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Using a self-guided app to provide communication strategies for caregivers of young children with developmental disorders: A pilot investigation

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Abstract

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One important evidence-based component of early communication interventions in high-income countries is teaching parents and other primary caregivers to provide communication opportunities in daily activities to stimulate the development of beginning communication skills. To address some of the barriers to communication interventions for children with developmental disorders (DD) in rural South Africa, we developed a prototype Web-based selfguided app for caregivers to use at home with their children with DD who were at the beginning stages of communication development. The purpose of this study is to examine how this app intervention functioned for caregivers and its secondary effects on their children. Fifty-one caregiver-child dyads were randomly assigned to either a typical care intervention group (a 30minute hospital-based intervention once a month) or the self-guided mobile health technology (MHT) app plus the typical care intervention. We assessed both the caregivers and their children. The majority of the 27 caregiver-child dyads (81%) assigned to the app group used the app and completed a mean of 35.8 sessions across the 48 sessions (mean range = 5.08-15.75). Eighty percent of these caregivers employed the "help" function of the app (M per caregiver = 9.89). The caregivers who completed 44–48 sessions reported that more than half of the children moved from pre-symbolic forms of communication (e.g., crying) to symbolic forms of communication (e.g., words) by the end of the intervention. Compared to the typical care group, the caregivers perceived that their children's success increased even though their difficulties remained stable. The app group showed a very modest gain in expressive language while the typical care group did not. The findings suggest that the self-guided app framework shows promise as a supplement to traditional monthly speechlanguage intervention in South Africa.

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KEYWORDS

caregivers, communication, intellectual disability, LMIC, mobile health technology

Children with developmental disorders (DD), such as autism, cerebral palsy, and intellectual disability, are at extremely high risk for developing severe speech and language disorders secondary to their primary disability (Boivin & Giordani, 2013). These communication difficulties negatively affect children's growth, learning, long-term development, and later employment, thereby reducing the overall quality of life (Beukelman & Light, 2020; Yeargin-Allsopp & Boyle, 2002). Importantly, these communication difficulties result in great challenges interacting with others including primary caregivers/parents, family members, peers, and healthcare providers.

Estimates suggest that between 200 and 250 million young children in low- and middle-income countries (LMICs) are not reaching their developmental potentials (Morelli et al., 2017; Zhang et al., 2021). For children with DD, early intervention (EI) to facilitate their development is the global standard of care (Brown & Guralnick, 2012; Romski et al., 2015), but providing EI in LMIC contexts is challenging.

South Africa is a linguistically diverse LMIC with 11 official languages, including English. Many of South Africa's multilingual population speak two or more languages, with English regarded as the language of power and perceived opportunity (Msila, 2011). For children with DD in South Africa, resources are scarce. EI often begins too late in the developmental window because their DD has not yet been identified or medical and rehabilitation support is limited (Redfern et al., 2016). Children with DD and their caregivers often live far from public hospitals where speech-language therapy (SLT) services are available but transportation to these sites is limited. Families come from diverse linguistic backgrounds and health care providers have overwhelmingly large caseloads that result in reduced access to EI (Kathard & Pillay, 2013). Therefore, children with DD under 6 years of age receive minimal EI services. For example, when available, SLT is typically provided at a rate of once a month in government-funded public hospitals as part of children's primary health care. Once the children are 6-9 years old, they attend government-funded special needs schools where these services are continued. The number of speech-language therapists (SLTs) in South Africa is modest at best and those who speak multiple languages including indigenous South African languages are even more limited (Adams et al., 2019; Moonsamy et al., 2017). The general lack of culturally and linguistically appropriate assessment and intervention materials and procedures further complicates SLTs' abilities to provide EI services to all children (Khoza-Shangase Mophosho, 2018; Romski et al., 2018; Van der Linde & Kritzinger, 2013). When services are available, they are typically fragmented (with poor coordination of care and conflicting information between practitioners from different disciplines) and not family-focused. This negatively affects the quality of services and overlooks the important role of the family in communication development, often resulting in poor attendance in services (Balton et al., 2020). Together these issues limit the delivery of services; negatively affecting young children with DD's ability to participate, develop, and learn to communicate with their families at home and in the community.

TEACHING CAREGIVERS STRATEGIES TO COMMUNICATE WITH THEIR CHILDREN

One successful evidence-based component of EI interventions in high-income countries is teaching parents to provide communication opportunities in daily routines at home to stimulate the development of beginning communication skills (Brady et al., 2009; Roberts & Kaiser, 2015; Romski et al., 2010; Sevcik & Romski, 2016). These successful strategies have been employed with a broad range of children with DD. Roberts and Kaiser's (2015) metaanalysis of 18 studies found that when language interventions teach parents communication skills to use with their children, the language skills of children with DD improve significantly. Importantly, they also reported that parentreport measures and observational measures both detected these differences. Smith and colleagues (2011) reported that parents of children with DD who received this type of instruction also perceived increases in their children's communicative success and decreases in their children's communicative difficulty. Romski et al. (2007) reported that parents were able to implement communication intervention strategies as well as interventionists across 12 weeks for young children with DD. Stockwell et al. (2019) provided remote communication coaching with a smartphone to parents of children with motor and communication disorders in the United Kingdom over eight weeks. They reported a 50% attrition rate but success in implementation. The parents, however, suggested that the number of sessions should be reduced to better integrate the intervention into the family's life.

