The Development and Validation of the Parental Roles in Intervention Task Tool for Use with Parents of Children with a Disability

by

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Dedication

This thesis is dedicated to my parents:

Mom and dad, you made this possible in every way.

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Abstract

This study develops and preliminarily validates the PRITT, an instrument to measure the parental role in intervention, for use with young children with a disability. Parental roles in intervention, i.e., the tasks and responsibilities that parents perform in intervention, are widely reported to be important for intervention outcomes. A quantitative instrument to measure parental roles in intervention has potential clinical applications to initiate negotiations about the roles parents may want to assume and the supports they require to perform the tasks associated with these roles. Additionally, the measure has applications as a research tool to empirically test relationships implied in the literature. A mixed method design was employed for the instrument development and validation. Phase 1 included instrument construction whereby items were generated from a scoping review and a Likert-type response scale was selected. In Phase 2 content and face validity of the PRITT were established and the survey questionnaire was piloted. During Phase 3, the online survey questionnaire was administered to parents of young children with a disability enrolled in rehabilitation interventions (i.e., occupational therapy, physiotherapy, and speech-language therapy) in South Africa. In Phase 4 of the study, the underlying factor structure of the PRITT was explored and internal consistency and test-retest reliability analyses were conducted. Results indicate that the preliminary validity and reliability have been established for the PRITT for use with parents of young children with a disability. Refinements of the PRITT are recommended based on future administrations with a more diversely representative sample of South African parents.

Keywords: Child; Disability; Early childhood intervention; Operationalization, Parental role in intervention; Quantitative measuring instrument; Rehabilitation; Reliability; Validity.

CHAPTER 1

PROBLEM STATEMENT AND RATIONALE

1.1 Introduction

This chapter poses the research problem addressed in the study and highlights the significance and relevance of the study. The problem statement and the rationale for the study are detailed first. Thereafter, the chapter offers a list of important and frequently used terms and definitions followed by a list of abbreviations and acronyms. The chapter concludes with an overview of the chapters of the thesis.

1.2 Rationale and problem statement

Parents or main caregivers of children with a disability have vital and fundamental roles to play in their child's rehabilitation interventions (i.e., occupational therapy, physiotherapy, and speech therapy). Defined as the set of tasks or responsibilities attributed to parents in intervention (Sugden et al., 2019), parental roles in intervention are generated and developed within the interpersonal relationships between the parent, child, and professional(s) that are so intrinsic to the intervention process (Carroll & Sixsmith, 2016; Davies et al., 2017; King et al., 2014; Tsai et al., 2008). Parents of children with a disability extend their parenting roles to include responsibilities and tasks beyond those associated with typical parenting to allow them to partake in their child's rehabilitation interventions (Albright et al., 2016; Lutz et al., 2012; Minnes et al., 2015).

Evidence suggests that parents who assume active roles in their child's intervention show deeper engagement in intervention (D'Arrigo et al., 2016; Davies et al., 2017; King et al., 2014) which, in turn, promotes intervention efficiency and efficacy (King et al., 2019). Our roles are generated and modified through iterative interactions with the environment. Specifically, it is through exchanges with professionals (Davies et al., 2017, 2019) that parents formulate and develop expectations for their own and the professional’s roles (Hessell, 2004; Smart et al., 2019). Parents who understand the professional’s intentions and expectations are motivated to get involved during sessions and transfer intervention to the home i.e., assuming more in- and out-of-session responsibility (Carroll & Sixsmith, 2016; King et al., 2019; Phoenix, 2017). Similarly, parents who are provided with opportunities to discuss their roles can negotiate their preferred level of engagement and the supports they may require to perform the tasks associated with the role (Hurtubise & Carpenter, 2011). The parental role in intervention is affirmed as parents recognize that their participation in intervention supports their child’s progress (King et al., 2019). Growing parental competence (i.e., improving 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. Through repeated positive interactions, 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 confidence to tackle more active roles in their child’s intervention (King et al., 2019; King et al., 2019).

Role negotiation and open communication with parents are reported to be critical elements of delivering family-centered care (Hurtubise & Carpenter, 2011). However, there is a gap in implementing these elements in clinical practice (Aarthun & Akerjordet, 2014; Davies et al., 2017; Smith & Samuels, 2021). Although the shift towards family-centered care points to parents enacting increasingly active roles in their child's intervention, the literature suggests that both parents and professionals are unsure of exactly what the tasks and responsibilities of these parental roles entail (An & Palisano, 2013; Dodd et al., 2009; Hurtubise & Carpenter, 2011). Furthermore, the limited literature regarding parental roles in intervention notes a marked absence of discussion and negotiation around parental roles in intervention (Davies et al., 2017; Rix & Paige-Smith, 2008).

Despite the importance of the parental role in intervention being widely reported (Kemp & Turnbull, 2014; Osher & Osher, 2002; Robert et al., 2015), research on the specifics of what the different types of roles entail is limited. There is a lack of clarity regarding the tasks and responsibilities that parents are expected to perform to enact their roles in their child's intervention (Davies et al., 2017). There are also currently no available instruments to measure parental roles in intervention or to delineate the tasks and responsibilities parents should perform associated with the different types of roles.

Unclear role boundaries cause parents considerable stress and confidence threats that strain their capacity to juggle multiple and competing demands (Boshoff et al., 2016; Carman et al., 2013; Safe et al., 2012; Shepherd et al., 2017). In the absence of knowledge regarding different role possibilities for parents, professionals seem to revert to the expert model and inadvertently prescribe passive roles to parents (Davies et al., 2017; Smart et al., 2019; Watts Pappas et al., 2016). Consequently, parents may not receive the supports they require from professionals to assume active roles (Davies et al., 2017; Watts Pappas et al., 2016). When professional expectations of parental roles are hidden or parental and professional role expectations are misaligned, trust is compromised in the parent-professional relationship (Davies et al., 2017; King, Chiarello, Ideishi, D'Arrigo, et al., 2019; Smart et al., 2019). Ultimately, this has a negative influence on parental belief in the professional and on any assurance that the intervention plan can effect change (King, Chiarello, Ideishi, D'Arrigo, et al., 2019). In these instances, parents seem to limit their involvement in intervention and they may even purposefully disengage from intervention (Carroll & Sixsmith, 2016; Davies et al., 2017; Forsingdal et al., 2013; King, Chiarello, Ideishi, D'Arrigo, et al., 2019; Shepherd et al., 2017). The potential for intervention to support child development and promote family outcomes is limited when parental engagement is suboptimal or parents disengage from intervention (D'Arrigo, et al., 2016; King, Chiarello, Ideishi, D'Arrigo, et al., 2019).

A parental role in intervention measure has the potential for clinical use to create opportunities to discuss the types of roles parents may want to perform in their child's rehabilitation interventions. Parents and professionals would be able to discuss and negotiate parental readiness, willingness, and capacity to assume increasingly active responsibility and tasks associated with active roles. Furthermore, parents and professionals can identify the types of supports parents may require to initiate role task and responsibility shifting to parents. They can also discuss the implications of parents assuming different roles for therapy outcomes in terms of intervention efficiency, i.e., length of time spent in intervention, and effectiveness, i.e., how well it achieves its expected outcomes in terms of child development. This will allow parents to make informed decisions about their roles in their child’s intervention. The measure could also be repeated at different intervals to indicate how parental roles may change over the course of intervention. As a research tool, the measure can contribute to professional's theoretical understanding of the parental role that is deemed so important for intervention outcomes. The instrument offers a means of quantitatively measuring the construct of parental roles in intervention that has, to date, only been qualitatively described. This also offers future possibilities in terms of testing implied relationships from rehabilitation and intervention literature between parental roles and parental engagement.

The main aim of this study was, therefore, to develop and preliminarily validate a quantitative instrument to measure parental roles in intervention for parents of young children with a disability enrolled in rehabilitation interventions in South Africa.

1.3 Terminology

The following terms are defined as they are frequently used in this thesis.

Disability

For this study, the term disability refers to children who have long-term physical, communicative, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others" (Republic of South Africa, 2015, p. 10).

Early intervention

In this study, the term early intervention refers to the supports and services provided to young children (under the age of 7 years in South Africa) and their families to minimize the effect and advancement of a medical condition or disability on their development (Samuels et al., 2012; Shonkoff & Meisels, 2000).

Engagement

Engagement refers to "a multifaceted state of affective, cognitive, and behavioral commitment or investment in the client role over the intervention process" (King et al., 2014, p. 2).

Family

The term family refers to the collection of people who are biologically or maritally related who are involved in daily household matters and those who provide regular support to each other (Schlebusch, 2015).

Intervention

The term intervention refers to "an approach or practice" that underlies service delivery (King et al., 2017, p. 122). Intervention may be traditional, child-centered, i.e., professionally implemented, and driven by a child-centered focus or it can be family-centred, i.e., driven by the needs and priorities of the family supported by the professional service provider.

Measuring instrument

In this study, the term measuring instrument refers to the survey used by the researcher to assist in the evaluation of the study participants or respondents (Boateng et al., 2018).

Parent

This study uses the definition of parent from the co-parenting literature which refers to a parent as the person (or people) with decision-making responsibility for the supervision, care, or rearing of a child and does not only refer to a biological mother or father (McHale, 2007; Samuels, 2013). A parent in this study refers to a child's designated primary caregiver which may be a family member, relative, or a biologically unrelated person such as a friend or neighbor (Kyarkanaye et al., 2017; Schlebusch et al., 2016).

Parenting

Parenting refers to the variety of functions, tasks, duties, or responsibilities that parents undertake to foster their child's achievement of socially and developmentally appropriate skills (Sandler et al., 2011).

Parental involvement

The term parental involvement refers to a range of parental activities related to intervention and the parental experiences while attending i.e., being physically present in and around intervention (Hoover-Dempsey & Sandler, 1997; Imms, Granlund, et al., 2016). In this study, parental involvement is considered related to parental engagement.

Parental engagement

Parental engagement is defined as both a process of "engaging with" intervention and a 'fluid internal state' of "engaging in" intervention (D'Arrigo et al., 2016, p. 1). The term further refers to a "co-constructed" connection (Bright et al., 2015, p. 645) or "a multifaceted state of affective, cognitive, and behavioural motivational commitment or investment in the client role over the treatment process" (King et al., 2014, p. 2).

Parental participation

Parental participation denotes the contributions that parents make as they take part in their child's intervention (Bright et al., 2015; Hock, et al., 2015; King et al., 2015).

In this study, parental participation is regarded as related to the construct of parental engagement.

Parental role expectations

Parental role expectations refers to the pre-emptive beliefs that parents hold related to procedures, outcomes, the professional, or any other aspect of the intervention and its implementation (Hessell, 2004; Smart et al., 2019).

Parental roles in intervention

Parental roles in intervention refers to the set of tasks and responsibilities that parents perform in their child's intervention (Smith & Samuels, 2021; Sugden et al., 2019). The parental role in intervention is framed in the interpersonal exchanges involving the professional, parent, child, and intervention (Davies et al., 2017; Tsai et al., 2008).

Parent professional relationship

In this study, the parent-professional relationship refers to the dynamic range of feelings experienced by and attitudes that are expressed in interactions between the professional and parent (Norcross, 2010). It is referred to as therapeutic when this relationship supports positive outcomes (Cole & McLean, 2003; Reeder & Morris, 2018).

Professional

In this study, the term professional refers to a rehabilitation provider who is trained and registered, and provides intervention support services as a physiotherapist, occupational therapist, or speech-language therapist.

Rehabilitation interventions

Rehabilitation interventions refer to the developmental interventions predominantly available to young children and their families in South Africa including physiotherapy, occupational therapy, and speech-language therapy (Kyarkanaye et al., 2017; Samuels et al., 2012).

Reliability

Reliability is concerned with the consistency of an instrument's measurements (Knekta et al., 2019, p. 2) and refers to "the degree to which a measuring instrument is free from measurement error" (L. B. Mokkink et al., 2012, p. 9).

Role

A role refers to the set of tasks or behaviours that a person performs that go along with occupying a specific position in a social group. Roles provide us with an identity and provide the requirements to fulfil to enact that identity (Kielhofner et al., 1980).

Role expectations

Role expectations refer to the set of underlying beliefs that a person holds regarding the behaviours, responsibilities, and tasks that are required to enact the role (Kielhofner et al., 1980).

Therapy

The term therapy in this study refers to the therapeutic process. It is a "holistic term, referring to all factors and processes with therapeutic value" (King et al., 2017, p. 122).

Therapy session

The term therapy session refers to a "therapeutic encounter" or goal-driven interaction between the professional, parent, and/or child where some kind of treatment dose is applied (King et al., 2017, p. 122). The nature of the interactions that occur during a therapy session is related to the intervention approach (Hart, 2009; King et al., 2017).

Validity

Validity refers to a characteristic of the use of a measuring instrument concerned with accuracy (Knekta et al., 2019). Validity is defined as the extent to which an instrument measures the construct that it is designed to measure (L. B. Mokkink et al., 2012, p. 9).

1.4 Abbreviations

CVI:	Content Validity Index
CVI-I:	Content Validity Index -Item level
CVI-S:	Content Validity Index -Scale level
DSA:	Developmental Systems Approach (Guralnick, 2019)
ECI:	Early Childhood Intervention
EFA:	Exploratory Factor Analysis
ICF:	International Classification of Functioning, Disability, and Health
KMO:	Kaiser-Meyer-Olkin Measure of Sampling Adequacy (Kaiser, 1974)
MOHO:	Model of Human Occupation (Kielhofner & Burke, 1980)
OT:	Occupational therapy
PCA:	Principal Components Analysis
PRITT:	Parental Role in Intervention Task Tool
PT:	Physiotherapy
SLT:	Speech-language therapy

1.5 Outline of chapters

Chapter 1 introduces the problem statement and rationale for the study and includes an outline of each of the chapters contained in the thesis. This chapter also delineates the important terms and includes a list of abbreviations used in the study.

Chapter 2 provides a review of the literature and a detailed description of the theoretical underpinnings of the study. This chapter includes a definition and presents a theoretical breakdown of the construct of the parental role in intervention. In this chapter the rationale for developing a measure of parental roles in intervention is outlined and the identified gap in the literature regarding parental roles in intervention is presented.

Chapter 3 outlines the methodology and procedures of this research study. This chapter discusses the aims of the study, design and presents the research phases of the study.

Chapter 4 details the construction of the survey instrument including the Biographical Questionnaire and the Parental Role in Intervention Task Tool (PRITT), the new measure of parental roles in intervention that is the focus of this thesis.

Chapter 5 explains the procedures employed in the expert review of the PRITT to establish content and face validity. Two panels of experts were involved in reviewing the PRITT: subject matter and context professional experts and target population experts i.e., parents of children with a disability.

Chapter 6 details instrument development and evaluation. First, the PRITT was developed with pretesting. The pilot study results and recommendations are presented. This chapter also outlines the participants and data collection procedures of the study.

Chapter 7 presents the results of the study according to the study sub-aims. The preliminary validity and reliability of the PRITT is established and the results from the sample population are analyzed and the representativeness of the sample is discussed.

Chapter 8 presents a critical discussion of the results and reviews the strengths and limitations of the study and this chapter concludes with recommendations for future research.

1.6 Summary

This chapter presented introduced the problem statement and outlined the rationale for the study. It also delineated the important terms and included a list of abbreviations used in the study. The chapter closed with an outline of each of the chapters contained in the thesis.

CHAPTER 2

LITERATURE REVIEW

2.1 Introduction

This chapter reviews the literature published on the main construct of the study, namely parental roles in intervention. The chapter presents the importance of the parental role in intervention related to the potential for parents to act as agents of change in their child's life. This is framed within the implied links across the literature between parental engagement and active parental roles in intervention. The concept of a role, parenting role, and the parental role in intervention are defined related to the results of the scoping review conducted to identify and describe parental roles in intervention in terms of the tasks and responsibilities linked with each role. The conceptual model is presented thereafter. The chapter concludes with a rationale for a quantitative instrument to measure the types of roles that parents perform in their child's rehabilitation interventions.

2.2 Parents as agents of change

The field of early intervention has progressed and aims to capitalize on the potential for parents to act as agents of change in their child's life (McWilliam, 2015). The family environment has an enormous influence on a child's development (Klatte et al., 2020; Whiteside-Mansell et al., 2013). This is because a child's learning takes place within the context of the relationships that they form with those around them, the most important and influential of which is with their parents (King et al., 2017; McWilliam, 2015). The Developmental Systems Approach (DSA; Guralnick, 2005) explains that factors including a child's current developmental characteristics interact with other factors present within the caregiving environment (i.e., family patterns of interaction and family resources) to influence a child's developmental outcomes. Family patterns of interaction, including parent-child transactions, family orchestrated child learning experiences, and the health and safety provisions that parents make for their child, therefore, form the proximal processes that provide the foundation for how a child views, experiences and copes with the demands of the outside world (Guralnick, 2011; Nelson, 2000; Shonkoff & Fisher, 2013; Whiteside-Mansell et al., 2013). How parents interact with their child, the quality and frequency of these interactions, and the types of activities that parents and children engage in together have an impact on a child's developmental outcomes (Mahoney & Nam, 2011). The effects of a child's disability can cause confidence threats for parents and strained resources may disrupt family patterns of interaction, resulting in a need for outside supports in the form of rehabilitation interventions (Guralnick, 2011).

Traditionally-implemented interventions are based on the belief that the developmental outcomes of a child with a disability are directly supported by professionals i.e., the quantity and frequency of therapy sessions (McWilliam, 2012). Contrary to this belief, however, is that children learn best when they are provided with learning opportunities in their naturally occurring routines rather than through singularly occurring mass trials (i.e., intensive, frequent intervention sessions) (Lane et al., 2016; McWilliam, 2015). Learning through participation in activities with their family is more meaningful for a child with a disability compared to learning in isolation, e.g., traditionally implemented interventions (McWilliam, 2015). Furthermore, children with a disability require early learning experiences that are prolonged and intensive (Hoffman, 2016). Parents can support their children to apply their developing skills in real-world environments by encouraging maintenance and transfer of the skills to additional contexts (King et al., 2017). Parents, therefore, hold the potential to deliver interventions that foster meaningful progress in the real world for their child with a disability. Unlike a young child with a disability, parents can gain from short-duration, intensive learning experiences and they can transfer their learned skills into other environments (McWilliam, 2015). Parents are also “uniquely placed” (Melvin et al., 2019, p. 1) to encourage “the daily engagement required to try, practice and feel ownership for behaviors and skills learned in rehabilitation" (King et al., 2017, p. 335). They can transfer the knowledge, skill, and strategies that they learn from their interactions with professionals into their everyday lives to the advantage of their child and family (King et al., 2017; McWilliam, 2015). As a child spends the majority of their time with their parents, parents are experts regarding their child (Lee, 2015b) and they have particular and exclusive insight to craft interventions that can best support their child and family (Hoffman, 2016). If parents are regarded as their child's primary interventionist and therapy is considered to be what happens between formal contacts with professionals (i.e., therapy sessions), then the potential of the caregiving environment to provide developmentally enhancing learning experiences for their child with a disability in meaningful contexts can be facilitated optimally (McWilliam, 2015).

2.3 Pediatric rehabilitation intervention as a context to facilitate change

As a child's participation in intervention is dependent on their parent's motivation and involvement in intervention to a large extent (D'Arrigo et al., 2019), the processes that culminate to influence parental experiences of intervention must be examined to understand how to promote more active involvement for parents in intervention (King et al., 2019; Phoenix, 2017). Intervention outcomes are a result of complex transactions, i.e., mutually influential interactions between the agents involved in therapy (the parent, child, and professionals) over the course of intervention. These transactions must be explored to advance professional proficiency to facilitate positive outcomes and to promote change for families and their child with a disability (King, 2017). How intervention sessions are carried out, interpreted, and engaged with matters (King et al., 2018). For this reason, this thesis has a parent-centric focus. The constructs discussed should be considered as one, albeit incredibly important, aspect of the dynamic transactions that occur between the parent, professional, child, and intervention systems within the 'situated context' of therapy (King et al., 2017, p. 1829).

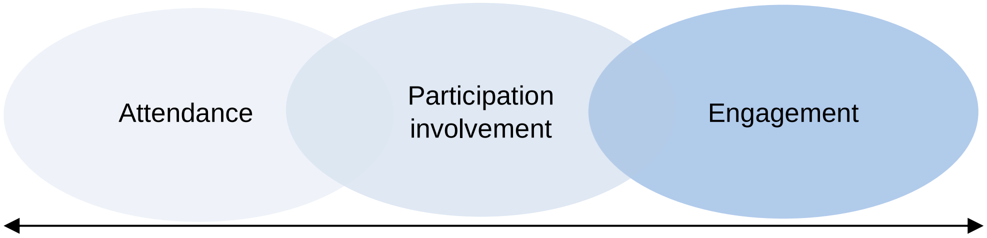
Engaging parents in the planning, decision making, and implementation of early interventions has been linked with positive intervention outcomes for both the child with a disability and their family (King et al., 2017; King & Chiarello, 2014; Lee, 2015). Parents who work with professionals can formulate and optimize learning opportunities that align with the child's capabilities and meet their family's needs (Sukkar et al., 2017). Therapeutic parent-professional relationships which are characterized by a robust working rapport, trust, and constructive exchanges (Reeder & Morris, 2018), are linked with creating an inviting environment that encourages parental participation and involvement in intervention (Carroll & Sixsmith, 2016). Parents and professionals can work together to design and implement effective and efficient interventions for the child with a disability and their family (Guralnick, 2008; Sukkar et al., 2017).

2.4 Implied links between parental engagement and parent roles in intervention

The literature proposes that within the intervention context, parents may assume different roles depending on their level of engagement (Davies et al., 2017; Forsingdal et al., 2013). The terms 'participation', 'involvement,' and 'engagement' have been used interchangeably in the literature (Imms, 2017; King, Chiarello, Ideishi, D'Arrigo, et al., 2019). In this study, these terms are referred to as a continuum of related constructs (Figure 2.1). Parental participation refers to the active contributions that parents make as they partake in their child's intervention (Hock et al., 2015; King et al., 2015). Based on the framework of the International Classification of Functioning (ICF-CY) (World Health Organisation, 2007), Imms et al. (2017) describe the construct of participation as comprised of two major elements; namely frequency of attendance, and involvement. From this perspective, attendance refers to being physically present in a therapy session whereas involvement refers to the "experience of participation while attending" a life situation such as an intervention session (Imms, Granlund, et al., 2016, p. 36). Attendance is thus a requirement for involvement i.e., one cannot develop the level of commitment and investment linked with involvement without being present. The term involvement suggests more than parents simply being present during a therapy session. Parental involvement therefore includes a level of connection between the parent and the professional that develops from shared investment or commitment to achieving intervention outcomes (Bright et al., 2015). Involvement, as defined in the family of Participation Related Constructs (fPRC) model (Imms, Adair, et al., 2016), 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 (Imms, 2017; King, Chiarello, Ideishi, Ziviani, et al., 2019; Melvin et al., 2019, p. 1). An engaged client is ready (i.e., emotionally receptive), willing (i.e., cognitively receptive), and able (i.e., has the required knowledge, skills, and sense of competence) to actively partake in intervention (King et al., 2017; p. 2).

Figure 2.1.

A Continuum of Engagement-Related Constructs.



Across the literature, the type of roles that parents adopt in their child’s intervention are suggested to be linked with the level of parental engagement (D’Arrigo Ziviani, Poulsen, Copley, & King, 2016; King et al., 2014). Forsingdal et al. (2013) allude to links between parental involvement and parental roles in intervention in their M-RIGS model, suggesting that parents take on different roles in the goal setting process depending on their preferred level of involvement. Although involvement is not explicitly defined in the study, it is indicated to be linked with empowerment, shared decision-making power, partnership and belief in the potential of intervention to effect change i.e., engagement. It is further implied in the intervention literature that parental roles have a part to play in parental engagement at various points across the process of intervention. The importance of parents understanding the boundaries of their roles is highlighted by Carroll and Sixsmith (2016) in their study that mapped the trajectory of the development of parent-professional relationships in intervention. Uncertainty regarding the boundaries of parent and professional roles in the experimenting stage of the parent-professional relationship was identified to limit parental capacity to engage with professionals. Links between different parental conceptions of their roles and varying levels of involvement over the course of intervention were reported by Davies et al. (2017) as well. In this study, parents reported that some roles related to them transporting their child to therapy and providing information about their child’s needs (described as passive roles) were related to taking less responsibility for and control over their child’s intervention i.e.: indicating lower levels of engagement. In other literature, parental roles that include decision making and transfer of intervention out of sessions, are implied to be linked with a more equal relationship with the professional, shared goals and high parental investment in intervention i.e.: high levels of engagement (Forsingdal et al., 2013; James & Chard, 2010). Hurtubise and Carpenter (2011; p. 85) question whether parents of children with a disability are ‘ready, willing, and able’ to perform the active roles linked with the high level of engagement that is expected of parents in family-centered interventions.

2.5 Changing roles in intervention

The roles of the parent and the professional have shifted as the field of early intervention has recognized the importance of parental engagement and the potential for parents to deliver meaningful interventions (Dodd et al., 2009; Hurtubise & Carpenter, 2011; McWilliam, 2012). Across rehabilitation intervention literature it is espoused that increasingly active parental roles in intervention are linked with facilitating improved parental, family, and child outcomes (D’Arrigo et al., 2016; Davies et al., 2017, 2019; King et al., 2014) which, in turn, promote intervention efficiency and efficacy (King, Chiarello, Ideishi, D’Arrigo, et al., 2019). Through their repeated exchanges with professionals, parents formulate and develop expectations for their own and the professional's roles (Davies et al., 2017; Hessell, 2004; Smart et al., 2019).

According to Smart et al. (2019; p. 108) when parents and professionals explore and discuss their respective expectations, this creates "shared opportunities to shape their roles". These opportunities provide a means for professionals to adapt to parental expectations and provide necessary supports (Hurtubise & Carpenter, 2011; Smart et al., 2019). Parents who understand the professional's intentions and expectations are motivated to participate actively during therapy sessions and are more likely to carry over intervention into other environments i.e., assume more in- and out-of-session responsibility (Carroll & Sixsmith, 2016; King, Chiarello, Ideishi, D'Arrigo, et al., 2019; Phoenix, 2017). In a study investigating experiences of engagement, King, Chiarello, Ideishi, Ziviani, et al. (2019) found that the parental role in intervention is affirmed as parents identify that their participation in intervention is facilitating their child's progress. It is further explained that growing parental competence (i.e., Improving knowledge and skills) further motivates parents to adopt increasingly active responsibility (more active in-session tasks) and encourages the transfer of learned intervention strategies into their daily lives (assuming more active out-of-session roles). These recurring positive interactions encourage experiences of satisfaction, enjoyment, and a sense of connection from engaging in intervention. Over time, these positive associations with parent-professional transactions foster a commitment to shared goals which further fosters parental competence and confidence to adopt increasingly active roles in their child's intervention (King, Chiarello, Ideishi, D'Arrigo, et al., 2019; King, Chiarello, Ideishi, Ziviani, et al., 2019).

2.6 Defining the construct of a role

A role is defined as a set of required behaviors that go along with occupying a position in a social group according to Kielhofner's Model of Human Occupation (MOHO) (Kielhofner & Burke, 1980). From this perspective, it is proposed that occupational roles organize actions; a great deal of how we organize our everyday routines and rituals are organized, is informed by the internalized concept of roles. Roles also influence how skills are used to act on the environment. MOHO (Kielhofner & Burke, 1980) explains that roles provide identities and also indicate the necessary behavioral requirements to fulfill an identity. Applying the MOHO perspective, Blesedell Crepeau et al. (2004) explain that adults recognize that they should behave in certain ways to enact the roles that they see themselves fulfilling. Occupational role behaviors, therefore, stipulate specific routines of action associated with a particular role in that they prescribe when, in what context or setting, with whom, and how often the actions or behaviors should be enacted (Kielhofner & Burke, 1980)

2.7 Parenting roles

Adults can take on a range of roles related to different areas of their lives. This may include roles related to employment (e.g., employee, manager, or colleague), community (e.g., friend, neighbor), or family (e.g., parent, spouse, child) (Rowbotham et al., 2011). The types of roles that we assume and how these roles are performed is influenced by an array of personal characteristics (i.e., values, attitudes, interests, skills, motivation, etc.) and the environment (i.e., the situations we find ourselves in, societal influences, etc.). Of the possible roles an adult can perform, the parenting role is considered a central human occupation (Farber, 2000; Kielhofner & Forsyth, 1997).

Parenting refers to the variety of functions and responsibilities that parents undertake to foster their child’s achievement of socially and developmentally appropriate skills (Sandler et al., 2011). The parenting role is regarded as one of the most challenging roles that an adult may acquire in their lifetime (Llewellyn, 1994). On a personal level, parenting shapes character and has deep private meaning (Farber, 2000). Parenting is likewise regarded as a public activity as it is a shared experience and it is influenced by various factors within the parent's environment, family, the community, and the public (Llewellyn, 1994).

2.8 Parenting roles for parents of children with a disability

The parenting role is particularly intensive for parents of children with a disability (Dodd et al., 2009). Parents of children with a disability extend the concept of their parenting roles to meet their child's special needs: meaning that they take on a variety of responsibilities over and above the parenting roles that are assumed by the parents of typically developing children (Boshoff, et al., 2016; Lutz, et al., 2012; Safe et al., 2012). These extended roles may be related to parents attending to their child’s medical or daily care needs or they may also be associated with treating behavioral concerns (Kruse, 2012; McWilliam et al., 2009; Whiting, 2014). Similarly, participating in rehabilitation interventions to address their child’s developmental challenges results in extended parenting roles for parents of a child with a disability (Albright et al., 2016; Minnes et al., 2015).

2.9 Parental roles in intervention

The parental role is a fundamental part of rehabilitation interventions designed to support the child with a disability and their family (Kemp & Turnbull, 2014; Osher & Osher, 2002; Robert et al., 2015). Intervention literature highlights that there is a range of possible options for parents of a child with a disability regarding their role in intervention and that parents perform different types of roles across the intervention process (Forsingdal et al., 2013; McWilliam, 2015; Osher & Osher, 2002). While there is considerable literature available describing extended parenting roles related to caregiving for parents of a child with a disability in their everyday lives or attending to their child's daily care and medical needs (Boshoff et al., 2016; Lutz et al., 2012; Safe et al., 2012; Whiting, 2014), research examining the parental role in intervention is limited (Davies et al., 2017). Despite the importance of the parental role, research has not yet established the tasks and responsibilities that parents are expected to perform to enact the different parental roles in intervention. The research that has been conducted is reported in discipline-specific studies, primarily from the field of speech-language therapy (Davies et al., 2017, 2019; Sugden et al., 2019; Watts Pappas et al., 2016).

Research seems to have looked primarily at the roles performed by parents of children with developmental delays (Bowen & Cupples, 2004; Davies et al., 2017; Sugden & Chambers, 2003; Sugden et al., 2019; Watts Pappas et al., 2016) or particular types of disabilities, i.e., Autism Spectrum Disorder (Burrell & Borrego, 2012; Tsai et al., 2008). Studies have mostly been conducted on particular stages of intervention, for example in goal setting (Forsingdal et al., 2013) and homework implementation (Burrell & Borrego, 2012; Sugden et al., 2019). Forsingdal et al. (2013) highlighted that there is a range of roles for parents to potentially perform during the goal setting phase of intervention. Related to homework implementation, professionals seem to prescribe a set of activities for parents to practice at home to reinforce professionally-driven interventions (Burrell & Borrego, 2012; Sugden et al., 2019). This may link with the findings from a study by Davies et al. (2019) who reported that professionals may have a clearer conception of certain parental roles i.e., roles related to homework implementation, but they may be unsure of other more active roles related to collaboration. The absence of discussion and negotiation of parental roles is also noted in the available literature on parental roles (An & Palisano, 2013; Hurtubise & Carpenter, 2011).

2.10 A proposed conceptual model of parental roles in intervention

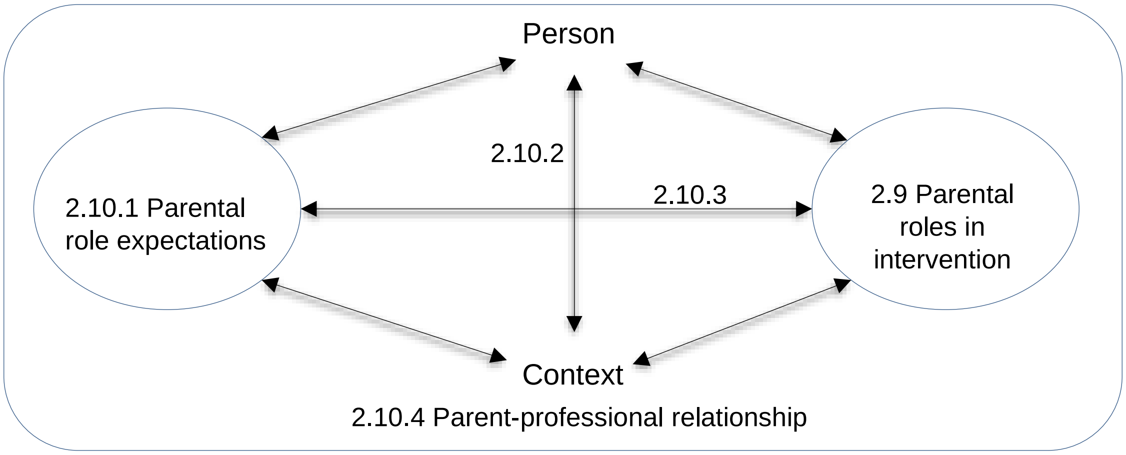
To the researcher’s knowledge, no specific theory has been consistently applied to the construct of parental roles in intervention. One theory that comes close, however, and may be suitable is the aforementioned MOHO perspective (Kielhofner & Burke, 1980). The occupational role perspective has previously been applied to examining the general caregiving aspect of the parental role for parents of children with a disability (Lofti et al., 2014; Riyahi et al., 2017). Symbolic interaction theory (Aksan et al., 2009) may also offer insight to understand the related roles and counter roles that parents and professionals play in the context of their interpersonal relationship.

The parental role in intervention is defined as a set of tasks and responsibilities attributed to the parent in intervention (Sugden et al., 2019) and it evolves through interpersonal relationships i.e., between the parent, child, and professional(s) (Davies et al., 2017; Tsai et al., 2008). This aligns with the MOHO perspective (Kielhofner & Burke, 1980) which outlines that role expectations influence actual role performance strongly. Parents continually make judgment calls about whether they can perform a role based on their perceptions of their capacity to be efficient in the role (Hessell, 2004). Personal characteristics influence expectations by directing motives and intentions, actual ability, what is considered as interesting, and marked as important (Kielhofner & Forsyth, 1997). Expectations develop constantly as information received from the environment is obtained, sorted, and meaning is added. Personal characteristics and the context interact with internal processes to influence expectations iteratively. Experiences and knowledge influence expectations by way of these internal processes in an organized and contextualized manner through volition (Kielhofner & Forsyth, 1997).

Parents have expectations of the role they could enact in their child's intervention from when therapy is initiated (Hessell, 2004; Phoenix et al., 2019; Smart et al., 2019). These expectations are influenced by an array of personal and contextual factors unique to that particular parent in their specific situation (James & Chard, 2010; Watts Pappas et al., 2016). Through their interactions with professionals in the context of therapy, parental expectations develop to influence the type of role and associated tasks and responsibilities that they will perform (Davies et al., 2017). It is through these influential interactions that parents can acquire the skills, knowledge, and confidence that are required to tackle increasingly active roles in their child's intervention (Davies et al., 2017; Forsingdal et al., 2013; Hurtubise & Carpenter, 2010). The conceptual model of the study, displayed in Figure 2.2 below, will be explained in the section that follows.

Figure 2.2.

A Proposed Conceptual Model of Parental Roles in Intervention.



2.10.1 Parental role expectations

Parents hold varied expectations about their role in intervention. Role expectations or constructions refer to the beliefs that parents hold regarding what they should do, i.e., the tasks and responsibilities they should perform, to facilitate their child's progress (Hessell, 2004; Smart et al., 2019; Walker et al., 2005). Some parents have specific notions about what their role in their child's intervention should entail (Russell, 2003) whereas other parents report being unsure of what to expect from intervention and uncertain about what their role will entail (Carroll & Sixsmith, 2016; Davies et al., 2017; Phoenix et al., 2019; Watts Pappas et al., 2016). For the most part, and particularly in the initial stages of intervention, many parents seem to expect the professional expert to be the 'fixer'. These expectations are presumably formed based on their previous healthcare experiences in medical model type interactions (Phoenix et al., 2019; Russell, 2003). These experiences (i.e., traumatic birth experiences, extensive medical testing, receiving a diagnosis, etc.) typically happen around the time they become involved in intervention for their child with a disability and can disrupt a parent's conception of their role (Hurtubise & Carpenter, 2011). Piggot et al. (2003, p.

