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The importance of context in early autism intervention: A qualitative South African study

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Abstract

The majority of individuals with autism spectrum disorder live in low- and middle-income countries and receive little or no services from health or social care systems. The development and validation of autism spectrum disorder 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 low- and middle-income countries. This study qualitatively explored contextual factors relevant to the adaptation of a caregiver-mediated early autism spectrum disorder intervention in a low-resource South African setting. We conducted four focus groups and four in-depth interviews with 28 caregivers of young children with autism spectrum disorder and used thematic analysis to identify key themes. Eight contextual factors including culture, language, location of treatment, cost of treatment, type of service provider, support, parenting practices, and stigma emerged as important. Caregivers reported a preference for an affordable, in-home, individualized early autism spectrum disorder intervention, where they have an active voice in shaping treatment goals. Distrust of community-based health workers and challenges associated with autism spectrum disorder-related stigma were identified. Recommendations that integrate caregiver preferences with the development of a low-cost and scalable caregiver-mediated early autism spectrum disorder intervention are included.

Keywords

autism spectrum disorder; caregivers; contextual factors; early intervention; focus group; low- and middle-income country; qualitative methods; South Africa

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Introduction

Autism spectrum disorder (ASD) is considered a major global public health challenge and the majority of individuals with ASD live in low- and middle-income countries (LMICs), such as South Africa, and receive limited services from health or social care systems (Abubakar et al., 2016; De Vries, 2016; De Vries and Bölte, 2016; Franz et al., 2017; Khan et al., 2012). ASD has been 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 is from the United States and other high-income countries (Elsabbagh et al., 2012; Khan et al., 2012). This lack of evidence from LMICs presents a substantial gap in knowledge regarding the majority of the global ASD population (Elsabbagh et al., 2012). Furthermore, there is a need for ASD research in sub-Saharan African settings given that less is known about the prevalence and treatment of ASD in Africa than on any other continent in the world, and many African people with ASD urgently need services (Abubakar et al., 2016; Ametepee and Chitiyo, 2009; De Vries and Bölte, 2016; Franz et al., 2017).

Early intensive behavioral intervention for young children with ASD has been shown to reduce the severity of 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). Neural plasticity of the young brain may account for the effectiveness of such early ASD treatment practices (Dawson, 2008; Dawson and Zanolli, 2003). The majority of evidence supporting the efficacy of early ASD intervention lies in the implementation of intensive programs that are delivered by highly skilled professionals (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 et al., 2012). Involving caregivers in treatment delivery has been suggested as a possible mechanism to combat the financial and human resource barriers that 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; Reichow et al., 2013). In addition, emerging evidence supports the effectiveness of caregiver-mediated early ASD interventions in low-resource settings (e.g. Divan et al., 2015; Kasari et al., 2014; Rahman et al., 2016).

Caregiver insight into the needs of their children, their families, and the broader ASD community (Mereoiu et al., 2015) could help to inform ASD treatment practices. For example, caregiver perspectives of ASD treatment can demonstrate which factors support or hinder service delivery (Stadnick et al., 2013). Caregivers of children with ASD report significant economic and emotional impact of care, and higher rates of caregiver stress in comparison to families of children with other developmental disabilities (Abbeduto et al., 2004; Estes et al., 2009). The importance of caregiver perspectives appears to be gaining traction. Of the 13 peer-reviewed articles of ASD caregivers' perspectives in sub-Saharan Africa published to date, 12 have been published in the past 10 years (Alli et al., 2015; Ambikile and Outwater, 2012; Du Toit and Kok, 1999; Fewster and Gurayah, 2015; Gona et al., 2015, 2016; Greeff and Van der Walt, 2010; Kapp and Brown, 2011; Meiring et al., 2016; Mitchell and Holdt, 2014; Olivier and Hing, 2009; Schlebusch et al., 2016; Tilahun et

al., 2016). In these articles, caregivers report (1) personal challenges that include their own emotional distress (Fewster and Gurayah, 2015), family routines and quality of life (Schlebusch et al., 2016), lack of family support (Du Toit and Kok, 1999; Olivier and Hing, 2009), difficulties managing children's growth and development (Alli et al., 2015), and stigma and shame regarding their child's condition (Ambikile and Outwater, 2012; Gona et al., 2016; Tilahun et al., 2016); (2) challenges related to interacting with the health care system that include delayed diagnosis and treatment (Mitchell and Holdt, 2014), lack of support from providers (Du Toit and Kok, 1999; Olivier and Hing, 2009), lack of support for the adolescent to adult transition (Meiring et al., 2016), and the influences of traditional medicine on treatments received (Gona et al., 2015); and (3) factors that promote resilience (Greeff and Van der Walt, 2010; Kapp and Brown, 2011). No publication to date has reported on caregiver perspectives on contextual factors of importance for effective and sustainable early ASD intervention.

