

RESEARCH ARTICLE

A narrative review on the prevalence of autism in a South African context

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ABSTRACT

Cultural perspectives are important when exploring caregivers' experiences. However, not much research has been conducted in South Africa on the experiences of caregivers who are taking care of children living with an autism spectrum disorder. This study was aimed at reviewing literature on the experiences of caregivers living with autistic children. A narrative review was employed as the research method and information was purposively extracted from different databases such as Google Scholar, ScienceDirect and EBSCOHost to collect data. It was gathered that caregivers have insufficient knowledge and understanding regarding the child's autism diagnosis. We also found that caregivers experience socio-economic and psychological challenges. Little social support is enjoyed by caregivers from community and family members as a coping strategy. Thus, we conclude and recommend that caregivers need a form of intervention that will help or assist their psychosocial well-being while providing care for their children. Moreover, caregivers have limited knowledge of autism and experience psychological challenges that are associated with the autism diagnosis of their child. This affects their subsequent abilities to efficiently provide care to the children.

Keywords: autism spectrum disorder; caregivers; culture; narrative review; psychological challenges

1. Introduction

Autism spectrum disorder (ASD) is a disorder that spans all global spheres of functioning for the child diagnosed with the disorder. However, no individual exists in isolation. Thus, the caregivers caring for children living with ASD also endure effects from their caregiving experience. The symptoms of ASD present from infancy, as early as eight months, and endure throughout the individual's lifespan, placing a significant strain on the functional and financial functioning of the family and the healthcare systems^[1].

Psychological disorders in South Africa are a difficult subject to grasp and contextualise. This is because of the rich cultural and linguistic diversity of the country and, to a certain extent, the effects of Apartheid^[2]. In the Apartheid system, which was marked by racial inequality, special schools for black children were under-resourced and only a few of them were accessible, with strict admission criteria^[3]. Due to the inequalities of services received during the Apartheid era, some of the caregivers or parents were not equipped regarding ASD^[4,5]. This implies that psychological disorders such as autism were undiagnosed and untreated in certain racial groups. This consequently led to the norm of not treating certain disorders in certain cultures.

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Hence, after the Apartheid era, it became important that we map the existing literature on the prevalence of autism in a South African context wherein there are different racial and cultural groups. Assessing the existing literature on autism using a cultural lens is imperative as we get to know what the cultural views are that caregivers and parents have towards ASD or psychological treatment.

2. Background information

Despite the early identification of autism symptomatology, the statistical knowledge of the prevalence and incidence of autism in South Africa is currently unclear. A decade ago, a literature review by studies suggested that there is a trend of an increase in the diagnosis of autism in developed countries^[6-8]. A recent study also indicated a rise in autism prevalence in developed countries globally^[9]. This observed rise in prevalence can be hypothesised to be due to more educational programmes, affordability of healthcare services or even intervention programmes. The prevalence of autism is at approximately 1.5%, as estimated by the World Health Organization (WHO)^[9,10]. Based on these findings, with different population groups and sample sizes, the estimate of the prevalence of autism globally can be estimated to range between 0.5% and 2%. However, the prevalence of autism is lower in developing countries than in developed countries. There is still an observed trend of an increase in the prevalence of autism diagnosis^[3].

2.1. Clinical description of ASD

The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) is the primary manual used in the description and diagnosis of disorders, including autism. The DSM-5 groups previously distinctive DSM-IV-TR-related disorders, which include autism disorders, Asperger's syndrome, and pervasive developmental disorder, under the autism spectrum disorder diagnostic criteria^[2]. ASD is a clinical disorder that can also be identified as heterogeneous as it manifests in a spectrum^[6,11-16]. This is further elaborated by the Lancet Commission, which suggests it is referred to as being heterogeneous as the symptoms manifest differently between individuals living with this disorder and within the individual across their life span^[9]. There are numerous ways that different symptoms of varying severity can present in children living with ASD.

Core symptoms of ASD have been identified across different age groups and populations. Children diagnosed with ASD present with, among other symptoms, deficiencies in language, social interaction, and repetitive stereotypical patterns in their behaviour^[17-19]. The impairment in social behaviours presents as preferences to be alone, avoidance of eye contact, and gaze shifting^[20-22]. Besides presenting with these social behavioural problems, children diagnosed with autism also have an impairment in recognising and responding to the social behaviours of others.

The core symptoms of autism are prevalent throughout age groups. However, the manner of presentation of these symptoms may differ according to age. There are 4 key differentiating characteristics in toddlers, namely (1) avoiding eye contact, (2) not responding when called by name, (3) lack of pointing to redirect caregiver's attention, and (4) deficits in showing objects to caregivers to share social interests^[23]. There are other associated symptoms that are not used in the diagnostic criteria for autism. These symptoms remain challenging for caregivers and affect families and diagnosed children just as much as the core symptoms of autism. Some of these challenges include anxiety, hyperactivity, and obsessive-compulsive behaviours^[24,25].