15) suggest that early emotionally overwhelming, and challenging experiences force some parents into a 'state of unreadiness' which limits their capacity and willingness to take an active role in their child's intervention. For these parents, confidence threats can have a negative impact on their engagement with professionals in intervention. However, other parents may hold expectations to be involved in their child's intervention in more active ways from the initiation of therapy. Forsingdal et al. (2013) suggest that some parents may want to take responsibility and ownership for intervention earlier on in the intervention process and engage with professionals in planning and goal setting. These parents may have previous experiences with intervention (possibly with another of their children or another discipline of therapy) through which they frame their expectations (Hessell, 2004; Phoenix et al., 2019).

2.10.2 Parental experiences as a culmination of person-context interactions

Parental roles in intervention appear to be experienced in a way unique to each parent (James & Chard, 2010; Watts Pappas et al., 2016). The parental role in intervention is influenced by a complex interplay of factors in the systems in which it plays out. Across the literature, various factors are proposed to influence the type of role that a parent takes on in their child's rehabilitation interventions. The processes in which parental role expectations play out are indicated to be influenced by personal and contextual influences that affect actual role performance. This assumption is supported by research examining parental expectations and experiences of intervention (King et al., 2019; Smart et al., 2019; Hessel, 2004). These factors include, although are not limited to, factors related to the child, parent, family, home setup, therapy, professional, and intervention system. The particular factors have not yet been exhaustively investigated and the interplay of these factors is not fully understood. The context (or life situation) where parental roles play out is rehabilitation interventions (Imms et al., 2017; King et al., 2014). In this study, the setting was 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. The tasks associated with the identified parental roles were, therefore, further coded according to the setting i.e., whether they were performed during therapy sessions (in-sessions tasks) or outside of therapy sessions (out-of-session tasks).

2.10.3 From role expectations to role performance

When MOHO (Kielhofner & Burke, 1980) is extended to understand how parents move from an expectation of a role to performing the role, the concept of volition can be applied to offer insight into these complex transactional processes. Volition explains that influences from our internal knowledge storage and past experiences will interact to influence our behaviour choices (Kielhofner & Forsyth, 1997). For parents with medical model type experiences of healthcare, it makes sense that they lean toward dependency on professionals to direct intervention (Phoenix et al., 2019; Russell, 2003). As professionals are more experienced with intervention, they commonly hold the power in the parent-professional relationship (McKenzie & Müller, 2006; Rix & Paige-Smith, 2008). Added to this is that parents are learning to navigate complex intervention systems (Hurtubise & Carpenter, 2011). Additionally, parents who are unsure of what their role entails in terms of tasks and responsibilities, seem to rely heavily on the professional’s direction (Forsingdal et al., 2013; Reeder & Morris, 2020). As parents try to assimilate the information that they receive within the context of the parent-professional rapport, the professional's behavior and actions and cues from the organizational system can either support or hinder parental attempts to enact increasingly active roles (Davies et al., 2017; King et al., 2019; Phoenix et al., 2019). It is therefore proposed that the parental role in intervention be viewed within the complex transactional processes that occur between the parent, professional, and child in intervention.

2.10.4 The context of the parent-professional relationship

The parental role in intervention is linked with the tasks and responsibilities assigned to parents within the context of the relationships that influence it; the most influential of which seems to be the parent-professional relationship (Davies et al., 2019). MOHO (Kielhofner & Burke, 1980) explains that interactions strongly influence role expectations (i.e., how parents foresee themselves performing a role) as well as role performance (i.e., how they enact a role) (Blesedell et., 2004). Symbolic interaction theory (Aksan et al., 2009) also indicates that the meaning of a role lies within the social interactions in which it develops. From this perspective, each role is related to a counter role that develops as part of an iterative series of transactions in context (Aksan et al., 2009). This perspective has been applied to consulting relationships in intervention, albeit between professionals (Crowley & Sabatelli, 2008). It is believed that this perspective is suitable to frame the parental role as it explains that roles have a natural association with power. Roles and counter roles of the parties involved are influenced by an array of interacting factors that affect the balance of power in the relationship. When a consultee pursues the expertise of a consultant, due to the nature of their relationship, they generally accept the authority of the consultant. This application to parent-professional roles is supported by findings from intervention literature suggesting that parents are commonly inexperienced with intervention and experience emotionally challenging times when they begin intervention (Hurtubise & Carpenter, 2011; James & Chard, 2010). When the balance of power is addressed in intervention, this promotes the parental capacity to take control over intervention by affirming the parental contribution and creating opportunities for role negotiation (Reeder & Morris, 2018). Conversely, when power in the parent-professional relationship is not addressed, parental contributions are undermined and professionals retain primary responsibility for intervention (Lee, 2015a; Reeder & Morris, 2020; Rix & Paige-Smith, 2008; Smart et al., 2019).

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 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 also 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 then provide parents with contingent supports (i.e., information, skill, confidence affirming feedback) as required (King, Chiarello, Ideishi, D'Arrigo, et al., 2019).

It is not only a parent's actual ability or capacity (e.g., knowledge, skill, etc.) to perform a role that matters but also how competent they perceive themselves to be in carrying out the role that will influence whether they assume it (Hessell, 2004; Hurtubise & Carpenter, 2011). While we require certain skills and knowledge to enact a role, this is not the only influence on our ability to perform a role (Mumford et al., 2008). Our expectations of performance capacity, i.e., how confident we feel in our ability or our self-efficacy beliefs, are highly influential to our performance, more so than our actual ability (Hessell, 2004; Kielhofner & Forsyth, 1997). Across the rehabilitation literature, parental perceptions of competence and confidence are linked with a parent's ability to assume increasingly more active roles (Davies et al., 2017; Forsingdal et al., 2013; Hurtubise & Carpenter, 2011).

Interventions that incorporate parental capacity-building equip parents with the skills and knowledge required to take on more active roles in their child's intervention (Swanson et al., 2011). Coaching relationships replace patriarchally, "power-over relationships" that are associated with traditional, medical model approaches (Rush & Sheldon, 2011, p. 39). Over time, parents develop confidence from their growing perceived sense of competence that allows them to take on added responsibility in intervention (Hurtubise & Carpenter, 2017; Maclean & Chesson, 1991). 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).

2.11 Expected parental roles in intervention in the local context

The predominant medical model approach in which intervention professionals are trained and deliver services in South Africa (Samuels et al., 2012) indicates that parents will report enacting primarily more passive roles in intervention. This assumption is supported by available literature related to rehabilitation interventions in the local South African context (Coovadia et al., 2018; Kyarkanaye et al., 2017; Rowe & Moodley, 2013). A study by Saloojee et al. (2009) highlights that family-centredness is not the prevalent approach to intervention in the local context. The authors were unable to establish validity and reliability for the Measure of Processes of Care (MPOC-20) for use with parents of children with a physical disability attending rehabilitation interventions in public healthcare facilities in the Gauteng and Limpopo provinces. Although parents who participated in the study reported similar needs as compared with parents from international contexts, the ways that these parents spoke about intervention and their expectations of healthcare were different. While the MPOC was developed to examine parental experiences of the 'how' of intervention, and the current study is focused on role tasks i.e., what parents do in intervention, the influence of the intervention approach and context, and the related nature of parent-professional exchanges on parental roles is paramount to consider. The setup of local intervention systems and services as explained by Samuels et al. (2012) further entrenches the prevalent medical model approach with ensuing passive roles for parents in intervention (Smart et al., 2019; Swanson et al., 2011). South Africa has a dual healthcare 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 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 sector, which the majority of children with disabilities and developmental delays access, numerous factors influence the balance of power in the parent-professional relationship. Specifically, the limited availability of professionals and reported cultural and linguistic mismatches between parents and professionals limit parental autonomy in intervention (Kyarkanaye et al., 2017; Coovadia et al., 2018; Rowe & Moodley, 2013). Consequently, South African parents report difficulties with envisaging themselves assuming active roles in intervention (Kyarkanaye et al., 2017). Based on this, it is expected that in the South African context, that professionals retain primary responsibility for intervention planning and implementation.

2.12 Matched role expectations

The alignment of role expectations between parents and professionals seems to influence a parent's perceived satisfaction with their assigned roles. In some instances, the expectations of the parent and professional are naturally matched while in other cases, considerable discussion and negotiation are required to align expectations (Hurtubise & Carpenter, 2011; Phoenix et al., 2019; Smart et al., 2019). Parents are primed to get involved in their child's intervention where there is an alignment of role expectations by way of providing a “cognitive mindset” for parents to engage deeply (King, Chiarello, Ideishi, Ziviani, et al., 2019; p. 6). Parents who understand the professional's intentions and the aims of therapy report feeling equipped to perform more active role tasks and responsibilities. These parents understand why the chosen course of action is being followed and how their behavior (i.e., the role tasks they enact) will support intervention outcomes (King, Chiarello, Ideishi, D’Arrigo, et al., 2019). Using this knowledge, parents can better navigate intervention systems because they understand what tasks they should perform to support their child's progress (Hurtubise & Carpenter, 2017). Likewise, if professionals understand the parent's expectations of their role in intervention, they can provide the required supports (i.e., information, skills, confidence affirming feedback) for parents to contribute to planning and carrying out the intervention. Likewise, the professional is guided in terms of the resources and support those parents require. Professionals who take the time to get to know and understand parental expectations can assess their unique and changing needs to employ contingent, individualized strategies that invite and support parental participation and involvement (King, Chiarello, Ideishi, D’Arrigo, et al., 2019; p. 6; King, Chiarello, Ideishi, Ziviani, et al., 2019). This encourages parents to ask questions and share their concerns as the parent-professional relationship supports open communication.

These positive, affirming transactions encourage a robust parent-professional rapport to develop (King, Chiarello, Ideishi, D’Arrigo, et al., 2019). As parents perceive that their knowledge and skill are growing, they are more motivated to participate in therapy sessions (i.e., assume active in-session roles) and to transfer the strategies learned into their daily lives (i.e., assume active out-of-session roles). Over time, the compounding effects of these positive transactions lead parents and professionals to experience feelings of satisfaction, enjoyment, and a sense of connection. The knowledge sharing and joint understanding that results from these transactional processes motivates parents to want to take on more active roles and collaborate with the professional (King, Chiarello, Ideishi, D’Arrigo, et al., 2019; King, Chiarello, Ideishi, Ziviani, et al., 2019).

2.12.1 Consequences of mismatched role expectations

Conversely, parents who are uncertain of their role and the professional's expectations find it challenging to commit to and invest in the intervention plan (Carroll, 2010; King, Chiarello, Ideishi, D’Arrigo, et al., 2019; Smart et al., 2019). When professional expectations are not communicated explicitly, parents may fail to see the vision of how the planned course of action (and specifically, their behavior i.e., the role tasks they perform) will translate to support intervention outcomes (King, Chiarello, Ideishi, Ziviani, et al., 2019). Misalignment of role expectations or miscommunication about the parent’s role is, therefore, linked with lower levels of involvement and even disengagement from intervention (King, Chiarello, Ideishi, D’Arrigo, et al., 2019).

The literature indicates a marked lack of open communication and negotiation between parents and professionals in intervention regarding the parental role (Davies et al., 2017; Watts Pappas et al., 2016). Role negotiation refers to an iterative process between the parent and professional(s) that enables them to develop a shared understanding of their own and each other’s roles without one party imposing their expectations on the other (Newton, 2000). This process supports parents in “negotiating the type and level of participation in their child’s care and intervention, and the types of roles they wish to assume” (Corlett & Twycross, 2006; Hurtubise & Carpenter, 2011). It is through a discussion of role expectations that parents and professionals can determine parental readiness to take on more active roles in their child’s intervention together (Hurtubise & Carpenter, 2011; Watts Pappas et al., 2016). Smart et al., (2019) explain that negotiation allows parents and professionals an opportunity to adapt their ways of working to accommodate one another’s perspectives. It is through the processes involved in discussing the role that parents may want to assume and the supports they may require to do so, that trust and a sense of connection are fostered within the parent-professional relationship (King et al., 2019; Smart et al., 2019).

Challenges with operationalizing and implementing family-centered interventions have been in part linked to the lack of negotiation of role expectations between parents and professionals (Forsingdal et al., 2013; Centre for Community Child Health, 2021). Parent-professional partnerships are undermined when role expectations are not discussed and expectations may "diverge and become incompatible" (Smart et al., 2019). In these instances, professionals seem to revert to the expert model with further consequences in terms of limiting the support they offer parents to assume more active roles (Smart et al., 2019; Davies et al., 2017). Parents express a feeling of dissatisfaction with intervention when their expectations regarding their roles in intervention are not met, i.e., they are assigned more passive or active tasks than they expect to or can perform, or if they are not provided with the required supports (i.e., information, skills, confidence affirming feedback) (Hessel, 2004; Smart et al., 2019). In these cases, parents report feeling as though responsibility for intervention is “dumped” on them causing unnegotiated role expectations to seem overwhelming (Reeder & Morris, 2020). This may mean that parents struggle to trust the professional and their belief in the intervention plan to effect change in their child’s and family’s life will be compromised (King et al., 2019).

2.13 The need for a quantitative instrument to measure parental roles in intervention

The implied relationship between parental engagement and parental roles in intervention has not been empirically tested. If a relationship does exist, encouraging parents to assume more active roles could offer a potential avenue to promote parental engagement to facilitate child and family outcomes. Parents and professionals could then negotiate their preferred level of engagement by negotiating the types of roles that they wish to assume in their child’s intervention as is suggested in the literature (Carroll, 2010; Hurtubise & Carpenter, 2011). In order to determine if there is a relationship between parental engagement and parental roles in intervention, the constructs of parental engagement and parental roles in intervention would need to be quantitatively measured in order to perform required statistical analyses. The Pediatric Rehabilitation Intervention Measures of Engagement (PRIME) research team has developed the Pediatric Rehabilitation Intervention Measure of Engagement-Parent (PRIME-P) (King et al., 2021) and the Pediatric Rehabilitation Intervention Measure of Engagement-General (PRIME-G) (Research version 2; King et al., 2015) which captures parental reports of their engagement in their child’s intervention. The PRIME-G (Research version 2; King et al., 2015) focuses on global engagement across intervention and the PRIME-P (King et al., 2021) focuses on engagement in a particular session. Both measures include items composed of statements about affective, cognitive, and behavioural engagement rated on an agreement Likert type scale (1= Strongly disagree to 7=Strongly agree). Following the establishment of the validity of one of these measures for use with South African parents of children with a disability, the instrument could be used to measure parental engagement. Before the possible relationship between parental engagement and parental roles in intervention can be tested however, a quantitative instrument to measure parental roles in intervention needs to be developed and validated for use with South African parents of children with a disability. As a research tool, this new measure can contribute to our theoretical understanding of the parental role in intervention that is deemed so important for intervention outcomes and which offers a means of quantitatively measuring the construct of parental roles in intervention that has, to date, only been qualitatively described.

An instrument to measure parental roles in intervention also has the potential clinical uses to stimulate opportunities to discuss the types of roles parents may want to perform in their child's rehabilitation interventions. This would take the responsibility away from parents to self-describe their role tasks or initiate role negotiations which may be challenging for parents who cannot conceive of what more active role tasks in intervention would involve. Parents and professionals could then negotiate role expectations and parental readiness to assume the increasingly active responsibility and tasks associated with these roles. Together parents and professionals can identify the types of supports parents may require to take on more active role tasks. They can also discuss the possible implications of parents assuming different types of roles for therapy outcomes in terms of intervention efficiency, i.e., length of time spent in intervention, and effectiveness, i.e., how well it achieves its expected outcomes in terms of child development. This will enable parents to make informed decisions about their roles in their child’s intervention. The measure could also be repeated at different time intervals to indicate how parental roles and parental support needs may change over the course of intervention.

2.14 Summary

This chapter examined the parental role in intervention construct as it relates to the changing nature of interventions. The concepts of a role, parenting role, and the parental role in intervention were defined. Then the range of parental roles in intervention were identified from the literature and delineated in terms of the tasks and responsibilities associated with each. A conceptual model for the parental role in intervention in this study was proposed whereby MOHO (Kielhofner & Burke, 1980) and Symbolic interaction theory (Aksan et al., 2009) were applied to explain how parents move from role expectations to role performance within the context of the interpersonal interactions between parents and professionals in intervention. Implied links between parental engagement and parental roles in intervention and the need for opportunities for parents to negotiate their roles and the supports they required to perform active roles in intervention were highlighted and presented as a justification for developing the new measure.

CHAPTER 3

METHODOLOGY

3.1 Introduction

This study aimed to develop and preliminarily validate an instrument to measure parental roles in intervention. This chapter outlines the methodology used in the study. The chapter begins by introducing the study aim and sub-aims. The research design, a mixed method design for instrument validation and development is detailed and the four phases employed in the study are outlined.

3.2 Aim of the study

The primary aim of the study was to develop and preliminarily validate a qualitative instrument to measure parental roles in intervention for use with parents of young children with a disability. To achieve this aim, the following sub-aims were addressed:

I. To identify and describe, using a scoping review, the types of roles and corresponding tasks and responsibilities ascribed to parents of children with a developmental delay, disability, or long-term health condition in the intervention literature.
II. To develop a quantitative measuring instrument to determine the types of roles that South African parents of a child with a disability assume in early intervention services.
III. To establish content and face validity of the developed instrument with expert review.
IV. To explore the dimensionality of the developed instrument by performing factor analysis.
V. To assess reliability by determining the internal consistency and test-retest reliability of the developed instrument.

3.3 Research design

This study uses a mixed method design for instrument development and validation (Zhou, 2019). The research phases employ qualitative and quantitative data as well as mixing of data to develop and validate the new instrument to measure parental roles in intervention. The use of mixed methods is suitable to "enhance the quality of instrument validation" (Zhou, 2019, p. 40). The research study phases were based on the best practice recommendations of Boateng et al. (2018) in their primer for developing and validating scales for health, social, and behavioral research.

3.4 Research study phases

The study was conducted in four phases (Figure 3.1).

Phase 1 involved the construction of the survey instrument i.e., the Biographical Questionnaire and PRITT. Item content for the PRITT was generated based on a qualitative investigation of parental roles in intervention from a scoping review of the rehabilitation, developmental, and intervention literature (Smith & Samuels, 2021). The extracted qualitative findings from the review, i.e., the coded descriptions of parental roles in intervention were then developed into items. The format and response scale of the survey questionnaire was also determined in this phase based on consultation with a statistician.

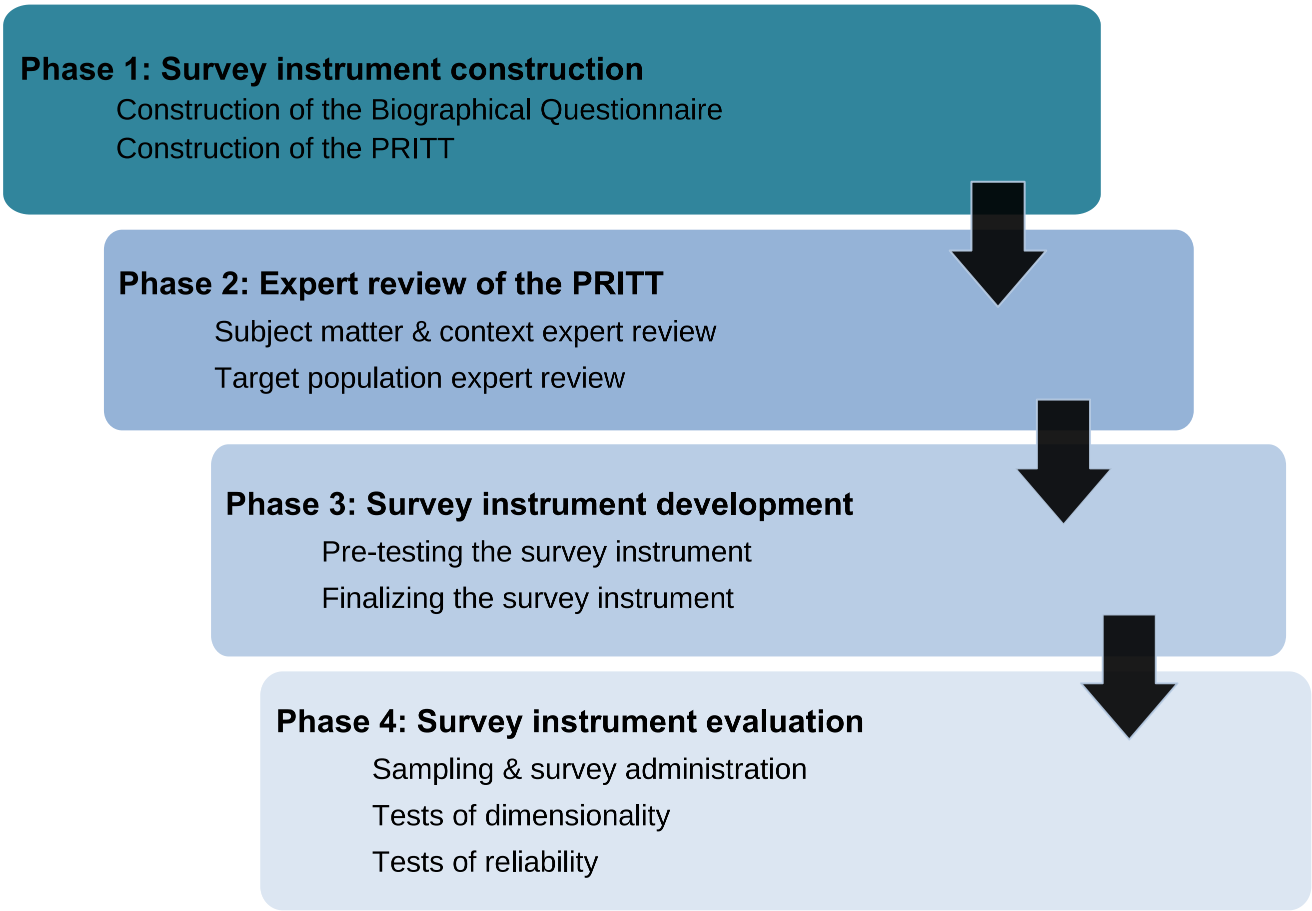
In Phase 2, online expert review was used to establish content and face validity of the PRITT. Content validity was established using the quantitative and qualitative feedback of subject matter and context experts. In the first step of the expert review, the experts provided quantitative ratings of specific aspects of the survey instrument and in step 2 the experts provided qualitative input in online focus group discussions. To establish face validity, target population experts provided qualitative feedback during cognitive interviews to review the survey instrument. The expert reviews were completed online

In Phase 3, the survey instrument administration procedures were pretested with an online pilot study. The survey instrument was refined and finalized based on the results and recommendations from the pilot study.

Lastly, in Phase 4, the survey instrument was administered as an online survey. Quantitative data collected during Phase 4 was used to explore the factor structure of the PRITT and the internal consistency and test-retest reliability of the PRITT were evaluated.

Each of the phases is described in detail in the subsequent chapters of this thesis. The research phases are graphically represented in Figure 3.1 below.

Figure 3.1.
Research Phases of the Study.



Data for the different phases of the study were collected online in response to constraints related to the national lockdown and social distancing protocols as a result of the COVID-19 pandemic (Rosenbaum et al., 2020). In Phase 2, subject matter and context professional experts completed a quantitative online rating checklist and provide qualitative feedback by participating in an asynchronous online focus group. Then, target population experts participated in online cognitive interviews. For Phase 3, the pilot study survey administration procedures mimicked the procedures used in Phase 4 namely, a self-administered online survey. Participants could access the online survey at a time and place convenient for them (Ball, 2019). Self-administered questionnaires were selected over interview administered surveys for the large sample size that was required to address the study aims (Alasuutari et al., 2008).

A disadvantage is that online surveys exclude participants who are not literate (Bernard, 2011), uncomfortable with technology, and are without internet access (Ball, 2019). This may affect the generalizability of the study results. It was necessary to adhere to the study timeline despite restraints related to the COVID-19 pandemic (Pepper & Burton, 2020). The email or mobile link for the online survey questionnaire was made available through parent organizations and by rehabilitation professionals.

3.5 Summary

This chapter outlined the primary aim of this research study, namely to develop and validate an instrument to measure parental roles in intervention and presented the sub-aims set out to address this primary aim. The research design was presented and the research study phases were outlined with an indication of online data collection methods employed for each phase of the study.

CHAPTER 4

SURVEY INSTRUMENT CONSTRUCTION

4.1 Introduction

This chapter outlines the procedures for the construction of the survey instrument, including the Biographical Questionnaire and Parental Role in Intervention Task Tool (PRITT). The chapter starts off by presenting the scoping review of the parental role in intervention used to identify item content for the PRITT. The construction of the PRITT involving item development from the qualitative descriptions of the parental roles in intervention from the scoping review and the response scale selection are then described.

4.2 Phase 1: Survey instrument construction

The survey instrument was comprised of the Biographical Questionnaire (Section A) and the new measure of parental roles in intervention, namely the PRITT (Section B). The construction of the survey instrument was based on recommended procedures from the instrument development literature (Boateng et al., 2018; DeVellis, 2017; Zhou, 2019) and is described in detail in the sections that follow.

4.3 Construction of the Biographical Questionnaire (Section A)

The Biographical Questionnaire (Section A) included questions to capture the relevant information needed to make inferences about the representativeness of the study sample. Specific questions regarding the sample including the type of parent, family composition, characteristics of the household, child, and the intervention were included.

4.4 Construction of the PRITT (Section B)

The PRITT was developed based on recommended procedures from the instrument development literature (Boateng et al., 2018; DeVellis, 2017). Initially, the researcher determined the boundaries of the parental role in intervention construct according to theory i.e., the Model of Human Occupation (MOHO) (Kielhofner & Burke, 1980) (Discussed in Chapter 2). Then, qualitative data on parental roles in intervention was gathered using a scoping review of the rehabilitation, developmental, and intervention literature (Smith & Samuels, 2021) to investigate the construct of interest (Zhou, 2019). The qualitative findings from the scoping review were then used to generate a pool of preliminary items. While items were generated, the format and response scale of the survey questionnaire was determined in consultation with a statistician (Boateng et al., 2018).

4.5 Identification of the content domain for the PRITT

DeVellis (2017) advises that the initial step of instrument construction includes determining the boundaries of the construct according to theory. To the researcher's knowledge, no particular theory has been consistently applied to the construct of the parental role in intervention. One theory that may be suitable is MOHO (Kielhofner & Burke, 1980) (See Chapter 2). From this perspective, the parenting role in intervention is delineated as a type of occupational role related to the family.

The next step involved naming and defining the dimensions of the construct to be measured. This ensures that the boundaries of the domain are clear and ensures that more relevant item content is generated in the later steps (Boateng et al., 2018). As discussed in Chapter 2, parenting is broadly defined as a set of tasks or duties that represent the responsibility that parents take on to meet their child's needs (Sandler et al., 2011). In previous studies, the parenting role was operationalized as a set of role task statements in a measuring instrument developed to assess the role performance of parents of children with a disability (Crowe et al., 1997; Rizzo, 1998) and to compare the parenting role performance of parents with and without disabilities (Lotfi et al., 2014; Riyahi et al., 2017). In this study, the parenting role in intervention is defined as a subset of the larger parenting role associated with their child with a disability's involvement in rehabilitation interventions and was operationalized as parental role task and responsibility statements.

4.6 Generation of potential items for the PRITT

The next instrument development step involved generating content to inform a collection of potential items (DeVellis, 2017) based on a scoping review of the rehabilitation, developmental, and intervention literature (Smith & Samuels, 2021). This qualitative investigation of the parental role in intervention construct was carried out to ensure sufficient representation of the construct (Boateng et al., 2018; Zhou, 2019). Initially, the researcher conducted a systematic search of the rehabilitation, intervention, and early childhood, intervention literature to determine if any existing measures could be located for adaptation and use in the study. The search was conducted using Academic Search Complete, CINAHL, E-Journals, Family and Society Studies Worldwide, Health Source: Nursing/Academic Edition, Humanities Source: Consumer Edition, MasterFILE Premier, PsychARTICLES, PsycINFO, Social Work Abstracts, and Teacher Reference Centre. The following search terms were used: parent* OR caregiver*, role* OR responsibilit*, measure* OR survey* or instrument*. No existing quantitative instruments could be located to measure the type of role that parents take on in their child's developmental intervention. Previously conducted studies that described the parent role in intervention utilized qualitative, semi-structured interviews with open-ended questions (Davies et al., 2017; Forsingdal, et al., 2013). This was not suitable for the current study due to practicalities i.e., time, sample size, and the type of data required to perform the statistical analysis to validate the instrument.

4.7 A scoping review of parental roles in intervention

A scoping review was, therefore, undertaken to address these gaps. The scoping review was published in a peer reviewed journal (Smith & Samuels, 2021) (See Appendix A). The primary aim of the scoping review was to identify and describe the roles performed by parents of children with developmental delay, disability, or long-term health conditions from the early intervention, rehabilitation, and developmental literature. Furthermore, the scoping review aimed to determine the tasks and responsibilities associated with each of the identified parental roles. As a secondary aim, the review was used to examine how the parental role in intervention construct has been conceptualized in the literature and who has ascribed these roles to parents in intervention i.e., parental self-report or professional report. As it is suggested that parents hold different views of their roles in intervention when compared to professional views (An & Palisano, 2013; Kruse, 2012), it was deemed important to ensure that the review captured parental perspectives. The qualitative findings from the review were used to operationalize the parent role in intervention construct as task and responsibility statements that were developed into items for the measure.

4.7.1 Procedure

4.7.1.1 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. 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 links have not been proven and so terms related to parental involvement and engagement were not included in the search terms. The search terms are detailed in Table 4.1. below.

Table 4.1.

Search Terms Used in the Search Strategy for the Scoping Review.

Term	Search term
Parent	Caregiv* OR famil* OR parent* OR father* OR mother* OR sibling* OR friend* OR neighbor* OR neighbor* OR
Role	Role* OR responsibilit* OR task* OR part* OR dut*
Intervention	Interven* OR rehab* OR therap* OR service* OR support* OR manage* OR care* OR provid* OR habilta* OR treat*

4.7.1.2 Article selection

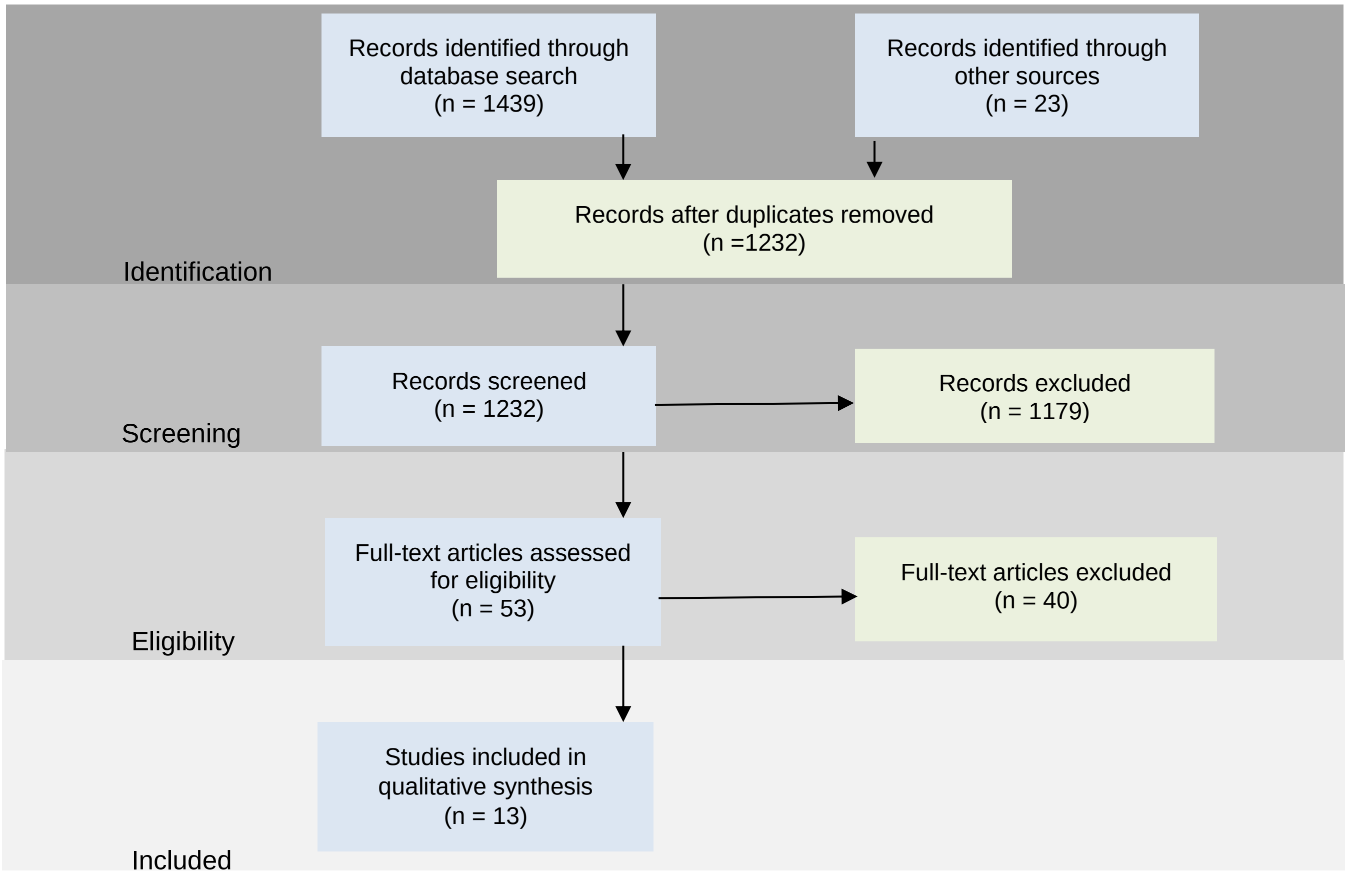
A total of 1439 articles resulted from the search criteria (Figure 4.2). After duplicates were removed, the researcher conducted an initial screening of the titles and abstracts of the literature sources to exclude those not related to the topic of the review (n= 1232). Thereafter, a hand search of the reference lists of the included articles was conducted and a forward citation search in Google Scholar was undertaken to identify any other primary literature sources. An additional 23 literature sources were included based on the forward citation and hand search of reference lists. A review of 53 of the full-text articles was conducted. Finally, 13 articles that met the inclusion criteria below were included and coded for role tasks (n=13). The extracted descriptions of the role tasks and responsibilities from the included articles are shown in Appendix C. The limited number of literature sources identified demonstrate that the parental role in intervention is poorly researched.

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. Literature sources were excluded if they described the role 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). Two reviewers blind reviewed each literature source at the title and abstract level to decide whether it should be included. Any discrepancies were resolved by consensus.

Based on these criteria, nine articles were included from the database search (Bowen & Cupples, 2004; Burrell & Borrego, 2012; Davies et al., 2017, 2019; Hurtubise & Carpenter, 2017; Maclean & Chesson, 1991; Sugden & Chambers, 2003; Sugden et al., 2019; Tsai et al., 2008). An additional four articles (Forsingdal et al., 2013; James & Chard, 2010; Rix & Paige-Smith, 2008; Watts Pappas et al., 2016) based on the hand search and forward citation search were included in the review (n=13; Figure 4.2).

Figure 4.2.

PRISMA Flow Diagram (Moher et al., 2009) of the Article Selection Process for Scoping Reviews.



4.7.1.3 Thematic analysis

Qualitative thematic analysis (Nowell et al., 2017a) utilizing Atlas.ti8 software (Paulus et al., 2017) was conducted to extract the parental role in intervention task statements from the included literature sources. After familiarisation with the data, the researcher compiled a codebook of initial a priori codes that defined parental roles in intervention common to the early intervention literature (Appendix B). In the first round, the researcher assigned a priori codes and open-coded other role descriptions or definitions that did not fit the a priori codes. In the second round, inductive codes were assigned to the open coded role descriptions. This process was repeated and themes were extracted from the data. Any discrepancies were discussed until consensus was reached.

4.7.1.4 Article coding

The descriptions of parental roles in intervention were varied across the included literature sources. Appendix C includes the parental roles and corresponding tasks and responsibilities extracted from the scoping review. A range of parental roles in intervention task statements ascribed to parents in intervention emerged from the data. The definitions of the parental roles in intervention were organized into themes.

