

Caregiver Descriptions of Joint Activity Routines and Perceptions of Acceptability of a
Caregiver Coaching Approach to Early Autism Spectrum Disorder Intervention in
South Africa

By:

Kevin Ramseur II

Duke Global Health Institute
Duke University

Date: _____

Approved:

Lauren Franz, Co-supervisor

Melissa H. Watt, Co-supervisor

Bronwyn Kaiser

Thesis submitted in partial fulfillment of
the requirements for the degree of Master of Science in the Duke Global Health Institute
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ABSTRACT

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Abstract

Background: Early detection and early intervention for autism spectrum disorder (ASD) is critical because it can reduce the severity of core ASD symptoms, and result in significant long-term improvements in language acquisition, social skills, cognitive abilities, and adaptive behaviors. Involving caregivers in the delivery of early ASD intervention is becoming increasingly important, particularly in low-resource settings, due to limited access to specialist ASD services. Currently, there is no published research on early ASD intervention in South Africa or sub-Saharan Africa (SSA). In addition, there are no published descriptions of caregiver-child joint activity routines, in which early intervention techniques can be embedded, or perceptions of the acceptability of a caregiver coaching approach.

Study Aims: This study aimed to elicit qualitative descriptions of caregiver-child joint activity routines in order to understand how the Early Start Denver Model (ESDM), an evidence-based early ASD intervention, could fit in a low resource South African setting. It also aimed to gauge the acceptability of a caregiver coaching intervention from South African caregivers of young children with ASD who received two taster sessions of caregiver coaching.

Methods: Participants were recruited from the Western Cape Education Department autism waiting list through convenience sampling. Four focus group discussions were conducted with 22 caregivers of young children with ASD, which gathered data on caregiver-child joint activity routines. Four additional families were

recruited to participate in two caregiver coaching sessions each. Four in-depth interviews were subsequently conducted with the six caregivers from these families, which gathered data on joint activity routines and acceptability of a caregiver coaching intervention. Data were analyzed through a qualitative content analysis approach, which used a combination of inductive and deductive methods to determine the salient themes and subthemes within the data.

Results: Caregiver descriptions of joint activity routines aligned with ESDM themes of object-based play, sensory social routines, and family routines. In object-based play caregivers reported engaging in turn-taking with their children, teaching skills across developmental domains, embracing child-directed activities, and managing challenges related to play in resource limited settings. In sensory social routines, caregivers described physical play, an awareness of the child's affect and engagement, increased child expressive communication, and willingness of the child to engage with different play partners. In family routines, caregivers reported child participation in meals and bath time. Caregivers reported that a caregiver coaching approach was acceptable and that they had acquired a variety of skills, including strategies to enhance their child's social communication. Caregivers preferred receiving coaching in their homes as opposed to in a clinic setting; however, limitations in physical space and financial resources were important considerations.

Conclusion: Training caregiver coaches and non-specialist workers narrows the treatment gap by providing access to children in need of early ASD intervention. This is

essential, because of the scarcity of psychologists and psychiatrists working in mental health in low and middle-income countries (LMIC). Descriptions from South African caregivers of caregiver-child joint activity routines and acceptability of the caregiver coaching approach contextualize the caregiver coaching intervention. These data will inform the adaptation and piloting of an early ASD intervention within a low-resource South African setting.

Dedication

To my parents Kevin and Pamela Ramseur, who instilled core values in me that reach far beyond the classroom. To my sisters Krystal and Kourtney Ramseur, my role models from birth. To all of the people who are feeling the pain of health and social inequities, our journey has just begun.

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1. Introduction

Autistic disturbances of affective contact were first described in 1943 by Dr. Leo Kanner, who characterized it as a fundamental disorder in which children have an inability to relate to themselves, people, and situations in an ordinary way (Kanner, 1943). He noted caregiver descriptions of “self-sufficient”, “happiest when left alone”, and “acting as if people weren’t there” among others. He also found that these children had good cognitive potential, did not differ physically from typically developing children, and their relation to people was altogether different. Over the last several decades, the Diagnostic and Statistical Manual of Mental Disorders has updated this definition several times, most recently describing Autism Spectrum Disorder (ASD), as a neurodevelopmental disorder characterized by persistent deficits in social communication and social interaction across multiple contexts and restricted repetitive patterns of behaviors or activities (American Psychiatric Association, 2013). While this definition continues to focus on behavioral patterns that start in early childhood, it includes the term spectrum to encompass the many ways that ASD manifests. Vast differences exist in intellectual ability and language impairment, deficits in social communication and restricted and repetitive behaviors, comorbid conditions, as well as etiological factors associated with genetic and environmental causes of ASD (National Academies of Sciences, 2015).

ASD cannot be detected at birth, but as research advances children are being diagnosed as young as 18-24 months (Zwaigenbaum et al., 2015). For infants and

toddlers, symptoms can include unusual visual fixation and examination, repetitive patterns of object exploration, and a lack of coordinated gaze, amongst other things (Rogers et al., 2014). Research on “red flags” or early indicators of ASD highlights traits such as delayed response to name, decreased reciprocal social play, and increased interest in objects as opposed to interest in people (Dow, Guthrie, Stronach, & Wetherby, 2017). Deficits in adaptive functioning, particularly socialization, communication and activities of daily living, are some of the defining features of ASD (Bal, Kim, Cheong, & Lord, 2015). Adaptive functioning is distinct from cognition, making it possible for individuals with ASD with any level of intellectual ability to adapt poorly in real-life situations. This is part of what makes ASD unique as a neurodevelopmental disorder – it is behaviorally defined. Because children with ASD have deficits in social communication, they fail to engage socially with other people and therefore receive less opportunities to learn from their social environment as children without the disorder do (Dawson et al., 2004).

A study on the epidemiology and global burden of ASD estimated that there are more than 52 million individuals (1 in 132) living with the disorder around the world (Baxter et al., 2015). While this was the first global estimation of ASD prevalence, it is important to note that there are many regions in the world where no population-based prevalence studies have been conducted. For example, no population-based ASD prevalence studies have been conducted in South Africa, or anywhere else on the entire African continent (Franz et al., 2017).

1.1 Early intervention for ASD

Early detection and early intervention for ASD, particularly within the first three years of life, is critical because it can reduce the severity of core ASD symptoms, and result in significant long-term improvements in language acquisition, social skills, cognitive abilities, and adaptive behaviors (Dawson, 2016; van Heijst & Geurts, 2015; Wetherby et al., 2014). In addition, early detection and early intervention can decrease long-term costs associated with special education services as well as supported employment and living situations (Cidav et al., 2017; Estes et al., 2015).

Behavioral therapies such as Applied Behavioral Analysis (ABA) approach early ASD intervention with the goal of understanding how changes in the environment affect human behavior (Schreibman et al., 2015). Developmental perspectives, on the other hand, focus primarily on early learning processes which serve as precursors to learning and social communication (Schreibman et al., 2015). Behavioral approaches struggle to adequately incorporate research on typical child development while formulating interventions, and developmental approaches leave out the behavioral principles which promote rapid skill building (Schreibman et al., 2015). Naturalistic Developmental Behavioral Interventions (NDBI) incorporate the strengths of both approaches by utilizing natural contingencies as well as a variety of behavioral strategies to teach developmentally appropriate skills within the child's natural environment (Dawson, 2016; Schreibman et al., 2015).

The Early Start Denver Model (ESDM) is one of the NDBI. ESDM was the first empirically-validated comprehensive intervention for toddlers with ASD (Dawson et al.,

2010). It is based on the notion that (1) early social, communicative, and cognitive skills are best learned within the context of meaningful and rewarding social-emotional exchanges, and that (2) lack of early social engagement is the main obstacle to learning in young children with ASD (Rogers, Dawson, & Vismara, 2012). ESDM aims to return the young children with ASD to the social circle of family life during their waking hours because that is where critical social learning occurs (Estes et al., 2015). In ESDM, children are provided with opportunities to initiate play, share control of materials, and take the lead in activities. ESDM targets skills that serve as precursors to language development, such as imitation and joint attention (Rogers et al., 2012; Schreibman et al., 2015).

1.2 Caregiver-Mediated Intervention Delivery

Early intervention for ASD can be delivered through caregivers by internalizing the strategies they are taught during caregiver coaching interventions, like the Parent-Early Start Denver Model (P-ESDM), and utilizing them with their child during caregiving routines and play activities (Estes et al., 2014; Green et al., 2015; Kasari, Gulsrud, Wong, Kwon, & Locke, 2010; Pickles et al., 2016; Rogers et al., 2012; Rogers et al., 2014; Vismara, Colombi, & Rogers, 2009). The World Health Organization's Mental Health Gap Action Programme (mhGAP) strongly recommends caregiver education and skills training as a component of treatment post-ASD diagnosis (World Health Organization, 2015a). Involving caregivers in treatment delivery is increasingly important for early intervention, particularly in low-resource settings, because there is limited access to ASD

services (Guler, de Vries, Seris, Shabalala, & Franz, 2017). In addition, early intervention approaches implemented in sub-Saharan Africa will need to incorporate local perspectives and be adapted to the local context, in order to create a sustainable approach (Guler et al., 2017).

