



Interventions for Primary Caregivers of Children with Autism Spectrum Disorder: A cross-sectional study of current practices of stakeholders in South Africa

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ABSTRACT

Background: Primary caregivers of children with autism spectrum disorder (ASD) face many challenges potentially impacting their mental health and well-being. Given their role in childcare, it becomes essential that primary caregivers be recognised as health care users who should receive interventions towards improved health, well-being and quality of life (QOL). The study aimed to describe the content, structure and mechanism of delivery of interventions offered to primary caregivers of children with ASD, with specific reference to QOL, in South Africa.

Method: A cross-sectional survey design was used to establish the interventions provided to primary caregivers as reported by health care and non-health care professionals who deliver interventions to children with ASD and their families, using an online questionnaire. Snowball sampling was implemented to access a sample of 61 respondents. Demographic data were analysed using descriptive statistics. Details of specific content of interventions were analysed according to identified intervention goals. Closed questions (binary and intensity scales) were analysed using frequencies and means and open-ended questions were thematically analysed with deductive reasoning using QOL domains as identified in relevant literature.

Results: Demographics of respondents are presented. Content of intervention included goals towards, awareness about ASD, interventions beneficial for the child with ASD and interventions beneficial for the primary caregiver. The structure and mechanism of delivery of interventions are described. Three QOL domains, development and activity, as well as social and emotional wellbeing, were more commonly targeted in interventions. Physical and material wellbeing were targeted to a lesser extent.

Conclusion: The QOL elements that are embedded in the described interventions described, highlight both strengths and limitations within current practices. Additionally, it is noted that interventions appear to primarily cater for the needs of the child, with gaps in catering directly for the needs of the primary caregiver. The mental health and wellbeing of the primary caregiver is essential for the child with ASD to develop and achieve their optimal potential. Therefore inclusion of the social, emotional and health needs of the primary caregiver need to be overt with specific outcomes towards improved QOL within interventions.

Key words: primary care givers, quality of life, autism, spectrum disorders, interventions

INTRODUCTION

Parents or primary caregivers of children with psychiatric disorders, including autism spectrum disorder (ASD) engage in the occupation of caregiving. The occupation of caregiving is however characterised by a high burden of care and decreased quality of life (QOL)^{1,2}.

The primary caregiver has significant influence on the child's occupational participation and wellbeing³, therefore it is essential that the health and well-being of the primary caregiver is maintained to manage the stressors that are associated with caring for a child with special needs. This need for support requires focused primary interventions for the primary caregiver as a client^{4,5}. In this paper, the authors describe the content, structure and mechanism of delivery of interventions offered to primary caregivers of children with ASD, with specific reference to quality of life, in the South African context.

LITERATURE REVIEW

Caregiving as an occupation embodies characteristics of being purposeful and meaningful, contextualised and requiring active

engagement⁶. Active engagement in the roles, tasks and routines of caregiving provide purpose and meaning for the primary caregiver as they achieve the goals of caregiving, develop skills, find meaning in life and connect with others⁷. Whilst the occupation of caregiving is laden with meaning and purpose, given that, the involvement of the primary caregiver is known to positively influence the health and well-being of the child with ASD^{3,7}, caregiving may be thwart with challenges such as high stress levels and burden of care in a context of stigma and poor access to resources^{4,8}. These challenges alongside the role strain placed on the primary caregiver and the tendency to neglect their own health, impact on their overall well-being and QOL^{4,9-11}.

