

Reconsidering Priorities for Digital Maternal and Child Health: Community-centered Perspectives from South Africa

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Especially in developing regions, parents are rarely given a direct voice in the design of digital maternal and child health (MCH) interventions. Instead, MCH needs and requirements are driven by organizations and health workers. In this research, we engage with both rural and urban parents and community leaders to better understand their challenges and priorities for digital MCH and propose a parent-centered agenda for human-computer interaction research. This paper reports on the community-based, digital MCH priorities identified in our research, and describes how we approached community discourse and co-design of digital initiatives for these priorities, through parent-centered workshops with low-resource South African communities. Furthermore, we provide the parent-centered design opportunities and tensions we discovered for digital MCH in South African contexts, such as designing for local contexts and languages, designing for accessibility and connectedness, and highlighting the underdeveloped digital MCH niches. Finally, we highlight the importance of including facilitators for co-design workshops, such as using intermediaries and design cards.

 ${\tt CCS\ Concepts: \bullet Human-centered\ computing \to Empirical\ studies\ in\ collaborative\ and\ social\ computing.}$

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1 INTRODUCTION

Community-based co-design (CBCD), a collaborative approach that aims to involve communities throughout the design process [33], is often utilised in low-resource settings [65] to engage with underserved communities [100]. Community-based co-design has been applied in diverse fields from agriculture [28] to health promotion [34, 86] and primary healthcare [62]. In the Global South, CBCD is becoming an increasingly popular research approach for reducing power disparities between researchers and participants and amplifying community voices and values. Its application in healthcare has also evolved, with particular focus on exploring the design space and co-creating interventions to support maternal and child health [27, 97, 107]. Community-based interventions in this regard have shown to be an effective approach for creating more sustainable solutions that are initiated and maintained by community structures, as opposed to external parties [65]. A particular limitation of the existing work in CBCD for maternal and child health (MCH) is that it is currently giving too much emphasis to public health priorities as the primary lens of enquiry and ideation, but overlooking the socio-cultural diversity of local communities, and how this can be leveraged to support innovation [76]. This tension in identifying MCH priorities can contribute to the sidelining of an intersectional approach to the health of mothers and children. Additionally, the historic exclusion of women in the design process, especially in the Global South, has contributed to misaligned objectives between the community and researchers, as well as a reinforcement of inter and intra-community power differentials. An examination of the CBCD approach in practice, and in particular, how it is applied with communities in the Global South, while considering all the complexities and tensions that arise when conducting such an approach, has been lacking. This is also true for research and developments that focuses on the design of computer-mediated technologies to support MCH challenges in low-resource communities [76]. The top-down nature of digital MCH development, in which health and ICT experts typically inform the design of these interventions may be attributable to projects failing to receive uptake, as their objectives may not always align with community needs [88].

To address the limited involvement of community stakeholders across diverse geographical regions in previous HCI research for digital MCH [36], particularly in South Africa [105], we started a multi-stakeholder project, entitled Co-designing Community-based ICTs Interventions for Maternal and Child Health (CoMaCH) ¹, to identify MCH priorities from communities perspectives and explore their role in the co-design and creation of digital maternal and child health initiatives in four geographical distributed and low-resource communities in South Africa. The CoMaCH project involved three phases of research including a scoping review on community-based co-design for maternal and child health in South Africa, interviews with community stakeholders on their digital MCH priorities, and generative community-based co-design workshops to prototype potential solutions for their identified digital MCH priorities.

¹https://comach.melissadensmore.com/

In this paper, we report on the third phase that identified and investigated MCH priorities in South African communities, including, but not limited to, accessibility to appropriate MCH and Early Childhood Development (ECD) information and improving maternal mental health, both of which have received limited attention in previous HCI research. We identified the various nuances of community priorities between rural and semi-urban settings in terms of culture, socio-economic circumstances, and varying level of community involvement. Based on our co-design findings, we found that, overall, community members seek more than only access to information, looking for meaningful "connectedness" with each other and their community leaders. Furthermore, we provide design strategies for conducting co-design with low-resource communities, based on the use of design cards as design aids to support co-creation, and the inclusion of local intermediaries to enrich our contextual understanding.

