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A scoping review of parental roles in rehabilitation interventions for children with developmental delay, disability, or long-term health condition

Katherine A. Smith, M. ECI*

Alecia E. Samuels, PhD

Author affiliations: Centre for Augmentative and Alternative Communication, University of Pretoria, South Africa

***Correspondence:** Katherine Smith
Centre for Augmentative and Alternative Communication, Room 2-36 Comm Path Building, University of Pretoria, Lynwood Road, Private Bag X20, Hatfield 0028, Pretoria, South Africa (smithkatherine12@gmail.com)

HIGHLIGHTS

- There are a range of distinct types of roles that parents could potentially take on in their child's rehabilitation interventions.
- The parent-professional relationship seems to influence the type of roles that parents take on in their child's intervention.
- The type of roles that parents adopt in their child's intervention seem to influence parental engagement.
- Parental roles can be placed on a continuum of passive to active tasks and responsibility.

ABSTRACT

The importance of parental roles in rehabilitation interventions (i.e.: the tasks and responsibilities assigned to parents in intervention) is widely reported but there is a paucity of information regarding the tasks linked with specific parental roles. A rigorous scoping review was conducted to understand the various roles that parents of children with developmental delays, disabilities, and long-term health conditions perform in intervention and the tasks and responsibilities associated with each role. The results confirm that parents take on distinct intervention roles which can be placed on a continuum from passive to active responsibility. Some parental roles are clearly associated with tasks completed in-session, some are linked with out-of-session tasks while others entail a combination of in-and out-of-session tasks. The in-session tasks linked with the learner role emerged as central to enabling parents to assume other in-and out-of-session roles. The results also highlight the influence of the parent-professional relationship on the type of roles parents take on in their child's intervention. The findings of the scoping review serve as the initial step in developing items for a tool to measure the type of roles that parents assume in intervention to empirically test the relationship between these roles and parental engagement.

Keywords: Rehabilitation; Intervention; Parental role; Child; Developmental delay; Long-term health condition; Disability; Involvement; Engagement

What this paper adds

An increasing number of studies are examining parents' experiences of rehabilitation interventions to promote their active participation in intervention. The literature suggests that parents may be required to take on more active roles to promote higher levels of engagement required in family-centred interventions. Parental roles in rehabilitation interventions have, however, received little attention and professionals seem to have a limited understanding of these roles. Professional capacity to support parents to take on more active roles is restricted when there is uncertainty regarding role possibilities for parents and the tasks associated with these various roles. Furthermore, parental stress associated unclear roles may mean that parents are less likely to participate in intervention. This paper adds to the literature by mapping the types of roles that parents could potentially take on in their child's

intervention and the passive to active tasks and responsibilities associated with each of these roles. The results could potentially assist professionals to understand the effects of promoting certain types of parental roles on the intervention process framed within their relationship with parents. The quality of this relationship has been shown to be related to levels of parental engagement in their child's intervention. Parents could also be supported to understand the boundaries of their roles and make informed decisions about how actively they wish to be involved in their child's intervention. It would also help parents understand the effect that these decisions could have on the type of support they can expect from professionals to meet their child and family's needs.

Keywords: Rehabilitation, intervention, parental role, child, developmental delay, long-term health condition, disability, involvement, engagement

1. INTRODUCTION

The Model of Human Occupation (MOHO) (Kielhofner & Burke, 1980) defines a role as a set of required behaviors that go along with occupying a position in a social group. Our concept of our occupational roles organizes our behavior and influences what we do daily (Kielhofner & Burke, 1980). Roles give us our identity and provide us with the requirements for how that identity is fulfilled (Blesedell Crepeau, Cohn, & Boyt Schell, 2004). Adults typically assume different roles that may be related to their employment (e.g. employee, colleague), community (e.g. neighbor), or family (e.g. spouse, parent). Specifically, parenting roles are considered a central human occupation (Kielhofner & Forsyth, 1997; Llewellyn, 1994). Parenting refers to the variety of functions or responsibilities that parents undertake to foster their child's achievement of socially and developmentally appropriate skills (Sandler, Schoenfelder, Wolchik, & MacKinnon, 2011).

The parental role in rehabilitation interventions is defined as the set of tasks or responsibilities attributed to parents in intervention (Sugden, Munro, Trivette, Baker & Williams, 2019). To meet their child's developmental needs, some parents of children with developmental delay, disability, or long-term health conditions may extend their occupational parenting role to incorporate a variety of tasks and responsibilities in

addition to those classified as typical parenting responsibilities (Lutz, Patterson & Klein, 2012; Safe, Joosten, & Molineux, 2012) These responsibilities may be related to meeting their child's extensive care, medical and developmental needs (Lutz et al., 2012; Safe et al., 2012) or participating in their child's rehabilitation interventions (Albright et al., 2016; Minnes, Perry, & Weiss, 2015).

Parental roles are regarded as central to rehabilitation interventions for children and their families (Kemp & Turnbull, 2014; Osher & Osher, 2002; Robert, Leblanc, & Boyer, 2015). Parents who assume active roles in their child's intervention can work with professionals to formulate and optimize learning opportunities that align with the child's capabilities and meet family needs (Sukkar, Dunst, & Kirkby, 2017). Quality parent-professional relationships, characterized by a robust working rapport, trust, and constructive exchanges (Reeder & Morris, 2018), are linked with fostering a supportive and caring environment that invites parents to participate in intervention (Carroll & Sixsmith, 2016). In this way, through their relationship, parents and professionals can work together to organize and implement effective support systems for the child and the family (Guralnick, 2008; Sukkar et al., 2017).

Parental roles in intervention are generated and develop within the interpersonal relationships that are so intrinsic to the intervention process between the parent, child, and professional(s) (Tsai, Tsai & Lotus Shyu, 2008; Davies, Marshall, Brown & Goldbart, 2017; King, Currie, & Petersen, 2014; Carroll & Sixsmith 2016). Humans generate and modify their occupational roles through dynamic interaction with their environment. These interactions influence their expectations and behavior (Blesedell Crepeau et al., 2004). Specifically, it is through iterative exchanges with professionals (Davies et al., 2017; Davies, Marshall, Brown & Goldbart, 2019) that parents formulate and develop expectations for their own and the professional's roles and knowledge to enact their roles (Hessel, 2004; Smart, Nalder, Rigby & King, 2019). Parents who understand the professional's intentions and expectations are motivated to get involved during sessions and carry over intervention to the home i.e., assume more in- and out-of-session responsibility (Carroll & Sixsmith 2016; King et al. 2019a; Phoenix, Smart & King, 2019). The parental role in intervention is affirmed as parents recognize that their participation in intervention supports their child's progress (King et al.; 2019b). Growing parental competence (i.e., improved knowledge and skills) motivates parents to adopt more active in-session tasks and transfer strategies

learned into their daily lives by assuming more active out-of-session roles. Positive interactions mean that parents and professionals experience satisfaction, enjoyment, and a sense of connection from engaging in intervention. This, in turn, supports a greater commitment to collaboratively-devised goals, further affirming parental roles in their child's intervention (King et al., 2019b; p. 6; King et al., 2019a).