With the increased interest in well-being and QOL as outcomes in health care, it is essential that health care professionals understand these concepts to ensure effective interventions for primary caregivers. The concept of QOL is a multi-dimensional concept that relates to the individual's perception of their life and satisfaction and is closest to the concept of health^{12,13}. In their study, Pinto et al¹⁴ reviewed the concepts of well-being and QOL across



a number of studies. The review revealed that well-being is closely related to psychological dimensions and can be understood in the context of mental health. In their paper, Felce and Perry's review¹³ of QOL studies revealed five domains of QOL, which include social well-being (relationships, social life, family life and community involvement), emotional well-being (spirituality, self-esteem, mental health management, satisfaction and fulfilment), development and activity (household activities, leisure, work, time management), physical well-being (health, personal safety, fitness and mobility) and material well-being (security, access to food, finances, housing, transport, meals, security and possessions)¹³. There is evidence demonstrating that the primary caregiver of a child has a huge influence on the child's occupational participation¹⁵. For example, the manner in which a child with ASD is cared for at home impacts on the educational, emotional and physical development of that child¹¹. Conversely, if a primary caregiver has emotional distress, poor health and/or a low level of well-being, they may present with poor caregiving skills that will inevitably impact the child's participation and development¹⁶. Moreover, vigilance noted in primary caregivers, specifically mothers, is a contributing factor for mental health issues such as anxiety, depression and stress which further lead to an impact on the QOL of the primary caregiver^{14,17,18}.

Research findings into caregiving justifies the need for the caregiver to be considered as the 'silent client'¹⁴. Alongside the burden of care and decrease in QOL of primary caregivers of children with ASD^{2,5}, these caregivers tend to neglect their own health and are subsequently in need of intervention^{9,10,11}. A review of the available literature highlights that interventions for children with ASD are usually intensive and individual in nature catering for the child's needs with secondary benefit to the primary caregiver^{19,20}. Historically, interventions for primary caregivers have been a hybrid of parent-mediated and parent support programmes. The outcomes in parent-mediated programmes are to benefit the child with ASD with the primary caregiver learning skills or techniques to affect change in the child's daily life and development²¹. Parent support programmes provide a direct benefit for the parent. In a recent scoping review of parent education and training programmes the most common programme objectives included understanding and learning strategies for communication, socialisation and managing behaviour of the child with ASD, reducing mental health concerns, parental stress and anxiety and decreasing parental isolation through the introduction of informal support between primary caregivers²². In occupational therapy and other health care disciplines, the narrative around understanding and catering for the systems around the child, including the wellbeing and health of the primary caregiver, is as important as providing for the needs of the child²³. It thus becomes imperative that the care of the primary caregiver becomes an essential component of interventions as the well-being of the primary caregiver results in better overall well-being of the child with ASD.

METHODS

Study Aim

This study aimed at describing the content, structure and mechanism of delivery of QOL interventions offered to primary caregivers of children with ASD in the South African context, through a questionnaire completed by stakeholders providing services for this population.

Study Design and Tool Development

A cross-sectional survey design was followed. An online questionnaire was constructed based on literature reviewed, and themes emanating from a scoping review on QOL interventions for primary caregivers of children with ASD²⁴. A total of 44 questions were divided into four sections namely, a) contextual information, b) content of intervention with primary caregivers of children with ASD, c) structure of intervention delivery, and d) mechanism of intervention delivery. Questions included binary response questions, intensity scales such as Likert scales, and open-ended questions. As

the snowball sampling method was used to recruit respondents, it was not guaranteed that a respondent would meet the inclusion criteria. A question on whether the respondent offered interventions to the primary caregiver of children with ASD was therefore posed to ensure that this inclusion criterion was met. A negative response automatically directed the respondent to the last section of the questionnaire.

Sampling

In the management of a child with ASD, a team approach is needed¹⁵. These teams include health care and non-health care professionals, educators and primary caregivers of children with ASD. In this study, respondents were targeted based on their experience and knowledge in the field of ASD. All respondents were individuals who provide interventions for primary caregivers of children with ASD as per the inclusion criteria for participation in the study. As the study was exploratory in nature, potential respondents were accessed via purposive snowball sampling. As an entry point, a list of potential respondents was developed by the first author. The list was inclusive of authors in the field of ASD in the country, names of presenters from specific conferences that covered ASD, two non-profit organisations, a principal from a Learners with Special Education Needs (LSEN) School, a paediatric neurologist from the department of health, a lecturer at a local university and an occupational therapist in private practice. An invitation to participate in the research with a link to the questionnaire was emailed to the entry point list inviting them to participate and to distribute to those they felt may be able to contribute.