Our research questions are:

- (1) What are the community attitudes and experiences surrounding MCH and digital MCH, and their digital MCH priorities?
- (2) What are the key design and socio-technical considerations for researchers, designers and practitioners who plan on doing co-design in low-resource communities?

2 BACKGROUND AND RELATED WORK

2.1 Maternal and Child Health in South Africa

South Africa is dedicated to achieving the Sustainable Development Goal (SDG) of eliminating preventable maternal and child deaths [82]. Although South Africa's maternal mortality rate (MMR) has decreased from 200/100,000 in 2012 to 113/100,000 in 2019, much work remains to be done in order to meet the Sustainable Development Goal of achieving an MMR of less than 70/100,000 by 2030 [30]. Additionally, between 2012 and 2019, the neonatal mortality rate in South Africa remained stable at 12/1,000 live births, far exceeding the South African National Department of Health's (NDOH) 2030 goal of 7/1,000 [30]. These rates could be attributed to the underlying determinants (e.g., access, poverty) and the existing gaps in South Africa's human and physical healthcare infrastructure, including the need for safer clinical facilities, diagnosis equipment, and medication resources, as well as training programs for healthcare workers, resulting in poor quality healthcare, inadequate diagnosis and treatment, an increase in infant mortality rates [48, 60], a high number of infections during pregnancy, early childhood pneumonia, an increased risk of mother-tochild HIV transmission, malnutrition, and many other MCH-related complications [2, 23, 75, 103]. When compared to the SDG targets, South Africa's rate of adverse birth outcomes, such as stillbirths and preterm births, remains unacceptably high, despite international agreement that these are preventable through improved quality of care [11]. Approximately 60 percent of maternal deaths and up to 50 percent of neonatal deaths are potentially avoidable [16, 55, 85]. This is consistent with data from 81 low- and middle-income countries, which indicates that between 2016 and 2020, roughly 25 percent of neonatal deaths and stillbirths might have been avoided with higher-quality pre- and postnatal care for pregnant women and newborns [15].

Global evidence indicates that micro-level interventions, including interventions at the health facility, health care worker, and patient levels, can reduce maternal and child mortality rates and stillbirth ratios. Complication readiness programs, community-based campaigns to strengthen preventative and caregiving practices such as improving immunization utilization and women's educational level, and quality improvement initiatives have been successful interventions [14, 91, 93]. We contribute to a further understanding on how to design such micro-level interventions by engaging with communities to implement more sustainable interventions that can improve MCH in South Africa.

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2.2 Co-design with Communities and Value Sensitive Design in Co-design

Community-based co-design is an approach that builds upon participatory research methods by fostering and deepening equal co-operation between individuals for addressing emerging challenges in their communities. In essence, CBCD moves from a "research on..." to a "research with..." approach, changing the ways communities are involved during the design process [65, 100]. Furthermore, this approach prioritizes community value structures, ideals, needs, socio-cultural realities to ensure that solutions are more likely to be implemented and used [46] to avoid mismatches between researchers and communities settings [100]. Such approaches include participatory methodologies for health that have recently been used to engage healthcare workers and users in examining, intervening, and executing new systems [32, 45]. These methods are typically used to address health inequalities and improve the patient experience for vulnerable communities as well as groups that have historically been marginalized and discriminated against in traditional research [32, 35, 100]. In particular, parent-centred projects still remain scarce as the focus has been on service delivery, especially from health workers. For example, Community Health Workers (CHWs) often act as proxies for communities because they are more likely to understand MCH challenges and are trusted by the community [49] and for years have played a significant role in the success of health initiatives [49].

However, the use of CHWs as proxies has unfortunately unintentionally reduced the attention to community structures and social relations as a means of research design and innovation [98]. Furthermore, traditional health services research often relies on top-down approaches wherein functionality is prioritized, in contrast to community-based, participatory methodologies were additional emphasis is given to user involvement and community engagement, to ensure that the co-designed intervention not only maximises target-user satisfaction [35] but may also significantly impact care [64]. The need for a contextual understanding of participants real life environments before including them in the design process is highlighted by HCI research [46] encouraging individuals to freely participate in research projects [39]. For example, previous research on sensitive topics found that nursing staff and parents were more eager to engage in a co-design study since they had previously established a rapport with them [58]. In our research, we initially engaged with our community participants through interviews to better understand their MCH contexts before engaging with them in co-design sessions.

