India, these gaps are more pronounced due to limited access to information, resources, and support systems. Consequently, parents may struggle to incorporate even basic self-care strategies into their daily routines or fail to recognize their importance, placing them at increased risk for long-term health problems.<sup>[15,17]</sup>

Given the crucial role of caregiver well-being in supporting the development and care of children with ASD, there is an urgent need to explore how parents perceive and implement self-care practices. Understanding caregivers' awareness, attitudes, and barriers to self-care can inform the development of tailored interventions that enhance parental well-being and, by extension, the quality of care provided to children.<sup>[14]</sup> Cultural factors, social stigma, and limited mental health resources further compound these challenges in India, particularly in regions such as Gujarat, underscoring the necessity for localized research.

Aim of the study: This study aims to assess the perception, awareness, and

implementation of self-care management strategies among parents of children with autism spectrum disorder across multiple domains, while identifying the challenges they face in maintaining personal well-being alongside caregiving responsibilities.

### **Objectives Of the Study:**

- To assess the level of awareness of self-care management strategies among parents of children with ASD.
- To evaluate the frequency and types of self-care strategies [physical, psychological, emotional, spiritual and professional] practiced by these parents.
- To investigate how parent's self-care practices are impacted by demographic factors such as age, gender, marital status and educational attainment.
- To identify common obstacles faced by parents in self-care strategies.

## **MATERIALS & METHODS**

**Study Design:** A quantitative survey study.

**Source of Data:** Data were collected from Shantvana Child Development Center [CDC] and various physiotherapy centers in Ahmedabad.

**Sampling Method:** Non-probability purposive sampling was employed to select participants.

**Sample Size:** A total of 104 parents were recruited, based on a statistical sample size calculation.

### **Selection Criteria:**

#### **Inclusion Criteria:**

- Parents of children aged 2–9 years diagnosed with ASD.
- Diagnosis confirmed using the Indian Scale for Assessment of Autism [ISAA] with a score above 70.
- Vanderbilt ADHD Diagnostic Parent Rating Scale [VADPRS] used to exclude children with ADHD.
- Both male and female parents.
- Parents proficient in English or Gujarati.

#### **Exclusion Criteria:**

- Parents of children with conditions other than ASD [e.g., Down syndrome, cerebral palsy] without a comorbid ASD diagnosis.
- Children with intellectual disability or other developmental disabilities.
- Parents with severe health conditions or who are bedridden.
- Parents with psychological issues or depression.
- Professional caregivers [e.g., social workers, therapists] not directly responsible for the child's daily care.

**Outcome measure:** To assess the awareness and practices of self-care management among parents of children with autism spectrum disorder [ASD], a structured questionnaire was used as the primary outcome measurement tool.<sup>[18]</sup> This tool focused on capturing the physical, emotional and social well-being of parents and their ability to manage self-care while handling the challenges of raising a child with autism.

## **PROCEDURE**

The study was conducted following ethical approval from the relevant institutional ethics committee. Parents of children with autism spectrum disorder [ASD] were recruited from physiotherapy clinics and the Shantvana Child Development Center in Ahmedabad. Participants were screened for eligibility based on the predefined inclusion and exclusion criteria, and written informed consent was obtained from all participants prior to data collection.

Baseline assessments were conducted to collect demographic information of the parents, including age, gender, educational level, and relationship status. Additionally, child-related data, such as age, gender, and age at diagnosis, were documented.

Data collection was performed using a structured Self-Care Assessment Tool designed to evaluate parents' awareness, perception, and implementation of self-care management strategies across multiple domains. All responses were carefully

recorded, and the collected data were entered into SPSS and Microsoft Excel for analysis.

### Statistical Analysis:

Descriptive statistics (mean, SD, frequency, and percentage) were used to summarize participant characteristics and self-care

practices. Pearson’s correlation assessed the relationship between child age and parental self-care, while one-way ANOVA examined differences based on education level. A p-value <0.05 was considered significant.

## RESULT

**Table 1: Child Demographics**

| Variable                       | Value                           |
|--------------------------------|---------------------------------|
| Mean Age at children Diagnosis | 2.84 ± 0.54 years               |
| Current Age of Child           | 5.21 ± 1.39 years               |
| Gender Distribution            | Male: 68 (65%) Female: 36 (35%) |
| Has Siblings (Yes)             | 46 (44%)                        |
| Mean Age of Siblings (if any)  | 9.8 ± 3.54 years                |

Table 1 presents the demographic details of the children included in the study. The mean age at diagnosis was 2.84 ± 0.54 years, and the current mean age was 5.21 ± 1.39 years, indicating an average gap of around two

years since diagnosis. Among the participants, 65% were males and 35% females. Nearly 44% of the children had siblings, with a mean sibling age of 9.8 ± 3.54 years.