1.3 Joint Activity Routines

Joint activity routines are social routines characterized by joint engagement and shared positive affect (Bruner, 1974) and involve two or more partners joining together to carry out an activity, such as reading a book, playing with toys, or eating a meal (Vivanti, Dissanayake, & Team, 2016). ESDM aims to teach developmentally appropriate skills by engaging the child in joint activity routines.

Different types of toy play fall in a sub-category of joint activity routines known as object-based play (Baranek et al., 2005). For example, play that involves pushing a toy car on a race track, or building puzzles. Social games which are marked by face to face interactions without an object and reciprocal behavior in social activities, (Sally J Rogers et al., 2012) fall in a sub-category of joint activity routines known as sensory social routines. For instance, tickle and chase games between caregivers and their young child. Mealtime, brushing teeth, and bathing and other activities of daily living, are in the sub-category of joint activity routines known as caregiving or family routines (Bagatell, Cram, Alvarez, & Loehle, 2014; Baharav & Reiser, 2010; Rogers et al., 2012).

1.4 Acceptability in Implementation Research

Acceptability is the perception among implementation stakeholders that a given treatment is satisfactory (Proctor et al., 2011). This concept is typically assessed based on the stakeholder's knowledge of or direct experience with the treatment, measuring concepts such as content, complexity, or comfort (Proctor et al., 2011). Acceptability data may be collected from the perspective of various stakeholders, such as program administrators, funders, providers, and consumers. Acceptability is dynamic and can change with experience (Proctor et al., 2011). Thus, acceptability may be different throughout various stages of implementation.

Appropriateness is the perceived fit, relevance, or compatibility of the evidence-based intervention for a given practice setting, provider, or consumer (Proctor et al., 2011). This also includes the fit of the intervention to address a particular issue or problem. 'Appropriateness' is conceptually similar to 'acceptability' and the literature reflects overlapping and sometimes inconsistent terms when discussing these constructs. Indeed, a series of laboratory and field studies recently revealed that although these terms are conceptually distinct, they are not meaningfully distinct in that rarely would it be the case that an intervention would be acceptable but not appropriate or vice versa (Lewis, 2016).

While there is growing recognition that involving parents and caregivers in treatment delivery is a mechanism to deliver evidence-based early intervention for ASD in low-resource settings, these interventions have primarily been developed in high-

income countries (Dawson et al., 2010; Kasari, Gulsrud, Paparella, Hellemann, & Berry, 2015; Vivanti et al., 2014). Intervention adaptation to a local, low resource setting, such as the public health care setting in South Africa, can enhance intervention “fit” and improve community adoption, implementation and sustainability (Stirman, Miller, Toder, & Calloway, 2013). Acceptability and appropriateness of an intervention are core implementation concepts that are key to the adoption and integration of evidence-based health interventions into clinical and community settings (Brownson, Colditz, & Proctor, 2017; E. Proctor et al., 2011; Proctor et al., 2009). Currently, there is no data documenting or describing the acceptability of caregiver coaching interventions in South Africa (Franz et al., 2017).

1.5 Aims of the study

There is currently work underway to adapt and assess the impact of a caregiver coaching intervention for early ASD, the Parent-Early Start Denver Model (P-ESDM), in South Africa (Franz et al., 2017; Rogers et al., 2012). There is growing recognition of the importance of involving caregivers in treatment delivery in low-resource settings (World Health Organization, 2015a).

Because no studies in sub-Saharan Africa have focused on early childhood ASD intervention, information must first be gathered on caregiver perspectives of ASD to obtain knowledge on the needs of families (Franz et al., 2017). Therefore, the first aim of this study was to provide qualitative descriptions of caregiver-child joint activity routines for young children with ASD in South Africa. To date, there are also no studies on the

impact of NDBI on young children with ASD in sub-Saharan Africa, and no empirical data are available on caregiver perceptions of the acceptability of caregiver coaching (Franz et al., 2017). Understanding the acceptability of a caregiver coaching approach is an important component of intervention implementation within the South African context (Franz et al., 2017). For this reason, the second aim of this study was to provide qualitative descriptions of the acceptability of caregiver coaching techniques from South African caregivers of young children with ASD who participated in two pilot sessions of P-ESDM.

This study presents qualitative descriptions of caregiver-child joint activity routines and acceptability of a caregiver coaching intervention from South African caregivers of young children with ASD to understand how P-ESDM would fit in this context. The long-term goal of this study was to address the gaps in early ASD intervention research in South Africa by providing contextual information for the implementation of a caregiver coaching intervention for early ASD in this setting.

2. Methods

2.1 Study Overview

This study includes data on two parts of the formative work to implement an early ASD intervention in South Africa.

1. Caregiver focus groups with 22 participants from diverse backgrounds which target the first aim of eliciting descriptions of caregiver-child joint activity routines. These caregivers were not given any additional intervention.
2. Individual interviews with 6 caregivers who were previously given 2 sessions of caregiver coaching: one in-home and one in-clinic. These sought to address both aims by providing data on the acceptability of a caregiver coaching intervention in addition to descriptions of joint activity routines.

The goal of this work was to inform a larger pilot study of a caregiver coaching intervention which engages young children with ASD via joint activity routines.

2.2 Setting

This study was conducted in Cape Town, South Africa, a city of 3.75 million people who come from diverse racial, ethnic, and socioeconomic backgrounds.

Approximately 42% of people in this area are of mixed race ‘Colored’, 39% Black African, 16% White, and 1% Indian/Asian. Although there are 11 official languages of South Africa, 41% of the people in Cape Town speak Afrikaans as their first language,

with 28% speaking isiXhosa and 27% speaking English according to the 2011 census. Others speaking any of a long list of other languages, including isiZulu, Sesotho, and Setswana (City of Cape Town, 2012).

According to the World Bank Group, South Africa has the greatest income inequality in the world with a Gini Coefficient of 63.4 (World Bank Group, 2017). In comparison, the United States has a coefficient of 41.0, which is the 63rd highest. To put the disparities in context, the top 10% of South Africans earn 58% of the nation's total income, while the bottom 70% combined earn merely 17%. There are more than 10 million people in SA living on less than \$1 per day (Mayosi & Benatar, 2014).

Approximately 25% of South Africans are unemployed, and upwards of 36% of households live below the poverty line, which is the equivalent of about \$3,487 annually for a 4-person residence. This severe economic inequality extends into the health sector, with disparities between private and public care. The public sector employs 30% of the physicians, whom are the sole provider of care for the 84% of South Africans who are uninsured (Mayosi & Benatar, 2014). Private healthcare, which costs on average 10 times more than public healthcare, employs the remaining 70% of physicians while only serving 16% of the population.

Based on data from the World Health Organization's Global Health Observatory, the United States has more than 60 times as many psychiatrists and psychologists working in mental health per 100,000 citizens than South Africa (World Health Organization, 2015b). South African youth experience the full range of risk factors to psychosocial well-being, including exposure to violence in the community, poverty and

stresses associated with living in households affected by HIV (Flisher et al., 2012). International epidemiological studies show that approximately 1 in 5 children and adolescents suffer from mental disorders. In the Western Cape Province, the site of the study, the ratio of mental health practitioners to children is 1 in 34,702, the second-highest of all provinces in South Africa (Flisher et al., 2012).

Health and economic disparities across South African communities may be related to the presentation and developmental outcomes of young children with developmental disabilities, including ASD. A retrospective case review conducted in a tertiary neurodevelopmental clinic in the Western Cape Province reported that black African children with ASD were more likely to be non-verbal at diagnosis (94%) than either 'colored' (77%) or white children (42%) (Springer, Van Toorn, Laughton, & Kidd, 2013). The authors suggested that differences in verbal communication abilities at presentation was more likely attributable to psychosocial factors, such as healthcare access or socioeconomic status, rather than biological factors, such as race or ethnicity.

Early ASD assessment and intervention services are not readily available for the majority of those affected who live in South Africa, including in the Western Cape Province. Children who are suspected of having ASD are usually seen at primary care facilities and referred to a neurodevelopmental clinic within a tertiary hospital for a formal diagnosis upon recommendation from the primary care physician. During this referral process, it may take up to 18 months for the children to be seen (Guler et al., 2017). In the Western Cape once the diagnosis is confirmed, children are eligible to receive approximately 30 minutes of occupational or speech therapy per month and their

names are added to the Western Cape Education Department Provincial ASD waiting list (van Schalkwyk, Beyer, & de Vries, 2016). In South Africa, children must be at least 7 years old to be eligible for public special education services (van Schalkwyk et al., 2016). In 2016, 940 children with ASD were enrolled in Special Education schools in the Western Cape and 744 children remained on the waiting list, 646 of whom were under the age of 7 years. There Special Education schools exist separately from the mainstream system, with 67 registered across the Western Cape (Western Cape Government, 2016). Between 2012 and 2015, the number of children on the waiting list for ASD special education services increased by 276% and this trend is expected to continue in the near future (Pillay, Duncan, & de Vries, 2017).