Across the literature, the types of roles that parents assume in their child's intervention are suggested to be linked with the degree of parental involvement (Hoover-Dempsey & Sandler, 1997; Walker et al., 2005) or engagement (D'Arrigo Ziviani, Poulsen, Copley, & King, 2016; King et al., 2014). In their study mapping the trajectory of parent-professional relationships in intervention, Carroll and Sixsmith (2016) uncovered that parents need to understand role boundaries to engage in intervention. Parents who understand their roles are ready to engage earlier in intervention and are willing to work to maintain their engagement over the course of intervention. For example, if the parental role involves ensuring that their child only attends the intervention session, this is suggested to be linked with limited participation or lower levels of engagement (Davies et al., 2017). If the parental role includes decision making and carry over of intervention out of sessions, this implies higher levels of parental engagement (James & Chard, 2010; Forsingdal et al., 2013). The literature alludes that, within the intervention context, parents may assume different types of roles that influence their level of engagement (Davies et al., 2017; Forsingdal, St John, Miller, Harvey, & Wearne, 2013). Studies on role negotiation in intervention (Dodd, Saggers, & Wildy, 2009; Hurtubise & Carpenter, 2011; p. 85) question whether parents are "ready, willing, and able" to assume more active roles linked with the higher level of engagement expected of parents in family-centered interventions. As yet, the relationship between the types of roles parents take on in intervention and their levels of engagement has not been empirically tested.

The terms 'participation', 'involvement,' and 'engagement' have often been used interchangeably in the literature (Imms et al., 2017; King et al., 2019a). For the purposes of this paper, it is suggested that these terms be viewed as a continuum of related constructs (Figure 1). Parental participation denotes the active contributions that parents make as they partake in their child's intervention (Hock, Yingling, & Kinsman, 2015; King, Desmarais, Lindsay, Piérart & Tétreault, 2015). Within the framework of the International Classification of Functioning (ICF-CY) (World Health

Organisation, 2007), Imms et al. (2017) explain that the construct of participation includes two major elements; namely frequency of attendance, and involvement. Within this definition, attendance refers to one's physical presence in the intervention session while involvement refers to one's "experience of participation while attending" a life situation such as an intervention session (Imms et al., 2017; p. 36; Imms, 2017). Attendance is, therefore, a prerequisite for involvement, meaning that one cannot develop the level of commitment and investment associated with involvement without being present. Involvement suggests more than parents being present. It indicates a degree of social connection between the parent and the professional that develops from shared investment or commitment to achieving intervention outcomes (Bright, Kayes, Worrall, & McPherson, 2015). Involvement, as defined in the family of Participation Related Constructs (fPRC) model (Imms et al., 2017), can therefore, be likened to engagement (Imms, 2017). Parental engagement refers to a parent's "overall involvement (e.g., behavioral coordination, attendance, participation in sessions, and/or out of sessions) and investment" (e.g., cognitive and affective involvement) with and in intervention (Melvin, Meyer, & Scarinci, 2019, p. 1; King et al., 2014; King et al., 2019b; Imms, 2017). An engaged client is ready (i.e., emotionally receptive), willing (i.e., cognitively receptive), and able (i.e., has the needed knowledge, skills, and ability) to actively partake in intervention (King et al., 2017; p. 2). For the purposes of this paper, engagement is the preferred term as it is used more consistently in rehabilitation interventions studies.

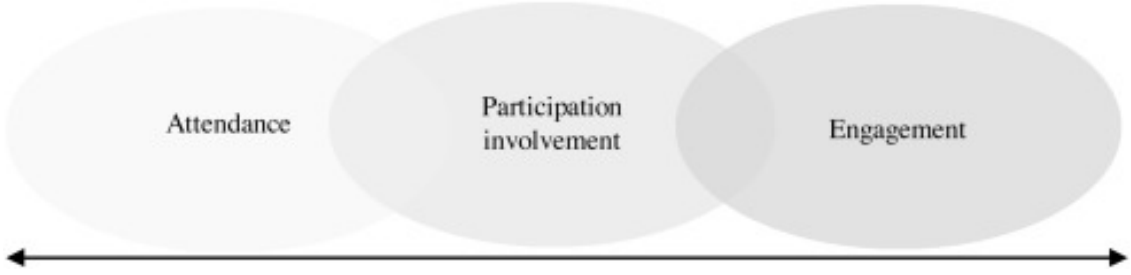

Fig. 1. A continuum of engagement related constructs.

The parent-professional relationship is highlighted as central to initiating and maintaining a parent's engagement in their child's intervention (D'Arrigo et al., 2019; King et al., 2019a; Melvin et al., 2019). The notion of a role is contextualized within the evolving relationship between the client (i.e., the parent) and the professional that is inherent to intervention (King et al., 2014). The quality of parent-professional

relationships determines whether trust and optimism (affective engagement), belief in the viability of the intervention (cognitive engagement), and capacity to carry through with interventions (behavioral engagement) are fostered (Melvin et al., 2019). Investing in a parent's initial engagement has been indicated to have a lasting influence on engagement later on in intervention (Carroll & Sixsmith, 2016; King et al., 2015) as it acts as a foundation upon which parents negotiate their roles and navigate intervention systems (Hurtubise & Carpenter, 2011). It is through the parent-professional relationship that professionals can continually assess how parents are coping with their level of engagement and the roles that they have assumed in intervention. Professionals can subsequently provide parents with contingent support (i.e., information, skill, confidence affirming feedback) as required (King et al., 2019a).

In a low-and-middle-income (LAMI) country like South Africa, promoting parental engagement, by way of supporting parents to assume more active roles in rehabilitation interventions, could be used to overcome considerable professional resource constraints. In South Africa, it is estimated that 11.2% of children have some form of disability with 28% of children aged 0-4 years and 10% of children aged 5-9 years being affected (United Nations International Children's Emergency Fund, Department of Social Development, & Department of Women, Children, and People with Disability, 2012). Children are placed at further risk by the indirect and direct consequences of the quadruple burden of disease and socio-economic circumstances (i.e., poverty, effects of HIV/AIDS and TB, maternal and child health, trauma, violence, non-communicable diseases) (Samuels, Slemming & Balton, 2012; Meintjes & Hall, 2018). There are insufficient professionals to provide rehabilitation services to the majority of the population within the strained public healthcare system (Van Niekerk, Dada & Tönsing, 2019). Moreover, the medical model that remains the prevalent approach across the main rehabilitation interventions i.e. occupational therapy, physiotherapy, and speech therapy (Samuels et al., 2012) may compromise parental power and relegate parents to more passive roles (McKenzie & Müller, 2005; Rowe & Moodley, 2013). In contexts characterized by limited resources and challenges with accessing and attending services, it is hypothesized that more active roles for parents could facilitate better intervention efficacy and effectiveness through the process of deeper engagement.