4.7.1.5 Themes: Roles ascribed to parents in the intervention literature

Bringer role

Three of the included articles described parents' roles as what was coded as the Bringer role. Two articles named this role the Attender (Davies et al., 2017, 2019) while the third article did not provide a name for the role (Tsai et al., 2008). In this role, parents assume responsibility for ensuring that their child attends intervention sessions. In naming this role, the term Bringer role 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 attendance.

Supporter role

The Supporter role involves parents encouraging their child's motivation to enjoy their intervention sessions with the professional. Although this role was not named in the article that described it (Watts Pappas et al., 2016), it was suggested to have a supportive function. This out-of-session task whereby parents encouraging their child's enthusiasm to participate in professionally-directed sessions is linked with the in-session Bringer role.

Informer role

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, and their child's behavior at home (Bowen & Cupples, 2004; Burrell & Borrego, 2012; James & Chard, 2010). 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).

Observer role

Two of the included articles described the parental role that 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 et al., 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.

Learner role

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; Maclean & Chesson, 1991). The parental tasks associated with this role require parents to learn technical information and gain the knowledge required to contribute to their child's intervention (Hurtubise & Carpenter, 2011; Rix & Paige-Smith, 2008). 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 (Bowen & Cupples, 2004; Burrell & Borrego, 2012; Sugden et al., 2019). 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).

Implementer role

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 role are enacted primarily 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 (Maclean & Chesson, 1991; Sugden & Chambers, 2003; Sugden et al., 2019; Tsai et al., 2008). It is, therefore, linked with the in-session Observer role. Parental tasks in this role are to act as helpers, interveners (Davies et al., 2017, 2019), or assistants to the professional (James & Chard, 2010). In this role, parents use the 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).

Adaptor role

The Adaptor role was described in six of the included articles (Burrell & Borrego, 2012; Maclean & Chesson, 1991; Rix & Paige-Smith, 2008) 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, Learner, and Implementer roles to make up their therapy activities (Bowen & Cupples, 2004; Davies et al., 2017; Rix & Paige-Smith, 2008). Parents will also make suggestions to professionals regarding activities that are matched to their child's developmental abilities (Burrell & Borrego, 2012; Davies et al., 2017).

Decision maker role

In their role as a Decision maker included in four of the articles, parents are regarded as fully capable of making decisions and are supported by professionals (James & Chard, 2010; Watts Pappas et al., 2016). When working with professionals, parents make decisions about the focus of intervention as well as the level and nature of their involvement (Forsingdal et al., 2013; James & Chard, 2010). They are expected to give their opinion and engage with professionals in a reciprocal dialogue about the focus of intervention (Maclean & Chesson, 1991; Watts Pappas et al., 2016) and how intervention is carried out (James & Chard, 2010; Watts Pappas et al., 2016).

Collaborative partner role

Six of the articles included descriptions of parents as Collaborative Partners. In this role, parents work with professionals “with both sides giving input to an equal partnership” (Burrell & Borrego, 2012; Forsingdal et al., 2013; James & Chard, 2010, p. 281). Parents and professionals, therefore, share equal responsibility for the implementation of the child’s intervention. Also termed the active partner (James & Chard, 2010), or collaborator (Maclean & Chesson, 1991), parents are experts concerning knowledge of their child and family system. Parents and professionals have shared power in decision-making, goal setting, and implementing interventions, as well as in defining outcomes (James & Chard, 2010).

Advocate role

Eight of the articles described parents taking on an Advocacy role that seems to begin when parents determine that external assistance is required (Hurtubise & Carpenter, 2011; Rix & Paige-Smith, 2008). Parents subsequently 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, 2019; James & Chard, 2010). Parents also coordinate to “bridge the gap” between intervention and other environments, e.g., encouraging transfer of their child’s rehabilitation intervention to the school setting (Maclean & Chesson, 1991; Sugden et al., 2019; p. 170). The Advocate role relates to managing intervention within broader organizational systems.

4.7.1.6 A proposed continuum of parental responsibility

The coded descriptions of parental roles included tasks such as parents holding responsibility for ensuring their child attended sessions, i.e., parents brought their child to the sessions and are therefore named the Bringer (coded as an in-session parental role task). Related to this was, supporting their child's enthusiasm for one-on-one therapy sessions conducted by the professionals (coded as an out-of-session parental role task and named the Supporter) (Davies et al., 2017). Another parental role task (coded as an in-session parental role task and named the Observer) involved parents watching and learning from the professional. They did not get involved in sessions but observed the sessions as passive learners so as not to 'get in the professional's way' (Sugden et al., 2019). Another task assigned to parents (coded as an in-session parental role task and named the Informer) was that of providing professionals with the information required to formulate an intervention plan and carry out therapy sessions (Hurtubise & Carpenter, 2011; James & Chard, 2010). This in-session task was described as related to the out-of-session parental role task as part of the Informer of coordinating and managing information sharing between different professionals and organizations (Hurtubise & Carpenter, 2011).

Associated with these more passive parental role task descriptions was that of the out-of-session parental role of the Implementer. As Implementers, parents are responsible for helping the professional and supporting their professional's intervention plan by completing prescribed practice activities at home (Burrell & Borrego, 2012; Davies et al., 2017, 2019; Sugden et al., 2019; Watts Pappas et al., 2016). Related to this out-of-session Implementer parental role task, parents may participate briefly during sessions to show professionals how the homework was completed (Davies et al., 2017; Watts Pappas et al., 2016). As Implementers, parents are highly reliant on the direction and guidance of the professional (Burrell & Borrego, 2012; James & Chard, 2010).

The underlying philosophy of these roles was related to compliance with the professional's agenda, instructions and expert opinion as necessary as parents lack the insight and knowledge to facilitate change in their child's abilities (Davies et al., 2017; Watts Pappas et al., 2016; O'Shaughnessy Carrol, 2016). This was translated in the literature as a dependency on professionals (i.e., profession-driven therapy) and passive participation during sessions (Forsingdal et al., 2013; Watts Pappas et al., 2016). Parents were described using words such as ‘uninformed consumers’ (James & Chard, 2010) and agents of the professional (Dunst et al., 2002) and in need of expert assistance (O’Shaughnessy Carrol, 2016). These parental role task descriptions were, therefore, placed on the passive side of the role task continuum (left side) that represents the responsibility for intervention in Figure 4.3.

Another parental role in intervention related to in-session tasks of gaining the skills and knowledge required to participate more actively in intervention was that of the Learner. While the Observer, described above, was related to passive learning, the parental role task descriptions associated with the Learner role were linked with more active participation. In the Learner role, parents ask questions, provide their opinion and explain to professionals what types of skills and information they require to be able to carry over intervention to the home (Hurtubise & Carpenter, 2011; Forsingdal et al., 2013). The Learner role emerged as a central in-session cluster of parental role tasks that seems to enable parents to assume increasing in-session and out-of-session responsibility. For this reason, it was placed in the middle of the role task continuum presented in Figure 4.3. Associated with the in-session Learner role, was that of the out-of-session Adaptor role. The parental role tasks linked with the Adaptor role include parents implementing their knowledge and skills from therapy to adapt the professionally prescribed activities to better suit and meet their child's and family's needs. Parents may also generate new therapy activities to support their child's skill development based on the parent's growing knowledge and understanding of how therapy works (Davies et al., 2017; 2019). This out-of-session cluster of parental role tasks is linked with more active parental involvement in intervention and is, therefore, represented on the active (right) side of the parental responsibility continuum in Figure 4.3 below.

The most active parental role tasks were aspirational as parents developed a partnership with professionals. In these roles, parents are regarded as highly capable of driving their child’s intervention plan and implementation (Dunst et al., 2002: James & Chard, 2010; Forsingdal et al., 2013). Parental role tasks associated with parents as Collaborative partners included shared decision-making power related to the focus and goals of intervention and how the intervention would be carried out (Forsingdal et al., 2013; James & Chard, 2010; Burrell & Borrego, 2012).

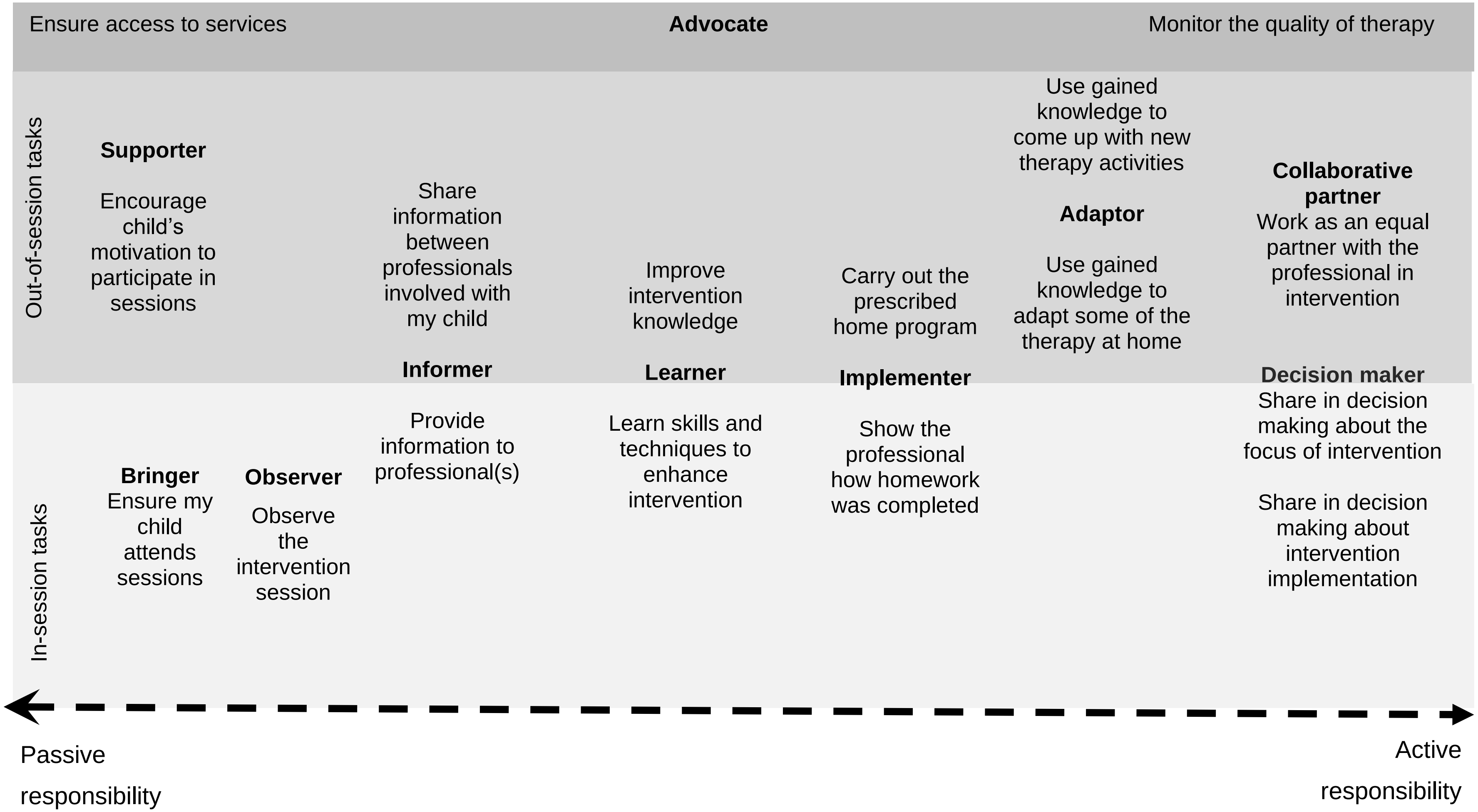
In this cluster of parental role tasks, parents are described in the literature as acting as active partners who are agents of change in their family (James & Chard, 2010). Parents hold a sense of ownership and hold shared responsibility for intervention as they work in partnership with professionals (Forsingdal et al., 2013).

The Advocate role emerged as a broader role related to parents acquiring the required external supports for their children and ensuring the quality of the intervention services as appropriate. This role seems to begin when parents deem that some kind of external assistance is required. Thereafter, they seek out their options and explore interventions. The main tasks associated with the Advocate role are related to ensuring that their child has access to services and then, once the child is enrolled, judging the quality of the services received (Rix & Paige-Smith, 2008).

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 expert professionals. 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 4.3 below.

Figure 4.3.

A Graphic Representation of Roles and Tasks Identified from the Scoping Review.



Boateng et al. (2018) recommend that during the item generation stage, that researchers should generate a pool of as many items as possible to ensure that the construct domain is adequately sampled. Best practice guidelines for item generation and development were followed to formulate task and responsibility statements into items from the coded role descriptions based on the qualitative data from the scoping review. The item wording was adapted to ensure that unambiguous language was used. Lengthy and double-barrelled items were avoided (DeVellis, 2017; Gehlbach & Brinkworth, 2011). The pool of items generated based on the scoping review can be viewed in Appendix D.

4.7.1.7 Determining the response format and scale of the PRITT

As the items were developed for the PRITT, the format and scale for the measure were determined and a time frame was set for the ratings. It is suggested that these steps occur concurrently to ensure that the items and format of the measuring instrument are aligned (DeVellis, 2017). During this process, the researcher consulted best practices for scale development (Boateng et al., 2018; Gehlbach & Brinkworth, 2011) and consulted with a Biostatistician to ensure that the data generated would be suitable to perform the statistical analysis (Hagan, 2014) to establish the validity of the PRITT.

DeVellis (2017) recommends that a clear and specific time frame be set for the rating of a measuring instrument. The literature indicates that the parental role in intervention can change over the course of intervention (Davies et al., 2017; Forsingdal et al., 2013). The time point at which participants rated themselves on the measure was, therefore, set in terms of the present. Participants were requested to rate their current parenting role in intervention indicated in the instructions and the wording tense of the items and a carrier phase for each item (i.e., My role is…).

In consultation with a Biostatistician, a 5-point Likert-type response scale was selected for the PRITT. McMillan and Schumacher (2010) suggest that the scale and response format of an instrument be selected based on the intended use of the data. Primarily, Likert-type scale data was selected as it produces the quantitative data required to allow for the required statistical analysis to be conducted (Hagan, 2014) to establish the validity and reliability of the instrument (Boateng et al., 2018). Using a 5-point scale is suggested as the best practice for selecting response anchors for unipolar items (Gehlbach & Brinkworth, 2011). Additionally, a Likert-type scale is user-friendly for participants and, therefore, appropriate for a self-administered survey (Willits et al., 2016). Furthermore, the response categories were labelled with construct-specific labels to enhance reliability. Reverse-scored items were not included (Gehlbach & Brinkworth, 2011). On this scale, the participants would rate how reflective (true) the parental role in intervention task statements were of their role in intervention. On one extreme, the scale indicated an option to rate the statements as not at all reflective (1=Definitely not true). The middle of the scale was represented by options to rate the statements as somewhat not reflective (2= Mostly not true), a neutral response (3= I'm not sure), and somewhat reflective (4=Mostly true). On the other extreme, the scale indicated an option to rate the statements as reflective (5=Definitely true). Version 1 of the PRITT can be viewed in Appendix E.

4.8 Summary

This chapter detailed the construction of the survey instrument. A qualitative investigation of the literature using a scoping review was used to identify the range of different roles parents have reported to perform in intervention. Analysis of the data collected from the scoping review identified the tasks and responsibilities associated with each role. The links between the codes, namely presenting the parental roles in intervention on a continuum of passive to active responsibility was also described. The procedures followed to develop items from the extracted role tasks were then detailed as well as the selection of the response format and scale for the newly developed measure, the PRIT

CHAPTER 5

EXPERT REVIEW OF THE PRITT

5.1 Introduction

This chapter details the procedures followed to establish face and content validity with expert review. It outlines the procedures involved to establish the content validity of the PRITT using quantitative and qualitative feedback from subject matter and context experts. Thereafter, the procedures employed to establish face validity with cognitive interview with parents of children with a disability are presented.

5.2 Phase 2: Expert review to establish content and face validity

Content validity refers to the degree to which a measuring instrument adequately samples the construct or domain to be measured (Mokkink et al., 2012). The content validity of a measure, including face validity, should be established early in the instrument development process (Gehlbach & Brinkworth, 2011). Establishing content validity entails an evaluation of the comprehensiveness of coverage of the content domain as well as the representativeness and clarity of the items (Boateng et al., 2018; Mokkink et al., 2012).

Boateng et al. (2018) recommend combining quantitative and qualitative viewpoints of professional and target population experts as best practices to establish content validity for a measuring instrument. Two panels of experts evaluated the PRITT to determine content and face validity. Firstly, a panel of subject matter and context professional experts provided quantitative and qualitative feedback to establish content validity of the PRITT. Thereafter, target population experts i.e., parents of children with a disability participated in cognitive interviews to establish face validity of the PRITT. The panels are described in detail below.

5.2.1 Subject matter and context expert review

In the first part of the expert review, subject matter and context experts were requested to evaluate the PRITT item and scale comprehensiveness, relevance, and clarity to determine content validity of the measure (Gehlbach & Brinkworth, 2011; Mokkink et al., 2012; Boateng et al., 2018). This review was completed in two steps. First, experts completed a quantitative rating checklist to evaluate the PRITT to compute Content Validity Index (CVI; Lynn, 1986) i.e.: the proportion of agreement between the experts was calculated at a scale and item level based on the expert ratings (Polit et al., 2007; Zamanzadeh et al., 2015). Items with CVI-I ratings tat were moderate or lower were flagged for discussion in the expert panel focus group discussions during step 2 of the subject matter and context professional expert review.

Secondly, experts provided qualitative feedback during an online focus group discussion.

5.2.2 Participants for the subject matter and context expert panel

The researcher applied purposive sampling to identify the potential subject matter and context experts invited to participate in the review. Purposive sampling allows the researcher to identify participants who demonstrate particular characteristics to ensure that necessary information is obtained as a result of their participation (Etikan, 2016). This sampling method aimed to identify participants with the required comprehensive understanding and familiarity to provide in-depth, reflective insights (Campbell et al., 2020) i.e., expertise related to the construct and local intervention context as the intended context of the use of the instrument.

5.2.3 Selection criteria

Professionals were deemed potential experts if they (i) held a relevant qualification (Baker et al., 2006), i.e., a rehabilitation or early intervention-related degree, and (ii) demonstrated clinical or research experience with the target population i.e., parents of young children who attend intervention. There were no minimum criteria set for the years of experience. It was required that all of the experts met these two preliminary criteria. Thereafter, two more specific criteria were applied to compile the list of potential experts. The first type of expert included (iii) subject matter experts i.e., professionals with particular knowledge and experience with the construct of interest (Boateng et al., 2018; Zamanzadeh et al., 2014). The researcher identified these experts from their collaboration on or involvement in at least one research study regarding parental roles in intervention from the literature included in the scoping review (Baker et al., 2006; Gehlbach & Brinkworth, 2011). The second type of expert included (iv) context experts i.e., professionals with research and clinical knowledge of the local South African intervention context in which the PRITT would be administered and validated (Zamanzadeh, et al., 2014).

Including experts with diverse expertise and knowledge aims to promote the quality of the expert feedback received (Jorm, 2015). Selection criteria for the expert panel participants are detailed in Table 5.1 below.

Table 5.1.

Selection Criteria for Subject Matter and Context Experts.

Criteria	Justification	Method of data collection
Rehabilitation or early intervention-related qualification	Holding a relevant qualification suggests that experts have the required knowledge and expertise in the subject matter of the study (Baker et al., 2006).	Self-report
Experience working with parents of children with a disability	Experience with the target population allows for professionals to give specific insight into the relevance of the items and scale for that population.	Self-report
Particular knowledge and experience with the construct of interest	Collaboration on research regarding the construct of interest provides participants with the comprehensive knowledge of the construct required for the review (Zamanzadeh, et al., 2014; Boateng et al., 2018).	Self-report
Knowledge of the local intervention context from research and/or clinical experience	Clinical practice and research experiences ensure that participants have the relevant training and experience (Zamanzadeh, et al., 2014).	Self-report

5.2.4 Sample size

The number of experts to be included for expert review has been widely debated in the literature. It is suggested by some authors that expert reviews can include as few as three experts but should be comprised of approximately ten to 15 experts (Burton & Goldsmith, 2002). In their best practice primer, Boateng et al. (2018) recommend that five to seven content experts be included in an expert panel to establish content validity.

Initially, 22 experts were invited to participate in the expert review. This included 11 subject matter and 11 context experts. Finally, one subject matter and five context experts agreed to participate in the review.

5.2.5 Recruitment of the professional experts

The researcher compiled a list of potential professional experts (not involved in the development of the PRITT) to be invited to participate in the professional expert review panel. Contact information i.e., an email address was obtained from internet searches, academic databases, and university websites.

5.2.5.1 Materials for recruitment of professional experts

The prospective professional experts were sent a personalized invitation email (Appendix F). The invitation email included the study title, the main aim of the study, and a summary of the expectations of the professional content experts. It also included a request to nominate other experts to participate in the expert review and in this case for the expert to provide their name, contact details (i.e., an email address), and a reason that this professional was considered an expert. This was used to judge whether the nominated professional met the selection criteria for the expert review. The experts who agreed to participate were requested to provide informed consent by completing the online informed consent form shared through Qualtrics (An electronic survey tool to which the University of Pretoria subscribes).

Once professionals provided consent to participate in the study, they were sent the survey link containing a detailed explanation of the conceptual domain, a description of the format, response scale, and intended scoring of the PRITT measure as well as a copy of the PRITT to refer to and the link containing the quantitative rating checklist shared with Qualtrics.

5.2.6 Description of sample

The participants included an Occupational therapist (n=1), Speech-language therapists (n=5), and a Researcher (n=1) with the majority of participants holding a Doctoral degree (n=10) and one participant holding a Master’s degree (n=1). Participants reported an average of 18 years of work experience with a range of 12 to 30 years of work experience. The professional expert’s current work experience included lecturing undergraduate and postgraduate students, undergraduate clinical supervision, clinical practice in the private or public sectors, acting as the head of a professional or parent organization, and research work. Many of the professional experts reported enacting multiple of these roles concurrently in various combinations.

5.3 Step 1: Quantitative expert review of the PRITT

In the first step of the expert review, the experts were requested to provide quantitative ratings of the PRITT. Experts should be well-versed in the theoretical and conceptual underpinnings of the measuring instrument that they are reviewing (Gehlbach & Brinkworth, 2011). The experts were emailed a comprehensive overview of the conceptual domain, description of the format, response scale, and intended scoring of the PRITT measure. They were then requested to complete a quantitative checklist to rate the item content, item style (i.e., clarity, construction, and wording), and item comprehensiveness (i.e., whether the total set of items sufficiently represents the content domain) (Artino et al., 2014; Gehlbach & Brinkworth, 2011) . The expert qualitative review checklist in contained in Appendix G. The experts were also requested to rate the relevance of the items to compute the Content Validity Index (CVI). CVI is the most frequently applied method of quantifying the content validity of a measuring instrument and its items (Almanasreh et al., 2019; Zamanzadeh et al., 2014).

5.3.1 Analysis of the quantitative expert review data

First, the quantitative ratings of the survey appearance and organization, item content, item style, and comprehensiveness were collated, the CVI was calculated and the quantitative feedback from the experts was analysed. The expert's comments and recommendations are detailed in Chapter 7 (Section 7.2.1.1). The experts' quantitative feedback was used to flag issues for discussion in step 2 of the expert review.

5.4 Step 2: Qualitative expert review of the PRITT

5.4.1 Focus group discussions

In the second part of the expert review, the expert participants were requested to participate in a four-day-long asynchronous focus group discussion conducted through Blackboard Learn, an online platform. Open-ended questions were posed to the experts regarding the item content, response scale, and construct stability (Appendix H). Data from the first step of the review i.e., the quantitative ratings were also introduced into the discussion thread for experts to suggest revisions to the flagged items. Experts were requested to suggest additional items and discuss the comprehensiveness of the PRITT. The stability of the parental role in intervention was also discussed to inform the interval period between the two tests in the test-retest reliability (Pilot, 2014).

Focus groups were conducted through an online platform due to the vast geographical distribution of the experts (Rivaz et al., 2019). The discussion ran asynchronously whereby participants did not have to be online at the same time to allow for participants to contribute as was convenient for them. The interval between the first part of the review and the focus group discussion in the second part of the review was intended to provide participants with time to reflect. This is suggested to result in more data and a larger range of responses generated in online focus group discussions (Reid & Reid, 2005). Participants were also provided with opportunities to revisit the discussion thread after the discussion was completed and they could also add or clarify comments when they were emailed the transcripts after the discussion thread was closed.

5.4.2 Analysis of qualitative data from focus group discussion

Following the completion of the focus groups, the researcher downloaded the thread. Qualitative thematic analysis (Nowell, Norris, White, & Moules, 2017) of the focus group transcripts was then conducted utilizing Atlas.ti8 software (Paulus, Woods, Atkins, & Macklin, 2017). The researcher compiled a codebook to be used for the initial phase of the analysis. The codebook included the major aspects to be addressed in the expert review namely relevance, representativeness, clarity, technical quality, simplicity, appearance, wording for the different aspects of the measure (i.e. Items, response scale). The researcher and study supervisor discussed the codes and refined them iteratively. Based on the findings of the expert review, changes were made to the PRITT (Appendix J: Version 2 of the PRITT). The results and amendments made to the PRITT following the focus group discussion are outlined in Chapter 7 (Section 7.2.2). Following the adaptations, the PRITT

(Version 2) was reviewed by the target population experts, i.e., a panel of parents, to establish face validity.

5.5 Target population expert review to establish face validity

Conducting a review of the PRITT by target population experts, i.e., parents of children with a disability aims to establish face validity. Face validity, a component of content validity, refers to the degree to which the intended population judges a measuring instrument as an appropriate measure of the construct of interest (Boateng et al., 2018). It is typically established after a measure is constructed and content validity is established (Zamanzadeh et al., 2014).

5.5.1 Cognitive interviews with target population experts

As the target population, parents of children with a disability were requested to participate in cognitive interviews to review the PRITT. This step was intended to capture the participant’s voice in the instrument development process and establish face validity (Boateng et al., 2018).

5.5.2 Participants for the target population expert review

5.5.2.1 Selection criteria

The selection criteria for the target population expert review panel were the same as the main study to mimic the intended participants of the study. The selection criteria for the target population of expert participants are detailed in Table 5.2 below.

Table 5.2

Selection Criteria for Target Population Experts.

Criteria	Justification	Method
Parents of a child with a disability whose child is currently enrolled in speech therapy, occupational therapy, or physiotherapy.	The same participant selection criteria as the main study to mimic the intended participants of the study	Online administration (WhatsApp or email link) of the PRITT (Version 2) and parental expert rating questionnaire
Parents had to be English literate to complete the online survey questionnaire.	The same participant selection criteria as the main study to mimic the intended participants of the study	Online administration (WhatsApp or email link) of the PRITT (Version 2) and parental expert rating questionnaire

5.5.2.2 Recruitment of the target population experts

The researcher recruited the target population experts through professionals i.e., physiotherapists, occupational therapists, and speech-language therapists. The researcher contacted several personal and work acquaintances to request them to extend the invitation to parents who met the selection criteria.

5.5.2.3 Sample size

Boateng et al. (2018) recommend that five to 15 experts partake in the target population review. The researcher recruited five parents of children with a disability to participate as target population experts.

5.5.3 Materials for recruitment of target population experts

5.5.3.1 Invitation message and reminder template

Prospective target population experts were sent the invitation template email or mobile link by the professionals who recruited them. The invitation included the title and main aim of the study, a summary of the participant selection criteria, and the expert review survey link (Appendix K).

5.5.4 Procedures

Once the target population experts agreed to participate, they were requested to complete an online informed consent form. After providing consent to participate, an appointment was set up for the cognitive interview. During the interview, the target population experts were sent the online questionnaire containing the survey instrument (i) Biographical Questionnaire and (ii) the PRITT. They were asked to, firstly, complete the PRITT measure and then review its content i.e., appearance and acceptability (Boateng et al., 2018). A verbal probing approach with retrospective probing was utilized whereby the target population provided feedback after completing the instrument (Blair et al., 2014; Hofmeyer et al., 2015). The target population expert cognitive interviews included open-ended probes about various aspects of the developed PRITT, including whether the PRITT items were representative of the parent role in intervention construct (Boateng et al., 2018). They were also requested to judge the layout and presentation of the survey questionnaire and ascertain whether it was simple and easy to follow as well as to evaluate the readability and ease of comprehension of the instructions, items and assess the Likert-type scale response categories (Hofmeyer et al., 2015). In addition, the target population experts were asked to make recommendations on other items representing the parental role in intervention construct that they thought should be included (Zamanzadeh et al., 2014).

The target population expert recommendations and the amendments made to the PRITT based on their feedback are detailed in Chapter 7 (Section 7.2.2).

5.6 Summary

This chapter detailed the procedures followed in the two-stage expert review to establish content and face validity of the PRITT. First, the procedures followed in the quantitative first step and qualitative second step of the subject matter and context expert review were detailed. Thereafter, the chapter outlined the target population review which included cognitive interviews with parents of children with a disability.

CHAPTER 6

INSTRUMENT DEVELOPMENT AND EVALUATION

6.1 Introduction

This chapter first describes the procedures, results and recommendations of the pilot study as part of Phase 3 of the study. Subsequently, a description of the participants, response rate considerations and participant selection criteria, and survey administration procedures for Phase 4 are provided. In the final part of the chapter, the data collection and data analysis procedures for Phase 4 are outlined.

6.2 Phase 3: Instrument development

In the third phase of the study, the PRITT was developed with pretesting in the pilot study. Following the pilot study, the PRITT measure was finalized for administration.

6.2.1 Pilot study

Following the adaptations that were made based on the feedback of the subject matter and context experts and target population experts, the survey instrument was pretested with a pilot study.

6.2.2 Aims of the pilot study

The main aim of the pilot study was to assess the procedures to be used to administer the survey instrument in Phase 4. The specific aims of the pilot study were as follows:

I. To evaluate the comprehensibility of the instructions of the survey instrument (Biographical Questionnaire and PRITT Version 3).
II. To evaluate the administrative procedures that to be followed in Phase 4.

6.2.3 Pilot study participant selection criteria

The selection criteria for the participants for the pilot study are detailed in Table 6.1.

Table 6.1

Selection Criteria for Pilot Study Participants.

Criteria	Justification	Method
Parents of a child with a disability whose child is currently enrolled in speech therapy, occupational therapy, or physiotherapy.	The same participant selection criteria as the main study to mimic the intended participants of the study	Online administration (Mobile or Email link) of the pilot study survey instrument
Parents had to be English literate to complete the online survey questionnaire.	The same participant selection criteria as the main study to mimic the intended participants of the study	Online administration (WhatsApp or email link) of the PRITT (Version 2) and parental expert rating questionnaire

6.2.4 Pilot study procedures

The procedures followed for the pilot study were intended to mimic, as close as possible, the procedures to be employed in Phase 4. Parents who agreed to participate in the pilot study were sent the survey instrument via an email or mobile message to complete it at a time and place convenient for them. Data obtained from the pilot study were used to review the instructions and procedures to be employed in Phase 4.

6.2.5 Materials

6.2.5.1 Invitation email and reminder email template

The pilot study invitation email was distributed to potential parent participants by professionals. The invitation email (the same as used in the main survey administration) included the title and main aim of the study, a summary of the participant selection criteria, and the survey link.

6.2.5 The pilot study of the survey instrument

Parents completed the pilot study survey instrument (See Appendix R) which included the Biographical Questionnaire and PRITT (Version 3).

6.2.6 Results and recommendations from the pilot study

The results and recommendations based on the pilot study can be viewed in Table 6.2 below.

Table 6.2.

Aims, Procedures, and Adjustments Made Based on the Pilot Study.

Aims	Procedures	Results	Amendments
To determine the clarity of the procedures	Participants were asked to identify procedures that were unclear or that they found difficult to understand.	Participants found the procedures easy to follow and understand.	No amendments were made.
To identify potential nonresponse questions.	All nonresponse questions were identified in the returned questionnaires. These questions were evaluated to identify missing data and to determine if there was a possible pattern indicating a problem with specific questions or items.	No nonresponse questions were identified in the completed questionnaires.	No problematic questions or items were identified.
To identify questions that were answered inappropriately (i.e., indicating questions interpreted incorrectly)	The returned questionnaires were evaluated for information provided that was incorrect or inconsistent.	No incorrect information or inconsistencies were identified in the completed questionnaires.	No amendments were made.

6.3 Phase 4: Instrument evaluation

Phase 4 involved the administration of the finalized survey instrument to parents of children with a disability who met the selection criteria. Thereafter, the collected data were statistically analysed to determine the factor structure, validity, and reliability of the PRITT. Descriptive statistics were employed to describe the types of roles parents reported to perform in intervention as means of evaluating the responsiveness of the sample.

6.3.1 Participants

6.3.1.1 Selection criteria

The selection criteria for participants included (i) parents of (ii) a child with a disability (iii) younger than seven years of age (iv) currently enrolled in (v) therapeutic intervention services i.e., physiotherapy, occupational therapy, and speech-language therapy in either the private or public sector. Parents also had to have (vi) a level of functional literacy in English to complete the online survey questionnaire. The justification and measurement of the participant selection criterion are detailed below.

First, parents were the selected respondents. The term “parent” refers to a person or people with decision-making responsibility for the supervision, care, or rearing of a child (McHale, 2004) and does not only refer to a biological mother or father. While the term ‘family’ or ‘caregiver’ is more commonly applied to describe the care and living arrangements within a broader definition of the family that is prevalent in South Africa (Richter, 2010; Schlebusch, Samuels, & Dada, 2016), the parent’s role in intervention necessitates a certain level of involvement and commitment more than simply providing care and is suggestive of decision-making power in the life of the child. The use of the term ‘parent’ was applied from co-parenting literature as this term delineates parenting responsibilities over and above the provision of care for a child. It is, therefore, believed that this level of commitment is better reflected by the term ‘parents’ rather than the broader term ‘family’ or ‘caregiver’.

Second, the child had a disability. “Disability” includes children who have long-term physical, communicative, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others” (Republic of South Africa, 2015; p. 10). The diagnosis of disability was based on parent reports due to the difficulties that some parents experience in acquiring an official diagnosis although their child is attending intervention services (Schlebusch, 2015). It was deemed unlikely that this criterion would include parents of children that are at-risk for disability due to biological factors (e.g., preterm birth) or environmental factors (Guralnick, 2019). These children are not commonly monitored in local health care services in South Africa and therapeutic intervention services often exclude children who are at-risk for disability (Samuels et al., 2012).

Third, the child with a disability was younger than seven years of age (i.e., between birth and six years; 11 months). This age period is reflective of the term ‘young children’ which refers to “the period from birth until the year before a child enters formal school” (Republic of South Africa, 2015; p. 10). Although international literature describes the early intervention population from birth to five years of age (Shonkoff & Meisels, 2000), in South Africa early intervention services are mainly provided to children with a disability from birth into their sixth year of age (Kyarkanaye, Dada, & Samuels, 2017; Samuels, et al., 2012).

Fourth, the child was enrolled in rehabilitation interventions i.e., occupational therapy, physiotherapy, speech-language therapy at the time of participating in the study. As the study construct may fluctuate over the course of intervention, it is believed that the data would be more reliable as a measure of the parent’s current type of roles. The medical model approach remains prevalent across the training of therapeutic disciplines that provide early childhood intervention services in South Africa (Samuels et al., 2012). Hence, no significant differences were expected between the practice of the intervention professionals. Furthermore, it is not indicated that the type of rehabilitation service influences the constructs in the available literature regarding parental roles in intervention (Forsingdal, et al., 2013).

Lastly, so that parents could complete the online survey questionnaire (which was only available in English), parents had to have a level of functional literacy and competency in English.

6.3.1.2 Sampling

This study used a non-probability, purposive sampling method to recruit participants. Purposive sampling allows the researcher to select participants that are most representative of the overall target population (Levy & Lemeshow, 2008; Sharma, 2017). This sampling method allowed the researcher to locate accessible participants that possess the specific characteristics (specified in Section 6.3.1.1 above) required for the study (Ball, 2019).

6.3.1.3 Recruitment of participants

To maximize recruitment, the researcher targeted both parent organizations and professionals as avenues for participant recruitment. There is no available database or collated information source that provides reliable information about i) the organizations that provide parents with support or ii) professionals providing therapeutic early intervention services to young children with disabilities in South Africa. First, the researcher conducted multiple internet searches to compile a list of organizations that provide support services and information to parents of children with a disability in the nine provinces. The researcher also contacted the head offices of familiar national disability organizations (e.g., Autism South Africa, Down Syndrome South Africa, etc.) via email to request contact details for their various branches in the different provinces across the country. The list of parent organizations is contained in Appendix J. While this list included only parent organizations with an internet presence and excluded informal and community support organizations without an internet presence, it is suitable for recruitment for an online survey as utilized in the study. Second, the researcher targeted professionals and two professional organizations to support professionals working with children with a disability (e.g., Centre for AAC Masters in ECI graduate listserve from the University of Pretoria, South African Neurodevelopmental Association).