2.3 Participants

Participants included 28 caregivers of young children with ASD in Cape Town, South Africa. Caregivers consisted of 22 mothers, 5 fathers, and 3 grandmothers (see Table 1). The study participants came from a variety of ethnic backgrounds, with the demographic make-up being 43% colored, 43% black, 7% white, and 7% Asian/Indian. It is also of note that 91% of the children in the study were male.

There were 22 participants who engaged in focus group discussions and were exposed to no other form of intervention. To participate in focus group discussions, caregivers had to meet the following inclusion criteria: (1) be a primary caregiver of a child with a confirmed diagnosis of ASD between the ages of 24 and 59 months, (2) the caregiver's home would be no more than 1 hour by car from the Division of Child and

Adolescent Psychiatry, and (3) have the ability to travel to the Division of Child and Adolescent Psychiatry at the University of Cape Town for an interview or focus group (Guler et al., 2017). The 22 focus group discussion participants provide the majority of the data on caregiver-child joint activity routines and did not participate in the caregiver coaching sessions.

There were 6 participants who received two ‘taster’ sessions of caregiver coaching and were subsequently interviewed on either an individual or family basis. One Mother-Father and one Mother-Grandmother pair did the coaching and interviewing sessions together. To participate in the individual in-depth interviews and pilot caregiver coaching sessions, there were additional criteria: (4) be able to converse in English for intervention coding and fidelity purposes, (5) be willing to allow key stakeholders to work with the family for 1 in-clinic and 1 in-home pilot session, (6) be willing to participate in an in-depth follow-up interview, and (7) be willing to allow pilot therapy sessions to be video recorded for caregiver and therapist fidelity. Exclusion criteria were as follows: the child had a (1) neurodevelopmental disorder with a known genetic cause (for example, trisomy 21), (2) significant sensorimotor impairment, (3) major physical health problems, or (4) uncontrolled seizures. The six participants in pilot caregiver coaching and individual interviews provide all of the data on acceptability of a caregiver coaching intervention and provide some data on caregiver-child joint activity routines as well.

Recruitment was conducted using the Western Cape Education Department autism waiting list utilizing a convenience sampling approach. Participants had various

levels of experience with ASD services. Each participant had access to the low intensity intervention services from the South African Department of Health – 30 minutes per month of speech or occupational therapy. A small number of participants paid out of pocket for applied behavioral analysis services in addition to the public health care services. None of the focus group participants had any prior experience with a caregiver coaching early ASD intervention.

Table 1: Participant demographics

Data collection mode	In-depth interviews	Focus group discussions	Total
Number of total caregivers	n = 6	n = 22	n = 28
Gender of caregiver (n, %)			
Male	1 (17)	4 (18)	5 (18)
Female	5 (83)	18 (82)	23 (82)
Race/ethnicity (n, %)			
Colored	2 (33)	10 (45)	12 (43)
Black African	4 (67)	8 (36)	12 (43)
White	0 (0)	2 (9)	2 (7)
Asian/Indian	0 (0)	2 (9)	2 (7)
Caregiver role (n, %)			
Father	1 (17)	4 (18)	5 (18)
Mother	4 (66)	16 (73)	20 (71)
Grandmother	1 (17)	2 (9)	3 (11)
Gender of child with ASD (n, %)			
Male	4 (100)	16 (89)	20 (91)
Female	0 (0)	2 (11)	2 (9)

ASD: autism spectrum disorder

Colored is a South African label for individuals with mixed ethnic heritage

Only In-Depth Interview participants participated in the pilot intervention

2.4 Procedures

Data were collected within the Division of Child and Adolescent Psychiatry at the University of Cape Town in Cape Town, South Africa. The study was approved by both the University of Cape Town Human Research Ethics Council (HREC) and the Duke Institutional Review Board (IRB) (UCT HREC: 039/2015 Duke IRB protocol: Pro0006292).

Four focus group discussions with 22 caregivers of young children with ASD and four in-depth interviews were conducted with 6 caregivers of young children with ASD. Interviews and focus groups were co-facilitated by UCT faculty members and a Duke MSc-GH student. All focus groups and interviews were conducted in a private clinical setting. The focus group discussion guide contained 32 open-ended questions (Appendix A). Questions aimed to gather information on caregiver's short and long-term goals for their child, caregiver experiences using current ASD services, caregiver-child play and daily routines, attitudes towards acceptability and feasibility of a caregiver coaching intervention, and contextual factors that would be important for designing an early ASD intervention in South Africa. The in-depth interview guide contained 36 open-ended questions, and differs only in that it asks caregivers to describe their experiences in two pilot sessions of caregiver coaching (Appendix B). The current analysis uses data elicited on caregiver-child play and daily routines, and caregiver attitudes towards the acceptability of a caregiver coaching intervention. The length of the focus groups ranged from 30 minutes to 3 hours, depending on the size of the groups and the depth of

participant discussion. In-depth interview length ranged from 30 minutes to 2 hours. One focus group was conducted in isiZulu, the primary language of the participants, and translated into English for transcription purposes. All other focus groups were conducted in English, with brief isiXhosa and Afrikaans phrases interspersed throughout the discussion. These phrases were translated into English for transcription purposes. All of the in-depth interviews were conducted in English but included some isiXhosa and Afrikaans phrases as well.

In-depth interview participants consisted of six individuals from four families who had taken part in two pilot sessions of a caregiver coaching intervention. These sessions lasted one hour each, with one session being conducted in the clinic, and the other session occurring in the participants' homes. The caregiver coaching sessions focused on intervention techniques from the Parent Early Start Denver Model and were delivered during caregiver-child play activities or daily routines (e.g. feeding or brushing teeth) (Rogers et al., 2012). Due to the experience of these families with a caregiver coaching intervention, they were interviewed separately from the focus group participants. The in-depth interviews with each of the families occurred approximately four months after completing their pilot caregiver coaching sessions.

2.5 Data Analysis

Data were coded via a qualitative content analysis approach. Content analysis involves identifying emerging themes to describe meaningful concepts within the data.

This process includes four steps: 1. highlighting exact words from the text which appear to capture key thoughts or concepts, 2. approaching text by making notes of initial thoughts, 3. labelling emerging codes which are reflective of multiple key thoughts, and 4. sorting these codes into categories based on how they relate, developing meaningful themes and subthemes that describe the data (Hsieh & Shannon, 2005). This process of data interpretation generates increased knowledge of social phenomena (Cho & Lee, 2014).

Within the content analysis method, data may be approached in an inductive or deductive way depending on the research goals (Elo & Kyngäs, 2008). For this study, both deductive and inductive analysis methods were used. Deductive analyses test whether raw data are consistent with the current evidence (Thomas, 2006). Deductive content analysis is used when the structure of analysis is based on current evidence and the purpose of the study is theory testing (Elo & Kyngäs, 2008). Inductive analyses consist of condensing transcript data into brief summaries which demonstrate the link between the research question and the raw data and developing a framework for the underlying structure of experiences or processes that are evident in the raw data (Thomas, 2006). Inductive content analysis is used when prior knowledge is lacking about the theory being tested, because the categories are derived from the data (Elo & Kyngäs, 2008).

For *caregiver-child joint activity routines*, a deductive approach was taken, meaning an investigation was conducted in order to test the validity of a specific theory (Thomas, 2006). The P-ESDM therapy model considers joint activity routines to be the

basic context for teaching (Rogers et al., 2012). Descriptions of joint activity routines that occur between a caregiver and their young child with ASD do not exist in South Africa, therefore we aimed to elicit narratives of such behavioral interactions between the caregivers and young children with ASD. Themes, such as object-based play, sensory social routines, and family routines were used as broad a-priori categories to determine whether P-ESDM conceptualized joint activity routines could fit in the South African context.

For *Acceptability of PESDM*, an inductive approach was taken, meaning the interview transcripts were used to derive themes by interpreting the data (Thomas, 2006). Acceptability is the perception among stakeholders that a given treatment is satisfactory. In this study, it is a measure of the caregivers' experiences in two sessions of a caregiver coaching intervention. This provides some insight into how the therapy model will fit within their setting. Data on acceptability were generated through in-depth interviews. The themes which emerged described skills that caregivers acquired through the caregiver coaching intervention, and their reflections on intervention acceptability.

Focus groups and individual interviews were all audio and video recorded, and then transcribed. All transcripts and videos were read thoroughly and viewed twice before beginning the coding process. Two coders analyzed each individual quote, line by line, to identify themes and subthemes within the transcripts. Data were compiled into matrices to synthesize the information, using direct quotes from participants to describe the salient themes and subthemes of the transcripts. The themes and subthemes were

finalized via an iterative coding process. Consensus occurred through regular sessions in which coders reviewed themes, sub-themes, and associated quotes.

