

**MEASURES FOR SOCIAL SUPPORT IN RAISING A CHILD WITH A
DISABILITY: A SCOPING REVIEW**

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ABSTRACT

Background The benefits of social support for caregivers raising a child with a disability have been identified in the literature. These benefits include the improvement of the mental and physical well-being of the caregivers, improvement in caregiving styles, and overall improvement of family quality of life. Whilst the benefits of social support are widely reported, the definitions and measures of social support in the literature are varied.

Method A scoping review was therefore undertaken to identify and describe the tools used to measure social support of primary caregivers (i.e. parents or grandparents) raising a child (0–18 years) with a congenital disability in international studies. Ten databases were systematically searched.

Results Sixteen studies were included in the review, from which nine social support measures were identified. Attributes of the measures were searched from their referenced papers and described in terms of their reported psychometric properties.

Conclusions Through the identification of the measures of social support and ensuring its accurate measurement, direction can be provided for intervention by allowing professionals to detect and address social support available. Future recommendations for research are made.

Keywords: caregivers, grandparents, parents, psychometric properties, social support

INTRODUCTION

Caregivers raising a child with a congenital disability face various challenges, including high levels of caregiver psychological distress (Al-Gamal & Long, 2013; Caley, 2012), difficulty in managing the child's behaviour (Raina *et al.*, 2004; Wodehouse & McGill, 2009), poor caregiver coping strategies (Cappe *et al.*, 2011) and social isolation of caregivers due to the caregiving demands and social stigma around disability (Hanass-Hancock *et al.*, 2013). Nevertheless, caregivers use various strategies to cope with raising a child with a disability. Studies identifying these coping strategies (Al-Gamal & Long, 2013; Gothwal, Bharani, & Reddy, 2015; Heiman, 2002; Judge, 1998; Siklos & Kerns, 2006; Sipal & Sayin, 2013) consistently mentioned social support as an important factor for facilitating coping in caregivers raising a child with a congenital disability (Sipal & Sayin, 2013; Tak & McCubbin, 2002).

Social support is an important family resource (Migerode *et al.*, 2012) as a mediator for coping with stressors (Tak & McCubbin, 2002), offering several positive outcomes for caregivers, the child and the family as a whole (Bailey *et al.*, 2007). Specific outcomes of social support relate to the life of the caregiver (Canary, 2008; Ekas *et al.*, 2010) and act as a valuable protective factor for the caregiver when raising a child with a disability (Fuentes-Peláez *et al.*, 2014). Social support is argued to influence the adaptability of caregivers who face stressful and challenging situations (Benzies & Mychasiuk, 2009; McConnell & Savage, 2015) by improving coping strategies (Tang *et al.*, 2015) and caregiving abilities to appraise challenges they face (Mhaka-Mutepfa *et al.*, 2014). These positive influences of social support may buffer the effects of stress (Sipal & Sayin, 2013) and facilitate positive health and well-being for the caregiver (Casale *et al.*, 2014; Moore & Miller, 2007). Other positive outcomes of having social support include positive caregiving styles (Guralnick, 2011), such

as displaying competence in caregiving and nurturing the child's self-esteem (Werner, 1996), improved caregiving quality (Brand *et al.*, 2014) with better developmental outcomes for the child (Huang *et al.*, 2014; Guralnick, 2011), improved family quality of life (Kresak *et al.*, 2014) and overall enhanced family resilience (McConnell & Savage, 2015).

According to Green and Rodgers (2001), social support acting as a protective factor for carers within communities has been of mounting interest to researchers to understand social support is needed to encourage successful, healthy caregiving processes (Guralnick, 2011). With positive outcomes for the child with a disability, overall family resilience is key to ensuring a positive outcome for the at-risk family as a unit (Benzies & Mychasiuk, 2009). Resilience is facilitated by protective factors such as social support, where the family well-being is increased (Newland, 2014), which in turn enables the adaptability of the caregiver in light of caregiving stressors (Britner *et al.*, 2003; McConnell *et al.*, 2014). Adaptability due to social support is thus valuable because it attends to the caregiver's emotional, psychological, physical, informational, instrumental and material needs (Fuentes-Peláez *et al.*, 2014). Therefore, family-centred intervention services encourage families to use social supports available within their community when raising a child with a disability (Dunst, 2000; Rosenbaum *et al.*, 1998). Whilst the benefits of social support have been highlighted in the literature, it remains a complex construct (Heitzmann & Kaplan, 1988).

The complex construct of social support has been defined as 'information leading a person to believe that he is cared for and loved, valued and esteemed, and is important in a network of mutual obligation and communication' (Cobb, 1976 p300). More recently, the definition of social support has been described as the process which arises from formal support (medical or professional) and informal sources (extended family, friends and neighbours) around the caregiver and family (Landry-Meyer, Gerard, & Guzell, 2008). The

importance of social networks (Landry-Meyer *et al.*, 2008) or of their perceived or received support (Uchino, 2009) has similarly been used to define or measure social support. In this scoping review, social support refers to the support received from outside of the family.

Social support is considered as a process where specific types of support are provided (Cantwell *et al.*, 2014; McConnell *et al.*, 2014), including emotional, informational, practical or instrumental support (Benson, 2012). Social support is also referred to as a source (e.g. professionals) (Kresak *et al.*, 2014), type (e.g. informal support) or need (e.g. psychological need) (Brand *et al.*, 2014; Hayslip & Kaminski, 2005). However, there is unanimous agreement regarding the benefits of social support on various outcomes and highlights the need to strengthen the relationship between the construct of social support and how it is measured (Sarason & Sarason, 2009).

The measurement of social support provides a path for intervention, specifically when various other components such as caregiving stress are prevalent (Guralnick, Hammond, Neville, & Connor, 2008). A variety of social support measures have been developed to specifically and practically measure the dimensions of social support (Alloway & Bebbington, 1987). With the complexity of social support as a construct within the context of caregiving stressors, support networks and sources of support are easily overlooked or remain undetected in family intervention (Guralnick *et al.*, 2008). Furthermore, there is limited information to guide researchers and professionals in the clinical context regarding the use of appropriate social support instruments for families raising a child with a disability. Accordingly, a scoping review was conducted to identify social support measures for such caregivers. Scoping reviews aim ‘to examine the extent, range and nature of research activity’

to map and describe the field of study using a rigorous methodology (Arskey & O'Malley, 2005 p6). Therefore, the following aims guided the review:

- 1) To identify and describe studies that have measured social support for caregivers raising a child with a congenital disability with specific reference to purpose, setting, participants, the definition of social support provided and the social support measure used.
- 2) To describe the social support measures identified from findings in the first aim in terms of the rationale from the authors for developing a measure, referring to Kimberlin and Winterstein (2008).