6.3.1.4 Materials for recruitment

6.3.1.4.1 Parent and professional organizations permission letter and reply slip

The permission letter to the parent organizations (Appendix M) and professional organizations (Appendix P) included details such as the title of the study, the rationale for the study, and the objectives of the study. The permission letter also contained details regarding what was expected of the parent organization, and what would be expected of potential participants. The participants' ethical rights and information about how the data collection, handling, storage, and security were also included in the permission letter. It was also explained that participants would be requested to provide their email addresses after completing the survey questionnaire to be sent a second survey link 10-14 days later. Each organization was sent a reply slip to complete and provide permission to participate in the study.

6.3.1.4.1 Invitation email and reminder email template

After the parent organizations provided permission via the reply slip, the researcher sent 1) an invitation email template to send to their email listserve and 2) a reminder email template to send to their email listserve two weeks later and an invitation pamphlet to be posted to their social media (Appendix O and Appendix Q). The invitations also included the title and main aim of the study, a summary of the participant selection criteria, and the survey link. It also included a request to forward the email and survey link to other parents who met the selection criteria and the researcher’s contact details.

6.3.2 Response rate

To disseminate the study invitation, the researcher distributed the survey invitation and questionnaire link to 133 professionals personally across the 9 provinces. Furthermore, 2 professional and 37 parent organizations were contacted to request permission to use the organizations' email list serves and social media platforms to distribute the questionnaire. Of the 34 parent organizations contacted, 15 organizations agreed to disseminate the study information letter and survey link. The study invitation and survey link were also shared through the Masters in Early Childhood intervention at Centre for AAC listserve which contains 249 email addresses and shared via the Centre for AAC’s Facebook page which has 2111 followers and has an estimated 900 views per month.

It is not possible to quantify the return rate due to the study invitation and link being shared online via third parties. Of the responses, 38,5% (37) of the parent respondents reported that they received the questionnaire from a professional, while 36,4% (35) reported that they received the questionnaire link from a parent organization or their child's school. A further 3,1% (3) of parents reported having received the study invitation from a friend via social media and 21,9% (21) of respondents reported to have received the study invitation from another parent.

Given the potentially extensive reach of the recruitment avenues, the response rate was low despite the researcher's attempts to maximize recruitment and is an acknowledged limitation of the study. Possible reasons for the low response rate related to the practicalities of online and mobile access, factors influencing parental capacity to participate in the study and the possible influence of parent organizations and professionals as gatekeepers will be explored in the section that follows.

6.3.2.1 Possible reasons for the low return rate

The study questionnaire was administered through Qualtrics, an online survey platform that provides respondents with the option of completing the survey on a desktop computer or mobile device. Furthermore, recordings of the questions were made available on the platform to make the survey more accessible for parents with low literacy. Given the high penetration of mobile devices in South African homes (Fischer et al., 2021), it is presumed that factors other than device availability affected the response.

The financial impact of the COVID-19 pandemic (Mbunge, 2020) coupled with the high cost of data and the need to use data for other reasons i.e., online schooling, work, and so forth (Fischer et al., 2021) may have dissuaded parents from completing the questionnaire. For this reason, the researcher could have provided a financial incentive to motivate participation. Williams (2020) also suggests that while mobile technology is extensive, not all devices are equipped with internet access or potential participants may lack the technical know-how and confidence to navigate an online survey platform. More likely is that parents experienced challenges with inadequate signal and bandwidth to complete the questionnaire. One parent organization that assisted with recruitment reported this to the researcher on behalf of parents. This may account for the high rate of parents abandoning the questionnaire (46%) within the first three questions of Section A (Biographical Questionnaire).

The survey was only available in English. English is the sixth most common home language in South Africa, with most households speaking isiZulu (25,3%), isiXhosa (14,8%), and Afrikaans (12,2%) at home (Statistics South Africa, 2018). Parents for whom English is not their home language may have favored completing the survey in their home language and, therefore, might not have participated in the study.

Parents have reported heightened and persistent levels of perceived stress and strain with increased caregiver burden related to the direct and indirect effects of the COVID-19 pandemic (Petts et al., 2021). Together with reduced access to support (Barnett & Jung, 2021; Mbunge, 2020), the effects of the pandemic seem to be magnified for parents of children with a disability (Brown et al., 2020) and female caregivers i.e., the majority of respondents in this study (Petts et al., 2021). Given the already high rate of pre-pandemic socio-economic strain and resultant heightened effects of financial strain on local families post-pandemic (Mbunge, 2020), parents may have been overwhelmed by their multiple and competing demands (Brown et al., 2020) and considered participation in the study as a low priority.

Parent organizations were requested to assist with recruitment by sharing the study invitation and survey link with their email listservs and social media platforms. The challenges of working with organizations acting as gatekeepers for the recruitment of potential participants are documented in the literature. Organizations report research fatigue as the most common deterrent when faced with research requests (Nicholson et al., 2013; Williams, 2020). Added to this is that the feedback from researchers and the outcomes from past research is regularly not provided to organizations which can cause reluctance to facilitate further research requests (Rankin & McFadyen, 2016; Williams, 2020). On the other hand, gatekeepers may see the potential benefits and worth of the research but may not share the study invitation and information due to limited time and capacity (Williams, 2020). This is noted given the role these organizations play in supporting families (and this during a particularly challenging period related to the direct and indirect effects of the COVID-19 pandemic). Cumulatively, this could mean that the parent organizations had more urgent priorities than disseminating the study invitation and survey link. It is also possible that the researcher did not identify some parent organizations given the lack of availability of information regarding parent organizations to the wider public, i.e., the most recent publication on parent organizations available on the internet is dated 2015.

The COVID-pandemic has influenced access to healthcare (Mbunge, 2020). The discontinuation of many aspects of healthcare service delivery during the national COVID-19 lockdown coupled with the well-documented, pre-existing service delivery challenges and subsequent shifts to front line services and acute care, indicates that it is likely that access to continuing rehabilitation services was severely affected for many families and their children. During and following the national COVID-19 lockdown, many professionals shifted (at least in part) to providing telehealth services and rotational work scheduling (Bulmer & Bull, 2021; Schlesinger Michelow, 2021). Requests to share the study invitation may have placed a strain on professionals' time and capacity resources and resulted in pressure on professionals to use their limited online communication and session time for a research study. Professionals may have selected to keep the focus on intervention. Rankin and McFanden (2016) highlight that a gatekeeper may also not be inclined to share research invitations if they fail to see the potential impact of the research. Considering that the study focuses on the PRITT as a research tool currently, it is possible that professionals could not see the benefits that the study would bring to their clinical, day-to-day practice resulting in apathy in disseminating the study invitation and survey link.

6.3.3 Description of participants

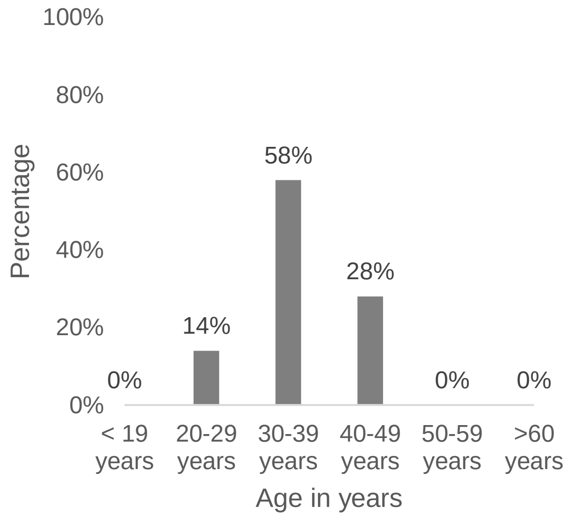
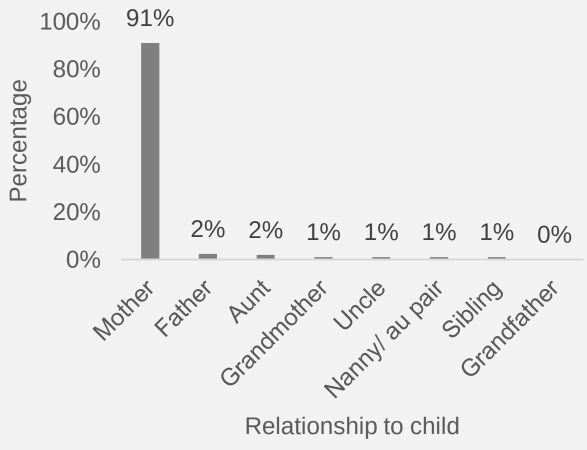
A description of the 96 parent respondents is provided below. The parent demographics (i.e., demographic information of the parent who completed the survey and demographic information of the child with a disability), family and household characteristics (i.e., the household composition and the household income), and intervention characteristics (i.e., enrolment in the different rehabilitation therapies, setting of therapy and sector enrolled in therapy) are outlined.

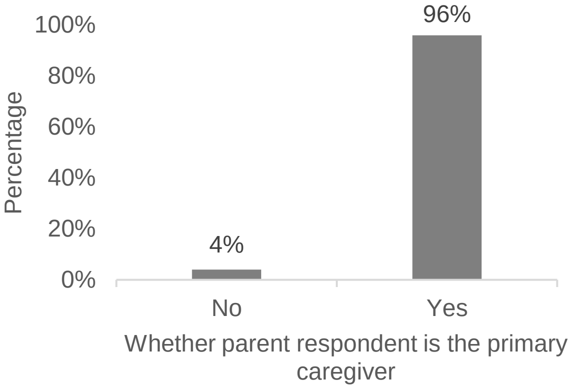
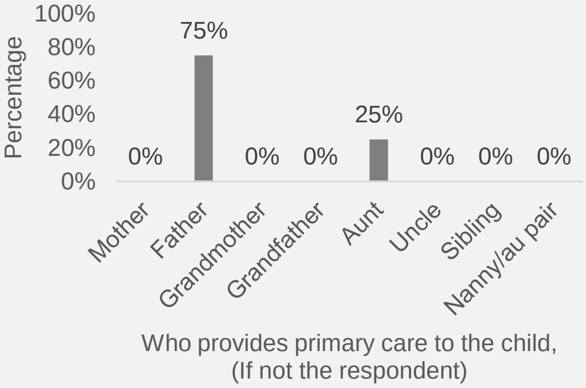
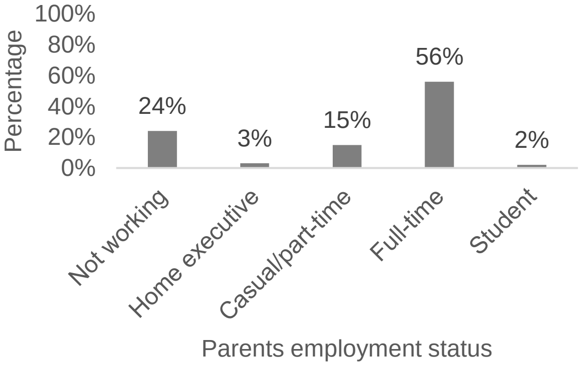
A total of 98 parents completed the survey questionnaire. Two responses were removed as the children did not meet the age-related selection criteria (i.e., they were older than 7 years of age). Finally, 96 responses were included in the analysis.

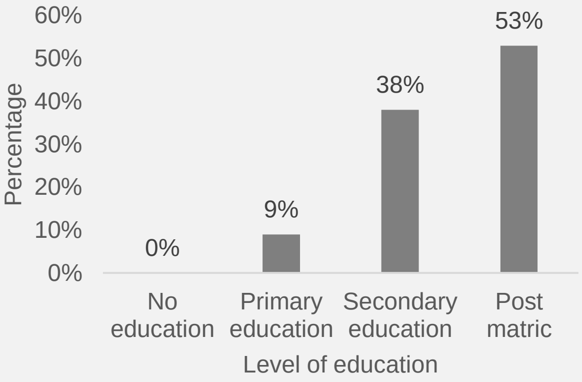
Table 6.3 below describes the demographics of the parent respondents (n=96). The parent’s relationship to the child with a disability, educational background, and employment status and described.

Table 6.3.

Biographical Description of Parent Respondents (N=96).

Biographical description of parent respondents	Results
Age of parent The age of the parent respondents varied from 23 years of age to 49 years of age (M = 34,48, SD =8,40). 0% (0) of respondents were younger than 19 years, 14% (13) of respondents were between 20-29 years of age, 58% (56) of respondents between 30-39 years of age, 28% (27) of respondents between 40-49 years of age, 0% (0) of respondents reported between 50-59 years of age, And 0% (0) of respondents older than 60 years of age.	
Parents relationship to the child Of the 96 parents who completed the survey: 91% (87) of respondents were mothers, 2% (2) were fathers, 1% (1) a grandmother, 2% (2) were aunts, 1% (1) an uncle, 1% (1) a nanny/ au pair, and 1% (1) a sibling.	

Biographical description of parent respondents	Results
Whether parent respondent is the primary caregiver for the child with a disability 96% (92) parents reported providing primary care and, 4% (4) of respondents reported another caregiver providing primary care.	
Primary caregiver other than parent respondent Respondents reported the child's primary caregiver to be: the child's father (75%; 3) or the child's aunt (25%; 1).	
Employment status of the parent respondent Of the parent respondents: 24% (24) were not working, 3% (3) were home executives, 15% (15) were part-time or casually employed, 56% (56) were employed full-time, and 2% (2) were students.	

Biographical description of parent respondents	Results
Level of education of parent respondent Of the parent respondents: 53% (51) hold a post-secondary school qualification, 38% (36) completed secondary school education, and 9% (9) completed primary school education. None (0%; 0) reported no formal education.	

From the information provided in responses to the Biographical Questionnaire, the age of the parent respondents varied from 23 years of age to 49 years of age. None (0%; n=0) of the parent respondents reported their age as younger than 19 years of age, while 14% (n=13) of parent respondents reported their age as between 20-29 years of age, 58% (n=56) of parent respondents reported their age as between 30-39 years of age, 28% (n=27) of parent respondents reported their age as 40-49 years of age, none (0%, n=0) of parent respondents reported their age as 50-59 years of age, or as older than 60 years of age.

Of the 96 parent respondents who completed the survey, the majority (91%; n=87) of respondents were mothers. The remaining parent respondents were either fathers (2%, n=2) were fathers, a grandmother (1%, n=1), aunts (2%, n=2), an uncle (1%, n=1), a hired caregiver such as a nanny/ au pair (1%, n=1), or the child's adult (1%, n=1) or a sibling (1%, n=1).

The majority of the parent respondents, (96%, n=92) parents reported themselves to be the primary care provider for the child with a disability while 4% (n=4) parent respondents reported another caregiver providing primary care to the child with a disability. The parent respondents who reported they were not the primary caregiver (4%, n=4) reported the child's primary caregiver to be the child's father (75%, n=3) or aunt (25%, n=1).

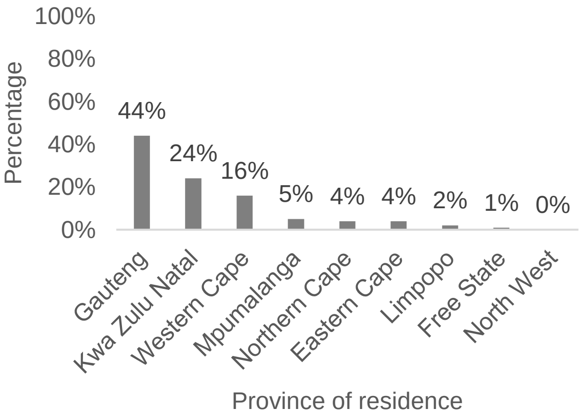
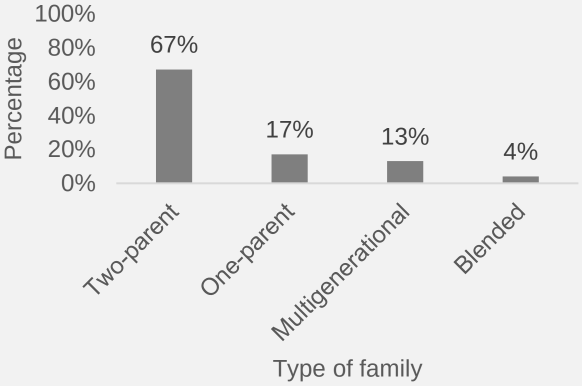
The majority of the parent respondents reported being working or employed full-time (56%, n=56), while almost a third of parent respondents (24%, n=24) reported that they were not currently working.

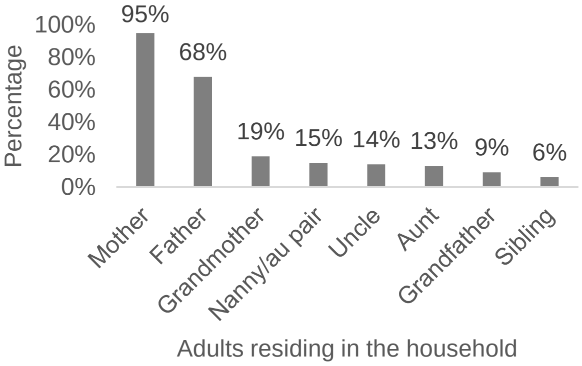
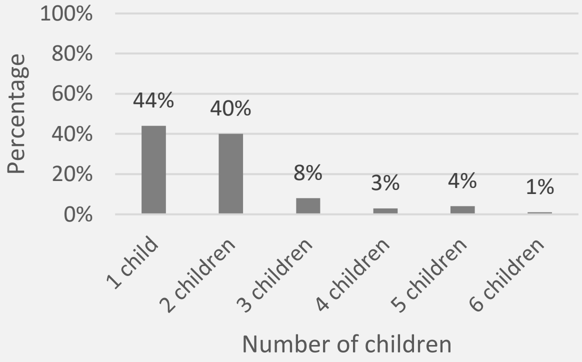
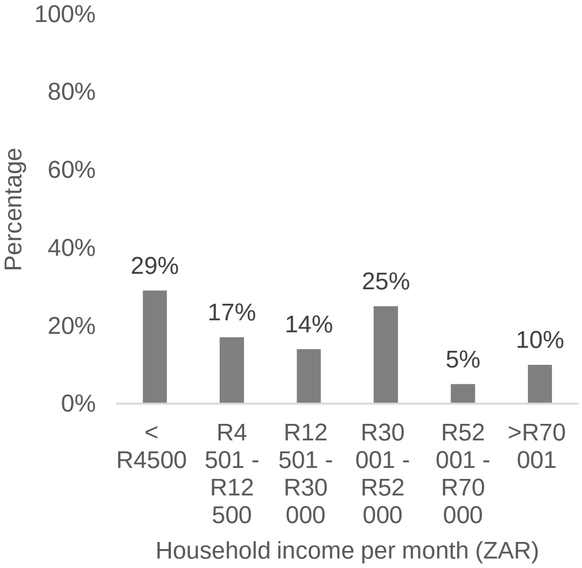
In terms of the level of education of the parent respondents, just over half (53%, n=51) reported holding a post-matric qualification, while the remaining majority of respondents (38%, n=36) reported having completed secondary school education, and some parents (9%, n=9) of parents reported having completed primary school education. None of the parent respondents reported having no education.

Table 6.4 includes demographic details of the household and family. The type of family, household composition, and income are described.

Table 6.4.

Biographical Description of Family and Household.

Biographical description of family and household	Results
Province of residence Of the respondents: 44% (42) resided in Gauteng, 24% (23) resided in KwaZulu-Natal, 16% (15) resided in the Western Cape, 5% (5) resided in Mpumalanga, 4% (4) resided in the Northern Cape, 4% (4) resided in the Eastern Cape, 2% (2) resided in Limpopo, 1% (1) resided in the Free State. None (0%,0) resided in the North West.	
Type of family Of the families included in the study: 67% (64) reported two-parent families, 17% (16) reported one-parent families, 13% (12) reported multigenerational families, and 4% (4) reported blended. families	

Biographical description of family and household	Results
Adults living in the household The parent respondents reported that the following adults reside in their households: mothers resided in 95% (91), fathers in 68% (65), grandmothers in 19% (18), a nanny or au pair in 15% (14), uncles in 14% (13), aunts in 13% (12), grandfathers in 9% (8), siblings in 6% (5).	
Children living in the household The parent respondents reported that the households (M=2,14; SD=2,9): 44% (42) included one child, 40% (38) included two children, 8% (8) included three children, 3% (3) included four children, 4% (4) included five children, and 1% (1) included six children.	
Household income In terms of household income per month, parent respondents reported: less than R4500 in 29% (28), between R4501 and R12500 in 17% (16), between R12500 and R30000 in 14% (13), between R30001 and R52000 in 25% (24), between R52001 and R70000 in 5% (5), more than R700001 in 10% (10).	

In terms of the province of residence, the majority of respondents (44%, n=42) reported residing in Gauteng. Just under a quarter of the remaining respondents (24%; 23) reported residing in KwaZulu-Natal and (16%; n=15) in the Western Cape. The rest of the respondents reported residing in Mpumalanga (5%, n=5), the Northern Cape (4%, n=4), the Eastern Cape (4%, n=4), Limpopo (2%, n=2), or the Free State (1%, n=1). None (0%,0) of the respondents reported residing in the North West province.

Of the families of the parent respondents from the study, the majority (67%, n=64) were described as two-parent families, with the remainder described as one-parent families (17%, n=16), multigenerational families (13%, n=12), or as blended families (4%, n=4).

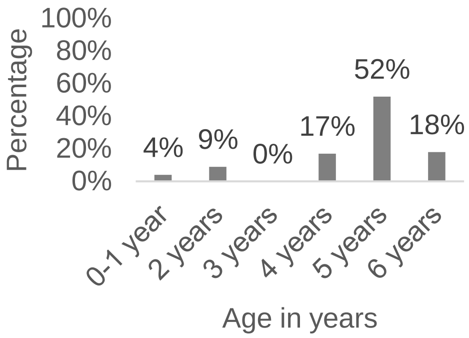
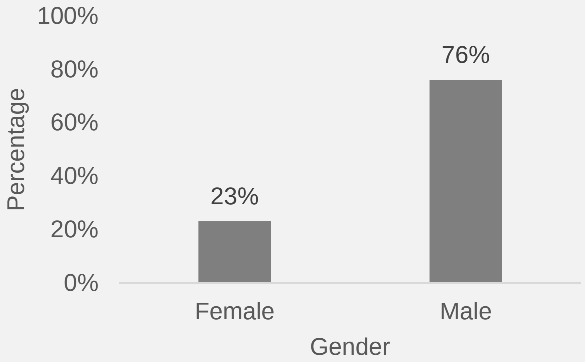
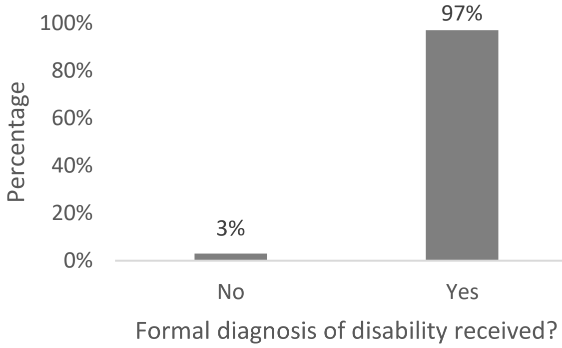
The parent respondents reported that the majority of households had mothers (95%, n=91) and fathers (68%, n=65) residing in the household. Some households also included grandmothers (19%, n =18), a nanny or au pair (15%, n =14) uncle (14%, n=13), aunt (13%, n=12), grandfather (9%, n=8), and siblings (6%, n=5) residing in the households. The majority of households included one child (44%; n=42) or two children (40%; n=38) living in them.

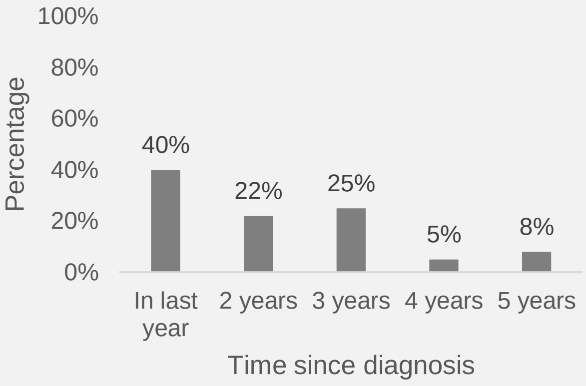
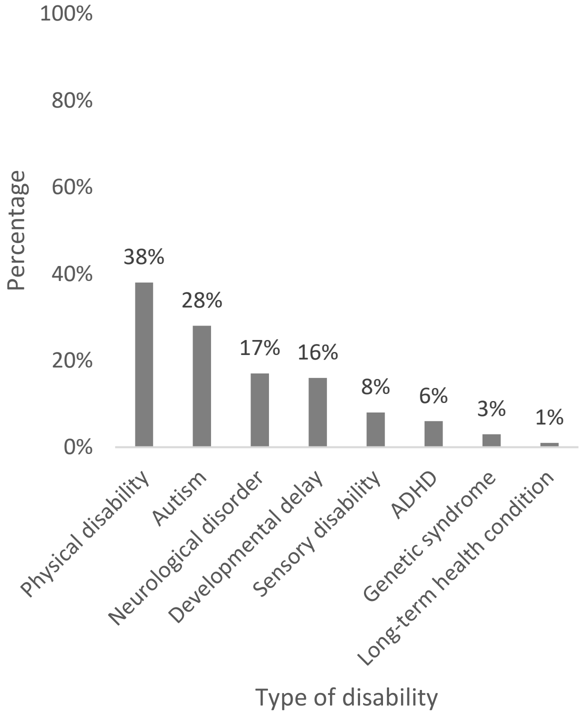
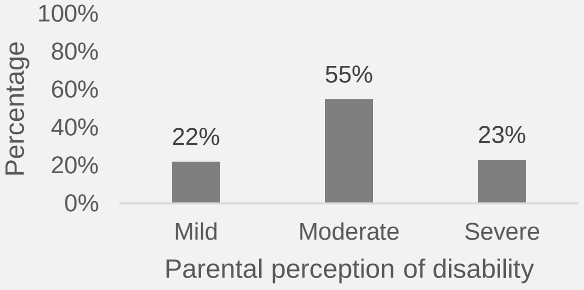
In terms of monthly household income, almost a third of the respondents reported a monthly household income of less than R4500.00 per month (29%, n=28) or a monthly income of between R30001.00 and R52000.00 per month (25%, n=24). The other parent respondents reported a monthly income of between R4501.00 and R12500.00 per month (17%, n =16), between R12500.00 and R30000.00 per month (14%, n=13), or between R52001.00 and R70000.00 per month (5%, n=5). Some parents reported a monthly income of more than R700001.00 per month (10%, n=10).

Table 6.5 below describes the demographics of the child with a disability. The child’s age, gender, type of disability, level of severity of the disability (based on the parental report), and time since diagnosis are described.

Table 6.5.

Demographics of the Child with a Disability.

Biographical description of the child	Results
Age of the child The ages of the child with a disability (M=4,13 years; SD=16 months) ranged from: 1 year or under: 4% (4) 2 years: 9% (9) 3 years: 0% (0) 4 years: 17% (16) 5 years: 52% (50) 6 years: 18% (17)	
Gender of the child with a disability The parent respondents reported the gender of their children as: 23% (22) female, and 76% (73) male.	
A formal diagnosis of disability Of the children: 97% (93) children had received a formal diagnosis, and 3% (3) had not.	

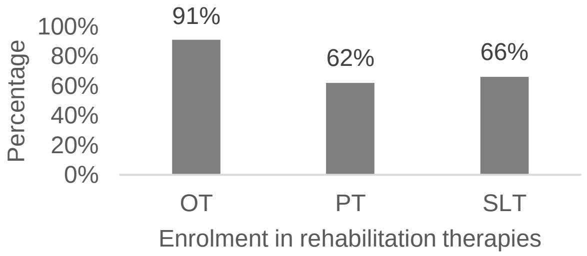
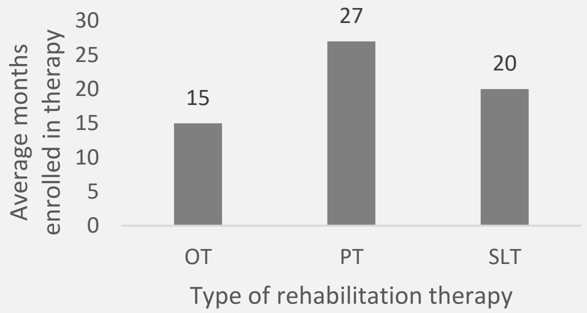
Biographical description of the child	Results
Time since diagnosis Of the 93 children that had received a formal diagnosis, the average reported time since diagnosis was 18 months, with parent respondents reporting that: 40% (38) in the last year, 22% (21) about 2 years ago, 25% (24) about 3 years ago, 5% (5) about 4 years ago, 8% (8) about 5 years ago.	
Type of disability of the child Of the children included in the study: 38% (36) had a physical disability, 28% (27) had autism spectrum disorder, 17% (16) had a neurological disorder, 16% (15) had developmental delay, 8% (8) had a sensory disability, 6% (6) had ADHD, 3% (3) had a Genetic syndrome, 1% (1) had a long-term health condition.	
Parental perception of the severity of disability Of the parent respondents: 22% (21) described the disability as mild, 55% (53) described the disability as moderate, 23% (22) of parents described the disability as severe.	

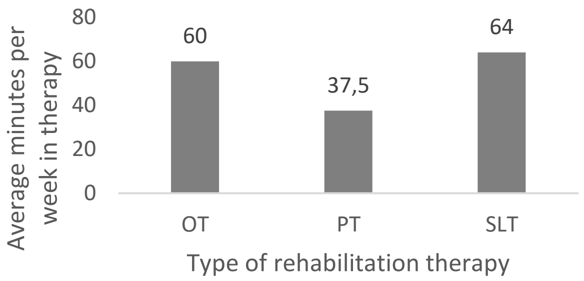
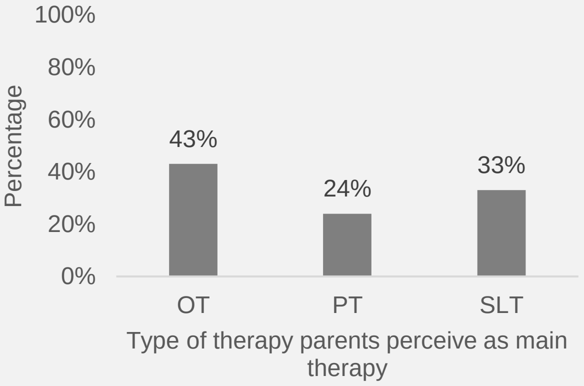
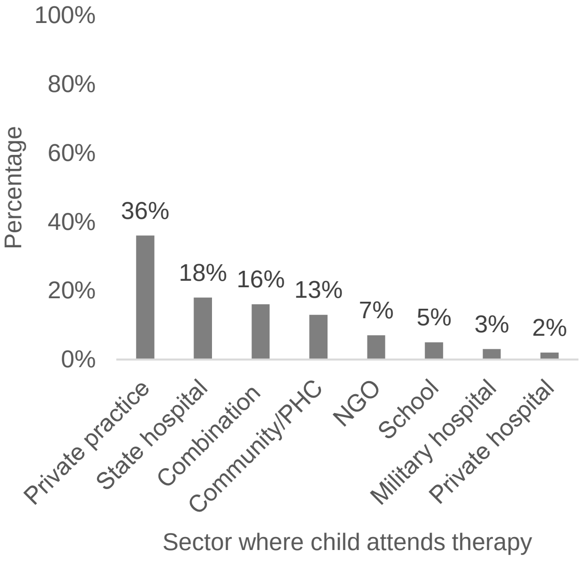
Parent respondents reported that their children's ages varied between 8 months and 6 years of age. The majority of the children were 5 years of age (52%, n=50) and were males (76%, n=73). The type of disability of the children varied. Most of the children (97%, n=93) had already received a formal diagnosis of their disability and of these children and most had received a formal diagnosis in the last year, (40%, n=37), the last 2 years (22%, n=21), or the last 3 years (25%, n=23). Parent respondents reported that they perceived their child's disability to be moderate in most cases (55%, n=53), with some parent respondents reporting the severity of their child's disability as severe (23%, n=22) and mild (22%, n=21).

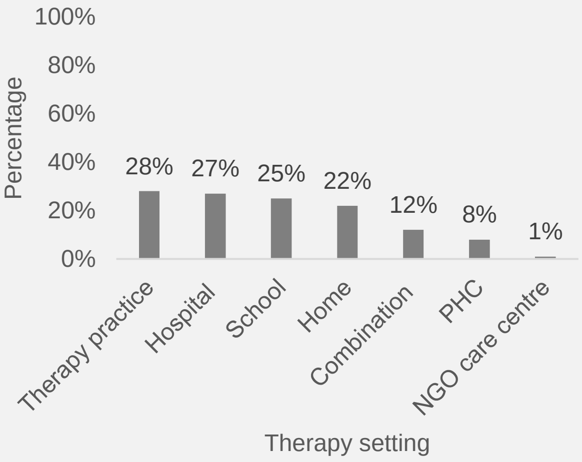
Table 6.6 describes the demographics of the rehabilitation therapy services. The rehabilitation therapy discipline, time in therapy, frequency of therapy, setting, and context of therapy are described.

Table 6.6.

Demographic Description of Rehabilitation Therapy Services.

Demographic description of rehabilitation therapy services	Results
Enrolment in rehabilitation therapies Parent respondents reported: 91% (87) enrolled in OT, 62% (59) enrolled in PT, 66% (63) enrolled in SLT.	
Time enrolled in rehabilitation therapies Parent respondents reported: 15 months (SD=10,06) enrolled in OT, 27 months (SD=10,25) enrolled in PT, 20 months (SD=12,38) enrolled in SLT.	

Demographic description of rehabilitation therapy services	Results
Minutes of rehabilitation therapies per week Parent respondents reported an average of: 60 minutes (SD=22,15) in OT, 37,5 minutes (SD=35,54) in PT, and 64 minutes (SD=16,03) in SLT.	
Type of rehabilitation therapy parents perceived as the main therapy Of the parent respondents the main therapy as: 43% (41) reported OT, 24 % (32) reported PT, 33% (23) reported SLT.	
The sector where the child attends therapy In terms of the sector in which their child attends therapy, parents reported: 36% (35) at a private practice or therapy center, 18% (17) at a government or State hospital, 16% (15) a combination of the private and public sector, 13% (12) at a community or primary healthcare clinic, 7% (7) at a Non-Governmental Organisation, 5% (5) at a school, 3% (3) at a Military hospital, and 2% (2) at a private hospital.	

Demographic description of rehabilitation therapy services	Results
Setting where the child attends therapy 28% (26) at a private therapy center or practice, 27% (27) at a government or hospital, 25% (24) at state or government school, 22% (21) at home, 12% (12) in a combination of settings, 8 % (8) at a primary healthcare or community clinic (PHC), 1% (1) at a Non-governmental Organization (NGO) care center.	

Parent respondents reported that the majority of their children (91%; n=87) were enrolled in Occupational therapy with an average time enrolled between 15 months and 27 months. Children attended between 37,5 and 64 minutes of therapy per week. Just under half of the parent respondents reported that they perceived Occupational therapy as their child's main therapy (44%; n=41). The majority of parent respondents reported that their child attends rehabilitation therapies in the public sector (60%; n=58), which includes either a governmental hospital or state hospital or school or primary healthcare clinic.

6.4 Data collection materials

6.4.1 Participant information letter and consent form

The participant invitation email and reminder email and a mobile message included details about the purpose of the study and what was expected of the participants. It also explained the participant’s voluntary rights to participate, their right to withdraw from the study with no consequences, and the procedures put in place to maintain their confidentiality as well as the procedures out in place to secure and store the data provided by the participant. Participants who were willing to participate were requested to click on the survey link. They were then redirected to the online consent form where they were requested to record their understanding of the requirements of the study and their voluntary participation in the study. Once participants provided consent to participate in the study, they were redirected to the survey questionnaire. After participants completed the survey questionnaire, they were requested to provide their email address to be sent a second link to complete the survey 10 days later with an instruction to complete the retest survey within 4 days of receipt of the link.

6.4.2 Online survey questionnaire

The survey questionnaire was made available to participants through Qualtrics (an electronic survey tool) (Appendix O). After participants clicked on the survey link, they were redirected to the Participant information letter and consent form. Parents were required to read the information letter and provide consent to participate in the study before they were redirected to the survey questionnaire. The survey questionnaire consisted of the Biographical Questionnaire (Section A) and the PRITT (Section B) (Appendix P).