**Table 2: Parent Demographics**

| Variable            | Value   |
|---------------------|---|
| Mean Age of Parent  | 36.23 ± 5.12 years  |
| Gender              | Male: 47 (45%) Female: 57 (55%)   |
| Relationship Status | Married: 95 (91%) Widowed: 2 (2%) Single: 2 (2%) Separated: 2 (2%) Divorced: 3 (3%)       |
| Education Level     | Secondary: 5 (5%) Higher Secondary: 7 (7%) Undergraduate: 56 (54%) Postgraduate: 36 (34%) |

Table 2 summarizes the demographic characteristics of the parents. The mean age of parents was 36.23 ± 5.12 years. The sample included 45% males and 55% females. Most parents were married (91%), while a small proportion were widowed,

single, separated, or divorced. Regarding education, the majority were undergraduates (54%), followed by postgraduates (34%), with fewer having secondary or higher secondary education.

**Table 3: Physical self-care item**

| S No. | Physical Self-Care Item                        | Most Common Response | Brief Interpretation                        |
|-------|--|----------------------|---|
| 1     | Eat regularly [e.g., breakfast, lunch, dinner] | Frequently (42%)     | Majority maintain regular eating habits     |
| 2     | Eat healthy                                    | Frequently (34%)     | Mixed eating habits; 31% eat healthy rarely |
| 3     | Exercise                                       | Never (55%)          | Very low engagement in regular exercise     |
| 4     | Get medical care when needed                   | Rarely (34%)         | Many delay or avoid medical care            |
| 5     | Take time off when needed                      | Rarely (48%)         | Breaks and rest are often neglected         |
| 6     | Get massages                                   | Never (76%)          | Most do not engage in therapeutic self-care |
| 7     | Physical activity [dance, walk, sports, etc.]  | Never (70%)          | Limited participation in active recreation  |
| 8     | Get enough sleep                               | Rarely (47%)         | Sleep is frequently insufficient            |
| 9     | Take vacations                                 | Occasionally (52%)   | Occasional vacationing observed             |
| 10    | Take day trips or mini-                        | Occasionally (52%)   | Many take short breaks sometimes            |

|    |                        |                         |  |
|----|------------------------|-------------------------|--|
|    | vacations              |                         |  |
| 11 | Gardening or yard work | Rarely (45%)            | Low participation in outdoor maintenance |
| 12 | Other [Physical]       | Rarely (46%) (combined) | Other activities done infrequently       |

Table 3 illustrates the parents' physical self-care practices. Most participants reported frequent regular eating habits (42%), but only 34% ate healthy foods regularly. Exercise and physical activities showed poor adherence, with 55% never exercising and 70% never engaging in recreational physical activity. Medical care and adequate

rest were often neglected, as many rarely sought medical helps (34%) or took time off (48%). Activities like massages (76%), gardening (45%), and other physical self-care practices were rarely performed. Overall, physical self-care among parents was limited and inconsistent.

**Table 4: Psychological Self-Care Item**

| S No. | Physical Self-Care Item                       | Most Common Response | Brief Interpretation                           |
|-------|---|----------------------|--|
| 1     | Attend personal therapy                       | Never (38%)          | Most do not attend therapy regularly           |
| 2     | Journal writing                               | Never (50%)          | Journaling is largely avoided                  |
| 3     | Read literature unrelated to autism           | Rarely (40%)         | Leisure reading is limited                     |
| 4     | Reduce areas of stress in life                | Occasionally (45%)   | Some effort to manage stress, but inconsistent |
| 5     | Spend time with partner (without children)    | Rarely (48%)         | Personal couple time is infrequent             |
| 6     | Say "no" to extra responsibilities            | Rarely (56%)         | Assertive boundary setting is weak             |
| 7     | Strive for balance (work, family, play, rest) | Rarely (42%)         | Balance across life domains is hard to achieve |
| 8     | Other (Psychological)                         | Occasionally (44%)   | Minimal engagement in other psychological acts |

Table 4 presents the psychological self-care patterns of parents. Most participants never attended personal therapy (38%) and rarely engaged in journaling (50%). Leisure reading (40%) and stress reduction (45%) were practiced occasionally. Activities promoting emotional balance, such as

spending time with a partner (48%) and saying "no" to extra responsibilities (56%), were infrequent. Overall, parents showed limited engagement in psychological self-care, with inconsistent efforts toward stress management and emotional well-being.