To date, 12 peer-reviewed manuscripts on ASD intervention have been published in sub-Saharan Africa (Akande, 1998, 1999, 2000; Alant et al., 2013; Bello-Mojeeed et al., 2016; Bunning et al., 2014; Geils and Knoetze, 2008; Louw et al., 2013; Pansegrouw and Alant, 1995; Silver, 1970; Travis and Geiger, 2010; Wong et al., 2014). These studies examined a variety of therapeutic approaches (e.g. operant conditioning, augmentative and alternative communication, and pharmaceutical drug therapies). Three of the studies incorporated a parent-coaching component (Bello-Mojeeed et al., 2016; Bunning et al., 2014; Pansegrouw and Alant, 1995). To date, there have been no publications on caregiver-mediated early interventions, in which parents are trained to deliver therapeutic intervention to their child, in sub-Saharan Africa.

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 et al., 2012; Wang et al., 2011). If one chooses to adapt an intervention for a different setting, it is important to consider contextually relevant factors that would inform the adaptation (Daley et al., 2013). Qualitative studies may be helpful in assessing the perceptions of caregivers of children with ASD (Al-Busaidi, 2008; Cridland et al., 2015). The objective of this study was to explore the perspectives of South African caregivers of young children with ASD, assessing which contextual factors they deemed important to consider in early ASD intervention. A broader goal of this study was to inform the process of adaptation of caregiver-mediated early ASD intervention for new contexts.

Methods

Setting

The study was conducted in Cape Town, South Africa. Cape Town is the second largest city in South Africa with a population of approximately 3.74 million people (Statistics South Africa (SSA), 2012). One in four people in Cape Town are unemployed, 54% did not graduate from high school, and 47% live below the poverty line (SSA, 2012). In all, 42% of the population in Cape Town describe themselves as "Colored" (a South African term for mixed-race), 39% as "Black African," 16% as "White," and 1% as "Indian or Asian" (SSA, 2012). There are 11 official languages in South Africa. In all, 41% of individuals living in

Cape Town speak Afrikaans as their first language, while 28% speak isiXhosa, and 27% speak English as first language. The remaining 4% of the Cape Town population report their first language to be isiNdebele, isiZulu, Sepedi, Sesotho, Setswana, SiSwati, Tshivenda, Xitsonga, or a foreign or non-official South African language, such as Arabic or French (SSA, 2012).

South Africa is a country marked by social and economic disparities (SSA, 2014). These disparities are evident in the national public health sector which provides care for approximately 84% of the South African population, but is staffed by only 30% of the medical workforce in the country (Mayosi and Benatar, 2014). Annual per capita expenditure on health in the private sector is approximately 10 times that of the public sector (Coovadia et al., 2009). In the Western Cape Province, the site of this study, like most places in sub-Saharan Africa, access to ASD assessment and intervention services is extremely limited (Franz et al., 2017; Van Schalkwyk et al., 2016). The typical path to an ASD diagnosis includes evaluation in a primary care clinic and referral to a tertiary level neurodevelopmental clinic where the wait time for a clinical diagnosis of ASD is approximately 18 months. The only published study from the Western Cape Province that reports characteristics of children with a pervasive developmental disorder diagnosis attending a public developmental clinic notes a median age at diagnosis of 42 months (range: 15–106 months) (Springer et al., 2013). In this retrospective case review, a significantly higher proportion of Black African children were non-verbal at diagnosis (94%) compared with children of mixed ethnic heritage (77%) and Caucasian children (42%). The maternal education level of the sample was higher compared to parents of children attending other clinics in the same hospital. The racial variation in verbal ability at diagnosis was purported to be due to socioeconomic barriers to care (Springer et al., 2013).