Specific information was sought relating to the population group and sample size on which the measure was devised, its internal structure, the reported content and construct validities and reliability of the measures. The details of how the measure was created are usually provided in the relevant authors' published article (Rainey, Nispen, Zee, & Rens, 2014).

METHOD

Search Strategy

A university librarian knowledgeable in the field of social sciences was consulted in developing the search terms and search strategy; thereafter, a systematic search was conducted using the library-based search engines EBSCOhost and Scopus. Ten computerised databases were searched, namely *Academic Search Complete*, *Africa Wide*, *CINHAL*, *ERIC*, *Family & Society Studies World*, *Health Source – Nursing/Academics*, *MEDLINE*, *Social Work Abstracts*, *PsychINFO* and *E-Journals*. Key search terms were identified using literature related to the scoping review question, together with the *Medical Subject Heading* (MeSH) thesaurus to retrieve all relevant studies irrespective of how the authors used the

keywords (Schlosser, Wendt, Angermeier, & Shetty, 2005). The search terms used were ‘support*’, ‘scale*’, ‘measure*’, ‘parent*’, ‘kinship*’, ‘grand*’, ‘child*’ and ‘disab*’; the truncation (*) allowed for variations to be included in the results list. Adaptations and other specifications were applied to the individual databases to focus the search and allow for more specificity. For example, there was further refining of terms for the keyword ‘child*’ to include ‘infants’, ‘newborns’, ‘infant’, ‘all infant’, ‘child’ and ‘preschool’. The reference list of each study was searched for any additional social support measures which may have been used or referenced. No further measures were found.

Selection Criteria

Studies for inclusion in this scoping review were selected using the criteria described in Table 1.

The psychometric properties of the measures were described as reported in the included study. If the study did not sufficiently describe the psychometric properties of the measure, the original paper was searched for that reported these details. The full reported reference of the social support measure was noted within the bibliography of each study. The reference was then hand-searched and found to be either another article or a paper in which the creator(s) and author(s) of the measure describe the psychometric properties of the tool. The main paper or article included details regarding the initial aim of the measure and main constructs, the country, population group and sample size on which the measure was devised. Further attention was paid to the description of the internal structure of the scale and how the method of content validity, the construct validity and the reliability scores of the measure were ensured. Since the attributes of the social support measure were essential, information

Table 1. Selection criteria

Inclusion criteria	Exclusion criteria
ARTICLE SELECTION	
Population	
Parent(s) or grandparent(s) primarily involved in raising a child with a congenital disability	Other types of caregivers
Child is below the age of 18 years Infant Newborn Pre-schoolers	Pre-term Older than 18 Young adults
Child has a congenital disability or syndrome defined as a disability identified right from birth, and which is most likely to give rise to further disabilities, requiring lifelong care and rehabilitation (World Health Organization, 2012)	Child has acquired disability/HIV/health conditions/mental illnesses
Outcome	
Author(s) explicitly state and describe the measure for social support used with the measure of either sources AND/OR types of social support AND/OR degree of social support AND/OR satisfaction of social support AND/OR amount of social support	Other supports than social support
Design	
Any quantitative design or mixed method design	Purely qualitative designs Theoretical papers Systematic Reviews
Publication type	
English only, published between 1980-2015 as full-texts in peer reviewed journals	Theses, conference papers, independent assessment tools
MEASUREMENT SELECTION	
Measure is referenced in bibliography of included study	Measurement is not referenced or incorrectly referenced
Social support measure is in the form of a questionnaire	
Measure is in English	

from the referenced paper by the 16 included studies was used as far as possible for the description of the studies and that of the measures.

Results

The systematic search results are illustrated in the PRISMA diagram (Moher, Liberati, Tetzlaff, & Altman, 2009) depicted in Figure 1.

A total of 4148 articles were independently screened on a title level by each of the three authors, culminating in 80% agreement. Thereafter, two reviewers independently screened the articles at abstract and full-text level. Disagreements at abstract level were included until full-text review (Schlosser *et al.*, 2007) with discussion and consensus was reached. From the 54 articles selected on abstract level, 26 were excluded as they did not measure social support, and instead measured support for mothers of infants and children without a disability, professional support for family needs, support from grandparents, professional support to mothers with depression, support to the child with a disability, general parenting stress and social strain. The remaining 28 articles were reviewed on full-text level; nine articles were excluded as they were studies about intervention programmes or the child had no disability, leaving 19 studies for analysis. Three studies were further excluded due to the measure not being in English, the measure being qualitative in nature and the measure not being obtainable in the cited article. The final number of 16 included articles was reached, for which the general characteristics of the studies are described in Table 2. In line with the scoping nature of this review topic, a description of the studies and the social support measures was undertaken, rather than a critical appraisal, as per scoping review guidelines developed by Arskey and O’Malley (2005).