6.4.2.1 Section A: Biographical Questionnaire

The Biographical Questionnaire was comprised of 22 questions relevant to assessing the representativeness of the sample.

6.4.2.2 Section B: The PRITT

The finalized PRITT containing 19 items comprised Section B of the online survey questionnaire (Appendix P).

6.4.2.3 Test-retest survey link

At the end of the survey questionnaire, parents were requested to provide their email addresses. It was explained that Qualtrics would store this information confidentially so the T1 and T2 responses could be paired and that they would receive a second survey link 10 days later to complete the PRITT a second time. The results of the second survey were used to establish test-retest reliability.

6.5 Data collection procedures and ethical considerations

Before proceeding with the study, ethics approval was obtained from the Research Committee of the University of Pretoria's Faculty of Humanities

(HUM033/0419; see Appendix U). Ethical considerations such as the protection from harm, obtaining informed consent, protecting the privacy and confidentiality of the participants, and minimizing the potential misinterpretation and misuses of results were addressed in the study.

Firstly, the researcher identified i) organizations that provide support and information to parents of children with a disability and ii) professional organizations for therapeutic interventionists (i.e., occupational therapists, physiotherapists, and speech-language therapists) (see Section 3.5.3 for a description of recruitment). The parent support organizations and professional organizations were initially contacted via email and sent an information letter and a reply slip. The information letter informed them of the aims of the study and explained what would be required from the organizations should they agree to participate. Following approval from the organizations, the researcher shared an initial invitation email template and a reminder email template (both containing the survey link) with the organizations. The parent support organizations and professional organizations then shared (i) the invitation email containing the survey link and (ii) a reminder email containing the survey link two weeks later with their member listserve. Professionals and parents were also requested to share the email with other parents of children with a disability who met the selection criteria.

6.6 Data analysis and presentation

Following data collection, the researcher exported the completed questionnaires from Qualtrics into an MS Word Excel document. The researcher checked the data for missing data and incomplete questionnaires were removed. The data cleaning was then checked by the Statistician. Data were analysed using IBM SPSS Statistics Version 22 and AMOS version 22. After all the data was entered into SPSS, descriptives were used to run a check on the data.

The statistical procedures followed and their rationale is described in Table 6.7 below according to the respective sub-aim of the study.

Table 6.7.

Statistical Procedures Followed to Address the Sub-Aims of the Study.

Sub-aim of the study	Statistical procedure and rational
Sub-aim IV: To explore the dimensionality of the developed instrument by performing factor analysis.	Exploratory factor analysis as a dimension data reduction technique and to explore the underlying factor structure of the PRITT.
Sub-aim V: To assess reliability by determining the internal consistency and test-retest reliability of the developed instrument.	Inter-item correlations and Cronbach's alpha to evaluate the internal consistency of the PRITT. Paired samples T-tests to determine the test-retest reliability of the PRITT.

6.7 Summary

In this chapter, the pilot study was presented in terms of results and recommendations. A description of the study participants, return rate, and participant selection criteria were also provided. Finally, the data collection and data analysis procedures were outlined.

CHAPTER 7

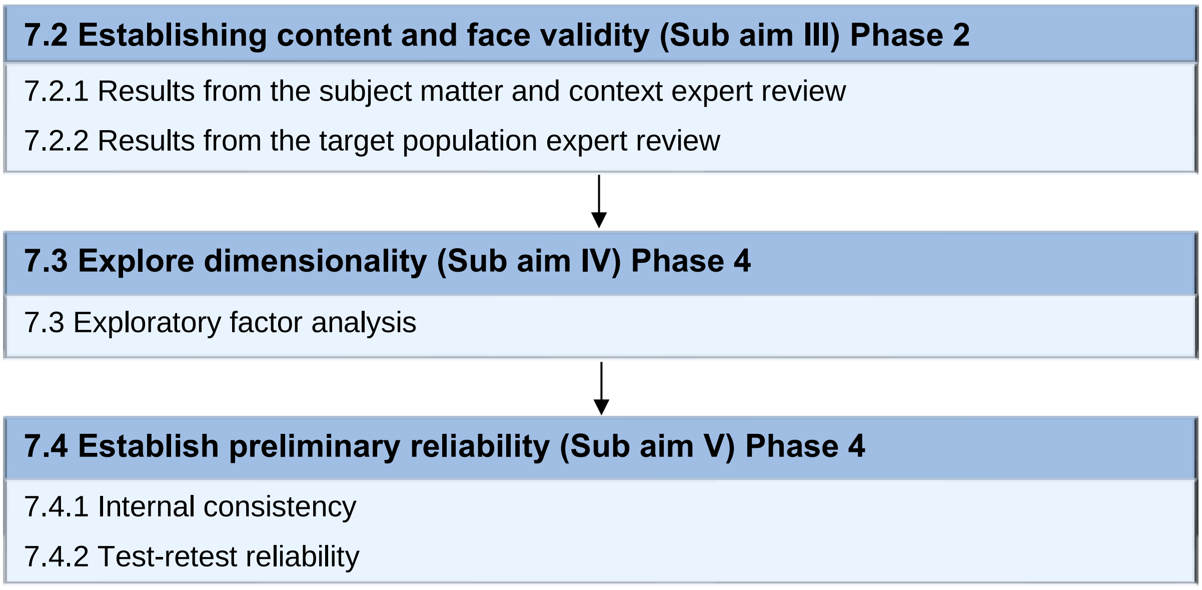
RESULTS

7.1 Introduction

The main aim of the study was to develop and establish preliminary validation of a quantitative instrument to measure parental roles in intervention for use with parents of children with a disability. To achieve this aim, first, the different types of parental roles were identified through a scoping review. The tasks and responsibilities associated with each role were then extracted and refined as items and the response scale was selected for this new measuring instrument, the PRITT. Content and face validity were then established using expert review in two phases and the study survey instrument was piloted. The survey was then administered to parents of young children with a disability. Data were analysed to explore the dimensionality of the PRITT and the reliability of the PRITT was assessed. The structure of the chapter and the sections in which the specific sub-aims will be addressed are outlined in Figure 7.1 below.

Figure 7.1

Schematic Representation of the Presentation of the Results of the Study.



7.2 Establishing content and face validity

During the development of the PRITT, steps were taken to ensure that the content was relevant and provided a comprehensive representation of the construct of parental roles in intervention for the target population (Prinsen et al., 2018). Content and face validity were established before the survey was administered. The procedures utilized to establish the content and face validity of the PRITT are detailed in Chapter 5 (Section 5.2). The results and interpretations are outlined below.

7.2.1 Establishing content validity

7.2.1.1 Step 1: Quantitative expert ratings

In the first step of the expert review, six professional subject matter and context experts completed a quantitative rating scale to rate the relevance, comprehensibility, and coverage of the PRITT item content and response scale. The results of the professional subject matter and context expert review are detailed in Table 7.1 (CVI ratings) and Table 7.2 (Rating scale feedback) below.

Using the quantitative data obtained from the first step of the professional subject matter and context expert review, the Content Validity Index (CVI; Lynn, 1986) i.e.: the proportion of agreement between the experts was calculated (Polit et al., 2007; Zamanzadeh et al., 2015). To compute the CVI, experts rate the relevance of the instrument items on a 4-point Likert scale (*1= Not relevant to 4= Highly relevant*) (Zamanzadeh et al., 2014). CVI ratings were calculated on an item level (CVI-I) and scale level (CVI-S).

CVI has been criticized for susceptibility for chance agreement to occur between rater (Wynd et al., 2003). This is overcome by including more than five expert raters. Increasing the number of experts “decreases the likelihood for chance agreement because it brings the expert ratings closer to a normal distribution” (Wynd et al., 2003, p. 511). In this study, more than five expert raters were included and the ratings from step 1 were considered with the expert’s qualitative feedback from the focus group discussion from step 2.

Guidelines for CVI-I interpretation indicate that perfect agreement (CVI-I =1) is required for item retention where fewer than five experts are included in the review

(Grant & Davis, 1997; Zamanzadeh et al., 2015). When more than five experts participate in the review, as with this study, items are retained if they have an CVI-I of 0.83 or better, i.e., if there is modest agreement between the experts. Items with an CVI-I of less than 0.70 are recommended to be reworked or considered for elimination (Polit et al., 2007). Due to the limited item pool, no items were eliminated based on the CVI ratings. Items with CVI-I ratings of less than 0.83 were given specific attention in the expert panel focus group discussions during step 2 of the subject matter and context professional expert review. On a scale level, both the Universal agreement CVI-S (UA) and Average CVI-S (Ave) were calculated. An CVI-S score of 0.80 is considered as the lower limit of acceptability (Polit et al., 2007; Zamanzadeh et al., 2015).

Table 7.1.

Summary of CVI Ratings and Interpretation from Expert Review.

Item	1/2 rating	3/ 4 rating	CVI-I	Interpretation
1	1	5	0.83	Relevant item
2	2	4	0.67	Revision required
3	1	5	0.83	Relevant item
4	0	6	1.00	Relevant item
5	0	6	1.00	Relevant item
6	0	6	1.00	Relevant item
7	0	6	1.00	Relevant item
8	0	6	1.00	Relevant item
9	0	6	1.00	Relevant item
10	0	6	1.00	Relevant item
11	1	5	0.83	Relevant item
12	0	6	1.00	Relevant item
13	0	6	1.00	Relevant item
14	1	5	0.83	Relevant item
15	2	4	0.67	Revision required
16	1	5	0.83	Relevant item
17	1	5	0.83	Relevant item
CVI-S (UA)=0.90			CVI-S (A) =0.88	Relevant scale content
Number of items indicated as relevant = 15 Number of items indicated as requiring revision= 2				

As indicated in Table 7.1, two of the items, namely Item 2 (Supporter: My role is to encourage my child to be enthusiastic about therapy) and Item 15 (Advocate: My role is to make sure my child gets the therapy that they need) were identified for revision based on unacceptable CVI-I ratings. The other 15 items were rated as relevant with modest or perfect agreement among the experts.

The CVI-I and CVI-S ratings indicate that the professional subject matter and context experts concluded that the content of the total instrument provides a relevant reflection of the parental role in intervention construct at scale level.

The results and recommendations from the professional subject matter and context expert ratings and comments from step 1 of the professional subject matter and context expert review can be viewed in Table 7.2 below.

Table 7.2.

Aims, Procedures, Results, and Adjustments Made Based on the Quantitative Feedback from Experts in the First Step of the Expert Review.

Aims	Procedures	Results	Amendments
To evaluate the appearance of the PRITT.	Experts were asked to evaluate whether the appearance i.e., the layout, design, look and feel of the PRITT would motivate responses.	The majority of the experts (n=5) agreed that the appearance of the PRITT motivated a response. One expert disagreed and suggested that the survey questionnaire could have a more modern layout.	No changes were made to the layout or design of the PRITT.
To evaluate the organization of the PRITT.	Experts were requested to assess whether the PRITT was logically organized.	The majority of the experts (n=5) agreed that the organization of the PRITT and individual items was logical. One expert disagreed and suggested that related items could be grouped and listed under headings and organized to follow the phases of intervention.	The questions in the Biographical Questionnaire were grouped under headings related to the nature of the questions i.e., questions about the family composition and household, child, intervention. The PRITT items were randomly ordered to minimize response bias.

Aims	Procedures	Results	Amendments
To evaluate the instructions of the PRITT.	Experts were asked to judge whether the instructions were comprehensible, easy to follow, clear, and straightforward.	All of the experts (n=6) agreed that the instructions are comprehensible, easy to follow, clear, and straightforward.	No changes were made to the instructions.
To evaluate the wording of the PRITT items.	Experts were asked to evaluate whether the PRITT items were concisely worded and unambiguous. They were asked to highlight word choices that could be challenging for participants to understand.	The majority of experts (n=5) rated the wording of the PRITT items as sufficiently concise. Half of the experts (n=3) rated the wording unambiguous. The experts reported two specific items (Items 1 and 16) as similarly worded and possibly difficult to distinguish from one another and one item (Item 17) as potentially unclear or confusing for parents. It was also commented that the terms ‘therapy’ and ‘intervention’ were used interchangeably.	The three specified items (Items 1, 16, and 17) were flagged for discussion in the focus group discussion. It was determined that the term ‘therapy’ was preferable to ‘intervention’ as this is the term most commonly used by parents.

Aims	Procedures	Results	Amendments
To evaluate the use of jargon or technical language.	The experts were requested to judge the use of jargon and technical language in the PRITT.	Most of the experts (n=4) agreed that the use of jargon or technical language was minimal. The two experts that disagree highlighted the use of particular words, namely: Adapt, skills, techniques, decision-making, implementation, and monitor, as overly technical and potentially problematic for parents to understand.	The specified words and respective items were flagged for revision in the focus group discussion. It was also determined that a terminology (what do we mean by…?) section would be included in the PRITT survey questionnaire.
To evaluate the specificity of the items and identify any items that asked more than one question.	The experts were requested to rate the specificity and evaluate whether the PRITT items were asked one question at a time.	All of the experts (n=6) agreed that the PRITT items were specific and asked one question at a time.	No changes were made in terms of the specificity of the items.
To evaluate the ease of comprehension of individual items of the PRITT.	The experts were requested to rate whether the individual PRITT items were easy to understand.	Most of the experts (n=4) agreed that the individual PRITT items were easy to understand. Two of the experts disagreed and reported that specific items (Items 1, 15, and 16) and highlighted particular words that may make it challenging for parents to	Specific items and wording choices were flagged for discussion in the expert panel focus group discussions.

Aims	Procedures	Results	Amendments
		understand the nuanced differences between the PRITT items.	
To identify any items indicating bias.	The experts were requested to determine if any items were formulated in a biased manner.	All of the experts (n=6) agreed that the items were unbiased.	No changes were required.
To evaluate the response scale.	The experts were asked to indicate if the response scale and categories would be easy for participants to understand	Half of the experts (n=3) rated the response scale as easy to understand. The experts who disagreed suggested amending the scale to an agreement scale or using a nominal yes/no response scale. Most of the experts (n=4) agreed that response scale categories were clear and would be easy for participants to respond to. Two experts commented that the response scale should be changed to an agreement scale to make it more clear and easier for participants to respond.	The response scale categories were flagged for discussion in the focus group discussion.
To evaluate the comprehensiveness of the PRITT items.	The experts were requested to judge the comprehensiveness of	The majority of the experts agreed that the items were comprehensive (n=5). One expert commented that the process of problem	This issue was flagged for discussion in the focus group discussion.

Aims	Procedures	Results	Amendments
	the PRITT survey questionnaire items, i.e., whether they adequately represent the parental role in intervention construct.	solving and reflection associated with coaching relationships may not be adequately represented in the items while another expert reported that the nuanced differences between the role tasks statements may be challenging for parents to understand.	

The CVI ratings were considered with the feedback of the experts from rating checklist in step 1 to flag items for discussion in step 2 of the review for possible revision. As is shown in Table 4.2, the experts identified specific words from particular items that they identified may be challenging for parents to understand. The experts highlighted words such as ‘adapt’ as in Item 6 (Adaptor: My role is to use the knowledge that I’ve gained to adapt some of the therapy at home), ‘skills’ and ‘techniques’ included in Item 7 (My role is to use the knowledge I’ve gained to suggest new therapy activities) and Item 11 (Learner: My role is to learn the skills or techniques that can enhance my child’s intervention) was highlighted as potentially problematic. The Decision maker role tasks including Item 12 (My role is to be part of decision making about what to focus on in therapy) and Item 13 (My role is to be part of decision making about how therapy should be carried out) were both flagged due to the term ‘decision making’. The use of the word ‘monitor’ in Item 17 (My role is to monitor the quality of the therapy) was also flagged as possibly challenging for parents to understand. Furthermore, the experts identified that Item 1 (My role is to make sure that my child goes to therapy sessions) and Item 16 (Advocate: My role is to make sure my child gets the therapy that they need) were similarly worded.

In their feedback from step 1 of the review, the experts further indicated that parents may find it challenging to to understand the response scale. They suggested that the response scale could be amended to an agreement Likert type scale or a nominal response scale. As a nominal scale would not provide the data required for the statistical analysis, the Likert type scale response categories were also flagged for discussion in step 2 of the review.

One expert suggested that the process of problem solving and reflection associated with coaching relationships may not be adequately represented in the items. This expert provided a reference for a particular literature source discussing the process of problem solving and reflection associated with coaching relationships. The researcher familiarized herself with this literature source and the particular definitions of problem solving and reflection included therein. This expert’s feedback was introduced related to the comprehensiveness of the coverage of the items in the PRITT during step 2 of the review.

The results and recommendations from the professional subject matter and context expert ratings and comments from Step 2 of the review i.e., the focus group discussions can be viewed in Table 7.3 below

Table 7.3

Aims, Procedures, and Adjustments Made Based on the Subject Matter and Context Expert Review Focus Group Discussions.

Aims	Procedures	Results	Amendments
To discuss the comprehensiveness of the PRITT items	Experts were asked to discuss whether the items collectively reflect the parental roles in intervention construct, i.e., discuss the comprehensiveness and coverage of the PRITT. The experts were requested to discuss possible revisions to flagged items, i.e., wording or phrasing changes.	The experts mostly agreed that the items collectively reflect the parental role in intervention construct. .	It was suggested that there was possible conceptual overlap between the Bringer role task items and Advocate role task items. It was also suggested that the Adaptor role tasks required range and should include adapting activities as well as more active role tasks like integrating intervention into daily routines. It was also recommended that the Supporter role item be amended to reflect parents motivating their child’s participation in therapy.
	Experts were requested to identify tasks or responsibilities related to the parental role in intervention that should be added to the PRITT i.e., identify underrepresented roles.	One expert indicated that problem solving and reflection were not represented by the PRITT items. The other experts did not agree.	Upon revisiting the coded data, it was determined that the processes of problem solving and reflection were included in the Intervener, Collaborative partner, and Decision maker roles.

Aims	Procedures	Results	Amendments
To discuss the response scale	The expert panel was asked to discuss the response scale categories in terms of appropriateness for the construct and the target population.	Experts indicated concern with parents understanding the scale of "Trueness" (*1= Definitely not true* to *5= Definitely true*)	Based on the feedback from the first step of the expert review, it was deemed necessary to use an agreement scale (*1= Disagree* to *5= Agree*).
	Experts were requested to identify and discuss any potential issues with the comprehensibility or interpretation of the response scale.	The experts questioned whether parents would comprehend and interpret the “Trueness” scale and recommended that an agreement scale would be more appropriate.	
To discuss the stability of the parental role in intervention construct.	Experts were requested to discuss the stability of the parental role in intervention construct with regards to informing the time interval for test-retest reliability.	The experts agreed that parental roles in intervention could change over the course of intervention. Experts indicated that a time frame of three months or at critical transition periods i.e., shifts in influencing systems and factor changes could influence the role tasks that parents perform. The experts supported the suggestion that parent roles could remain stable over a two-week retest interval provided that the system remained stable.	The data from the expert focus group indicate that the parental roles can be expected to remain stable over a two-week test-retest period.

7.2.2 Step 2: Qualitative feedback from focus group discussion

Following the completion of the professional subject matter and context expert focus group discussions in step 2 of the review, the researcher downloaded the thread. Qualitative thematic analysis (Nowell et al., 2017b) of the focus group transcripts was then conducted utilizing Atlas.ti8 software (Paulus et al., 2017). The researcher compiled a codebook to be used for the initial phase of the analysis. The codebook included the major aspects to be addressed in the content validity - focused expert review namely relevance, representativeness, clarity, technical quality, simplicity, appearance, wording for the different aspects of the measure i.e., items, response scale. One question focused on the stability of the parental role in intervention construct and addressed the test-retest reliability interval. During the first round of coding, the researcher applied the *a priori* codes and open-coded any aspect of the focus group discussion transcript that fit with the *a priori* codes. Thereafter, during subsequent coding rounds, names and definitions were being generated for the open codes iteratively in discussion with the study supervisor.

The comments and suggestions from the professional subject matter and context experts from Step 2 of the review were considered alongside the coded descriptions of the tasks and responsibilities associated with the parental roles in intervention. The researcher and study supervisor reverted to the theoretical grounding of the role task statements to determine whether amendments were to be made to the items. The amendments are explained below and the changes made to the particular items are detailed in Appendix I.

As indicated in Table 7.3, the professional subject matter and context experts reported that the PRITT item content provided comprehensive coverage of the parental role in intervention construct. Word choice revisions were suggested to enhance the comprehensibility of the items. This included amending the wording for certain items. Examples were added to Item 1: Bringer to differentiate it as related to ensuring attendance and to differentiate this item from being related to access to intervention. The wording of the Advocate: Item 16 was also amended to indicate its intention of securing access to services.

The experts also indicated that the wording of Item 2: Supporter should be amended to reflect the intention behind the support that parents provide (and not simply to support their child's enthusiasm for therapy. Item 2 was, therefore, amended to reflect this (Supporter: My role is to motivate my child to participate during therapy sessions).

It was also suggested that the intervention-implementation role tasks required range i.e., to include activity adaptations as with the Adaptor role tasks as well as more active role tasks associated with integrating therapy strategies and techniques into daily life and family routines. It was determined that these role tasks required separation into two different role types. These tasks were therefore included as, firstly, the Adaptor role tasks (Item 6 and Item 7) with a focus on therapy activity adaptations and feedback to the therapist regarding new activity suggestions and, secondly, the Intervener role tasks (Item 18 and 19) with a focus on the integration of therapy strategies and techniques into daily routines. Although these roles tasks were coded under the Adaptor role following the analysis from the scoping review, the expert feedback highlighted the difference in terms of the level of active responsibility attributed to the Adaptor and Intervener role tasks. It was deemed necessary to indicate these sets of tasks as two related but distinct role types as they represented different levels of active responsibility on the continuum of roles.

Based on the feedback from the professional subject matter and context experts, the coded descriptions of the Decision maker role were reconsidered. Based on the feedback of the experts, the items of the Decision maker were more broadly worded to reflect the two major phases of decision-making in intervention namely, decisions related to, firstly, goal setting and, secondly, therapy plan implementation.

Furthermore, an open-ended question (namely: Is there anything that you would like to share about your role (i.e.: the tasks and responsibilities you perform) in your child's therapy that was not captured in this survey? Please explain.) was added at the end of the survey questionnaire for parents to specify any role tasks that they felt were not included in the PRITT items.

In summary, the findings of the professional subject matter and context expert review panel indicate that the PRITT has content validity. Following the recommended amendments, the PRITT was reviewed by a panel of target population experts to establish face validity.

7.2.2 Establishing face validity

The procedures employed for the cognitive interviews that established the face validity of the PRITT with the target population experts are detailed in Chapter 3 (Section 3.6.4.1). The target population experts included parents of children with a disability.

Parent experts reported that the instructions, terminology section, and items of the PRITT were easy to understand and that, for the most part, the response scale was easy to use. Two parents highlighted that it may be challenging for some parents to distinguish between the two polar response categories of the Agreement scale (*1= Disagree*, *2= Mostly Disagree*). Furthermore, one parent suggested that the response categories should be numbered. Based on this feedback, the response categories of the Likert-type scale were amended (to 1=*Strongly Disagree* to 5=*Strongly Agree*). The response categories were also numbered (1-5). The feedback of the parent experts and amendments made to the PRITT following their feedback from the cognitive interviews can be viewed in Table 7.4 below.

Table 7.4

Aims, Procedures, and Adjustments Made Based on the Target Population Expert Review.

Aims	Procedures	Results	Amendments
To evaluate the layout of the PRITT.	Participants were asked to provide feedback on the appearance and organization of the PRITT.	All of the parents (n=5) reported the layout and appearance of the PRITT to be easy to follow and user-friendly. No changes to the layout were recommended.	No amendments were made to the layout of the PRITT.
To evaluate the instructions and terminology "What do we mean by?" sections used in the PRITT.	Participants were requested to provide feedback on ease of comprehension and simplicity of the instructions used in the PRITT.	All of the parents (n=5) reported the instructions and terminology "What do we mean by?" sections to be easily comprehensible and straightforward. No suggestions for improvement or amendment were provided.	No amendments were made to the instructions of the PRITT.
To evaluate the wording of the items of the PRITT.	Participants were asked to provide feedback on the understandability and simplicity of the wording of the items of the PRITT.	The parents reported the item wording to be easily understandable and simple (n=5). No specific words, phrases, or items were reported to require amendment.	No amendments were made to the wording of the PRITT items.
To evaluate the Likert-type response scale	Participants were requested to provide feedback on ease of comprehension and simplicity of the response scale used in the PRITT.	Four parents found the rating scale easy to understand. Two parents reported difficulties with understanding the difference between the polar and mid response categories (i.e., *1=*	The response categories of the Likert-type scale were amended to 1=*Strongly Disagree* to 5=*Strongly*

used in the PRITT.	*Disagree* and 2=*Mostly Disagree* and 4= *Mostly Agree* and 5=*Agree*). One parent suggested that a numeric could be included.	*Agree* and the Response categories were numbered (1-5).

In summary, therefore, both expert reviews indicated that the PRITT demonstrated adequate content and face validity.

7.3 Exploring the dimensionality of the PRITT with Exploratory Factor Analysis

The final instrument was then administered through a survey to 96 parents of children with a disability who met the selection criteria (outlined in Section 6.3.1.1).

Exploratory factor analysis (EFA) was employed as a dimension data reduction technique (Bandalos & Finney, 2018; Orcan, 2018) to explore the underlying factor structure of the PRITT (Taherdoost et al., 2014; Worthington & Whittaker, 2006). As the PRITT was developed with a tentative multidimensional factor structure hypothesis regarding the relationship between items, this was deemed an appropriate method. EFA is typically conducted when there is “little theoretical basis for specifying a priori the number and patterns of common factors” (Taherdoost et al., 2014, p. 376).

Components were extracted using Principal Components Analysis (PCA). The components with eigenvalues greater than 1.0 were rotated using Varimax software to generate an orthogonal solution (Samuels, 2016) shown in Table 7.5 below.

Table 7.5.

Results of the EFA: Factor Loadings from the Rotated Component Matrix.

Item	Factors	Component 1	Component 2
Item 5	Learner: Use gained knowledge to suggest new therapy activities to the therapist	0.81	
Item 7	Observer: Observe session to learn how to do activities at home	0.79	
Item 8	Implementer: Carry out the home program developed by the therapist	0.90	
Item 9	Advocate: Monitor the therapy that child receives	0.77	
Item 10	Intervener: Try and include therapy strategies into daily routines	0.92	
Item 11	Implementer: Report back to the therapist on how well the home program went since the last session	0.88	
Item 12	Collaborative partner: Work together with the therapist to ensure that session goals are achieved	0.87	
Item 13	Learner: Improve knowledge about therapy	0.90	
Item 14	Intervener: Report back to the therapist on ease of fitting therapy strategies into daily routines	0.86	
Item 15	Learner: Learn the skills and techniques needed to support child's progress	0.83	
Item 16	Advocate: Ensure child has access to appropriate therapy	0.87	
Item 17	Informer: Provide information to therapists about child	0.84	
Item 18	Collaborative partner: Work as an equal partner with the therapist	0.78	
Item 19	Adaptor: Use knowledge gained to try and adapt therapy activities at home	0.80	
Item 1	Informer: Share information between professionals involved with child		0.80
Item 3	Decision maker: Give input on the therapy plan		0.76
Item 4	Supporter: Motivate the child to participate during therapy sessions		0.85
Item 6	Bringer: Ensure child gets to therapy sessions		0.79
Kaiser Meyer Olkin Measure of Sampling Adequacy (KMO)		0.90	
Bartlett's Test of Sphericity		0.00	
Eigenvalues		14.7	1.08
% Variance explained		81.51%	1.08%

The Kaiser-Meyer-Olkin Measure of Sampling Adequacy (KMO; Kaiser, 1974) was used to assess the adequacy of the sample size for EFA. A minimum acceptable score for this test is 0.5 (Kaiser, 1974). An average value higher than 0.6 is acceptable for samples of fewer than 100 respondents (Samuels, 2016). As indicated in Table 7.5, the KMO is higher than the minimum acceptable score. This suggests that the sample size is adequate for EFA to be performed (Taherdoost et al., 2014).

Bartlett's Test of Sphericity (Bartlett 1950) produces a chi-square statistic (Thompson, 2006). Results must be significant ($p<.05$) for factor analysis to be appropriate (Taherdoost et al., 2014). As shown in Table 7.5 above, Bartlett's Test of Sphericity (Bartlett 1950) result is significant and indicates that conducting factor analysis on this data is suitable.

The correlation matrix produced from the factor analysis was assessed to ascertain whether the items were related and to what degree they were related. A factor loading represents the Pearson correlation between the factors and the extracted component. The larger the loading, the more the factors are indicated to be a pure measure of the component (Howard, 2016). It is further recommended that a substantial number of large correlations is adequate for factor analysis but how large the correlation is, is unimportant.

A researcher can have greater confidence that a strong relationship exists when the component matrix displays higher factor loadings. Factor loadings should be greater than 0.32 to provide interpretive value (Comrey & Lee, 1992). Comrey and Lee’s (1992) guidelines are most commonly employed to interpret factor loadings: 0.71=excellent, 0.63=very good, 0.55=good, 0.45=fair and 0.32=poor.

The correlation matrix shown in Table 7.5 produced large correlations among 18 of the items suggesting that factor analysis is an appropriate statistical methodology. One of the items (Item 2) presented with cross-loading (i.e., correlations highly similar across two components) and was removed before conducting further analysis (Boateng et al., 2018). Component 1, named Active, contains 14 factors (comprising 78% of the total factors) included in the study which all load in the excellent range. The four factors, (comprising 22% of the total factors) that load into Component 2, named Passive, load in the excellent range.

The components were named Component 1: Active and Component 2: Passive following consideration of the content of the items. The factors that loaded onto Component 1: Active are linked with more direct involvement in intervention. Component 1 loaded with more active (in comparison to Component 2) role tasks associated with accessing, managing intervention, and directly implementing interventions with different underlying intervention approaches. Some of the role tasks that loaded onto Component 1: Active directly linked with intervention implementation are enacted during an intervention session such as the Observer (Item 7), Informer (Item 17), Learner (Item 13 and 15), Collaborative partner (Item 12). The other role tasks that loaded onto Component 1: Active are most commonly performed outside of therapy sessions including the Implementer (Items 8 and 11), Adaptor (Items 5 and 19), Intervener (Items 10 and 14).

The factors that loaded into Component 2 included more passive tasks related to parents ensuring their child's attendance of intervention and promoting their child’s enthusiasm to encourage participation in professional-directed sessions. Also included, is a role task related to parents acting as an information liaison to convey information between professionals involved in their child's care. Item 3 (coded as one of the tasks associated with the Decision maker role) relates to parents providing their input to inform the plan for their child’s therapy. Of interest, when the nature of the tasks associated with the factors that loaded into Component 2, is that these role tasks are typically performed earlier on in the therapy process and are linked with parents being indirectly involved and taking less responsibility for their child’s intervention.

7.4 Tests of reliability

Reliability, a required condition for validity, refers to the extent to which a measuring instrument is free from measurement error to yield consistent results (Knekta et al., 2019; L. B. Mokkink et al., 2012). It is not adequate to simply examine internal consistency to establish the reliability of a developed measuring instrument. It is also necessary to consider the stability of a measuring instrument over time to determine its ability to provide reproducibly consistent results. In this study, 27 parents completed the PRITT at T2.

7.4.1 Internal consistency reliability

The internal consistency provides an estimate of the reliability of the measurement based on the assumption that there should be a correlation between items that measure a construct (Boateng et al., 2018). Internal consistency reliability was calculated using Inter-item correlation, Cronbach alpha, item-total correlation, and item-total statistics (Salkind, 2012). Inter-item correlations indicate the extent that scores are related to an instrument. The ideal average inter-item correlation score should be in the range of 0.2 to 0.5. Low average inter-item correlations (less than 0.2) indicate that the items do not represent the construct while high average inter-item correlations (higher than 0.5) indicate possible redundancy (Piedmont, 2014). Cronbach's alpha reliability scores should be between 0.70 to 0.80 to be deemed acceptable while an alpha score of 0.90 is regarded as 'excellent' (Kline, 2011). Low Cronbach alpha scores (values of 0.50 or less) may indicate that too few items are included in the instrument or could indicate poor interrelation between items, i.e., that items represent too diverse a construct (Tavakol & Dennick, 2011). Internal consistency does however work against content validity when Cronbach alpha values are too high (values above 0.95). This may indicate redundancy and that the instrument content is too narrow (Neuendorf, 2003). In this case, as Cronbach's alpha is sensitive to instrument length, items can be removed to address redundancy (Tavakol & Dennick, 2011).

Table 7.6.

Summary Item Statistics and Cronbach Alpha for Components of the PRITT.

		Inter-Item Correlations			Cronbach Alpha	
	N of Items	Median	Range	Interpretation	α	Interpretation
Component 1: Active	14	0.88	0.28	High	0.98	Inadequate
Component 2: Passive	4	0.74	0.19	High	0.91	Acceptable

The Inter-item correlations and Cronbach alpha for the PRITT components are illustrated in Table 7.6 above. The average inter-item correlations are high for both Component 1: Active and Component 2: Passive. The Cronbach Alpha scores for Component 1: Active are elevated and may indicate redundancy in the item content. The Cronbach Alpha scores indicate acceptable internal consistency for the items on Component 2: Passive.

The researcher considered removing items from Component 1: Active to address the redundancy indicated by the high Inter-Item correlations and Cronbach alpha. However, when any particular one item was removed and the Cronbach alpha analysed again, the Item-Total Statistics indicated that the Cronbach alpha score was largely unaffected as shown in Table 7.7 below. This suggests that redundancy in Component 1: Active cannot be addressed by removing any one particular item.

Table 7.7.

Item-Total Statistics for Components of the PRITT.

Item	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
Component 1: Active		
Item 5	0.90	0.99
Item 7	0.93	0.99
Item 8	0.95	0.99
Item 9	0.80	0.99
Item 10	0.97	0.99
Item 11	0.93	0.99
Item 12	0.95	0.99
Item 13	0.97	0.99
Item 14	0.92	0.99
Item 15	0.96	0.99
Item 16	0.94	0.99
Item 17	0.97	0.99
Item 18	0.92	0.99
Item 19	0.95	0.99
Component 2: Passive		
Item 1	0.81	0.89
Item 3	0.87	0.87
Item 4	0.73	0.92
Item 6	0.83	0.88

7.4.2 Examining test-retest reliability

Test-retest reliability refers to the “consistency of scores across two separate measurements over time” (Polit, 2014, p. 1713). It is regarded across the literature and, particularly, endorsed by the researchers from the COSMIN group to be more consequential for instrument development and validity than internal consistency reliability (Mokkink et al., 2010). Unlike internal consistency reliability analyses, test-retest reliability is not sensitive to increased instrument length. Polit (2014) recommends that test-retest data be examined early on in the instrument development process to inform item retention and removal decisions.

To determine the test-retest reliability of the PRITT, paired-samples t-test was conducted. Parents who provided consent (n=27) received a retest survey link 10 days later with instruction to complete the retest survey within 4 days of receiving the retest survey (T2) link. T2 responses were submitted within 10-14 days following T1 with a mean test-retest interval of 12 days (SD= 1,87).

Larger correlations indicate higher test-retest reliability and lower correlations (values closer to zero) indicate lower reliability (Boateng et al., 2018). The results of the paired samples correlations and paired samples t-tests are outlined in Table 7.8 below.

Table 7.8.

Test-retest Reliability: Paired Samples t-test (n=27).

		Mean difference	95% CI	t	df	Sig. (2-tailed)
Pair 1	Active_T1 & Active_T2	0.53	[-0.30, 0.44]	0.36	26	0.72
Pair 2	Passive_T1 & Passive_T2	-0.13	[-0.54, .021]	-0.87	26	0.39

As shown in Table 7.8, t (27) =0.36 for Pair 1 (Active_T1 & Passive_T2). For Pair 2 (Passive_T1 & Passive_T2), t (27) =-0.87. No significant difference was found between T1 and T2 indicating that the PRITT provides a stable measurement of the parental role in intervention construct with a two-week approximate test-retest interval.

7.5 Parental responses to the PRITT

Overall, the parental responses indicated a high proportion of agreement and strong agreement across the majority of the role task statements. Respondents made use of the range of the response categories. A consistent portion of respondents (10%) indicated strong disagreement. The middle response category (3= Not Sure) was utilised less frequently than the other response categories for the majority of the role task statements. These results indicate that the parent respondents seem to have a clear idea of the roles they perform in their child's intervention.

The descriptive statistics, mean scores and standard deviations for the parental responses to the PRITT are detailed below in Table 7.9 below.