If parents are invited by professionals into open, honest negotiations of their respective roles, parental engagement could be further supported (Hurtubise & Carpenter, 2011; Smart et al., 2019). Some parents seem to assume certain types of roles (e.g.: actively observing intervention, implementing interventions or advocating for their child from the start of intervention) provided they feel they have been equipped with the necessary information, skills and confidence to assume these roles (Forsingdal et al., 2013; Davies et al., 2017). Parents may be ready and willing to assume increasingly active roles in their child's intervention as they become familiar with intervention systems and their confidence and sense of competence grow (Hurtubise & Carpenter, 2011; Davies et al., 2017). However, parents experience considerable stress when their roles in intervention are uncertain (Carroll & Sixsmith, 2016; Davies et al., 2017) with potential long-term consequences for intervention outcomes (Buckingham, Brandt, Becker, Gordon, & Cammack, 2016; Imms, 2017; King et al., 2019b). Both parents and professionals may be unsure of parents' roles in intervention (An & Palisano, 2013; King et al., 2015), which may be due to the marked lack of discussion about parental roles. Parents who are unsure of their roles and professional expectations find it challenging to commit to and invest in the intervention plan. They cannot see how the proposed course of action, and specifically their behavior, will translate into intervention outcomes (King et al., 2019b). When parents are prescribed roles by professionals, rather than selecting their preferred roles, they may be unsure of how to enact them causing them further distress (Davies et al., 2017; Kruse, 2012). If parents perceive themselves as ill-equipped and unsupported to perform the tasks related to their roles in intervention, e.g.: having to implement a home program without knowledge and skills support, they may intentionally limit their roles (Davies et al., 2017; Shepherd, Kervick & Morris, 2017). Parental stress and uncertainty can also limit parental engagement (Carroll & Sixsmith, 2016; Boshoff, Gibbs, Phillips, Wiles, & Porter, 2016) or cause parents to disengage purposefully as a coping mechanism (Shepherd et al., 2017). Parental engagement thus appears to be fluid, involving periods of lower levels of involvement or temporary disengagement (Bright, et al., 2015; D'Arrigo et al., 2016). Child and family intervention outcomes may be compromised when parents show persistently lower levels of engagement or are disengaged from intervention (Buckingham et al., 2016; Imms, 2017).

Despite the widely espoused importance of parents adopting certain roles in intervention (Kemp & Turnbull, 2014; Osher & Osher, 2002; Robert et al., 2015), there is a limited understanding of the variety of roles that parents could potentially assume in intervention (Davies et al., 2017). The intervention literature alludes that there are different types of roles that parents can assume (McWilliam, 2015; Osher & Osher, 2002), for example, in goal setting (Forsingdal et al., 2013) or intervention implementation (Davies et al., 2017). As yet, it remains unclear exactly what these different types of intervention roles are, and what they mean for parents in intervention in terms of specific tasks and responsibilities.

For this reason, a scoping review was undertaken of the rehabilitation literature for children, to understand the roles that parents have adopted in rehabilitation interventions and the tasks and responsibilities ascribed to these roles. This review forms part of a larger study aimed at developing and validating a tool to identify and describe parental roles in intervention and to empirically test its relationship to parental engagement implied in the literature. The results of the review will be used to generate a collection of potential items (DeVellis, 2017; Boateng, Neilands, Frongillo, Melgar-Quiñonez, Young, 2018) for the parental roles in intervention measure. This newly developed measure will then be validated and undergo reliability testing. A quantitative tool to measure parental roles in intervention is intended to remove uncertainty about parental roles in intervention and to initiate opportunities for parents to reflect on their current and aspirational roles. This can serve as a starting point for parents and professionals to discuss and negotiate parental roles in intervention with a clear understanding of the implications for their engagement and intervention efficiency (i.e., quantity of intervention including frequency and length of time spent in intervention) and effectiveness (i.e., how well it achieves its expected outcomes) (Fingerhut, 2009; Buckingham et al., 2016).

2. PURPOSE OF THE REVIEW

This research review aims to provide an overview of the types of roles that parents of children with developmental delays, long-term health conditions, or disability have taken on from the intervention literature. Additionally, the review aims to describe the tasks and responsibilities attributed to these roles and further describe whether these tasks are performed during or outside of intervention sessions. The aims, therefore, include, firstly, a scoping systematic search of the intervention

literature, secondly, a synthesis of the findings and, thirdly, a description of the implications of these findings for intervention.

3. METHODS

3.1. Procedure

3.1.1. Literature search strategy

In consultation with a librarian, a systematic search was conducted in the following databases: Academic search complete, CINAHL, ERIC, E-journals, Family and Society studies worldwide, Healthsource: Nursing/Academic Edition, Healthsource: Consumer edition, Humanities Source, and Masterfile Premier. The search was limited to literature sources available in English. Search terms included *parental role AND child* AND *disability* OR *disorder* OR *developmental delay* OR *chronic health condition* AND *intervention* (Appendix A). Following multiple trial searches, it was deemed necessary to search specifically for the term ‘role’ in the title and abstract to improve the relevance of the search results. While some of the literature implies a link between parental roles in intervention and involvement or engagement, these terms were not included in the search terms as trial searches revealed too many irrelevant hits.

3.1.2. Article selection

The searches were conducted in June 2019. Literature sources were included in the review if they (a) identified and described parental roles as related to (b) their child’s occupational therapy, physiotherapy, or speech therapy intervention (c) for children between the ages of 0-18 years of age (d) with a disability, developmental delay, or disorder or long-term health condition. Included literature sources also had to be available in English to provide access to complete the review. No limitation was set for the year of publication. Literature sources were excluded if they described the roles of those other than parents (e.g., roles of healthcare professionals) or if they described parental roles that were not related to their child’s intervention (e.g., general caregiving role). Literature sources were also excluded if they described the role of the parent in intervention of adult children (i.e., older than 18 years of age).

During the initial search, a total of 1439 references were retrieved. Following the exclusion of duplicates, this number was reduced to 1232. Following title and

abstract screening, 1179 articles were excluded and a review of 53 of the full text articles was conducted with 41 excluded. A hand search of the reference lists of the selected articles together with a forward citation search in Google scholar was undertaken and an additional 23 literature sources were included. Finally, 12 articles were included and coded in the scoping review. A total of 10 articles from the database search and an additional two articles from the hand search and forward citation search met the inclusion criteria in the review (n=12; Figure 2).