Value sensitive design (VSD), initiated in the 1990s, attempts to give theory and methodology to account for human values in a guiding and methodical way throughout the design process. Engaging both our moral and technical imaginations is essential to this strategy [26]. Later works by Friedman, Hendry and Boring [25] focus on value sensitive design methods which include value-oriented mock-up, prototype, or field deployment which could help researchers interested in digital maternal and child health to honour these values. In their work, they speak about how VSD addresses questions such as: which values are important in a given design case; whose values are they and how are they defined with respect to the given context; which methods are suited to discover, elicit, and define values [26]. In our work with communities, we consider community sensitivities and implement VSD by first engaging with communities directly through conversations and learning about their contexts, values and needs before approaching design. Thereafter, in our codesign activities, we involve community proxies in conversations and facilitation to help maintain their community structures and values throughout the design process.

2.3 Co-design for Maternal and Child Health in Low-resource Settings: Opportunities and Challenges

The use of co-design methods for maternal and child health, in particular, has become increasingly prominent [72]. The improvement of healthcare quality and access has been exemplified in participatory research with, and for, mothers to design interventions that support them during the period from conception until two years after birth [80, 111].

Co-design projects that have been conducted in low-resourced regions provide valuable considerations for co-design with communities. For example, Wardle et al. [106] on co-design and breastfeeding highlighted the need to empower mothers through positive reinforcement during design activities, as well as the great amount of time and preparation required to participate in design activities when participants are caring for a baby as this affects active involvement. We took this into account when planning our workshops and prepared with thorough protocols and facilitator training.

Other examples of the application of community-based participatory research techniques in low-income settings include, Limaye et al. [51] who carried out a project in rural communities in Peru with community health workers (CHW) and mothers. Using CBCD to develop and share community-created content, the researchers facilitated the identification of community-specific MCH needs and attempt to address them collaboratively through digital storytelling workshops with community health workers (CHW) [51]. They concluded that the digital stories addressed community-specific challenges through narrative persuasion using local voices and photography. The initiative was well received by the intended audience and could be used as a model for creating instructional initiatives that are adapted to the needs of the local community. Finally, D'Ignazio et al. [19] and Gibson & Hanson [29] also worked with mothers using co-design approaches for designing digital postpartum technologies. Their work built on the existing research on working with mothers, and particularly proposed that Feminist HCI [6] and human-centered design offers an important and effective framework for designers to understand postpartum experiences, and promote the use of new technologies to improve these experiences.

Although co-designing is an innovative way to develop with and for mothers, it is not without challenges. Besides the challenges that involve contrasting priorities and objectives between researchers and communities and financial and skill limitations, there exists interpersonal and socio-cultural challenges that need to be considered. For example, Mustafa et al. [66] shows how religion and patriarchal norms influence mothers' lack of control over their own health, the sharing of misinformation, and the overall design of maternal and child health interventions in low-resource Pakistani settings. When socio-cultural factors are overlooked, unsuitable and unsustainable interventions may arise [3], also posing challenges in relation to "transferability" of methods or solutions [97, 108] and ensuring that locally-relevant interventions are community-owned. In addition, when the inequalities to digital access of health services are neglected, it reinforces these inequalities of those who already have resources and digital literacy skills [35].

Despite the increase of work done in the HCI research in MCH in South Africa, previous research prioritizes addressing physical illnesses such as obesity [8], HIV, and diabetes [92] contributing to adverse maternal outcomes and complications during pregnancy, with limited work on mental health for pregnant women or new mothers. Furthermore, as stated in the previous section, the majority of HCI and MCH research in African countries, and particularly in South Africa, have engaged mainly with Community Health Workers (CHWs) and other intermediaries [63, 73] rather than working directly with community members and parents who are the direct beneficiaries of the planned interventions [98].

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Our work engages directly with parents, CHWs and other caregivers in an attempt to further understand the different communities' values and priorities, both physical and emotional, and identify their respective nuances within the different communities.

