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Review Article

Quality of life interventions for primary caregivers of children with autism spectrum disorder: a scoping review

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Background: Raising a child with autism spectrum disorder is associated with high levels of stress. Primary caregivers are a group at risk of mental illness and reduced quality of life. Although interventions for the child with autism spectrum disorder exist, there are few or no interventions focusing on the physical, emotional and psychological needs of the primary caregivers.

Objectives: The aim of this scoping review paper was to identify and describe quality of life interventions offered to primary caregivers of children with autism spectrum disorder. The content, structure, and mechanism of delivery of these interventions, including their contribution to improving the quality of life of these caregivers, are discussed.

Method: A scoping review protocol and methodology was developed and implemented according to a five-step process; namely, identification of the research question including the PICo, identification of suitable studies using selected search strings, selection of studies using PRISMA guidelines, charting of the results, and collation and summarising of the information. Reviewers were active at various stages to maintain the rigour of the study. Twenty one studies were reviewed and eligible for analysis.

Results: The content and trends in structure and mechanism of delivery are described. Three themes emanated from the interventions' content. The studies were analysed according to quality of life domains addressed in the interventions.

Conclusion: The scoping review highlights current practices informing interventions for primary caregivers of children with autism spectrum disorder and may serve as a guide by practitioners and researchers for developing future evidence-based interventions for this population.

Introduction

Raising a child diagnosed with autism spectrum disorder (ASD) places strain on the family unit, specifically on primary caregivers (PCG) (Giovagnoli et al., 2015). Interventions are often primarily developed to cater for the needs of the child with ASD (CASD) and benefits to the parents are usually secondary (Cohn, 2001; Moosa, 2013). Primary caregivers of CASD need to be recognised as individuals requiring support since they often feel unheard and are, at times, frustrated in catering for their children's needs. Caring for the CASD is often followed by the neglect of the PCG's own physical, emotional, and psychological needs (Baker-Ericzen, Brookman-Freeze, & Stahmer, 2005; Dardas & Ahmad, 2014).

Mothers of CASD generally face the greatest burden of care as they take on the primary responsibility to care for the child (Boyd, 2002; Ludlow, Skelly, & Rohleder, 2012) resulting in increased mental strain leading to the risk of depression and anxiety. Studies that measured stress and psychological well-being in mothers of CASD found that behavioural difficulties in the child increased the stress levels in mothers (Lecavalier, Leone, & Wiltz, 2006). Furthermore, psychological

well-being was affected by challenging behaviours and managing family relationships (Lewis et al., 2006). Regardless of the natural or expected nurturing role of the mother, there are some studies that have considered the effects of ASD on both parents. Yet, a limited understanding about the role of the father remains (Martins, Walker, & Fouche, 2013; Potter, 2017). The needs and psychological well-being of fathers of CASD are poorly understood (Hartley et al., 2012). Studies that include both parents of CASD indicated a poorer response rate (Benson, 2006; Lecavalier et al., 2006) and a higher attrition rate from fathers. This negatively impacts on the awareness around the needs of fathers (Norlin & Broberg, 2013). However, a study in the United States measuring the psychological well-being, pessimism, and coping of 135 fathers of adolescents and young adults with ASD as compared to other developmental disabilities revealed that the fathers of CASD had higher levels of depressive symptoms (Hartley et al., 2012). To this end, mothers and fathers as PCG of CASD are vulnerable to mental illness and increased levels of stress.

The psychological impact and stress that parents of CASD experience inevitably impact on their quality of life (Dardas & Ahmad, 2014; Lee, Harrington, Louie, & Newschaffer, 2008). Quality of life (QOL) is a multidimensional concept that includes subjective evaluations of positive and negative aspects of life (CDC, 2016). As QOL is of interest in the fields of health and social sciences, numerous research studies (Shek & Lee, 2007) have been undertaken to investigate and understand this construct. A systematic review including 21 articles on QOL of parents of CASD concluded that parental QOL was negatively impacted by raising a CASD, however the factors contributing to this decline in QOL were unclear (Eapen & Guan, 2016). Similarly, a study with 224 parents of CASD investigating parental health-related quality of life (HRQOL) revealed an increase in clinical depression symptoms, higher caregiver burden, and less happiness as reported by parents (Kuhlthau et al., 2014). In South Africa (SA), a study was conducted with 180 families to determine the correlation between family routine, cognitive appraisal, and family QOL (Schlebusch, Samuels, & Dada, 2017). The study revealed higher satisfaction in family QOL with the implementation of structured family routines, while families were least satisfied with their emotional well-being (Schlebusch et al., 2017). This overview of QOL literature indicates a relationship between the increased stress and emotional strain of raising a CASD with the reduction of QOL of the PCG.

Interventions for PCG aimed at preventing mental illness and improving well-being are limited. This was noted in a recent scoping review which aimed to identify and summarise all peer-reviewed publications on ASD in Sub Saharan Africa (SSA) (Franz, Chambers, von Isenburg, & de Vries, 2017). Data from 53 articles were extracted. Twenty-eight of these articles were South African (SA) studies. Only one of the nine studies provided an intervention for PCG in the form of parental coaching. Positive changes were noted in the skills of the mother and adolescent CASD (Pansegrouw & Alant, 1996).

To further understand the needs of PCG of CASD and the current literature available in this area, the authors present the findings of a scoping review of interventions for PCG of CASD with a focus on quality of life.

Methods

Scoping reviews assist with reviewing, assessing, and reporting on evidence in a less extensively reviewed research area in order to identify research gaps and inform practice (Khalil et al., 2016). A scoping review was deemed necessary by the authors when an initial literature search yielded little evidence on interventions for PCG of CASD. The scoping review protocol was developed and reviewed by a Biomedical Research Ethics Committee (UKZN) which is registered with the South African Department of Health's National Health Research Ethics Council (ethics number: BE469/16). Based on a five-step methodological framework proposed by Arksey & O'Malley (2005), the following processes were followed.

Step 1: Identifying the research question

An iterative process was followed in refining the research question, given that the scope of literature was unknown. As familiarity with the literature was gained, the scoping review question and search

terms were further refined with additional limits. The final research question was formulated using the population, interest, and context (PICO) framework.

PICO

The PICO framework is used to identify the Population, Interest, and Context to develop the research question and search strategy (Stern, Jordan, & McArthur, 2014). The population was identified as the PCG of children with ASD aged five to nine years old. In this review, PCG refers to the individual or individuals who care for the CASD. PCG is used as a term to include the biological parent, foster or adoptive parents, grandparents, step-parents, elder siblings or other adults who may provide care to the child (Moran, Ghate, & van der Merwe, 2004). The choice of the developmental age range of five to nine years old was stipulated given that a formal diagnosis of ASD would have been established. At this stage of the child's development, the PCG may require the greatest support as opposed to PCG of older children who develop strategies that assist them in daily life and cope better over time (Gray, 2006; Dardas & Muayyand, 2014).