3. Results

This analysis explores: 1) caregiver descriptions of joint activity routines, and 2) perceptions of acceptability of a caregiver coaching intervention. Descriptions of joint activity routines aligned with the P-ESDM themes of object-based play, sensory social routines, and family routines. Descriptions of acceptability of a caregiver coaching approach revealed a variety of skills acquired by caregivers during the two coaching sessions, as well as reflections on the intervention itself. Each of these aims will be discussed in detail along with their corresponding themes.

3.1 Caregiver-child joint activity routines

Caregiver-child joint activity routines involve two or more partners joining together to carry out an activity, such as reading a book, playing with toys, or eating a meal (Bruner, 1974). This section is comprised of the major a-priori joint activity routine themes analyzed through the deductive coding approach: object-based play, sensory social routines, and family routines.

3.1.1 Object-based play

Object-based play between a child and their caregiver involves looking at toys and using them in conventional ways, as well as more complex actions, such as using symbolism in play (Baranek et al., 2005). The main subthemes that caregivers described in this section were dyadic engagement, caregivers incorporating learning into play, caregivers joining in play, and barriers and innovations related to play in low-resource

settings. Dyadic engagement was described by caregivers as interactions between themselves and their children with ASD using a play object. Caregiver incorporating learning into play includes any variety of object-based play activities in which they are able to teach academic, social, speech, and communication skills during their interaction. Caregivers joining in play captures instances of caregivers following their child's lead into play activities. Barriers and innovations related to play in low-resource settings discusses socioeconomic issues caregivers face and how they respond with resourceful solutions.

Dyadic engagement

Dyadic engagement involves interactions between children and caregivers, and is characterized by their back-and-forth exchanges with one another while playing with objects (Gupta, Bone, Lee, & Narayanan, 2016). Caregivers described many object-based activities, the majority of which involved turn-taking where the caregiver and child were did activities such as building blocks together, taking turns placing puzzle pieces, and using creativity and imagination during their play.

The caregiver below is a mother describing recent growth in her child's object-based play abilities. In the past, the child has not shown interest in turn-taking during play sessions with their caregiver. Now, he has begun to share blocks with her during play, which she attributes to her continued efforts to show and share objects with him.

C: Well really just to allow him to do things on his own... so showing him and sharing with him when we play. So, I will take a turn, and then he will take a turn. And that is so cool because he never used to do that before. So now I will say, "And my block?" and then he will pass a block to me. Before it would be me just

passing to him, but now he will take a block and pass it to me. Before he would take everything, but now he stands there, takes one at a time, and passes it to me.

- Interview 4

The following is an example of object-based play that is shared between the child and the caregiver and is imaginative in nature. Using the toy, the child is able to interact in different ways with his caregivers and sibling and take on different roles.

C: He does a lot with imaginative play... we have this shop toy, and he will either be the shopkeeper and I will be customer... or we will do the reversal and then he involves his sister and his father. And also, he has a kitchen set... so he will cook the food and ask me what I want for breakfast, and then he will make it and bring it and I will have to eat it... and then I will have to make him something.

- Focus Group 2

One caregiver outlines how she has taken information she learned at government sponsored therapy sessions and put it to use to create dyadic engagement during object-based play. During play interactions with her child they take turns putting together puzzles.

C: One thing I have learned that they teach us at the speech/OT is that we must play with him in terms of the games. So, you must always be the person that is playing with him. So, if he puts a piece of puzzle then you also put a piece of puzzle, and then it is like my turn and his turn.

- Focus Group 1

Caregiver incorporating learning into play

Caregivers incorporating learning into play is critical for child development, as the primary caregivers typically spend more time with the child than any other person (Green et al., 2015). Caregivers described using technology to teach words, colors, and

activities, using puzzles to teach cognitive skills, and using picture books to teach language.

The following excerpt describes how one child is able to learn through the use of technology. The interactions he has with a smartphone appears to teach him skills that he is able to transfer to play materials.

C: I can hand him my phone, and he will go into his peace zone and watch and imitate what he hears. So, with him it is very much technology... it is media that is helping. So that is like his awareness of how to speak, how to interact... colors, puzzles... he can actually learn like that. So, after he watches something, and I give him a puzzle to do, he is so fast with like the counting 1 to 10.

- Focus Group 1

Beyond the sort of learning illustrated in the above quote in which the child uses technology and transfers those skills to puzzles, children are also learning language by using technology. This example describes a child learning new words related to his interest in a television show.

C: If I just start him before the thing is on, everything is off, and I will say, "Put on Sponge-Bob". He will put the screen on, put the sound on, and then he will go. And he will go right to his folder, go into Sponge-Bob, and say, "Sponge-Bob". So... with him media has helped him. So, I know they say that you must not let your child sit by the TV, you must not let him watch too much stuff, but it has helped him in that regard.

- Focus Group 1

Knowing numbers and letters were a few of many other cognitive skills that were outcomes of these caregiver-child interactions. One caregiver described how working on puzzles together has helped her son learn to count.

C: Yeah, he likes to play puzzles as well. You know the eight-piece puzzles? ... and then the letters as well... like the 1, 2, 3... he counts to 30... he can count. We will buy the eight-piece puzzles for him... and he likes to put them together.

- Focus Group 1

This caregiver describes using picture books to teach her child different animals, and in the process, he makes eye contact by looking to his caregiver for confirmation.

C: In the beginning, it was just one-on-one with the puzzles, and he likes pictures. So, with him, he will always take a book because he knows there are always pictures in his books, and he will come to you, look at you, point at something, then look at you and say, "Sheep" ... something like that. So, he will always look at you for confirmation that it's right.

- Focus Group 1

Caregiver joining in play

Caregiver joining in play includes any object-based play activity in which the child initiates the activity and the caregiver follows the child's lead and engages with them in their chosen activity. Caregivers noted that following the child's interests promoted interactions between them and their child. In addition, helping children use play objects as they were intended helped to make activities more developmentally appropriate for their child.

Caregivers noted that if the child initiated an activity they were more likely to stay engaged in the activity and allow the caregiver to join them in their play. Below, a caregiver describes how he is able to use this strategy in an array of activities.

C: If I see their interest moving one way... I will try and jump onto that. I do not always initiate it, because I will be busy doing something around the house, but I will see one of the boys looking to do that, then I will get involved there for a moment and try to get him to interact with whatever it is, whether it is his puzzle pieces placing, colored sticks being pushed into polystyrene, or whichever just to color code those. Then, I will try and move forward with that.

- Focus Group 2

Following the child's lead also serves as an opportunity to build expressive communication skills, as demonstrated below.

C: We have a mat on the floor in the lounge that has all of the car patterns and drawings of the roads and things like that. So, when he wants to play, and he has his car... I will also go and fetch a car... and we will just like "vroom... vroom" and drive around. He is trying to make the car sounds, which is cool.

- Interview 4

The following quote describes how a caregiver followed her child's interest in cars and in so doing helped him transition from repetitive play with cars, lining them up, to playing appropriately with them where he drove them around and made car sounds.

C: He loves cars. He used to just line them up, but I tried for him not to just line them up. I would go down and play with him and indicate that it is a car and it is driving like "vroom" ... you know, with sound. So – I go down and play with him – "vroom". He did not do anything. But one time he surprised me when he was playing alone with his cars. I hear the sound "vroom!", and I'm like "Okay!". "Yes X! The car!" Drive like that!" Vroom". And then, again, I saw him drive it around [motions a circle with her hand] and turn and all that. So now he does not go straight to lining them up.

- Focus Group 1

Barriers and Innovations related to play in low-resource settings

Barriers and innovations related to play in low-resource settings captures descriptions of caregivers' socioeconomic limitations as well as how they think creatively within their means to provide object-based learning opportunities for their child.

Caregivers note that the variety of toys available in therapy sessions often contrasts with what the lack of toys at home. This dialogue between interviewer and caregiver explains how one mother thinks about her child not having toys at home.

I: Is another thing we should consider what you guys have at your home to use? What you guys have in your home... like the porridge... and washing that you

guys do every day – should we think about using those things instead of all these toys here and then going home where he will not be able to practice? Do you think that's important too?

C: I also think about that every time, because sometimes I do not have these things, and they are not the things I am going to have tomorrow. That was also in my mind: How is this thing going to help me, going to help him?

- Interview 3

This sentiment is expressed again later in the interview, when the caregiver explains that her son is in need of new toys, which is something that she is unable to provide.

I: Are there any like toys or anything like that that he really likes, or does he feel the same about all of them?

C: For so long at home I have not had those kinds of toys, but I think he needs some. He needs some toys now. He needs something different now.

- Interview 3

Another caregiver described how he is able to use more affordable objects to create situations that his son will encounter in the outside world.

C: Because of autism... the things that we see are helpful for these children are the same things that we find in South Africa. Even if it is traditional... an example... this seat. There are plastic chairs that we find in the shop. They might be expensive, but there is a way to take a small wood, make it as a seat, and then teach him how to sit on that. So that when he goes to the next place and he finds a seat, he will know how to use it. How to sit and eat. I think we need to focus on something that is helpful.