Table 7.9

Means and Standard Deviations for the Parental Responses to the PRITT.

Item	Role task	Strongly Disagree n (%)	Disagree n (%)	Not sure n (%)	Agree n (%)	Strongly Agree n (%)	Mean	SD
Component 1: Active								
Item 5	Adaptor: Use gained knowledge to suggest new therapy activities to the therapist.	10 (10)	1 (1)	0 (0)	45 (47)	40 (42)	19	21.7
Item 7	Observer: Observe session to learn how to do activities at home.	10 (10)	0 (0)	5 (5)	57 (59)	24 (25)	19	22.95
Item 8	Implementer: Carry out the home programme developed by the therapist.	10 (10)	0 (0)	2 (2)	51 (53)	33 (34)	19	22.08
Item 9	Advocate: Monitor the therapy that child receives.	10 (10)	5 (5)	10 (10)	52 (54)	19 (20)	19	19.02
Item 10	Intervener: Try and include therapy strategies into daily routines.	10 (10)	0 (0)	0 (0)	54 (56)	32 (33)	19	23.44
Item 11	Implementer: Report back to the therapist on how well the home programme went since the last session.	10 (10)	2 (2)	0 (0)	49 (51)	35 (36)	19	21.72
Item 12	Collaborative partner: Work together with the therapist to ensure that session goals are achieved.	10 (10)	0 (0)	1 (1)	52 (54)	33 (34)	19	22.64
Item 13	Learner: Improve knowledge about therapy.	10 (10)	0 (0)	0 (0)	53 (55)	33 (34)	19	23.21

Item	Role task	Strongly Disagree n (%)	Disagree n (%)	Not sure n (%)	Agree n (%)	Strongly Agree n (%)	Mean	SD
Item 14	Intervener: Report back to therapist on ease of fitting therapy strategies into daily routines.	10 (10)	2 (2)	6 (6)	49 (51)	29 (30)	19	19.61
Item 15	Learner: Learn the skills and techniques needed to support child's progress.	10 (10)	0 (0)	4 (4)	51 (53)	31 (32)	19	21.42
Item 16	Advocate: Ensure child has access to appropriate therapy.	10 (10)	0 (0)	0 (0)	48 (50)	38 (40)	19	22.39
Item 17	Informer: Provide information to therapists about child.	10 (10)	0 (0)	0 (0)	57 (59)	29 (30)	19	24.22
Item 18	Collaborative partner: Work as an equal partner with the therapist.	10 (10)	0 (0)	11 (11)	48 (50)	27 (28)	19	18.78
Item 19	Adaptor: Use knowledge gained to try and adapt therapy activities at home.	10 (10)	0 (0)	6 (6)	55 (57)	25 (26)	19	22.04
Component 2: Passive								
Item 1	Informer: Share information between professionals involved with child.	15 (16)	0 (0)	2 (2)	47 (49)	32 (33)	19	20.12
Item 3	Decision maker: Give input on the therapy plan.	10 (10)	4 (4)	2 (2)	73 (76)	7 (7)	19	30.23
Item 4	Supporter: Motivate child to participate during therapy sessions.	14 (15)	21 (22)	2 (2)	42 (44)	17 (18)	19	14.58
Item 6	Bringer: Ensure child gets to therapy sessions.	10 (10)	7 (7)	11 (11)	46 (48)	22 (23)	19	16.02

Table 7.9 displays the descriptive statistics (M, SD) from the PRITT. The scores ranged from 1 (Strongly Disagree) to 5 (Strongly Agree). The ratings for Component 1: Active indicate consistent strong agreement and agreement across the role task statements. It is also interesting to note that a consistent portion of the respondents (10%) indicated strong disagreement with the each of the role task statements.

For Component 2: Passive, a consistent portion (10% to 15%) of the respondents indicated strong disagreement with the role task statements. The role task statement for Supporter (Item 4) showed a higher proportion of strong disagreement and disagreement (37%). Responses on Bringer (Item 6) also demonstrated a higher percentage of strong disagreement and disagreement (17%) and of respondents being unsure about this role task (11%) as compared to the other role task statements.

7.6 Summary

Chapter 7 presented the results, statistical analysis, and interpretation of the data according to the sub-aims set out for the study. The main aim of the study was to develop and preliminarily validate an instrument to measure parental roles in intervention, named the PRITT. Construct and face validity for the PRITT using expert review. EFA results indicated a two-factor structure with strong factor loadings. Tests of internal consistency indicated possible redundancy. Test-retest analysis indicated that the PRITT provides a stable measurement of the parental role in intervention construct. In the last section of the chapter, the parental responses to the PRITT were presented. The results indicate that a high proportion of agreement and strong agreement across the majority of the role task statements for most of the parent respondents. These results indicate that preliminary reliability and validity have been established for the PRITT.

CHAPTER 8

DISCUSSION AND CONCLUSIONS

8.1 Introduction

As discussed in the literature review, parents play a fundamental role as agents of change to promote their child's development especially for children who are at risk or who have a disability and who attend early intervention services (King et al., 2017; Lane et al., 2016). This is an acknowledgment of changes in early intervention service delivery (King et al., 2019; Phoenix, 2017). Traditionally-implemented interventions promote the active role of the professional to take responsibility for interventions that address the needs of the child with a disability (McWilliam, 2012). An evolved view of intervention places the importance of parental involvement and engagement with parents assuming increasingly active roles in order to encouraging meaningful outcomes for the child with a disability and their family (Davies et al., 2017; Hurtubise & Carpenter, 2017; King et al., 2018). Parents can take primary responsibility to direct the focus and implementation of intervention and facilitate the transfer of meaningful skills for their child into natural learning environments (Hoffman, 2016; McWilliam, 2015). The recognition of the importance of parent involvement and parents working together with professionals in early intervention to facilitate child and family outcomes requires an acknowledgement of the shift of their roles as well (Dodd et al., 2009; Forsingdal et al., 2013; Hurtubise & Carpenter, 2011)

Despite the importance of the parental role in intervention being widely reported (Kemp & Turnbull, 2014; Osher & Osher, 2002; Robert et al., 2015), prior to this study the limited research on parental roles meant that the specifics of what the different types of roles entailed, in terms of the tasks and responsibilities that parents were expected to perform, were unclear (Davies et al., 2017; Smith & Samuels, 2021). The uncertainty and marked lack of negotiation around parental roles in intervention meant that parents were offered limited supports to enact more active roles (Hurtubise & Carpenter, 2011; Reeder & Morris, 2020; Smart et al., 2019). This is counteractive to promoting parental involvement and engagement and limits the potential of intervention to facilitate meaningful child and family outcomes (Hessell, 2004; King, Chiarello, Ideishi, D'Arrigo, et al., 2019; Smart et al., 2019). Furthermore, there were no existing instruments to measure this construct and test the implied relationship from the rehabilitation and intervention literature between parental roles and parental involvement and engagement (Smith & Samuels, 2021).

The main aim of this study was therefore to develop and establish preliminary validation of a quantitative instrument to measure the parental role in intervention for use with parents of children with a disability. To achieve this aim, the content and face validity of the PRITT was established, the factor structure was explored and the reliability of the PRITT was examined.

This chapter starts off by discussing the importance of a validated instrument to measure parental roles in intervention. It then evaluates the validation and reliability results by commenting on the representativeness of the study sample to frame the extrapolated conclusions based on the findings of the EFA, reliability, and validity analysis. The way forward in terms of refining the PRITT taking into account the representativeness of the study sample is then discussed. The chapter closes with a discussion of the study's strengths and the limitations and the conclusions of the study.

8.2 Potential contributions of a validated quantitative measuring instrument of parental roles in intervention

With the development and validation of this instrument it is now possible to empirically test the implied relationship from the rehabilitation and intervention literature between parental roles and parental involvement and engagement. The literature suggests that the type of role a parent performs influences their readiness, willingness and ability to engage in intervention (Forsingdal et al., 2013; Hurtubise & Carpenter, 2011). In particular, matched parental and professional role expectations are indicated to foster parental readiness and willingness to get involved. The support (i.e., information, skills and confidence-affirming feedback) shared during role negotiations and parent-professional interactions encourages parental capacity to perform more active tasks and responsibilities in intervention (King, Chiarello, Ideishi, Ziviani, et al., 2019; Smart et al., 2019). The PRITT has potential to be used a means of initiating the processes that are indicated to facilitate parental engagement in intervention i.e., practical, role task-focused supports of parental competence and confidence. In this way parents can be supported to take on more active role tasks and responsibilities during sessions (i.e., the Learner role) with possible benefits for parental in-and out-of-session engagement in intervention. The PRITT also has potential uses to initiate discussions and outline the tasks and responsibilities associated with more active role tasks for parents in intervention. This is important as parents seem to struggle to see themselves in more active roles and may not be able to conceive of what more active role tasks would involve for them in intervention (Carroll & Sixsmith, 2016; Kyarkanaye et al., 2017). Parents and professionals can then negotiate the types of supports required to start the process of role task and responsibility shifting to parents.

8.3 Representativeness of the sample

It should be acknowledged that there was generally a low response rate on the study survey. This must be considered when addressing the validity findings and generalizability of study results (Etikan, 2016; Richiardi et al., 2013). While a low response rate does not necessarily equate with reduced validity or diminished study quality (Morton et al., 2012), the representativeness of the sample should be considered. The goal of attaining larger sample sizes lies in eliminating variance concerns. A larger sample increases the likelihood of including diverse respondents and capturing a range of potential responses on an instrument (Gamst et al., 2017). Certainly, no sample can be “perfectly reflective of the population” (Osborne & Costello, 2018, p. 1). Regardless of the exact sample size, a sample should, ideally, reflect the range of responses expected from the population with whom the instrument will be used (Gamst et al., 2017). The demographic characteristics of the sample (outlined in Section 3.4.2) will be discussed, with regards to what is known about the profile of parents and children in South Africa, to frame the representativeness of the study sample.

In this study, the response rate was higher in certain provinces (i.e., Gauteng, Kwa-Zulu Natal, and the Western Cape). Given that Gauteng is highly populated, having the highest response rate from this province is not surprising. This may also be explained by the fact that the researcher resides in Gauteng. Similarly, as the study supervisor originates from the Western Cape, the high response rate in these provinces may be related to increased networking. Also, a particular NGO was instrumental in assisting with the survey dissemination in Kwa-Zulu Natal. This could explain higher responses in these provinces. There was a notably poorer response rate in the other provinces (i.e., Mpumalanga, the Northern Cape, the Eastern Cape, Limpopo, Free State, and no responses from the North West province) despite target recruitment attempts in these provinces. There is however no specific evidence to suggest that parental responses would vary considerably based on province of residence. It is possible that the varying response rates across provinces may be linked with other factors (outlined in Section 3.6.3) such as mobile device-related factors (i.e., data costs), the availability of the survey in English only and home language of potential respondents, and, most likely, factors related to gatekeeping. These findings seem to support the importance of building a rapport with potential gatekeepers to ensure that they understand the importance of a study as well as ensuring that research findings are reported back to gatekeepers to encourage future collaborations (Rankin & McFadyen, 2016; Williams, 2020).

Mothers were the primary survey respondents and they were reported to be the majority of primary care providers, as is typical in South Africa (Department of Social Development, 2009; Meintjes & Hall, 2018). This suggests high representativeness of the sample in this regard. As with many studies examining parental experiences, fathers were underrepresented (Forsingdal et al., 2013; McBride et al., 2017) as were other co-parenting caregivers who may have provided a different perspective. South African children are most likely to reside with and/or be raised by their mothers or an alternate female caregiver in single-parent (Department of Social Development, 2009; Schlebusch et al., 2016) or multigenerational families (Kyarkanaye et al., 2017; Meintjes & Hall, 2018). In this study sample, there was a higher proportion of two-parent families. Of interest is that in the Gauteng and the Western Cape provinces, census data suggest that children are more likely to live in two-parent households (Statistics South Africa, 2018). Given that a large majority of the study responses came from these two provinces, this could explain the higher rate of two-parent households reported in this study.

Another demographic factor of the sample to discuss is that of parent respondents' employment status and the household income demographics. This study sample indicated higher reports of employment and higher household income compared to national averages (Statistics South Africa, 2018, 2021). This may have something to do with the challenges parents experience relative to data costs which is likely to have affected socio-economically disadvantaged parents' completion of the survey. This highlights the need for creative means of distributing study invitations that are cost effective for potential respondents. It may also be that socio-economically disadvantaged parents have limited access to rehabilitation therapies and, therefore, are not represented as the study selection criteria included current enrolment in one or more of the specified rehabilitation therapies.

In terms of intervention-related demographics, the majority of the parent respondents reported that their children attend rehabilitation therapies in the public sector. Positively for the sample representativeness, this is in line with statistics that indicate that the public sector services the majority of the population (Kyarkanaye et al., 2017; Rowe & Moodley, 2013). Given the documented challenges of the limited number of professionals available to service this overburdened sector (Samuels et al., 2012), this highlights a promising potential use of the PRITT i.e., to encourage more naturalistic interventions delivered by parents in meaningful contexts in the home and community. Thus, the PRITT could be used to initiate the processes of role task and responsibility shifting to parents which holds potential as a means to facilitate a broader shift in the way interventions are delivered. This links with parents assuming the increasingly active roles that are associated with family-centered interventions (Hurtubise & Carpenter, 2011) that would allow them to provide more intensive, regular and meaningful intervention supports to their child (King et al., 2017; McWilliam, 2015) in order to address service delivery challenges.

A positive aspect of the representativeness of the sample, the respondents included parents of children with a range of different types of disabilities. The majority of parents perceived their child’s disability as moderate. This aligns with local statistics suggesting that more children present with mild to moderate disabilities in South Africa (Republic of South Africa, 2015). Literature suggests that the type and nature of a child’s difficulties related to their disability may influence the parent’s capacity to take on certain roles in their child’s intervention (Sugden et al., 2019; Watts Pappas, McAllister, & McLeod, 2016) although the pattern of influence is unclear. It is further suggested that parents who perceive their child’s difficulties to be less severe may be more motivated to take on active roles (Watts Pappas et al., 2016). While there is not sufficient research to indicate that parental reports of their roles in their child’s intervention will differ according to the type of their child’s disability, this may indicate that the experiences of parents of children with different types of disabilities may be more similar than different. This supports the findings that the PRITT is validated for use with parents of children with a range of different types of disabilities.

The parental responses to the PRITT items were positive in that parents appeared to report performing active roles in intervention. While this information was not the primary aim of the study, it does offer insight into interpreting the representativeness of the sample. As discussed in the literature review in Chapter 2, the literature from the local intervention context (Kyarkanaye, 2016; McKenzie & Müller, 2006; Rowe & Moodley, 2013; Saloojee et al., 2009) indicates that parents are expected to report more passive roles in intervention in a service delivery system that is still largely based in the medical model (Samuels et al., 2012). The positive parental responses in this study therefore differed from the expected patterns of responses. There are several possible reasons for this. While every attempt was made to share the study invitation widely, it is acknowledged that a certain type of parent (i.e., the highly engaged parent) may be more willing to participate in this type of study. Lower engaged and disengaged parents may not have received the study invitation (e.g., they were not currently enrolled in therapy, had a different type of relationship with the professionals, or had stopped attending therapies) or may have shown apathy towards participating in the study. It is also possible that the positive parental responses are related to certain demographic factors. Notably, almost all of the parent respondents reported that their children had received a formal diagnosis of their disability and, for the majority, the diagnosis had been made more than a year ago. It is suggested in the literature that parents may be more willing and ready to take on active roles in their child's intervention when longer periods of time have elapsed since receiving a diagnosis for their child's difficulties (James & Chard, 2010; Piggot et al., 2003). Parents also reported longer time enrolled in intervention with higher average hours of therapy attendance and more frequent therapy contacts (50 minutes of therapy weekly). This seems to support indications from the literature that as the parent-professional relationship develops over time, this may encourage parents to perform active roles (Hurtubise & Carpenter, 2011). Along this line, it may be that more frequent contact encourages the development of trust by allowing parents time to understand their roles and develop the knowledge and skills to perform them, thus supporting them to take on more active roles in intervention although research is required to substantiate this.

In summary, although the response rate was lower than expected and the sample was not as representative across the provinces or in terms of socio-economic factors, the study sample reflects many of the characteristics of parents known to be common in the local population of parents of children with a disability. Thus, it is suggested that the PRITT is validated for use with parents (predominantly mothers and female caregivers) of children with a range of disabilities who access the main rehabilitation therapies in both the private and public sectors. The majority of parents reported performing active roles, possibly indicative of the study sample not being fully representative of the range of expected parental perspectives. This may indicate that the study findings most likely represent the higher engaged and more actively involved parent. The representativeness of the sample is taken into consideration in the discussion of the implications of the study findings and conclusions drawn from the data that follow.

8.4 Conclusions drawn from the data

8.4.1 Implications of the results of EFA

The dimensionality of the PRITT was explored using EFA to examine the underlying factor structure (Taherdoost et al., 2014; Worthington & Whittaker, 2006).

The findings of the EFA indicated a two-component structure to the PRITT. The component names, Component 1: Active and Component 2: Passive, were identified following consideration of the content of the items with the coded descriptions of the parental roles in intervention from the scoping review that informed item development. The factors that loaded into Component 1: Active showed active role tasks as compared to passive role tasks that comprised the factors that loaded into Component 2: Passive. Of interest from the results of the EFA is that more items (14 items) loaded onto Component 1: Active as compared to Component 2: Passive (4 items). Given that active roles are associated with parents taking on more responsibility (Forsingdal et al., 2013; Hurtubise & Carpenter, 2011) and, therefore, performing a wider range of tasks in their child's intervention, it follows that more of the factors load into Component 1: Active.

The factor loadings seem to support the findings of the scoping review in terms of the centrality of information exchange and skill learning for parents to perform active roles (Hurtubise & Carpenter, 2011; Smith & Samuels, 2021). In line with this, an Informer role task (Item 17) loaded onto Component 1. In terms of the other learning-related roles, it was expected that the Observer role (Item 7) would load onto the passive component and the Learner role tasks (Item 13 and Item 15) onto the active component. The difference between these roles is the intervention approach and nature of the learning with the Observer being linked with more passive observational learning (Sugden et al., 2019; Watts Pappas et al., 2016) and the Learner role associated with directive parent-professional learning exchanges (Hurtubise & Carpenter, 2011). These findings seem to indicate a commonality of information sharing and learning irrespective of the exact nature of the learning and information exchange. Across the literature, growing parental competence is linked with parents feeling equipped to tackle active roles in intervention (McClean & Chesson, 1991; Hurtubise & Carpenter, 2017).

It would appear that the factor loadings also support links suggested based on the scoping review (Smith & Samuels, 2021) between parents gaining skills and information (through performing in the Observer and Learner roles) and performing direct therapy implementation-related roles. The Implementer (Item 8 and Item 11), Adaptor (Item 5 and Item 19), Intervener (Item 10 and Item 14), and Collaborative

Partner (Item 12 and Item 19) roles also loaded onto Component 1: Active. Literature illustrates the importance of parental learning and capacity-building to equip parents with the skills and knowledge to implement intervention (Davies et al., 2017; Sugden et al., 2019) and integrate strategies into their daily lives (Hurtubise & Carpenter, 2011; Reeder & Morris, 2020; Swanson et al., 2011). Also of interest is the commonality between information exchange and learning-related roles (Informer, Observer, and Learner) with the Collaborative partner role (Item 12 and Item 19) in Component 1. As identified in the scoping review (Smith & Samuels, 2021), parents who perform the Collaborative partner role develop a more equal relationship with professionals and they work in a partnership with professionals which leads to a sense of ownership of intervention (Forsingdal et al., 2013; James & Chard, 2010). The EFA finding seems to support links from the literature illustrating that information exchange empowers parents to take on active roles in intervention by promoting a more equal balance of power in the parent-professional relationship (Reeder & Morris, 2020).

The Advocate role (Item 9 and Item 16) which was coded as a broader and overarching role in the scoping review (Smith & Samuels, 2021) also loaded onto Component 1: Active. This findings seems to reflect information management-related tasks that parents perform when they make decisions about services required to meet their child’s needs as they source and acquire appropriate resources and perform ongoing monitoring of the services their child receives (Hurtubise & Carpenter, 2011; Tsai et al., 2008). The EFA findings appear to support the notion that as parents gain information, skills and confidence, this allows them to better navigate the broader intervention system in their Advocate role (Hurtubise & Carpenter, 2011).

The factors that loaded into Component 2: Passive included roles that were mostly coded as passive roles in the scoping review (Smith & Samuels, 2021). The Bringer role (Item 6) and Supporter role (Item 4) were coded in the review as the most passive role options for parents. These roles are related to parents ensuring their child’s attendance of therapy (Davies et al., 2017; Tsai et al., 2008) and encouraging their child’s participation in professionally-implemented intervention sessions (Watts Pappas et al., 2016). The EFA findings also indicate that a role task of the Informer role (Item 1) loaded onto Component 2. When the nature of this role task item is considered against the other information exchange role tasks from Component 1: Active (Informer (Item 17), Observer (Item 7), and Learner (Item 13 and Item 15), this supports that parents enacting the Informer role task (Item 1) simply act as passive messengers to share the information between professionals and do not engage in any type of reciprocal exchange (James & Chard, 2010). It therefore follows that this Informer role task (Item 1) loaded together in Component 2: Passive.

One of the Decision maker role tasks (Item 3), which also loaded onto Component 2, relates to parents providing their input to inform the plan for their child’s therapy. The Decision maker role (Item 2 and Item 3) was coded in the scoping review (Smith & Samuels, 2021) as an active role related to parent having shared decision making power and engaging in mutual planning with the professional regarding the focus and implementation of intervention (Burrell & Borrego, 2012; Forsingdal et al., 2013; James & Chard, 2010). Given the association of the Decision maker role with parents taking more active control of intervention, it was expected that this role (Item 2 and Item 3) would load onto Component 1: Active. The loading of the Decision maker role task (Item 3) into Component 2: Passive was, therefore, unexpected. The other Decision maker role task (Item 2) was removed due to cross-loading. There are possible explanations for both of these findings. Firstly, it is worthwhile to note that the role descriptions coded from the scoping review for the Decision maker role were largely aspirational (Smith & Samuels, 2021). It is therefore possible that the role tasks were not as detailed as parents had not experienced performing them. Secondly, the wording selected for the Decision maker role tasks may require revision. These role tasks were worded to reflect shared decision making between the parent and professional, i.e., ‘give input on’ as opposed to parents taking primary decision-making responsibility reflected with wording such as ‘make decisions about’. This wording selection may have meant that the role tasks were interpreted differently by parents from what was intended, i.e., as more passive tasks. This finding indicates that there is room for progress in delineating the role tasks parents perform when they engage in the processes of shared decision-making with professionals in intervention. For these reasons, and although Item 2 was removed due to cross-loading before the reliability analysis was conducted, it is recommended that the Decision maker role tasks (Item 2 and Item 3) be reworked in future refinements of the PRITT rather than removed.

8.4.2 Implications of internal consistency reliability results

The internal consistency analysis results indicated high Inter-item correlations for both components, high Cronbach's alpha scores for Component 1: Active of the PRITT and excellent scores for Component 2: Passive. There are several points to consider when interpreting the internal consistency results in this study. Given that internal consistency scores essentially indicate the extent that each of the items of an instrument consistently contributes to the total score (Streiner, 2003a), these findings were considered with the fact that the PRITT is not intended to produce a total score i.e., where higher scores on a measuring instrument indicate better performance. As a number of the total factors loaded onto Component 1: Active and given that Cronbach's alpha is susceptible to artificial increase when the length of the instrument is increased (Neuendorf, 2003), it is plausible that the number of items in this component could have contributed to the elevated internal consistency scores. It follows then that the suggestion from literature to remove items could be employed to address the redundancy suggested by the high internal consistency scores (Tavakol & Dennick, 2011).

Item removal decisions pose a challenge in the case of the PRITT as when any particular one item was removed, the internal consistency scores were unaffected. The reason for this is not clear but may be related to the various role tasks building on one another to some extent. Revelle and Zinbarg (2009; p.9) highlight a consideration with item interrelatedness is that internal consistency scores do not necessarily distinguish between when "each item is related to only a small proportion of the other items in the test from the case in which each item is related to every or nearly every other item in the test". Measures of internal consistency are, therefore, likely to be high when items seemingly measure one related construct (Streiner & Norman, 2003). It seems possible then that these results could be related to the underlying idea of the role tasks becoming incrementally more active as a parent assumes increasing responsibility for intervention. As suggested based on the scoping review (Smith & Samuels, 2021) and other literature that indicates that parental roles can be placed on a continuum of passive to active responsibility (Davies et al., 2019; Osher & Osher, 2002), it is expected that the highly engaged parent who would primarily report performing more active roles (e.g., Learner, Adaptor, Intervener, Decision maker, Collaborative partner, and Advocate roles) would also report performing the roles that were coded on the other, more passive side of the continuum (e.g., Bringer, Supporter). Another possible reason for this result could that it is a reflection of the underlying commonality across the various roles of being generated and developed within the parent-professional relationship through interpersonal interactions (Carroll & Sixsmith, 2016; Davies et al., 2017; King et al., 2014; Tsai et al., 2008).

A last possible reason for the high internal consistency scores could be related to the pattern of parental responses in this study. The internal consistency of an instrument theoretically shows whether items proposed to measure a construct produce consistent scores. It follows then that if items measure one construct, respondents would answer them in a similar manner (Tang et al., 2009). While the internal consistency for this measure was reliable, and given the positive responses of the sample in the current study, it is suggested that in future, some items (related to the Implementer, Adaptor, Intervener, and Decision maker roles) could be refined and the internal consistency reliability of the PRITT could be further examined using a larger and more diversely representative South African sample.

8.4.3 Implications of test-retest reliability results

Test-retest reliability scores indicate the likelihood of instrument score changes when the instrument is readministered after a time interval (Streiner & Norman, 2003). Test-retest reliability was assessed in this study using paired samples t-tests with a sample of 27 parents and a retest interval of two weeks. The findings indicate that the PRITT demonstrates stability over a brief retest interval.

Appropriate sample sizes for test-retest reliability analysis are not extensively covered in the literature. This is presumably because stability analyses are commonly conducted early on during piloting in instrument development studies and so typically involve small sample sizes (Bujang & Baharum, 2017). Sample size recommendations for retest studies are commonly determined on a case-by-case basis with some indication that the T2 sample should comprise at minimum 10% of the T1 sample. For paired samples t-tests, the rule of thumb is to aim for a minimum of 2 pairs of 30 participants per sample (Burnham, 2014). The sample size for T2 in this study (n=27) meets the minimum requirement of 10% of the T1 sample. It falls just short of the rule of thumb for paired samples t-tests.

The test-retest interval of two weeks was determined based on the guidelines set out by the COSMIN group (L. B. Mokkink et al., 2012) and confirmed to be appropriate with the feedback of the subject matter and context experts during the expert review. The literature regarding parental roles in intervention indicates that some degree of role change can be expected over the course of intervention dependent on the interaction of numerous factors (Davies et al., 2017; Forsingdal et al., 2013). There is insufficient, rigorously collected data to make inferences about the exact nature of this role change for parents in intervention over different time intervals. As indicated by the experts who participated in the expert review, and given the complexity and interaction of factors that may influence the parental role in intervention, it is reasonable to assume that if a system (involving factors related to the child, parent, family, intervention, and professional) remains relatively stable across the retest interval, that parental reports of their roles in their child's intervention will also remain stable. From the expert discussion and the available literature (Davies et al., 2017), it is suggested that parental roles in intervention may change over a longer time interval (months as compared to weeks) and at transition points. These transitions could include changes in the setting of rehabilitation services (e.g., moving from services rendered in a hospital to services at school) or what parents perceived as transitions (e.g., developmental milestone achievements, starting preschool, change in professional, etc.). The usability of the PRITT could be extended to track potential role changes over the course of intervention.

8.4.4 Implications of establishing content and face validity

When an instrument is developed, most importantly, the construct to be measured must be sufficiently delineated and its domains defined (Boateng et al., 2018). Individual items within the instrument must then be appraised by experts to determine whether they reflect the breadth of the construct as intended (Gehlbach & Brinkworth, 2011). As the parental role in intervention has been largely under-investigated and poorly delineated (Davies et al., 2017; Smith & Samuels, 2021), considerable time was allocated to defining the construct and determining its boundaries and the PRITT was extensively reviewed by experts to establish content and face validity.

The findings of the subject matter and context and target population expert reviews suggest that the PRITT presents with adequate content validity and that the PRITT items are sampled adequately from the parental roles in intervention construct. The strength of the factor loadings from the EFA findings supports that the PRITT adequately samples the content domain of the parental role in intervention. These findings support the conceptualisation of the parental role in intervention put forward based on the findings of the scoping review (Smith & Samuels, 2021) and seem to further support the operationalization of the parental role in intervention construct as a collection of task and responsibility statements with determinate, measurable elements.

These findings considered with the representativeness of the sample further support that the content and face validity of the PRITT is validated for use with parents (predominantly mothers and other female caregivers) of children with a range of disabilities who access the main rehabilitation therapies (i.e., occupational therapy, physiotherapy and speech therapy) for use in the private and public sectors in South Africa. These findings seem to indicate the potential clinical uses of the PRITT as a means for parents and professionals to begin discussing the options available to parents in intervention. Parents can begin envisaging themselves in more active roles and the process of role task and responsibility shifting to parents in intervention with the required supports from professionals can be initiated.

8.5 Conclusions on the overall validity and reliability of the PRITT

The current evidence from this study suggests that the PRITT provides a preliminarily valid and stable quantitative measurement of the parental role in intervention construct. As with any newly developed instrument, further and repeated research is required to justify these preliminary findings (Wolfaardt & Roodt, 2005). Given the positive parental responses from the current study, it is suggested that the reliability and validity of the PRITT be further examined utilizing a larger and more diversely representative sample of South African parents to inform possible revisions of the items. The preliminary content validity and reliability of the PRITT as a measure of parental roles in intervention for use with parents of young children with a disability have been established.

8.6 A critical review of the research

The following are presented as the strengths of this study:

This study makes a theoretical contribution by presenting a first conceptual definition of the previously poorly understood and under investigated construct of parental roles in intervention. Given the espoused importance of the roles that parents perform in their child's intervention (Carroll & Sixsmith, 2016; Davies et al., 2017; King et al., 2014; Tsai et al., 2008), this study takes an initial step to understanding a construct that may offer professionals insights into delivering interventions and focused information, skill and confidence support to parents to promote child and family outcomes.

The preliminary underlying factor structure extracted based on EFA demonstrates strong factor loadings to support the conceptual definition of parental roles in intervention presented in the study and the established content and face validity.

A further theoretical contribution of this study is that it brought together concepts from parallel fields to offer clarity of terminology related to parental roles. The study used the MOHO perspective (Kielhofner et al., 1980), primarily applied in Occupational therapy research, to define the role concept and applied volition as a means of understanding how parents move from a role expectation to role performance. The study also included applications from children's mental health literature (Smart et al., 2019) and applied Symbolic interaction theory (Aksan et al., 2009) to outline the influence of parent-professional interactions on parental roles in intervention.

The focus on reporting parental perspectives is a particular strength of this study. The scoping review included studies (although limited in number) reflective of parental perceptions of their roles in their child's intervention as a first step to unpack the construct of parental roles in intervention. The current study also reported parental perspectives. Given the importance of the parental experience and the considerable impact that parents have on their child's development, research efforts to examine the processes that influence parental experiences of intervention for professionals to understand how to promote more active involvement for parents in intervention are critically important (King et al., 2019; Phoenix, 2017).

The operationalization of the parental role in intervention construct, as a collection of task and responsibility statements with determinate, measurable elements, has particular value for future research efforts. The PRITT has potential research applications to explore the possible relationship between parental roles and parental participation engagement implied in the literature.

The uncertainty and lack of negotiation around parental roles is a contributing factor to the sub-optimal operationalization and implementation of family-centered interventions in early intervention service delivery (Centre for Community Child Health, 2021), especially in the local intervention context (Samuels et al., 2012; Smith & Samuels, 2021). The PRITT has future potential clinical usability to stimulate role negotiations between parents and professionals and initiate the process of role task and responsibility shifting to parents.

The research design of the study was adequately rigorous to allow for preliminary validity and reliability of the PRITT to be established. The methods employed such as including quantitative and qualitative viewpoints of the professional subject matter and context experts (Artino et al., 2014) and cognitive interviews with parents as the target population align with recommended best practice for establishing content and face validity (Boateng et al., 2018; DeVellis, 2017).

The following are identified as limitations of the study:

The small sample size (n=96) is a limitation of the study as is the homogeneity of the sample. Certain of the provinces were better represented than others and the parent respondents were mostly mothers. As with many studies on parental perspectives, the perspective of fathers was underrepresented in this study. Further and repeated administrations of the PRITT are required to establish its validation for a larger, more heterogeneous sample of South African parents.

Furthermore, the sample produced generally positive responses that may not reflect the full range of experiences of South African parents in intervention. It is challenging to capture the experiences of less engaged and, most particularly, disengaged parents (Buckingham et al., 2016; D'Arrigo et al., 2016). Future administrations of the PRITT, with careful consideration of how to capture diverse parental perspectives, are required to establish its validation for a more diversely representative sample of South African parents.

Another limitation of the study is that only preliminary validation and reliability could be established. Due to the fact that the parental role in intervention is an under-investigated construct and that there are no existing measures that operationalize similar constructs, only EFA was conducted and the study could not examine other types of validity such as construct validity, convergent or divergent validity (Boateng et al., 2018; L. B. Mokkink et al., 2012). Furthermore, the internal consistency findings indicate the PRITT requires revisions of some of the items.

8.7 Recommendations for further research and service delivery

Studies with a focus on ongoing validation of the PRITT are an imperative focus for future research. Data from continuing research is required to substantiate the preliminary validity of the PRITT established in this study (Wolfaardt & Roodt, 2005).

Future research should include Confirmatory Factor Analysis (Brown, 2015) to confirm the suggested factor structure from this study and evaluate the construct validity of the PRITT.

A further focus of future research and validation studies should be to determine how different types of caregivers (e.g., fathers, coparents in extended family systems) respond to the PRITT, given that in this study mothers were the predominant respondents.

Future research should build on the conceptual model presented in this study and map the possible influence of factors (such as parent, child, family, and intervention factors) which are suggested to influence the type of role a parent performs in their child's intervention and how these factors could influence role change over the course of intervention.

Research in the future should also explore adaptations to the PRITT to promote its usability with a wider range of parent populations such as those with low literacy (i.e., accessibility adaptations such as the use of an augmentative and alternative communication system). The potential for translation into other languages for use in multilingual populations should also be considered in further research on the PRITT.

Revisions of the PRITT should continue with a focus on promoting its future use in the long-term as a clinical tool.

Further research should establish meaningful partnerships with parents to develop parent-researcher-designed studies to explore parental roles in intervention.

A focus area for future research should include exploring the implied relationship between parental engagement in intervention and the types of roles parents assume in intervention. Related to this, is that the implications of supporting practical, role task-focused means of facilitating parental competence and confidence to take on more active role tasks and responsibilities during sessions (i.e., the Learner role) with possible benefits for their out-of-session engagement in intervention should be further developed in future research.

8.8 Conclusion

This study makes the contribution of a theoretical conceptualization of the parental role in intervention construct and operationalizes parental roles in intervention as the tasks and responsibilities that parents perform in their child's intervention. To the researcher's knowledge, the PRITT offers the first quantitative measure of the construct of parental roles in intervention that is deemed to be important for intervention outcomes. It is suggested that, with refinement and validation established for a more heterogeneous and representative sample of parents, the PRITT can be utilized to further develop the research agenda of the field of early childhood intervention.

8.9 Summary

This chapter presents and deliberates conclusions drawn from the data. The implications of the study findings were discussed. An evaluation of the findings indicates that although some refinements of the PRITT, and further investigation of its validity with a more diversely representative sample are required, the study makes a valuable and novel contribution to the field of early childhood intervention in terms of the conceptualization and operationalization of the parental role in intervention construct. The study also contributes the preliminarily validated PRITT which has potential future use as a research tool and, in the long-term, as a clinical tool.

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Appendices

Appendix A

Post-print of article published on scoping review.

Please note that this is the post print version of the following article:

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

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.

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

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.

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).

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.

METHODS

Procedure

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.

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).

Insert Figure 2 about here.

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.

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.

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.

RESULTS

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 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).

Insert Table 1 about here

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.

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.

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.

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).

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.

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).

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).

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).

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.

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.

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).

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.

Insert Figure 3 about here.

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.

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.