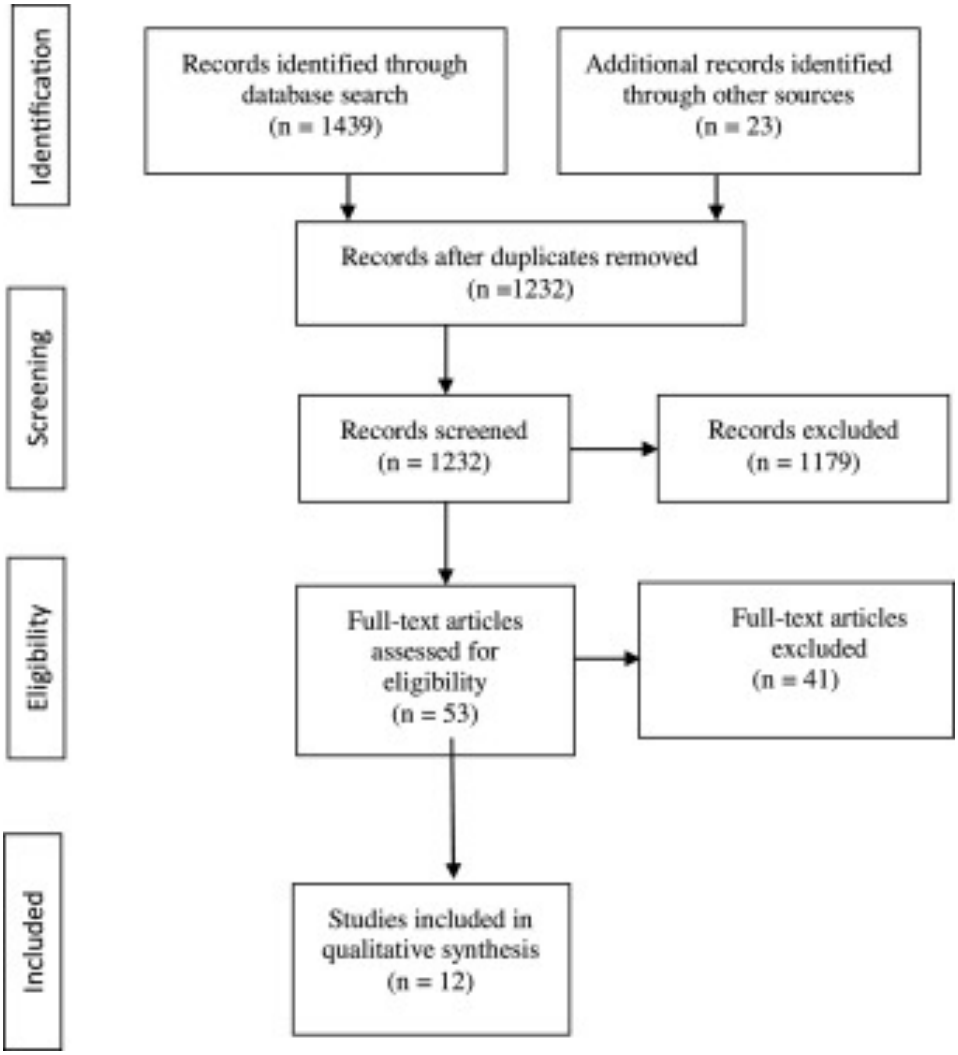

Fig. 2. Study selection represented in a PRISMA flow diagram (Moher et al., 2009).

Two reviewers (the authors of the paper) blind-reviewed each literature source using Rayyan, a systematic review online platform (Ouzzani, Hammady, Fedorowicz, & Elmagarmid, 2016) at the title and abstract level. Where decisions could not be made on these levels, full text screening was undertaken independently. Inter-rater

agreement at the title and abstract level screening was 98 %. Uncertainty regarding one of the articles at full-text review level was resolved by discussion between the first and second authors and reverting to the aims set out in the scoping review protocol.

3.1.3. Thematic analysis

Qualitative thematic analysis (Nowell, Norris, White, & Moules, 2017) utilizing Atlas.ti8 software (Paulus, Woods, Atkins, & Macklin, 2017) was conducted on the included articles. Following Braun and Clarke's (2006) guidelines for thematic analysis, the researchers familiarized themselves with the data. The first author generated initial codes independently and then both authors reviewed and refined the themes iteratively. The codes evolved as the researchers discussed and reviewed the data.

3.1.4. Article coding

For each article, the first author coded for the following: authors, year, country of origin, study aim, study design, study methods, and sample size. The number and type of parents or caregivers included, the socioeconomic circumstances, the type of childhood disability, type of intervention, and therapy setting were coded. The parental role name, description including in-and out-of-session tasks and responsibilities attributed to the roles, as well as summaries of the main findings, discussion, recommendations, and limitations were included for each study.

4. RESULTS

4.1. Study designs and demographics

All of the included sources were published in peer-reviewed journals and were reported as descriptive studies (n=12) (Table 1). The articles were published between 1991 and 2019 in America (n=3), Australia (n=4), England (n= 3), Scotland (n=1), and Taiwan (n=1). The included studies utilized qualitative, open-ended data collection tools (n=12). Parents were interviewed in most of the studies (i.e., mothers and fathers; n=8). Two studies interviewed only mothers and two articles did not specify the type of parent. Included parents were between the ages of 31-39 years, however, most of the studies (n=8) did not report parental age. Other parent descriptors included the race (n=1) and education levels (n=4) of the parents. There were no studies from LAMI

Table 1. Parental role in intervention names with tasks ascribed to parental roles extracted during the review.

Authors	Year	Title	Parental role name	Tasks ascribed to parental role	Who ascribed the parental role
Sugden & Chambers	2003	Intervention in children with developmental coordination Disorder: The role of parents and teachers.	Not named	Implement activities and program Adapt activities to fit into daily routines	Parents
Watts Pappas, McAllister & McLeod	**2016**	Parental beliefs and experiences regarding involvement in intervention for their child with speech sound disorder	Observer	Observe the session and work with the child at home May participate briefly in the intervention session to show how homework activities were completed	Parents
			Not named	Facilitate child's motivation, enjoyment and participation	
			Primary decision-maker	Be involved in goal setting and make decisions about intervention	Parent (Aspirational)
Tsai, Tsai, & Lotus Shyu	**2008**	Integrating the nurturer–trainer roles: Parental and behavior /symptom management processes for mothers of children with autism	Trainer role	Include training activities in daily routines Co-ordinate and maintain services Conduct behavioural training Nurturing own abilities; learn from professionals about reinforcing correct behaviours, inhibit problematic behaviours,	Parents
			Not named	Explore possible treatment methods or training programs	Parents
			Education	Learn technical information and specific therapy techniques	Professionals
Bowen & Cupples	**2004**	The role of families in optimizing phonological therapy outcomes	**Trainer**	Learn novel intervention activity-related skills Give feedback to the therapist, Adapting activities to the child	Professionals
			Homework implementer	Complete homework activities during therapy blocks and during breaks from therapy	Professionals
Hurtubise & Carpenter	**2011**	Parents' experiences in role negotiation within an infant services program	Learner or student	Get to know the child and recognising their potential Gain knowledge of their child's condition and treatments and the skills and competencies to support the child at home	Parents

Authors	Year	Title	Parental role name	Tasks ascribed to parental role	Who ascribed the parental role
Maclean & Chesson	**2012**	Factors affecting parents' role as co-therapists: A pilot study of parents of children with motor-learning difficulties	**Information liaison**	Acquire, manage, and disseminate information with health professionals, between health professionals, and with community agencies Gather information for professionals about their child's behaviour Advise on the feasibility of integrating intervention suggestions into daily routines Provide feedback about progress	Parents
			Advocate	Be involved in decision making Find and acquire appropriate resources and services to meet the child's needs	Parents
			Collaborator	Collaborate in all aspects of intervention Give information to guide the intervention and information about child's needs, preferences, and developmental history Be involved in the development and implementation of the intervention Implement intervention in natural environments	Parents (Aspirational)
			Education	Learn techniques for different treatments	Parents
			Training	Practice skills to facilitate the quality of parent-child interactions	Parents
Davies, Marshall, Brown & Goldbart	**2017**	Co-working: Parents' conception of roles in supporting their children's speech and language development	Advocate	Seek advice and support Making a judgement that intervention is needed	Parents
			Intervener	Help their child	Parents
			Attender	Attend appointments	Parents
			Implementer	Complete prescribed activities	Parents
			Adaptor	Adapt approach to the child's needs	Parents
Rix & Paige-Smith	**2008**	A different head? Parental agency and early intervention	Teacher/co-interventionist	Gain a knowledge base to supports their child's learning Deliver the interventions Problem solve to identify new ways of carrying out activities	Parents