Following diagnosis, children's names are added to the Western Cape Education Department waiting list for public sector special education services. There are currently more than 500 children on the "autism waiting list" in the Western Cape Province for public sector special education services and the current estimated wait time for enrollment in ASD-specific schools is over 3 years. In South Africa, the statutory school-going age is 7 years and no government preschools exist. Therefore, no child with ASD under the age of 7 years has access to public sector educational programs (Van Schalkwyk et al., 2016). ASD therapeutic services within the public health sector are extremely limited. While some children with ASD who are served in public sector have access to low-intensity intervention (e.g. one 30-min session per month of either speech or occupational therapy), waiting lists for these services range from 1 to 6 months and many children with ASD do not receive these services at all. Even in the private sector, services vary in quality and many are not evidence-based. Furthermore, private sector special education preschools are available in the Western Cape Province, but require caregivers to pay out-of-pocket for all service expenses.

Participants

Participants included 28 caregivers of young children (7 years or younger) with ASD. In all, 22 caregivers participated in focus group discussions, and six caregivers took part in in-depth interviews. Mothers (n = 20), fathers (n = 5), and grandmothers (n = 3) participated.

The sample consisted of caregivers from diverse cultural and ethnic backgrounds (Table 1). 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 ASD aged 7 years or younger and (2) have the ability to travel to the Division of Child and Adolescent Psychiatry at the University of Cape Town (UCT) for the interview or focus group. Language was not considered as an exclusion or inclusion criterion due to the availability of multilingual translators on the research team. Focus group participants were recruited via convenience sampling from the Western Cape Education Department autism waiting list for special education services. During recruitment, participants were contacted via telephone off the Western Cape Education Department autism waiting list if they had a child aged 7 years or younger and were asked if they would like to participate in the study. If they agreed, participants were assigned a date to participate in a caregiver focus group discussion. Participants in the focus groups varied in their level of engagement with ASD intervention services. All participants had access to public sector low-intensity intervention (e.g. one 30-min session per month of either speech or occupational therapy) provided by the South African Department of Health. A minority of participants payed out-of-pocket for additional services (e.g. applied behavior analysis or special education preschool). None of the focus group participants had previous experience with a caregiver-mediated early ASD intervention. As part of a pre-pilot study, four Cape Town families participated in two “taster” sessions of a caregiver-mediated early intervention. The sessions included one clinic and one in-home parent-coaching session. Both sessions were 60 min in length. Given that these families had received the “taster” experience, we were keen to evaluate their perceptions separately from the views of other caregivers of young children with ASD. For this reason, in-depth interviews were conducted with each of these families, approximately 4 months after their “taster” sessions.

Focus group and in-depth interview guides

The focus group guide contained 32 open-ended questions, the choice of which were informed by previous focus groups with parents of young children with ASD (e.g. Stahmer et al., 2011), as well as input from South African co-investigators. In this article, only data relating to one component of the qualitative guide were incorporated in the analysis, which focused on whether contextual factors were relevant to the adaptation of an early ASD intervention in South Africa. The contextual factors from the focus group guide that were explicitly brought up by the focus group facilitators and elicited for discussion by participants included culture, language, location of treatment, cost of treatment, type of provider, parenting practices, length of treatment, support, proof that a treatment works, and familial needs. Example question items include “Do you think culture is or is not important when making an autism treatment for families in South Africa?” and “Do you think how much time it takes to learn a treatment is or is not important when making an autism treatment for families in South Africa?” Several other topics were also discussed during the focus groups, that fall out of the scope of this article, including caregivers’ perceptions of (1) short- and long-term goals for their child’s development; (2) educational, therapeutic, and medical services their child received; (3) what an “ideal” ASD intervention would look like; (4) whether or not early ASD interventions are perceived as important; (5) description of typical parent-child play; (6) acceptability of a caregiver-mediated early ASD intervention

model; and (7) utility and appropriateness of using videos or photographs to record families participating in ASD interventional research.

Four in-depth interviews were conducted with six participants. Two of the four interviews were conducted with two participants at once (husband–wife and mother–daughter). The in-depth interview guide contained 36 open-ended questions, many of which were identical to the questions asked in the focus group discussions. Additional in-depth interview questions explored caregivers' perceptions of the feasibility of a caregiver-mediated early ASD intervention model.