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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Appendix B

Codebook used for scoping review of parental roles in intervention

Code	Definition of code
Bringer	Ensure that child attends intervention sessions
Observer	Observe the therapy session Help foster the child's enthusiasm for therapy
Learner/student	Getting to know the child, recognise the child's and their own potential. Learn how to facilitate the child's progress
Implementer	Carryover homework assignments and strategies at home
Adaptor	Adapt develop the strategies they have acquired rather than simply implementing given activities only
Passive	Follow the professional's lead
Advocate	Campaign for improved quality of life for their child, access to services Fight for your child's right in the system and educate and inform people in different settings
Information liaison	Give the professional information about home life. Provide information about the child's learning styles, likes and dislikes and preferences
Middleman	Collect, consolidate, and share information about their child with and between professionals and organisations
Primary decision maker	Make decisions about intervention i.e., what to focus on and how to implement intervention
Influencing factor	A factor identified to impact on the type of role a parent assumes or how they perform the role tasks and responsibilities

Definition/ conceptual definition	Conceptual definition or explanation of what a parental role is and how parental roles are generated or developed
Role	The things that a parent does (i.e., the tasks) to be involved in their child's intervention

Appendix C

Parental roles extracted from the literature

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	Parents
			Primary Decision maker	Be involved in goal setting and make decisions about intervention	Parent (Aspirational)

Authors	Year	Title	Parental role name	Tasks ascribed to parental role	Who ascribed the parental role?
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
Bowen & Cupples	2004	The role of families in optimizing phonological therapy outcomes	Education	Learn technical information and specific therapy techniques Learn novel intervention activity-related skills	Professionals
			Trainer	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

			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
Maclean & Chesson	2012	Factors affecting parents' role as co-therapists: A pilot study of parents of children with motor-learning difficulties	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

Authors	Year	Title	Parental role name	Tasks ascribed to parental role	Who ascribed the parental role?
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 solves to identify new ways of carrying out activities	Parents
			Policing	Oversee what the therapist does	Parents
Forsingdal, St John, Miller, Harvey, & Wearne	2013	Goal setting with mothers in child development services	Dependent	Ensure that homework is done Receive information	Parents
			Active participator	Take action to seek help (e.g., ask for more instruction) Give feedback on how the homework activities went	Parents

Authors	Year	Title	Parental role name	Tasks ascribed to parental role	Who ascribed the parental role?
			Collaborator	Work in partnership with professionals to develop and review goals Engage in mutual planning	Parents
Davies, Marshall, Brown & Goldbart	2019	Speech language therapists' conceptions about their own and parents' roles during intervention with preschool children	Helper	Complete provided activities at home	Professionals
			Learner	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
			Advocate	Coordinating scheduled therapy sessions with other commitments Bridging the gap between therapy and teachers/school	Parents

Authors	Year	Title	Parental role name	Tasks ascribed to parental role	Who ascribed the parental role?
James & Chard	2010	A qualitative study of parental experiences of participation and partnership in an early intervention service	Informant Assistant Equal partner	Provide information Help implement intervention A balanced relationship or even friendship that develops over time	Parents Parents Parents (Aspirational)

Appendix D

Pool of items generated based on the scoping review

No.	Preliminary item pool
1	I make sure that my child attends intervention/ therapy sessions
2	I make sure that he/she is enthusiastic about therapy, enjoys it and that he/she participates
3	I watch the therapy session to learn how to do the prescribed home practice exercises and let the therapist do their job.
4	I look out for ideas of how to do activities at home with my child.
5	I learn the skills I need to carry over intervention at home.
6	I carry out the homework activities that are prescribed by the therapist.
7	I may explain or participate in the session to practice these skills for the therapist to make sure I am doing the homework as I should be.
8	I adapt the strategies I have learnt from therapy to fit my child and into our family life.
9	I make up my own activities to practice therapy-related skills.
10	I collaborate with therapist to identify goals and the focus of intervention.
11	I collaborate with therapist to implement therapy in my child's natural environment.
12	I collect, consolidate and share information about my child and his progress with and between relevant people (i.e., therapists, the school and other organisations).
13	I give feedback to the therapist about my child's progress in other environments.
14	I identify concerns, seek out advise, campaign for the services and therapies that my child needs and judge the progress.
15	I educate professionals/therapists about his/her likes, dislikes, needs, condition, etc.
16	I oversee the therapy.
17	I judge the quality of the therapy received.

Appendix E

Version 1 of the PRITT

Instructions. This questionnaire contains statements about your role as a parent in your child's therapy. Please read each statement and circle the number that best defines your role in your child's therapy. Please describe yourself *as you really are now*, not as you would like to be in the future. There is no "right" or "wrong" answer. Please answer every question, even if it does not apply to you very well. Your answers will be kept strictly confidential.

No.	**Role task statement**	**Very untrue**	**Untrue**	**Neutral**	**True**	**Very true**
1	My role is to make sure that my child goes to therapy sessions.	1	2	3	4	5
2	My role is to encourage my child to be excited about therapy.	1	2	3	4	5
3	My role is to watch the therapy session.	1	2	3	4	5
4	My role is to learn how to do therapy activities at home.	1	2	3	4	5
5	My role is to learn information about my child's condition.	1	2	3	4	5
6	My role is to learn the skills or techniques that I need to carry-over therapy into our home.	1	2	3	4	5
7	My role is to do the therapy activities at home that the therapist gives me.	1	2	3	4	5
8	My role is to take part in therapy sessions to practice my skills.	1	2	3	4	5

9	My role is to change the therapy homework activities to fit my child and family.	1	2	3	4	5
10	My role is to make up my own therapy activities.	1	2	3	4	5
11	My role is to work with the therapist to come up with therapy goals.	1	2	3	4	5
12	My role is to work with the therapist to monitor my child's progress.	1	2	3	4	5
13	My role is to share information with and between people (e.g., therapists, teachers, doctors).	1	2	3	4	5
14	My role is to give feedback to the therapist about my child's progress.	1	2	3	4	5
15	My role is to tell therapists about my child (i.e., likes, dislikes, needs, condition etc.).	1	2	3	4	5
16	My role is to make sure my child gets the therapy that they need.	1	2	3	4	5
17	My role is to supervise the therapy.	1	2	3	4	5

Appendix F

Expert invitation email and a reminder email

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Humanities 100.
1919 - 2019
Centre for Augmentative
& Alternative Communication

10 March 2021

Dear Dr. Karen Hurtubise

RE: REQUEST FOR PARTICIPATION IN EXPERT REVIEW PANEL

My name is Katherine Smith and I am currently undertaking a doctoral study in Early Childhood Intervention through the Centre of Augmentative and Alternative Communication at the University of Pretoria.

Study title: The development and validation of the parental role in intervention tool for use with parents of children with a disability

Researcher: Katherine Smith
Contact details: [redacted]

Supervisor: Dr Alecia Samuels
Contact details: [redacted]

I would like to invite you as a professional working in the area of rehabilitation and early intervention to participate in the expert review of the Parental Role in Intervention Task (PRITT) intended to measure the type of role that parents of young children with a disability take on in intervention.

RATIONALE FOR THE STUDY

As you know the parental role is regarded as central to intervention. Parents may take on a range of different roles that allow them to participate in intervention (Davies et al., 2017; Forsingdal, et al., 2013). Parents of a child with a disability extend their parenting role to include responsibilities and tasks beyond those associated with typical parenting. This may include ensuring that their child attends intervention, providing information to professionals, and sharing information between professionals and organizations.

Parents may also extend their role to include implementing intervention strategies in their daily lives (Albright et al., 2016; Lutz, et al., 2012; Minnes, et al., 2015).

While extending their parental roles allows parents to cope with their child's special needs, it can also have negative consequences (Boshoff et al., 2016; Safe, et al., 2012). Parents who feel unsupported or are uncertain regarding the boundaries of their role in intervention and how to enact them, experience considerable stress (Boshoff et al., 2016; Carman et al., 2013; Safe et al., 2012; Shepherd, et al., 2017). Stress and uncertainty associated with the extended parenting role in intervention can limit the parent's ability to engage (Carroll & Sixsmith, 2016; Davies et al., 2017; Forsingdal et al., 2013) or may cause parents to purposefully disengage (Shepherd et al., 2017) from intervention with long-term and potentially serious consequences for intervention.

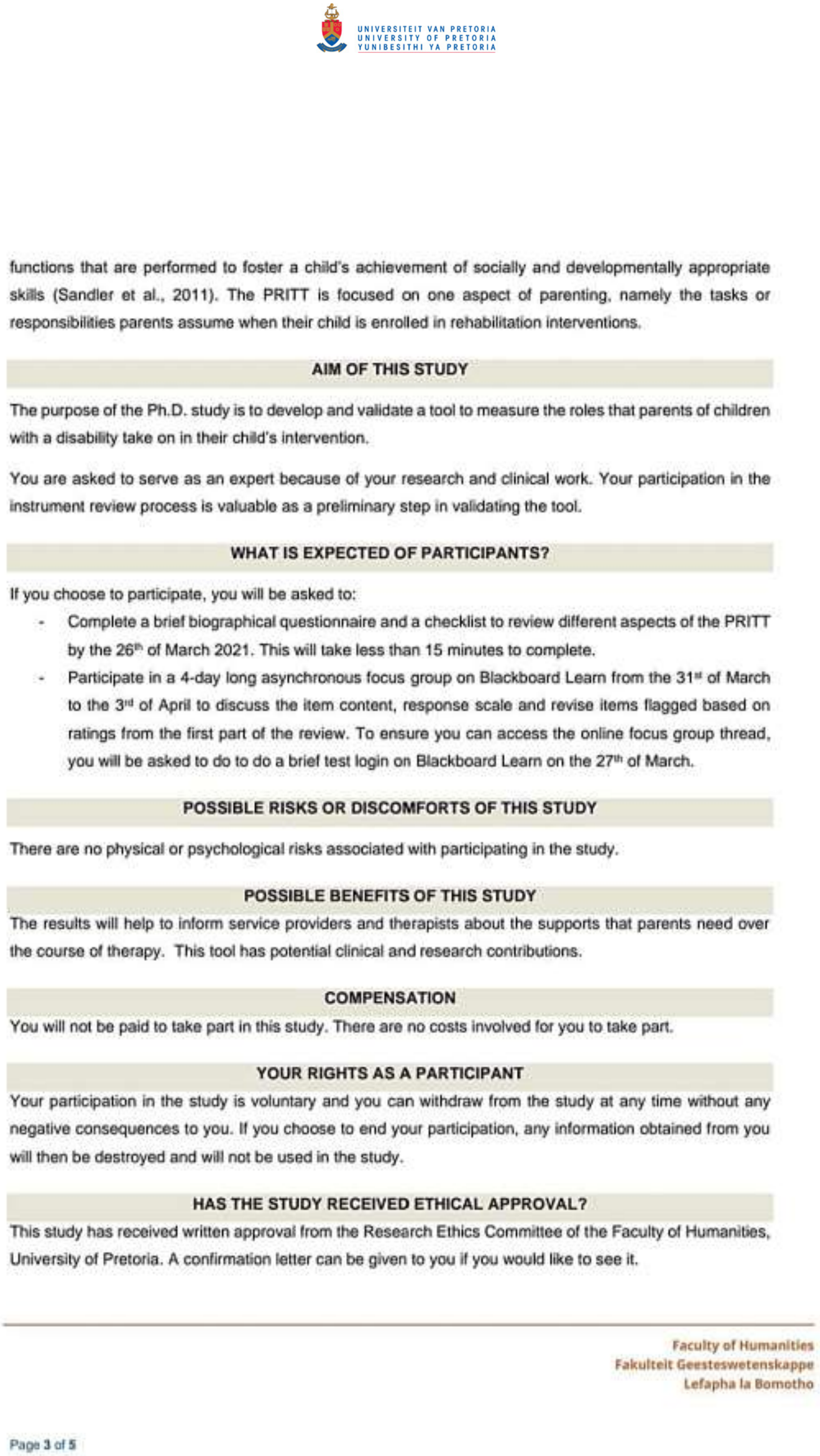
The literature suggests that parents may be required to take on more active roles to promote higher levels of engagement required in family-centered interventions. Parental roles in rehabilitation interventions have, however, received little attention and professionals seem to have a limited understanding of these roles (Davies et al., 2017; An & Palisano, 2013; King et al., 2015). Furthermore, there seems to be limited negotiation of parental roles in intervention (Davies et al., 2017; 2019; Rix & Paige-Smith, 2008; Carroll & Sixsmith, 2016; Hurtubise Carpenter, 2011). To date, there are no tools available for parents to rate and reflect on their and professionals to assess the parental role in intervention. 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

A validated tool to measure and describe parental roles would assist both professionals and parents in creating opportunities to discuss and negotiate the types of roles parents may want to assume in their child's intervention. Parents and professionals can then discuss how different types of parental roles will influence therapy outcomes in terms of intervention efficiency, i.e.: length of time spent in intervention, and effectiveness, i.e.: how well it achieves its expected outcomes in terms of child development.

A BRIEF INTRODUCTION TO THE TOOL

The Parental Role in Intervention Task Tool (PRITT) consists of 16 statements describing the tasks or responsibilities associated with different parental roles in intervention extracted from a scoping review of the rehabilitation and intervention literature (Smith & Samuels, 2021).

The parental role in intervention is defined as a sub-category of the parental role that is associated with a set of tasks or responsibilities that are expected of a parent as a result of their child being enrolled in rehabilitation interventions (i.e.: occupational therapy, physiotherapy, and speech therapy). This definition of the parental role in intervention is based on the perspective of the Model of Human Occupation (MOHO) (Kielhofner & Burke, 1980), which explains that the concept of our occupational roles organizes our behaviour and influences what we do daily (Kielhofner et al., 1980). Adults will take on different roles that may be related to their employment (e.g.: employee, colleague), community (e.g.: neighbour), or family (e.g.: spouse, parent). Specifically, the parenting role is considered a central human occupation (Kielhofner & Forsyth, 1997; Llewellyn, 1994). Parenting refers to the collection of responsibilities that are undertaken or



functions that are performed to foster a child's achievement of socially and developmentally appropriate skills (Sandler et al., 2011). The PRITT is focused on one aspect of parenting, namely the tasks or responsibilities parents assume when their child is enrolled in rehabilitation interventions.

AIM OF THIS STUDY

The purpose of the Ph.D. study is to develop and validate a tool to measure the roles that parents of children with a disability take on in their child's intervention.

You are asked to serve as an expert because of your research and clinical work. Your participation in the instrument review process is valuable as a preliminary step in validating the tool.

WHAT IS EXPECTED OF PARTICIPANTS?

If you choose to participate, you will be asked to:

- Complete a brief biographical questionnaire and a checklist to review different aspects of the PRITT by the 26th of March 2021. This will take less than 15 minutes to complete.
- Participate in a 4-day long asynchronous focus group on Blackboard Learn from the 31st of March to the 3rd of April to discuss the item content, response scale and revise items flagged based on ratings from the first part of the review. To ensure you can access the online focus group thread, you will be asked to do to do a brief test login on Blackboard Learn on the 27th of March.

POSSIBLE RISKS OR DISCOMFORTS OF THIS STUDY

There are no physical or psychological risks associated with participating in the study.

POSSIBLE BENEFITS OF THIS STUDY

The results will help to inform service providers and therapists about the supports that parents need over the course of therapy. This tool has potential clinical and research contributions.

COMPENSATION

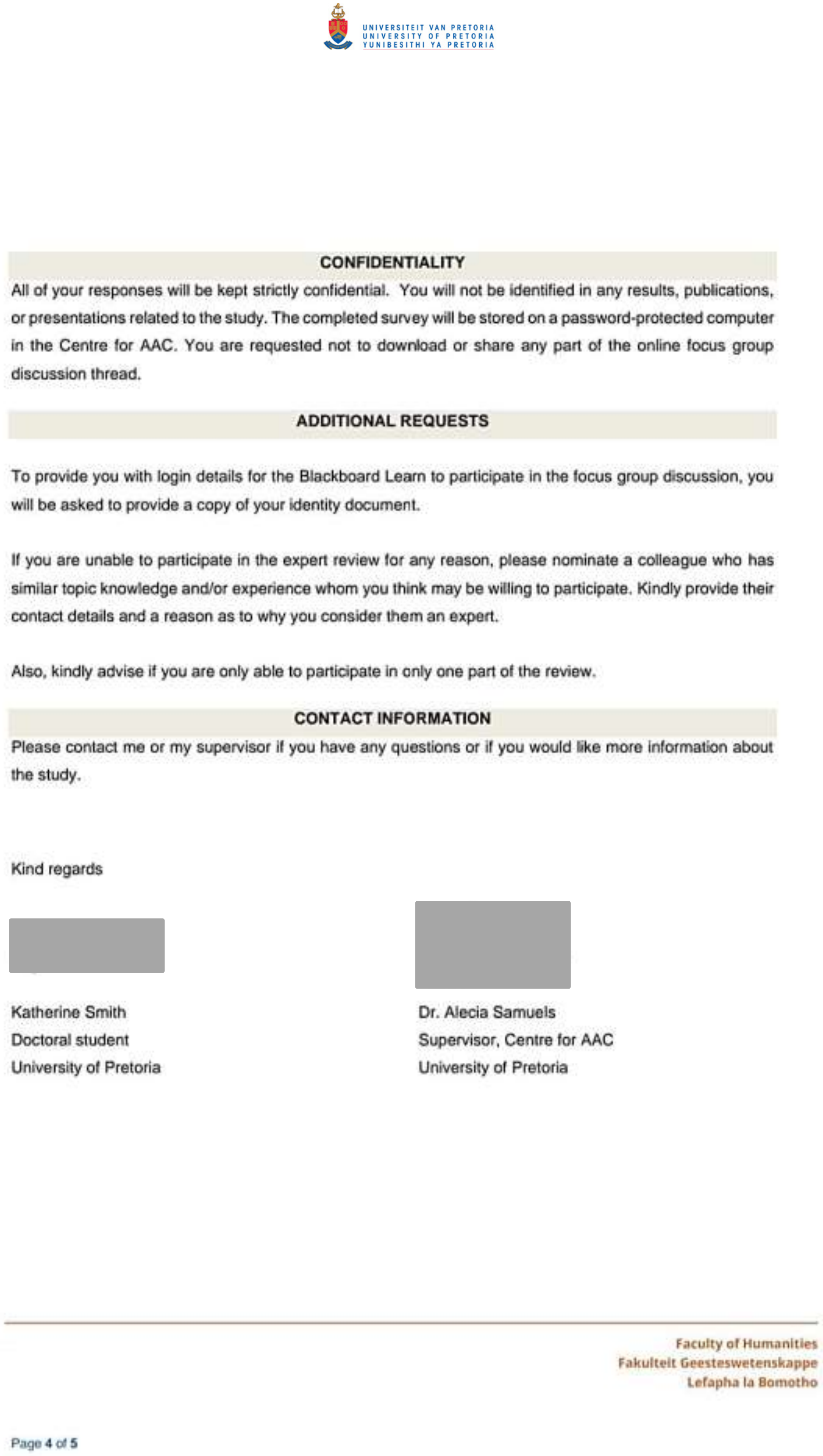
You will not be paid to take part in this study. There are no costs involved for you to take part.

YOUR RIGHTS AS A PARTICIPANT

Your participation in the study is voluntary and you can withdraw from the study at any time without any negative consequences to you. If you choose to end your participation, any information obtained from you will then be destroyed and will not be used in the study.

HAS THE STUDY RECEIVED ETHICAL APPROVAL?

This study has received written approval from the Research Ethics Committee of the Faculty of Humanities, University of Pretoria. A confirmation letter can be given to you if you would like to see it.



CONFIDENTIALITY

All of your responses will be kept strictly confidential. You will not be identified in any results, publications, or presentations related to the study. The completed survey will be stored on a password-protected computer in the Centre for AAC. You are requested not to download or share any part of the online focus group discussion thread.

ADDITIONAL REQUESTS

To provide you with login details for the Blackboard Learn to participate in the focus group discussion, you will be asked to provide a copy of your identity document.

If you are unable to participate in the expert review for any reason, please nominate a colleague who has similar topic knowledge and/or experience whom you think may be willing to participate. Kindly provide their contact details and a reason as to why you consider them an expert.

Also, kindly advise if you are only able to participate in only one part of the review.

CONTACT INFORMATION

Please contact me or my supervisor if you have any questions or if you would like more information about the study.

Kind regards

[redacted]

Katherine Smith
Doctoral student
University of Pretoria

[redacted]

Dr. Alecia Samuels
Supervisor, Centre for AAC
University of Pretoria

WRITTEN CONSENT TO PARTICIPATE IN EXPERT REVIEW

- ✓ I understand the process of this study and the risks or discomforts, and the benefits of the study.
- ✓ I have been given time to read all the written information about the study.
- ✓ I understand what is expected of me during the study.
- ✓ I have had enough time to ask questions and I have no objections to participating in this study.
- ✓ I am aware that the information obtained in the study will be anonymously processed and presented in the reporting of results.
- ✓ I understand that I will not be penalized in any way should I wish to discontinue my participation in the study.
- ✓ I am participating willingly.
- ✓ I have received a copy of this informed consent agreement.

Participant's name: ______________________
Date: ______________________
Participant's signature: ______________________

Appendix G

Expert qualitative review checklist

SECTION A: BIOGRAPHICAL INFORMATION

1. What is your profession?

1.1 Occupational therapist	1
1.2 Physiotherapist	2
1.3 Speech therapist	3
1.4 Other	4

2. What is your highest qualification?

2.1 Diploma	1
2.2 Bachelor degree	2
2.3 Master degree	3
Doctoral degree	4

3. How many years of working experience do you have? _________________years

SECTION B: RATINGS OF THE PRITT

1. The appearance of the survey questionnaire will motivate participants to respond.

Agree	1
Disagree	2

2. The survey questionnaire is logically organized.

Agree	1
Disagree	2

3. The individual items are logically organised.

Agree	1
Disagree	2

4. The instructions are easy to follow.

Agree	1
Disagree	2

5. The instructions are clear and make sense.

Agree	1
Disagree	2

6. The wording of the items is concise.

Agree	1
Disagree	2

7. The wording of the items is unambiguous.

Agree	1
Disagree	2

8. There is limited use of technical language.

Agree	1

Disagree	2

9. The items are specific.

Agree	1
Disagree	2

10. The items ask one question at a time.

Agree	1
Disagree	2

11. It is easy to understand what is being asked.

Agree	1
Disagree	2

12. The items are unbiased i.e., asked in a neutral way and will not lead participants to respond in a particular way.

Agree	1
Disagree	2

13. The response scale is easy for participants to understand.

Agree	1
Disagree	2

14. The response scale options are clear.

Agree	1
Disagree	2

15. The response scale options allow for participants to respond appropriately.

Agree	1
Disagree	2

16. The survey items adequately represent the parental role in intervention construct.

Agree	1
Disagree	2

SECTION C: Content Validity Index

No.	Item	Irrelevant	Mostly Irrelevant	Mostly Relevant	Relevant
1	My role is to make sure that my child goes to therapy sessions.	1	2	3	4
2	My role is to encourage my child to be enthusiastic about therapy.	1	2	3	4
3	My role is to watch the therapy session to learn how to do home practice exercises.	1	2	3	4
4	My role is to carry out the home programme developed by the therapist.	1	2	3	4
5	My role is to show the therapist what we did at home since the last session.	1	2	3	4
6	My role is to use the knowledge that I've gained to adapt some of the therapy at home.	1	2	3	4
7	My role is to use the knowledge I've gained to suggest new therapy activities.	1	2	3	4
8	My role is to provide information to therapists about my child (i.e., likes, dislikes, needs, condition etc.).	1	2	3	4
9	My role is to share information between professionals involved with my child (e.g., therapists, teachers, doctors).	1	2	3	4
10	My role is to improve my knowledge about my child's therapy.	1	2	3	4
11	My role is to learn the skills or techniques that can enhance my child's intervention.	1	2	3	4

12	My role is to be part of decision making about what to focus on in therapy.	1	2	3	4
13	My role is to be part of decision making about how therapy should be carried out.	1	2	3	4
14	My role is to work as an equal partner with the therapist in my child's intervention.	1	2	3	4
15	My role is to share responsibility with the therapist for how intervention is planned and carried out.	1	2	3	4
16	My role is to make sure my child gets the therapy that they need.	1	2	3	4
17	My role is to monitor the quality of the therapy.	1	2	3	4

The expert review checklist is now complete. Thank you for your time and expertise.

Appendix H

Focus group script

Welcome to the PRITT Expert Focus Group test login.

Thank you for your willingness to participate in the expert focus group discussion that will run from the 31st of March to the 3rd of April. Your time and expertise are hugely appreciated. This serves as a test login to ensure that you have access to the group.

Kindly post a response any time of the day or night between the 27th and 29th of March into the test login conversation to confirm that you can access the focus group discussion.

You can answer the question by selecting "Reply to all" and then type your response into the space provided. You can submit your response by clicking on "Post message".

Please let me know if there are any issues.

Katherine

Welcome & Introductions

- Introduction

Thank you for making the time available to participate in this online focus group discussion.

As you know, my name is Katherine Smith. I am a speech therapist and a Ph.D. student at the Centre for Augmentative and Alternative Communication (Centre for AAC) at the University of Pretoria. Dr. Alecia Samuels, the study supervisor may join the discussion over the next few days.

I am interested in the roles that parents of children with a disability take on in early intervention. As you know, the parental role is regarded as central to intervention and parents may take on a range of different roles that allow them to participate in intervention.

About the study

My Ph.D. study focuses on developing and validating a quantitative tool to measure the types of roles that parents of young children (0-6 years) with a disability take on in their child's rehabilitation interventions i.e., occupational therapy, physiotherapy, and speech therapy.

As part of my Ph.D. study, I conducted a scoping review of the roles that parents have taken on in their children's rehabilitation interventions (Smith & Samuels, 2021) which is attached and cites some of your research in this area. The review identified descriptions of the roles assigned to parents of children with developmental delays and disorders, disability, and long-term health conditions. Based on this review, 16 task or responsibility statements were extracted from the literature. The review formed the initial step in generating a pool of potential items for the tool.

The focus group questions are intended to elicit discussion about the item content, and comprehensiveness. You will be given the opportunity to discuss items that were flagged based on the qualitative reviews in the initial part of the review. Additionally, the stability of the parental role in intervention construct will be discussed.

You are asked to serve as a content expert because of your research and/or clinical experience and expertise. Your participation in the instrument review process is a valuable preliminary step in validating the tool.

Procedures of the online focus group

- This focus group discussion will be open for **four days**. You can post your response over the course of the discussion. The discussion will also remain open for a week afterward and you are invited to contribute any additional comments during this time.
- You can contribute to the discussion as frequently as you are able.
- Access to the discussion group is available any time of the day or night.
- Each question will have its own discussion "conversation". You can answer the question by selecting "Reply to all" and then type your response into the space provided. You can submit your response by clicking on "Post message".

- You are also strongly encouraged to respond to each other’s contributions and engage in a discussion.
- You are welcome to use "emoticons" to supplement your messages.
- The facilitation forum can be used throughout the focus group for any questions, comments, or conversations that do not specifically relate to any one of the questions.
- As focus group participants are encouraged to contribute as openly as possible. For confidentiality purposes, participants are asked not to download the threads or share any information from this group.
- You decide to leave the focus group at any time.

Test login question: Please introduce yourself in terms of your profession, research, and clinical interests.

Expert focus group discussion

Question 1:

In this question, your comments on the stability of the parental roles in intervention construct would be appreciated. The literature indicates that parents may take on different roles throughout intervention. This is specifically regarding decisions about the appropriate time interval for test-retest reliability.

Question 2:

For the next question, I would appreciate your comments related to the comprehensiveness of the items in the PRITT tool in terms of whether they collectively reflect the parental roles in intervention construct.

a. Are there any items that may require revision e.g., wording changes?

Using your cumulative ratings in terms of item relevance, the following items were flagged for revision:

Item 2: My role is to encourage my child to be enthusiastic about therapy.

Item 16: My role is to make sure my child gets the therapy that they need.

Item 17: My role is to monitor the quality of the therapy.

The other items received ratings of mostly relevant/ relevant (CVI-I= .83 and CVI-I=1.00; S-CI= .90)

Specific words highlighted as requiring revisions:

Adapt, skills, techniques, decision-making, focus, implementation

Monitor and adapt are tricky words to be using, jargon linked.

Your comments also suggested that the following items were similar:

Item 1: My role is to make sure that my child goes to therapy sessions.
Item 16: My role is to make sure my child gets the therapy that they need.

Item 5: My role is to show the therapist what we did at home since the last session.
Item 6: My role is to use the knowledge that I've gained to adapt some of the therapy at home.

Item 12: My role is to be part of decision making about what to focus on in therapy.
Item 13: My role is to be part of decision making about how therapy should be carried out.

Item 13: My role is to be part of decision making about how therapy should be carried out.
Item 14: My role is to work as an equal partner with the therapist in my child's intervention.
Item 15: My role is to share responsibility with the therapist for how intervention is planned and carried out.

b. Based on your expertise in this field, please comment if there are any additional tasks or responsibilities related to the parental role in intervention that should be added to the tool.

Comments in the first part of the review suggest that the tool does not reflect parental roles related to coaching type parent-professional relationships, problem-solving, and reflection.

<u>Question 3</u>:

In this question, I would appreciate it if you could comment on the response scale. Do you find the response choices appropriate? Can you identify any potential issues with the response scale and/ or its anchors?

Based on your comments from the first part of the review, it was suggested that there the degrees of agreement of the scale of true-not true may be problematic.

It was suggested that a slider scale of Not true- True may be more user-friendly.

It was suggested that an agreement scale would be more easily understood.

“Definitely not true” was preferred as an anchor over “Not very true”

<u>Question 4</u>:

For the next questions, your comments regarding the range of roles would be appreciated. To what extent do you think the range of roles described in the PRITT occurs in the SA context?

- Sharing information (Item 9) should not be a parent’s role but if therapists communicated and collaborated more, it wouldn’t be the parent’s role.
- And isn’t it really our professional role to ensure parents develop their skills, to facilitate information sharing, no then.

Appendix I

Amendments made to the PRITT items based on the feedback of experts

No.	Item before expert review	Amended item based on expert feedback	Justification
1	Bringer: My role is to make sure that my child goes to therapy sessions.	Bringer: My role is to make sure my child gets to therapy sessions (that is Bring them myself, get someone to bring them, or organize transport to drop them off).	Examples added to specify that this item is related to the child's attendance.
2	Supporter: My role is to encourage my child to be enthusiastic about therapy.	Supporter: My role is to motivate my child to participate during therapy sessions.	Wording amended to reflect the intention behind the support parents provide.
3	Observer: My role is to watch the therapy session to learn how to do home practice exercises.	Observer: My role is to learn how to do activities at home by observing the therapy session.	Wording altered for specificity
4	Implementer: My role is to carry out the home programme developed by the therapist.	Implementer: My role is to carry out the home programme developed by the therapist.	No amendments necessary.
5	Implementer: My role is to show the therapist what we did at home since the last session.	Implementer: My role is to report back to the therapist on how well the home programme went since the last session (that is show or tell the therapist either myself or via a family member or friend, or send them a message via email or phone or in the therapy book).	Examples added to make the item applicable to the local context and for all parents, not only those who attend sessions with their child.
6	Adaptor: My role is to use the knowledge that I've gained to adapt some of the therapy at home.	Adaptor: My role is to use the knowledge I've gained to suggest new therapy activities to the therapist.	Specificity added to indicate parents adapting therapy activities.
7	Adaptor: My role is to use the knowledge I've gained to suggest new therapy activities.	Adaptor: My role is to use the knowledge that I've gained to try and adapt some of the therapy activities at home.	Wording amended to include a trial-and-error process for parents.

No.	Item before expert review	Amended item based on expert feedback	Justification
8	Informer: My role is to provide information to therapists about my child (i.e., likes, dislikes, needs, condition etc.).	Informer: My role is to provide information to therapists about my child (e.g., likes, dislikes, needs, condition, etc.)	No amendments necessary.
9	Informer: My role is to share information between professionals involved with my child (e.g., therapists, teachers, doctors).	Informer: My role is to share information between professionals involved with my child (e.g.: therapists, teachers, doctors etc.)	No amendments necessary.
10	Learner: My role is to improve my knowledge about my child's therapy.	Learner: My role is to improve my knowledge about why child's therapy.	No amendments necessary.
11	Learner: My role is to learn the skills or techniques that can enhance my child's intervention.	Learner: My role is to learn the skills and techniques needed to support my child's progress.	Wording amended to indicate the intention behind the role, i.e., facilitating progress.
12	Decision maker: My role is to be part of decision making about what to focus on in therapy.	Decision maker: My role is to give input on setting goals for my child's therapy (i.e., What to focus on in therapy).	Wording amended for specificity; examples provided to explain the concept of a goal.
13	Decision maker: My role is to be part of decision making about how therapy should be carried out.	Decision maker: My role is to give input on the plan for my child's therapy (i.e.: How to achieve therapy goals).	Specificity of specificity; examples provided to explain the concept of a plan.
14	Collaborative partner: My role is to work as an equal partner with the therapist in my child's intervention.	Collaborative partner: My role is to work as an equal partner with the therapist in my child's therapy.	No amendments made.
15	Collaborative partner: My role is to share responsibility with the therapist for how intervention is planned and carried out.	Collaborative partner: My role is to work together with the therapist to ensure that session goals are achieved.	Wording altered for specificity and to indicate the intention underlying parents and professionals working together.
16	Advocate: My role is to make sure my child gets the therapy that they need.	Advocate: My role is to make sure that my child has access to appropriate therapy.	Wording amended to reflect broader access to services and the parent's judgement call made.

No.	Item before expert review	Amended item based on expert feedback	Justification
17	Advocate: My role is to monitor the quality of the therapy.	Advocate: My role is to monitor the therapy that my child receives (for example Check the quality of therapy, judge the professional advice etc.).	Item wording amended and examples added for specificity.
18		Intervener: My role is to try and include therapy strategies into our daily routines.	Item added based on expansion of Adaptor role tasks following expert's feedback.
19		Intervener: My role is to report back to the therapist on how easy or difficult it is to fit therapy strategies into our daily routines.	Item added based on expansion of Adaptor role tasks following expert's feedback.

Appendix J

Version 2 of the PRITT

No.	Statement	Disagree	Mostly Disagree	Not sure	Mostly Agree	Agree
1	My role is to share information between professionals involved with my child (e.g., therapists, teachers, doctors etc.)	1	2	3	4	5
2	My role is to give input on setting goals for my child's therapy (i.e., What to focus on in therapy).	1	2	3	4	5
3	My role is to give input on the plan for my child's therapy (i.e., How to achieve therapy goals).	1	2	3	4	5
4	My role is to motivate my child to participate during therapy sessions.	1	2	3	4	5
5	My role is to use the knowledge I've gained to suggest new therapy activities to the therapist.	1	2	3	4	5
6	My role is to make sure my child gets to therapy sessions (i.e., Bring them myself, get someone to bring them, or organize transport to drop them off).	1	2	3	4	5
7	My role is to learn how to do activities at home by observing the therapy session.	1	2	3	4	5
8	My role is to carry out the home programme developed by the therapist.	1	2	3	4	5
9	My role is to monitor the therapy that my child receives (e.g., Check the quality of therapy, judge the professional advice etc.).	1	2	3	4	5
10	My role is to try and include therapy strategies into our daily routines.	1	2	3	4	5

11	My role is to report back to the therapist on how well the home programme went since the last session (that is show or tell the therapist either myself or via a family member or friend, or send them a message via email or phone or in the therapy book).	1	2	3	4	5
12	My role is to work together with the therapist to ensure that session goals are achieved.	1	2	3	4	5
13	My role is to improve my knowledge about my child’s therapy.	1	2	3	4	5
14	My role is to report back to the therapist on how easy or difficult it is to fit therapy strategies into our daily routines.	1	2	3	4	5
15	My role is to learn the skills and techniques needed to support my child’s progress.	1	2	3	4	5
16	My role is to make sure that my child has access to appropriate therapy.	1	2	3	4	5
17	My role is to provide information to therapists about my child (for example likes, dislikes, needs, condition etc.).	1	2	3	4	5
18	My role is to work as an equal partner with the therapist in my child’s therapy.	1	2	3	4	5
19	My role is to use the knowledge that I’ve gained to try and adapt some of the therapy activities at home.	1	2	3	4	5

Appendix K

Parent invitation template email and mobile link for cognitive interview

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Humanities 100.
1919 - 2019
Centre for Augmentative
& Alternative Communication

21 May 2021

Dear parent or parents

RE: REQUEST FOR PARTICIPATION

My name is Katherine Smith and I am currently undertaking a doctoral study in Early Childhood Intervention through the Centre of Augmentative and Alternative Communication at the University of Pretoria.