Data management and analysis

The questionnaire was managed using an online survey management system²⁵ and was open for a period of six months. Respondents were able to email the first author with any queries. Data were extracted from the questionnaires using MS Excel. Demographic data were analysed using descriptive statistics to provide a respondent profile. Qualitative data were extracted verbatim from the open ended questions. The intervention content was analysed thematically according to the goals for intervention as identified by the respondents. Goals were placed in categories linked to similar themes of content covered in the interventions. The intervention content was further analysed through deductive reasoning using pre-coded QOL domains as outlined by Felce and Perry¹³. These domains included (1) physical well-being, (2) emotional well-being, (3) social well-being, (4) development and activity, and (5) material well-being as aforementioned. This analysis indicated which QOL domains were targeted by the various interventions. Quantitative data highlighting the structure and mechanism of delivery of interventions were analysed using MS Excel, and are described using frequencies and percentages of these variables. Tabulations and graphical representation was provided where necessary.

Ethical considerations

Full ethical approval was granted for this study from the Biomedical Research Ethics Committee of the University of KwaZulu-Natal (BE469/16). Informed consent was included in the questionnaire explaining the purpose of the study and that participation was voluntary. To maintain the confidentiality of respondents, access to the questionnaires was password protected. All data were treated as confidential as the questionnaire provided respondents with a unique respondent code. The distribution of the links for the questionnaire were unknown as snowball sampling resulted in anonymity of respondents. Anonymity was ensured as a number was assigned to each respondent.

RESULTS

The interventions that are offered to primary caregivers of children with ASD in South Africa are described according to their content, structure and mechanism of delivery. Furthermore, the content of interventions are described against QOL domains¹³.



Profile of respondents

The sample size was $n=61$. Respondents hailed from private practices ($n=23$), Department of Health facilities ($n=18$), non-profit organisations ($n=18$), Department of Education facilities ($n=14$), higher education groups/organisations ($n=6$) and a business entity ($n=1$). Thirty-eight respondents indicated that they provided interventions for primary caregivers of children with ASD. These respondents included a business entity, a researcher, a behaviour therapist, a principal of a school, educators, a speech therapist, occupational therapists, counselling psychologist, paediatric neurologist and regional development officers from a non-profit organisation. Of the remaining twenty-three questionnaires, $n=22$ were incomplete and $n=1$ being invalid for analysis as it was completed by a respondent who did not provide services to primary caregivers of children with ASD.

Profile of the primary caregivers of children with ASD receiving intervention as indicated by respondents

Interventions were provided to biological mothers ($n=36$), biological fathers ($n=33$), grandparents ($n=26$), extended family members ($n=18$), step parents ($n=16$), adoptive parents ($n=14$) and siblings ($n=14$). The age of the children with ASD to whom services were rendered by the respondents ranged between 3-4 years ($n=26$), 5-6 years ($n=31$), 7-9 years ($n=33$), and 10-13 years ($n=18$).

Profile of the teams involved in providing interventions for the primary caregivers of children with ASD

In the questionnaire, respondents were asked whether they worked in a team or independently. The results indicated that multidisciplinary teams (MDT), ranging from two to four members, were involved in the provision of interventions for primary caregivers of children with ASD. Furthermore the questionnaire required the respondents to identify the professions represented in their teams as well as the responsibilities within their specific context. The types of professionals and specific responsibilities were extracted from the data to provide an overview of the team structures as presented by this sample. *Table 1* below provides an outline of the various professionals and responsibilities of each within the teams represented as highlighted by the respondents in this study.