In LMICs, there is limited integration of families into SLT services though there are some beginning attempts to work directly with families. In a meta-analysis of 21 random control trials focused on parenting interventions in LMICs on three continents, Zhang et al. (2021) reported that parenting interventions that focus on parents' responsivity improve the overall early development of children. Zhang et al. also noted that the effects were stronger in rural areas and for parents who were not highly educated. While none of these studies focused on children, Bunning et al. (2014) reported on the impact of a "home-based caregiver-implemented intervention" employing low technology augmentative and alternative communication methods with children with significant communication disorders in rural Kenya. Caregivers' perceptions of the children's communication improved significantly. Gona et al. (2014) added to this study by interviewing the caregivers to gain more details about their experiences. Before the intervention, caregivers described feelings of "isolation, burden, and pain", while after the intervention experience, the caregivers had more positive views of their children and their caregiving. Overall, there is a need for additional research related to caregivers' participation in their children's communication development in LMICs.

THE ROLE OF MOBILE HEALTH TECHNOLOGY

The World Health Organization (WHO) defines mobile health technology (MHT) as "the use of smartphones, tablets, and other mobile devices to deliver health care and preventive health services" (WHO, 2011, 2018). Applications on smartphones and tablet computers are changing health service delivery across the globe. MHTs can collect data, record conversational samples, motivate children as part of speech and language intervention (Furlong et al., 2018), and remind parents to talk to their children (Carta et al., 2013). These applications also can supplement developmental assessments and interventions for children with DD (e.g., Wainer & Ingersoll, 2014; Warren et al., 2018) and deliver communication interventions specifically for these children (Douglas et al., 2017). Parents also are sharing video recordings with their SLTs via smartphones to provide examples of their child's behavior at home (Stockwell, et al., 2019). Currently, much of what we know about how MHTs are used, however, is from research conducted in high-income English-speaking countries (HIC; Morelli et al., 2017). Only 5% of all research, including that on disability, is conducted in LMICs (Yegros-Yegros et al., 2020).

In South Africa, people typically have at least one form of mobile technology and use it to text and talk (International Telecommunications Union, 2014). In a systematic review, Ojo (2018) showed that using MHT to provide a range of health services, with a focus on HIV/AIDS, is burgeoning in South Africa. Despite the potential for MHT intervention to address a wide variety of health disparities, minimal data are available regarding the use of MHTs for the early communication development of children with DD in South Africa. A self-guided app that provides caregivers with knowledge about communication may provide a starting point for potentially facilitating the communication opportunities caregivers provide to their children in general and beyond the limited SLT services currently provided.

Web-based self-guided caregiver app

To address some of the barriers to EI for children with DD in South Africa, we developed a prototype selfguided Web-based app, "Nna le wena" (meaning "me and you"; DeLeo et al., 2021) for open access use. Before the development of the app, focus group input solicited from potential users (South African caregivers and SLTs) guided the design of the app, the suggested mobile technology, and the languages to be used in the app (Bornman et al., 2020). The focus groups suggested that we use a Web-based tablet and not a smartphone because of the cost of data and variability in the technologies. In terms of the language, caregivers felt strongly that English should be the language presented on an app for caregiver instruction. In South Africa, Black African parents typically choose to educate their children in English not only as a pedagogical issue but also as a political one. When children reach Grade 4, English is the chosen language for education by 80% of South Africa's school-going population, despite English being the first language for less than 10% of the population (Department of Basic Education, SA, 2010). English appears to have a "linguistic magnetism" for many South African parents and hence it is becoming the defacto language of instruction for the majority of children in the country from as early as pre-school, due to pressure from parents (Evans & Cleghorn, 2014). Standard written forms of indigenous African languages have not yet been developed to the point where they function as fully-fledged academic languages (Sibanda, 2019). It is also likely that after Grade 4 parents/caregivers received their education in English, which might explain why they suggested we create the app in English with Setswana support.