Authors	Year	Title	Parental role name	Tasks ascribed to parental role	Who ascribed the parental role
			Policing	Oversee what the therapist does	Parents
			Dependent	Ensure that homework is done Receive information	Parents
Forsingdal, St John, Miller, Harvey, & Wearne	**2013**	Goal setting with mothers in child development services	**Active participator**	Take action to seek help (e.g. ask for more instruction) Give feedback on how the homework activities went	Parents
			Collaborator	Work in partnership with professionals to develop and review goals Engage in mutual planning	Parents
			Helper	Complete provided activities at home	Professionals
Davies, Marshall, Brown & Goldbart	**2019**	Speech language therapists' conceptions about their own and parents' roles during intervention with preschool children	**Leaner**	Learn information and techniques to support their child's development	Professionals
			Adaptor	Adapt interactions and modify activities independently	Professionals
Sugden, Munro, Trivette, Baker, & Williams	**2019**	Parents' experiences of completing home practice for speech sound disorders	Not named	Observe to learn Practice skills for home implementation	Parents
			Observer	Observe the session	Parents
James & Chard	**2010**	A qualitative study of parental experiences of participation and partnership in an early intervention service	Advocate	Coordinating scheduled therapy sessions with other commitments Bridging the gap between therapy and teachers/school	Parents
			Informant	Provide information	Parents
			Assistant	Help implement intervention	Parents
			Equal partner	A balanced relationship or even friendship that develops over time	Parents (Aspirational)

countries. Most of the articles did not report socio-economic status (n=11) with one study reporting it as a low to middle-income context. The majority of the studies included children under the age of six years (n=7) while the other studies reported on older children between the ages of 9-17 years (n=2). Three studies did not specify the age of the children. Nearly all of the included articles, except one, reported the child's condition (n=11) including autism (n=2), Down syndrome (n=1), Developmental Coordination Disorder (n=1), a neurodevelopmental condition (n=1), motor learning difficulties (n=1), speech and language disorders (n=4). The majority of the studies investigated parental roles in speech therapy (n=7), while one study reported on parental roles in occupational therapy. One study reported on parental roles in early intervention (i.e., Combination support services for young children under 4 years of age) and four studies reported on parental roles in unspecified multidisciplinary therapies. In most of the studies, the intervention setting was reported as clinic or center-based (n=6) while one study reported clinic and home-based intervention and another reported school-based intervention. Four of the studies did not specify the intervention setting. Nearly all of the studies described parental perceptions of their roles in intervention (n=11) while one study reported their roles from the perspective of professionals (i.e., speech therapists).

4.2. Roles ascribed to parents in the intervention literature

The descriptions of parental roles in intervention were varied across the included articles. It emerged from the data that a range of role types has been ascribed to parents in intervention. The definitions of the parental role in intervention, i.e., descriptions of the role in terms of role tasks and responsibilities, were coded and organized into themes. Eight different types of parental roles in intervention themes emerged and are described below.

4.2.1. Bringer

Three of the included articles described parents' roles as what we coded as the Bringer role. Two articles named this role the Attender (Davies et al., 2017; 2019) while the third article did not give a name for the role (Tsai et al., 2008). In this role, parents assume responsibility for ensuring that their child attends intervention sessions. Naming this role, the Bringer was preferred, as the name Attender implies that parents themselves attend the intervention session with their child. However,

closer reading indicated that this role involved parents merely facilitating their child's attendance of intervention sessions with the professional and not their own attendance.

4.2.2. Supporter

The Supporter role involves parents encouraging their child so that they are motivated to enjoy their intervention sessions with the professional. Although this role was not named in the article that described it (Watts Pappas, McAllister & McLeod, 2016), it was suggested to have a supportive function. The out-of-session task of encouraging their child's enthusiasm to participate is linked with the in-session bringer role.

4.2.3. Informer

Four of the included articles described parents as Informers, although other studies named this role the information liaison (Hurtubise & Carpenter, 2011) and informant (James & Chard, 2010). This role is considered a passive information management role. In terms of the tasks assigned to this role, parents gather, organize, and are responsible for sharing information with and between professionals and organizations (Hurtubise & Carpenter, 2011). Parents are, therefore, responsible for providing professionals with information i.e., their child's likes, dislikes, family needs, parental concerns, their child's behavior at home (James & Chard, 2010; Burrell & Borrego, 2012; Bowen & Cupples, 2004). Within sessions, parents are also tasked with identifying child and family needs. Outside of sessions, parents are tasked with sharing information about their child's progress with professionals and staff in various environments e.g., the intervention setting, school, or other medical professionals (Hurtubise & Carpenter, 2011).

4.2.4. Observer

Two of the included articles described the parental role which was coded as the Observer. In this role, parental tasks include bringing the child to the intervention and watching the intervention sessions to learn from the expert professional (Sugden, Munro, Trivette, Baker, & Williams, 2019). Watts Pappas et al. (2016) explain that parents then have the responsibility to repeat the prescribed activities at home based on their observations without any explicit instruction from the

professional. This role implies learning via passive observation rather than an active reciprocal learning exchange with professionals.

4.2.5. Learner

Seven of the articles included in the review referred to parents gaining active skills and knowledge in the Learner role. This role was also named as the student, (Bowen & Cupples, 2004) an education or a training-related role (Burrell & Borrego, 2012; McClean & Chesson, 1991). The parental tasks required in this role involve parents learning technical information and gaining the knowledge required to contribute to their child's intervention (Rix & Paige-Smith, 2008; Hurtubise & Carpenter, 2011). This appears to be a more active in-session role and entails parents learning facilitation strategies and therapeutic techniques taught to them by the professional or from information materials rather than relying on their observational skills alone (Sugden et al., 2019; Bowen & Cupples, 1991; Burrell & Borrego, 2012). There is reciprocity in the parent-professional learning exchanges and parents take responsibility for their learning to develop knowledge of the child's condition and rehabilitation intervention principles and application (Davies et al., 2019; Hurtubise & Carpenter, 2011).

4.2.6. Implementer

In the Implementer role, described in eight of the included articles, parents have the responsibility to carry out homework activities shown to them by the professional. Tasks associated with the implementer are primarily enacted outside of intervention sessions. Parents must reinforce the intervention by completing home practice activities such as home programs prescribed by the professional based on their in-session observations (O'Shaughnessy Carroll, 2016; Sugden et al., 2019; Tsai et al., 2008; Sugden & Chambers, 2003; McClean & Chesson, 1991). It is, therefore, linked with the in-session Observer role. Parental tasks in this role are to act as helpers, interveners (Davies et al., 2019), or assistants to the professional (James & Chard, 2010). In this role, parents use in session time to demonstrate to the professional (Watts Pappas et al., 2016) or report back to the professional about how the activities were conducted at home (Forsingdal et al., 2013).

4.2.7. Adaptor

The adaptor role was described in six of the included articles (Briddle & Mann, 2000; Burrell & Borrego, 2012; Rix & Paige-Smith, 2008; Maclean & Chesson, 1991) and named by Davies et al. (2017; 2019). This role has also been named the co-therapist (Maclean & Chesson, 1991) and co-interventionist (Rix & Paige-Smith, 2008). Parents are responsible for sharing and discussing ideas of what they think may work better for their child and family with professionals (Rix & Paige-Smith, 2008). As Adaptors, parents can extend their tasks beyond simply implementing prescribed activities as they have an in-depth understanding of their child's abilities and intervention principles. The adaptor role, therefore, involves parents using the knowledge, skills, and confidence they have developed through their Observer, Leaner, and Implementer roles to make up their own therapy activities (Rix & Paige-Smith, 2008; Davies et al., 2019). Parents will also make suggestions to professionals regarding activities that are matched to their child's developmental abilities (Briddle & Mann, 2000; Burrell & Borrego, 2012).