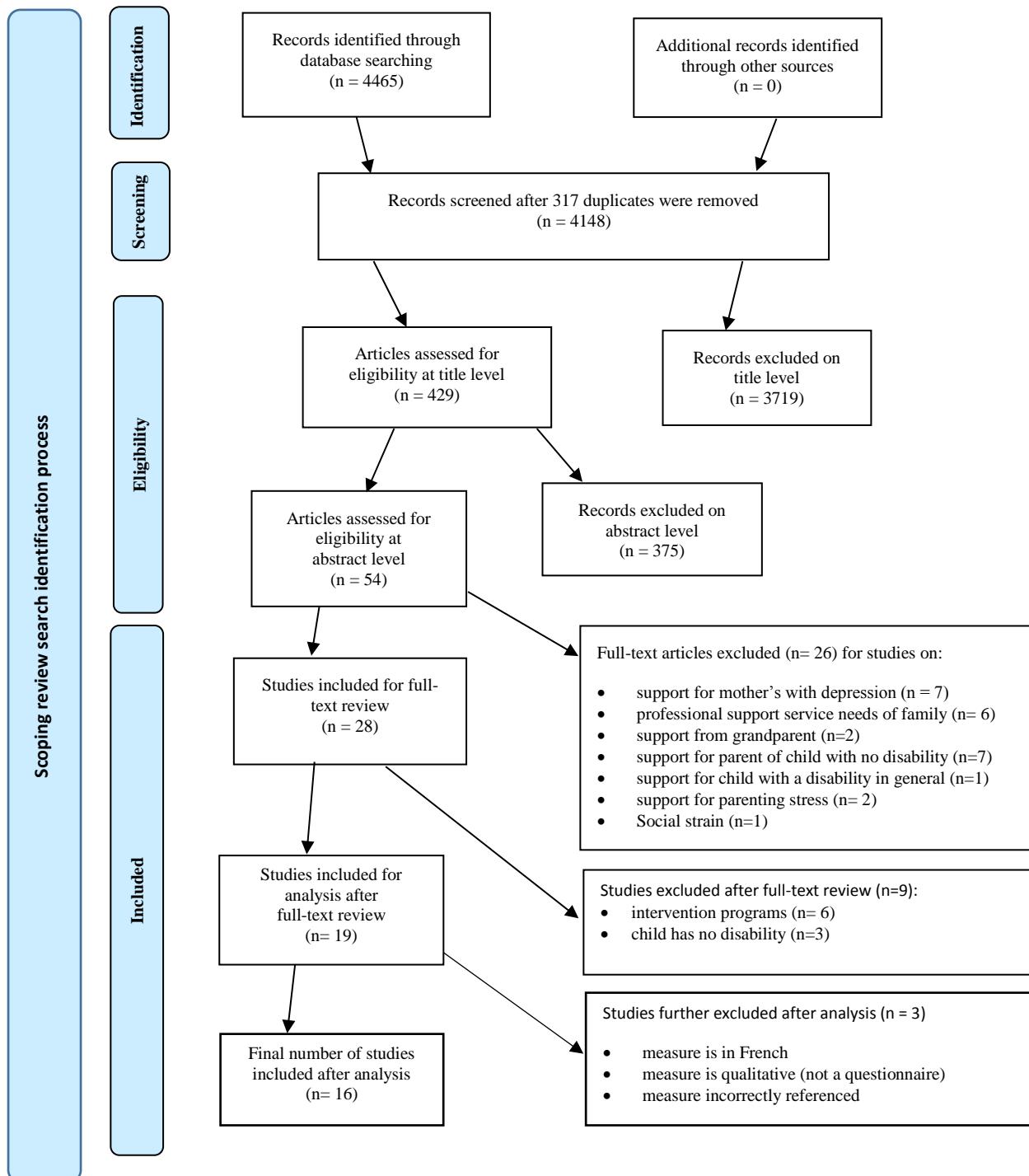


Figure 1. PRISMA Flow diagram adapted from Moher, Liberati, Tetzlaff, Altman, & The PRISMA Group (2009)

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Table 2. Description of characteristics of included studies

Title, author(s) and published year of study	Location and setting of study	Participants and sample size (N)	Reported definition of social support	Other constructs measured in study	Measure used in study(ies)
An Evaluation of a Family-Centred Support Service for Children with a Significant Learning Disability (Truesdale-Kennedy, M., McConkey, R., Ferguson, P., & Roberts, P., 2006)	Northern Ireland; Services for families caring for a child with a learning disability	Families (N= 69) caring for a child with a learning disability	Not mentioned	Evaluation of family services	
Social support provided to caregivers of children with cerebral palsy (Pfeifer, L. I., Silva, D. B. R., Lopes, P. B., Matsukura, T. S., Santos, J. L. F., & Pinto, M. P. P., 2013)	Sao Paulo, Brazil; Paediatric Occupational and Physical Therapy Sector, Neurology department of University Hospital	Caregivers - Mothers (N= 44), grandmothers (N=4) and aunt (N=2) of a child with cerebral palsy	Not mentioned	Child's motor function	Social Support Questionnaire (SSQ; Devised by Sarason, Levine, Basham, & Sarason, 1983)
Social support networks among families of children with craniofacial anomalies (Benson, B. A., Gross, A. M., Messer, S. C., Kellum, G., & Passmore, L. A., 1991)	Country not specified; For craniofacial deformity group - waiting room of Craniofacial Clinics For non-craniofacial deformity group - waiting room at paediatrician	Mothers and fathers (N= 72) of a child with facial deformity/no facial deformity	Not mentioned	Severity of child's disability Severity of child's FD 'handicap' Attractiveness of child	
Families of children with Prader-Willi syndrome: stress-support and relations to child characteristics (Hodapp R. M., Dykens, E. M., & Masino, L. L., 1997)	California, New York New England; 3 parent groups: - the Prader-Willi Syndrome Association (USA) - the Prader-Willi California Foundation, - the Prader-Willi Alliance (New York-New England)	Parents - Mothers (N= 39) and fathers (N= 3) of children with Prader-Willie Syndrome	Not mentioned	Parent and family problems Behaviour problems of child	Family Support Questionnaire (FSQ; Devised by Kazak,1987)

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Title, author(s) and published year of study	Location and setting of study	Participants and sample size (N)	Reported definition of social support	Other constructs measured in study	Measure used in study(ies)
Impact of perceived social support and depression on the parental attitudes of mothers of children who are deaf (Sipal, R. & Sayin, U., 2013)	Ankara, Turkey; Speech and language schools for children who are deaf	Mothers (N=103) of deaf children	Mentioned	Parental attitudes toward child Depression symptoms	
Perceived stress, perceived social support, and wellbeing among mothers of school-aged children with cerebral palsy (Skok, A., Harvey, D., & Reddiough, D., 2006)	Melbourne, Australia; Clinics at the Royal Children's Hospital in Melbourne, Australia	Mothers (N= 43) of children with cerebral palsy	Mentioned	Severity of disability Perceived stress Psychological adaptation and physical health Life satisfaction Wellbeing	
Psychological distress and perceived support among Jordanian parents living with a child with cerebral palsy: a cross-sectional study (Al-Gamal, E., & Long, T., 2013)	Jordan; Paediatric physical therapists at the targeted health care centres and schools	Parents – Mothers (N=134) and fathers (N= 70) of a child with cerebral palsy	Not mentioned	Motor ability of child Perceived stress Depression symptoms Strengths and difficulties of child	Multidimensional Scale of Perceived Social Support (MSPSS; Devised by Zimet, Dahlem, Zimet, & Farley, 1988)
Network characteristics, perceived social support, and psychological adjustment in mothers of children with Autism Spectrum Disorder (Benson, P., 2012)	Massachusetts, USA; Recruited into the study from a variety of public and private schools, multi-system special needs programs, and autism service organizations	Mothers (N=142) of children with Autism	Mentioned	Network characteristics Depression levels Subjective well-being Parent, child and family characteristics	