**Table 5: Emotional Self-Care Item**

| S No. | Emotional Self-Care Item                        | Most Common Response    | Brief Interpretation                              |
|-------|---|-------------------------|---|
| 1     | Stay in contact with important people           | Occasionally (39%)      | Moderate efforts to maintain emotional connection |
| 2     | Re-read favorite books or watch favorite movies | Rarely (36%)            | Comfort activities are not regularly pursued      |
| 3     | Allow yourself to cry                           | Rarely (41%)            | Emotional release is not frequently practiced     |
| 4     | Find things that make you laugh                 | Occasionally (49%)      | Humor is occasionally sought as emotional support |
| 5     | Attend a support group                          | Occasionally (43%)      | Some participation, but not consistent            |
| 6     | Other [Emotional]                               | Mixed (Occasional-Rare) | Minimal engagement in other emotional practices   |

Table 5 highlights the emotional self-care practices of parents. Many participants

occasionally stayed in contact with important people (39%) and found things

that made them laugh (49%), indicating moderate emotional engagement. However, comfort activities like re-reading favorite books or watching movies (36%) and emotional expression through crying (41%) were practiced rarely. Participation in

support groups (43%) was occasional but inconsistent. Overall, parents demonstrated moderate emotional self-care, with limited and irregular involvement in supportive or restorative activities.

**Table 6: Spiritual Self-Care Item**

| S No. | Spiritual Self-Care Practice        | Most Common Response        | Brief Interpretation                                  |
|-------|-------------------------------------|-----------------------------|---|
| 1     | Make time for reflection            | Frequently (38%)            | Regular reflection is prioritized by many             |
| 2     | Spend time in nature                | Occasionally (50%)          | Nature exposure is moderately practiced               |
| 3     | Find spiritual connection/community | Occasionally (41%)          | Some seek spiritual belonging, but not consistently   |
| 4     | Be open to not knowing              | Rarely (42%)                | Comfort with uncertainty is low                       |
| 5     | Cherish optimism and hope           | Occasionally (45%)          | Hope and positivity are moderately cultivated         |
| 6     | Meditate                            | Rarely [35%] or Never (36%) | Meditation is infrequently practiced                  |
| 7     | Pray                                | Occasionally (41%)          | Prayer is a common spiritual outlet                   |
| 8     | Sing                                | Rarely (47%)                | Singing is not a frequent emotional-spiritual release |
| 9     | Read inspirational literature       | Occasionally (38%)          | Some engagement with uplifting content                |
| 10    | Other [Spiritual]                   | Mixed (Low frequency)       | Additional practices are minimal                      |

Table 6 outlines the spiritual self-care practices of parents. A notable portion frequently engaged in reflection (38%), while spending time in nature (50%) and cherishing optimism (45%) were practiced occasionally. Spiritual connection (41%) and prayer (41%) were moderately observed. However, activities like

meditation (35% rarely; 36% never) and singing (47% rarely) were less common. Overall, parents demonstrated moderate engagement in spiritual self-care, focusing more on reflection and hope, with limited participation in meditative or expressive practices.

**Table 7: Professional Self-Care Item**

| S No. | Professional Self-Care Item         | Most Common Response  | Brief Interpretation  |
|-------|-------------------------------------|-----------------------|---|
| 1     | Take breaks during the workday      | Rarely (46%)          | Breaks are often skipped, possibly due to caregiving strain |
| 2     | Make quiet time for task completion | Occasionally (38%)    | Some attempt to manage tasks with focused time              |
| 3     | Balance daily workload              | Occasionally (35%)    | Workload balance is attempted but inconsistently maintained |
| 4     | Set limits with clients/colleagues  | Occasionally (36%)    | Boundary-setting occurs moderately but not strongly         |
| 5     | Other (Professional)                | Mixed (Low frequency) | Very few pursue other forms of workplace self-care          |

Table 7 summarizes the professional self-care practices of parents. Most participants rarely took breaks during work (46%), reflecting limited attention to rest amid responsibilities. Efforts to create quiet time

(38%), balance workload (35%), and set boundaries (36%) were occasional but inconsistent. Overall, professional self-care was infrequently practiced, indicating challenges in maintaining work-life balance

and self-boundaries due to caregiving demands.

