

A Qualitative Study of Contextual Factors' Impact on the Adaptation of a
Caregiver-Mediated Early Autism Intervention in South Africa

by

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

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Abstract

Background: Autism Spectrum Disorder (ASD) is a major global health challenge as the majority of individuals with ASD live in low- and middle-income countries (LMICs) and receive little to no services or support from health or social care systems. Despite this global crisis, the development and validation of ASD interventions has almost exclusively occurred in high-income countries, leaving many unanswered questions regarding what contextual factors would need to be considered to ensure the effectiveness of interventions in LMICs. This study sought to conduct explorative research on the contextual adaptation of a caregiver-mediated early ASD intervention for use in a low-resource setting in South Africa. **Methods:** Participants included 22 caregivers of children with autism, including mothers (n=16), fathers (n=4), and grandmothers (n=2). Four focus groups discussions were conducted in Cape Town, South Africa with caregivers and lasted between 1.5-3.5 hours in length. Data was recorded, translated, and transcribed by research personnel. Data was then coded for emerging themes and analyzed using the NVivo qualitative data analysis software package. **Results:** Nine contextual factors were reported to be important for the adaptation process including culture, language, location of treatment, cost of treatment, type of service provider, familial needs, length of treatment, support, and parenting practices. One contextual factor, evidence-based treatment, was reported to be both important and not important for adaptation by caregivers. The contextual factor of stigma was identified as an emerging theme and a specifically relevant challenge when developing an ASD intervention for use in a South African context. **Conclusions:** Eleven contextual factors were discussed in detail by caregivers and examples were given regarding the challenges, sources, and preferences related to the contextual adaptation of a parent-mediated early ASD intervention in South Africa. Caregivers reported a preference for an affordable, in-home, individualized early ASD intervention, where they have an active voice in shaping treatment goals. Distrust of community-based nurses and health workers to deliver an early ASD intervention and challenges associated with ASD-based stigma were two unanticipated findings from this data set. Implications for practice and further research are discussed.

Dedication

For all of the families that participated in this study, I dedicate this work to you and the task of continuing to find novel ways to address the mental health needs of low-resource global communities. Thank you for your willingness to share your experiences with me. You all have truly inspired me to ensure more families are given an active voice to tell their stories and advocate for themselves in ways that will contribute to the scientific community and diminish the stigmatization of mental health disorders worldwide.

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1. Introduction

Autism spectrum disorder (ASD) is a lifelong neurodevelopmental condition that can impair an individual's social, verbal, cognitive and behavioral development and impact their daily functioning (American Psychiatric Association [APA], 2013). Symptoms include social communication impairments, restricted interests, and repetitive behaviors (APA, 2013). Comorbidities are common and can include language impairment, intellectual disability, sensory deficits, seizure disorders, anxiety disorders, and attention deficit hyperactivity disorder (APA, 2013). Given the diversity of comorbidities that individuals diagnosed with ASD may experience, the clinical presentation of ASD results in a wide range of challenges and abilities. Currently, there is no cure for ASD (APA, 2013), but early behavioral intervention has shown to be a cost-effective approach to improve language acquisition, cognitive abilities, and adaptive behaviors among children diagnosed with ASD (Interagency Autism Coordinating Committee [IACC], 2011). ASD is reported to occur across all ethnic, racial, and socioeconomic groups, with boys reportedly almost 5 times more likely to be diagnosed with ASD than girls (Centers for Disease Control and Prevention [CDC], 2014). The most recent prevalence data from the CDC reports that 1 in every 68 children have ASD (CDC, 2014).

ASD is considered a major global public health challenge as the majority of individuals with ASD live in low- and middle-income countries (LMICs) and receive no services or support from health or social care systems (Khan et al., 2012). ASD has shown to account for over 7.6 million disability-adjusted life years and approximately 0.3% of the global burden of disease (World Health Organization [WHO], 2013). While ASD research has gained momentum on a global scale in recent years, it is important to note that the majority of ASD research and prevalence data is almost exclusively from the US and other high-income countries (Elsabbagh et al., 2012; Khan et al., 2012). This apparent lack of evidence from LMICs presents a substantial gap in knowledge regarding the majority of the global population (Elsabbagh et al., 2012).

Furthermore, there is presently a need for more ASD research in African settings, as there is less known about the prevalence and treatment of ASD in Africa than on any other continent in the world, and there are many African people with ASD who urgently need services (Ametepee & Chitiyo, 2009).

In 2013, the UN General Assembly acknowledged the desperate need for improved ASD services globally and adopted a resolution calling for comprehensive and coordinated efforts in the management of ASD (United Nations [UN], 2013; WHO, 2013). Economically, the growing burden of ASD poses substantial financial concerns to the global community (Leigh & Du, 2015). A recent report indicates that the annual economic burden of ASD in the US will be estimated at approximately \$268 billion for 2015 and \$461 billion for 2025. However, these estimates are conservative and are based on the current ASD prevalence rate. Therefore, if the prevalence of ASD continues to increase at a consistent rate, the economic burden of ASD by 2025 is estimated to reach \$1 trillion in the US alone (Leigh & Du, 2015), at which point the cost of ASD care will surpass the cost of diabetes and ADHD care combined (Leigh & Du, 2015). The growing economic burden related to ASD in LMICs and on a broader global scale remains unknown.

Early intensive behavioral intervention for young children diagnosed with ASD has been shown to reduce core ASD symptoms and has demonstrated significant long-term improvements in language acquisition, social skills, cognitive abilities, and adaptive behaviors (Estes et al., 2015; IACC, 2011). According to the Interagency Autism Coordinating Committee of the NIH, the majority of evidence supporting the efficacy of early ASD intervention lies in the implementation of high intensive, evidence-based programs that are delivered by specialized professionals for 40 hours a week (IACC, 2011). These best practices pose substantial implementation costs and present sustainability and feasibility challenges in low-resource settings (Divan et al., 2015; Peters-Scheffer, Didden, Korzilius, & Matson, 2012).

Involving caregivers in treatment delivery can serve as a potential strategy to combat the financial and human resource barriers that can hinder the delivery of evidence-based treatment to young children with ASD in low resource settings (Divan et al., 2015; IACC, 2011; Kasari et al., 2014). The WHO has endorsed the importance of caregiver skills training in the care and treatment of children with developmental disorders (WHO, 2015). Caregiver involvement in treatment has shown to support the sustained improvement of ASD symptomatic severity among children as young as two years old (Kasari et al., 2014). One specific way in which caregivers can be incorporated into early ASD intervention is through a caregiver-mediation approach (National Institutes of Health [NIH], 2013). Caregiver-mediation can be defined as training a caretaker to serve as a therapist to mediate the delivery of interventional techniques to his or her own child (NIH, 2013). In a recent study, the effectiveness of a caregiver-mediated early ASD intervention was conducted in a low-resource setting (Kasari et al., 2014). Results showed significant improvement in children's social communication after just 2 hours per week of in-home parent-mediated therapeutic intervention over a 12-week period (Kasari et al., 2014), indicating the effectiveness of low-intensity, caregiver-mediated early ASD interventions in resource-restricted settings (Kasari et al., 2014).

Given the significant emotional and economic burden associated with raising a child with ASD (Estes et al., 2009), along with parents insight into the needs of their children, their families, and the broader ASD community (Mereoiu, Bland, Dobbins, & Niemeyer, 2015), it is essential that caregiver experiences inform ASD treatment practices. For example, caregiver perspectives of ASD treatment can demonstrate which factors support or hinder the service delivery process (Stadnick, Drahota, & Brookman-Frazee, 2013). These considerations are especially important when attempting to address the limited knowledge regarding caregivers' perspectives and ASD interventional research in Africa. Peer-reviewed literature of ASD caregivers' perspectives in Sub-saharan Africa is currently limited in scope, with only eight articles published to date (Alli,

Abdoola, & Mupawose, 2015; Du Toit & Kok, 1999; Fewster & Gurayah, 2015; Gona et al., 2015; Greeff & van der Walt, 2010; Kapp & Brown, 2011; Mitchell & Holdt, 2014; Olivier & Hing, 2009). Results from these articles can begin to illustrate the challenges and preferences expressed by caregivers of children with ASD living in Africa, including caregiver emotional distress (Fewster & Gurayah, 2015), lack of support from family and providers (Du Toit & Kok, 1999; Olivier & Hing, 2009), influences of traditional medicine and witchcraft (Gona et al., 2015), delayed diagnosis and treatment (Mitchell & Holdt, 2014), factors that promote resiliency (Greeff & van der Walt, 2010; Kapp & Brown, 2011), and difficulties with managing children's growth and development (Alli et al., 2015). However, a gap in the literature remains regarding both caregivers' perspectives of early ASD treatment as well as what contextual factors would be important for the adaptation of an early ASD intervention for use in an Africa setting.