Procedure and data collection

All study procedures were approved by the ethical review boards at Duke University and the UCT (Duke IRB Pro00062592 and UCT HREC 039/2015). Prior to data collection, the research was explained to each participant by a research assistant and the participants signed an informed consent. A handheld audio-recording device and video-recording equipment captured the focus groups and interviews. One focus group and one interview was conducted almost entirely in isiZulu and were moderated by a Zulu-speaking member of the research team. The other focus groups and interviews were conducted almost entirely in English; however, when participants were not able to find the correct expression in English, they were encouraged to use isiXhosa or Afrikaans phrases.

The in-depth interviews and focus groups were held in a small private space. Each interview and focus group was moderated by at least one member of the South African research team. They lasted between 1 and 3.5 hours in length. All participants received ZAR100 (approximately US\$7), as a “thank you” and to cover travel expenses.

Data analysis

Data were transcribed verbatim and cross-checked for accuracy. The focus group and interview that were conducted in isiZulu were transcribed and translated into English by a native isiZulu speaker. In addition to isiZulu, there were several phrases spoken by participants in isiXhosa and Afrikaans. These phrases were transcribed and translated into English by native isiXhosa and Afrikaans speakers. All identifiable information, such as the names of people or local organizations, were removed in the final transcriptions.

After transcription, all data were read by two members of the research team, who were trained in qualitative coding procedures through formal coursework and consultation with qualitative experts. The data were analyzed via thematic analysis utilizing version 11 of the NVivo software package (QSR International, 2012). Thematic analysis is a systematic process that involves making inferences by analytically and objectively identifying emerging patterns in written transcriptions of recorded data (Braun and Clarke, 2006). After reviewing all the transcripts several times, the two coders created tentative labels for data based upon thematic meanings that were emerging from the data and then identified relationships between those labels to develop a hierarchy of thematic codes. After discussion of these codes, a project-specific master codebook was developed that compiled all the thematic codes in an electronic format. After importing the master codebook into NVivo, a series of procedures were implemented to code the transcripts with the codebook while still allowing

for the emergence of novel themes, or new codes that were not included in the original master codebook. Each coder independently reviewed one transcript at a time, coding for themes with the codes in the master project codebook. Each coder independently reviewed each transcript twice to ensure comprehensiveness of their qualitative coding. While coding each transcript, each coder made note of any novel themes that required discussion on whether they should be added to the master codebook.

Once each coder independently completed coding each transcript, the inter-coder reliability was calculated. Additional codes were added to the master codebook upon discussion between the reviewers and any coding discrepancies were resolved. This iterative double-coding process was implemented for all eight transcripts (e.g. the study's four focus groups and four in-depth interviews), one at a time, to code salient emergent themes. The average inter-coder reliability score for all coded data was 0.79, indicating reliability for the development of a comprehensive master codebook.

Upon completion of data coding, an in-depth analysis of contextual factors was performed. The data were examined to identify recurring themes and subthemes. Data analysis occurred through queries run in NVivo to identify representative quotes and develop thematic summaries.

Results

The analysis focused on the exploration of caregiver perspectives of important South African contextual factors potentially relevant to an early ASD intervention. In all, 10 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, and parenting practices. Stigma emerged spontaneously as a relevant contextual factor. The contextual factors of familial needs, length of treatment, and evidence-based treatment did not produce sufficient data to be relevant for discussion, suggesting that participants did not consider these factors important for contextual adaptation. Therefore, those three factors were not included in the results. Table 2 illustrates the eight contextual factor themes and their corresponding subthemes. Each of the highlighted contextual factors will be discussed in detail.

Culture

Caregivers cited culture as “quite important” and noted that it requires “sensitivity.” Culture-specific challenges identified included the multicultural South African population, immigrants and refugees, traditional beliefs about being cursed, and the importance of respecting and incorporating familial culture into the therapeutic process. The caregivers described the challenges associated with the multicultural South African population by describing South Africans as “very different (from one another)” both in their backgrounds and beliefs. The majority of caregivers felt that providers should demonstrate sensitivity and an understanding of families’ cultural beliefs and practices and incorporate this knowledge when working with their family or their child. For example, caregivers noted that treatment approaches for teaching caregivers how to toilet train their child may need to be adapted based upon a family’s cultural background.