2.2. Diagnosis of ASD

Autism has core symptoms that present from early childhood and are persistent and distinctive. Symptoms of autism can appear in children as early as 8 months^[21]. Thus, caregivers can begin noticing deviations from normal development during the early childhood developmental phase. Early detection and intervention are crucial as they can assist in reducing the severity of symptoms and, furthermore, result in the improvement of

associated deficits^[26]. Moreover, early intervention that is intensive for children with ASD has been suggested to reduce the severity of symptoms and has been shown to result in significant improvement in adaptive behaviour, cognitive functioning, language acquisition, and the development of social skills as a long-term outcome^[27]. It is crucial that interventions are implemented to mediate the effects of autism. Children diagnosed with mild and subtle signs are likely not to be diagnosed^[22]. The implication is that these children would struggle with integrating successfully into society. Thus, screening tools are necessary for the early detection and intervention of autism to ensure the adaptation of children living with autism.

The diagnosis of autism is made by a professional based on the diagnostic criteria of the DSM-5. Autism is diagnosed based on reported behaviour and observations^[9]. This is a result of the insufficient understanding of the pathophysiology of ASD^[2], in which case biologically based testing has not been developed. Thus, the diagnosis of neurodevelopmental disorders includes clinical interviews and the use of standardised tests^[28]. Multiple screening tools have been developed in developed (Western) countries. These screening tools do not serve the function of diagnosis but rather detect individuals at high risk of developing ASD^[29]. The function of screening tools is to ensure early detection as it would likely result in decreased symptomatology, an increase in language abilities, and improvements with peer interactions^[30]. However, there is a lack of standardised screening and diagnostic tools in South Africa^[31]. Many of these screening tools need to be adapted and normed for use in developing countries such as South Africa.

3. Problem statement

Autism is a disorder that knows no borders, as it is experienced globally. Autism is a globally prevalent neurodevelopmental disorder^[27,32]. The majority of individuals with autism live in developing countries, such as South Africa, and experience difficulties in services from the health and social care systems. Intervention and outreach programmes that are developed in the cultural context can reduce disparities in the healthcare system by providing information that is culturally appropriate to support ethnic minorities^[33]. Caregivers of children living with autism are more likely to show negative emotions such as symptoms of depression, stress, frustrations, emotional pain, and helplessness^[15,34–37]. These psychological challenges lead to shame and social isolation. Therefore, coping mechanisms such as seeking social support, mental healthcare, and acceptance of situations (such as a child living with autism) are more common among caregivers of children living with autism^[38,39]. To that end, the researchers aimed to synthesise literature on the experiences of caregivers living with autistic children.

4. Methodology

The researchers adopted a narrative review as the research method. Narrative reviews involve collecting a wider amount of literature from different journals and textbooks with the purpose of critiquing and summarising data on a particular phenomenon^[40]. Narrative reviews are adopted when the researcher(s) attempt to provide an overview of a certain topic and potentially identify gaps in the existing literature. On that score, the researchers used narrative review in order to gather, critique, and summarise existing information on the experiences of caregivers living with autistic children. To select relevant articles, the researchers ensured that they used different databases such as Google Scholar, ScienceDirect and EBSCOHost to collect data. To be selected, the researchers used a purposive sampling technique to purposively select the article that matched the selected keywords and was within the 10-year projection.

5. Findings and discussion

In this paper, the reviewers conducted data extraction wherein they put the sampled articles on the data charting to be able to identify the emerging themes. From the sampled articles, the researchers have noted the caregivers' experience, socio-economic challenges, and psychological challenges faced by caregivers.

5.1. Psychological challenges faced by caregivers raising autistic children

Providing care to individuals who cannot perform basic tasks independently can be an overwhelming task. While focusing on providing care, it can become difficult for caregivers to meet their own psychological needs, such as autonomy and competence, as they adapt to their caregiving responsibilities^[41]. The below-mentioned psychological challenges correlate as multiple studies indicate that there is some relationship between them. For example, fatigue symptoms are associated with high levels of stress, depression and anxiety^[42]. Caregivers' state of mental well-being may have effects on the child; therefore, it is important that holistic intervention plans also take into consideration the caregiver's mental health.

5.1.1. Depression and stress

Studies indicate that caregivers of children living with ASD may suffer from depression. The depression scale is used to assess symptoms of depression, which include dysphoria, hopelessness, anhedonia, and meaninglessness^[43-45]. In the study by Smith and colleagues, findings indicated that more than one-third (1/3) of mothers who care for their children living with ASD scored higher on a depression scale than the clinical threshold^[45]. Given that the psychological challenges are correlated, anxiety and depression are secondary outcomes precipitated by stress^[46].

Caregiving stress is defined as the distressful and discomfort experiences that are associated with the duties of caregiving^[47]. Providing care for children living with ASD is extremely difficult due to the associated multiple impairments and commodities, differences in manifestation, and the lack of consensus on the management of ASD^[48]. Studies have indicated that stress levels are higher in parents of children living with ASD than in other parents^[48,49]. It is suggested that coping with stress is a transitional process where methods of coping vary across context and time in relation to the dynamics of stressful events^[50]. Implicated factors that affect stress levels include the child's age, the severity of the symptoms, the personality of the caregiver, family unit functioning^[19], behavioural problems of the child, and deficits in socialising and communicating^[49]. Associated with stress is the feeling of anxiety. Hoffman reported in his study that caregivers indicated that worrying about the future increased their stress levels.