**Table 8: Correlation Between Demographic and Self-Care Variables Among Parents**

| Variables  | Pearson r | p-value | Interpretation   |
|--|-----------|---------|--|
| Number of children – Physical self-care            | 0.378     | 0.028   | More children are associated with slightly better physical self-care. May indicate increased health awareness. |
| Child’s age – Physical self-care                   | 0.578     | 0.0028  | As children grow older, parents tend to engage more in physical self-care, possibly due to reduced dependency. |
| Child’s age – Psychological self-care              | 0.358     | 0.0256  | Older children are associated with slightly better psychological self-care among parents.                      |
| Physical – Psychological self-care                 | 0.421     | 0.0001  | Individuals taking care of their physical health also tend to address psychological needs.                     |
| Physical – Emotional self-care                     | 0.675     | 0.0001  | Strong relationship—suggests holistic self-care: emotional and physical aspects go hand-in-hand.               |
| Physical – Spiritual self-care                     | 0.486     | 0.001   | People who maintain physical health also practice more spiritual habits.                                       |
| Physical – Workplace self-care                     | 0.302     | 0.007   | Physically well individuals are more likely to manage workplace boundaries and breaks.                         |
| Psychological – Emotional self-care                | 0.521     | 0.0001  | People caring for their minds also manage emotional needs effectively.   |
| Psychological – Spiritual self-care                | 0.425     | 0.0001  | Strong link between mental well-being and spiritual practices.   |
| Psychological – Workplace self-care                | 0.621     | 0.025   | Mentally aware individuals show better work-life boundary setting.   |
| Emotional – Spiritual self-care                    | 0.625     | 0.0001  | Deep link—those emotionally tuned in also show spiritual engagement.   |
| Education level – Awareness level                  | 0.41      | 0.001   | Higher education is strongly linked to higher awareness about self-care.                                       |
| Reading inspirational literature – Awareness level | 0.195     | 0.0486  | Small but significant link between reading inspirational content and self-care awareness.                      |

Table 8 presents the correlations between demographic factors and self-care variables among parents. A significant positive relationship was found between most self-care domains, indicating that improvements in one area often coincide with others. For example, physical and emotional self-care ( $r=0.675$ ,  $p=0.0001$ ) showed a strong association, reflecting a holistic self-care approach. Child’s age correlated positively with both physical ( $r=0.578$ ,  $p=0.0028$ ) and psychological self-care ( $r=0.358$ ,  $p=0.0256$ ),

suggesting parents engage more in self-care as children grow older. Education level also showed a significant association with self-care awareness ( $r=0.41$ ,  $p=0.001$ ), implying that higher education enhances understanding and practice of self-care. Overall, the results indicate interconnectedness between self-care dimensions and demographic factors, emphasizing that better awareness and maturity promote healthier self-care behaviors.

**Table 9: One-Way ANOVA Showing Relationship Between Education Level and Domains of Self-Care Among Parents**

| Variables               | F value | p-value | Interpretation   |
|-------------------------|---------|---------|--|
| Physical Self-Care      | 9.675   | 0.083   | Not statistically significant [ $p > 0.05$ ]. Variation between groups exists, but it is not strong enough to confirm a meaningful difference in physical self-care. |
| Psychological Self-Care | 11.886  | 0.047   | Statistically significant [ $p < 0.05$ ]. There is a significant difference in psychological self-care between groups.   |
| Emotional Self-Care     | 21.761  | 0.007   | Statistically significant [ $p < 0.05$ ]. Strong evidence of a significant difference in emotional self-care across groups.  |

|                     |       |       |  |
|---------------------|-------|-------|--|
| Spiritual Self-Care | 8.291 | 0.215 | Not significant [ $p > 0.05$ ]. No meaningful difference across groups in spiritual practices.   |
| Workplace Self-Care | 3.985 | 0.438 | Not significant [ $p > 0.05$ ]. Variation in workplace self-care is not statistically confirmed. |

Table 9 shows the relationship between parents' education level and various self-care domains using one-way ANOVA. Psychological ( $p=0.047$ ) and emotional self-care ( $p=0.007$ ) demonstrated statistically significant differences across education levels, indicating that higher education is linked to better self-care in these areas. However, physical ( $p=0.083$ ), spiritual ( $p=0.215$ ), and workplace self-care ( $p=0.438$ ) did not show significant variation, suggesting that education has limited influence on these domains. Overall, the findings highlight that education primarily impacts psychological and emotional aspects of self-care, rather than physical or occupational dimensions.