The interest in the PICO was to identify and describe services and programmes that were specifically geared towards PCG of CASD particularly targeted towards the improvement of their QOL. The focus was on the content, structure, and mechanism of delivery (MOD) of these interventions.

Lastly, the context included the identification of global interventions limited to programmes for PCG of CASD (Stern et al., 2014). The research question for the scoping review was formulated as: "What interventions, in relation to content, structure, and MOD are provided for PCG of CASD aged five to nine years old in order to improve QOL of PCG?"

Step 2: Identifying relevant studies

The search term autism* OR autism spectrum disorder* was used according to the revised Diagnostic and Statistical Manual of Mental Disorders 5th Edition (DSM-5). Use of the revised term allowed for the latest and most relevant literature to be accessed. Intervention* OR services* AND primary caregiver* OR parent* AND quality of life* OR well-being* OR wellness* were keywords used separately with child* OR children* AND autism* OR autism spectrum disorder*.

These search terms were placed in four databases; namely, EBSCOHOST, WorldCat libraries, JANE (Journal Author Name Estimator), and Google Scholar. Grey literature was limited to online sources only. There were no exclusions of studies based on year of study. However, the change of terms in the DSM-5 as noted previously would have excluded studies addressing intervention with Asperger's or Pervasive Developmental Disorders. Only studies written in English were included.

Step 3: Study selection

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) format was used to guide the selection procedure by two reviewers (Moher et al., 2009). As indicated in Figure 1, the literature search yielded 343 potential studies. Three duplicates were found with 340 articles eligible for screening by review of the title and abstracts. A further 242 articles were excluded as the title and abstract did not meet the criteria of providing an intervention for PCG. The remaining 98 full texts were reviewed by the first author with a further 58 articles being excluded. These exclusions were based on interventions that did not clearly demonstrate direct therapeutic benefit for the PCG and without consideration of their needs. The remaining 40 articles were reviewed by three reviewers (authors of this paper) who further excluded articles based on the level of evidence within the study and age-group of the children as per the selection criteria. Opinion reports, narrative reviews, and unpublished programmes were excluded. Twenty-one ($n = 21$) articles were included in the final review.

Step 4: Charting the data

"Charting" describes a technique for synthesising and interpreting qualitative data by sifting and sorting material according to key issues and themes (Ritchie & Spencer, 1994). Three reviewers were active in steps III and IV to ensure rigor in the searching, screening, and inclusion process

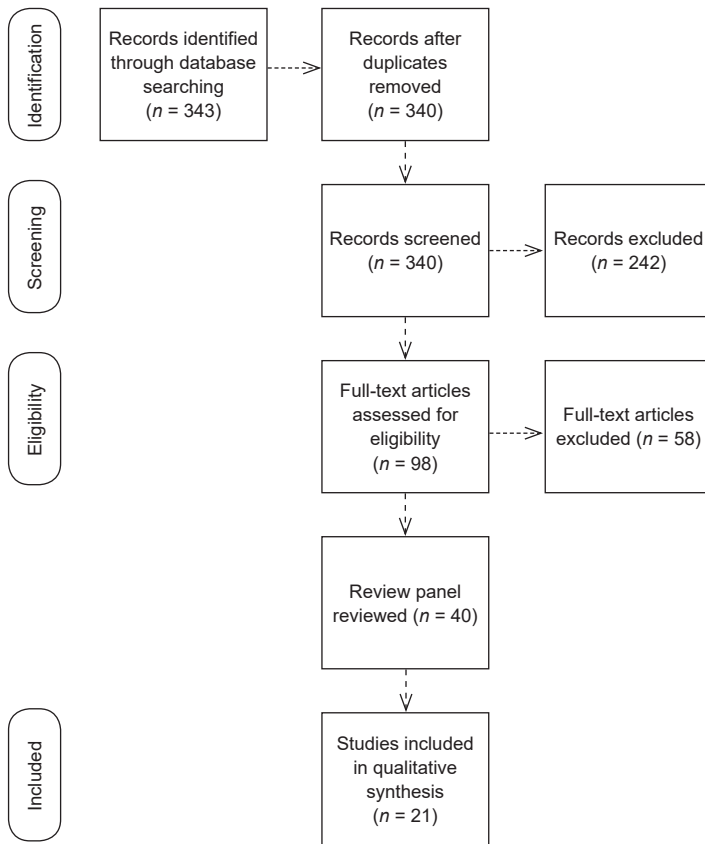


Figure 1: PRISMA format for selection of studies

and later in the charting of the data. The concept of care co-ordination was used as a framework to understand interventions. Following an in-depth analysis of care co-ordination theoretical frameworks, Van Houdt and colleagues (2015) identified 14 key concepts across twelve theoretical frameworks. Key concepts included “external factors”, “cultural factors”, “need for coordination”, “exchange of information”, “(inter)organisational outcome”, “quality of relationship”, “patient outcome”, “team outcome”, “structure”, “tasks characteristics”, “goals”, “administrative operational processes”, “knowledge and technology”, and “roles”. The last six concepts were chosen by the three reviewers as the explanations of the concepts linked well with the research question and the aim of the study. Through discussion and consensus the reviewers created two overarching pragmatic headings to describe the interventions namely “structure” and “MOD”. The elements of “structure” include intervention approaches, intervention facilitation, and timeframes of the interventions which were drawn from the key concepts of “structure”, “goals” and “roles”. The MOD represents the presentation format, the techniques used, and materials provided to the PCG which were drawn from the key concepts of “task characteristics”, “administrative operational processes” and “knowledge and technology”.

The reviewers used the research question and previously mentioned concepts to develop a matrix. The matrix included selected studies’ characteristics, thematic content of the interventions, trends in MOD, and QOL domains targeted in the interventions. The reviewers independently charted the data for the included studies according to the matrix prior to discussion and consensus.

Step 5: Collating, summarising, and reporting the results

The last step in the methodological framework (Arksey & O'Malley, 2005) includes reporting of results which is presented in the ensuing section of this paper.

Results

Characteristics of the studies

The 21 articles included in the review were published between 2005 and 2016. The studies emanated from United States of America ($n = 11$), Asia ($n = 5$), Europe ($n = 4$), and Australia ($n = 1$). Ten studies included both mothers and fathers. Various levels of evidence were reported, including randomised control trials (RCT) ($n = 5$), pre-test/post-test ($n = 3$), mixed methods ($n = 3$), qualitative ($n = 3$), quasi-experimental ($n = 3$), non-randomised control ($n = 1$), pre-post single group ($n = 1$), observational within-group ($n = 1$), and pre-post crossover ($n = 1$). Table 1 presents the characteristics of the 21 studies.