3 RESEARCH CONTEXT AND METHODS

3.1 Background

In May 2020, we started a project to investigate the role of communities and co-design approaches in the creation of digital maternal and child health initiatives in different regions of South Africa. The project team consists of a cross-cultural and interdisciplinary group of researchers (seven from South Africa and 13 from abroad) with backgrounds in public health, nutrition, social sciences applied to health, medical sciences, psychology, and human-computer interaction. The project consisted of three phases. The first phase included a scoping review on how community-based co-design of ICTs health innovations for maternal and child health in South Africa. The second phase included a qualitative study of interviews with key community stakeholders such as mothers, fathers, other caregivers, and community health Workers (CHWs) to identify and understand the existing challenges these stakeholders face when engaging with maternal and child health (MCH) care. The results from phase I and phase II inform the third phase of the project that conducted community-based co-design workshops in which community participants prioritised the challenges identified in phase II and brainstormed possible solutions and co-created prototypes to address them. The study was reviewed and approved by ethical boards from four institutions (University of Cape Town, University of Limpopo, University of Witwatersrand, Human Sciences Research Council) in South Africa and confirmed by one from abroad (Cardiff University). We had four project workshops that enabled the research team to discuss preliminary findings and help redefine the focus of the research activities. Considering the nature of this exploratory study that did not examine socio-demographic differences or influences, and the existing ethical concerns of conducting the study during the COVID-19 pandemic that can be tiresome for our participants, we did not collect socio-demographic information to lower the burden of participation [61] of low-resourced communities.

3.2 Research settings

South Africa is a culturally diverse country with nine provinces and eleven official languages ². To ensure cultural diversity, our project included rural and semi-urban areas of South Africa and purposefully selected different geographical locations leveraging the existing relationships with local communities of our project partners: Sweetwaters in KwaZulu-Natal (KZN) province, Soweto in the Gauteng province, Ga Dikgale, Ga Mamabolo and Ga Mothiba within rural Limpopo province, and Cape Town in the Western Cape province.

Sweetwaters - KwaZulu-Natal Province: Sweetwaters is 97Km outside Pietermaritzburg in the uM-gungundlovu district and is zoned as a low-income, rural area with a household income of R2,400 per month 4 (\$1 = R14.68) 3 . This community comprises of around six hundred thousand people and is representative of the Zulu population in KZN with 100% of the population listed as Zulu speakers 4 .

Soweto - Gauteng Province: Soweto is a peri-urban, low-to-middle income area in Gauteng province, South Africa. Soweto is South Africa's largest township located in Johannesburg. This township

²https://www.brandsouthafrica.com/south-africa-fast-facts/geography-facts/language

³http://www.statssa.gov.za/publications/P0318/P03182019.pdf

⁴https://wazimap.co.za/profiles/municipality-KZN225-the-msunduzi/

comprises of around 1,3 million with the dominant language being- isiZulu 5 . The average monthly income for this region is R2,500 6 .

Dikgale - Limpopo Province: Ga-Digkale is zoned as a rural, low-income area with a monthly income of R1,250 7 and is located 90km east of the city of Polokwane. This community is representative of the Sepedi people with 95% of the 9 353 people in this population listed as speaking Sepedi 8 .

Cape Town - Western Cape Province: Athlone has a population of roughly 38,288 people. The area is zoned as an urban, low-to-middle income area with a monthly income of around R4,791 per month. This population is predominantly English speaking with approximately 44% of the population listed as English speaking followed by 36% Afrikaans and 15% isiXhosa ⁹. The final workshop was conducted with a local NGO that is based in Athlone, and offers services such as physical, speech, and occupational therapy to mothers of children who would otherwise not be able to afford these services.

3.3 Participant recruitment

The project researchers and co-facilitators at each research site were responsible for participant recruitment by leveraging their existing relationships with the communities. Each project partner was briefed to recruit mothers, fathers, CHWs, and other caregivers from their respective communities through the relevant community research coordinator teams. However, in Cape Town, the participants were recruited via the NGO with which we partnered.