## DISCUSSION

Autism Spectrum Disorder is a complex neurodevelopmental disorder characterized by persistent deficits in social communication, restricted interests, repetitive behaviours, and challenges in adaptive functioning. Caring for children with ASD poses unique challenges for families, particularly for parents, who are the primary agents in implementing self-care strategies and managing daily routines. [2] These routines encompass essential aspects such as hygiene, feeding, social interactions, and other adaptive behaviours. Parents' perceptions and awareness of these strategies are vital because they influence the effectiveness of interventions and the overall quality of life for both the child and the family unit. [9] Understanding these parental experiences is crucial to designing interventions that are not only child-focused but also caregiver-inclusive, promoting family-centered care and improving outcomes for children with ASD. The present study included 104 parents of children with ASD. Children were typically diagnosed between 2.3 and 3.4 years (mean age  $2.84 \pm 0.54$ ), reflecting early childhood

as a critical period for self-care development. The majority of children were male [65%], consistent with global prevalence trends showing higher ASD incidence in boys. The mean current age of the children was  $5.21 \pm 1.39$  years, highlighting that early to middle childhood remains a period of intensive caregiving demands. Among the participating families, 56% had no additional children, and the mean age of siblings was  $9.8 \pm 3.54$  years. Most parents were married (91%) and female (55%), emphasizing the predominant role of mothers in caregiving responsibilities. The average parent age was 36.23 years, with 54% holding undergraduate degrees and 34% postgraduate degrees, suggesting that many parents were well-educated and potentially capable of engaging with complex caregiving information.

**Physical Self-Care:** The findings regarding parental physical self-care highlight significant challenges. Only 42% of parents reported eating regular meals frequently, and a mere 34% maintained consistent healthy eating habits. Physical activity was markedly low: 55% of parents never engaged in exercise, and 70% rarely participated in recreational activities such as sports or swimming. Sleep disruption was common, with 60% rarely or never achieving adequate rest. Access to medical care was limited; only 20% of parents frequently received care when required. Leisure activities, including vacations, gardening, or other restorative pursuits, were infrequent. These data indicate that caregivers of children with ASD face considerable barriers in maintaining physical well-being, aligning with previous literature emphasizing caregiver vulnerabilities. [19,20,21]

Parental physical activity is often compromised due to caregiving responsibilities. Smith et al. (2019) [19]

reported that parents frequently skipped exercise owing to time constraints, fatigue, and limited childcare options. Zaidman-Zait et al. (2017) <sup>[20]</sup> similarly observed that increased stress and lack of personal time reduce opportunities for physical activity, as parents prioritize therapy sessions and child routines over their own fitness, resulting in sedentary lifestyles and heightened risk for chronic illnesses.

Nutritional habits are similarly affected. Ashinie C. et al. <sup>[21]</sup> noted that caregivers often maintain irregular meals, rely on fast food, and consume fewer fruits and vegetables. Contributing factors include stress, time scarcity, and the need to accommodate children's selective eating behaviours. The cumulative effect of inadequate diet, lack of exercise, and disrupted sleep patterns compromises caregivers' overall health, highlighting the importance of structured interventions targeting lifestyle behaviours.

Sleep disturbances represent another critical concern. Meltzer and Mindell (2007) <sup>[22]</sup> emphasized that parental sleep is frequently interrupted by co-sleeping, night awakenings, and anxiety about the child's safety. Gallagher et al. (2010) <sup>[23]</sup> linked poor sleep to elevated stress levels, impaired immune function, and decreased cognitive performance, creating a cycle where fatigue undermines the ability to engage in healthy self-care practices.

Medical self-care is often deprioritized among caregivers. Weiss et al. (2013) <sup>[24]</sup> found that parents delay or avoid seeking healthcare due to prioritization of their child's needs and financial constraints. Seymour et al. (2012) <sup>[25]</sup> reported untreated chronic conditions, including hypertension, migraines, and musculoskeletal disorders among caregivers. Navigating complex healthcare systems for their children often contributes to parental burnout, further reducing attention to their own preventive care.

