

Note: This is Online Supplementary Document 1 of Berson, J., & Adams, S.N. (2024). South African caregivers of children with autism during COVID-19: A scoping review, *South African Journal of Communication Disorders*, 71(1), a1017. <https://doi.org/10.4102/sajcd.v71i1.1017>

TABLE 1: Code book.

Article number	Code	Description of code	Total frequency of code
1, 3, 4, 5, 6, 8, 12, 14, 17, 18, 21, 22, 24, 25, 27, 29, 30–33, 36	Anxiety, distress and mental health	When a participant mentions how the COVID-19 pandemic has negatively impacted their psychological wellbeing as a result of many different aspects relating to restrictions and challenges with their child, this increases feelings of anxiety, fear, being overwhelmed, worried and even depressed	72
2, 3, 6, 7, 8, 12, 16, 19, 21, 22, 23, 32, 34, 35, 36	Restrictions of COVID-19 causing behavioural difficulties	Both researchers and participants make mention of noticeable increases in new or exacerbated behavioural issues in children with ASD causing further negative impacts on caregivers	60
2, 3, 4, 6, 7, 8, 10, 12, 15, 17, 18, 20, 21, 22, 23, 25, 29, 30, 31, 32, 36	Lack of access to, or difficulties with therapy or health services (including telehealth)	Referring to participants having difficulty with access to telehealth services, and both therapy and educational services because of the restrictions and rules around lockdown during the COVID-19 pandemic	38
7, 9, 11, 17, 18, 24, 31, 32	Increased parental responsibility and resilience	Both researchers and participants make mention of increased responsibilities in their roles to carry out daily routines, their own occupations, caring for their child and upholding their progress from therapy and school in the home environment. However, many caregivers showed resilience with these changes and the ways in which they approached the challenges identified	28
10, 17, 19, 20, 21, 22, 23, 30, 31, 35	Coping with changes in routine	The COVID-19 pandemic lockdown and restrictions changed the way in which children with ASD and their caregivers carried out their daily routines which was difficult to manage specifically for children with ASD because of their need and preference for structure as reported by researchers and participants	22
15, 24, 33, 35	Medical support and adaptations made for the therapeutic requirements	Researchers made suggestions that it was imperative for adaptations to be made in order for medical and therapeutic interventions and assistance to be given and made available when caregivers should need them	18
7, 16, 32, 34, 35, 36	Increased remote counselling or health care services for both caregivers and children	Many studies commented on the importance of available mental health services for caregivers of children with ASD to assist them in managing their feelings and negative psychological states and wellbeing during the pandemic	15
6, 11, 22, 23, 25, 27, 29	Financial implications (including loss or suspension of jobs)	Participants reported increased stress related to the loss of jobs and income as they were unable to work in person during the COVID-19 fluctuations and restrictions	15
1, 13, 17, 18, 20	Regression in skills	This refers to researchers' conclusions of the reported decline of behavioural and social skills in children with ASD	10
6, 11, 22, 23, 25, 27, 29	Uncertainty of lockdown conditions	Participants indicated feelings of uncertainty regarding the changing rules and levels of lockdowns, as they did not know when these periods would end or when return to pat routines would occur. Participants reported across studies that COVID-19 was unknown as to when an end was in sight	9
8, 15, 22, 24, 32, 35	Sleep issues	This was seen to be a result of the changes in routine, where disruptions in sleep was reported being shortened or longer for both children and caregivers with ASD	8
10, 16	Structure in daily routines	Some researchers make suggestions to utilise structured activities to ensure tasks are completed, organised and structured according to a routine so their children may better cope during the pandemic, and caregivers may have some time for self-care with preparation and intention	8
2, 4, 12, 25, 32	Parental concerns over health	Some participants reported feeling fear of themselves and their children contracting the virus and falling ill during the pandemic where health care services were difficult to access and caring for a child at home was significantly more difficult	7
13, 15, 20	Limited physical activity	Researchers and participants reported that the inside of many homes was unsafe or ill-equipped, small and without private gardens, to carry out adequate physical activity and exercise which caused a number of other issues such as changes in mood or sleep as well	7
7, 31, 35	Isolation, loneliness and helplessness	Many participants reported feeling lonely and that other caregivers may not be able to understand their situation caring for a child with ASD during the pandemic. There was often no one to relate to and seek comfort from leading to these negative feelings as reported	6
10, 18, 20, 30	Need for mental health and psychological assistance policies	Researchers suggest that specific policies be put into place ensuring and providing consistent and available mental health services to caregivers of children with ASD if they should need this	6
8, 19, 34	Online family support	Researchers made suggestions that organised phone calls or online methods of communication be made regularly between families to provide some support to caregivers of children with ASD	6
22, 26, 27	Structured play and environment in the home	Researchers recommend caregivers formulate plans and structures when conducting educational, play or therapeutic activities and daily routines in the home environment	6
31, 36	More research to determine the acceptability of telehealth across services for this population	Researchers highlight the core symptoms of ASD and how that may impact their ability to participate properly in remote learning and telehealth services	6
24, 33	Increased financial support for parents of children with ASD	Participants feel increased stress because of the loss or suspension of jobs causing financial difficulties. Researchers suggest certain policies be followed allowing financial relief and support for caregivers of children in this population who require such a means of support to lessen struggle during the pandemic and after	5

Table 1 continues on the next page→

TABLE 1 (Continues...): Code book.

Article number	Code	Description of code	Total frequency of code
16, 18, 31	Demands of caregiving with remote learning	Participants reported having difficulty attending to their own needs and responsibilities as they were required to supervise and assist with online learning their child may be participating in which was reported to be demanding and time consuming	5
30	The anxiety of caregiver correlating to worsening behaviours	Participants report increased feelings of anxiety and worry regarding the management of behaviours that began to worsen during the pandemic and the uncertainty of how to handle this change. The anxiety was felt as they did not hold the knowledge of how to assist their children in improving these behaviours using specific techniques or stimulation.	5
35	Increased social support	This was a general means of support some participants stated needed referring to support from friends, family, health care workers and teachers	5
20	A positive outlook on circumstances to increase resilience	Researchers suggest a shift in perspective and aiming for positivity may assist caregivers in getting through their circumstances while trying to build on positive aspects that arise	4
26	Support and interaction of friends and family	Participants reported that support through interaction in some way with family and friends was a significant way to assist them in their feelings and experiences during the pandemic	4
20	Eating related difficulties	Researchers indicate that shopping for food became difficult during the pandemic, especially for specific foods that children with ASD prefer. This caused worry in caregivers who could not provide their children with nutritious meals they could tolerate	2

ASD, autism spectrum disorder.