Content of intervention

The content of the interventions provided for the PCG were thematically analysed with clear themes emerging across the selected studies. These are illustrated in Figure 2.

The intervention content noted in the studies is further represented in Table 2 which presents the intervention name, purpose of the study, purpose of the intervention, and an outline of the intervention. The emergent themes, as noted in Figure 2, are reflected under each intervention in Table 3.

Structure and mechanism of delivery

Eleven studies specified the approach that was used in the intervention for PCG. The most commonly used approach was group-work, followed by collaboration with the family. Seven interventions used a combination of approaches. Three studies based their interventions on theoretical frameworks; namely the Model of Family Stress (McCubbin, 1993), the Family Partnership Model (Davis & Day, 2010), and the Ecological Validity Framework (Bernal, Jimenez-Chafey, & Rodriguez, 2009).

Table 1: Characteristics of the included studies in chronological order ($n = 21$)

Year	Author/s	Research design	Country	Sample
2016	Dababnah & Parish	Mixed methods	USA	17
2016	Stuttard et al.	Non-randomised control	USA	35
2015	Ingersole & Berger	Randomised control trial	USA	27
2015	Magana, Lopez and Machalicek	Mixed methods	USA	19
2015	Noiinomi et al.	Pre-test and post-test	Japan	24
2014	Ji, Sun, Yi & Tang	Quasi-experimental	China	42
2014	McAleese et al.	Mixed methods	Northern Ireland	83
2014	Preece	Quasi-experimental	United Kingdom	11
2014	Rivard et al.	Qualitative	USA	176
2014	Shrivastav	Pre-post single group	India	25
2014	Whitney & Smith	Randomised control trial	USA	120
2013	Al-Khalaf et al.	Qualitative	Jordan	20
2013	Chiang	Pre-test and post-test	USA	9
2013	Feinberg et al.	Randomised control trial	USA	59
2013	Poslawsky et al.	Randomised control trial	Netherlands	77
2013	Weiss et al.	Pre-test and post-test	Canada	35
2012	Samadi, McConkey & Kelly	Pre-post crossover	Iran	37
2011	Probst & Glen	Observational within-group	Germany	24
2010	Mulligan et al	Qualitative	Canada	13
2009	Keen, Couzens, Muspratt, & Rodger	Quasi-experimental	Australia	39
2005	Giarelli, Souders, Pinto-Martin, Bloch, & Levy	Randomised control trial	USA	31

<p style="text-align: center;">LEARNING ABOUT ASD</p> <ul style="list-style-type: none"> • Diagnosis • Communication • Safety • Sensory difficulties • Barriers experienced with ASD 	<p style="text-align: center;">INTERVENTIONS SPECIFIC TO THE CASD</p> <p>Getting help with treatment for my child</p> <ul style="list-style-type: none"> • Assessment • Treatment plan • Assistance in implementing treatment plan • Review of child's progress <p>Getting the 'know how' to care for my child</p> <ul style="list-style-type: none"> • Social skills • Play skills • Academic skills • Functional skills • Sleeping 	<p style="text-align: center;">INTERVENTIONS SPECIFICALLY FOR THE PCG</p> <p>Getting the support I need</p> <ul style="list-style-type: none"> • Psychological • Informal • Networking with other PCG • Coaching • Provision of resources <p>Getting the 'know how' to care for my child</p> <ul style="list-style-type: none"> • Social skills • Play skills • Academic skills • Functional skills • Sleeping
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Figure 2: Representation of themes of content emerging from the interventions

Almost half of the studies ($n = 10$) did not specify the qualifications or specialisations of those providing intervention for the PCG. However, six indicated that health care professionals with specialisation in the field of ASD facilitated the intervention. Over half ($n = 11$) of the interventions required facilitation from persons with experience in ASD.

There was variability in the included studies that stipulated timeframes ($n = 15$). Most studies indicated a 12-week timeframe for the intervention provided to the PCG. All except for one study indicated a once a week meeting during the course of the intervention. Poslawsky and colleagues (2013), Feinberg and colleagues (2013), and Samadi, McConkey, and Kelly (2012), implemented interventions for five, six, and seven sessions respectively. However, frequency and duration of these sessions were not specified. Frequency is the amount of contact within a given period (for example, once a week) and duration is the length of that contact (for example a 30 minute session). In Keen and colleagues' (2009) study, participants engaged in a two-day workshop followed by ten home visits or self-directed sessions over a period of six weeks. Rivard and colleagues (2014) indicated that their intervention included regular meetings. Giarelli and colleagues (2005) provided contact with participants at one week and three months post diagnosis.

The mechanism of the delivery of interventions describes the manner in which the content of the programme was presented to the participants. This included techniques, presentation method, and materials used in the intervention. The findings are tabulated in Table 4.

Quality of life domains targeted in interventions

Felce and Perry (1995) outlined five QOL domains after reviewing fifteen QOL studies. These domains (namely, "physical well-being", "emotional well-being", "material well-being", "social well-being" and "development and activity") included further subcategories (Felce & Perry, 1995). A few studies linked their interventions to general QOL. However, the reviewers classified the studies according to the QOL domains outlined by Felce and Perry's (1995). Table 5 presents the QOL domains covered in the studies. The majority of the studies addressed development and activity and emotional well-being in their interventions. The domains less likely to be addressed or not addressed in the interventions were social, physical, and material well-being.