Leisure and recreational engagement are similarly limited. Harper et al. (2012) <sup>[26]</sup> highlighted that behavioural

unpredictability, lack of inclusive environments, and social stigma reduce participation in family outings or vacations. Benson and Karlof (2009) <sup>[27]</sup> reported that limited recreational opportunities exacerbate caregiver fatigue and social isolation. Even brief leisure activities are rare due to the constant mental burden of caregiving, reducing overall quality of life and compounding both physical and emotional stress.

To address these physical self-care barriers, interventions should include accessible caregiver-focused nutritional counselling <sup>[20]</sup>, flexible home-based physical activity programs adapted to caregiving demands <sup>[21]</sup>, evidence-based behavioural sleep support incorporating stress management and sleep hygiene <sup>[23]</sup>, caregiver health tracking integrated into ASD services <sup>[24]</sup>, and inclusive, low-stress leisure opportunities such as respite care, caregiver retreats, and sensory-friendly family outings <sup>[27]</sup>. These interventions can help maintain parental health and sustain their capacity to support children with ASD.

**Psychological Self-Care:** Parental engagement in psychological self-care was found to be minimal. Only 9% of parents reported frequent therapist visits, while 38% never engaged in professional psychological support. Activities such as journaling, reading unrelated literature, and intentional stress reduction were infrequent. Over 60% rarely or never spent quality time with partners without children, and many struggled to set boundaries or decline additional responsibilities, heightening the risk of burnout. These findings underscore a substantial gap in psychological self-care awareness and practice among caregivers of children with ASD.

Existing literature reinforces these observations. Hayes and Watson (2013) <sup>[28]</sup> reported that parents of children with ASD experience higher parenting stress than those of neurotypical children or children with other disabilities. The demands of constant caregiving, emotional regulation challenges, and lack of social support

contribute to psychological fatigue. Pottie and Ingram (2008) [29] highlighted that adaptive coping strategies, such as seeking social support and engaging in restorative activities, reduce stress. However, our study revealed that such strategies are underutilized, reflecting a need for targeted interventions.

Parents often prioritize their child's needs over their own, perceiving self-care as selfish or indulgent. This results in neglect of mental health while managing daily routines, meltdowns, therapies, and societal stigma [28,29]. Parent-focused interventions should include psychoeducation on stress management, boundary-setting, and daily self-care routines, alongside accessible support groups and counselling.

**Emotional Self-Care:** Emotional self-care practices were generally underutilized. While 59% of parents occasionally maintained contact with important individuals, 40% rarely or never did. Emotional outlets such as crying (54%) or humor (41%) were infrequently employed. Participation in support groups was limited, with 43% rarely or never attending. These data indicate social isolation, emotional suppression, and potential burnout.

Previous studies support these findings. Smith et al. (2010) [19] and Woodgate et al. (2008) [30] emphasized that peer interaction and social support improve mental health outcomes in ASD caregivers, while their absence increases depressive symptoms and fatigue. Neely-Barnes et al. (2011) [31] noted that parents of children with ASD experience greater emotional stress and lower self-compassion compared to parents of children with other disabilities. Phelps et al. (2009) [32] emphasized that expressive emotional activities such as storytelling or humor are essential for resilience, yet our study found low engagement in these strategies. Barker et al. (2011) [33] highlighted that prolonged caregiving can lead to emotional suppression, which may maintain family stability in the short term but exacerbate long-term strain. Kuhlthau et al. (2014) [34] further emphasized that

parental emotional well-being directly affects the child's developmental and behavioural progress. Supporting emotional self-care is therefore essential not only for parents' mental health but also for effective caregiving.

**Spiritual Self-Care:** Spiritual self-care showed moderate engagement among parents. Practices such as personal reflection (67%), spending time in nature (63%), prayer (69%), and valuing community connections (59%) were common. However, meditation (71%), acceptance of uncertainty (40%), and engagement with inspirational literature were infrequent. These patterns reflect both the importance of spiritual coping and the limitations imposed by time constraints and caregiving demands.