- Interview 2

3.1.2 Sensory social routines

Sensory social routines are joint activity routines in which the child is engaged in face to face social activities or games that usually do not include toys or other objects (Rogers et al., 2012). Singing, dancing, and tickling are just a few of the sensory social play activities described by caregivers. The two main subthemes included caregiver awareness of child affect and social cues, for example, recognizing that the child was enjoying the sensory social activity, wanted the activity to continue, and that shared positive affect was related to their child's ability to learn, and the variety of play participants their children came into contact with during sensory social routines.

Awareness of affect and social cues

Awareness of affect and social cues includes a variety of situations in which a caregiver understands the child's emotional state and communication attempts during sensory social activities. Caregivers reported understanding that their children enjoy tickling and physical contact, they recognized when the child was interested in them and when they wanted an activity to continue, and they were able to deduce that fun and shared positive affect was related to their child's ability to learn.

The description below explains how one caregiver is aware of her child's positive affective state and knows that her child enjoys physical activity, especially tickling.

C: X likes being in touch you know. For instance, he likes when someone tickles his ear, and another thing sometimes I put my tongue into this ear and he is tickling, "Ah!". He wants to be tickle-y. He likes all the physical contact. It is never like I tickle him, and he's says, 'don't touch me'. My daughter also does this. So, he is very physical actually. He jumps and does everything physically. So, he likes that kind of game. The only problem is the interaction with other kids,

that he does not interact with everybody, but as I said in that party, in that house, he was interacting with X... playing around and other things. So yeah... he likes playing, he likes to touch.

- Focus Group 1

Beyond all of the fun that is had with the tickling, it is evident that learning occurs during sensory social play. This caregiver noticed that her child began communicating both verbally and non-verbally when she wanted to be tickled.

C: Yeah, my child likes to be tickled as well. She will not stop you with tickling. And then she uses the same word, the first word that she was like talking about like mom, "tickle... tickle". Like yeah... she said it nicely because she likes it. She likes also to run and then you catch her, and then she likes to play more with me. Even with the daddy.

- Focus Group 1

Now, because the caregiver knows that the child is learning during tickling, she is able to use this strategy to teach other things. In the quote below, the caregiver describes her child learning colors through a tickle game.

C: And then, when you are playing... everything you are saying while you are playing, she will say it, even the color. What I am doing now, everything I'm doing with fun. Even if I am teaching her color, I will tickle her and say, "Look, that is blue" and then she will say, "Blue", and then you tickle again and you say, "Green" and then she will say, "Green" ... it is more fun when you are playing with her and then you are teaching at the same time. Yeah, I think it is really beneficial.

- Focus Group 1

The following caregiver describes changes in her child's affect based on the seriousness of the environment, stating that the child is 'learning more in playing'.

C: I have noticed with my child that when I am playing with her, she is more confident. And she is getting more words out when I am playing with her. When we are playing, I will say a word, she will say it, but when you are so serious, she

will not say it. When you are playing, she will say it. I think the nicer way of teaching my child is playing with her. It is very beneficial. It is very good. She is learning more in playing than being serious sitting on a table with the paper and pen and what... the writing, painting. But when you play... I think she is getting more in by playing.

- Focus Group 1

Understanding the child's social cues requires caregiver awareness of their communication attempts. As illustrated below, communication attempts do not just have to be verbal, but can include pulling a caregiver's hand to keep them engaged in a social game.

C: So – he is really good at interacting... and he wants to interact all the time... I mean like he will always call me or pull my hand and be like I want to play this, or I want to play a car game. I will have to go on his scooter and him on his bike and I will have to catch him.

- Focus Group 2

Caregiver understanding of child communication includes knowing both when the child is interested in playing with someone and when they would prefer to play alone. As illustrated below, the caregiver is aware of such in her son.

C: He will involve me if he wants to, but he likes to do things on his own. He is just somebody that if he is fine on his own then I can just leave him, and he'll carry on doing his thing, or he will get bored and the movie must be playing in the background as well as he is playing. If it is not on, then he freaks out. So, I try to get involved but sometimes he doesn't want me to... he will get upset. There are times when he will also say mommy or look or whatever, and then I know he wants me to play with him.

- Focus Group 2

Expressive language is also a way caregivers report that their children communicate with them during sensory social play.

C: Yes – he will come and ask you to play. If he wants to catch, you must catch... “Jula”, “Jula”. [in isiXhosa, meaning ‘toss’] And then he likes to play with that play dough. He will make a dog and say ‘woof! woof!’ and then he will give you yours to make your own dog.

- Focus Group 3

Similar to the previous quote, the following caregiver describes her son’s attempts to communicate. Here, however, the communication is non-verbal, and the child shows discrimination between partners based on his perception of who is best suited for the type of play he wishes to engage in.

C: Sometimes soccer, but he chooses what he wants to play. Maybe he will raise his hands and then we have to play [motioning a hand game]

I: Oh okay

C: Or maybe he will bring a ball and kick it to me. Or maybe he will not want to kick it to me. In his head, he knows that soccer is played by boys, so he will kick it to his uncle and if he does not want to play, he will go grab my hand and take me to his uncle. So, I understand, he wants me to ask his uncle to play with him.

- Focus Group 4

Variety of play participants

This sub-theme captures descriptions from caregivers of different play partners their children encountered during sensory social play activities. In object-based play, caregivers reported that they would be their child’s play participant. However, during sensory social play, caregivers described their children playing with other children in their community, and immediate and extended family members, including siblings, parents, grandparents, uncles, and aunts.

Playing with other children is important for any child to have the opportunity to develop meaningful peer relationships and appropriate social interaction skills (Watkins et al., 2015). In the following quote, a caregiver describes her child having fun while playing with other children, exhibiting positive affect and using communication skills to achieve desired outcomes.

C: Now, he is even playing with other children like... he is playing a lot and they are playing outside and jumping and singing. He likes to play, and he knows how to sing, and he knows he likes to sing. You can hear that he is singing those words... like what words that he knows. And playing with other children... the ball and whatever... and excited if he sees that ball... if he wants to play ball he can come to you and [in isiXhosa] “khaba”, Khaba is just kick, kick.

- Focus Group 3

A caregiver described the role the child's sister played in getting the child's attention, practicing eye contact, and approximating words.

C: The older child is very proactive. She knows that her sister has got the problem. She always gets down and plays with her... she also has the poor eye-contact. I do not know where she gets that from, but the other sister will come and be like, “Let's play... like focus” [motions finger to eyes] ... “You look at my eye”. but she is like now looking people in the eyes. If you are looking to her, she was shy, she did not want to talk [imitates cowering], but now you can see she is more focused, she has nice eye-contact, and she is trying to imitate words. She is really improving.

- Focus Group 1

Primary caregivers described interacting with their children in many forms of play, including sensory social routines.

C: We do puzzles and things... and he likes to chase. So, I must still chase... even at my age... I must run around the tables and doors and the thing is that his mom plays with him much more often. If she was sitting here now, she still follows your routine of 'there is a box of toys and you only get', she is very good in that way

with him. I think the development of an autistic child hinges on structure. She is good with him in terms of breakfast, lunch, and supper in-between his games.

- Focus Group 2

Because of the importance of community and kinship systems in South Africa, many other relatives tend to be involved in raising children (Schwartz, Theron, & Scales, 2017). Here, a caregiver describes her child's sensory social play with his uncle.

C: They play with other adults. For instance, when my brother comes around it is a totally different interaction. He comes by twice a month to visit us. I can see the interaction... it is at first the cuddles and so on... they are getting used to his energy and what he is. From then on, I withdraw and see. They say things to him that they do not say to me. I am like okay, carry on. It is a case of letting my brother know to follow and try certain things... and he gets different reactions.

- Focus Group 2

A variety of play partners during sensory social play results in a variety of play activities.

This caregiver mentions that there is a difference in the activities the child's aunt plays with him in comparison to her own playtime with her son.

I: Are there other adults besides you that play with X?

C: Yes, my sister. She plays with him.

I: What do they do together? Same things or something different?

C: No – like she will blow bubbles and he will chase the bubbles. Things like that.

- Interview 4

3.1.3 Family routines

Family routines, for example mealtime, bath time, and household chores, provide opportunities for caregivers to engage young children with ASD and teach social communication skills and adaptive behaviors that children need for daily life (Rogers et al., 2012).

Mealtime routines

The mealtime routine includes all activities related to the preparation and consumption of meals. Caregivers described mealtime routines such as saying prayers, setting the table, and helping with cooking.

Participating in mealtime routines involves the child understanding the expressive language and the gestures that go along with such activities. This caregiver describes their child leading the family in prayer before supper.

C: He is clever... because one time he surprised us with... we always pray with him in the evening. And then in the evening he will call you and we will pray our father. And so, he surprises us. One evening he came to stand in front of us before we ate, then he folds his arm, he does this (gesture praying), and then we are like okay. Then he prays by himself, we can't hear the words, but you know the sound... and then he finished. And then he did our father by himself from start to finish.