Table 1: Responsibilities of the MDT involved in primary caregiver interventions

Team member	Responsibilities
Medical practitioner	Prescription of medication, referral to other MDT, health maintenance.
Psychiatrist	Prescription of medication, assessment of child with ASD.
Psychologist	Assessment and therapy, family support and guidance, mental health management of the primary caregiver, behaviour management, counselling, parenting skills, stress management, coping strategies, psychological needs of the primary caregiver and child with ASD.
Occupational Therapist	Primary caregiver training, teaching new skills, provision of home programmes, training in activities of daily living, behavior management, social interaction, gross motor intervention, fine motor skills, visual perception, concentration, assessment in developmental delays, development of play, block therapy, dealing with sensory difficulties, toilet training.
Speech Therapist	Communication and use of AAC, training of staff in the use of communication systems, education of primary caregivers, social skills intervention, developing expressive and receptive language skills, feeding.
Physiotherapist	Physical development, fitness, physical exercises.
Social Worker	Screening, referral to non-governmental organisations, school placement, counsellor, mediator, parental support, grants, social needs management, resource assistance, housing, family relations.
Educator	Teaching literacy and numeracy, classroom support.
Headmistress	Support system for primary caregivers, staff training to improve interactions with and support for the primary caregiver.
Facilitators/au pair/tutor	Overseeing afternoon activities (homework and therapy programmes), providing support for the child with ASD and teacher in the classroom, and assisting with specific school subjects, building confidence in the child with ASD.

Intervention Content

Respondents were asked to outline the intervention content in the programmes they offered to primary caregivers in the form of goals of intervention. Through thematic analysis, three goals were extracted from the data. *Goals towards awareness about ASD* included education and creating awareness about the diagnosis of ASD, provision of resources, and modifications to the home environment. *Intervention goals beneficial for the child with ASD* included teaching the primary caregiver skills and strategies to help their child reach independence in activities of daily living, communication, socialisation and play; how to engage meaningfully with their child at home for optimal development in sensory, play, gross motor and fine motor development; providing knowledge on keeping a safe home environment for the child and provide skills to manage behavioural difficulties with the child with ASD. *Intervention goals beneficial for the primary caregiver* included provision of stress management skills, developing relationships with other primary caregivers in order to provide ongoing support and a means to assist them in accepting the diagnosis of ASD; providing opportunities to network with other primary caregivers of children with ASD; empower and enable primary caregivers to become advocates for their child with ASD to help them reach their full potential, provide support and hope for primary caregivers and families of children with ASD.

The three intervention topics namely *awareness of ASD*, *intervention beneficial for the child with ASD* and *intervention beneficial for the primary caregiver* are outlined in *Table II* (pages 44/45) according to the mechanism of delivery/activity used in the interventions, specific topics covered and QOL domains targeted in the interventions.

The *development and activity* QOL domain featured prominently in the interventions provided. The *emotional and social wellbeing* domains were evident when the intervention provided for the primary caregiver directly thereby catering for their needs and challenges in raising a child with ASD. These three QOL domains are further illustrated in *Figure 1* (page 46.) showing the sub-categories of the five QOL domains. Household activities ($n=20$) and time management ($n=17$) under the *development and activity* domain of QOL were examples that were covered in the interventions. Under the *social wellbeing* QOL domain, relationships ($n=28$) and social life ($n=25$) were most prominently catered for in interventions. Self-esteem ($n=20$) and stress management ($n=18$) under the *emotional wellbeing* QOL domain were most frequently catered for in the interventions for primary caregivers. The QOL domains of physical and material



Table II: Mechanism of delivery, intervention topics and quality of life (QOL) domains¹³ targeted in interventions