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Title, author(s) and published year of study	Location and setting of study	Participants and sample size (N)	Reported definition of social support	Other constructs measured in study	Measure used in study(ies)
Information and professional support: key factors in the provision of family-centred early childhood intervention services (Fordham, L., Gibson, F., & Bowes, J., 2011)	New South Wales, Australia; 2 large early childhood intervention agencies	Families (N=130) caring for a child with a disability	Not mentioned	Parent's perception of family centred approach by professionals Parent's perception of empowerment Typical daily events related to hassles Family context	Family Support Scale (FSS; Devised by Dunst, Jenkins, & Trivette, 1984)
Psychometric properties of the Family Support Scale with Head Start families (Hanley, B. U., Tassé, M. J., Aman, M. G., & Pace, P., 1998)	Franklin County, Ohio; 15 Head Start Centres of the Child Development Council (CDC)	Parents (mothers, fathers, step parent, grandparent and other) (N = 244) with at least one child enrolled in Head Start in Central Ohio	Not mentioned	No other constructs	
Support networks of single Puerto Rican mothers of children with disabilities (Correa, V., Bonilla, Z., & Reyes-MacPherson, M., 2011)	Puerto Rico; School districts, Early Intervention programmes, religious institutions and private organisations	Single mothers (N = 25) (never been married/separated, widowed or divorced) of children with a disability	Mentioned	Family system support network	
Stress and coping: A comparison of self-report measures of functioning in families of young children with cerebral palsy or no medical diagnosis (Britner, P. A., Morog, M. C., Pianta, R. C., & Marvin, R. S., 2003)	Virginia, West Virginia, Maryland, North Carolina and Washington DC; Clinics at University medical hospitals, Community hospitals and early intervention programmes	Mothers (N = 87) of children with severe cerebral palsy (N=27), mild cerebral palsy (N= 30) and no known medical diagnosis (N= 30)	Not mentioned	Marital functioning Need for support Parenting stress	
Stress and coping: A comparison of self-report measures of functioning in families of young children with cerebral palsy or no medical diagnosis (Britner, P. A., Morog, M. C., Pianta, R. C., Marvin, R. S., 2003)	Same as previous publication	Same as previous publication	Same as previous publication	Marital functioning Need for support Parenting stress	Support Function Scale (SFS; Devised by Dunst & Trivette, 1988)

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Title, author(s) and published year of study	Location and setting of study	Participants and sample size (N)	Reported definition of social support	Other constructs measured in study	Measure used in study(ies)
Stress, social support and well-being of Arab mothers of children with intellectual disability who are served by welfare services in northern Israel (Duvdevany, I., Abboud, S., 2003)	Northern Israel; Government services	Mothers (N= 100) of children with an intellectual disability	Mentioned	Stress and well-being	Quantitative Social Support Scale (QSSS; Devised by Duvdevany & Abboud, 2003)
Supporting parents of youths with intellectual disabilities and psychopathology (Douma, J. C. H., Dekker, M. C., & Koot, H. M., 2006)	Netherlands; Special schools	Parents (N= 289) of children with Intellectual Disabilities and Psychopathology	Mentioned	Child characteristics and parent characteristics	Need for Help Questionnaire (Devised by Douma, J. C. H., Dekker, M. C., & Koot, H. M., 2006)
Quality of life in adolescents with a disability and their parents: The mediating role of social support and resilience (Migerode, F., Maes, B., Buysse, A., & Brondeel, R., 2012)	Flemish Community, Belgium; Flemish Agency for Disabled Persons (FADP)	Parents – Mothers (N=90) and fathers (N= 42) of adolescents with a disability	Mentioned	Quality of life	Medical Outcome Study Social Support Survey (MOS-SSS; Devised by Sherbourne & Stewart 1991)
Family stress, perceived social support and coping following the diagnosis of a child's congenital heart disease (Tak, R Y., & McCubbin, M. 2002)	California, USA; Paediatric Cardiology Clinics	Parents – Mothers and fathers (N=92) of children with congenital heart disease	Mentioned	Caregiver stress and coping	Personal Resource Questionnaire (PRQ-85) Part II only (Devised by Weinert & Brandt, 1987)

Data Extraction

The 16 included papers were assessed independently by two authors through combined data extraction to meet the objectives set out in aim 1 to extract data based on whether the information was *mentioned* or *not mentioned* specific to: the name of the social support measure, the setting and participants for the study, and the definition of social support provided. Further from aim 1, data extraction was done to meet the objectives of aim 2. Disagreements among reviewers were clarified through discussion using the selection criteria initially agreed upon for data extraction. If consensus was not reached, a third unbiased reviewer was consulted, and full agreement was reached.

Included Studies

The following results relate to the data extracted from the 16 included articles (Table 2).

Definition of social support

Of the 16 articles included, a definition of the construct of social support was expressed in 8 of the 16 studies (Benson, 2012; Caley, 2012; Correa *et al.*, 2011; Douma *et al.*, 2006; Duvdevany & Abboud, 2003; Migerode *et al.*, 2012; Sipal & Sayin, 2013; Skok *et al.*, 2006; Tak & McCubbin, 2002). Douma *et al.* (2006) and Duvdevany and Abboud (2003) referred to social support as an interchange of commodities between individuals, where commodities refer to material, physical, informational and instrumental resources. Benson (2012) defined social support as the characteristics of interconnectedness, embeddedness and network size. Correa *et al.* (2011) contextualised social support within family interventions focusing on resources available to the family and caregiver, with support emerging from family, kinship, informal and professionals. Migerode *et al.* (2012) presented another dimension where social support is defined as a quantitative construct known as social

embeddedness referring to the number of networks, and as a qualitative construct referring to the satisfaction of social support received by the individual. Additionally, Sipal and Sayin (2013) defined social support as its helpfulness or perceived social support. Skok *et al.* (2006) defined social support relating to its effects on stress as a buffer to create coping mechanisms for the caregiver. Fordham *et al.* (2011) used a concrete definition referring to the types of support, while Pfeifer *et al.* (2013) referred to the satisfaction with support received and Truesdale-Kennedy *et al.* (2006) referred to the amount of support received. These various definitions of social support are critical to our understanding of this construct and the different aspects thereof.