This self-guided app provides caregivers with information about communication strategies to use with their children with DD during daily routines at home. It is not linked to monthly SLT sessions and its purpose is to educate the caregivers about beginning communication skills. The app content, adapted from an intervention protocol for young children with DD who were at the beginning stages of communication development and their families (Romski et al., 2010), provides information about expressive communication strategies for the caregivers to use with their children. The app consisted of three sections presented sequentially over 12-weeks: (1) creating communication opportunities, (2) modeling communication, and (3) responding to the child's communication. Each week, one of 12 strategies is illustrated in four child-focused activities (Bathing/Dressing, Book Reading, Mealtime, Play) repeated each week. After initially completing the activity, caregivers were able to repeat strategies and activities to obtain refresher information on employing strategies. They also could seek further clarification about the strategies via text/audio and video examples of the strategy via "help topics" on the app. Using a "Please Call Me" button on the app permitted them to communicate with the researchers in between monthly visits at no financial cost, and also allowed the caregivers to receive feedback from the researchers. Appendix A illustrates the app's Welcome and Help pages.

Based on the previously discussed feedback from the focus groups, the content was presented in Simple English with audio support in English and/or Setswana (spoken by a native speaker) for caregivers who preferred to hear the information. These options ensured that the content was accessible to all caregivers/parents regardless of whether they preferred to listen to or read the instructions. The fourth author (DL) built the Web-based app with input from the US and South African teams regarding features and automatic data collection and a graphic artist provided the visual design for the app.

CURRENT STUDY

The purpose of this study is to examine how the selfguided MHT app functioned for caregivers and to explore its secondary effects on their children. We asked four questions: (1) How did caregivers engage with the "Nna le wena" app?, (2) What were caregivers' weekly perceptions of their experience with the app?, (3) How did the caregivers who employed the app perceive their children's communication skills and how did their perceptions compare to the caregivers whose children received a typical care intervention? and (4) How did receptive and expressive language skills of the children in the app group compare to those in the typical care group?

METHOD

Research design

This study was approved by the IRB at Georgia State University and the Ethics Committee at the University of Pretoria. The provincial Department of health and the registrars from all hospitals gave their consent to participate in the study.

We conducted a Phase 1 clinical trial randomly assigning caregiver-child dyads to an app group or a typical care group. We employed Research Randomizer (www. randomizer.org) to randomly assign participants to each of the two groups and did not add any constraints to the randomization. The first- and second-research questions addressed the caregivers' participation with the app and included only the caregivers assigned to the app group. The third- and fourth-research questions compared the caregivers and the children in the app group with the caregivers and children in the typical care group.

The typical care group included children who received monthly hospital-based 30-minute SLT sessions focused on language enrichment and oral stimulation that is considered the current standard of care in South Africa for these children. Caregivers typically did not participate in these therapy sessions and waited outside while their children participated. At the study's end, we provided these caregivers with a Simple English written manual containing the same content as that included on the app for their use. We also answered any questions they had about the materials. Twenty-three of the 24 caregiver-child dyads assigned to the typical care group (96%) were seen for a monthly check-in, completed the pre- and postassessments and were included in the analyses.

The app group children received the same 30-minute SLT sessions once a month at the hospital and their caregivers received the self-guided app to support communication at home during routine activities. Of the caregiver-child dyads assigned to the app group, data were available from 27 at the onset of the study and 22 (81%) at the end of the study. The post-intervention data were collected when the caregiver and child ceased participation in the study.

The 12-week app group began with an introductory 90-minute face-to-face instructional session with individual caregivers during which research staff provided information about beginning communication development, the layout and content of the app, and how to integrate the strategies described in the app into everyday activities while communicating with their children. All caregivers in the app group received Samsung Galaxy A7 tablets to standardize the hosting of the app software on the same hardware. Hands-on practice operating the pre-installed app on the tablet also was provided. We employed principles of adult learning during training (i.e., role-playing, opportunities for hands-on practice, an open atmosphere in which caregivers could ask questions; Knowles et al., 2012). All caregivers in the app group left the training session with a tablet containing the app.

Participants

Through four public hospital SLT programs in South Africa, we recruited caregiver-child dyads, whose primary spoken language was Setswana, one of the dominant languages spoken around the capital city of Pretoria. SLTs shared information about the study with caregivers of children who were between 3–6 years of age and had a developmental disorder. The research staff contacted the caregivers who expressed interest in participating in the study and explained the purpose of the study and what was expected of them. Interested caregivers then completed the consent.

Fifty-one caregivers (49 female, 2 male) consented to participate in the study with their children with DD (30 boys, 21 girls) as described by hospital records. The caregivers' mean age was 32.8 years. In terms of education level, 45% completed grade 10 or less, 38% completed grade 12, 13% completed some college, and 4% completed some graduate education. Children were at the beginning stages of language development as determined by their receptive and expressive language subtest scores on the Mullen Scales of Early Learning (MSEL; Mullen, 1995). The caregiver-child dyads were randomly assigned to the app group (n = 27; Mean child CA = 49 months) or the typical care group (n = 24; Mean child CA = 52 months). An a priori power analysis, completed prior to the study's implementation, indicated that with an alpha of 0.05 and power of 0.80, a total sample size of 50 participants (25 participants in each group) was needed to detect a 0.50 effect size.