Eleven peer-reviewed ASD intervention studies in Africa have been published to date (Akande, 1998; Akande, 1999; Akande, 2000; Alant, Zheng, Harty, & Lloyd, 2013; Bunning, Gona, Newton, & Hartley, 2014; Geils & Knoetze, 2008; Louw, Bentley, Sorsdahl, & Adnams, 2013; Pansegrouw & Alant, 1995; Silver, 1970; Travis & Geiger, 2010; Wong et al., 2014). These interventions varied in their therapeutic approach (e.g. operant conditioning, augmentative and alternative communication, pharmaceutical drug therapies), with only two of the studies incorporating a parent coaching component into their intervention (Bunning et al., 2014; Pansegrouw & Alant, 1995). Both of these studies (Bunning et al., 2014; Pansegrouw & Alant, 1995) focused on how parent coaching could positively impact caregiver-child communication, and therefore, do not address how parent-mediated interventions could impact other core ASD symptoms. There have been no reported early ASD interventions conducted in Africa to date.

1.1 Study Objective

A number of studies in LMICs have called for greater caregiver involvement in intervention delivery as a cost-effective means of providing services and addressing the capacity

barrier (Hastings, Robertson, Yasamy, 2012; Wang, Michaels, & Day, 2011). It is however important to consider contextually relevant factors during the ASD intervention adaptation process (Daley, Singhal, & Krishnamurthy, 2013). Therefore, prior to the implementation of a parent-mediated early ASD intervention, formative research must be conducted to gain a greater understanding of contextually relevant factors that may require adaptation to ensure an intervention is acceptable and feasible in a low-resource setting. Qualitative studies, such as focus groups and in-depth interviews, may be helpful in assessing the perceptions of caregivers of children with ASD (Cridland, Jones, Caputi, & Magee, 2015). Since qualitative research aims to describe, decode, and explain a phenomenon (Al-Busaidi, 2008), it is a methodological approach that can provide the flexibility necessary to capture caregivers' unique life experiences and perspectives (Cridland et al., 2015). The objective of the present study was to explore the perspectives of caregivers of children with ASD through the line of inquiry of what is the impact of relevant contextual factors on the adaptation of a caregiver-mediated early ASD intervention for use in a low-resource setting in South Africa.

2. Methods

2.1 Study Design

This 10-week qualitative study consisted of four caregiver focus groups, one provider focus group, and four in-depth caregiver interviews. For the purposes of this paper, the data from the four caregiver focus groups will be reported and discussed.

2.2 Setting

The site of the present study was at the Division of Child and Adolescent Psychiatry at the University of Cape Town (UCT), South Africa. Cape Town is the second-largest city in South Africa with a population of approximately 3.75 million people (City of Cape Town, 2014). Approximately 25% of people living in Cape Town are currently unemployed, 50% did not graduate from high school, and 35% live below the poverty line. Forty-two percent of the population describe themselves as “Colored”, 39% as “Black African”, 16% as “White, and 1% as “Indian or Asian”.

UCT is a public research university located in the Western Cape Province (University of Cape Town [UCT], 2014). The Center for Autism Research in Africa is a research laboratory within Division of Child and Adolescent Psychiatry at UCT. The lab focuses on building research capacity in Africa and has as a particular interest in the development of caregiver-led interventions for autism and other neuropsychiatric disorders (UCT, 2014).

2.3 Participants

The research participants for this study included 28 caregivers of children with autism and 12 ASD service providers. Twenty-two caregivers participated in the focus group discussion portion of this study. The caregivers who participated in the focus groups included mothers (n=16), fathers (n=4), and grandmothers (n=2). The sample consisted of caregivers’ from diverse cultural, ethnic, socioeconomic, and racial backgrounds, and included several immigrants and

refugees from other regions of Africa. To participate in the study, the caregiver had to meet the following inclusion criteria: (1) be a primary caregiver of a child with a confirmed diagnosis of autism aged 7 years or younger, and (2) have the ability to travel to the Division of Child and Adolescent Psychiatry at UCT for the 2-3-hour focus group discussion. Participants were recruited via convenience sampling from the Western Cape Education Department autism waiting list for special education services.

2.4 Data Collection Procedures

All study procedures were approved by the ethical review boards at both Duke University and the University of Cape Town. Prior to data collection the research was explained to each participant by a research assistant and the participants signed an informed consent. Data was collected by a team of personnel which included two clinical psychologists and a master's-level research assistant. A handheld audio recording device was used alongside the clinic's video recording equipment to capture and record each complete focus group session. During data collection, focus group discussions were held in a small private space with a range of 2 to 10 participants at a time. Each group was moderated by at least one member of the South African research team and was structured by the focus group guide. Focus group discussions lasted anywhere from 1.5 to 3.5 hours in length. There were no costs or immediate risks involved for the caregivers who participated in the focus groups.

2.5 ASD Caregiver Focus Group Discussions

The focus groups explored caregivers' perceptions of: (a) important short- and long-term goals for their child's development, (b) educational, therapeutic and medical services their child received, (c) what an "ideal" ASD intervention would look like, (d) the importance of early ASD intervention, (e) how they play with their child, (f) acceptability of a parent-mediated early ASD intervention model, (g) contextual factors (culture, language, location of treatment, cost of

treatment, type of provider, parenting practices, length of treatment, support, evidence-based treatment, and familial needs) relevant to the adaptation of an early ASD intervention in South Africa, and (h) utility and appropriateness of using video clips or photographs to record families participating in interventional research. See Appendix A for the full caregiver focus group discussion guide. For the purposes of this paper, only data relating to (g) contextual factors was incorporated into the analysis.

Semi-structured focus group discussions were conducted with study participants. The focus group guide contained 32 open-ended questions. Additional probes and visuals were utilized as clarification and for data enrichment purposes when necessary.

2.6 Analysis

Digital video and audio recordings were utilized in the transcription of the data collected for this study. Data was transcribed verbatim by a research assistant and was cross-checked for accuracy by one of the co-principal investigators. One focus group was conducted almost entirely in isiZulu and was moderated by a Zulu-speaking member of the research team. This transcript was transcribed and translated into English by a native isiZulu speaker that was not directly affiliated with data collection. Due to the multilingual nature of the sample utilized in this study, there were several phrases or words spoken during data collection in the language of Afrikaans. These phrases and words were transcribed and translated into English by native Afrikaans speakers affiliated with the study, including one of the study's co-principal investigators. After completing transcription, all data was reviewed by the research team and inaudible data was noted in the final transcriptions.

Prior to the commencement of the qualitative coding process, a comprehensive, project-specific master codebook was developed by two members of the research team after careful independent review and discussion of all the data transcriptions. The data was analyzed via the process of content analysis utilizing version 11 of the NVivo software package (QSR

International, 2012). Content analysis is a systematic process that involves making inferences by analytically and objectively identifying emerging themes in written transcriptions of recorded data (Holsti, 1969). After the development of the master project codebook, a series of data analysis procedures were established and implemented to code the collected data for emerging themes to maximize intercoder reliability between the research investigators. Each coder independently reviewed one transcript at a time, coding for themes with the codes established in the master project codebook. Each coder independently reviewed each transcript twice to ensure accuracy and comprehensiveness of their qualitative coding. While coding, each coder made note of any emerging themes that required discussion as to whether they should be added to the master project codebook.

Once each coder independently completed coding a transcript, the intercoder reliability was calculated via a coding comparison query function available in the NVivo software package. Coding and emerging themes were then discussed between the coders to reach complete consensus. Additional codes were added to the master codebook upon discussion between the reviewers. This process was implemented for each of the four individual focus groups. The average intercoder reliability score was reported at .75, indicating acceptable reliability and the development of a comprehensive master codebook for this large data set. Upon completion of data coding, an in-depth analysis of the contextual factors was performed. Queries were run in NVivo to identify representative quotes and develop thematic summaries to describe the data embedded within each of the eleven topically-relevant contextual factor themes.