Table 2: Details of interventions including purpose and outline

Year	Author/s	Intervention name	Purpose of study and/or intervention	Intervention outline
2016	Dababnah & Parish	The Incredible Years (IY)	The Incredible Years is a play-based, skill-building intervention programme. IY was initially developed to target typically developing children with severe behavioural problems and their parents, but it has since been used as a prevention as well as treatment programme with populations at risk of challenging behaviours. The purpose of the study was to test the feasibility of IY with parents of young children with ASD. The goal was to assess the implementation processes and acceptability. A pre-post design was used with no control group in order to collect parent stress outcomes and acceptability data.	Four modules which focus on: (i) Child-directed play, (ii) Praise and incentives, (iii) Household routines, and (iv) Positive discipline. A group-based intervention intended to strengthen parent-child relationships, encourage positive discipline practices, develop children's social and emotional skills, expand parents' support networks and communication skills, and improve parent mental health.
2016	Stuttard et al.	Cygnnet Parenting intervention	Barnardo's Cygnnet programme is a six-session programme for parents of children aged 5–17 with a diagnosis of autism. The structure and approach of Cygnnet is based on the Family Partnership Model (Davis & Day, 2010). This model advocates a collaborative approach to working with families in order to develop parental self-efficacy and identify effective and realistic problem management strategies. This is achieved where professionals seek to combine their and parents' expertise. The purpose of this study was to: (1) compare parental outcomes for parents who attended the Cygnnet programme in areas where it was routinely offered in relation to parents who were on a waiting list to attend the programme, (2) explore the parents' perceptions of the programme's acceptability using parent attendance as an indicator and (3) provide preliminary data on the costs of delivering the intervention.	The aim of the Cygnnet parenting programme is to: (i) Increase parents' understanding of ASD, (ii) Develop parents' knowledge of how a child with autism experiences the world and what motivates their behaviour, (iii) Guide parents in how to manage and support their child's communication, play and behaviour through practical strategies, (iv) Direct parents to relevant ASD specific resources, and (v) Provide parents with opportunities to meet with other parents thereby sharing similar experiences, gaining support and learning from each other.
2015	Ingersole & Berger	Telehealth-based Parent-mediated intervention programme	ImPACT Online is a telehealth-based parent-mediated intervention for CASD adapted from Project ImPACT. Project ImPACT is a naturalistic, developmental-behavioural, parent-mediated intervention for young CASD. The purpose of this study was to: (1) describe the aforementioned parent training program for families of preschool-age children with ASD, (2) describe the implementation of this model in a preschool classroom and how teachers were trained to use it, (3) describe the outcomes of the pilot programme, and (4) discuss the outcomes and implications of implementing the model in public schools.	Parents were assigned to the self-directed group or the therapist-assisted group. Both groups received access to the secure, password-protected ImPACT Online website for up to 6 months. The therapist-assisted group were encouraged to work through the programme at the same pace as the self-directed group. Parents in the therapist-assisted group also received two 30-minute remote coaching sessions per week (24 sessions) via Skype video conferencing software by a trained therapist to assist them in learning the intervention. (i) The coach and parent clarified the content of the relevant lesson and coach helped the parent apply the information to their child. (ii) The coach, parent and child were involved. The parent received "live" feedback on their use of the intervention techniques as they practiced with their child.

Table 2 (continued)

Year	Author/s	Intervention name	Purpose of study and/or intervention	Intervention outline
2015	Magana, Lopez & Machallicek	Parents Taking Action	The purpose of this study is to (1) describe a culturally derived psycho-educational parent education intervention, Parents Taking Action (PTA), (2) present the results of a pilot study examining the feasibility, acceptability, and preliminary outcomes of the PTA intervention post implementation with Latino immigrant mothers of children with ASD.	The programme comprised of two modules. The focus of Module I (8 topics) was to provide parents with basic information about autism, advocacy, and navigating the system. The topics in module I were extensive ranging from "Understanding the development of social skills, play skills, and communication in young" to "Advocacy". The focus of Module II (8 topics) was to provide parents with information about evidence-based interventions, provide instruction on intervention strategies in order to improve their child's communication, social and play skills, and strategies to decrease problem behaviours.
2015	Noiinomi et al.	"Skippu-Mama" Programme	The "Skippu-Mama" Programme was developed specifically to increase QOL and reduce parental stress of mothers of CASD. The aim to achieve the aforementioned was by refreshing the mothers' minds and bodies. The purpose of the study was to develop the "Skippu-Mama" programme, assess its feasibility and its efficiency in reducing maternal stress and increase QOL in mothers of CASD.	Each session included: (i) Warm-up exercise (balancing ball), (ii) Mini lesson – different themes, (iii) Main workshop, and (iv) Relaxation or aromatherapy massage. In the first three sessions mothers were given an opportunity to observe and reflect on themselves, their children and their families. In the final three sessions there was: (i) A chance to express the strengths of their family, (ii) Formulate objectives for their family, and (iii) Direct help from other participants and benefit from the diverse experiences of the other mothers.
2014	Ji, Sun, Yi & Tang	Multidisciplinary Parent Education Programme	The Multi-disciplinary parent education programme included four disciplines namely community nursing, psychiatry, psychology and special education. The intervention aimed to improve caregivers' health-related QOL, through (1) teaching ASD related knowledge and skills, (2) stress and mood self-management, (3) how to deal with family problems. The purpose of this study was to assess the effectiveness of the above mentioned programme.	The content of the intervention included: (i) Learning basic information about ASD, (ii) Skills for taking care of CASD, (iii) Strengthen positive coping styles, (iv) Self-management of mood, (v) Enhance family functioning, and (vi) Using social support efficiently.
2014	McAleese et al.	Psychoeducational and psychotherapeutic	A psychoeducational group for parents of CASD based on an established programme developed by Wright and Williams (2007). The group aimed to increase parental knowledge of ASD and self-efficacy. This was achieved while providing peer and professional support before individual intervention was provided by the local service.	The group was aimed at increasing parental knowledge of ASD and self-efficacy, while providing peer and professional support prior to individual intervention. The course was structured as follows: Session 1: "What is autism spectrum disorder?" The workshop covered receiving a diagnosis of ASD, training on ASD including an explanation of symptomatology through the use of the "triad of impairments"

Table 2 (continued)