Diagnosis of disabilities in studies

From the 16 studies, social support was measured for caregivers of children with a diverse range of congenital disabilities, namely cerebral palsy (CP) (Al-Gamal & Long, 2013; Britner *et al.*, 2003; Pfeifer *et al.*, 2013; Skok et al., 2006), craniofacial deformity (Benson *et al.*, 1991), congenital heart disease (Tak & McCubbin, 2002), Prader-Willi Syndrome (Hodapp *et al.*, 1997), deafness (Sipal & Sayin, 2013), learning disability (Truesdale-Kennedy *et al.*, 2006) and intellectual disability (ID) in youths (Douma *et al.*, 2006; Duvdevany & Abboud, 2003) and disability in general (Migerode *et al.*, 2012).

Social support measured with other constructs

Many of the studies measured social support and its influences on broader constructs for caregivers of a child with a disability with varied results. Social support was highly needed by parents of youths with ID (Douma et al., 2006). Correa *et al.* (2011) highlighted the strong role in the informal networks of single mothers of children with disabilities. Additionally, social support was perceived to be more helpful with higher levels of marital

satisfaction of parents of children with disabilities (Britner et al., 2003). The function of social support also had a strong correlation with family experiences (Fordham *et al.*, 2011) but was social support was not always welcome by families if their needs were to be met (Truesdale-Kennedy et al., 2006). Hodapp *et al.*(1997) found no significant correlation between social support and stress of caregivers of children with Prader-Willie syndrome. However, Duvdevany and Abboud (2003) mothers of children with ID had lower parenting stress and higher well-being if they had higher amount of informal support resources. Social support also lowered depression and contributed to positive parenting of mothers of deaf children (Sipal & Sayin, 2013) with higher distress, parenting stress and depression for parents of children with CP who had poor social support (Al-Gamal & Long, 2013). Social support also had a full mediating effect on quality of life of parents of adolescents with disabilities (Migerode et al., 2012). Perceived social support further reduced depression and increased well-being in mother of children with autism (Benson, 2012), predicted well-being with moderate mediating effect on stress of mothers of children with CP (Skok et al., 2006), and predicted family stress and coping while influencing family resilience of children chronic illness (Tak & McCubbin, 2002).

Social support measures identified from the included studies

From the 16 articles, 9 measures were identified. Table 3 describes the relevant information accessed from the 16 studies regarding the internal structure of the social support measures. The studies were grouped in Table 2 according to the social support measures they used to highlight the overlap of studies that used the same social support measure (for example Benson *et al.*, 1991; Pfeifer *et al.*, 2013; Truesdale-Kennedy *et al.*, 2006). Despite the social support measure being dated, they continue to be used extensively; the date of the measures ranged from 1983 to 2013.

Table 3. Description of social support measures

Name of social support measure and author(s)	Source of additional psychometric information	Reported country, population group and sample size on which measure was devised	Reported aim and domains of measure	Reported rationale for using measure	Reported internal structure of measure	Reported content validity of measure	Reported construct validity of measure	Reported reliability of measure
Social Support Questionnaire (SSQ by Sarason, Levin, Basham & Sarason, 1983)	Assessing Social Support: The Social Support Questionnaire (Sarason, Levin, Basham & Sarason, 1983)	USA University of Washington University students N = 602	To measure 1) perceived availability (number of support) of social support (N) 2) satisfaction with social support received (S)	According to the known reliability and validity of measure (Truesdale-Kennedy et al., 2006) According to dimension(s) of social support measured in scale (B. A. Benson et al., 1991; Pfeifer et al., 2013)	Subscale N for the list the number of people available for support, a score is allocated for each support person listed Subscale S for satisfaction of support Likert scale 'very satisfied' to 'very dissatisfied.' Overall N and S scores are obtained by dividing the sum of N or S scores for all items by 27, the number of items.	Based on preliminary item analysis Piloting of possible scoring methods Computing the number of listed supports from pilot groups Assessing frequency of contact with social support	Established through Exploratory Factor Analysis Resulted in strong representation of the general concept of social support	Total = 0.97 Subscales: 1) N (number scale) scores = 0.97 2) S (satisfaction scale) scores = 0.94 Test-retest 4-week period r= 0.90 for N and r= 0.83 for S. Total scale retest r not mentioned
Family Support Questionnaire (by Kazak, 1987)	Families with disabled children: stress and social networks in three samples (Kazak, 1987) and Families of children with Prader-Willi syndrome: stress-support and relations to child characteristics. (Hodapp, Dykens & Masino, 1997) No other handsearched information was available	USA Clinics -Sample 1 (N=36) Families with children who are institutionalised v/s non-disabled children -Sample 2 (N= 43) Families of children with phenylketonuria (PKU) v/s children with no chronic physical or psychological problems. -Sample 3 (N=46): Families of children with spina bifida v/s children with non-handicapped children	To measure network density in terms of 1) source of support 2) type of support 3) density of support	Not mentioned in study (Hodapp et al., 1997)	1. List important people in past 4-6 Weeks (e.g. family members, friends or professionals - up to 14 names are possible 2. State relationship with the persons 3. State type of support provided by this person (emotional, informational, tangible, or service) 4. Density of the social network determined by dividing the number of actual relationships by the total number of possible relationships	Based on theoretical framework related to family stress and social network	Not mentioned	Not mentioned

Name of social support measure and author(s)	Source of additional psychometric information	Reported country, population group and sample size on which measure was devised	Reported aim and domains of measure	Reported rationale for using measure	Reported internal structure of measure	Reported content validity of measure	Reported construct validity of measure	Reported reliability of measure
Multidimensional Scale of Perceived Social Support (MSPSS by Zimet, Dhalem, Zimet & Farley, 1988)	The Multidimensional Scale of Perceived Social Support (Zimet, Dhalem, Zimet & Farley, 1988)	USA Duke University University students N= 275	To measure the adequacy of subjective social support from three specific sources: -Family -Friends -Significant other	According to dimension(s) of social support measured in scale (Sipal & Sayin, 2013) According to the known reliability and validity of measure (P. R. Benson, 2012) Not mentioned (Al-Gamal & Long, 2013; Skok et al., 2006)	12-item scale on a 7-point point Likert scale (1 = very strongly disagree to 7 = very strongly agree) to score perceived adequacy of support from family, friends, a significant other. Total of 28 points (out of a maximum of 84). Higher scores indicates greater perceived social support.	Based on literature review of theoretical function of social support as a buffer of stress and piloting of scales and revision of scales	Established through Exploratory Factor Analysis and Principal Component Analysis	Total= 0.88 Subscales: Significant other= 0.91 Family = 0.87 Friends = 0.85 Test-retest after 2 to 3 months r=0.85 of scale
Family Support Scale (FSS by Dunst, Jenkins & Trivette, 1984)	Winterberry Press assessment scale: Family Support Scale (Dunst, Jenkins & Trivette, 1984)	Country not mentioned Parents raising a young child at risk and/or presenting developmental delays N= 224	To measure helpfulness of social support	According to dimension(s) of social support measured in scale (Britner et al., 2003; Correa et al., 2011; Fordham et al., 2011; Hanley et al., 1998)	19-item measure helpfulness of sources of support on 5 point Likert scale (1 = 'not at all helpful' to 5 'extremely helpful') Score is obtained by adding the unadjusted scores of all 19 items to obtain the total of FSS score	Not mentioned	Established through Exploratory Factor analysis and Principal Factor Analysis Resulted in 5 factors: I Kinship (spouse/partner's friends, own friends, other parents, own children, church) II Spouse/partner support (spouse/partner, spouse/partner's parent, spouse/partner's relative/kin) III Social organisations (social groups/clubs, parent's groups, school/day care centres, co-workers) IV Informal support (own relative/kin, own parents) V Professional services (early intervention programs, professional helpers, family/child's physician, other professional agencies)	Total= 0.79 Split-half = 0.77 Subscales = 0.35 to 0.76 Test re-test: 1 to 2 year r= 0.50 for scale