3. Results

3.1 Contextual Factors

Eleven contextual factors were discussed, including: culture, language, location of treatment, cost of treatment, type of service provider, familial needs, length of treatment, support, evidence-based treatment, parenting practices, and stigma. Challenges along with preferences or sources for each contextual factor were reported. Stigma was the only contextual factor not directly queried in the study's focus group guide, but brought up organically by participants during discussion.

3.1.1 Culture

Caregivers cited culture as “quite important” and noted that it requires “sensitivity” during the adaptation process. Culture-specific thematic challenges were identified. These included: the multicultural South African population, power imbalances between caregivers and healthcare providers, and traditional beliefs about being cursed.

“Yeah – I think the culture thing... definitely plays a role in terms of the autism. I think we are fortunate perhaps because we go to see you different people... I think if I may say, I think people sometimes used to think autism is only white... it's a white thing. And now you're realizing, but it's not... because the more you go to the therapy sessions the more see different races and actually... it affects everybody. Because when I get into a therapy room, I see a White, I see a Colored, and I see a Black... And I was like, “Okay - but maybe this [having a child with ASD] is my blessing then”. Now, I have to work extra hard. Now, I have to talk and I have to make him [my son] see [different races] ... so is it cultural? Does it impact people... [different] people? Yes. And to some extent, I think that's the awareness” **[Multicultural]**.

“I think a lot of this [treating ASD] has to do with the person that diagnoses them because if they're really negative... and they're really like... how do I say... close-minded... they don't really help the parents. I mean it's like when my son was diagnosed it was like, “Oh you know they'll always be like this, and when they get older they might get worse because of not speaking, and all the tantrums and all of that”... My husband and I from the first night, we were researching, and then we came across all these things in America, that they were already doing, and then we had to go back to the neurologist and she's like, “No you guys are wasting your money... don't do all this stuff like you know your son is going to be like this”. When we left there, my husband told me, “You know we'd rather try everything there is and have false hope than have no hope”. Because when you come to her she gives you no hope. You know what I

mean so... that's why we tried anything and everything... because whatever we did worked" **Caregiver-provider power imbalance**.

"Um... the only problem we see... perhaps badly... you know in our townships, in our African [townships]... because there... people strongly believe in you know I've been bewitched, my child is not [sick]... you know. And like you were saying, [this is] culturally... but for me personally coming from a Christian background... my own belief is that look um... what made you kind of think that you're different from any other parent? And ah – another therapist told us um... and she said, "You know what, you guys are lucky because you have access to the therapies... the [hospital]" ... and she said, "You know go to the townships and its worse... that kid... I mean people will just think that that kid is cursed". That kid doesn't even get that information... the sharing that we are doing now. So – then maybe we have to do more awareness so that it doesn't impact the kids because our beliefs can actually make those kids never get an opportunity" **Traditional beliefs**.

A culture-specific preference that was expressed was to respect and incorporate families'

cultural values, for example in a therapeutic context:

"I think that it [therapy] must be adapted to the culture because for example you have a Christian and a Muslim house... they do different things... I mean it's different. With Christians... they have this thing about how often they go to church and how things must be done. And then you've got... different cultures. So I think it needs to be adapted to the culture. Like for instance a teacher must come in that's maybe Xhosa to a Xhosa household, or you know what I'm saying? Just to make it easier... I think the culture is important because you don't want to cross barriers. For instance, a Christian coming to a Muslim family... she can't train the child on potty training if she doesn't know that you must be able to use the bidet afterwards. So the culture is... using the right hand and not the left hand...it's actually quite important. There are specific things... to be sensitive around" **Respecting cultural values**.

3.1.2 Language

Language was reported as a "problem" and a potential "barrier [during treatment]" that can cause one to feel "bored or offended" and discourage "participation". "The eleven official languages spoken in South Africa" was identified as a language-specific thematic challenge.

"Well you see this is sort of a conundrum because at the end of the day, as a side of the culture becomes more aware of it [early ASD intervention] and it's hitting all different languages... all eleven of them. How are you actually going to be able to explain to those people in the homelands or whatever that have never been exposed to it? You know... in South Soweto or whichever, and so I think language is paramount" **11 official languages**.

"It is a problem for me... the language. Because I'm Zulu... and we are Zulus there in the house. Then there are Xhosa people that come in and then they talk to him in Xhosa, and then he's um... his uncle's wife is a colored [speaks Afrikaans] ... so we're [all] teaching him another language and then the Xhosa

[teacher] is teaching him another language [laughter]. So he's confused. It's confusing for him. I don't know" **[11 official languages]**.

Caregivers reported differences in their language preference for therapeutic service delivery, including instruction in English, instruction in a child's native language, and indecision regarding which language would be most effective for instruction. English was reported as the most frequent language preference for instruction.

"I think English is the best...because yes ... English... yeah I understand it. He quickly understands it like more than [Xhosa]...because even a child is quick to catch many things when he is also being taught in English. So instead of Xhosa, because some words...like my child, when he is sitting with his father he says certain words in English and knows words in English. Even where he goes to learn, there at speech [therapy], he is being taught in English. So there are English words that he knows. It might be faster [for him to learn] in English" **[English preference]**.

"I would love also my child to also speak Xhosa because you know he's a Xhosa speaker because it's his language. So – yeah... and he will of course... of course he will meet people, family, friends that speak Xhosa. And imagine if the child doesn't understand them... they speak in that situation... or he doesn't understand them when they speak Xhosa [to him]?" **[Native language preference]**.

"For me... um... what can I say is I'm confused now like... for my baby because what speech therapy told me like...I feel like if I teach him English maybe it can be um confusing him. I must now starting [to teach him] Xhosa... so that he can talk, and then after I can teach him English after that. But like now... because we are in town... our Xhosa it's mixed... you know it's different when we were in Eastern Cape you speak Xhosa... like very Xhosa. You know? Now, I don't know like for school like that thing [teaching him Xhosa first] is going to confuse him too when he's like going to school because I don't know if I must... look for school the first language is English or I must do what... I don't know. I'm confused" **[Indecision]**.

A language-specific preference that was reported by caregivers was matching a therapist to a family based on language:

"I think it's more important. You have to teach the parents the language they want their child to speak. If they want their child to speak Afrikaans, then it's better to do the therapy in Afrikaans with the parents. And then they can do it in Afrikaans. If they want the child to speak English, then do it in English. You know? Yeah with Xhosa... because other people they prefer like their children to speak Xhosa, they can learn other languages in the future too. I think do it in that language. I don't know that's my idea" **[Match therapist to family]**.

3.1.3 Location of Treatment

Location of treatment was frequently discussed during the focus groups. Chaotic home environments and lack of transferring skills between environments were identified as location-specific thematic challenges.

“Where you get the treatment would also determine on whether you’ve got other siblings involved in the house because that’s going to affect [in-home therapeutic delivery] if the sibling is coming over because he’s having a bad day... he’s going to interrupt everything [the therapy]... so... from a treatment perspective is there... would there be treatment centers [outside of the home] in the neighborhoods?” **[Chaotic home environment]**.

“Oh – no but I still have some concern. He has three siblings, but we still aren’t feeling like we’re doing enough at home. As a parent, I don’t feel empowered. My son’s well-being has been in the hands of therapists for the past three years. It’s like two different worlds... they’re doing certain things with him, but it doesn’t always carry over to the home. And what I feel like that does... it doesn’t... his emotional intelligence hasn’t grown. He can do all these things. He is playing with his blocks and Legos, but how far is he going to get once he’s done with [school]” **[Transferring skills between environments]**.

Location preferences reported included: in-home delivery, a combination of in-home and a clinical setting, school-based delivery, and clinic delivery. In-home delivery was reported as the most frequent location preference for instruction. Only one participated reported a disinterest in home-based services and a preference for clinic-based delivery.

“Well [if] it’s home-based... so it’s easier for us to do. And like to get the results, we’re there and we can see, and so it’s a hands-on approach. So – I mean like yeah like I said we do it [therapy at home] so, it’s just a method of taking it in like while we’re doing it... knowing that it’s actually a workshop for us at home. So – you’re actually going to be like studying your child and seeing what works for him. So that’s the easy part. It’s not like going to a session and wasting your time. Okay – you’re watching them play with the child; they’re getting the attention through the child. Like you’re just sitting there watching. So this is more of a way to get a hands-on approach... yeah” **[In-home]**.