Mechanism of delivery/activity	Topics covered	Quality of life (QOL) Domains				
		Emotional wellbeing	Material wellbeing	Development & Activity	Social wellbeing	Physical wellbeing
AWARENESS OF ASD						
Handouts/pamphlets	All ASD related topics					
Electronic/social media e.g. Emailing and Facebook	Any ASD related questions are answered and explored					
Counselling and verbal feedback	Information on ASD, Home programme, Emotional support	X				
Support Groups/ Training	Dealing with diagnosis, What is ASD? Social grants, School placement, Role of OT, Dealing with ASD issues (sensory, feeding, independence skills, transition to adulthood, behaviour, communication)		X	X		
INTERVENTION FOR THE CHILD WITH ASD						
Handouts/pamphlets	Behaviour modification & Toilet training			X		
Electronic/social media e.g. emailing and Messenger	All ASD related topics and Therapy goals					
Counselling, verbal feedback and parent meetings	Educating about diagnosis, Toilet training, Alternate forms of communication, Sensory concerns, Schooling options, Behavioural management, ADL training, Discussions about child's progress and wellbeing, Dealing with acceptance, Home screening test & Therapy options	X		X		
Home visit coaching	Use adult-learning principles to coach parents to use a variety of transactional supports to promote active engagement in their toddler during usual home activities			X		
Au pair/facilitators	Child-care, School and educational support, Supporting development, academics and minimising school stressors	X		X	X	
Individual treatment of the child with ASD including block therapy	Toilet independence & Activities of daily living (ADL) goals, Play goals, Sensory strategies & behaviour management, attention/communication & developmental stimulation, ADLs & Routine and Structure			X		
Education of the child with ASD	Literacy, Numeracy & School placement			X		
Workshops	All ASD related topics					
Parent education and training evenings	Play, Screen time, Fundraising & Social stories			X	X	



Table II continued from page 44

Mechanism of delivery/activity	Topics covered	Quality of life (QOL) Domains				
		Emotional wellbeing	Material wellbeing	Development & Activity	Social wellbeing	Physical wellbeing
INTERVENTION FOR THE PRIMARY CAREGIVER						
Electronic/social media e.g. WhatsApp groups and Messenger chats	"How to not go crazy"; "What to do with a meltdown" "How to cope as a brother or sister of a ASD" Follow up questions and support given	X		X		
Informal Discussions/daily chats with primary caregivers	General needs, Progress of the day, "How are things going at home?" "How can we support you?"	X				
Initial Contact mostly telephonic	Set up a face to face meeting and ask for a list of 'worries'	X				
Family support	How to cope with your child with ASD, Family outings and holidays: to dos and what not to do			X	X	
Workshops to Schools and centres and support staff	Assistance to family/extended family/support staff and schools, Physical needs of the primary caregiver through exercise				X	X
Referral to psychologist	Therapeutic intervention for the primary caregiver	X				
Outing	Parents and learners socialise with the teachers				X	
Progress notes	Celebrations of goals achieved, Red flags discussed, Education on strategies to use at home with accompanying resources	X		X		
Parent feedback meetings	Review of strategies being used at home and education on alternative strategies, Providing resources			X		
Discussion group	Issues causing anxiety and positives that have to be valued and acknowledged, "A Daddy evening" "A Mommy evening" "Let's talk about..." , Communication (speech therapist as speaker) & Physical activities (physiotherapist as speaker)	X			X	X

wellbeing as defined by Felce and Perry¹³ featured less in the interventions for primary caregivers.

Intervention structure and mechanism of delivery

In this study, structure and mechanism of delivery refers to how an intervention is presented, what resources are offered as well as the format of the intervention. Format relates to how the intervention is set out and arranged. Individual sessions appeared to be the most frequently used format to deliver intervention for the primary caregiver (n=29). Of these, the frequency of intervention on an individual basis were noted as follows: 'as the need arose' (n=10); 'weekly' (n=7); 'monthly' (n=6); 'fortnightly' (n=3) and 'daily' (n=3). The respondents chose the option of 'as the need arises' more frequently to describe how often a certain type of format was used. For example the following formats 'in a therapy group' (n=6), 'in a support group' (n=11), 'telephonic conversation' (n=17), 'via email' (n=11), 'via sms' (n=12), 'pamphlets' (n=16) and 'awareness days' (n=15) were chosen by respondents as an appropriate format 'as the need arose'.