Year	Author/s	Intervention name	Purpose of study and/or intervention	Intervention outline
	McAleese et al. (continued)		<p>The parents attended a three-day course facilitated through a specialist ASD service.</p> <p>The purpose of the study was to evaluate the psychoeducational group for parents of CASD. A pre and post course questionnaire developed by Wright and Williams (2007) was administered to the parents allowing for quantitative analysis and comparison of parents' understanding of ASD and their self-efficacy prior to and after course attendance. Additionally, participants completed a client experience questionnaire that obtained both qualitative and quantitative information relating to experience and satisfaction.</p>	<p>Session 2: "The sensory world of autism spectrum disorder". In this session parents learned about the sensory issues associated with ASD and explored intervention strategies. Session 3: "The use of visual strategies as behavioural intervention". CASD often have difficulties in understanding and delivering social communication, understanding social cues and developing new skills. These difficulties usually result in behavioural issues. The workshop discussed the theory behind why visual aids are believed to aid behavioural difficulties, promote independence and assist communication difficulties.</p>
2014	Preece	Dealing with Challenging Behaviours	<p>Dealing with Challenging Behaviours was a programme developed with the aim to assist parents in using positive parenting intervention. Given the challenging nature of ASD, physical interventions may be used incorrectly at home causing harm for the CASD as well as the PCG. This programme aimed to bridge this gap to allow parents to communicate openly about their struggles and develop healthy intervention strategies for challenging behaviours.</p> <p>The purpose of this study was to provide and evaluate a training course in physical interventions and positive behavioural support for a group of parents whose children presented challenging behaviour on a regular basis at home. Additionally the study evaluated the parents' confidence in understanding and managing their child's behaviour and on the use of physical intervention at home following the training course and 12 weeks later.</p>	<p>The training model content comprised:</p> <ul style="list-style-type: none"> (i) Positive behavioural components, such as understanding 'challenging behaviour', understanding emotions and behaviour, communication and de-escalation; (ii) Legal implications regarding rights, responsibilities and the use of physical interventions; and (iii) A small number of physical interventions were covered looking at a range of situations that could happen within the family home and community, where parents may need to intervene to keep the child, siblings, others or themselves safe. <p>Parents were taught how to respond to biting and hair-pulling; how to separate fights; safe holding, wrapping or escorting (with one and/or two adults); and how to safely disengage from holds to the arm, neck and body. Parents had multiple opportunities to practise these interventions in the two days and were required to demonstrate competency in their use.</p>
2014	Rivard et al.	Parent Education	<p>The purpose of this study was to investigate parents' perspectives on the quality determinants of services for young CASD. Objective one was to document the importance parents attributed to the four quality determinants as outlined by Barelds et al (2009). The second objective was to assess the parents' perceptions on to what extent these quality determinants were being implemented at a public service level. Thirdly the study aimed to measure the parents' satisfaction in the service delivery.</p>	<p>The Parent education programme was based on the needs of the parent of the CASD e.g. developing a communication system, toilet training, dealing with strategies to sleep, reducing and managing tantrums. A team approach was used as the younger child requires more attention as does the PCG. The programme also included workshops on ASD, early behavioural intervention for the CASD, individualised support and coaching, regular progress meetings with Health Care Professional and adapting intervention to the needs of the PCG and CASD.</p>

Table 2 (continued)

Year	Author/s	Intervention name	Purpose of study and/or intervention	Intervention outline
2014	Shrivastav	Occupational Therapy with Sensory Based Intervention and Parent Education Programme. The sensory programme was completed with the child and the education was undertaken with the mother on an individual basis.	The purpose of the study was to examine the occupational therapy intervention (Sensory based intervention and parental education) on children's behaviour and its impact on the maternal stress levels.	This consisted of: (i) Mothers understanding the nature of the child's sensory motor preferences and deficit (ii) Mothers are taught to assess the child's problems, (iii) List of sensory based activities generated according to child's preference, (iv) Taught strategies to structure the environment to adapt and compensate for the problem. (v) Therapist observes mother performing activities and mothers provide a video, and (vi) Feedback on video is given.
2014	Whitney & Smith	Online Journaling	The purpose of this study was to explore the effects of a journal writing intervention on the measured levels of maternal stress for mothers of children with socially disruptive behaviours. The study aimed to understand the effect of participation in an online journal writing intervention on (1) emotional disclosure, (2) the level of a child's disruptive behaviour on maternal stress, (3) the quality of mother-child relationship	Over an eight (8) week period, participants in the experimental group responded to eight prompts in eight writing sessions and were instructed to take no more than 15 min to journal. No restrictions on the number of sessions mothers could complete per week were given. This protocol follows previous research suggesting short bursts of writing (15 min) are sufficient to allow for emotional disclosure, however no restrictions on time allocated for each writing session was given. Prompts were selected to follow a structured writing protocol, making use of cathartic writing and expression of strong emotions that are highly affective and often internalized by the mothers. Journal entries were submitted via a secure online drop-box. There was no contact between the researcher and the participants during the eight (8) weeks' intervention. Procedural questions were responded to by the research assistant.
2013	Al-Khalaf et al.	Education programme for mothers	The program aimed to improve parental attitudes toward their children and to provide parents with information about ASD and how they could address their child's challenging behaviours. The program consisted of 12 sessions over 3 weeks. The purpose of this study was to explore whether the provision of the abovementioned education program for mothers of preschool age CASD, improved the mothers' coping skills, reduced their stress and enhanced their understanding about their child's behaviour. Additionally the study aimed to identify whether there were substantial differences between Jordanian mothers' and fathers' stress and coping skills in families with a CASD.	Education programme was developed to: (i) Help mothers understand and cope with their child's behaviours, (ii) To reduce the stress caused by limitations, in knowing how to prevent and manage the same, (iii) Help mother generate strategies to cope better. Sessions included: (i) Introductions general info provided (communication, social relations and behaviour), (ii) Communication and social difficulties, (iii) Discussion on repetitive behaviour and sensory processing, and (iv) Discussion on strategies to use during play time, ways to manage sleeping and eating problems

Table 2 (continued)

Year	Author/s	Intervention name	Purpose of study and/or intervention	Intervention outline
2013	Chiang	Parent Education Programme	The purpose of this study was to examine the effectiveness of a parent education program on decreasing parenting stress and increasing parental confidence and quality of life in parents of Chinese American CASD.	This parent education programme followed the following format: (i) 30 mins. Group discussions and role play on topics, (ii) 30 mins. ½ parents shared own experiences on parenting, and (iii) 30 mins. ½ parents shared info that they felt useful for other families. Topics covered included: Understanding ASD, Teaching communication, social academic, functional and play skills. Reducing challenging behaviour, Opportunities and outcomes for individuals with ASD, Coping strategies, communities resources.
2013	Feinberg et al.	Cognitive behavioural intervention and problem solving education	The purpose of this study was to investigate whether a brief cognitive behavioural intervention, problem-solving education (PSE) would decrease parenting stress and maternal depressive symptoms during the period immediately following a child's diagnosis of ASD.	Problem Solving Education included Goal setting, Brainstorming, Evaluating solutions, Choosing a solution and Action planning. PCG were taught how to use this strategy in managing their CASD.
2013	Poslowsky et al.	Video feedback intervention to promote Positive Parenting	The purpose of this study was to explore avenues to support parents of CASD by improving early parent-child interactions while maintaining the families' daily routines. The study focussed on a number of objectives: (1) Exploring the correlations between the stability of parents' experienced feelings about their child's ASD diagnosis and their subsequent coping style. (2) Adapting a tailored, short-term intervention protocol with the aim of enhancing the quality of the parent-child relationship in relation to the parental competences of the individual in raising a child with ASD. (3) Testing the effectiveness of the adapted intervention by assessing parental sensitive responsiveness to the CASD prior to and following the intervention. (4) Testing the effectiveness of the adapted intervention with regard to the children's joint attention and play behaviour. (5) To assess the improvement of parent-child interactions, using oxytocin as a pharmacological supplement.	Video feedback intervention to promote Positive Parenting (VIPP) is an evidence-based intervention protocol. The intervention is based on attachment theory. The VIPP was adapted specifically for parents and CASD. It was called Video-feedback Intervention to promote Positive Parenting for Children with Autism (VIPP-AUTI). The aim of VIPP-AUTI was to reduce the child's symptomatology by enhancing parental sensitivity to the autistic traits of the child. It was believed that showing parents their own interaction patterns may enhance their insight into the specific individual needs of the CASD, and result in more optimal parental responses. The VIPP-AUTI protocol consisted of five sessions. Four of which included "Attachment and Exploration", "Speaking for the child", "Sensitivity chain" and "Sharing emotions" with an additional autism-related component for each session. Session five was a booster session. The additional themes for autism were: (i) Mastery motivation and play, (ii) Joint attention, (iii) Daily problems and routine, and (iv) Emotions and (stereotypical) behaviour. The parents discussed these themes via specific video-sections thereby learning to 'read' the signals of their child and understand their child's strengths and weaknesses.