“That’s what I was thinking... a combination... definitely... because it’s fine coming into the home, but there are the other occasions where you might need to speak about something like one-on-one. I mean... you can’t be at home with the child going all around you, and then you are still trying to get the necessary information so you can be aware of a certain thing. So there’s hands-on training [in-home] ... then there is... there’s like quarterly [check-ins] with the clinic. Definitely – a combination” **[Combination]**.

“If this [parent-mediated early ASD intervention] could be possibly added into the mainstream education department... because almost irrespective if there are autistic kids in that school or not... share with the governing board so they

understand that this is what we [caregivers] want is this. So... for me it's just a case of letting us parents speak in the way of therapy... and letting our voice out and our opinions as much as everyone else. Because we get frustrated as much as anyone else" **[School].**

"For me when I show the therapist when he was trying the tricks he tries with me... it didn't work by her. You understand? And he listened because he's not in his own environment. He's in a new place so he has to listen. At home, if he don't want to listen, he don't listen. For now, for me, it's good I'm taking him there [to the clinic]. And I leave him there! It's peaceful and it's quiet. At home, he's screaming, he's crying, and he's doing mad things. Jumping up and down on the couch, he's not doing that there [at the clinic]. Because he must sit at a table nicely, he must draw at his place the... that's what I feel is good for me taking him there [to the clinic]. Because that's the problem I do have with him! For me at home, he can do whatever he wants to... it is fine. I do understand him. But for me to take him to some... some other peoples' houses... and behaving the way he do with the therapist then that would be good. Not him running up and down like you said, other people don't understand your situation... like I said they think that your child is naughty, or you don't teach your child the proper manners, but you know your own situation... you understand?" **[Clinic].**

Caregivers noted benefits of in-home therapeutic intervention including: convenience, understanding a family's situation, and understanding a child's behavior at home.

"I think the hard part would be the availability... to make yourself available. So on the last point of whether they should come into the home... I think that's going to be the best solution because um they would obviously come when everyone is around the table. So you'd actually be forced then also to make a slot in your diary... like I said now very often even to meet with your husband is a slot in your diary... so I think the time factor is the hard part. But if people are coming out to the house... first prize" **[Convenience].**

"I had one once somebody come out to come to our house, and it actually helped [my son] with the speech and to see the circumstances of the household. We had somebody like that come into our house. They just observed like they do at other treatments... to see how... what is he doing, how is he coping with the circumstances at the home and so on. But...yes it was actually helpful. It actually opened like... it actually opened our eyes actually in certain aspects [of ASD] also..." **[Understand family's situation].**

"I mean somebody coming to your home would be great because then I could learn like how to deal with [my son]'s frustrations, behavior, or like she said like eating at the table. He just likes to do his own thing. He doesn't even like to sit at the table, he'll want to eat and play. You know what I'm saying? Because it's almost like he's always stimulated... he likes to do lots of things... he's focused on one thing and he doesn't want to be disturbed. So learning how to actually sit... when it's mealtime to actually sit at the table and eat food" **[Understand child's behavior at home].**

3.1.4 Cost of Treatment

Caregivers perceived cost of ASD treatment to be an extremely important issue. One caregiver even emphasized this significance by stating, “if you can’t pay your way out [of ASD] ... you can’t help your child”. Cost-related thematic challenges identified included: existing financial burden of raising a child with ASD, lack of governmental financial support, and little disposable income.

“Like with my stuff... I sacrifice my funny time, my holidays... because I have to put a lot of money together for my child [with ASD]. Sometimes I can’t go on holiday with my other children because I have to put all the money for her. Yeah – it’s quite a sacrifice anyways. The cost... yeah” **[Existing financial burden of raising a child with ASD].**

“Yeah but... maybe I can add... is it possible in your research to make a recommendation to the State. To make a rebate. Because we’re paying a lot of money! And it’s like the State let us... let us down... you see. We’re going... you work there, you come, and you pay... all the frustration you’ve got it. But they don’t... I’ve phoned around. I couldn’t get anywhere. I think that they must think about it” **[Lack of government support].**

“Because unfortunately we don’t have like the money that you [focus group participants] have... like you usually have... so um... like they give only speech therapy like once a month. So – me and... me and [my son]’s father... if they call us to go do the speech therapy or that... or attend... then we go and interact with them and so on. That’s how we started all mostly. We’ll speak to him at home or... or... that helps a lot actually. It helps him mostly... yeah” **[Little disposable income].**

Caregivers reported that they would like services to be all-inclusive with no hidden costs, subsidized, and available to all children with ASD irrespective of their ability to pay for these services:

“And obviously... we’re not expecting her to be free, especially if they must come out to you [in-home delivery], but just a reasonable price. Considering how much we put in already. Yeah – like how much we also spent throughout the year because it’s only going to follow-up... if it does happen... because it’s only been a few years. And hopefully by then our children’s cured from all of this. Yeah... so... just a one-time fee...just one set fee.... There’s no extra costs or hidden costs in between... it’s just one set fee... and they come to you [in-home] for a specific amount of time” **[All-inclusive with no hidden costs].**

“I don’t know. They don’t subsidize the... the crèche ... they don’t balance either... to subsidize the crèche and make a tax rebate so the parent can benefit and when you pay you feel like “No... at least even a thousand rand is... it will be fine” **[Subsidized].**

“Because there are so many people that, some people that can’t help them because they don’t have the money. And, you need the money. I do now feel because I’ve met so many people... there’s not a lot of help out there for people that can’t afford it... because there’s so much potential in a lot of them, but there’s just no help” **[All children with ASD should get access].**

3.1.5 Type of Service Provider

Caregivers cited type of service provider as an important issue that impacts the quality and acceptability of ASD services. One caregiver noted, “Sometimes I just think it [the quality of care] depends on the therapist itself... how much they are willing to help you, or how much is just for their [own] benefit. It’s a hard time if [you] have those”. One service provider challenge identified was poor child-therapist fit:

“You [the therapist] must be able to relate to the child... must be able to be tolerant... because it’s [therapy] new for us and new for him. Because he’s very um withdrawn like... like he’ll see you and run away ... and I don’t want that. I want cooperation you know... he must feel welcomed and at ease and... stuff like that” **[Child-therapist fit].**

Provider preference included speech therapists, occupational therapists, and other parents with children with ASD.

“I think that most of the speech therapists... they’ve got more experiences with children... because they’ve been working for years with different children. Yeah... maybe... I can say maybe... they’re the best... you know. Because they’ve been maybe working with the ADH [ASD] children... autistic children for years... different children. I think they’re still the best. We still need them” **[Speech therapist].**

“Yeah... but I think [inaudible] and like I had this experience with them... he’s like, “You need to take him to an OT that knows to deal with kids because you get OT and then you get OT”. And then you get an OT that is specialist... specialized in kids with autism” **[Occupational therapist].**

“Like I would also... I would leave my child with a parent who has an autistic kid because I know that they’ve been there, they’ve done that. So I’d actually [rather] have them more in the hands of another [parent with a] kid with autism... who has an autistic kid... than with someone that’s at crèche that I know hasn’t had the studies. So – for me like I said... they can teach my kid, I can teach their kid... because we’ve all been there” **[ASD parent].**

Several caregivers distrusted community health workers:

“The reason why I [am] saying not a community worker is because here [in South Africa] they will tell us they understand your situation, but then they will go from your house and explain your situation to someone else... you

understand? And then not long after that... she... the community worker will change and there will be like this the EPWPs they change every time. Now you get a different community worker, then you must go through the whole process again and after that children go and... you understand?" **[Distrust of community health workers].**

"I don't prefer a community worker because maybe... if it's someone that is there in my place. I don't trust the people that are staying there. Because why? Maybe if I have a problem... she's [the community worker] is going to go out and talk about my problem. I prefer someone who is a professional because the professional is already taught that if someone has got a problem... it's confidential. It's between me and you. The only thing that you can do as a professional is to give me the advice... how to deal with that problem that I have and make sure that every time that you come... you make a follow-up. How far am I? How do I feel now? Like... something like that. But for community worker... no" **[Distrust of community health workers].**

Preferred provider attributes included: being a "professional", having passion, having patience, and being in a "permanent position".