The three most commonly used methods of delivery included verbal presentations (n=23), reading from handouts (n=16) and group discussions (n=12). Techniques used during interventions included face-to-face contact (n=21), discussions (n=21) and reflection (n=13). Twenty-one respondents provided handouts to primary caregivers as a resource. The most popular social media used to communicate with primary caregivers was WhatsApp (n=24) and Facebook (n=20).

Further elements explored in the format of interventions included the frequency (contact sessions), duration (length of total intervention offered) and contact duration (per session) which are illustrated in Table III (page 46). Eight respondents had fortnightly contact with primary caregivers during their intervention, four respondents' interventions lasted for 12 weeks and ten respondents indicated duration of contact as 60 minutes.

DISCUSSION

Caregiving can be a stressful occupation for primary caregivers of children with ASD. However, there is evidence to support the notion that primary caregivers can have a positive influence on the occupational participation of a child with ASD⁹. Within health care, the narrative around understanding the wellbeing and health of the primary caregiver, is as important as providing for the needs of the child^{2,8}.

In this paper, the authors described the quality of life interventions for primary caregivers of children with ASD within the SA context. Traditionally, the focus of ASD interventions has been on the child, with the primary caregiver's health, wellbeing and QOL being secondary or completely overlooked as part of the holistic management of the child^{9,10,11,21}.

It is evident from the results that the respondents in this study provided interventions beyond the traditional interventions as stated above and have included the primary caregiver in the holistic management (including QOL) of the child with ASD.



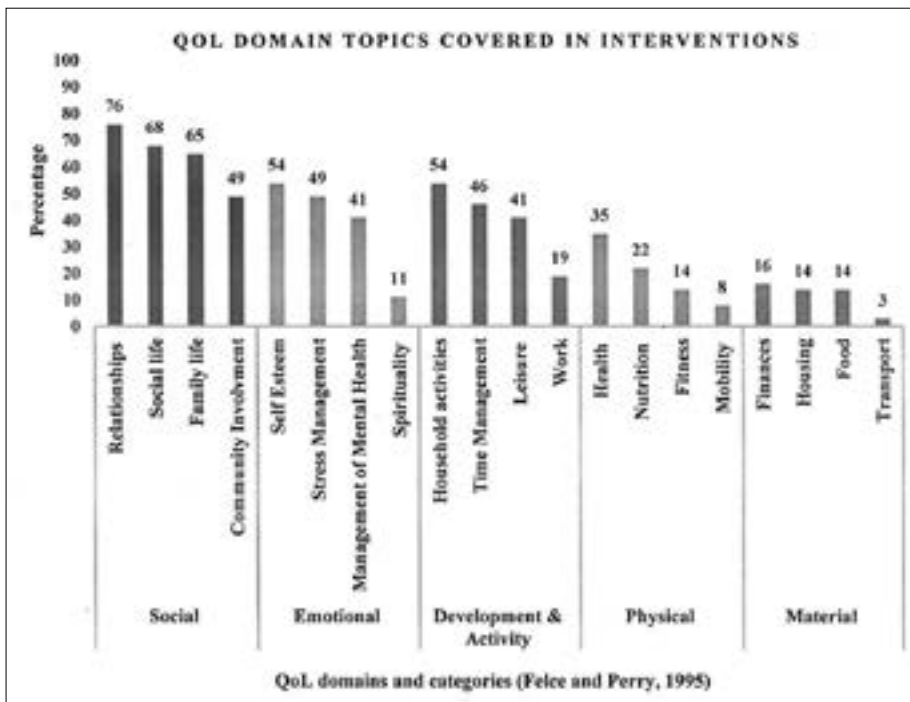


Figure 1: Quality of Life domains¹³ covered in the interventions for primary caregivers