4.2.8. Collaborative Decision-Maker

Six of the articles included descriptions of parents as Collaborative Decision-Makers. In this role, parents work with professionals "with both sides giving input to an equal partnership" (James & Chard, 2010, p. 281; Forsingdal et al., 2013; Burrell & Borrego, 2012). Parents and professionals, therefore, share equal responsibility for the implementation of the child's intervention. Also termed the active partner (James & Chard, 2010), choice maker (Dunst et al., 2002) or collaborator (McClean & Chesson, 1991), parents are experts concerning knowledge of their child and family system. Working with professionals, parents make decisions about the focus of intervention as well as the level and nature of their involvement (James & Chard, 2010). Parents are regarded as fully capable of making decisions and are supported by professionals (Dunst et al., 2002; Watts Pappas et al., 2016). They are expected to give their opinion and engage with professionals in a reciprocal dialogue about the focus of intervention (Watts Pappas et al., 2016; McClean & Chesson, 1991) and how intervention is carried out (James & Chard, 2010; Bruns & Fowler, 1999). Parents and professionals have shared power in decision-making, goal setting, and implementing interventions, as well as in defining outcomes.

4.2.9. Advocate

Eight of the articles described parents taking on an advocacy role that seems to begin when parents determine that external assistance is required. Parents then seek out advice, explore intervention options, and make decisions about which interventions are necessary (Davies et al., 2017; Tsai et al, 2008). It is, therefore, linked with information management roles such as the Informer, Learner, and Collaborative Decision-Maker roles, although it is a broader role. Parents have the responsibility to “oversee the professionals” (Rix & Paige-Smith, 2008; p. 13) and judge the quality of the intervention provided (Davies et al., 2017). Parents also coordinate to “bridge the gap” between intervention and other environments, e.g., encouraging carryover of their child’s rehabilitation intervention to the school setting (Sugden et al., 2019; p. 170). The advocate role relates to managing intervention within the broader organizational systems.

5. DISCUSSION

The purpose of this scoping review was to identify the different types of parental roles taken on by parents of children with a developmental delay, disability, or long-term health condition in the rehabilitation intervention literature. The set of tasks attributed to these parental roles and whether these tasks are enacted in-session or outside of intervention sessions was also described. The results of this review form the initial step in developing a quantitative measure to capture the various roles that parents may take on in their child's intervention by unpacking tasks and responsibilities associated with these roles.

The findings of the review confirm that there are numerous possibilities for parents in terms of the roles they could take on in their child’s intervention. Role theory proposes that roles can be characterized according to who performs the roles, what behaviors are associated with the roles, and in which context these behaviors are enacted (Biddle, 2003). Parental roles in intervention are defined by the responsibility or set of tasks assigned to parents in intervention (Sugden et al., 2019). The context (or life situation) in which parental roles play out would be rehabilitation intervention (Imms et al., 2017; King et al., 2014). The setting can be further specified as the places where intervention is implemented such as during therapy sessions or other settings outside of therapy sessions including, but not

limited to, the home, school, community, etc. This review further classified the tasks associated with parental roles according to the setting i.e., whether they were performed in- or out-of-sessions. Some of the parental roles (i.e., Bringer, Observer, Learner) are related to in-session tasks whereas other types of roles are linked with out-of-session tasks (i.e., Supporter, Implementer, Adaptor). Other parental roles (i.e., Informer, Collaborative Decision-Maker, Advocate) entailed a combination of in-session and out-of-session tasks (See Figure 3).

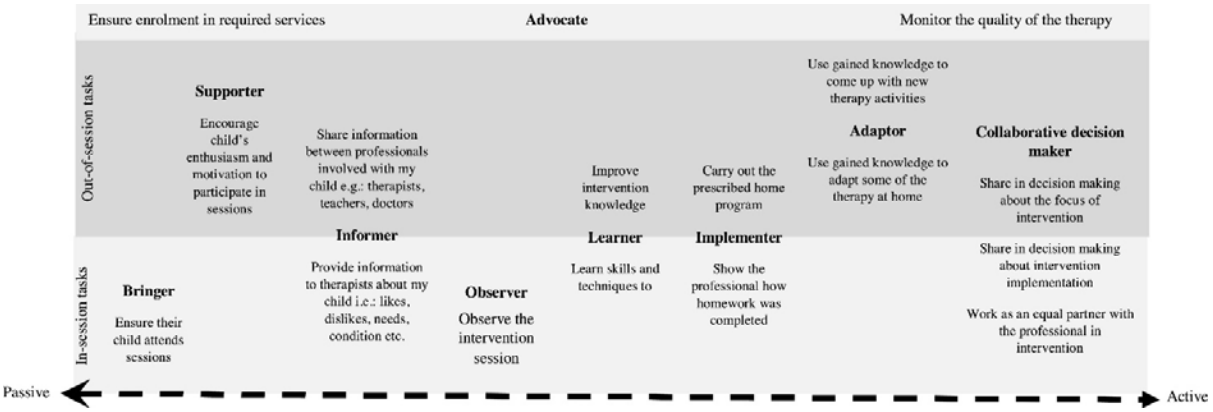

Fig. 3. Continuum of parental roles.

The findings of the review support the notion that parental roles in intervention can be placed on a continuum from passive to active responsibility which was first proposed by Osher and Osher (2002). This continuum is also described with one end represented by professionally-driven roles and the other by parent-driven roles (Davies et al., 2019; Dunst et al., 2002). In passive “cheerleading” roles, parents comply with interventions driven by the expert professional. Conversely, in more active roles, parents are “leaders” and make an active contribution to intervention (Osher & Osher, 2002, p. 51). The parental roles identified in the review are presented on a continuum of passive to active responsibility in Figure 3.

Meaningful in-session participation seems to equip parents with the knowledge and skill required to perform more active in-session and out-of-session tasks expected of them (Hurtubise & Carpenter, 2011; Sugden et al., 2019). The Bringer role appears to involve limited parental participation and professionals take primary responsibility for intervention (Davies et al., 2017). It seems obvious then that this role is associated with limited out-of-session carryover. When enacting the Observer role, parents act as passive information recipients (Forsingdal et al., 2013). Parental learning is dictated

by the professional and the intervention setting and out-of-session, parents act as Implementers (Watts Pappas et al., 2016). These roles are, therefore, placed on the passive side of the continuum of parental roles in intervention presented in the model shown in Figure 3. In contrast, the Learner role is associated with more active responsibility concerning the tasks parents enact and reciprocity in the parent-professional (student-teacher) exchanges (Hurtubise & Carpenter, 2011). The learner role emerged as a central in-session role that enables parents to assume other in-and out-of-session tasks. This role is placed on the more active side of the continuum as it is associated with parents taking on increasing responsibility for intervention. Parents explain that as they get to know about their child's condition and abilities, and understand their challenges, this allows them to understand how intervention can support their child and family (Davies et al., 2017; Hurtubise & Carpenter, 2011). Parents can subsequently integrate intervention into their interactions with their child with increasing creativity (Bowen & Cupples, 2004; Burrell & Borrego, 2012). It is through the repeated parent-professional teaching and learning interchanges that epitomize the Learner role, that parents gain the skills and knowledge they require to be able to take on increased responsibility in intervention (Hurtubise & Carpenter, 2011). Parents who understand how and why interventions work can adapt and suggest new activities (i.e., Adaptor) as compared to parents who simply carry out homework activities as prescribed (i.e., Implementer) based on passive observational learning (i.e., Observer). The difference, therefore, between the tasks associated with the Implementer and Adaptor roles lies in the parent's knowledge, skills, and developing confidence to take on increasingly active responsibility in intervention (Rix & Paige-Smith, 2008; Davies et al., 2017; 2019). Hence, the Adaptor was placed on the side of the continuum representing active responsibility (Figure 3).