As shown in Table 1, at the start of the intervention, the two groups were comparable on all five characteristics related to the caregivers (age, relation to child, relationship status, work status, and education) and four characteristics related to the child (age, gender, school / daycare attendance as well as therapy involvement). Although randomly assigned to groups, they differed on receptive and expressive language skills at the onset of the study as shown in Table 4.

After the participants consented, they completed the initial caregiver/child assessment and training, and received the tablet, five caregivers in the app group did not continue in the study. A review of demographic Journal of Intellectual Disabilities

information on the participants did not differentiate these five caregivers from the participants who continued in the study. Thus, there was an initial attrition rate of approximately 19% that is relatively comparable to MHT studies in other content areas (Eychenbach, 2005; Reinwand et al., 2015) and less than the attrition rate in the Stockwell et al. (2019) study. The remaining 22 caregivers (81%) assigned to the app group engaged with the app. Two of the 22 caregivers' tablet log and survey data were compromised/unreadable and the description for log and survey data is based on data from 20 caregivers.

Assessment measures

We assessed both the caregivers and the children. For the caregivers in the app group, the app automatically recorded the number of times caregivers viewed each of the three sections and strategies within, for which activities, and how often the caregivers employed the help feature. The collected log data provided fidelity data about the caregivers' use of the app over time (how often it was active and what components of the app they used). The caregivers in the app group also completed a weekly 10-item survey on the app to obtain their perceptions about their children's communication and the use of the weekly strategy (see Appendix B). Responses to items 1–5 and item 10 on the survey were consistent every week. Items 6-9 changed weekly based on the week's strategy. While the children were in the monthly SLT session at the hospital each of the two months in between the beginning and end of the data collection, the research staff met with the caregivers in the app group, downloaded data from the tablet, and addressed any questions, clarifications, or comments the caregivers had about the MHT app intervention including those related to technological assistance.

Pre- and post-intervention assessment measures also were collected for the caregivers and their children in both groups. In previously reported studies by the authors, the MSEL and the South African Caregiver Perception of Language Development (SA-CPOLD) were adapted culturally and linguistically into isiZulu, Setswana, Afrikaans, and South African English for use with children who are typically developing and children with DD using appropriate procedures (Pena, 2007; Bornman et al., 2010, 2018; Romski et al., 2018). The caregivers completed the questionnaire to assess caregiver perception of child communication success and difficulty (Romski et al., 2018). The 15-item questionnaire with a 5-point Likert scale (1 = strongly disagree; 5 = strongly)agree) was available in Simple English and Setswana, depending on caregiver choice. The highest score attainable would be 75. For the children, we assessed their

TABLE 1Participant characteristics

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Participant description	MHT app group (n = 27)		Typical care group $(n = 24)$	
	Mean (SD)	n (%)	Mean (SD)	n (%)
Caregiver characteristics				
Caregiver age (years)	32.39 (10.54)		33.30 (11.63)	
Relation to child				
• Father		0		2 (8.3)
• Mother		24 (88.9)		19 (79.2)
• Grandparent		2 (7.4)		3 (12.5)
• Paid Staff ¹		1 (3.7)		0
Relationship status				
• Married		6 (22.2)		8 (33.3)
• Partner		4 (14.8)		7 (29.2)
Single parent		16 (59.3)		8 (37.5)
• Widow		1 (3.7)		0
Work status				
• Unemployed		21 (77.8)		16 (66.7)
• Part-time employed		2 (7.4)		3 (12.5)
• Full-time employed		4 (14.8)		5 (20.8)
Education				
• Grade 10 or less		12 (44.4)		11 (45.8)
• Grade 12		9 (33.3)		10 (41.7)
• 1–4 years after school		5 (18.5)		2 (8.3)
• 5–7 years after school		0		0
• 8–10 years after school		1 (3.7)		0
Child characteristics				
Child age (months)	48.81 (11.29)		52.29 (12.42)	
Gender: Boys		15 (55.6)		15 (62.5)
Attends school or daycare		13 (48.1)		17 (70.8)
Therapies received				
Speech-language therapy	23 (85.2)		23 (95.8)	
Length of time in months therapy	14.63 (17.57)		18.86 (20.73)	
Frequency of therapy: monthly		23 (85.2)		22 (91.7)
Occupational therapy		14 (51.9)		10 (41.7)
Group		1 (3.7)		1 (4.2)
Individual		12 (44.4)		9 (39.1)
Length of time in therapy	24.00 (22.37)		28.80 (27.21)	
Frequency of therapy: monthly		14 (51.9)		11 (45.8)
Physiotherapy		15 (55.6)		10 (41.7)
Group		1 (3.7)		0
Individual		15 (55.6)		9 (37.5)
Length of time in therapy	23.31 (25.15)		30.40 (28.92)	
Frequency of therapy: monthly		15 (55.6)		10 (41.7)

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Note: Chi-square tests found no statistically significant baseline differences between the two groups on the above characteristics.