Name of social support measure and author(s)	Source of additional psychometric information	Reported country, population group and sample size on which measure was devised	Reported aim and domains of measure	Reported rationale for using measure	Reported internal structure of measure	Reported content validity of measure	Reported construct validity of measure	Reported reliability of measure
Support Function Scale (SFS by Dunst & Trivette, 1988)	Winterberry Press assessment scale: Support Function Scale (Dunst & Trivette, 1988)	Country not mentioned Parents of children with disabilities or delays and children at risk for poor developmental outcomes N= 121	To measure the need for types of social support	According to dimension(s) of social support measured in scale (Britner et al., 2003)	20-items measure the need for support three main areas, emotional, child support, practical on 5-point Likert scale for need for a types of support (1 = 'never' to 5 = 'quite often') The higher scores indicate more support and less need for help	Based on extensive interviews with parents of preschool-aged children	Established through Principal Factor Analysis Resulted in 5 factors: I Emotional support II Child support III Financial support IV Instrumental support V Agency support	Total = 0.87 Split-half = 0.88 Test re-test 1 month period r = 0.62
Quantitative Social Support Scale (QSSS by Duvdevany & Abboud, 2013)	Stress, social support and well-being of Arab mothers of children with intellectual disability who are served by welfare services in Northern Israel (Duvdevany & Abboud, 2013) No other hand searched information was available	Northern Israel Welfare services and non-serviced mothers Israeli Arab mothers of children with intellectual disability N= 100	To measure available support from family members, neighbours, friends, social organisations, professionals, formal services	According to the specific population of the study (Duvdevany & Abboud, 2003)	Subscales: -Formal support - Informal support 5 point Likert scale from 'not at all' to 'very much.' A high score indicates higher amount of support	Not mentioned	Not mentioned	Total = Not mentioned Subscales = 0.77 Tet-retest duration and score of scale not mentioned
Need for Help Questionnaire (Douma, Dekeer & Koot, 2006)	Supporting parents of youths with intellectual disabilities and psychopathology (Douma, Dekeer & Koot, 2006) No other hand searched information was available	Netherlands Special schools, day-care centres and other schools Parents of youths with psychopathology; N=982	To measure -need for types of social support -whether the need has been met - reasons for not seeking support	According to the specific population of the study (Douma et al., 2006)	Four subscales: -Parental perception (4 point Likert from 'very good' to 'very bad') -Need for support (4 point Likert from 'no need' to 'very strong need.') -Met need (4 point Likert from 'currently met' to 'unmet need') -Reasons for not seeking support out of 24 options (3 point Likert from 'not at all' to 'very much so')	Based on literature review and the use of a combination of other scale and the use of semi-structured interviews with eight parents of children diagnosed and seven service providers	Not mentioned	Not mentioned

Name of social support measure and author(s)	Source of additional psychometric information	Reported country, population group and sample size on which measure was devised	Reported aim and domains of measure	Reported rationale for using measure	Reported internal structure of measure	Reported content validity of measure	Reported construct validity of measure	Reported reliability of measure
Medical Outcome Study Social Support Survey (MOS-SSS, by Sherbourne & Stewart 1991)	The MOS Social Support Survey (Sherbourne & Stewart, 1991)	USA Clinics Patients with prevalent and treatable chronic conditions; N= 298	To measure types of social support -emotional support -informational support -tangible support - positive social interactions -affectionate support	According to dimension(s) of social support measured in scale (Migerode et al., 2012)	19-items on 5 point Likert scale from 'none of the time' to 'all of the time.' Score from 0 to 100, where the higher the score the more frequent the availability of the different types of support	Based on a review of available measures of social support	Exploratory Factor Analysis Confirmatory Factor Analysis Resulted in the five types of social support (emotional, informational, tangible, social interactions, affectionate)	Total = >0.72 Subscales = 0.72 to 0.87 Test re-test 1 year $r > 0.50$ as reported
Personal Resource Questionnaire (PRQ-85 by Weinert & Brandt, 1987)	Family stress perceived social support and coping following the diagnosis of a child's congenital heart disease (Tak & McCubbin, 2002) Personal Resource Questionnaire: A systematic review (Tawalbeh & Ahmad, 2013)	USA; Family Health Study data Families (men and women) managing multiple-sclerosis Sample 1 N= 449 Sample 2 = 450	To measure the level of perceived support in terms of 1) amount of supports available 2) the satisfaction of support received 3) the need for social support related to 10 specific situations	According to dimensions of social support measured in scale and the known reliability and validity of measure(Tak & McCubbin, 2002)	Sub-scale 1: -resources available -satisfaction with resources -resources accessed within past six months Subscale 2: 25-items with 7 point Likert scale 'very satisfied' to very dissatisfied' from 25 to 175 or higher scores.	Based on theoretical framework of Weiss' (1969, 1974) model of relational functions	Factor Analysis performed to revise PRQ-85 to PRQ-2000; Resulted in 25 items reduced to 15 items	Total= 0.92 Sub-sample 1 = 0.93 Sub-sample 2 = 0.90 Test-retest duration and score for entire scale not mentioned

Aims of the measures

The aims of the nine measures revealed that social support could be identified via concrete and measurable domains, such as amount of social support received, types of support (emotional, instrumental), sources of support (family, friends, significant other), need for support (frequent need, if the need had been met), helpfulness of social support and satisfaction of the social support received. Most of the measures aimed to tap into more than one of the domains of social support, for example the Family Support Questionnaire (FSQ) measured the sources, types and density of the social support received. Other measures, such as the Family Support Scale (FSS) which measured the helpfulness of social support and the Support Functions Scale (SFS) which measured the need for types of social support aimed to identify only one domain of social support. Certain measures provide a closed choice, such as the Medical Outcome Study Social Support Survey (MOS-SSS) for the types of social support received, or a closed choice for the sources of support, such as the Multidimensional Scale of Perceived Social Support (MSPSS) and the Quantitative Social Support Scale (QSSS). The Need for Help Questionnaire focuses on the domain of need for help or social support as it measures not only the types of help available but also whether the need had been met and the reasons for not seeking help.