Table 2 (continued)

Year	Author/s	Intervention name	Purpose of study and/or intervention	Intervention outline
2013	Weiss et al.	Social Skills Training Groups	<p>The Social Skills Training Groups is a community programme that includes both a child and parent group component that run simultaneously. The programme follows an unpublished manual. The groups are designed for youth between eight and 14 years of age, with a diagnosis of ASD. Youth are split into two age groups: 8–11 and 12–14 with the size of child group being limited to six to nine children. At least one parent/caregiver of a child is required to attend a concurrent parent group. The overall programme includes time for children to get acquainted with each other, learn and practice friendship skills, conversation, social problem solving, and dealing with emotions.</p> <p>The purpose of this study was to examine the direct and indirect outcomes of a social skills group intervention for children with high functioning ASD and their parents</p>	<p>Psychoeducation was based on specific topics that were determined by the parents e.g. parenting strategies, school problems, review of what children were learning, education on medication, development of social skills.</p>
2012	Samadi, McConkey & Kelly	Family Centred Short Course	<p>The purpose of this study was to develop and evaluate a short, group-based educational and family support course for Iranian parents. The study would evaluate the stress levels of the parents, their health status, family functioning and the ability of the parents to use more problem-focused coping strategies.</p>	<p>The content aimed to increase knowledge of ASD and interventions to promote child development; boost parental confidence and feelings of empowerment. Informal supports among parents were encouraged and a devise a set of training resources were developed for a specific context.</p>
2011	Probst & Glen	TEACCH-based intervention	<p>The TEACCH approach, emphasizing (a) "structured teaching" based on visual cues and this intervention specifically taught the concept of autism using causes, nature, lifelong consequences of autism, as well as treatment goals and methods (b) broad-spectrum cognitive-behavioural strategies such as exchanging experiences with other parents about development and behaviours of one's child and sensitizing them to family issues resulting from ASD and (c) close professional-parent cooperation as well as teaching strategies and skills for enhancing the child's development and behaviour management, focusing on the elements of Structured Teaching. Furthermore this intervention used methods of enhancing the child's functional communication, pre-academic skills, play skills, daily life routines and self-management skills. The parent training manual was structured according to the aforementioned goal domains and delivered to parents.</p> <p>This study had two overarching aims and two parts to the study. The first aim of the of this study was to examine the parental report on the implementation quality, effectiveness and social acceptance of a centre-based education and skills group training program for parents of CASD. The study looked at the parents' perceptions of the overall quality, trainer behaviour, group atmosphere and manual quality at the end of the group training.</p>	<p>The first intervention was group-based and followed the curriculum as outlined by the TEACCH approach.</p> <p>The second intervention was a home-based programme implemented with one child who will be called 'M'. The programme included the following:</p> <ul style="list-style-type: none"> (i) Child-centred goals to improve M's language and functional communication skills, pre-academic and play skills, social and emotional functioning in family, preschool and primary school; (ii) Parent-centred goals to enhance structured teaching skills (focusing on mother, the main care-giver), and establishing an adequate individualized autism disability concept; (iii) Teacher-centred goals of enhancing M's inclusive classroom adaptation, which included supporting his transition into the different school phases, establishing an appropriate individualized autism concept for him; and (iv) Health-professional-related goals of providing formal social supports for M in his family and classroom.

Table 2 (continued)

Year	Author/s	Intervention name	Purpose of study and/or intervention	Intervention outline
	Probst & Glen (continued)		At a 3 moth follow up the study evaluated the parenting skills, parental health, the family's emotional setting at home and the transfer onto the child's support system. The second aim of the study was to examine the effects of a TEACCH-based home programming intervention on child, parent, teacher, and health professional outcomes	
2010	Mulligan et al.	Information Resource book	The purpose of this study was to evaluate a newly created information resource book for parents of children newly diagnosed with ASD entitled Autism Spectrum Disorder: Information for Parents.	The Hospital for Sick Children, Child Development Centre (CDC) produced the ASD resource Autism Spectrum Disorder: Information for Parents. An online version of the resource book can be found at http://www.aboutkidshealth.ca/shared/PDFs/Autism.pdf . The book was written by a social worker and parent liaison in a regional autism team. Input from members of the interdisciplinary team (developmental paediatrician, neuro-psychologist, speech and language pathologist) and parents of CASD was included. Intended as a 'beginner's guide' to autism, this book offered a compendium of introductory information in a user-friendly, encouraging, and easy-to-read format.
2009	Keen, Couzens, Muspratt, & Rodger	Parent-Focussed	The intervention included two programmes namely a professionally supported parent-focused intervention and a self-directed video based intervention. Both programs aimed to encourage parent responsibility and the use of methods to promote social communication as well as to assist parents in integrating increased communication supports into daily family routines. The purpose of this study was to reduce parenting stress and increase parenting competence for families of children within 6 months of receiving an ASD diagnosis. The effects of two programmes were compared. The first programme was a professionally supported parent-focused intervention and the second was a self-directed video based intervention. The programmes were compared for levels of parenting stress, parenting competence and possible improvements in child behaviour.	The workshops provided information and parent education on the following topics: autism; social skills; communication; play; sensory difficulties; behaviour issues; strategies to improve social interaction and communication; embedding strategies within daily routines; using a balanced approach; and selecting a child-focused early intervention programme.
2005	Giarelli, Souders, Pinto-Martin, Bloch, & Levy	Nursing Intervention for parents	The Nursing intervention was modified from the usual care parents received immediately after receiving their child's diagnosis of ASD. The purpose of this study was to: (1) describe the parent-focused nursing intervention (2) describe the modification of the intervention protocol based on pilot testing (3) describe the effect of the nursing intervention on parents' perceived stress, impact of receiving the diagnosis, and use of services in comparison to a control group.	Refined nursing intervention: included: (i) One-hour telephone call scheduled within one week of receiving the diagnosis, and (ii) Two-hour home visit scheduled three months after the diagnosis.