Caregivers also highlighted certain cultural beliefs in South Africa regarding children with ASD being cursed, with a caregiver stating, “people will think that my child (with ASD) has been bewitched or ... bad things happened in our house ... maybe my aunt is not happy with me and she just cursed my child or cursed me or something.” Similarly, one caregiver reflected on how her mother and other women in her community denied her child’s diagnosis and believed that there were spirits trapped in her son’s throat that needed to be released through traditional practices of cutting so that he could speak. This caregiver explained that she “felt confused” during this time. She concluded that it was only through receiving information about ASD from health care providers at a hospital that she realized her son’s challenges were “not just a problem in his throat, that it was more than that.” Another caregiver described the impact of traditional beliefs about being cursed on ASD treatment:

The only problem we see ... you know in our townships, in our African (townships) ... people strongly believe in you know, “I’ve been bewitched, my child is not (sick).” Another therapist told us, “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.

Language

Language was reported as a “problem” and a potential “barrier” that can cause one to feel “bored or offended,” and can discourage participation. The 11 official languages spoken in South Africa and numerous additional languages spoken by immigrants and refugees were identified as a significant challenge. One caregiver described the daily challenges she experiences caring for her child with ASD in a multilingual community:

It is a problem for me ... the (many) languages. 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 isiXhosa, and then he’s um ... his uncle’s wife is a coloured (speaks Afrikaans) ... so we’re (all) teaching him another language and then the Xhosa (teacher) is teaching him another language. So he’s confused. It’s confusing for him.

Caregivers reported differences in their language preference for therapeutic service delivery, including instruction in English, instruction in the family’s native language, and indecision regarding which language would be most effective. However, English was most frequently reported as the preferred language, with some caregivers stating that they would like to learn English alongside their child. Caregivers who preferred their children to be taught in their family’s native language felt that their child could not be an active member of their household or community if they could not speak and understand his or her native language.

All of the caregivers felt that it was important to teach a child in whatever language his or her caregiver wanted their child to speak. Caregivers wanted the therapist to be matched to a family based on language. In addition, they wanted children to receive one language of

instruction across therapeutic and educational settings, as they felt this would prepare their children for school or being outside of the home. A caregiver described this preference:

I can also recommend others to teach their children in what (language) they are going to meet outside (of the home). Otherwise, if he (speaks one language) at home and gets a different language outside ... he's not going to perform well.

Location of treatment

Location of treatment was frequently discussed during the focus groups. Lack of skill transfer between settings (i.e. from clinic to home) was identified as a challenge. One caregiver noted:

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)?

Caregivers identified limited space, lack of materials/resources, and chaotic home environments as location-specific challenges. Many of these challenges arose from familial financial constraints or living in informal dwellings. One caregiver provided an example of the limited resources and space he had at his home in relation to teaching his son a feeding routine:

Like with the feeding. I don't know if I can call it an American way or something ... they think every child must have a table and two chairs ... and a fork ... which is most of us ... we don't even have that ... we don't even have space for them like you see.

Reported location preferences included in-home delivery, clinic or hospital delivery, a combination of in-home and a clinical setting, and school-based delivery. In-home delivery was most frequently reported as location preference, with caregivers noting its convenience and the fact that it would allow therapists to understand the family's living situation and their child's behavioral challenges in the home.

Cost of treatment

Cost of ASD treatment was raised as an important issue. One caregiver noted, "if you can't pay your way out (of ASD) ... you can't help your child." Cost-related challenges included existing financial burden of raising a child with ASD, lack of governmental financial support, and little disposable income due to poverty and/or being a single parent. Nearly, all of the caregivers described their children with ASD as "very expensive," with one caregiver stating that her "son's therapy costs more than (her) bond (mortgage)." Another caregiver further illustrated these financial challenges:

I have no choice because my finances limit me. So we need also to think about what we can do in this regard. If this family got this (financial) problem, how can we help them to raise their finances so that they can get the needs of their child (met). Because these kids are very expensive.

Caregivers reported that they would like services to be all-inclusive with no hidden costs, be subsidized and available to all children with ASD irrespective of their ability to pay for these services. A caregiver noted specific ways in which costly therapeutic materials could be replaced with local materials:

Even if it can be traditional ... you know ... an example ... this seat. There are plastic chairs that we find in the shop. They might be very expensive, but there is a way of having a small wood and 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 it's ... we need to focus on something that is helpful to local South African people.