Assuming increased decision-making power is also linked with parents adopting the Learner role (Hurtubise & Carpenter, 2011; Alsem et al., 2017). In the passive Informer role, parents provide professionals with information about the child and family so that the professional can plan intervention (Dunst et al., 2002; Lee, 2015). Parents are afforded limited responsibility for intervention (Forsingdal et al., 2013). Conversely, while enacting the Collaborative Decision-Maker role, parental and professional knowledge are considered complementary (James & Chard, 2010). This is an active parental role (Figure 3). Parents understand their rights and

responsibilities in intervention and how intervention can assist with addressing their concerns and priorities (Hurtubise & Carpenter, 2011; Bruns & Fowler, 1999). This allows parents to take control and direct the focus of intervention (Forsingdal et al., 2013). Parents who are consulted about their roles can guide professionals on their preferred level of engagement (Bruns & Fowler, 1999).

Parents seem to have a clearer idea of how to perform their role as their child's advocate within intervention systems (Davies et al., 2017). This role is associated with empowerment and parents regaining control over the intervention process (Boshoff, et al., 2016). Hence the advocate role is placed as an overarching role on the continuum. The results of the review indicate that the tasks related to the Advocate role are broad, associated with accessing and fighting for services within the system (O'Shaughnessy Carroll, 2016; Boshoff et al., 2016), and 'policing' professionals (Rix & Paige-Smith, 2008). It is, therefore, distinguished from information management (Informer, Learner) and decision-making (Collaborative Decision-Maker) roles although it is linked with these roles (Hurtubise & Carpenter, 2011). Early in intervention parents may assume an advocacy role to ensure access to services and determine which services are needed (Briddle & Mann, 2000; Rix & Paige-Smith, 2008). It is suggested that when parents feel that they are not being heard or that intervention is not meeting their expectations, that they will assume the advocacy role to fight for their rights in intervention (O'Shaughnessy Carroll, 2016).

The type of roles that parents adopt in their child's intervention is highly unique to that parent and their particular situation (Forsingdal et al., 2013; James & Chard, 2010). It is plausible that parents' perceptions of their intervention roles may not fit into the proposed role categories as some parents may incorporate tasks and responsibilities that overlap the suggested role categories. However, we would need to develop a measure based on these roles first. For the development and preliminary validation of the role measure a 5- point Likert type scale has been recommended by a statistician over an ordinal scale which will ask respondents to evaluate role task items from N*ot true of me* (1) to *Very true of me* (5). Similarly, the measure is not intended to produce only an absolute quantitative score and parental responses should be considered qualitatively as well. It is believed that this will capture the emerging parental roles and create opportunities for parents and professionals to

discuss the types of role parents may want to perform although they may not yet feel equipped to do so.

Expert review will also be conducted to assess, among other aspects, the comprehensiveness of the parental role in intervention task items. Expert review is intended to evaluate whether there may be additional parental roles and tasks that were not identified from the review. Exploratory factor analysis will then be used to examine the psychometrics of the proposed role measure based on the a priori assignment of items into specific role types. Confirmatory factor analysis will also be conducted. Factor loadings will be used to validate the assignment of the parental tasks and responsibilities into the specific role types. As the literature suggests certain links between parental role types, the analysis will also identify if there are redundant items and the extent to which items cohere with other items.

Information exchange seems to be a key factor in determining the type of roles that parents take on in intervention (Alsem et al., 2017). Reeder and Morris (2020) illustrate that information exchange empowers parents to take on more active roles in intervention by promoting a more equal balance of power in the parent-professional relationship. Interventions that incorporate parental capacity-building equip parents with the skills and knowledge to integrate interventions into their daily lives (Swanson, Raab & Dunst, 2011). Over time, parents develop confidence from their growing competence that allows them to take added responsibility in intervention (McClean & Chesson, 1991; Hurtubise & Carpenter, 2017). The coded descriptions of the Learner role from this review suggest a move towards a coaching model for the parent-professional relationship with the professional taking on an enabling, teaching role (McClean & Chesson, 1991; Hurtubise & Carpenter, 2017). Coaching relationships replace patriarchal, “power-over relationships” that are associated with traditional, medical model approaches (Rush, Shelden, & Hanft, 2003, p. 39). Addressing the balance of power by supporting parental capacity to take control over intervention affirms the parental contribution creating opportunities for role negotiation (Reeder & Morris, 2018; 2020). Conversely, when power in the parent-professional relationship is not addressed, parental contributions are undermined and professionals retain primary responsibility for intervention (Rix & Paige-Smith, 2008; Lee, 2015; Reeder & Morris, 2020).

With particular relevance to the South African context for which the role measure is being developed, the available intervention literature for this context (Kyarkanaye, Dada & Samuels, 2017; Coovadia, Jewkes, Barron, Sanders, & McIntyre, 2018; Rowe & Moodley, 2013) suggests that parents will enact primarily passive roles (e.g., Bringer, Informer, Observer, Implementer). One of the primary reasons for this is the predominantly medical model in which intervention professionals are trained as well as the setup of intervention systems and services (Samuels et al., 2012). Based on this, it can be assumed that in the South African context, the majority of professionals take primary responsibility for intervention planning, goal setting, and implementation. South Africa has a dual health care system, i.e., public and private, with the majority of professional resources available in the private sector (Coovadia et al., 2018). In this sector, medical funding policies may reinforce traditional professional-directed interventions (Rowe & Moodley, 2013), which are associated with a limited role for parents (Swanson et al., 2011). In the public healthcare setting, which the majority of children with disabilities and developmental delays access, the limited availability of professionals and the reported cultural and linguistic mismatch between parents and professionals, further limit parental autonomy in intervention (Kyarkanaye et al., 2017; Coovadia et al., 2018; Rowe & Moodley, 2013). Consequently, South African parents report difficulties with assuming active roles in rehabilitation interventions (Kyarkanaye et al., 2017).

The literature suggests that parents may take on different types of roles in the various stages of intervention. Certain types of roles appear to be more commonly associated with different phases of intervention (Davies et al., 2017; Forsingdal et al., 2013). Some parents may assume more passive roles (e.g., Bringer, Observer) in the earlier stages of intervention (Davies et al., 2017; Watts Pappas et al., 2016; Sugden et al., 2019). These types of passive roles may also be maintained by some parents over the course of intervention (Davies et al., 2017; Forsingdal et al., 2013). Other parents appear to take on increasingly active roles (e.g., Learner, Adaptor, Collaborative Decision-Maker, Advocate) as their knowledge and skills develop so they are equipped to navigate intervention systems with increasing confidence (Hurtubise & Carpenter, 2011; Forsingdal et al., 2013). Various factors (including parent, child, parent-professional, and intervention system factors) can influence the type of roles that parents assume. Parents of children with remediable or short-term

conditions may take on certain roles earlier on in intervention (Davies et al., 2017; Forsingdal et al., 2013; Watts Pappas et al., 2016). These parents seem to have a clear idea of their Implementer role and are highly motivated to perform this role to support professional-directed sessions. This, in turn, can result in intervention being more efficient and of shorter duration, allowing parents to better manage their intervention responsibilities with their other parenting roles (Burrell & Borrego, 2012; Davies et al., 2017; Sugden et al., 2019; Tsai et al., 2008).