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receptive and expressive language skills pre- and postintervention on the Setswana adaptation of the subtests of the *MSEL* (Bornman et al., 2018; Romski et al., 2018). (Bornman et al., 2018; Romski et al., 2018). We used raw scores to increase variability in the children's scores.

RESULTS

First, we describe how the caregivers engaged with the "Nna le wena" app and their weekly perceptions of their experiences with the app via log and survey data. Then, we provide the results from a comparison of the app group with the typical care group on caregiver SA-CPOLD performance and child pre- and post-intervention performance on the MSEL receptive and expressive language subtests.

Caregiver engagement with the app

As shown in Table 2, the 20 caregivers completed from 4 to 48 sessions (mean = 35.8 sessions). All 20 caregivers completed parts of Section "Teaching caregivers strategies to communicate with their children" (M = 10.43 sessions; range = 4–20 sessions), 15 completed parts of Section "The role of mobile health technology" (M = 24.13 sessions; range = 20–32 sessions), and the remaining 13 completed through Section "Current study" with 12 completing all 48 sessions and one completed 44 sessions (M = 23.72 sessions; range = 44–48 sessions). The mean range of use of

TABLE 2 Caregivers' use of the app across sessions

the app was from 5.08 times to 15.75 times across 12 strategies within the 3 sections. The caregivers engaged with the app most often within the first section with engagement stabilizing across the second and third sections. All four

activities were viewed by the caregivers though they accessed the mealtime activity most frequently (M = 34.00) followed by book reading (M = 29.75), play (M = 27.25), and bathing/dressing (M = 26.17).

Sixteen of the 20 caregivers (80%) employed the "help" function of the app regularly during all three sections (M per caregiver = 9.89). Four of the five caregivers who completed up to Section "Teaching caregivers strategies to communicate with their children" used the help function an average of 3.8 times. Both caregivers who participated only in Sections "Teaching caregivers strategies to communicate with their children" and "The role of mobile health technology", used the help function 2 and 38 times, respectively. Ten of the thirteen caregivers who participated in all three sections employed the help function a mean of 7.15 times. A few caregivers employed the "Please call me" function to contact the researchers and ask for additional support exclusively related to technology challenges.

The caregivers who completed up to Section "The role of mobile health technology" reported that they encountered external challenges beyond the app that prevented them from continuing to participate which was not a reflection of their willingness to continue or their perceived value of participation. Sadly, one of the caregiver's children passed away during the study and their participation ceased (after session 20). The other caregivers

			Use across activities					
Section	Session	# of caregivers	Meals	D/B	Play	Book	Total	Mean # of sessions
1	4	20 (100%)	117	71	58	69	315	15.75
1	8	18 (90%)	48	41	50	45	184	10.22
1	12	17 (85%)	32	29	33	38	132	7.76
1	16	17 (85%)	31	27	27	35	120	7.06
2	20	15 (75%)	30	27	24	32	113	7.53
2	24	14 (70%)	26	25	22	23	96	6.86
2	28	14 (70%)	22	17	20	22	81	5.79
2	32	13 (65%)	19	15	18	20	72	5.54
3	36	13 (65%)	23	18	17	17	75	5.77
3	40	13 (65%)	17	15	16	18	66	5.08
3	44	13 (65%)	20	15	28	17	80	6.15
3	48	12 (60%)	23	14	14	21	72	6.00
Mean		15 (75%)	34	26.17	27.25	29.75	117.17	7.46

Abbreviation: D/B, dressing and bathing.

	4	•		4			4								
		Q 6: Fr per day	equency	of using s	trategy	Q 7: Difficu child	lty of using t	he strategy w.	ith	Q 8: W use str	illingnes ategy aga	s to in	Q 9: Hel for child	lpfulness o l's commu	f strategy nication?
# of care givers	Strategy	0 times	1 time	2-5 times	>5 times	Very difficult	Difficult	Little difficult	Easy	Yes	Maybe	No	No help	Little help	Lot help
Section 1: Cree	tting communication opf	oortunities	S												
20	Wait	0.00	0.05	0.40	0.55	0.05	0.05	0.50	0.45	1.00	0.00	0.00	0.10	0.35	0.55
18	Give small amounts	0.06	0.11	0.28	0.56	0.06	0.06	0.33	0.56	0.94	0.06	0.00	0.17	0.33	0.50
17	Provide choices	0.00	0.18	0.41	0.41	0.06	0.06	0.41	0.35	1.00	0.00	0.00	0.12	0.29	0.59
17	Disrupt environment	0.00	0.06	0.35	0.59	0.00	0.00	0.41	0.47	0.88	0.12	0.00	0.06	0.47	0.47
Section 2: Moc	leling communication														
15	Speak slowly	0.00	0.00	0.33	0.67	0.00	00.00	0.47	0.47	1.00	0.00	0.00	0.13	0.40	0.47
14	Simplify adult model	0.00	0.00	0.21	0.79	0.00	0.00	0.43	0.57	1.00	0.00	0.00	0.00	0.36	0.36
14	Describe	0.00	0.07	0.43	0.50	0.00	00.00	0.50	0.50	0.93	0.07	0.00	0.00	0.50	0.50
13	Ensure face-to-face	0.00	0.08	0.46	0.46	0.00	0.00	0.62	0.38	0.85	0.15	0.00	0.00	0.54	0.46
Section 3: Rest	onding to the child's con	nmunicatı	ion												
13	Respond	0.00	0.08	0.38	0.54	0.00	0.00	0.31	0.46	0.85	0.15	0.00	0.08	0.46	0.46
13	Repeat & add	0.00	0.15	0.31	0.54	0.00	0.00	0.54	0.38	0.92	0.08	0.00	0.08	0.54	0.54
13	Fill in the blank	0.00	0.15	0.31	0.54	0.00	0.00	0.54	0.38	0.85	0.15	0.00	0.15	0.31	0.54
12	Ask open-ended questions	0.00	0.08	0.50	0.42	0.00	0.00	0.25	0.67	0.17	0.00	0.17	0.00	0.42	0.58
	MEAN	0.00	0.08	0.37	0.55	0.01	0.01	0.44	0.47	0.87	0.07	0.01	0.07	0.41	0.50