Benson and Karlof (2009) [27] observed reliance on prayer and community support with limited mindfulness practices. Phelps et al. (2009) [32] similarly noted that spiritual coping strategies are often underdeveloped. Broader spiritual practices, including meditation and acceptance, can enhance resilience (Samata Pandya et al., 2018) [35], while Hodge et al. (2010) [36] emphasized spirituality's role in fostering hope and identity. Integrating culturally sensitive spiritual support into caregiver interventions may improve emotional and psychological resilience.

**Professional Self-Care:** Parents reported significant gaps in professional self-care. Nearly 46% rarely took breaks such as lunch, 20% never did, and only 51% occasionally had uninterrupted quiet time for tasks. Workload balance was inconsistently maintained; 47% managed it sometimes, 29% rarely, and 24% never. Boundary-setting was practiced by 50% but neglected by 44% of parents. Low awareness and prioritization contributed to these patterns.

These findings align with previous research. Sadziak et al. [2019] [37] found that skipped breaks and heavy workloads contribute to caregiver exhaustion. Brookman et al. [2005] [38] reported role overload and emotional strain among parents, while Karst

and Van Hecke (2012) <sup>[14]</sup> emphasized that boundary-setting protects against burnout but is challenging for highly engaged caregivers. Neece et al. (2012) <sup>[39]</sup> noted that daily caregiving stress compounds emotional strain. Miranda Mak et al. (2020) <sup>[40]</sup> found that parents who manage workload effectively and allocate quiet time report greater resilience. Common barriers include lack of time (37%), work stress (25%), sleep deprivation (15%), schedule imbalance, financial strain (each 9%), and limited social support (3–2%). Rivard et al. (2014) <sup>[41]</sup> and Zhang et al. (2023) <sup>[42]</sup> similarly reported that these factors impair self-care and increase psychological distress. Interventions targeting time management, stress reduction, and flexible work policies are crucial to support caregiver well-being and optimize child outcomes.

The present study demonstrates that self-care among parents of children with ASD is multifaceted, encompassing physical, psychological, emotional, spiritual, and professional domains. Key barriers include time constraints, caregiving demands, sleep disruption, work stress, and financial strain. Caregivers often prioritize the child's needs over their own, resulting in low engagement in therapy, leisure, stress relief, and boundary-setting. While some parents value spiritual and emotional coping strategies, their implementation is inconsistent.

These findings are consistent with prior literature. Studies consistently indicate that caregivers of children with ASD experience elevated stress, social isolation, reduced physical activity, poor nutrition, sleep disturbances, and diminished emotional and psychological well-being. <sup>[37, 38, 40]</sup> The interplay of caregiving responsibilities, systemic healthcare barriers, and societal expectations creates persistent tension and reduces opportunities for self-care.

Targeted interventions are essential to address these challenges. Physical self-care programs should incorporate nutritional counselling, exercise strategies adapted to limited time, and structured sleep support.

Psychological interventions should emphasize stress management, adaptive coping, and participation in support groups. Emotional self-care can be enhanced through expressive activities, humour, and social engagement, while spiritual care should encourage meditation, reflective practices, and community connection. Professional self-care requires time management training, workload balancing strategies, and boundary-setting support. Collectively, these interventions can improve parental resilience, reduce burnout, and enhance caregiving outcomes, ultimately benefiting children with ASD.

In conclusion, parents of children with ASD face significant challenges across multiple domains of self-care. These challenges stem from caregiving responsibilities, societal pressures, and systemic barriers rather than personal neglect. Targeted, multidimensional interventions that address physical, psychological, emotional, spiritual, and professional self-care are necessary to support caregiver well-being. By prioritizing the health and resilience of parents, interventions not only enhance parental quality of life but also promote better developmental and behavioural outcomes for children with ASD. Long-term caregiver support should be an integral component of comprehensive autism care strategies, recognizing that parental well-being is fundamental to effective family-centered interventions.

## **CONCLUSION**

In conclusion, the findings underscore that parents of children with ASD face multifaceted challenges that hinder effective self-care across physical, psychological, emotional, spiritual, and professional domains. Addressing key barriers such as time constraints, work stress, and financial limitations is vital to fostering sustainable self-care habits. Interventions that provide tailored support including accessible counseling, stress management programs, flexible work policies, and enhanced community resources can empower parents

to better manage their caregiving roles while safeguarding their own health. Promoting holistic well-being for caregivers ultimately contributes to improved family functioning and more positive developmental trajectories for children with ASD.

#### **Declaration by Authors**

**Ethical Approval:** Approved

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