Interventions described in this study were provided for the extended family. They were geared primarily towards the biological mothers and fathers, although a large percentage of respondents provided interventions for grandparents, extended family members and siblings. The nature of ASD compels family members to step in

Table III: Frequency, duration and length of contact of interventions provided to primary caregivers of children with ASD

		NUMBER (%)
FREQUENCY OF CONTACT	Daily	6 (24%)
	Weekly	7 (28%)
	Fortnightly	8 (32%)
	Monthly	4 (16%)
	3-Monthly	2 (8%)
	6-Monthly	1 (4%)
	As required	7 (28%)
	Once off	3 (12%)
DURATION OF INTERVENTION	12 weeks	4 (16%)
	12 months	5 (20%)
	Fortnightly for 3 months	3 (12%)
	3 hours once a week	3 (12%)
	Once off	4 (16%)
	As required	17 (68%)
LENGTH OF CONTACT	15-20 minutes	7 (28%)
	30-45 minutes	7 (28%)
	60 minutes (1 hour)	10 (40%)
	90 minutes (1.5 hours)	3 (12%)
	2-4 hours	9 (36%)
	1 day	1 (4%)
	2 days	1 (4%)
	As required	5 (20%)

to share the burden of care with the biological mothers and fathers, often becoming the primary caregiver themselves, depending on the parents' work responsibilities and ability to cope^{26,27}. Studies confirm the need to provide interventions for the entire family due to the pervasive effects and burden of ASD on the family resulting in an overall decrease in family wellbeing^{28,29}.

Multidisciplinary teams were responsible for providing interventions to primary caregivers in this study as opposed to input from one professional source. Children with ASD have special health needs, therefore requiring specialised attention and care³⁰. Primary caregivers also require this type of care. The educational, medical, allied health, and social work professionals provide specialised interventions for the primary caregiver, as indicated in this study, which appears to be in keeping with international studies presenting the need for this team profile^{22,30}.

The interventions offered to primary caregivers of children with ASD within SA seem to be in keeping with international standards as noted in a scoping review conducted by the authors²⁴. Awareness of

ASD was a theme extracted from the intervention content which included education about the diagnosis and resources about the condition. Education and awareness provides an essential guideline for management of the child with ASD as the primary caregiver deals with the daunting process of diagnosis^{31,32} is well known that delayed diagnosis and poor understanding complicates and delays the management of the child with ASD³³. Educating the primary caregiver at this point is vital, as the child with ASD requires early intervention for optimal functional outcomes³⁴.

Interventions to benefit the child with ASD included content that focussed on providing the primary caregiver with skills to manage the child with ASD in relation to activities of daily living, fostering development in communication, play and education, and teaching the primary caregiver strategies to manage the child's behaviour. The typical presentation of a child with ASD includes deficits in reciprocal social interaction alongside impaired communication with resisted, repetitive and stereotypical movements and behaviour²⁹. This presentation in the child with ASD dictates the areas that require intervention directly with the child with ASD and the nature of skills required by the primary caregiver. The aspects of communication, behaviour and social engagement are needed to function effectively in areas of occupation hence the focus of intervention for the child with ASD was noted in the literature review.

The results obtained in this study regarding interventions for the primary caregiver were closely linked to the child with ASD with little focus on the direct needs of the primary caregiver. A child's diagnosis of ASD has an impact on the family therefore it becomes difficult to separate the child's intervention from the intervention provided to the primary caregiver³⁵. The primary caregiver's psychological well-being is vulnerable resulting in a risk of developing mental illness as they juggle all the demands of caregiving amidst other roles. Caregiving may be seen as imposed upon the parent who often sacrifices their occupational choices for the benefit of their child with ASD and/or family⁴. Primary caregivers who possess good health and have a sense of wellbeing may provide more optimal parenting that affords the child with ASD a better opportunity to reach their full potential through occupational participation³⁶.