Type of service provider

Caregivers cited type of provider as an important issue that impacts the quality and acceptability of ASD services. Provider occupational preferences included speech therapists, occupational therapists, and other parents of children with ASD. A significant proportion of caregivers did not wish to receive any services from community health workers, who were perceived as less professional and more likely to have high turnover. Specific emphasis was given regarding distrust of community health workers who lived in the same community as the caregiver. A caregiver reported:

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.

Differences were reported among caregivers on the importance of having credentials or university-based training as opposed to experience working with children with ASD. For example, one caregiver stated:

I prefer the professional. Because he know 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 other things if maybe I'm not coping.

Another caregiver stated, "It isn't necessary that they have to have the qualifications. It's the experience more than qualifications."

Support

Support-related challenges included broken family structures, single-parent households, co-parenting from different households, and low awareness of ASD perceived by caregivers resulting in limited support. The challenge of low awareness of ASD was frequently discussed:

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.

Sources of support (or lack thereof) included spouses/partners, grandparents, other parents of children with ASD, extended family, ASD service providers, and the community. Spousal/partner support was the most frequently reported source of support; however, inconsistencies were common. One couple commented on how they reached a place of support and understanding in their relationship:

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 (our 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.

Extended family, when present and available, was depended upon to provide support, advice, and approval. Other parents of children with ASD were also identified as a valuable support network. Caregivers also cited ASD service providers as a source of support, especially when it came to explaining an ASD diagnosis to one's spouse or extended family.

Parenting practices

Themes identified included diversity in parenting styles, trial-and-error parenting, differences between parenting a child with ASD and a typically developing child, and corporal punishment. Caregivers frequently spoke about the need to adapt traditional parenting practices, such as disciplinary techniques, for their child with ASD. One caregiver described this challenge in relation to having typically developing children before having a child with ASD:

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. 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."

In addition to the above themes, caregivers wanted feedback for improvement in their parenting approach. However, they wanted therapists to meet them where they were—in terms of the specific skills they needed to learn, and underlined that as caregivers, they knew their children best:

Because he's my blood ... you never dispel that ... so for me the first prize would be um ... teach me ... 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.

Stigma

Stigma emerged spontaneously as a theme. Caregivers reported being blamed for their child's behavior, their children being labeled as "naughty," experiencing stigma due to immigrant or refugee status, as well as encountering societal stigma that resulted in caregiver isolation, secrecy, and shame. One caregiver shared, "other people don't understand your situation, and they think your child is naughty, or you don't teach your child the proper manners." Caregivers noted the high frequency in which their children were labeled as "naughty" by extended family, educators, health care professionals, and the outside community:

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 (restaurant) not knowing that the movie's on." That's the problem that we have. 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.

Caregivers described the stigma they experienced when rearing a child with ASD. One caregiver described going to great lengths to hide nappies (diapers) in her grocery bag as she did not want her neighbors to know her son was still wearing them. Another described:

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 they 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.

Stigma was experienced by caregivers from health care professionals, educators, family members, and the community at large. One caregiver described:

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 my community in my 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 ... in a different community, it won't be as easy to gossip.

As previously noted, community health workers were also noted as a source of stigma. Family members were cited as a frequent source of stigma, with one caregiver stating:

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.

The community was most frequently reported to be one of the main sources of stigma. One caregiver reported:

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 ASD) must stay as it is ... a secret. 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. 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.

Discussion

In this study, caregivers provided qualitative feedback and endorsed eight contextual factors important to consider for early ASD intervention in South Africa. South Africa is a multicultural, multilingual country and these factors serve as both a facilitator and barrier when working to provide ASD care. Sensitivity to a family's culture and matching therapist to family by language emerged as a preference. However, most caregivers also wanted the language of therapy instruction to be English. The majority of caregivers identified in-home service delivery as the most appealing and convenient option, if available. The existing cost of ASD treatment was burdensome for families, and thus intervention cost appears to be an important factor to consider in this setting, where many families have limited financial resources. In terms of the type of provider families wanted to work with, some expressed distrust of community health workers or clinic nurses, due to previous experiences of being the subject of gossip and ridicule, with a specific disinterest in working with community health workers who lived in their own community. Interpersonal and community support was identified as a crucial factor that influenced caregiver coping. Low community awareness of ASD was reported to limit access to potential support systems. Parenting practices were diverse, but many participants expressed the desire to improve their parenting skills to be equipped better to handle the difficulties associated with raising a child with ASD, thus suggesting that a parent-training approach may be acceptable in this setting. An interesting finding from this study was the recurring theme of stigma that was brought up by the focus group participants and was not originally included in the study's question guide. Similar to other qualitative research conducted in sub-Saharan Africa (Ambikile and Outwater, 2012; Gona et al., 2016), caregivers expressed feelings of isolation, secrecy, and shame when describing the mislabeling of their child as "naughty" by family members and the community. A unique contextual component of South African community-based stigma reported by participants was that experienced from clinic nurses and community health workers (Republic of South Africa Department of Health, 2011), in which participants drew comparisons between the stigma they felt from having a child with ASD to health-based stigma and breach of patient confidentiality for people living with HIV/AIDS in South Africa. While South Africa only has 0.7% of the world's population, it has approximately