"I mean someone who's like qualified... not someone who is just like taken off the street and, "Okay - this is how you do it". That's what I think to myself when I took my son to [a crèche] in Plumstead. You know like these weren't teachers at all, these weren't professionals, they just took them and taught them how to teach ABA. So when my son was at the school what happened is he was toilet trained, but he was speaking by then. He knew how to go to the toilet, but because there was a gate... when he wanted to go to the toilet the teacher just wouldn't take note. So then he would wet him, and I was like, "Why is he wetting?" He always goes to the toilet with my mom, with my sister...in the shopping center...he can show when he needs to use the toilet. Then I realized that no these people don't actually know what they're doing. And they didn't even know how to handle the kids... The one girl that was there you could tell she was someone that was out of school, looking for a job" **[Professional].**

"Yeah – you know for me they must have the degrees for it. Because the thing is the people [ASD service providers] ... you get some people [ASD service providers] that will do it for the money and then you get some people that's got the passion" **[Passion].**

"And the patience they [ASD service providers] do have... it's incredible. Yes and they take the time... But I was like, "Oh Lord, I will leave this child!" [laughs]. But [I] just go and get my head straight. But then, they [ASD service providers] will sit there and talk to him, and I say lord thank you for these people" **[Patience].**

"So I feel it's a professional in their job... so they're going to stay there... they are permanently in their job. Because with the healthcare community you can't say that's a permanent position that you [are] going to be in for so many years... you understand. That's the thing" **[Permanent position].**

Differences were reported among the caregivers regarding the importance of having credentials versus having previous experience working with children with ASD.

“I prefer the professional. Because he know what he’s... what he’s doing, and he know how to do it. And then he got his certificate. He’s a professional of that. And then, he will suggest some... some other things if maybe I’m not coping, but he can know how to deal with that lack of coping” **[Credentials]**.

“It isn’t necessary that they [ASD service providers] have to have the qualifications. It’s the experience more than qualifications” **[Experience]**.

3.1.6 Familial Needs

Matching intervention targets to specific familial needs was reported as an important factor that could make therapeutic techniques “easier to learn” and “easier to apply to your child”. Furthermore, caregivers noted the importance of service providers going into the home to assess familial needs in order to “see [the family’s] situation... what [they] are facing every day”. Hence, caregivers called for individualization of the parent-mediated early ASD intervention based upon familial needs:

“But what I also feel is there’s no use if they come when it’s the child’s play time. They need to come when you have a specific thing you need to address... like maybe like mealtime you know so they need to be there when it’s mealtime to see issues. So if they come when it’s playtime or homework time... and they’re fine with that thing and you’re also not getting the input. Now you have to change your times around for the therapist. Yeah – but I mean like um when I say like with my son I’d like him to... for them to be able to show him how to sit and eat with us, and they can’t come at like 3 o’clock when it’s not mealtime because now I have to let him eat at that time” **[Individualized]**.

3.1.7 Length of Treatment

Length of treatment was reported as an important consideration when developing an intervention for young children with ASD. Challenges identified included: children with ASD taking longer to learn and retain new skills, and parents busy schedules.

“And she... the child does two steps forward, one step backward. That we have to understand. She go two... bump, bump [moves hands in forward motion] ... and then come back. And so on... yeah... just give it time. Definitely. That’s what I’ve learned” **[Children take longer to learn]**.

“I think the hard part of it is the... like you said... the busy life. You know mom and dad must go to work. Our... which we don’t have too much time with our children anyway... it would depend how... what is your time or how you do

timing during the day. If you are working from 8 to 6 or from 8 to 7 or from 8 to 4...you come back from work... maybe you've got some cooking for your children... you don't have too much time with your child to sit... the therapist that is job, that is work... he's living from it, he's doing it. But we don't have too much choice. It's hard to be a working mother... working father. But I think we can overcome that" **Parents are busy**.

Caregivers reported different preferences for treatment frequency and duration.

Frequency preference ranged from daily sessions to a few times a week. Some caregivers desired treatment with no time limit.

"And like you said with the hour... yes we will say that an hour [a day] is not enough, but the kid also gets... it's like too much [for her]. It's too much for them. So an hour actually works. But you need like an hour everyday" **Daily**.

"Yeah or like... it's maybe three times a week for an hour or something like that... the specifics [need to be] detailed" **A few times a week**.

"You know I will agree... even if you give me um how long [the treatment will last] ... it's sole depending on that child... how you do it with your child. You understand? So for me there's no time... there's no time away from him because every day the time I spend with him or what... go to the hospital... there's more than enough time for me to get to know the child every time because every day there's something new you learn about your child. So – for me time... a long period of time say... that is what is going to happen in six months. Now, you base on that six months, "OK my child is going to do this and this", and then after that six months the child is not doing what you expected him to do... you understand? There's no time limit" **No limit**.

3.1.8 Relational, Interpersonal, and Community Support

Relational, interpersonal, and community support were perceived as important when caring for a child with ASD. Support-related challenges included: co-parenting from different households, low awareness and acceptance of ASD, and single parent households:

"You know um unfortunately we stay in the same area but we're not living together. We... she's living in a Wendy house... um I'm still living with my mother. And the thing is that it's quite difficult... you know... it's... it's very hard. Um... unfortunately she can't go work because of him now... looking after him" **Co-parenting, not living together**.

"Also involving the parents more... and also not only like family members as well... educating and make them aware because a lot of them like you mentioned they don't know like what autism is... or they'll say like, "What is that?" There is a problem... an underlying issue... it's difficult when you're in a situation where you've got like support... like I've got my family... my parents and um maybe it's like outside members like my in-laws or whatever the case may be... and you do one thing, and they do the other thing. They're not

educated enough and they don't understand your child. So the consistency... having that balance with everybody knowing what to do in a situation, or them being aware and knowing what autism is and like... for instance you do something, and then maybe they do something else... and that's not the way you want it to be..." **Lack of awareness and acceptance of ASD].**

"I mean he can be wrong [a pediatric neurologist]. Because I mean with autism not a lot of... not a lot of um... therapists know how to deal with autism. A doctor... they will say your child is sick... not knowing he's autistic. So sometimes there's not enough um... how can I say? Not enough understanding... what is that word? Like when you show something on TV? Awareness! There's not enough awareness of it [ASD]... um... and that's the main thing" **Lack of awareness and acceptance of ASD].**

"Okay. Guys I just need to tell you that I'm a divorced mommy... I work at [inaudible] so in terms of the financial... you know that part... so I applied for the disability [grant] fund, and thank god that I came out all right... I come home [from work] late at night" **Single-parent].**

Sources of support included: spouses/partners, grandparents, other ASD parents, extended family members, ASD service providers, and the outside community. Spousal/partner support was one of the most frequently reported sources of support:

"My wife I mean... you see... it's the two of us. So we balance off each other... when we're both at home... yeah... I mean it's very tough I mean because there's two of them [two children diagnosed with ASD]" **Spousal/partner support].**

"What is changing it [spousal support]? It is every day... talking about it [ASD] all the time... telling him what I'm going through and what he needs to understand about [my son]. Reading, giving him reading materials so he can read [about ASD] ... see for himself. Um... because it's not that females like to over exaggerate. And he thinks I just want to exaggerate everything. So I am going to give him the proof man. This is the way it [ASD] is, this is what I'm faced with. You're not facing this alone. You know? So - I think that's it" **Spousal/partner support].**

Inconsistencies in support provided by the spouse or partner was also reported:

"Another interesting thing is the daddy is teaching in Paarl... at a disabled school. So at the moment the daddy comes in with this negative energy... you know... because this son is his second son - right, but now it's like he's in denial [about ASD]. You know he teaches with those children [with ASD] every day, but it's like he doesn't know how to handle his own child. He comes in with this [negative] energy then... with such a whole lot of confusion... mommy's teaching this, grandma's this, grandad's this... and then now you [the daddy] come" **Spousal/partner inconsistencies].**

"But, for my partner... he doesn't... he doesn't understand... I try to explain each and every time what's going on. And then he... he just tell me... to tell me, "Oh - this boy is going to talk, he doesn't have nothing wrong, I don't see anything wrong, it's just a lack of speech". Because he... his mom said he [my

partner] talk when he was about sevens... six, seven [years old]. So – for him even like he’s supportive with like the money if I say, “Now, I’m going to attend this, and this, and this... see... or my baby is sick, or I must take my baby to be supported”. But to... to do things... and if I come maybe today... if I give me this paper [about ASD] ... I gave him, you must read here, it was all about this [ASD]. He is not going to do that” **[Spousal/partner inconsistencies]**.

Focus group participants who were grandmothers discussed the supportive role they played in rearing their grandchild with ASD:

“I mean I’m the gran, but I mean I had to be an integral part of the support structure” **[Grandmother support]**.