3.4 Identification of Key Maternal and Child Health (MCH) Challenges

Five researchers conducted an exploratory qualitative study across the different research settings conducting 30 semi-structured interviews with key stakeholders including mothers, fathers, and CHWs to better understand the existing MCH challenges in South Africa (8 mothers at Cape Town; 4 CHWs and 8 mothers at Limpopo; 5 CHWs, 3 mothers and 2 fathers at KZN; and 8 mothers, 2 of which are also CHWs, at Soweto). Interviews included exploratory questions related to the participants' maternal and child healthcare-seeking behaviors, the use of existing MCH applications and government healthcare resources, and any MCH concerns and wishes participants might have. Interviews were conducted in their local language Xhosa, English or Afrikaans for Cape Town, seTswana, Zulu or Southern Sotho for Soweto, Zulu, for KZN and finally, Sepedi for Limpopo. Written and verbal informed consent was obtained before the interviews started.

Interviews were conducted online or in person, depending on the COVID-19 lockdown restrictions in local community. Interviews were recorded, transcribed and stored on a secure data cloud only accessible to the researchers. Interview transcripts were coded and thematically analysed collectively by 5 researchers that conducted the studies. A deductive coding approach was used for the initial coding whereby we used predefined codes for the codebook referencing the various aspects covered in the interviews across the sites. Within these codes, more specific and inductive subcodes were created based on participant responses to the initial codes. Through this process, the teams at each research site identified community MCH challenges, which were then presented to the full research team. The project team then collaboratively discussed and prioritized these challenges, and asked researchers to add additional challenges if they feel anything was missing. The project

⁵http://www.statssa.gov.za/publications/P0318/P03182019.pdf

⁶https://wazimap.co.za/profiles/ward-79800042-city-of-johannesburg-ward-42-79800042/

⁷http://www.statssa.gov.za/publications/P0318/P03182019.pdf

⁸https://wazimap.co.za/profiles/ward-94703017-makhuduthamaga-ward-17-94703017/

 $^{^9} https://wazimap.co.za/profiles/ward-19100044-city-of-cape-town-ward-44-19100044/city-of-cape-town-ward-44-1910004/city-of-cape-town-ward-44-1910004/city-of-cape-town-ward-44-1910004/city-of-cape-town-ward-44-1910004/city-of-cape-town-ward-44-1910004/city-of-cape-town-ward-44-1910004/city-of-cape-town-ward-44-1910004/city-of-cape-town-ward-44-1910004/city-of-cape-town-ward-44-1910004/city-of-cape-town-ward-44-1910004/city-of-cape-town-ward-44-1910004/city-of-cape-town-ward-44-1910004/city-of-cape-town-ward-44-1910004/city-of-cape-town-ward-44-1910004/city-of-cape-town-ward-44-1910004/city-of-cape-town-ward-44-1910004/city-of-cape-town-ward-44-1910004/city-of-cape-town-ward-44-1910004/city-of-cape-town-ward-44-1910004/city-of-cape-town-wa$

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team and community representatives finally voted for their highest-ranking priorities by selecting up to 3 challenges that were more important for them. From the community challenges from the interviews and the challenges proposed by the researchers, we identified the 10 most important challenges in Maternal and Child Health across the four communities: These challenges/needs are (in no particular order): a) Parent well being, b) Traditional healers versus western medicine, c) Postpartum care, d) Building parenting skills in early life, e) Accessible and affordable access to health information, f) COVID-19 vaccine hesitancy, g) Misinformation, h) Personalised and timely support, i) Health worker emotional support for parents, and other caregivers and finally j) Involving fathers.