Rationale for the use of measure by included studies

The rationale for selecting a social support measure was either stated based on the known reliability and validity of the measure (Benson, 2012; Tak & McCubbin, 2002; Truesdale-Kennedy *et al.*, 2006) or not clearly stated, where it could be inferred that the instruments were chosen for the relevant dimension of social support being measured for the study. Such dimensions include perceived social support (Al-Gamal & Long, 2013; Sipal & Sayin, 2013; Skok *et al.*, 2006), need for, sources of and helpfulness of social support

received (Benson *et al.*, 1991; Britner *et al.*, 2003; Correa, Bonilla, & Reyes-Macpherson, 2011; Fordham, Gibson, & Bowes, 2011; Hanley, Tasse, Aman, & Pace, 1998; Hodapp, Dykens, & Masino, 1997), amount and types of social support (Migerode *et al.*, 2012; Pfeifer *et al.*, 2013) and satisfaction of social support received (Pfeifer *et al.*, 2013; Tak & McCubbin, 2002). For other studies, a scale was devised to suit the specific population being researched (Douma *et al.*, 2006; Duvdevany & Abboud, 2003).

Population and setting in which the measure was devised

The nine measures were devised on various populations, most of which were not specifically on caregivers of a child with a disability. The SSQ and MSPSS were developed on university undergraduate students, to investigate the types of social support they received; the MOS-SSS and FSQ were devised in clinical settings where families of adult patients were consulted for the development of the measure. The Personal Resource Questionnaire (PRQ-85) used secondary data from the Family Health Study to devise the questionnaire for carers of terminally ill adult patients. The only measures devised on caregivers, mostly parents, of children with disabilities or at risk of a disability were the QSSS, Need for Help Questionnaire, the SFS and FSS.

Internal structure of the scales

The internal structures of the measures were adequately described by all the studies, where most were self-report questionnaires, with Likert response scales. For those measures tapping into more than one domain of social support, a combination of responses was required. For example, the questionnaires which measured the sources of social support (SSQ and FSQ) required the respondent to list the support available to them from a certain timeframe, for instance the past 4–6 weeks. A score was then given for each person listed.

The Likert scale responses for each measure varied according to the domain being measured. Satisfaction of social support received the scale ranging from ‘very satisfied’ to ‘very dissatisfied’ (SSQ; PRQ-85). Frequency of support or help needed varied from ‘never/none of the time’ to ‘quite often/all of the time’ (QSSS, SFS, MOS-SSS). The helpfulness of support varied from ‘not at all helpful/very strongly disagree’ to ‘extremely helpful/very strongly agree’ (FSS, MSPSS); the availability of social support varied from ‘not at all’ to ‘very much’ (QSSS). The Need for Help questionnaire contained three subscales to measure perception of social support from ‘very good’ to ‘very bad’; the need for support contained subscales from ‘no need’ to ‘very strong need’; reasons for not seeking support ranged ‘from not at all’ to ‘very much’. The FSQ has a different layout; the respondent lists the people who have been helpful in the past 4–6 weeks, followed by stating the relationship this person has with the respondent and the type of support they provided. The density of the social network was then calculated by dividing the number of relationships by the total number of possible relationships.

Content validity of scales

Content validity relates to whether the items in the scale measure the operationalised main construct (Kimberlin & Winterstein, 2008). This validity is established using the judgment of experts from the field of study through rigorous processes such as literature reviews, focus groups, expert panels for piloting and refining of the items for the scale (DeVen *et al.*, 2007). From the reported information of the nine social support measures, several preliminary steps were followed to ensure content validity. Two measures (SSQ and MSPSS) were devised on large populations of university students, where preliminary item analysis and literature reviews were used respectively, followed by rigorous piloting on large samples of student populations with constant revisions made to the scales. The other

measures were mostly based on theoretical frameworks and the functions of social support, specifically how it is perceived and available to the individual (SSQ), its effect on stress (QSSS, FSQ & MSPSS), the need for help (Need for Help Questionnaire), the health and well-being of individuals (MOS-SSS) or the model of relational functions by theorists such as Weiss (1969 cited in Weinert & Brandt, 1987) in the PRQ-85. The SFS and FSS were devised using themes generated from semi-structured interviews with parents within the field of early intervention.

Construct validity of scales

The construct validity of a scale refers to whether the variables are linked to the theoretical construct for which the scale is intended to measure, displayed through correlations in line with expected patterns (Kimberlin & Winterstein, 2008). Only three measures (FSQ, Need for Help Questionnaire and QSSS) had no information regarding factor analysis. The other six measures stated that factor analysis was carried out. Exploratory Factor Analysis (SSQ) or only Principal Factor Analysis (SFS) or both (MSPSS) or Confirmatory Factor Analysis and Exploratory Factor Analysis (FSS and MOS-SSS) or Sequential Factor Analysis was used (PRQ-85). For some measures, the factor analysis that was carried out provided a method of revising the scale and reducing the number of items in the scale to better the measure overall or to ensure that the constructs measured in the scale were appropriate. For example, the PRQ-85 that contained 25 items was reduced to 15 items, leading to a new revised scale, the PRQ-2000. Through factor analysis, Zimet *et al.* (1988) confirmed that the constructs of three sources of perceived support (family, friends and significant other) in the MSPSS were understood by participants. This confirmed their theoretical underpinning of Procidano and Heller (1983 cited in Zimet *et al.*, 1988) that these three sources are consistent sources of support. Sarason *et al.* (1983) reported strong factor

analyses, indicating that the SSQ measured and represented different dimensions of the general concept of social support.