- Focus Group 1

Participation in mealtime routines requires that the child pay attention to their environment and learn from the behaviors of others. In the next quote, a caregiver describes how her child helps prepare the table for mealtimes after watching someone take the pot of food off of the stove.

C: He knows, because he normally sees somebody standing by the stove, and he knows as soon as they take off the pots, when we put on the plates, he knows exactly that we are going to eat. And then he goes, has a seat and waits, or sometimes he opens the spoon drawer and he takes out the spoons and gives each and every one a spoon to get ready. Because he knows as soon as we lay the plates, it's time to eat.

- Focus Group 4

Along with mealtime routines, caregivers also interpret the child's attempts to communicate hunger and thirst.

C: We read signs like body language, the time of the day, are they hungry – yes... okay he is at the fridge, he is clearly hungry, or he is thirsty.

- Focus Group 2

In the next description, the caregiver discusses how she built on her child's interest in cooking by doing activities in the kitchen that teach meal preparation.

C: Cooking and baking, because they are involved in the kitchen. He showed an interest when he was in ABA therapy and we did a lot of cooking. So, I will call him into the kitchen when I am not in a rush and I will get him to mix the batter and all that, and he always licks the bowl when we are done. He wants to be involved now, so he takes out the spoons and stuff like that.

- Focus Group 2

The following caregiver describes her child helping his grandmother with washing dishes and other clean-up activities. This sort of cooperative helping often occurs with extended family members when they are a part of the child's environment (Jarrett, Bahar, & Kersh, 2016).

C: Grandma runs around with him and takes him to the washing line. He helps, he likes doing stuff for you, like washing dishes and asking, 'mama can I help'. The time of bonding and in the water with the cutlery, but not the dangerous stuff. In the bathroom, helping him, we let him guide us.

- Focus Group 2

Bath time routines

In bath time routines caregivers described teaching their children names for parts of their body while washing, singing songs and playing a variety of other games.

This caregiver teaches expressive language during bath time by labelling parts of the body with her child.

C: During bath time, you can teach him the parts of the body while you are bathing... you say this is the head, I am washing your face, and then she is getting it in – you know. Because you do not have too much time to sit and work,

but at least that bath time you can use it as a time for teaching. I am washing your face, I am washing your arms, I am washing your fingers... everyday there is something that gets... that I can say one day, “Mommy – I’m washing my fingers” or he can say fingers, thumb, like yeah.

- Focus Group 1

Here, a caregiver describes how establishing a culture of fun surrounding bath time helped her child stay engaged and practice turn-taking skills.

C: Sometimes we just do silly things, and he likes that. Like when it is time to wash his face... I will just throw the wet rag up and say catch and he will go [gasp] and it is funny and then I will throw it to him and he will throw it back to me. He finds these things hilarious... these unexpected things.

- Focus Group 2

Below a caregiver describes how she builds expressive language and incorporates sensory social play into bath routines.

C: One of our favorite play times is bath time. I will get him in the bath with me, and we will play bubbles and all of those things and he quite enjoys that, and we sing in the bath.

- Focus Group 2

3.2 Caregiver perceptions of acceptability of a caregiver coaching intervention

Assessing caregiver perceptions of acceptability of a caregiver coaching intervention is the second of two specific aims of this study. Because this intervention has not been implemented in a South African setting, it is important to understand how it is perceived by caregivers within this context. Data on acceptability will provide insight on the fit of the intervention. This section includes reflections from four in-depth interviews with six caregivers who discuss their experiences with two one-hour coaching sessions – one session that occurred in the clinic and another that occurred in their home.

3.2.1 Acquired skills

Acquired skills refers to parenting techniques and child behaviors that caregivers described to have gained as a result of their experiences in two caregiver coaching sessions.

Caregivers described having learned strategies to gain their child's attention, such as getting down to their child's eye level. They also describe doing less to predict the child's needs thereby creating opportunities for their child to approach them and initiate communication. Once they had captured the child's attention, caregivers were able to work on improving social communication skills through imitation and developmentally appropriate expressive language. They were also more aware of when their child was attempting to communicate with them. Caregivers reported that they were able to teach the intervention skills they had learned to others who at times acted as caregivers to their child. They also reported that they were able to apply the skills they had acquired to other settings and routines.

Gaining the child's attention

Caregivers described a number of different strategies they learned to help them 'get the gaze' of their children, including getting down to the child's eye level, speaking with different accents or intonations, and allowing the child to request help instead of doing things for them.

This quote describes how a caregiver learned to try different ways of attracting her child's attention. Her success in doing so has resulted in an increased awareness of her child's communication attempts.

C: For me it is to play with X, to get his attention. Before he could not even sit down and look at me. But now, I try to sit down and try to attract him and get his attention. Look at me, ask me for music, now we can communicate. Even if he cannot talk, we communicate more than before. It was easy for me to communicate with X. Even if he cannot talk.

- Interview 2

The caregiver below learned that she must gain her child's attention before they communicate. This impacts not only the caregiver-child relationship, but it also extends to family who thought the child was simply disobedient.

C: I think we did not really try at first to catch the attention or get the gaze. I think that was such an important key and now that I know everything I want to do... let me first get his gaze, because before I thought this child is not interested in anything. My family would say, "Oh – he's so naughty because he doesn't listen to you". Now I understand him better, so I can explain better to them and they can understand him.

- Interview 4

Caregivers reported using unconventional strategies to gain their child's attention when conventional methods were unsuccessful. The following caregiver discusses how she attracts her child through the use of a different accent.

I: So, there was nothing they did that kind of felt foreign to you, or felt like this is not how you do it?

C: No, but you remember I told you about the... accent [laughs].

I: Yes! Tell us more about that again!

C: X's accent! So sometimes... I cannot get X's attention... and then I will just go over into my X's accent, and he'll like look because he really likes the accent.

I: That's so funny. So that's like a way to get his attention to... like get the gaze or use an American accent?

C: So, you want to bring that culture part into it. But it works for him. He likes it. So, X also does it [laughs]. Yes, we have a few Americans in the house. [laughs]
- Interview 4

Here, a caregiver describes doing less to predict her child's needs, which creates a situation where her child needs to look to her for assistance.

C: And um... to teach him how to wait to ask... to look at me and ask... because before he used to come in and if he needs the cup I'd just give. But now, I don't give him the cup, I just wait for him to look at me. So that I can give him the cup. And it's a lot of things... to play with him, to teach him how to take turns. I play, you wait for me, then you play. It's a lot of things.

- Interview 2

Strategies to increase social communication

Caregivers report learning strategies to increase their children's social communication skills, particularly imitation and providing the child with interactions containing developmentally matched language. Both of these strategies help to increase child vocalizations and promote the foundations of speech (Rogers et al., 2014).

Caregivers learned how to recognize word approximations and other communication-based vocalizations.

I: Was there anything that stood out as most helpful that you learned?

C: Yeah. There are several things. To imitate X's sounds... it helps. I think it was X that told me that when he says "BA" you just say "BA" ... just imitate him... I

can see he likes that. Sometimes he says his own words. And he will repeat that word for the whole week. He says “UD” ... we will say “UD” ... and he laughs so his younger brother and I just imitate him. We will be like “UD” and he loves it.

- Interview 2

This example illustrates how a caregiver learned to ‘reduce her language’ to developmentally match her child therefore promoting growth in her child’s expressive communication skills.

C: I also try to make words that he can imitate. Sometimes he does, sometimes he does not, but now he is imitating us. When the school bus comes, me and him say it... and they taught me how to reduce my language when I am talking to him. When you reduce your language, sometimes X is going to repeat that. I say the same words every time, I do not change the words.

- Interview 2

Activities of daily living and personal independence

Caregivers reported that they were able to integrate the skills they learned from the two pilot sessions into daily routines at home. Acquired personal independence skills included brushing teeth, eating food, and riding the school bus. Visual supports were used to assist in the acquisition of certain skills.

This following caregiver describes using pictures to teach her child the steps involved in brushing his teeth.

C1: We try, because they give us a routine to learn to do with him every morning... wake up, wash your face, and brush your teeth, but yes, we try. Somewhere there was the soap... the pictures of mom, grandma and his brother on the wall brushing. He follows those pictures, so he knows when to rinse.
C2: If the words say grandma... he is going to say it in Xhosa. He says [Xhosa] “Makhulu”.

C1: If you change this word and put another word “gogo” instead, look and he say, “gogo”.

I: And so, it sounds like you guys have been able to use some of the things that you learned back in February while at home? How frequently do you use them?

C1: Everyday – because we still have those pictures. Even now we do not have those pictures, because we just cut them. He is still always saying “mom” “gogo”, “X”, “X”. And then it’s toothbrush!

C2: Toothbrush! Toothpaste!

C1: He remembers all of those things. He looks at the picture.

I: He has seen his pictures that X put X. So, he got the toothbrush and toothpaste and says toothbrush, toothpaste, and he always laughs when he saw them.

- Interview 1

The following caregiver describes a feeding routine she established with her son, who has learned to feed himself since participating in the caregiver coaching sessions.