17% of the global burden of HIV infection (Karim et al., 2009). Much of the care for those living with HIV/AIDS is provided by clinic nurses and community health workers (Treves-Kagan et al., 2016). The effects of HIV/AIDS on the South African community, even in the context of developing an early intervention for ASD, remain highly relevant.

While peer-reviewed publications on ASD intervention and family perspectives in sub-Saharan Africa are somewhat limited, several contextual factors from this study are supported by the existing literature. Gona et al. (2015) reported that culture was important to consider in an African setting where beliefs regarding traditional medicine and “being cursed” were prevalent. Two South African studies have noted the financial burden of raising a child with ASD (Du Toit and Kok, 1999; Mitchell and Holdt, 2014). Limitations in social support due to the lack of ASD knowledge have been previously reported (Du Toit and Kok, 1999; Fewster and Gurayah, 2015; Olivier and Hing, 2009). Two publications document caregivers’ dissatisfaction with ASD service providers who do not provide individualized care (Du Toit and Kok, 1999; Fewster and Gurayah, 2015). It has been previously reported by caregivers that children with ASD in sub-Saharan Africa are mislabeled as “naughty,” stigmatized in community settings, and attributed with explanatory models for the etiology and curability of their condition (Ambikile and Outwater, 2012; Du Toit and Kok, 1999; Fewster and Gurayah, 2015; Gona et al., 2015, 2016; Tilahun et al., 2016). ASD intervention literature conducted in sub-Saharan Africa supports the idea that parent coaching may be acceptable to caregivers of children with ASD (Bello-Mojeed et al., 2016; Bunning et al., 2014; Pansegrouw and Alant, 1995), but has neglected to focus on what contextual factors may support or impede such interventions.

This study adds to the current body of literature in several ways. First, it provides a detailed account of the lived experiences of a diverse, multicultural sample of families impacted by ASD in South Africa, a proportion of the global population that is vastly under-represented in ASD research (Elsabbagh et al., 2012; Franz et al., 2017). Second, it highlights key contextual factors that should be considered in early ASD intervention programs in this setting. Third, the intersection of stigma and provider type, particularly caregivers’ aversion to receive ASD intervention services from community health workers from their local community, has public health implications when deciding on which type of provider to train in early intervention strategies in South Africa.

In an effort to integrate caregiver preferences outlined in this article with the development of a sustainable, low-cost early intervention, the following is recommended: (1) given the diversity of languages spoken in South Africa and caregivers reporting indecision regarding what language would be best to use with their child, it is important that caregivers are informed that bilingualism does not negatively affect language development in young children with ASD (Hambly and Fombonne, 2012; Reetzke et al., 2015; Valicenti-McDermott et al., 2013). Regardless of the language therapists or teachers use with their child in other settings, it is imperative that caregivers provide their children with rich, developmentally appropriate language input that connects the child culturally and socially with their communities. (2) The selection of the type of nonspecialist to deliver early ASD intervention in South Africa should be made with care, as trust in community-based workers and clinic nurses appears to be eroded in this setting, and may impact community utilization