Reliability of scales

The reliability of a measure relates to the measurement error which is recorded when the instrument is devised, with a focus on reducing the error in the measurement process as far as possible (Kimberlin & Winterstein, 2008). Measurement error and how this was reduced was not mentioned in any of the nine measures. The coefficient of reliability ranges from 0.00 to 1.00; a higher coefficient indicated greater reliability of the scale (Kimberlin & Winterstein, 2008). The reliability scores for three measures (Need for Help Questionnaire, FSQ and QSSS) were not found within the information about the scale or in the studies that used the measures. From the nine measures, the SSQ had the highest reported reliability score of 0.97, followed by the PRQ-85 with 0.92, the MSPSS with 0.88, the SFS with 0.87, the FSS with 0.79, and the MOS-SSS with 0.72. The reliability of the SSQ, MSPSS and PRQ-85 provided justification for use by 3 of the 16 included studies (Benson, 2012; Tak & McCubbin, 2002; Truesdale-Kennedy *et al.*, 2006). The reliability of a measure is also determined by testing the stability of the measure, where its test-retest reliability is carried out at two different points in time (Kimberlin & Winterstein, 2008). The time interval between the re-testing of the scale should ideally take place during a period long enough for the first administration of the test to not affect the results of the second test (Kimberlin & Winterstein, 2008). Only five measures (SSQ, SFS, MSPSS, FSS and MOS-SSS) had this information available. The re-test of the SSQ and SFS was performed after one month. The SSQ had a reported stability over a four-week period with high correlation for the subscales N of 0.90 and S of 0.83; however, no total test-retest score was mentioned in the information available (Sarason *et al.*, 1983). The SFS had a resultant reliability of 0.62 for the entire scale

after a one-month retest period (Dunst & Trivette, 1986). The MSPSS was retested after a period of 2–3 months with a high reported stability of 0.85 for the entire scale and adequate stability during this time (Zimet *et al.*, 1988). The FSS and MOS-SSS were retested after one year. The FSS successfully detected stability in social support relationships over time with a test-retest reliability of 0.50 for the total scale (Dunst, Trivette, & Jenkins, 1984). The MOS-SSS did not specify their test-retest score, but was reported to be above 0.50 (Sherbourne & Stewart, 1991).

DISCUSSION

The current scoping review aimed to identify and describe various instruments that have been used in studies investigating social support for caregivers of a child with a congenital disability. The development of research in the field of social support for caregivers of a child with a congenital disability is encouraging, where evidence-based tools exist for measuring social support. However, the limited number of studies highlighted in this review reflects the dearth of research on social support for this specific population of caregivers. Identifying the benefits and shortcomings of the social support measures available results in a greater likelihood of selecting, adapting and implementing them effectively to tap into the different facets and benefits of social support for families in need.

The overall impression of how the 16 studies reported the social support measures remains moderate according to their reported psychometric properties, where the attributes of some of the measures were not readily available. A failing in many of the studies concerns their neglecting to mention how they adapted the instrument to the specific population of their study. This is specific to the included studies (Al-Gamal & Long, 2013; Benson *et al.*, 1991; Benson, 2012; Pfeifer *et al.*, 2013; Sipal & Sayin, 2013; Skok *et al.*, 2006; Truesdale-

Kennedy *et al.*, 2006) which used questionnaires devised on a population other than caregivers of a child with a disability (e.g. the SSQ and the MSPSS devised on undergraduate university students). This implies that greater consideration must be given to the content validity of the instrument, especially when researchers aim to measure social support for this specific and complex population of caregivers of children with a disability. From the scoping review, the QSSS, The Need for Help Questionnaire, the SFS and the FSS could potentially be used.

The current review found that while some social support measures are more commonly used (e.g. the MSPSS is used by four studies), the majority would probably not perform well if rated against a strict psychometric checklist such as the COSMIN, the COensus-based Standards for the selection of health Measurement INstruments checklist, which is widely deemed a useful tool for reviewing measuring instruments (Mokkink *et al.*, 2010; Terwee *et al.*, 2012). The poor fairing of the measures on the COSMIN would be due to the poor availability of information regarding the internal consistency, criterion validity, reproducibility (agreement and reliability), responsiveness or floor and ceiling effects. An absence of adequate psychometric information may imply either of the following: 1) the authors of the included articles were not able to access in-depth psychometric properties of the questionnaires to include these in their study; 2) the availability of the psychometric properties of the social support measures are not readily available to researchers unless the authors of the measures are contacted directly.

The combination of the various social support measures identified in this review concludes that developments in this field suggest a move towards measuring social support as a construct by using self-reported measures for caregivers of a child with a congenital

disability. However, given the close relationship between social support and the context thereof, it is imperative that the selection of such self-reported measures be described and validated. Furthermore, greater research is required to account for undescribed psychometric properties, such as internal consistency, agreement, reliability, responsiveness, interpretability and various areas of validity. As an advancement, social support measures require further longitudinal testing to ensure the responsiveness of a particular measure over a period.

This review did not include grey literature (unpublished or non-indexed studies or theses). Future research should expand on the current scoping review by including other studies on health conditions, which may unearth further instruments used to measure social support for caregivers. The limited number of scales available for measuring social support in families raising a child with a congenital disability typically indicates that further development of quantitative measures for this population is needed. Measures which are sensitive in terms of reliability and grounded in sound validity are necessary. The ability to measure the construct of social support within the context of caregivers of a child with a disability is a growing need. For social support to be effective, a balance is required between the recipient's needs and the provider's sensitivity to the recipient's circumstances, for example stressful events they face (Uchino, 2009). Thus, the field of research of social support is a promising area, as the practical implementation and facilitation of social support requires an analysis of the mutual interaction of the recipient and provider of the support. According to Sarason and Sarason (2009), further research is needed to identify and explore the types of relationships that facilitate the provision of social support, including what cognitive schemas would lead a person to provide social support. Finally, further knowledge is required regarding the 'personal, social and biological correlates' of receiving and

providing social support (Sarason & Sarason, 2009). The more social support one receives, the more support they are willing to offer to others. Thus, devising and using social support measures in family-centred services continue to play a major role in evidence-based service provision and in advancing research on the efficacy of these services.

Key Message:

Social support is a complex construct that has been defined in various ways in literature.

Social support has many benefits for caregivers when raising a child with a disability.

This review uncovered a limited number of studies which described measures for social support.

The included studies that describe measurement tools for social support have shortcomings in addressing the psychometric properties of the tools.

The accurate measurement of social support provides direction to intervention by allowing professionals to identify social supports available to caregivers as a resource and protective factor.

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