I: He feeds himself though?

C: He can feed himself now. I can make porridge and put it in a small [inaudible]

I: And is that new X because before were you feeding him?

C: It is new. I must look in his eyes and say, “You want the porridge now?” and he will show me “Ee!” Ee! Ee!”. [Inaudible]. In the morning, I wash his mouth, go to make the porridge, put it on the floor, then he must go eat. He sits and eats.

- Interview 3

Caregivers contrasted the speed at which their child gained skills when they were taught at school with the two caregiver coaching sessions they had received. In the

excerpt below, a mother describes how she saw noticeable improvements in her child's willingness to eat independently after one coaching session.

C: For me, it is like I am not really seeing improvement. It has been six months already, so I am not seeing major improvement. I see more improvement when we do things at home, and with X we had a one-day session with her and after the weekend of following what she did it was amazing. He was eating on his own after that, it was such a huge step for us. It is like he does not need me to come and feed him, or before I had to force feed the spoon just to get him to taste something. Now he will taste it on his own. And that was so amazing. That was such an accomplishment for us.

I: So, the changes that you saw from that day seem to be much bigger than the other ones?

C: ... than the six months at school.

- Interview 4

Here, the caregiver establishes a routine for getting her child on the school bus. She is applying strategies she learned during the 2 caregiver coaching sessions.

C: Now when the bus comes, I was surprised. When the bus was coming, I used to say, "Beep! Beep! The bus is coming! Let's go... let's go... let's go!" ... and we would jump. So now X says, "Beep! Beep!". I say "Bus is coming! Let's go! Let's go! Let's go!" you see... he is saying that. [laughs]. When he said that I was very happy and now I say that every time... "Beep! Beep!". He comes straight to you, "Bus is coming! Let's go! Let's go! Let's go!". You see, he is imitating us because we are imitating him. Everything he says we just imitate him. Even if it is meaningless, we just imitate him. And he likes it, because maybe he does not know, maybe he thinks it is a word or a nice thing people say.

- Interview 2

Later in the interview, the caregiver explains using strategies to help the child with transitions. She engages the child in sensory social play before getting him onto the bus every morning, and this strategy appears to assist with this necessary daily transition.

C: We heard from that training that we must be detectives of our children. So that is what we are doing now. We look at X when there is something wrong and we find a way. One example, he refused to enter the bus for three days. He just started doing that and I did not know why it was happening. When the bus comes, I say, "Okay... let's come, take the bag". He starts crying...he does not want to enter on the bus. So even if he gets onto the bus, he cries until he gets into school. So, D told me, "Maybe he doesn't like the way you come in and rush him out of the house". So, we started going outside for 20 minutes before the bus comes. We play, then I bring the ball, he plays with his brother, they run away, then he knows he is going to be outside. Instead of bringing him outside and going "Come, come, let's go, let's go". I take him outside for 20 minutes and he plays and when the bus came X just opened the gate and went on happily.

- Interview 2

Generalizing skills

Caregivers reported that they were able to generalize the skills they had learned to different situations and teach family members how to apply them.

In the quote below, the caregiver describes how other family members, who were not a part of the original training have been taught to use intervention strategies, for example getting the child's gaze and offering choices.

C: It was a little frustrating at the beginning trying to understand. Putting my mind to it, asking more questions, and understanding made it easy to adapt and add it into home life. Even my family is adding it in now. My mom does it. She will not just ask him something, she will try to get his gaze and say, "Would you like this?" and she would offer him something else as well so there would be two things and he would have a choice and he could actually touch the one that he wants.

I: And so, you taught her those things?

C: Yeah. It was cool.

- Interview 4

The following caregiver describes teaching others to bring items to the child's eye level in order to gain his attention.

I: And what was hard about it?

C: Nothing really. You can fit it in everywhere. At home, at school, even at church just explaining to the sisters, because they were like, "X! X!" trying to get his attention. I told them that whatever it is you want to show him, bring it up to where he can see, and he will look. Now they know what to do.

- Interview 4

In this description, a caregiver reports that her family has adjusted their overall approach to interacting with the child and easily integrated intervention strategies into their daily interactions.

I: How do you feel like this treatment fits with your family's needs?

C: I do not see it as a treatment honestly X. It is so easy it is like part of life, so now it is just adapting how we do things. It is just a little bit extra, but it is not that major, because once you get your mind set on it you can actually just include it everywhere.

- Interview 4

3.2.2 Reflections on caregiver coaching approach

Reflections on the caregiver coaching approach described caregivers' experiences with the intervention. Subthemes include descriptions and comparisons of clinic and in-home experiences, resource limitations in their home environments, and how they overcome challenges.

Clinic versus in-home captures the improvements over the course of the coaching sessions, and the advantages and disadvantages of clinic or home-based therapy models. Recognizing and addressing limitations illustrates caregiver reported contextual challenges related to implementing this intervention in South Africa and demonstrates how caregivers plan to persevere despite these challenges.

Clinic versus in-home intervention delivery

In the excerpt below, the caregiver discusses noticeable improvements in her child's behavior after one in-home therapy session. This is contrasted with 6 months in school, in which she did not notice any changes. Because of this, she prefers participating in a home-based model.

C: No – I think it was easier at home. That is why I said I would prefer somebody coming to the house because I saw more change in him after that session, and we started implementing things that we learned at home and I could see there were changes. So, that is what I am saying – at school there were no changes at six months, at home a few days of doing things and we are getting good results.

- Interview 4

The following compares caregiver experiences of the clinic and home-based therapy sessions. This mother preferred in-home delivery, as she believed her child was more comfortable in his home environment.

I: What differences did you notice between interacting at the clinic and at home?

C: I think at home was definitely more comfortable, because he is in his own environment, so he feels like, “Okay – you’re coming to my place now so... I’m going to do what I like doing and you can join in”. It was not like he had to wait.

I: So, you could see that there was something different for X between the clinic and at home?

C: Yeah – definitely.

- Interview 4

Recognizing and addressing limitations

All of the caregivers who received the 2-session caregiver coaching reported significant resource limitations. The clinic setting has funding that provides for mental health professionals, a wide variety of toys and games, and a defined space that is used for caregivers to engage in joint activity routines with their children. This is not always the case while at home, as caregivers described having a limited number of toys and space. However, another caregiver explains how pilot caregiver coaching sessions helped address such issues.

This caregiver explains the difficulties she experiences at home, because she does not have any room for her child to play games. When he is forced to stay inside, he becomes restless, because he is actively trying to explore his environment.

C: Another thing that is very difficult for me is my house and my space. My house is very small. I do not mean that they must build me a house, I just need a space for X. Because every time X likes to be around this corner and that corner – you see what I mean – but my house is smaller than even this place.

I: So, it is not so much about what you were taught... it is about the space?

C: It is about the space. That is also working to him. When it is raining, I was staying in the bed because there is no space that he can stay. After opening the door, do you know what X is going to do first?

I: He takes off.

C: [nods]

- Interview 3

Here, a grandmother describes the disparity in the toys available in the clinic compared to at home. Although her experience with therapy has been easy, not having the same toys at home has caused some difficulties.

C: It is easy. It is not hard. It is easy, but then the things that make it difficult is sometimes we do not have exactly the things that they have in here... But it is not difficult for him... because he always follows, he always remembers the things he does there... they both do.

I: So, the challenge is that sometimes you do not have the same...

C: We do not have the same stuff.

- Interview 1

The father below describes feelings of self-empowerment and self-efficacy from his experiences in the caregiver coaching approach. Prior to the 2-session training he thought that his child could not be raised in their current environment, but now he has hope and direction for the future.

I: What was it like for people to teach you in your own house?

C: I realized there was a difference. Before we used to blame the area or the house. "No, we can't raise this child here, the problem is where we live" you see? But now, people came and told us how we can do this while we are there, and it really helped. Yeah.

I: So, it helped for them to see where the child is?

C: Yes.

- Interview 2

4. Discussion

This study utilized a qualitative approach to elicit descriptions of caregiver-child joint activity routines in the daily lives of South African caregivers of young children with ASD, and investigate the acceptability of caregiver coaching techniques within the context of early ASD intervention. The joint activity routine descriptions in object-based play, sensory social routines, and family routines from South African caregivers of young children with ASD suggest that ASD intervention techniques may be imbedded within these caregiver-child interactions. The descriptions of caregiver experiences in caregiver coaching suggest that this approach may be acceptable to South African caregivers.

Within joint activity routines, three major themes were analyzed: object-based play, sensory social routines, and family routines. While using objects in play, caregivers reported that they engage in a variety of dyadic, turn-taking games with their children, teach skills that cut across developmental domains, participate in child-directed activities, and manage challenges related to play in resource limited settings. During sensory social games, caregivers described active, physical play and an awareness of the child's emotions. During sensory social routines children showed increased expressive communication and willingness to engage with a number of different play partners. In family routines, caregivers detailed child participation in meal preparation and noted verbal communication that occurs during bath time. The data provide a description of how an NDBI that uses joint activity routines to engage and teach young children with ASD could fit in the South African setting. Evidence of caregivers using joint activity

routines indicates a degree of ‘fit’ with the current construction of P-ESDM and will inform the adaptation of its manual and training approach.