5.1.2. Fatigue

Resiliency in caregiving becomes worn out when there are no adaptive coping mechanisms in place to replenish strength. Fatigue is defined as an overwhelming, persistent weakness and exhaustion that manifests mentally and physically^[51,52], which is not relieved by resting and can affect the daily function and cognition of an individual^[53]. Moreover, mothers of children living with ASD reported significantly higher levels of fatigue associated with stress, anxiety, and depression symptoms^[42]. Similarly, sleep disturbances are prevalent among children living with ASD regardless of age^[52]. Given the need for caregivers to be constantly present when caring for a child living with autism, they often experience extreme exhaustion, facing daily challenges arising from the child's sleep disturbances.

5.2. Socio-economic challenges experienced when raising an autistic child

Child rearing is a laborious task and childhood disorders such as autism make it more strenuous. This is because caring for children diagnosed with autism, as compared to those without autism, has greater demands, such as more time, patience, and effort^[54]. Thus, there is more pressure on caregivers of children living with

disorders such as autism. The long-term or short-term impacts of autism diagnosis on caregivers, however, have not been fully explored^[55]. Autism is a heterogeneous disorder with different combinations of manifestation of symptoms. The responsibility of caring for a child living with autism is unfathomable and the probability of caregivers developing mental health issues is high^[54,56]. Furthermore, a diagnosis such as autism can be associated with stigmatisation that can affect both the diagnosed child and the caregiver^[57]. Caregivers reported having problems with accepting the diagnosis and understanding the problems that their children experience^[56]. The experiences and problems faced by caregivers are as diverse as the diversity of autism presentation.

5.2.1. Affiliate stigmatisation

Multiple studies have shown the negative effects on stress levels, psychological and emotional well-being, and the subjective burden of affiliate stigmatisation^[58]. Stigmatisation presents as assumptions and labels that are placed on an individual and/or associated persons^[59]. It is suggested that the caregivers' experiences from Western cultures of stigmatisation can be due to multiple aspects that may include insufficient knowledge of autism, lack of social support, and stereotypical comments^[60]. The cyclical effects of stigmatisation can also include exclusion from the community and less access to goods and services^[61]. Thus, in addition to dealing with the challenges presented by autism, caregivers also have to face external challenges from the community.

5.2.2. Financial struggles

Caregiving for a child living with a disorder inevitably introduces additional costs as compared to caring for children without a disorder. It is suggested that the economic domain of raising a child living with ASD entails the alteration of the financial position exerted by an ASD diagnosis on the family^[62]. Children diagnosed with ASD require care that includes intensive interventions and specialised educational services once they commence with school and life support throughout their lifespan^[63]. Furthermore, the autism schools in South Africa are only partially subsidised by the government^[64]. This leaves caregivers with the burden of paying the additional cost of education. At the time that children start attending school, families raising children with ASD endure mounting costs related to educating the child^[65]. However, families in developing countries still experience challenges with gaining access to these interventions and educational services^[20]. Managing the core and associated symptoms of ASD necessitates the collaboration of a multi-disciplinary team, access to which typically requires substantial financial resources.

6. Conclusion

This study showed that caregivers are affected in different domains (for instance, socio-economic, psychosocial, and psychological) of their lives due to providing care to children living with autism. Training and psychosocial support for caregivers is recommended for caregivers. Formal and informal support groups and/or organisations can be contacted to provide programmes that can support or help caregivers to cope while they give care to their children. Caregivers had coping mechanisms (such as seeking social support, mental healthcare, and acceptance of situations) to help deal with their duties and responsibilities while giving care.

7. Recommendations

We recommend that the replication of this review by other scholars includes more databases, as this study was limited by the number of databases accessed. Furthermore, other reviewers may look at the cultural differences of caregivers with regard to their experience of psychological challenges. Caregivers may have different experiences that may have varying cultural psychological challenges that can be explored. Moreover, there should be a study conducted that explores which interventions would be most relevant to assist caregivers with psychological challenges. These interventions can include forming support groups for caregivers to

alleviate feelings of isolation, providing psychotherapy to caregivers, and community psycho-education to alleviate the stigmatisation.

Author contributions

Conceptualization, MR, FM and WT; methodology, MR, FM and WT; software, FM and CM; validation, CM; formal analysis, MR, FM and WT; investigation, MR, WT, and CM; resources, MR, FM and WT; data curation, MR, and FM; writing—original draft preparation, MR, FM, WT, and CM; writing—review and editing, FM, WT and PE; visualization, CM and PE; supervision, FM and WT. All authors have read and agreed to the published version of the manuscript.

Conflict of interest

The authors declare no conflict of interest.

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