“Like even with [my daughter] um... she instructs me really... she’s the parent... I’m only the grandparent. So she’ll tell me mommy he’s not having that. Because the grandparent in me will sneak him things. He’s not having that, and I’m leaving now and this is what you’re going to be doing with him” **[Grandmother support]**.

“I’m active support... I can tell you I’m active support” **[Grandmother support]**.

Several caregivers reported receiving support from their child’s grandparents:

“I want grandma be involved because she looks after [my son]. Communication is really important. Just the involvement – when mommy’s not there, grandma needs to be able to assist and be part. Grandpa must be... because they are the whole day with [my son]. And also there’s just that understanding... you know... open-minded...they must tell you exactly if they have concerns. Because sometimes they tend to... you know... not always... what can I say? They say one thing but then they do something else” **[Grandparent support]**.

“For me also... to educate myself, to equip myself, in order to assist [my son] and to explain to grandma and grandpa what this session was about... they can also get understanding and get excited” **[Grandparent support]**.

“I stay with my parents so they can also get education I can teach them as well. Because I mean at the end of the day they’re also part of my family” **[Grandparent support]**.

Extended family members provided relational support:

“And with us you know because my son is on a special diet, and our family knows what he can eat and what he can’t eat. And when he goes to play over there or stay with him... and they need to make sure that they have food that he can eat... or they make a plan like that. Yeah it’s like my mothers, my sisters... even like the broader family like if he goes to a party they know he can’t eat, so they make sure there’s things that he can eat” **[Extended family support]**.

Other parents of children with ASD were noted to be part of the support network:

“I think just the sharing... the sharing of the information and I think for most of us even the fact that we’re still here... it’s Saturday afternoon... like I took my

daughter for ice skating and I said to her, “I’m dropping you off at ice skating and then I’m coming to the session because we all want to learn”. But I think that the information sharing as well. I think maybe sometimes um... it’s good to talk to somebody as well...yeah – other parents as well. Because we’re so far from each other... they live in Pinelands, you stay in Plumstead, you stay wherever... and we don’t get to support [each other]. And the fact that if you can just call me... you know... “I’m having this problem now... um how do you deal with it” ... I can refer to you. And we could actually... you know... be the support network to each other” **[Parent with ASD child support].**

Caregivers also cited ASD service providers as a source of support:

“When my son was diagnosed because no one in my family knew what it was we had to explain to them what it is. At [an ASD advocacy group], I asked one of them if they would mind coming one morning to our house with all of our family there so that they could explain it because they understand it more, and that’s what we did and it was very hard for us because they can explain more than what we knew at that time. And it made everyone just understand it so much more, and it made it easier because then everyone helps you more. It really did” **[ASD service provider support].**

Community support was cited as both difficult to obtain and as a very useful source of support when it was present:

“If people come [over] then we will tell the people like um he’s autistic and this is what... that’s why he’s like that. We talk about it and we make people aware of it. Like the people in the road [in my township] already knows about what [my son] is and that... so they know how to handle him if they maybe see him outside or that. Yes. Like a neighbor next door...if he goes play next door... then she knows how to handle him. So we don’t keep him away from that” **[Community support].**

“In America... oh okay. Now – this is what I wanted to ask. How is in... in other countries you know they say about the autism? Because I have friend overseas and they said to me... there’s one in Canada... and they told me look autism here yes there is a lot of awareness about this thing, and even their [ASD] centers... there is more support from the government and all the things. So – maybe because we’re a developing country... I don’t... I don’t know. I just maybe I want to listen... according to your experience you know... what is different here?” **[Lack of community support].**

3.1.9 Evidence-Based Treatment

Evidence-based treatment was reported as both an important and not an important consideration when adapting a parent-mediated early ASD intervention:

“And I think that proof that the treatment works is paramount to everything there because, and that rest assure if there is proof that it works than all those other things are capable and are moldable to make the whole thing adaptable to the mindsets, and the cultures, and so on of South Africa. Definitely. And I think that South Africans are generally that way” **[Important].**

“Well – you’re going to need subjects to work on in that regard. So some people will start out fresh and they need your support. So you can help them also, and they can be ready for the next families. So – some of them aren’t going to have all the [evidence]... like okay they’re going to have experience though that’s different... a difference in that. But, in this new thing coming into the home, that’s different for them also. So it’s not necessarily that they need too much proof of this treatment that it works with other families because you could have been the family that can help them [develop it]” **[Not important].**

Contextual challenges impacting evidence-based practice in South Africa included the conflict between the early intervention evidence-base and available services, variability in intervention outcomes, and rate of progress:

“I’m sorry but can I just maybe say that I think that’s the problem. I mean I think research has shown... I mean... we’re like often on the Internet. Like researching what’s the best time [for intervention], and people will even tell you the best time is around eighteen months...when people can already start seeing like the kid is not interacting by then. Okay so... so they say the best time like [some] said is like three years and two and half and... that’s the time when we started noticing. But, no... no... no... but he’s not saying the few words that he should be saying, and things like that. So – the question we both have is like... okay if they do say that time... the intervention time is around two and half... three years... why does [X]... who is seen as the center that has everything around... I think it’s [X] and it think there’s another one... [X]. Why do they then start at the age of six? Because that’s the time... and I mean I’m not saying don’t look at kids that are six years old... I’m saying should you then not in terms of what the research has shown... I mean should you then not start at the age of... let’s say three” **[Conflict between early intervention evidence and available services].**

“Then again it might work for someone and not work for the next person. Or... it might be that it will work for the next person but it just takes longer than it works for you... you know. It depends” **[Variability in interventional outcomes].**

“Because you can’t just like have him there [in therapy] for three months, you take him out. You go look for another thing. You’re not going to see... somebody will tell you... um it will take two years for you to actually see [results]. But that’s why I think the importance of the early intervention. Because you’re going to be frustrated if you want to put him there [in school] at six years... because now he’s ready to go to school. Um... but... I think the important part is the patience that you have to have for any therapeutic approach that will help” **[Variability in rate of progress].**

3.1.10 Parenting Practices

Parenting practices was reported as an important consideration when adapting a parent-mediated early ASD intervention in South Africa. Challenges identified included: the differences

between parenting a child with ASD versus a typically-developing child, diversity in parenting styles, and trial-and-error parenting:

“Yes because what happened was... I’ve got two children that’s older than my son... he’s the baby. And so I just thought, he’s just plain naughty. Whatever he was doing, people were telling me no he’s a boy... he’s slow... he’s a slow boy... the boys are normally slower than the girls. And I was treating him the same as what I would’ve treated my other kids. So – when I found out that my son was autistic... it was very bad for me. I went through depression because I thought oh my word I was treating this child like normal, if he was naughty I hit him, “You’re naughty! Don’t do that! Take a corner” **[Differences between parenting an ASD vs. typically developing child].**

“Yes! I’ve actually told you that... it’s easy to look up... you know normal children; you have normal children you just know what to do. You know... but you’ve got this one child [with ASD] that you just don’t know what to do with him [Laughs]. You can’t do the same as what you were going to do with him” **[Differences between parenting an ASD vs. typically developing child].**

“But I think when working with your child... your child feels comfortable in the family setting first and foremost. So automatically each one of us is different in parenting style. And unless there’s abuse involved and all those stuff... I think um you basically need to rear your child in the way you rear your child. There’s no hard and fast. And you go in and find that it’s different peoples’ opinions in terms of child rearing and things like that. But in the home you’re going to do things your way inevitably. So – it’s just so this therapist can come in and tweak what you’re doing. It’s not to tell you, “Listen stop that, do it like this” ... because you’ve already tried for a hundred times to teach the child in that way... so now it’s going to be more confusing if you have to completely change the way you’re doing it” **[Diversity in parenting styles].**

“But over time, I learned with the mistakes. And when I look backward, I say well sometimes at that point I was wrong. At that point, it was just my frustration plus the stress from work and... so I took everything... unnecessary things on myself” **[Trial-and-error parenting].**

“I want us as a family to be empowered, we must know that we are doing meaningful things with him. We’re guessing – we’re doing things... some things work, something’s don’t. We want guidance from a professional” **[Trial-and-error parenting].**

Caregivers reported wanting feedback for improvement in their parenting approach, wanting therapists to meet them where they were – in terms of the specific skills they needed to learn, and underlined that caregivers knew their children best:

“Because he’s my blood... you never dispel that... so for me the first prize would be um... teach me... and if you could have a program where you maybe you monitor me, maybe on a monthly basis in terms of how well I do... um with him... then rather to have this person [teach my son] um... yeah. Because – I’m saying... let’s say if you just come... let’s say if you would’ve come let’s say as the expert... the first prize would be teach me how to do that with my kid... then

if that can work maybe then ... you go and look for somebody else because the best person that would know how to do that would be you as a parent first. Because you'd want to have the best thing for him" **[Feedback for improvement]**.