Primary caregivers cope over time and their needs in relation to their child with ASD fluctuate depending on the child's developmental stage. These needs may taper off as the child gets older³⁷. Regardless of the child's stage of development the primary caregiver is an integral part of the child's life; therefore their health, well-being



and QOL needs to be overtly recognised and addressed in practice. Despite the recognition that the primary caregiver is key to the care of the child with ASD, it is noted from this study that the focus of intervention is mostly to benefit the child. Besides the inclusion of child related interventions, the needs of primary caregivers should also be understood in order to receive the relevant support for a better QOL.

The QOL domains targeted in the interventions for primary caregivers in this study were development and activity, social well-being and emotional well-being. The domain of development and activity is concerned with the acquisition of skill in order to achieve competence or independence in activities such as work, leisure, housework and education¹³. The focus on occupational participation, attainment of skill and fostering independence in a range of activities within the interventions provided for primary caregivers may account for the propensity of this domain.

In the context of the child with ASD, social and emotional well-being relates well to the presentation of ASD. Social support is a mediating factor in the psychological well-being of the primary caregiver of a child with ASD in that if social support is absent the mental health of the primary caregiver declines^{36,38}. Moreover, participation in social activities provides an important coping strategy in mothers of children with ASD³⁹. Within this study social well-being was addressed by providing intervention to improve relationships, social life and family life which is related to the stressors expressed by primary caregivers such as difficulties with family members, stigma and managing their daily lives with the child with ASD^{15,16}. Self-esteem was the aspect that most respondents targeted in the domain of emotional well-being within their interventions with primary caregivers. This links well with the literature that states that primary caregivers lack confidence in their efficiency as caregivers³⁸. Gaps noted in the interventions provided in this study within the domain of emotional well-being were stress management and management of mental health. These two aspects need to be explicit outcomes within an intervention for primary caregivers as there is evidence that primary caregivers report high levels of stress and mental health difficulties^{2,5}.

The QOL domains of physical and material wellbeing were less evident in the interventions. Evidence has shown that physical activity and fitness, noted in the physical wellbeing QOL domain, has a positive impact on emotional wellbeing⁴⁰. Material wellbeing should be considered especially given the financial strain and burden primary caregivers struggle with daily in raising a child with ASD⁴¹. The definition of health according to The World Health Organization (WHO) is that it is a state of complete physical, mental and social wellbeing and not merely the absence of disease⁴². Therefore it is important to consider the inclusion of all the QOL domains within interventions in an attempt to improve the health and wellbeing of primary caregivers.

LIMITATIONS OF THE STUDY AND FUTURE RECOMMENDATIONS

The limitation of this study was that data were accessed from respondents who provided interventions for primary caregivers of children with ASD and not from the primary caregivers who received interventions. There is also sampling bias given the sampling strategy used in this study. Given the limited knowledge about interventions offered to primary caregivers in SA, research exploring the perceptions of primary caregivers in relation to services they received would be valuable in the future.

CONCLUSION

This paper described the interventions provided to primary caregivers of children with ASD from a cross-sectional survey of service providers in South Africa. The interventions appear to primarily cater for the needs of the child, with gaps in catering directly for the needs of the primary caregiver. Given that the mental health and well-being of a primary caregiver is essential for the child with

ASD in developing and achieving their optimal potential, interventions targeting the social, emotional and health needs of the primary caregiver need to be overt with specific outcomes towards improved QOL for these primary caregivers. The paper provides a point of departure from which interventions for primary caregivers of children with ASD may be planned and implemented towards improving their overall QOL needs.

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AUTHOR CONTRIBUTIONS

DL Fewster. Primary researcher as PhD candidate. Tool development, recruitment of participants, data collection and analysis, write up of the article.

Assoc. Prof. Uys Supervisor in PhD project and practical input in design of the questionnaire, review and contribution to the article writing.

Assoc. Prof. Govender Supervisor in PhD project and practical input in concept development, research design, review of the article and writing assistance.

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