Table 3: Content of interventions – emergent themes

Year	Author/s	Intervention name	Intervention content			
			Learning about ASD	Intervention specific to CASD	Getting the support I need	Intervention specific to PCG Getting the "know how" to care for my child
2016	Dababnah & Parish	The Incredible Years (IY)		X		X
2016	Stuttard et al	Cygnets Parenting intervention	X	X	X	
2015	Ingersole & Berger	Telehealth-based Parent-mediated intervention programme	X			
2015	Magana, Lopez & Machalicek	Parents Taking Action	X	X	X	X
2015	Noinomi et al	"Skippu-Mama" Programme		X	X	X
2014	Ji, Sun, Yi & Tang	Multidisciplinary Parent Education Programme	X	X		X
2014	McAleese et al	Psychoeducational and psychotherapeutic	X			
2014	Preece	Dealing with Challenging behaviours	X			
2014	Rivard et al	Parent Education		X	X	
2014	Shrivastav	Occupational Therapy with Sensory base and parent education programme		X		
2014	Whitney & Smith	Online Journaling				X
2013	Al-Khalaf et al	Education programme for mothers	X	X	X	
2013	Chiang	Parent Education Programme	X	X	X	
2013	Feinberg et al	Cognitive behavioural intervention and problem solving education				X
2013	Poslawsky et al	Video Feedback Intervention to promote Positive Parenting				
2013	Weiss et al	Social Skills Training Groups		X	X	X
2012	Samadi, McConkey & Kelly	Family Centred Short Course	X		X	
2011	Probst & Glen	TEACH-based intervention	X	X	X	X
2010	Mulligan et al	Information Resource book	X			X
2009	Keen, Couzens, Muspratt & Rodger	Parent-focussed	X	X		X
2005	Giarelli, Souders, Pinto-Martin, Bloch, & Levy	Nursing Intervention for parents	X	X	X	X

Table 4: Representation of the techniques, presentation format and materials used in interventions

Year	Author/s	Techniques													Presentation					Materials									
		Group work	Peer support	Role play	Goal setting	Problem solving	Modelling	Reflection	Journaling	Homework	Discussions	Brain storming	Face-to-face/one-on-one	Telephonic	Power points	Videos	Case report	Formal teaching	Online	Groups/workshop	Self-directed	Home visit	Manual	DVD	Activity sheets	Resource pack/handouts			
2016	Dababnah and Parish		X	X															X								X	X	
2016	Stuttard et al							X	X	X					X	X									X			X	
2015	Ingersole and Berger			X				X	X											X								X	
2015	Magana et al									X										X								#	
2015	Noinomi et al		X							X					X	X				X									
2014	Ji, Sun, Yi and Tang									X					X	X				X									
2014	McAleese et al																			X									
2014	Preece						X	X	X	X											X								
2014	Rivard et al								X																				
2014	Shrivastav								X											X									
2014	Whitney & Smith									X																			*
2013	Al-Khalaf et al	X	X																										X
2013	Chiang	X	X	X																									X
2013	Feinberg et al					X														X									X
2013	Poslawsky et al						X	X													X								X
2013	Weiss et al								X																				X
2012	Samadi et al								X												X	X							X
2011	Probst and Glen	A					A	A	A	A												B							A
2010	Mulligan et al	X																		X									X
2009	Keen et al	X	X																										X
2005	Giarelli et al																												X

*Prompt given for each journal session

manual for parents and facilitators

A = group based intervention; B = single case study

Table 5: Quality of Life domains targeted in studies (*n* = 21)

Year	Author/s	Quality of Life Domains				
		Physical well-being	Emotional well-being	Social well-being	Material well-being	Development and activity
2016	Dababnah & Parish			X		
2016	Stuttard et al.					X
2015	Ingersole & Berger					X
2015	Magana et al. Machalicek		X	X		X
2015	Noiinomi et al.		X			
2014	Ji, Sun, Yi & Tang		X	X		
2014	McAleese et al.					X
2014	Preece					X
2014	Rivard et al.	X	X			
2014	Shrivastav		X			
2014	Whitney & Smith		X			
2013	Al-Khalaf et al.		X			
2013	Chiang					X
2013	Feinberg et al.		X			
2013	Poslawsky et al.					X
2013	Weiss et al.		X			X
2012	Samadi et al.		X	X		X
2011	Probst & Glen					X
2010	Mulligan et al.					X
2009	Keen et al.		X			
2005	Giarelli et al.					X

Discussion

The aim of the scoping review was to map the current literature on interventions for PCG of CASD with a focus on identifying and describing services and programmes for PCG. The review highlighted the dearth of literature available on interventions provided to PCG of CASD. The 21 reviewed studies emanated from 12 countries across four continents. In a 2017 scoping review by Franz and colleagues, 24 467 articles presenting with content on ASD were accessed from seven continents, including North America, Europe, Asia, Australia, South America, North Africa, and sub-Saharan Africa (SSA). Detailed analysis of these articles was not conducted as it fell outside the scope of the study. Therefore, it is unknown how many articles included interventions for PCG. Even though the search terms for this review were different to those used by Franz and colleagues (2017), it is clear that research is limited on interventions for PCG of CASD. Similarly there are limited studies in Sub-Saharan Africa (SSA) presenting interventions for PCG of CASD. The current study did not yield any articles emanating from SSA. The dearth of studies originating from SSA was confirmed by Franz and colleagues (2017) who accessed one article on interventions for PCG of CASD in SA. This intervention study by Pansegrouw and Alant, 1996 yielded positive change in the mother-child dyad through parent coaching. Given the date (1996) of this study and the dearth of literature, a gap is noted in the field of ASD in relation to the care of the PCG. The articles accessed in this scoping review highlighted intervention content that was comprehensive and relevant corresponding to the needs of the CASD. Content included awareness and education about ASD, interventions for the direct benefit of the CASD, and interventions for the PCG. Even though the PCG were included in the interventions, the common denominator was the CASD. Inclusion of awareness and education about ASD in order to adequately equip the PCG is in keeping with the initial needs at the time of diagnosis. The PCG emotional distress begins at diagnosis when they are seeking answers (Altiere & von Kluge, 2009; Ryan & Salisbury, 2012). Primary caregivers experience distress when their child is diagnosed with ASD as the condition

is unfamiliar and obscure. This results in feelings of concern, anxiety, and confusion alongside the need for knowledge about the condition and how to manage their child (Makino, Wond, King, Hartma, & Penner, 2017). Early intervention is a pre-requisite for the optimal development of a CASD, therefore education of the PCG in ASD and management becomes vital (Wang, 2012).