"He's a good boy. And you as a parent you used to think that as well. But if somebody maybe could've teach me... I mean earlier... say that maybe you... you have to maybe interact, maybe you know does he look in your eyes, and things like that. Then, I mean I would've maybe do things better. Um... and not take for granted that no he's a quiet kid. And things like that... I mean... you know [what] I mean, and not wait until two and a half years when I don't see the words coming out. So it's good that you learn as parents how to... and I think earlier we learn better parenting techniques [the better] ... am I bad mother because he's on the autism spectrum? No. But could I've had done things better? If... yes I could have perhaps done things better... maybe and not take for granted that he's a sweet, quiet kid" **[Feedback for improvement]**.

"And then the mother would be telling the therapist he doesn't like this... she would get more out of the child then. So the participation there is coming from... sometimes you learn to know your kid so much better than any therapist would get to know them. So – working hand-in-hand... I find that that's another issue. Where the therapist might see it as what do you know? The child is here to learn what we are teaching the child, but you know... you're the parent. You're the parent or I'm the academic. So – maybe to get an even keel in terms of let's work together... it's the child's interest that we have at heart. So when come to...to an agreement... let's try it that way and begin to... and I find with lots of these... these therapists... you don't find that they're working together. But when you go to the State for their support... you don't... it's there way or otherwise you are just a spectator. And that's where the problem lies" **[Meeting the caregiver where they are at]**.

"Yeah... so first it [techniques] must make sense to you that is what I have learned. It makes sense to me, OK this is the reality... this is what I'm facing now. You understand? So this is the way I must go forward with it. So that's the main thing. Understanding first yourself, and then [teaching] your child" **[Meeting the caregiver where they are at]**.

"Something is in your child... even the therapist himself, he can't... you know... understand it [your child's condition] more than you because you are the parent and you understand your child more. You can break the barriers between you and your child" **[Caregivers know their children best]**.

3.1.11 Stigma

Stigma emerged as a theme reported by caregivers. Challenges identified included: being blamed for their “naughty” child’s behavior and societal stigma that results in isolation, secrecy, and shame:

“Like if I go to the movies and I want to get a ticket... my child is going mad. But like... somebody’s keeping him... like holding him down, and the teller will actually say, “Oh – your child’s naughty”, and so I’m like “No – he’s autistic.

He wants to be at Spur not knowing that the movie's on". So... so... so that you will say, "What's that [ASD]?" That's the problem that we have. That's why you can't take your kids to the mall... um... but yeah" **["Naughty" child]**.

"Listen – there's a reason why I don't take my child also to the mall like it is a nightmare. He wants to pull on everything. He just wants to run, and he can run fast. I mean yes I am an adult, but he can drain you. It is also the labeling... how they label your child. Like other parents will look and like... oh your child's naughty and things like that" **["Naughty" child]**.

"Because see for him not being able to talk now at this moment in the area where we're living at... we don't let... she don't let him actually to play outside. To be honest... because of with the children they are funny. They are funny with him. And, he don't actually know what's going on... he thinks that everything is normal, but like the children outside they will say like, "Oh he's so big but he can't talk", or then look at him funny. But then there's other children that will... that do understand, but the thing is that you get the nasty ones also. So for me also like you said... a long-term goal for him for him to be talking normal you know, and interact with other children... to normal stuff that a normal boy is supposed to do" **[Isolation]**.

"Yes – giving an example... um... my uncle...came with her friend's wife... they came for the treatment. The day that we were taking them to the airport, they came in from Angola. The wife stand right there, they said, "Oh guys, I want to tell you something. Please. Keep this information as a secret. Don't tell other people that my child has got [autism]... he's got epilepsy [say he as epilepsy]... he's fitting" **[Secrecy]**.

"Like now, I still buy the nappies [diapers]. But for me now it's difficult to buy a nappy... like I'm shy to carry a nappy because the people [in my neighborhood] know that's he's [my son] four. I just buy the nappies... if I am going to buy the nappies I must carry that bag... the Pick-N-Pay bag. And then I must cut it in the middle and make it two pieces, and then put it [the nappies] in that bag because I'm shy. But for my aunt – yo! She just carry the nappies as it is and then I said to my aunt, "Don't you think the people are asking themselves what's going on in that house?" and she said, "Aye! Fuck them" [laughs]. Because they can see [my son] with the underwear and the pants... why do they think that [my son] can wear a nappy, they won't think that. They will think maybe I'm going to a baby shower or something. Maybe after two months [laughs] when you are going to the baby shower each and every two months. She said, "Ha-ha. They won't care" **[Shame]**.

Stigma was felt from healthcare professionals (nurses and community health workers),

educators, family members, and the community at large:

"I think definitely you're gonna get the... the issue regarding the trust. Um... let's say somebody that knows you... it's almost like you know [with] HIV people don't go to the clinic if the sister is there at the clinic. I mean if I may make an example like that because unfortunately... some people are not at the level to understand what is autism all about. They... they will go out and tell the neighbor next door, "You know so and so's kid is this", and they don't even talk about autism" **[Healthcare professionals]**.

“Yeah but listen... people from Nyanga... I’m a medical doctor. I’ve been working in Mitchell’s Plain... I’m not working there anymore. I worked there. People from Nyanga [are] coming from Mitchell’s Plain clinic because they can’t go to Nyanga clinic. Because the nurse thinks they are neighbors. They know the nurses, but they [are] still afraid [of] the neighbor... she can still talk to [her] other friend and then you know [tell her] that she’s HIV positive. And so it is very difficult” **Healthcare professionals**.

“I used to hear them... they are people like nurses...that are working maybe in the clinic area when maybe they see people... they say, “Hey – that one is sick”. Yes – I’ve heard it happen to other people, but then now... that’s why I don’t want it to happen to me” **Healthcare professionals**.

“But for [using a] community worker... no. Maybe I’m walking or dressed nice, and she’s going to be like [points], “Look at that one there. She’s got a problem... blah, blah, blah” ... telling the other people about me. No – I prefer professional. I don’t want someone that lives in my area. I also don’t want that [working with someone from your community in your home], someone who is right there - who is in your community. They will spread the information... whatever is happening in your house. But the person who is taken from far [a different community], it won’t be as easy [to gossip]” **Healthcare professionals**.

“Because you [educators] can’t just take an autistic kid and you don’t know how [to deal with them]. And I mean they labeled him naughty and his behavior just went down... like he used to fight with the kids and things. And then I went to go fetch him one day, and one of the parents said um... the kids shouted “There’s X”... like my son... “That’s the one that hits us all”... And the parents like came to talk to me and then I told them the situation and she’s like, “Oh!”... now she knows that, she understands, and she can tell her kid how to respond to an autistic kid because they [other parents] don’t get told that... they [other parents] just get told [by the educators] - oh a kid hit my kid. So they just think that he’s naughty, they don’t know the whole story” **Educators**.

“When you tell somebody [in your family] he has autism, they’re like oh... they don’t know... they think you just crazy. Like they think your child is just being naughty or whatever the case may be. But they need to understand... because maybe your son doesn’t look you know like mentally retarded or something like that. So they just look [at them] like they’re naughty kids, but actually they’re not” **Family**.

“You... you know... it’s that our culture. He doesn’t want to come out of the box. So he [my uncle] said that this information [his child’s condition] must stay as it is. Um... the way the church where she’s going... the pastor tells her that, “No this is the devil”. He doesn’t know... you must do this, why are you putting all of this around your head? This is unnecessary. Take it away. Take it away. Just be free. But you know this culture thing... and as she said the awareness as well. It’s difficult... especially in the township like you said. It’s so sad... an innocent child that we have to give unconditional love but ...we discriminated her” **Community**.

“No we’re talking more about the community. Like okay you’ve got neighbors, but I [don’t] really... we don’t really socialize. They don’t know me... I don’t know them. We just say, “Hi” at the gate... you know. But in the community where people like the neighborhood is very important... some people they don’t

want the neighbor to know what is happening in the house. But the thing is the trust. The thing is the trust. She's still my neighbor... she will or can speak to the other people" **Community**.