TABLE 3 Proportion of responses on questions 6–9 about the specific strategies found to be Most helpful

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were unable to get time off from work to attend a monthly visit, had inadequate transportation access to the hospital, and one caregiver had her child removed from her by social services for suspected child abuse.

Caregiver weekly survey outcomes

The caregivers reported that their children attempted to communicate with them from Week 1 through Week 12. How the children communicated varied greatly from crying to using spoken words and children often used multiple forms of communication. The thirteen caregivers who completed 44 to 48 sessions reported that more than half of their children moved from pre-symbolic forms of communication (e.g., crying) in the first week to symbolic forms of communication (e.g., words) by the end of the 12 weeks. Table 3 details the caregivers' responses to questions 6–9 about the specific strategies and how helpful they were to them. The majority of the caregivers reported that they used each strategy consistently between two to five times or more. They also reported that all but one strategy was only a "little difficult" or "easy" to employ. Overall, the caregivers reported that all these strategies were helpful to develop their children's communication and they would use the strategies again with their children except for the "asking open-ended questions" strategy.

Finally, the majority of caregivers (92%) took advantage of listening to the spoken version of the materials. Across the study, 53% of the caregivers listened to both the Simple English and Setswana, some listened to Simple English only (33%) and a minority listened to Setswana only (8%).

Pre-post app assessment

Figure 1 provides a CONSORT flow diagram of the participants' progress through the study.

Of the 24 caregiver-child dyads assigned to the typical care group, 23 (96%) were seen for a monthly check-in, completed the pre- and post-assessments, and were included in the analyses. One of the children passed away



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early in the study and did not complete the post-assessment. Of the caregiver-child dyads assigned to the app group, data were available from 27 at the onset of the study and 22 (81%) at the end of the study. The data were collected when they ceased participation in the study.

Table 4 provides descriptive statistics for the caregivers' perceptions of child communication development on the SA-CPOLD in terms of perceived child communication success and difficulty pre- and post-intervention. Also shown are the secondary pre-post child language results on the MSEL receptive and expressive scales. The right most two columns of Table 4 show tests of baseline equivalence for all measures. The t-statistic and effect size for the app minus typical conditions are shown.

To estimate the effects of the app intervention, we fit pre-post regression models for the two caregiver measures (success, difficulty) and the two language measures (receptive language, expressive language; see Table 5 for the estimates; Little, 2013). We controlled for the differences in the children's receptive and expressive language at the onset of the study (the pretest is a predictor). Neither of the models had a statistically significant effect for the app group. For the caregiver measures, the modelbased effect sizes (Hedges g; Hedges, 2007) were 0.07 for success and 0.11 for difficulty. The effect sizes for expressive and receptive language were 0.41 and -0.42,

App group

n

27

27

27

27

Pretest

35.6 (6.2)

20.8 (3.6)

8.7 (4.7)

11.7 (6.6)

Mean (SD)

Because of the influence of a few outlier child observations, we also fit robust weighted regressions (SAS PROC ROBUSTREG; SAS, 2015) for the language measures. Most of the estimates were similar, but for expressive language, the robust intervention estimate shrank by more than half (1.29 to 0.44) suggesting a large influence from the outlier child observations.

Though the differences were not significant, the caregivers in the app group perceived that their children had less difficulty at the end of the intervention than when they began. The caregivers in the typical care group did not perceive any differences. Neither group perceived changes in their children's communication success which is consistent with the children's performance. Even given the initial differences in language between the groups, the results suggest some promise for child gains in expressive language but not for receptive language.