From the literature, it appears that many parents of children with a disability or long-term health condition seem to want, at least early in the intervention process, for the professional to take control of intervention (Forsingdal et al., 2013; Hurtubise & Carpenter, 2011; James & Chard, 2010). Piggot, Hocking, Paterson, & Paterson (2003) explain how parental stress, associated with coming to terms with their child's diagnosis and beginning intervention, may mean that parents are not ready to engage and take an active role in intervention. The initial stages of intervention are commonly associated with high stress levels, vulnerability, low confidence, and overwhelming confusion for parents (Carroll & Sixsmith, 2016; James & Chard, 2010; Boshoff, et al., 2016). Added to this is that parents are learning to navigate complex intervention systems (Hurtubise & Carpenter, 2011). During these times parents may struggle to process the information provided by professionals and may even avoid information exchange to cope (Alsem et al., 2017). Parents also express that coming to terms with their child's sometimes slower progress can be demotivating (Briddle & Mann, 2000; Piggot et al., 2003; Rix & Paige-Smith, 2008).

There is a suggestion from the articles reviewed that the parental roles were not necessarily selected by parents. There was a marked lack of discussion and negotiation of parental roles in the included studies (Davies et al., 2017; Rix & Paige-Smith, 2008). Parents appear to take cues from the professional's actions, and communication with little discussion and negotiation of roles (Davies et al., 2017). This is echoed in a recent paper by King et al. (2019a) investigating parental engagement.

> If the parent's chair is in the corner and you're working with the child over here, it does send a message…it suggests a philosophy to treatment, which is I treat your child…I am the therapist and you're not actively engaged throughout the process…You can't be a partner and be in the corner…there's a lot of conscious thought to little things that seem subtle, that actually say a lot. (p. 8).

Parents may, therefore, be relegated to more passive roles, albeit inadvertently, by way of the professional's behavior, (Davies et al., 2017) and the makeup of the therapy environment (King et al., 2019b). Given reports of parental willingness to take on increased responsibility for intervention (Hurtubise & Carpenter, 2011; Davies et al., 2017) and the mostly aspirational descriptions of more active roles in this review, it is questionable whether the identified parental roles can be considered negotiated or parent-led.

Family-centered interventions focus on empowering parents to take an active role in partnership with professionals in intervention (Alsem et al., 2017). This aligns with policies that promote patient activation (Carman et al., 2013), autonomy, and user involvement (Aarthun & Akerjordet, 2014). However, Watts Pappas et al. (2016) explain that in truly family-centered interventions, professionals should encourage parents to make choices about their preferred level of engagement. Professionals should support parents and provide opportunities for further parental engagement as and when parents are ready. Professionals must be cautious of imposing their expectations on parents without assessing parental preparedness and capacity to take on more active roles (Davies et al., 2017; Hurtubise & Carpenter, 2011; Lee, 2015). While certain types of more active roles are suggested to be linked with promoting parental engagement and associated with improved child and family outcomes (Kemp & Turnbull, 2014; Osher & Osher, 2002), these roles are linked with considerable parental distress when they are not selected by parents or negotiated with them (Davies et al., 2017; Kruse, 2012). It is, therefore, important that parents are afforded opportunities to reflect on their role expectations and negotiate their preferred roles. Despite the majority of included articles purporting to provide family-centered services, there appeared to be a marked lack of opportunity afforded to parents to reflect on and negotiate their roles in intervention. Many professionals may prescribe roles to parents (Davies et al., 2017). This could mean that the opportunities to engage parents in intervention and select their preferred roles are missed.

Parent-professional rapport facilitates more active roles for parents in intervention (Kemp & Turnbull, 2014). The parent-professional relationship serves as a promising avenue to encourage task shifting from professionals to parents to assist with equalizing the power dynamic. Parents highlight that when professionals focus

on rapport-building early on in intervention, parental engagement is invited and scaffolded (King et al., 2019a). This investment in a parent's initial engagement has been indicated to have a lasting influence in intervention (Carroll & Sixsmith, 2016; King et al., 2015). It is through the parent-professional relationship that parental coping, their level of engagement, and the role that parents have assumed in intervention can be continually assessed. Professionals can then provide parents with contingent support (Information, skill, and confidence affirming feedback) as required (King et al., 2019a).

This is especially important in an under-resourced context such as in South Africa where parents still struggle to envisage or take on more active roles (Kyarkanaye et al., 2017). Maximizing the buffering effect of relationships plays a key role in intervention efforts that aim to reduce cumulative risk exposure and facilitate positive parenting in challenging circumstances (Richter, 2004; Shonkoff & Fisher, 2013; Whiteside-Mansell et al., 2013). Professionals, therefore, need to reflect on how their role can progress outside of assessment and intervention to assume a coaching role that fosters more active roles for parents (Davies et al., 2017). Professionals must, therefore, expand their roles to initiate and drive toward more collaborative relationships with parents. This is paramount in LAMI countries like South Africa, where parents recognize the importance of collaboration (Kyarkanaye et al., 2017) but may be unsure of how to action it.

5.1. Suggestions for future research

The findings of this review suggest that further investigation is required to understand factors associated with role taking for parents in intervention. This includes examining whether the type of intervention influences the types of roles parents take on and possible relationships between parental role types and child and family outcomes. Further research is recommended to understand the influencing factors e.g. related to the parent, child, professional, therapy, intervention system, etc. and how these factors interact to influence the types of parental roles in intervention. Another avenue for future research includes examining parental factors including necessary accommodations made by parents to be able to take on more active roles in intervention and the relationship between parental roles and parental well-being and related constructs (i.e.: stress, self-efficacy). Furthermore, given the availability of technology and increasingly creative implementation of telehealth services, research

may also be required to understand how parental roles in intervention may be affected when parents (and possibly children) and professionals are not physically present together in intervention sessions. There is a need for continuing research on role negotiation and the parent-professional relationship in encouraging parents to take on more active roles. As in the larger project, there is a need to examine suggested links between parental roles and parental engagement in intervention.

5.2. Limitations of the study

A major limitation of the review is the small number of articles included which restricts the generalizability of the findings to some extent. Although the authors have discussed the implications of parental roles to a LAMI country like South Africa, the proposed setting for a future larger study, it is acknowledged that the results of this review will need to be interpreted with caution in relation to a LAMI context. The majority of the articles also included little to no information regarding the socio-economic conditions of the parents and families. This shows a need for additional context-specific research before items can be generated for a new parental role measure that is contextually valid. The small number of articles included also highlights inconsistencies in role-related terminology used in the intervention literature. Given the suggested links between parental engagement (and related terminology such as participation and involvement) the number of studies included in the study could have been limited by the exclusion of these terms from the search terms. This is an acknowledged limitation of the review.

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Declaration of interest statement

The authors report no conflicts of interest.

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