4. Discussion

Culture was a relevant contextual factor when discussing the importance of adapting an early ASD intervention for the diverse, multicultural South African population. Language was reported to serve as both a facilitator and barrier when working to provide ASD care in a country with 11 official languages, highlighting the importance of matching families with therapists based on one's mother tongue or preference. For location of treatment the majority of caregivers identified in-home service delivery as the most appealing and convenient option. The existing cost of treatment was a burdensome contextual factor for parents. Cost of treatment thus appears to be an important factor to consider in the adaptation of an early intervention in this low-resource setting. Type of provider was an unexpectedly controversial topic. Caregivers expressed substantial distrust in sharing personal information with members of their own community, for example community health workers or local clinic nurses, out of fear of being the subject of gossip and ridicule in their neighborhood or township. Therapy tailored to familial needs was identified as important to caregivers of young children with ASD. Length of treatment further echoed this degree of flexibility and child-based individualization, as caregivers reported that the preferred intensity and length of an intervention was dependent upon the abilities and progress of their child. Interpersonal, relational, and community support was identified as crucial factor that impacted the coping and development of both the child with ASD and his or her family. Lack of awareness and acceptance of ASD was reported to limit access to potential support systems for families impacted by ASD. Evidence-based treatment was viewed as requirement by some and an incentive by others, showcasing diversity in terms of caregivers' willingness to participate in the development of ASD intervention development in the South African setting. Parenting practices were diverse, however, many participants expressed the desire to improve their current parenting skills in order to be better equipped to handle the difficulties associated with raising a child with ASD.

An interesting finding from this study was the emerging theme of stigma. Caregivers identified stigma as an important contextual factor that was not originally included in the study's focus group guide. Many expressed feelings of isolation, secrecy, and shame when describing the mislabeling of their child as "naughty" by family members and the community at large. A unique component of community-based stigma was that experienced from clinic nurses and community health workers. Participants drew comparisons between health-based stigma and breach of patient confidentiality for people living with HIV/AIDS in South Africa and what they had experienced or feared to experience when seeking care for their children with ASD.

While peer-reviewed publications on ASD intervention and family perspectives about ASD in sub-Saharan Africa remain sparse several contextual factors, presented in this study, are supported by the existing literature (Alli et al., 2015; Du Toit & Kok, 1999; Fewster & Gurayah, 2015; Gona et al., 2015; Mitchell & Holdt, 2014; Olivier & Hing, 2009). Gona and colleagues (2015) reported that culture was important to consider in an African setting where beliefs regarding traditional medicine and "being cursed" were prevalent. Parents' concern regarding lack of child skill generalization across settings has previously been reported (Alli et al., 2015). Two South African studies have noted the financial burden of raising a child with ASD (Du Toit & Kok, 1999; Mitchell & Holdt, 2014). Limitations in social support due to the lack of ASD knowledge have been reported (Du Toit & Kok, 1999; Fewster & Gurayah, 2015; Olivier & Hing, 2009). Two recent publications document caregivers' dissatisfaction with ASD service providers who do not provide individualized care (Du Toit & Kok, 1999; Fewster & Gurayah, 2015). It has also been previously reported that children with ASD in South Africa are frequently mislabeled as "naughty" kids and stigmatized in community settings (Du Toit & Kok, 1999; Fewster & Gurayah, 2015). While the majority of peer-reviewed ASD intervention literature conducted in Sub-Saharan Africa falls out of the scope of this study because none of the studies focused on an early ASD interventional approach (Akande, 1998; Akande, 1999; Akande, 2000; Alant et al.,

2013; Bunning et al., 2014; Geils & Knoetze, 2008; Louw et al., 2013; Pansegrouw & Alant, 1995; Silver, 1970; Travis & Geiger, 2010; Wong et al., 2014), the findings in the present study support the literature that found the incorporation of parent coaching into a therapeutic program to be considered acceptable by caregivers of children with ASD (Bunning et al., 2014; Pansegrouw & Alant, 1995).

This study adds to the current body of literature in several ways. Firstly, this study contributes the presentation of a variety of novel, detailed accounts and life experiences regarding rearing a child with ASD in Africa. This contribution to the broader ASD research literature base can serve to provide a greater knowledge of the lived experiences of a diverse, multicultural sample of families impacted by ASD living in a LMIC, a proportion of the global population that is vastly underrepresented in current ASD research. Secondly, the qualitative data analyzed provides detailed perspectives into not only caregivers' perceived importance of contextual adaptation, but also provides a range of challenges, sources, and preferences relevant to 11 specific contextual factors, all of which were spontaneously raised by caregivers during discussion. Finally, it is important to note that this is the first study to explore caregivers' perspectives of contextual factors relevant to the adaptation of an early ASD intervention in sub-Saharan Africa. Therefore, it adds to a growing body of literature on the adaptation of early ASD interventions in low-resource global settings (Divan et al., 2015; Rahman et al., 2016).

4.1 Implications for Practice

Based on qualitative caregiver report, caregivers desire affordable, in-home, individualized early ASD intervention, where they have an active voice in shaping treatment goals. Caregivers distrust community based nurses and community health workers to deliver an early ASD intervention. Stigma is prevalent and is an important factor to take into account when adapting an early ASD intervention for a South African setting.

4.2 Implications for Further Research

Several key findings were spontaneously raised by study participants, particularly the issue of stigma. Caregivers expressed distrust of community health workers and clinic. Caregivers expressed a preference for being served by professionals living outside of their local community. In order to enhance the chances of developing an early ASD intervention that will be acceptable and feasible within the existing system of care in South Africa, an important next step would be to explore which sector (e.g. health, education, social development, or the non-profit sector) and what type of provider (e.g. early child development workers, community health workers, preschool/crèche staff, or the Western Cape autism outreach team) will be the most feasible and sustainable to deliver a caregiver-mediated early ASD intervention.

4.3 Study Strengths and Limitations

The strengths of the present study reside both in the sample and methodology. Firstly, the sample was diverse which allowed for a rich exchange of dialogue amongst participants, with a range of perspectives being reflected. The sample included caregivers that differed in terms of their age, gender, native language, religion, race, ethnicity, socioeconomic status, and educational level. In addition, the caregivers in the sample represented children diagnosed with ASD that differed in terms of their age, gender, age at diagnosis, and ASD severity. Secondly, the qualitative focus group discussions were active, well-attended, and provided rich detail of relevant contextual factors.

There are several limitations that may have impacted the results of this study. Firstly, given the general dynamics of focus group discussions, some participants may have been more vocal than others, while others may have felt uncomfortable disclosing personal information in a group setting. This is particularly of concern when grouping diverse individuals together for discussion that come from very different cultural or socioeconomic backgrounds. Specific focus group moderation techniques were utilized to encourage the equal participation of all focus group

participants, however, the potential participant bias of the data cannot be discounted. Another limitation to this study was the general lack of caregiver knowledge and unfamiliarity with research practices that arose throughout data collection. Participants that expressed a lack of knowledge in terms of specific concepts or topics required additional prompting and explanation. In addition, specific measures had to be taken to properly moderate group discussion to avoid participants digressing.

5. Conclusion

Despite the vast importance in the implementation of early ASD interventions and the benefits that can be gained through the utilization caregiver perspectives to inform the treatment of ASD, there continues to be a substantial lack of research conducted on these topics in LMICs, leaving many unanswered questions and limiting the generalizability of the current evidence base. This study set out to explore this gap in knowledge through the collection of caregivers' perspectives relating to the impact of contextual factors on the adaptation of a parent-mediated early ASD intervention to be used in a low-resource South African setting. The detailed qualitative data collected during focus group discussions presented a clear caregiver preference for an affordable, individualized, parent-mediated early ASD intervention that can be delivered in a home-based setting. Beyond this preference, distinct contextual challenges were raised by participants that have not been previously reported in the literature, including distrust of community-based service providers as well as diverse sources of ASD-based stigma. Collectively, these findings present a clear call-to-action regarding the importance of developing acceptable, culturally appropriate, and feasible early ASD interventions that can be contextually adapted to diverse low-resource and underrepresented communities around the world.

Appendix A

FOCUS GROUP QUESTIONS – PARENTS/CAREGIVERS

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]
 - 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. 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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