DISCUSSION

Typical care group

Pretest

Mean (SD)

38.24(6.48)

20.17(4.59)

15.7 (9.5)

17.4 (8.2)

Our pilot data provided a substantial amount of information about the use of the self-guided app by South African

Posttest

Mean (SD)

40.32 (7.27)

19.13 (5.04)

15.6 (9.4)

18.8 (8.4)

n

23

22

23

23

Baseline

t

1.42

-0.55

 -3.39^{*}

 -2.73^{*}

Difference

D

-0.41

-0.96

-0.77

0.16

TABLE 4 Caregiver perception means on the SA-CPOLD and MSEL pre- and post-intervention

n

22

22

22

23

Posttest

40.0 (5.1)

20.0 (4.3)

10.1 (6.4)

12.7 (6.4)

Mean (SD)

Note: SA CPOLD, South African Caregiver Perception of Language Development. MSEL, Mullen Scales of Early Learning. Baseline Difference, to	ests of baseline
equivalence across groups at pretest (app—typical): t-test (* $p < .05$) and Cohen's d = D (Cohen, 1988).	

n

21

23

23

23

т	A	B	L.	Е	5	Regression	estimates
ы.		D	1.1	L'		RCEICSSION	commanco

Outcome

SA CPOLD Success

Expressive MSEL

Receptive MSEL

SA CPOLD Difficulty

	SA CPOLD success		SA CPOLI	D difficulty	Expressive language		Receptive	language
Effect	Est.	SE	Est.	SE	Est.	SE	Est.	SE
Intercept	39.92	1.41	10.22	0.71	10.00	0.74	16.83	0.91
Pretest	0.29	0.15	0.90	0.06	0.98	0.06	0.82	0.08
Intervention	0.44	1.96	0.44	0.98	1.29 ^a	1.02	-1.78	1.33
R^2	0.09		0.65		0.87		0.73	
effect size	0.07		0.18		0.41 ^b		-0.42	

Abbreviations: OLS, ordinary least squares regression estimate. SE, standard error. Effect size, Hedges's g (Hedges, 2007). ^arobust regression estimate = 0.44.

^brobust effect size = 0.18. No intervention estimates were statistically significant. App group n = 27; Typical Care group n = 24.

caregivers as the primary participants and secondarily, to a lesser extent, its effects on their children's receptive and expressive language skills. The majority of caregivers from the app group used the app consistently and reported some perceived changes in their children's expressive communication on the weekly survey. The pattern of caregiver app use, beginning high and then stabilizing, is consistent with other MHT studies that report that app use drops after the initial use (Breitenstein et al., 2017). The caregivers reported that the app helped as they communicated with their children. The spoken version of the materials supplemented the written materials and reinforced the content for the caregivers. These pilot findings suggest that this self-guided app could provide information about communication support for caregivers of beginning communicators with DD. The caregivers' reports were consistent across strategies though caregivers found the asking openended questions strategy more difficult to use than the other strategies.

The secondary data provided a comparison with caregivers and their children who participated in the typical care group. These data provided information about the caregivers' perceptions of their children's communication skills and the children's receptive and expressive language skills. While these findings were modest at best, the gain in children's expressive language for the app group begins to show some promise. The app strategies presented to the caregivers were focused on expressive language skills as the caregivers focused on creating opportunities for child communication, responding to their children's communication attempts, and modeling communication. Thus, modest secondary effects on the children's expressive communication without observable effects on receptive communication are reasonable.

Even though our a priori power analysis indicated we had a large enough sample to detect effects, we were unable to account for the level of unexpected attrition across the intervention in the sample. With a larger sample who completed all 48 sessions, we may have been able to detect significant differences and stronger effect sizes that better complemented the caregivers' reports about their children's expanded language skills. Caregiver report is often devalued in the research literature even though there are several reports in the literature that demonstrate that caregiver report mirrored observational assessments of young children's language skills (e.g., Dale, 1991; Roberts & Kaiser, 2015).

Another influence on the language findings may have been the receptive and expressive language measures themselves. Intervention studies of children at the beginning stages of language development find that children often struggle to demonstrate changes on standard language measures (Sevcik & Romski, 2016). The inclusion Journal of Policy and Practice in Intellectual Disabilitie

of caregiver-child interaction measures (e.g., turn-taking, vocabulary size) may capture some changes in language development before they are observed on a standard measure. In future studies, inclusion of both standard and observational measures may assist in obtaining a more complete view of child gains in both groups.

A few unforeseen limitations compromised our planned research design. First, while the randomization resulted in comparable groups on the caregiver and child demographic variables, the app group began the study with lower expressive and receptive language scores than the typical care group. While we accounted for this difference in our analyses, in the future, a constrained randomization procedure would ensure the groups are comparable on these critical variables.