In terms of caregiver perceptions of acceptability of a coaching approach, two major themes emerged: child and caregiver acquired skills and reflections on the caregiver coaching approach. Skills that caregivers acquired through the caregiver coaching sessions included a variety of strategies that enhance their child’s social communication skills, such as getting down on their knees to maintain eye contact and simplifying their expressive language in an effort to increase child vocalizations. Caregivers also began using visual aids to support child performance of daily routines, such as brushing teeth, and taught other members of their family and community how to interact with their child using strategies they had learned in caregiver coaching. Caregivers preferred receiving coaching in their homes as opposed to in a clinic setting, because they found it to be more comfortable for their child and resulted in positive changes in child behavior. However, some caregivers did experience limitations in physical space and financial resources in their homes. Based on these descriptions, South African caregivers are able to incorporate ESDM skills into their daily routines and may find caregiver coaching as an acceptable approach to early ASD intervention. These data comprise the full body of literature on acceptability of early ASD intervention in South Africa, a concept which will be measured repeatedly throughout the implementation process.

4.1 Implications for further research

Currently, there are no publications on early ASD interventions in sub-Saharan Africa (Franz et al., 2017). Additionally, there is no peer-reviewed research describing either joint activity routines or acceptability of early ASD intervention that utilizes a caregiver coaching approach in sub-Saharan Africa (Franz et al., 2017). The descriptions of joint activity routines provided in this study suggest that an early ASD intervention that uses joint activities occurring between caregiver and child to teach intervention strategies may fit within a South African setting. Given the scarcity of specialist providers in most LMIC, it is unlikely that there will be enough highly trained therapists to provide intervention to children in need in the coming years (de Vries, 2016). For this reason, involving parents and caregivers of young children with ASD in treatment delivery is a potentially powerful mechanism to deliver early intervention in low-resource settings. There is consensus that parent/caregiver education and skills training should be an essential component after an ASD diagnosis. This recommendation is clearly articulated in the WHO Mental Health Gap Action Programme (mhGAP) for developmental disabilities including ASD (World Health Organization, 2015a). This study therefore begins to fill key gaps in early ASD intervention literature in South Africa, and more broadly in sub-Saharan Africa, by offering qualitative descriptions of caregiver-child joint activity routines and qualitative descriptions from caregivers on perceptions of acceptability of a caregiver coaching approach for early ASD intervention.

Currently, research is being conducted in South Africa to adapt and assess the impact of a caregiver coaching intervention, the Parent-Early Start Denver Model (P-

ESDM) that will be delivered to caregivers by non-specialist workers (Franz et al., 2017). The results of the current study suggest that joint activity routines occurring between caregiver and child can be used to embed P-ESDM intervention techniques, and that the caregiver coaching approach may be acceptable. Importantly, acceptability of an intervention should be measured periodically throughout implementation stages as stakeholder perceptions of the interventions change over time as they become more familiar with intervention techniques (Proctor et al., 2011).

4.2 Limitations

Study limitations include the following: (1) using the Western Cape Province as the sample population may affect generalizability of findings to other regions of South Africa, because the Western Cape is one of the more economically well-resourced areas of the nation (Statistics South Africa, 2012); (2) while the sample for the focus groups included 22 caregivers, there were only 6 caregivers participated in the coaching sessions and subsequent in-depth interviews, and this small number of participants limits generalizability of findings, particularly related to the acceptability of a caregiver coaching approach; (3) this study only measures acceptability at one time point, in an ongoing process of implementation of a new intervention in a novel environment. These study results are only the beginning of a multi-step process that will need to continue across P-ESDM implementation in South Africa; (4) Although there were no noticeable differences between FGD and IDI descriptions of joint activity routines, IDI exposure to the caregiver coaching intervention may affect their daily interactions with their child.

5. Conclusion

Early ASD intervention is challenging in low-resource settings due to the lack of mental health service providers (World Health Organization, 2015b). Involving non-specialists as caregiver coaches and involving caregivers in early ASD treatment delivery may help to address the treatment gap by increasing the proportion of children receiving early intervention. With the gap in treatment for ASD in LMIC, such as South Africa, being almost 100% (Rahman et al., 2016) working with non-specialist providers and caregivers is crucial. Understanding caregiver-child joint activity routines and caregiver perceptions of the acceptability of caregiver coaching provides important contextual knowledge which will be used to adapt and implement a caregiver coaching intervention for a low-resource South African setting.

Appendix A

FOCUS GROUP QUESTIONS – PARENTS/CAREGIVERS

Introductory blurb: Thank participants for attending; introduce yourselves; introduce purpose of the group: *“We want to learn about the needs of families who have children with autism in South Africa. We would like to use what we learn from talking with you to change a treatment for autism that can be taught to parents, so we can use it in South Africa.”*

Questions:

1. Please can you describe your child for us [**Parental Perception/Values**]
 - a. What is most important to you about your child’s growth?
 - b. What are your short-term goals for your child?
 - c. What are your long-term goals for your child?

2. Does your child use any services for their autism?
[**Values/Experiences/Services**]
 - a. What types of services does your child use?
 - b. What do you like or not like about these services?
 - c. What types of services would you like your child to receive?
 - d. What would the “best” autism service look like?
 - e. How useful are services for children with autism when they are very young?

3. We are interested in finding out more about how you play with your child.
[**Parent-child play**]
 - a. Do you play with your child?
 - b. Are there other adults besides you that play with your child?
 - c. Can you tell us about the games you or other adults play with your child?
 - d. How do you know your child is having fun when you play with them?

4. What would you think about being taught how to do therapy with your child?
[**Attitude/Acceptability – parent mediated techniques**]

We would like to show you a video clip [of Noleen/Nokuthula/Sally/Aubyn working with parents to teach them a specific skill] so you can see an example of what we mean.

- a. Would you be interested in learning how to do this type of therapy with your child?
 - b. What do you think would be easy about learning how to do this therapy with your child?
 - c. What do you think would be hard about learning how to do this therapy with your child?
 - d. What would you think about someone coming into your home to teach you how to do this with your child?
5. How do you think the following things would be important when making an autism treatment for families in South Africa? [**Contextual Factors**]
- a. Culture
 - b. Language
 - c. Where you get the treatment
 - d. Cost of the treatment
 - e. Who teaches you (for e.g. speech therapist or occupational therapist or community health worker)
 - f. How you already parent your child
 - g. How much time it takes to learn
 - h. How much support you have from your partner or other family members
 - i. Proof that the treatment works
 - j. How the treatment fits with your family needs
6. How do you feel about the use of video clips or photographs from local families who have helped us in our research? Is it useful or not useful? Appropriate or not appropriate?
7. Is there anything we missed?

Appendix B

IN DEPTH INTERVIEW QUESTIONS

Questions:

1. Please can you describe your child for us
[Parental Perception/Values]
 - a. What is most important to you about your child's growth?
 - b. What are your short-term goals for your child?
 - c. What are your long-term goals for your child?

2. Does your child use any services for their autism?
[Values/Experiences/Services]
 - a. What types of services does your child use?
 - b. What do you like or not like about these services?
 - c. What types of services would you like your child to receive?
 - d. What would the "best" autism service look like?
 - e. How useful are services for children with autism when they are very young?

3. We are interested in finding out more about how you play and spend time with your child.
[Parent-child play/Daily routines]
 - a. Do you play with your child?
 - b. Are there other adults besides you that play with your child or spend time with them?
 - c. Can you tell us about the games you or other adults play with your child?
 - d. How do you know your child is having fun when you play with them?
 - e. Can you tell us about other things you do with your child everyday (for e.g. bathing, feeding)

4. When we saw you in February we worked with you in the clinic and at home and taught you different ways to work with your child.
[Attitude/Acceptability/Feasibility of parent mediated intervention]
 - a. What was that like for you?

- b. How did it make you feel?
 - c. How do you think it made your child feel?
 - d. What was easy about learning to work with your child?
 - e. What was hard about learning to work with your child?
 - f. What do you feel about having someone come into your home to teach you how to work with your child?
 - g. Would you be interested in continuing to learn different ways to work with your child?
 - h. Have you been able to carry on using some of the things you were taught?
5. How do you think the following things would be important when making an autism treatment for families in South Africa? [**Contextual Factors**]
- a. Culture
 - b. Language
 - c. Where you get the treatment
 - d. Cost of the treatment
 - e. Who teaches you (for e.g. speech therapist or occupational therapist or community health worker)
 - f. How you already parent your child
 - g. How much time it takes to learn
 - h. How much support you have from your partner or other family members
 - i. Proof that the treatment works
 - j. How the treatment fits with your family needs
6. How do you feel about the use of video clips or photographs from local families who have helped us in our research? Is it useful or not useful? Appropriate or not appropriate?
7. Is there anything we missed?

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