Directly linked to the awareness of ASD was the need for PCG to understand how to cater for their child's needs (Bruder, 2000). As an integral part of the development, care, and well-being of the CASD, the PCG should claim recognition as a valuable resource for the child (Baker-Ericzen et al., 2005; Dardas & Ahmad, 2014). As a resource to benefit the child's development, the interventions assisted PCG in managing the treatment needs of their child and the "know how" to develop and improve their children's skills. These skills are essential as the PCG is a constant figure who provides the physical, emotional, material, social, and therapy needs of the child (Bruder, 2000). Interventions providing the "know how" for PCG were in keeping with the needs of a CASD such as addressing skills needed to manage activities of daily living, communication, development, and behaviour (Davis & Carter, 2014; Kuhaneck et al., 2015).

To achieve favourable therapy outcomes for the child, the mental and physical health of the PCG requires attention (Davis & Carter, 2008; Osborne et al., 2008) as well as their ability to cope with the long-term implications of raising a CASD (Feetham, 2011). Interventions catering for the needs and the improved QOL of PCG require overt attention within interventions provided by ASD stakeholders, thus changing the narrative of the PCG to "client/patient" with their unique set of needs. The intervention content in the reviewed studies offered to PCG focused on support for the PCG and providing skills on how to care for themselves. The characteristics of ASD are all-encompassing, affecting all areas of life for the PCG, CASD, and family (Hutton & Caron, 2005; DeGrace, 2004). Therefore, it is not surprising that topics covered in these sections appeared to be a consequence of caring for a CASD or linked to ASD. For example, networking with other PCGs as a form of support and stress management which is incurred from raising a CASD (Bromley et al., 2004; Estes et al., 2009). The ongoing care of the CASD requires PCG and family members to make constant changes and accommodations which aid towards the improvement of QOL for the CASD and overall family functioning (Rizk, Pizur-Barnekow, & Darragh, 2011; Gurayah, 2017). The characteristics of ASD, such as poor communication, difficult behaviours, and limited reciprocal signs of affection towards the PCG, may be the source of the PCG challenges, frustrations, and stress. This dictates the need for interventions to focus on the child (Baker-Ericzen et al., 2005; Dardas & Ahmad, 2014). The reviewed studies included interventions that provided support and skills to better cope with their CASD. The studies reflecting the theme "getting the support I need" included opportunities to meet and share with other PCG. Sharing difficulties and successes allow PCG to gain support and a perception that they are not alone in their struggles which promotes mental health and well-being (Ekas et al., 2010; Lu et al., 2015; Rizk et al., 2011). The studies reflecting the theme "getting the 'know how' to care for myself" included activities such as management strategies for self and family, goal setting, and stress management. These skills address the PCG as the "client/patient" drawing attention to their emotional, psychological, practical needs, and improvement in QOL (DePape & Lindsay, 2014; Frantz et al., 2017; Perez-Algorta et al., 2018). One study focussed purely on the need of the PCG in an online journaling programme that used emotional disclosure to successfully reduce maternal distress (Whitney & Smith, 2014).

It is evident in the literature that parental QOL is negatively impacted by raising a CASD (DePape & Lindsay, 2014; Eapen & Guan, 2016). Thematic analysis of the intervention content revealed that the majority of the studies in this paper included topics that were strongly linked to the QOL domains of development and activity and emotional well-being. Development and activity was noted in the practical skills taught to PCG who are required to fulfil the daily tasks and activities of their CASD (McStay et al., 2014). Similarly, the domain of emotional well-being was noted in the supportive activities provided to PCG to minimise the effects of the emotional strain PCG experience in raising a CASD (Davis & Carter, 2014; Kuhaneck et al., 2015). Fewer studies addressed social well-being which is contrary to the social burden that PCG experience given the incidence of stigma and the social awkwardness that comes with having a CASD (Wang et al., 2012; Woodgate, Ateah, & Secco, 2008). Strain in social relations and socialisation is experienced in the sphere of ASD for the CASD,

the PCG, and the family (Schlebusch et al., 2017). Thus, interventions for PCG should address the QOL domain of social well-being more explicitly.

In the reviewed studies, family collaboration was a common approach which links closely to how ASD impacts on all aspects of family-life as well as the effect on family members (Schlebusch et al., 2017). Primary caregivers express difficulties with family members, stigma, and managing their daily lives with CASD (Brookman-Frazee et al., 2006; Dardas & Ahmad, 2014). Good family functioning is a vital source of support for the family (Johnson et al., 2011). Therefore, the intervention of the family should be included in ASD interventions in order to provide a holistic intervention that preserves the family unit.

Eleven interventions were facilitated by persons with experience in the field of ASD of which six were professionals specialising in ASD. The discourse around who is responsible or qualified to implement interventions for PCG is essential to map the way forward for providing a good quality service (Dymond et al., 2007). It is noted that the non-professionals were often caregivers themselves who received training in the intervention under the supervision of a trained individual. The input of PCG is invaluable as they can relate to other PCG and feel less isolated which links closely to the approach of peer support that was mentioned in some of the studies (Mandell & Salzer, 2007). Realistic goals need to be set in meeting the needs of PCG in both developed and developing countries where task shifting may need to be considered and where governmental structures invest resources into training specialists in the field of ASD.

Considering the mechanisms of delivery of the reviewed studies, there were commonalities in timeframes, techniques, presentation format, and materials across interventions. These aspects were tailored to the needs of the PCG and the particular intervention being offered.

Conclusion

Research in the area of ASD is growing rapidly as early detection of ASD in children has gained momentum. With this, the need for a holistic approach to caring for families of CASD becomes essential, especially for the PCG. This need to recognise the PCG as a “client/patient” with focussed intervention is clear from studies that highlight the stressors involved in caring for a CASD. With focussed interventions for the PCG, the family unit may be preserved and ensures not only the well-being and good QOL of the CASD but the PCG as well.

In a South African context, it was noted that there is a dearth of literature on interventions for PCG. This paper provides the health care professional with possible guidelines on setting up interventions for PCG of CASD. The developmental “life span” of the PCG intervention is seen in the progression of content starting with education about ASD and ending with ways to manage their mental health and well-being. The overview of the structure and MOD provides the stakeholder of ASD with a framework for developing these aspects in an intervention. The noted improvement in QOL alludes to the PCG as the “client/patient” who can benefit from interventions. This paper has raised the need for a change in discourse in the health care team in terms of holistic care for families of ASD.

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