A second limitation is attrition. Almost immediately, five caregivers did not return for their monthly SLT sessions after they completed the initial MHT app training and took the tablet and app home. Neither the SLTs nor our staff were able to contact them. Demographic information did not reveal specific factors that may have influenced why these caregivers dropped out of the study. Other MHT studies in different content areas report similar attrition rates and it may be a common finding in MHT research in LMICs (Eysenbach, 2005; Reinwand et al., 2015). In further studies, it also will be critical to ensure a sample size that accounts for at least a 20% to 30% level of attrition and that the groups are equivalent in terms of expressive and receptive language skills. Further studies with larger samples and less attrition are needed to evaluate how well the current, promising effect size in expressive language can be replicated, or whether there might be moderating effects such as family circumstances or environmental influences.

A third limitation is that factors external to the study may have influenced caregivers to follow through with the app across the entire study. In addition to individual caregiver challenges, there were worker strikes in the area due to upcoming political elections which hampered safe access to the hospital during the study's implementation. There also were major power outages dubbed "load shedding" because South Africa's main electricity provider was unable to meet the electrical demands of the country, with catastrophic implications for many sectors, including health (Laher et al., 2019). These factors may have severely impacted communication due to an inability to recharge cellular phones, inadequate network signals, and loss of internal electrically dependent telephonic systems. These external factors are very real considerations in LMIC research settings and may require more flexibility in the data collection timeline than was available in this study. These factors need to be taken into consideration when designing studies in

LMICs. In the future, additional selection criteria may ensure that caregivers can commit to participate in this supplemental home app use.

This study also has implications for disability research in LMICs across the globe. While there have been increases in studies that describe children's communication, there are few studies that report interventions with caregivers which require longer-term participation and commitment. Increasing culturally and linguistically diverse assessment measures and strategies may be a starting point for such research by providing additional ways to measure change (e.g., Romski et al., 2018). The impact of broader external factors that affect a country's infrastructure can not be overlooked.

One future direction for this research is the integration of the caregiver app used at home with the child's monthly SLT sessions. This direction would require a reconsideration of how SLT interventions are currently delivered in South Africa. Currently, there is little integration of parent education and support within SLT interventions. This may be the result of the substantial need for more SLTs in South Africa. We anticipate partnering with the South African Department of Health to discuss and consider the steps required.

In conclusion, this pilot study assessed a self-guided prototype Web-based app for caregivers of children with DD. It highlights the complexity of conducting intervention research that requires more than a one-time commitment in a LMIC where systemic influences of the environment are confounding variables beyond the study's control. The caregivers' comments about the prototype app provide important feedback about the value of such an app from the caregivers' perspective. The caregiver perceptions and the expressive language results suggest that with a larger stable sample size and the inclusion of caregiverchild communication interaction measures, this app can be assessed on a larger scale in South Africa. The app content can also be adapted to other major languages in the diverse South African linguistic environment with revisions to the text and videos. This self-guided caregiver app may empower caregivers and facilitate their communication with young children with DD and associated speech and language impairments. This framework may also have usefulness in other countries around the globe to support and empower caregivers as the drivers of early communication interventions.

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CONFLICTS OF INTEREST

We have no known conflicts of interest to disclose.

ETHICS STATEMENT

The Institutional Review Board (IRB) of Georgia State University in Atlanta, GA and the Ethics Committee of the University of Pretoria, Pretoria South Africa approved this study.

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APPENDIX A

Welcome page and example from a help page of the app.



APPENDIX B

Caregiver survey: Example of app weekly.

Instructions: When you finish all four activities for the week, please answer these ten multiple-choice questions about your experience. Answer these questions as best you can. There are no right or wrong answers

Question	Answer
1. Did your child use words, pictures, or hand movements to communicate during the activities?	() Yes () No
2. How did your child communicate? (Choose ALL below that happened).	 () Sounds or noises (for example: crying, laughing, or baby noises) () Saying words () Facial expressions (for example: smiling, frowning) () Looking (for example: pointing with eyes) () Hand motions or actions (for example: reaching, pointing, clapping) () Pictures () My child did not communicate
3. What way did your child use most often to communicate? (Choose only one).	 () Sounds or noises (for example: crying, laughing, or baby noises) () Saying words () Facial expressions (for example: smiling, frowning) () Looking (for example: pointing with eyes) () Hand motions or actions (for example: reaching, pointing, clapping) () Pictures () My child did not communicate
4. How often did your child communicate with you during the activity?	 () More than 5 times () 2-5 times () Once () Never
5. Which activity worked best?	() Mealtime() Dressing and Bathing() Playing() Book reading
6. How often did you use the WAITING strategy during an average day?	 () More than 5 times () 2-5 times () Once () Never
7. How difficult was it for you to use WAITING?	 () Easy () A little bit difficult () Difficult () Very difficult
8. Will you use WAITING again?	() Yes () No () Maybe
9. Do you think WAITING helped your child communicate?	() It helped a lot() It helped a little() It did not help
10. Did you listen to the audio instructions in the app?	 () I listened in English () I listened in Setswana () I listened in both English and Setswana () I did not listen to any audio