of services. (3) Caregiver-mediated ASD interventions should incorporate strategies that assist caregivers in identifying, strengthening, and mobilizing their social support networks. Strategies may include caregiver-coaching sessions that train more than one parent or caregiver online or in-person support groups among cohorts of families participating in an intervention. The feasibility of online support services is suggested by the growing number of Internet users in South Africa, which is currently estimated to be over 50% of the population (International Telecommunication Union (ITU), 2016). (4) In an effort to combat stigma, establishing or strengthening partnerships with local, national, and international non-profit organizations and other agencies to improve awareness of developmental disorders and advocate for improved access to effective intervention services is warranted (e.g. similar to other global initiatives such as the WHO (2008) mhGAP programme). Furthermore, given caregiver report of the influence of traditional medicine on individuals' beliefs regarding the etiology and curability of ASD, it may be important to consider the collaborative role traditional healers could play in helping to combat the stigma of having a child diagnosed with ASD in South Africa (Gureje et al., 2015). (5) Finally, in order to develop an early ASD intervention that will be acceptable and feasible within the existing system of care in South Africa, it is important to consider the ways in which local belief systems and parenting practices may influence effective parent-training interventions. Furthermore, we must explore which sector (e.g. health, education, or the non-profit sector) and what type of provider (e.g. early child development workers, community health workers, or preschool/ crèche staff) would be the most feasible and sustainable to deliver a short-term caregiver-mediated intervention. It is important to acknowledge that the preference for treatment setting (e.g. in-home vs. in a clinic) and credentials of a service provider (e.g. university educated) expressed by some caregivers in this study are likely incompatible with a low-cost, scalable early autism intervention in a low-resource setting (Tekola et al., 2016; Thornicroft et al., 2010).

There are several limitations that may have impacted the results of this study. The study's sample may not be representative of all caregivers of children with ASD living in the Western Cape, given that participants were recruited using convenience sampling procedures. 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. Specific focus group moderation techniques were utilized to encourage the equal participation of all focus group participants; however, this potential bias 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. This may have contributed to participants engaging in off-topic conversations with other participants during the focus groups. Explicit instructions regarding research procedures as well as the process that would be used to conduct the focus groups were provided to all study participants prior to data collection. In addition, general reminders were used to keep participants on track when discussion digressed to off-topic conversation.

Conclusion

This was the first study to explore caregiver perspectives of contextual factors relevant to the adaptation of an early ASD intervention in sub-Saharan Africa. This qualitative data

presented a caregiver preference for an affordable, individualized, early ASD intervention where caregivers are trained to work with their children in a home-based setting. Contextual challenges raised by participants included distrust of community-based health service providers as well as the intersection of diverse sources of ASD-related stigma in South Africa. As early ASD intervention emerges as an area of increased focus in sub-Saharan Africa, it will be important to integrate locally relevant contextual data into early intervention approaches and find ways to balance contextual factors raised by caregivers with the development of low-cost, sustainable caregiver-mediated early autism interventions.

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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 ^a	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.

^aColored is a South African ethnic label for individuals with mixed ethnic heritage.

Table 2

Eight contextual factor themes with listing of subthemes.

Themes	Subthemes
Culture	Multicultural South African population Immigrants and refugees in South Africa Traditional beliefs about being “cursed” Respecting and incorporating familial culture
Language	Eleven official South African languages Languages of immigrants and refugees Preferences (English, native language, undecided) Matching therapists to families by languages One language of instruction
Location of treatment	Lack of skill transfer between settings Limited space at home Lack of materials/resources at home Chaotic home environment Preferences (home, clinic, hospital, school, combination of home and clinic) Benefits of home-based therapy (convenient, understanding family’s situation, understanding child’s behavioral challenges)
Cost of treatment	Existing financial burden of raising a child with ASD Lack of governmental financial support Little disposable income (poverty, single-parent families) Preferences (all-inclusive with no hidden costs, subsidized, available to all) Use of local materials
Type of service provider	Preferences (speech therapist, occupational therapist, other parent of a child with ASD) Not a community health worker from the same community Needs a college degree or certificate Needs previous experience with children with ASD
Support	Broken family structures Single-parent households Co-parenting from different households Low awareness of ASD Sources of support or lack thereof (spouses/partners, grandparents, parents of children with ASD, extended family, ASD service providers, community) Support inconsistencies between partners/spouses
Parenting practices	Diversity in parenting styles Trial-and-error parenting Differences between parenting a child with ASD versus a typically developing child Corporal punishment Desire for feedback to improve parenting practices Teaching caregivers the skills they need most Parents know their child best
Stigma	Blamed for your child’s behavior Child labeled as “naughty” Immigrant or refugee status Isolation, secrecy, shame Sources of stigma (family, educators, health care professionals, and community)

ASD: autism spectrum disorder.