Study title: The development and validation of the parental role in intervention tool for use with parents of children with a disability

Researcher: Katherine Smith
Contact details: [redacted]

Supervisor: Dr Alecia Samuels
Contact details: [redacted]

AIM OF THIS STUDY

The purpose of the main research study is to find out more about the types of roles that parents take on as part of their child's rehabilitation therapies (i.e.: speech therapy, occupational therapy and physiotherapy).

As part of the study, I have developed a tool to evaluate the types of roles that parents take on in intervention called the Parental Role in Intervention Task Tool (PRITT). I would like you to complete the PRITT and then participate in a short interview to evaluate different aspects of the tool including the instructions, items, wording and the rating scale.

WHO ARE THE PARTICIPANTS?

If you are a parent or a co-parent of a child with any type of developmental difficulty or disability you are invited to participate.

WHAT IS EXPECTED OF PARTICIPANTS?

If you choose to participate in a cognitive interview regarding the questionnaire, you will be asked to, firstly, complete the survey. The survey includes (Section A) biographical questions and (Section B) questions

Fakulteit Geesteswetenskappe
Lefapha la Bomotho

Centre for Augmentative and Alternative
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wwwcaac.up.ac.za

about the role that you take on in your child's occupational therapy, physiotherapy or speech therapy. It will take will take about 10 minutes to complete the questionnaire. Secondly, you will be asked to participate in a telephonic interview regarding various aspects of the questionnaire. The interview will take approximately 30 minutes.

POSSIBLE RISKS OR DISCOMFORTS OF THIS STUDY

There are no physical or psychological risks associated with participating in the study.

POSSIBLE BENEFITS OF THIS STUDY

The results will help to inform service providers and therapists about the supports that you as parents need over the course of therapy.

I will share the results and outcomes of my study with various parent organizations, early intervention centres and support groups who are helping children with a disability and their families. I will also share the results with you, should you wish to receive them.

COMPENSATION

You will not be paid to take part in this study. There are no costs involved for you to take part.

YOUR RIGHTS AS A PARTICIPANT

Your participation in the study is voluntary and you can stop completing the questionnaire and withdraw from the study at any time without any negative consequences to you. If you choose to end your participation, any information obtained from you will then be destroyed and not be used in the study.

HAS THE STUDY RECEIVED ETHICAL APPROVAL?

This study has received written approval from the Research Ethics Committee of the Faculty of Humanities, University of Pretoria. A confirmation letter can be given to you if you would like to see it.

CONFIDENTIALITY

All of your responses will be kept confidential. You or your family will not be identified in the any results, publications or presentations related to the study. The completed survey and the audio recordings and transcriptions of the cognitive interviews will be stored on a password protected computer in the Centre for AAC.

CONTACT INFORMATION

Please contact me or my supervisor if you have any questions or if you would like more information about the study.

Kind regards

[redacted]
Doctoral student
University of Pretoria

[redacted]
Supervisor, Centre for AAC
University of Pretoria

WRITTEN CONSENT TO PARTICIPATE IN INTERVIEW

- ✓ I understand the process of this study and the risks or discomforts, and the benefits of the study.
- ✓ I have been given time to read all the written information about the study.
- ✓ I understand what is expected of me during the study.
- ✓ I have had enough time to ask questions and I have no objections to participate in this study.
- ✓ I am aware that the information obtained in the study will be anonymously processed and presented in the reporting of results.
- ✓ I understand that I will not be penalised in any way should I wish to discontinue with the study.
- ✓ I am participating willingly.
- ✓ I have received a copy of this informed consent agreement.

Participant's name: ____________________
Date: ____________________
Participant's signature: ____________________

Appendix L

Parent invitation mobile message and link for cognitive interview

Good day,

I was given your details by (Professional name) who said you are willing to help me refine the tool that I developed for my PhD study on the types of roles that parents take on in their child’s occupational therapy, physio therapy or speech therapy by participating in an interview. The goal of the interviews is to assist me with making the tool as user-friendly for parents as possible.

Please let me know when would suit you to do the interview which will take about 30 minutes.

The interview can be done via a phone call, Zoom, or WhatsApp call. You can choose which is easiest for you.

I will send you the survey link, and you can view the tool through your email or WhatsApp. During the interview, you will be asked to complete the tool which contains 19 statements (it takes about 10 minutes to complete). You will be asked to give feedback as you read the instructions and the items. For example, if there is a word you don’t like or does not sound right in the sentence, or you can point out anything that is confusing. You will also be asked to identify any tasks or responsibilities that are not covered in the tool that you feel should be added.

Before the time, if you could please click here (https://pretoria.eu.qualtrics.com/jfe/form/SV_9zzNTXqYtcz0vmR) to consent to participate in the interview and provide some biographical information. This part will be anonymous. Your information will be collated with the other parents’ information.

I am very grateful for your time and willingness. I look forward to ‘meeting’ you.

Katherine

PhD student, Centre for AAC, University of Pretoria

Contact details: [redacted]

Appendix M

Parent organisation invitation template email and mobile link

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Humanities 100.
1919 - 2019
Centre for Augmentative
& Alternative Communication

[redacted]

RE: REQUEST FOR PERMISSION TO SHARE INFORMATION LETTER AND SURVEY LINK TO CONDUCT RESEARCH

My name is Katherine Smith and I am currently undertaking a doctoral study in Early Childhood Intervention through the Centre of Augmentative and Alternative Communication at the University of Pretoria. I am writing to request permission from your organization to assist me to recruit participants for a research study.

Research topic: The development and validation of a parental role in intervention task tool for use with parents of children with a disability

The purpose of my research is to find out more about the types of roles that parents adopt as part of their child's rehabilitation therapies (i.e.: occupational therapy, physiotherapy or speech therapy) and how this is related to parents' participation and investment in therapy. The study aims to develop an understanding of how parents cope with the extended roles can be associated with therapy for their child with a disability.

As part of my Ph.D. study, I have developed a tool for parents to complete describing the different types of roles that they may possibly take on in their child's rehabilitation interventions (i.e.: occupational therapy, physiotherapy or speech therapy). I am requesting parents to complete this tool to establish the validity (i.e., whether the instrument accurately measures what it intends to measure) and reliability (i.e.: whether the instrument provides consistent results) of the developed tool.

Who are the participants for the study?

I hope that your organization will allow me to recruit participants to take part in the study. The criteria for participants are as follows:

1. A parent or co-parent of a child with a disability (i.e.: that is person/people with executive decision-making responsibility for the supervision, care or rearing of the child)
2. The child should be under seven years old (i.e.: between 0-6 years and 11 months)
3. The child should be currently enrolled in occupational therapy, physiotherapy and/or speech therapy services in any sector (i.e.: private or public sector).
4. The family can reside in any of the nine South African provinces

What do participants have to do?

Potential participants will receive an email containing an information letter and a survey questionnaire link. They will be asked to click on the link and complete the survey questionnaire at a time and place that is convenient for them. It will take them less than 20 minutes to complete the survey.

Participation in the study is voluntary and all responses will be kept confidential. Participants will not be identified in the any results, publications or presentations related to the study. Furthermore, there will be no costs incurred by your organisation or the individual participants.

What will be expected of you as an organisation/institution?

If you agree to provide permission, your organisation will be expected:

1. To distribute an email containing the survey link (provided by the researcher) to your organization's email list serve and any social media platforms.
2. To direct any queries or questions from parents to the researcher.

Will your organization have access to the research results?

I am happy to share and report the results of the finding from the study with your organization. If you are interested, you may receive a free copy of the results (please indicate this choice). Alternatively, you are welcome to receive a dissemination summary (a short graphic representation summarizing the results of the study) that you may also share with your organization's members' list serve and on social media.

Thank-you for considering this request. I look forward to a favourable response.

Please feel free to contact either myself of my supervisor if you have any further questions.

Kind regards

[redacted]

Katherine Smith
Doctoral student
University of Pretoria

[redacted]

Dr. Alecia Samuels
Supervisor, Centre for AAC
University of Pretoria

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Organization reply form giving permission to conduct research

To whom it may concern

RE: Permission to conduct research

On behalf of ____ (Name of organisation), I am writing to formally indicate our awareness of the research proposed by Katherine Smith, a Ph.D. student at the Centre for AAC, University of Pretoria. We are aware that she intends to conduct her research by means of a self-administered survey questionnaire. An invitation email containing information regarding the study and a link for the questionnaire will be shared via our email listserve and via social media.

I, ____ (Name), hereby give permission for the organisation to share an invitation email containing information regarding the aims of the study and a link for the survey questionnaire with the organisation’s members via email and via the organisation’s social media. I am also aware that the parents/main caregivers will be informed about all aspects of the study, specifically about their voluntary participation and the confidential treatment of all information.

Regards

Name: ________________________________

Signature: ________________________________

Date: ________________________________

Appendix N

List of parent organisations contacted to share survey invitation

1. *Autism SA: 011 484 9909; info@autismsouthafrica.org.*
2. *Down syndrome SA: 086 136 9672; dssaoffice@icon.co.za ; dssa.odo@icon.co.za.*
3. *Sunshine association: 011 642 05/6/7; info@sunshine.org.za.*
4. *Malamulele onward: (011) 484 9456; andrew@cpchildren.org.*
5. Disabled Children's Action Group (DICAG): 021 761 3531; sandra@dicag.co.za.
6. *Lebuwe centre (Atteridgeville centre for people with disabilities): (012) 373-8929; info@lebuwe.org.za.*
7. *National association for persons with cerebral palsy: 082 349 9630; elizma.woods@napcp.org.za.*
8. *United cerebral palsy association of South Africa: 011 435 0386/ 7/ 8/9; marie@ucpsa.co.za.*
9. *Disabled People South Africa: 078 179 3241; ceo@dpsa.org.za; w.qaji@webmail.co.za.*
10. *South Africa Disability Alliance: 0609670258; secretary@sadisability-alliance.co.za.*
11. *Association for and of Persons with Disabilities (Umthatha); 047 535 0703/4; Email: ikrehab.admin@telkomsa.net.*
12. *Association for the Rehabilitation of People with Disability (REHAB) East London: 043 722 1811 or 043 722 9680/ 043 743 5270; diffable@iafrica.com.*
13. *Association for persons with disabilities Free State (Bloemfontein): 051 430 2883; office@apdfreestate.co.za/ elzarie@apdfreestate.co.za.*
14. *Association with persons with disabilities Free State: 0114522774; nationaloffice@ncppdsa.org.za.*
15. *Baby therapy centre: 012 348 2060; admin@babytherapycentre.org.za.*
16. *Gauteng North services to people with disabilities: 012 328 6447; vpg@mweb.co.za.*
17. *Children's Assessment and Therapy Centre Houghton: 031 208 5117; neln@medicine.wits.ac.za.*

18. *Parents for Children with Special Education Needs (PACSEN): 012 333 0149; pacsengauteng@absamail.co.za.*
19. *Pretoria Disability: 012 328 6447; laetitia@disabilitypretoria.org.za.*
20. *Alexandra Disability Movement Tel: 011 882 1147; jerryadm@telkomsa.net.*
21. *Atteridgeville Association for People with Disabilities: 012 373 8928/9.*
22. *Mamelodi Association for People with Disabilities: 012 801 1448*
23. *Tsakane Association for the Physically Disabled: 011 738 4909.*
24. *West Rand Association for the Physically Disabled: 011 660 7964/5; wrapd@intekom.co.za.*
25. *KZN Cerebral Palsy Association: 086 615 3913; info@kzncerebralpalsy.co.za.*
26. *Siyakwazi Kwanzimakwe: 071 274 6285; cathy@siyakwazi.org.*
27. *CREATE CBR, Scottsville, Kwazulu-Natal: 033 345 5088; admin@create-cbr.co.za.*
28. *Support Group for Parents with Special Needs in Durban.*
29. *APD Limpopo: 015 291 1787.*
30. *Mpumalanga centre for Autism and special needs: eloisemaritz@gmail.com.*
31. *Western cape association for persons with disabilities: 021 55 2881/ director@wcapd.org.za/ director.southcape@wcapd.org.za.*
32. *Bhabhisana Baby Project: https://bhabhisana.org.za; info@bhabhisana.co.za.*
33. *Cape Town Reable Centre: 021 637 1204/5; reable@iafrica.com.*
34. *Down syndrome association Western cape: 0219198533; info@downwc.co.za.*
35. *Iris house: sue@iris-house.org, shakira@iris-house.org.*
36. *Autism Western Cape: 012 462 8232; admin@awc.org.za; zaida@awc.org.za.*
37. *Western Cape Cerebral Palsy Association: info@wccpa.org.za.*

Appendix O

Study information and invitation pamphlet for parents

Are you a parent of a child with a disability under 7 years of age who is currently enrolled in one or all of these rehabilitation therapies (speech therapy, occupational therapy or physiotherapy) in South Africa?

If you are, I would be grateful if you would complete the survey that forms part of my PhD study and includes questions about your role in your child's rehabilitation therapies.

From this research, I hope that professionals can get a better understanding of working with parents in the early intervention field. Information from the survey will help professionals to offer you, as parents, the support that you may need to figure out what type of role you want to take on in your child's therapy and what this means in the long-run (e.g.: how effective the therapy will be or how long your child will stay in therapy).

Please complete the survey and share this email and survey link with any other parents currently living in South Africa that you think may be interested in participating. It will take approximately 15 minutes to complete the survey.

Follow this link to the survey or copy and paste the URL into your internet browser:
https://pretoria.eu.qualtrics.com/jfe/form/SV_002902WeJVBYxwO

If you would like more information on the study, please contact me.

Katherine Smith
Ph.D. student, Centre for AAC, University of Pretoria
[redacted]

Appendix P

Professional organisation invitation template email or mobile link and reply slip

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Humanities 100.
1919 - 2019
Centre for Augmentative
& Alternative Communication

21 July 2021

[redacted]

RE: REQUEST TO SHARE INVITATION LETTER AND SURVEY LINK

My name is Katherine Smith and I am currently undertaking a doctoral study in Early Childhood Intervention through the Centre of Augmentative and Alternative Communication at the University of Pretoria. I am writing to request permission from your organization to assist me to recruit participants for a research study.

Research topic: The development and validation of a parental role in intervention task tool for use with parents of children with a disability

The purpose of my research is to find out more about the types of roles that parents adopt as part of their child's rehabilitation therapies (i.e.: occupational therapy, physiotherapy or speech therapy) and how this is related to parents' participation and investment in therapy. The study aims to develop an understanding of how parents cope with the extended roles can be associated with therapy for their child with a disability.

As part of my Ph.D. study, I have developed a tool for parents to complete describing the different types of roles that they may possibly take on in their child's rehabilitation interventions (i.e.: occupational therapy, physiotherapy or speech therapy). I am requesting parents to complete this tool to establish the validity (i.e., whether the

Fakulteit Geesteswetenskappe
Lefapha la Bomotho

Centre for Augmentative and Alternative
Communication, Room 2-36, Com path
Building, Lynnwood Road
University of Pretoria, Private Bag X20
Hatfield 0028, South Africa
Tel +27 (0)12 420 2001
Fax +27 (0) 86 5100841
Email saak@up.ac.za
wwwcaac.up.ac.za

instrument accurately measures what it intends to measure) and reliability (i.e.: whether the instrument provides consistent results) of the developed tool.

Who are the participants for the study?

I hope that your organization will allow me to recruit participants to take part in the study. The criteria for participants are as follows:

1. A parent or co-parent of a child with a disability (i.e.: that is person/people with executive decision-making responsibility for the supervision, care or rearing of the child)
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3. The child should be currently enrolled in occupational therapy, physiotherapy and/or speech therapy services in any sector (i.e.: private or public sector).
4. The family can reside in any of the nine South African provinces

What do participants have to do?

- Potential participants will receive an email containing an information letter and a survey questionnaire link. They will be asked to click on the link and complete the survey questionnaire at a time and place that is convenient for them. It will take them less than 20 minutes to complete the survey.
- Participation in the study is voluntary and all responses will be kept confidential. Participants will not be identified in the any results, publications or presentations related to the study. Furthermore, there will be no costs incurred by your organisation or the individual participants.

What will be expected of you as an organisation/institution?

If you agree to provide permission, your organisation will be expected:

1. To distribute an email containing the attached survey invitation and survey link (provided by the researcher) to your organization's email list serve and any social media platforms.
2. To direct any queries or questions from parents to the researcher.

Will your organization have access to the research results?

I am happy to share and report the results of the finding from the study with your organization. If you are interested, you may receive a free copy of the results (please indicate this choice). Alternatively, you are welcome to receive a dissemination summary (a short graphic representation summarizing the results of the study) that you may also share with your organization's members' list serve and on social media.

Thank-you for considering this request. I look forward to a favourable response.

Please feel free to contact either myself of my supervisor if you have any further questions.

Kind regards

[redacted]

Katherine Smith
Doctoral student
University of Pretoria
[redacted]

[redacted]

Dr. Alecia Samuels
Supervisor, Centre for AAC
University of Pretoria

Organization reply form giving permission to conduct research

To whom it may concern

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I, ____ (Name), hereby give permission for the organisation to share an invitation email containing information regarding the aims of the study and a link for the survey questionnaire with the organisation's members via email and via the organisation's social media. I am also aware that the parents/main caregivers will be informed about all aspects of the study, specifically about their voluntary participation and the confidential treatment of all information.

Regards

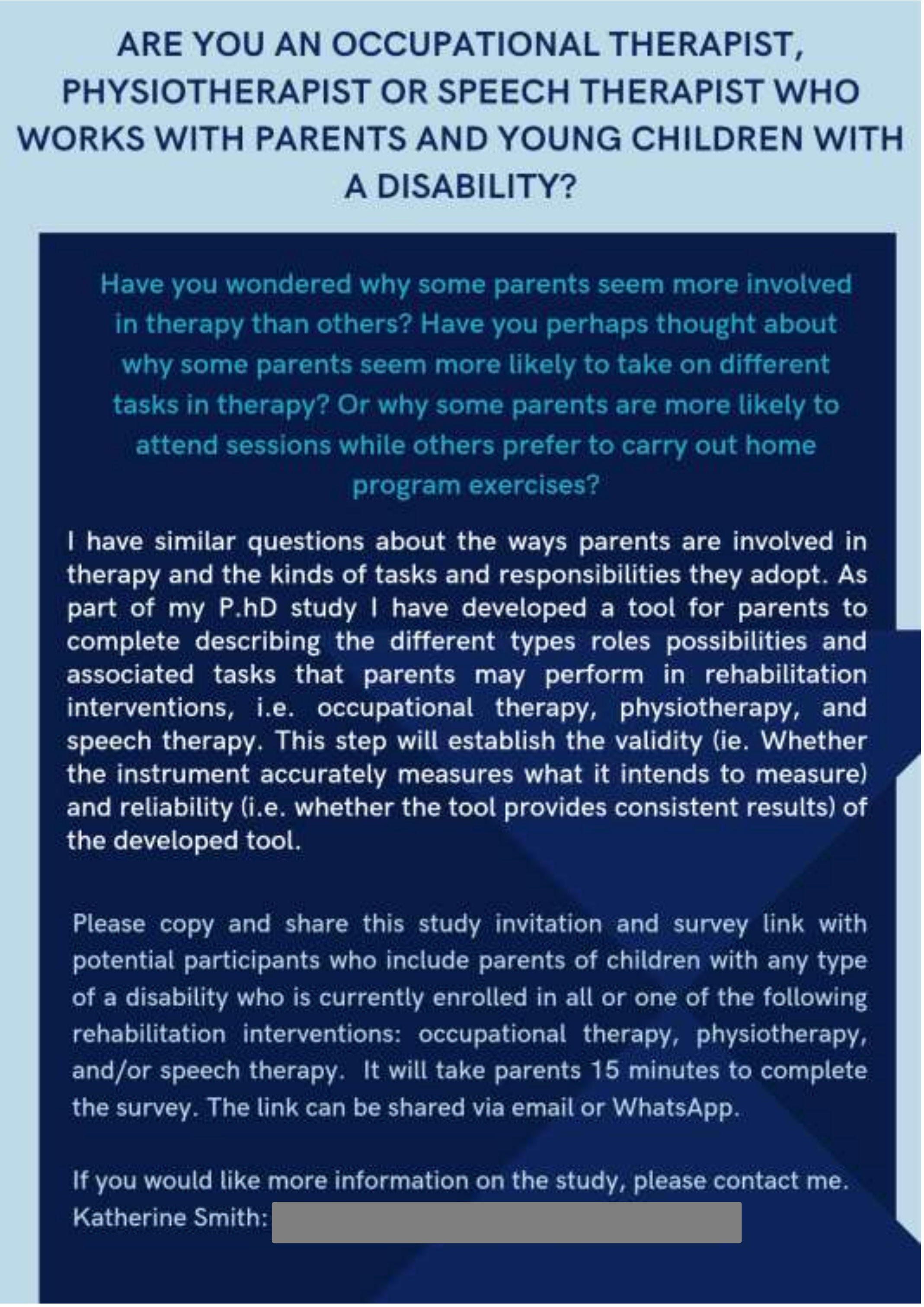
Name: ________________________________

Signature: ________________________________

Date: ________________________________

Appendix Q

Study information and invitation pamphlet for professionals



ARE YOU AN OCCUPATIONAL THERAPIST, PHYSIOTHERAPIST OR SPEECH THERAPIST WHO WORKS WITH PARENTS AND YOUNG CHILDREN WITH A DISABILITY?

Have you wondered why some parents seem more involved in therapy than others? Have you perhaps thought about why some parents seem more likely to take on different tasks in therapy? Or why some parents are more likely to attend sessions while others prefer to carry out home program exercises?

I have similar questions about the ways parents are involved in therapy and the kinds of tasks and responsibilities they adopt. As part of my P.hD study I have developed a tool for parents to complete describing the different types roles possibilities and associated tasks that parents may perform in rehabilitation interventions, i.e. occupational therapy, physiotherapy, and speech therapy. This step will establish the validity (ie. Whether the instrument accurately measures what it intends to measure) and reliability (i.e. whether the tool provides consistent results) of the developed tool.

Please copy and share this study invitation and survey link with potential participants who include parents of children with any type of a disability who is currently enrolled in all or one of the following rehabilitation interventions: occupational therapy, physiotherapy, and/or speech therapy. It will take parents 15 minutes to complete the survey. The link can be shared via email or WhatsApp.

If you would like more information on the study, please contact me.
Katherine Smith: [redacted]

Appendix R

Version 3 of the PRITT used in the pilot study

No.	Statement	Strongly Disagree	Disagree	Not sure	Agree	Strongly Agree
1	My role is to share information between professionals involved with my child (e.g., therapists, teachers, doctors etc.)	1	2	3	4	5
2	My role is to give input on setting goals for my child's therapy (i.e., What to focus on in therapy).	1	2	3	4	5
3	My role is to give input on the plan for my child's therapy (i.e., How to achieve therapy goals).	1	2	3	4	5
4	My role is to motivate my child to participate during therapy sessions.	1	2	3	4	5
5	My role is to use the knowledge I've gained to suggest new therapy activities to the therapist.	1	2	3	4	5
6	My role is to make sure my child gets to therapy sessions (i.e., Bring them myself, get someone to bring them, or organize transport to drop them off).	1	2	3	4	5
7	My role is to learn how to do activities at home by observing the therapy session.	1	2	3	4	5
8	My role is to carry out the home programme developed by the therapist.	1	2	3	4	5
9	My role is to monitor the therapy that my child receives (e.g., Check the quality of therapy, judge the professional advice etc.).	1	2	3	4	5
10	My role is to try and include therapy strategies into our daily routines.	1	2	3	4	5
11	My role is to report back to the therapist on how well the home programme went since the last session (that is show or tell the therapist either myself or via a family	1	2	3	4	5

	member or friend, or send them a message via email or phone or in the therapy book).					
12	My role is to work together with the therapist to ensure that session goals are achieved.	1	2	3	4	5
13	My role is to improve my knowledge about my child's therapy.	1	2	3	4	5
14	My role is to report back to the therapist on how easy or difficult it is to fit therapy strategies into our daily routines.	1	2	3	4	5
15	My role is to learn the skills and techniques needed to support my child's progress.	1	2	3	4	5
16	My role is to make sure that my child has access to appropriate therapy.	1	2	3	4	5
17	My role is to provide information to therapists about my child (for example likes, dislikes, needs, condition etc.).	1	2	3	4	5
18	My role is to work as an equal partner with the therapist in my child's therapy.	1	2	3	4	5
19	My role is to use the knowledge that I've gained to try and adapt some of the therapy activities at home.	1	2	3	4	5

Appendix S

Survey instrument for data collection

SECTION A: BIOGRAPHICAL QUESTIONNAIRE

1. Please indicate how you received this survey link.

From another parent	1
From a parent support organisation	2
From a Physiotherapist, Occupational therapist or Speech therapist	3
Other, please specify:	4

2. What is your relationship to the child with a disability?

Mother	1
Father	2
Grandmother	3
Grandfather	4
Aunt	5
Uncle	6
Nanny/ au pair	7
Sibling	8

3. What is your age? ______________(months)

4. Who are the adults living in your household? Please check all that apply.

		No	Yes
4.1	Mother	0	1
4.2	Father	0	1
4.3	Grandmother	0	1
3.4	Grandfather	0	1
4.5	Aunt	0	1
4.6	Uncle	0	1
4.7	Nanny/au pair or paid caregiver	0	1
4.8	Sibling	0	1

5. How many children live in your household? ______________________________

6. Which of these options best describes your family?

One-parent family i.e., one parent and child(ren)	1
Two-parent family i.e., two parents and child(ren)	2
Blended family i.e., two separate families joined into one family	3
Multigenerational family i.e., more than one generation living together	4

7. Are you the primary care provider to the child with a disability?

No	0
Yes	1

7.1 Who is the primary care provider to the child with a disability?

		No	Yes
7.1.1	Mother	0	1
7.1.2	Father	0	1
7.1.3	Grandmother	0	1
7.1.4	Grandfather	0	1
7.1.5	Aunt	0	1
7.1.6	Uncle	0	1
7.1.7	Nanny/au pair/paid caregiver	0	1

8. In which province do you live?

Eastern Cape	1
Free state	2
Gauteng	3
KwaZulu-Natal	4
Limpopo	5
Mpumalanga	6
Northern Cape	7
North west	8
Western Cape	9

9. What is the highest level of education that you have completed?

No schooling	1
Primary education	2
Secondary education	3
Post Matric	4

10. What is your employment status?

Employed full-time	1
Employed part-time / casual	2
Not working currently	3
Home executive	4
Self-employed	5
Student	6

11. What is the total monthly household income?

Less than R4500 per month	1
Between R4 501 and R12 500 per month	2
Between R12 501 and R30 000 per month	3
Between R30 001 and R52 000 per month	4
Between R52 001 and R70 000 per month	5
More than R70 001 per month	6
I don’t want to share this information	7

12. What is your child’s gender?

Female	1
Male	2

13. What is your child’s age? ________________

14. What type of disability does your child have? _______________

15. Has your child's disability been formally diagnosed?

No	0
Yes	1

15.1 How long ago was your child's disability diagnosed? ______months

16. How would you describe the level of your child's disability?

Mild	1
Moderate	2
Severe	3

Please provide details about your child's therapy. Please type your responses in the boxes provided.

Therapy	No	Yes	Time since therapy began	Hours per week
17. Occupational therapy	0	1	17.1_____months	17.2_______hours
18. Physiotherapy	0	1	18.1_____months	18.2_______hours
19. Speech therapy	0	1	19.1_____ months	19.2_________hours

20. Which of these therapies do you consider to be your child's primary or main therapy?

Occupational therapy	1
Physiotherapy	2
Speech therapy	3

21. In which sector does your child receive therapy?

Community or primary healthcare clinic	*1*
Private hospital	*2*
Private practice or therapy centre,	*3*
State hospital	*4*
Military hospital	*5*
Combination of the private or public sector	*6*
School	*7*
NGO	*8*

22. What setting does your child receive therapeutic intervention?

		No	*Yes*
22.1	*Hospital*	*0*	*1*
22.2	*PHC*	*0*	*1*
22.3	*School*	*0*	*1*
22.4	*Therapy centre or practice*	*0*	*1*
22.5	*Home*	*0*	*1*
22.5	*Combination of the private or public sector*	*0*	*1*
22.6	*NGO/ care centre*	*0*	*1*

Section B: Parental Role in Intervention Task Tool

Instructions. Please read the 19 statements below and mark the extent to which you agree or disagree with these statements as to your current role in your child's rehabilitation therapies (i.e., Occupational therapy, Physiotherapy or Speech therapy).

There is no "right" or "wrong" answer. The PRITT provides a description of the tasks and roles you perform as a parent. It is not meant to give a total score or put forward any type of assessment of you as a parent or of therapy.

Please describe yourself as you really are now, not as you would like to be in the future. Please answer every question, even if it does not apply to you very well. Your answers will be kept strictly confidential.

Terminology

What do we mean by…?

Therapy: Includes the process of planning goals and how to achieve them, attending sessions for occupational therapy, physiotherapy or speech- language therapy

Goal: The aim or goal of your child's therapy which is what you want them to learn, develop or achieve from therapy.

Plan: How the goals or aims of therapy will be achieved including the therapy activities, strategies or techniques

No.	**Statement**	Strongly Disagree	Disagree	Not sure	Agree	Strongly Agree
1	My role is to share information between professionals involved with my child (e.g., therapists, teachers, doctors etc.)	1	2	3	4	5
2	My role is to give input on setting goals for my child's therapy (i.e., What to focus on in therapy).	1	2	3	4	5

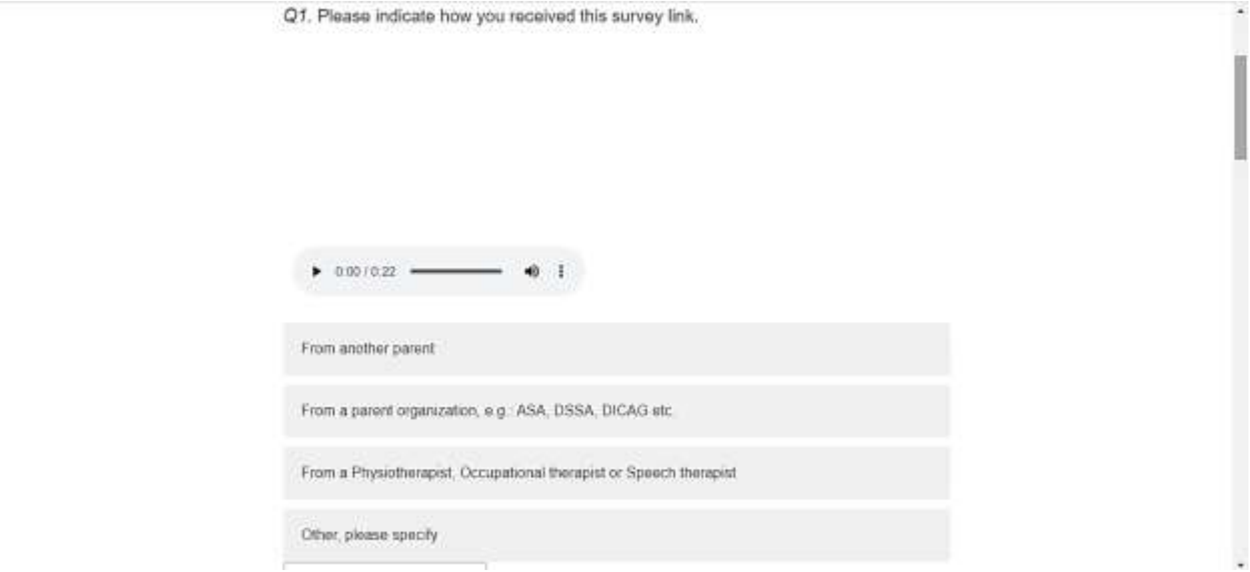
3	My role is to give input on the plan for my child's therapy (i.e., How to achieve therapy goals).	1	2	3	4	5
4	My role is to motivate my child to participate during therapy sessions.	1	2	3	4	5
5	My role is to use the knowledge I've gained to suggest new therapy activities to the therapist.	1	2	3	4	5
6	My role is to make sure my child gets to therapy sessions (i.e., Bring them myself, get someone to bring them, or organize transport to drop them off).	1	2	3	4	5
7	My role is to learn how to do activities at home by observing the therapy session.	1	2	3	4	5
8	My role is to carry out the home programme developed by the therapist.	1	2	3	4	5
9	My role is to monitor the therapy that my child receives (e.g., Check the quality of therapy, judge the professional advice etc.).	1	2	3	4	5
10	My role is to try and include therapy strategies into our daily routines.	1	2	3	4	5
11	My role is to report back to the therapist on how well the home programme went since the last session (i.e., show or tell the therapist either myself or via a family member or friend, or send them a message via email or phone or in the therapy book).	1	2	3	4	5
12	My role is to work together with the therapist to ensure that session goals are achieved.	1	2	3	4	5
13	My role is to improve my knowledge about my child's therapy.	1	2	3	4	5

14	My role is to report back to the therapist on how easy or difficult it is to fit therapy strategies into our daily routines.	1	2	3	4	5
15	My role is to learn the skills and techniques needed to support my child's progress.	1	2	3	4	5
16	My role is to make sure that my child has access to appropriate therapy.	1	2	3	4	5
17	My role is to provide information to therapists about my child (for example likes, dislikes, needs, condition etc.).	1	2	3	4	5
18	My role is to work as an equal partner with the therapist in my child's therapy.	1	2	3	4	5
19	My role is to use the knowledge that I've gained to try and adapt some of the therapy activities at home.	1	2	3	4	5

The questionnaire is now complete. Thank you for taking the time to respond.

Appendix T

Screenshots of online survey questionnaire



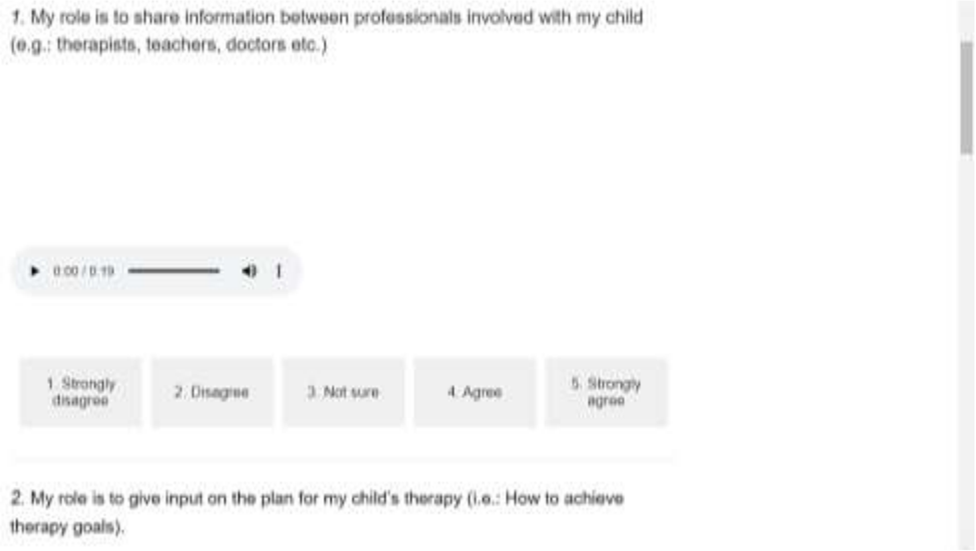
Q1. Please indicate how you received this survey link.

From another parent

From a parent organization, e.g.: ASA, DSSA, DICAG etc

From a Physiotherapist, Occupational therapist or Speech therapist

Other, please specify



1. My role is to share information between professionals involved with my child (e.g.: therapists, teachers, doctors etc.)

1. Strongly disagree | 2. Disagree | 3. Not sure | 4. Agree | 5. Strongly agree

2. My role is to give input on the plan for my child's therapy (i.e.: How to achieve therapy goals).

Appendix U

Ethical approval letter

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Fakulteit Geesteswetenskappe
Lefapha la Bomotho

Humanities 100.
Since 1919

20 October 2020

Dear Miss KA Smith

Project Title: The development and validation of a parental role in intervention task tool for use with parents of children with a disability
Researcher: Miss KA Smith
Supervisor(s): Dr AE Samuels
Department: CAAC
Reference number: 26017203 (HUM033/0419) (Amendment)
Degree: Doctoral

Thank you for the application to amend the existing protocol that was previously approved by the Committee.

The revised / additional documents were reviewed and **approved** on 20 October 2020 along these guidelines, further data collection may therefore commence (where necessary).

Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the amended proposal. Should your actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

We wish you success with the project.

Sincerely,

[redacted]

Prof Innocent Pikirayi
Deputy Dean: Postgraduate Studies and Research Ethics
Faculty of Humanities
UNIVERSITY OF PRETORIA
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