3.5 Development of Challenge and Ideation Design Cards

Development of the Challenge Design Cards. Based on the identified challenges, we took a human-centered design approach and designed a set of challenge design cards to visually represent the challenges to the community, ensuring a clear understanding of the challenges before asking them to brainstorm potential solutions. We began this process with three researchers communicating the ten challenges to a professional graphic designer in South Africa through various iterations of feedback. In each iteration, we attained feedback from multidisciplinary project researchers and other local stakeholders part of the research project looking at the quality and correctness of the challenge depictions. The graphical illustrations of the challenges and their names and phrasing were refined over time. For example, for the "Traditional Healer" challenge card, it was suggested by researchers who were familiar with Traditional Healers to make the healer's gender clearer as a woman through her attire as traditional healers are more typically women in the local communities. For the "Affordable and Accessible MCH information" card, this one was revised from "Affordable access to MCH information" to include accessibility barriers not related to affordability as well, such as transport and language barriers. The card illustrations were printed back-to-back with the text printed in the local language (Soweto and Sweetwaters - isiZulu, SeTswana and SeSotho, Limpopo - Sepedi, Cape Town - Afrikaans) on the reverse side, as English was not all participants' first language. This was done by asking project researchers that were native speakers of each research site's language to translate the texts (see figure 1).

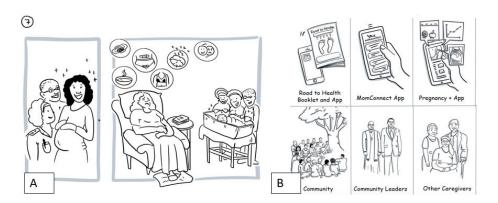


Fig. 1. Example of a Challenge Card showing postpartum care (A) and Design Cards showing stakeholders and technology (B)

3.5.2 **Development of the Ideation Design Cards** . Informed by the community interviews and a scoping literature review on digital MCH interventions, we developed various scenarios to construct the ideation design cards to facilitate the ideation process during the co-design workshops with our low-resource communities. Moreover, taking previous studies that employed design cards and design card principles into account [31, 109], a draft set of ideation cards were identified focusing on relevant contextual information focusing on the stakeholders, places, technology, and resources that represented the community and were included in the co-design process of a digital MCH initiative. Once again, the researchers communicated these with the graphic designer in a series of feedback iterations to appropriately represent the ideation cards' depictions. Examples were also sent to the graphic designer as a guide, especially for unfamiliar technology cards. Aligned with previous research on pictorial representations for low-resourced communities [90, 102] and card's design [54, 99], the ideation cards were designed with minimal text, using plain black and white line drawings that depict men, women, buildings and surrounds which are representative of both rural and semi-urban areas of South Africa. The concepts captured in the ideation cards were not exhaustive but represents technology, places, stakeholders, and resources available to an average South African community. We did not discount any of the above design cards due to feasibility or affordability. Previous studies employing card-based mediums for design such as the Envisioning cards [24] and IDEO Method Cards [41] have demonstrated to enhance design exploration and effectively provide cues to support the brainstorming process of potential ideations [31]. Although we take note on how these were previously used for their respective work, they were not African-centered and there exists a gap in accessible, African-centered design cards. Furthermore, the Envisioning cards (stakeholders, time, values, pervasiveness) [24] used in the context of homeless young people, differ to our design cards as they were created with a set of activities written on each card. Reading and understanding these activities require high literacy from users. Our design cards are more simple pictorials with labels to be incorporated in the ideation and co-design process with low-income and lower-literacy communities. The photographic images in the envisioning cards are not the focal point of the cards, the written activities are. Our card's pictorial illustrations were carefully drawn to be the focal visual aid for participants to identify with and relate to during the ideation process.

3.6 Community-based Co-design Workshops

The Inclusion of Intermediaries: respecting the sociocultural context. South Africa's rich cultural diversity and the eleven official spoken languages had the potential to introduce unintended complexities as spoken languages and cultural practices can differ between provinces as well as rural and semi-urban settings. Language is known as a significant barrier to collaborative codesign settings between researchers and community members who do not speak the same language [87, 96]. Cultural nuances presented, which are often missed or not understood by researchers who are not a part of the particular culture or who do not know the culture well can also introduce interesting, unintended consequences [70, 97] such as not understanding cultural specific gender roles and turn taking. We thus decided to make use of intermediaries (local research facilitators with similar levels of experience in qualitative research) that not only speak the local language, but also understands the different cultures well. We up-skilled these intermediaries in co-design methods and design thinking by providing training from two members of the research team with experience in co-design methods. In Limpopo, Soweto, and Sweetwaters, the intermediaries were local researchers; in Cape Town, they were NGO members who provided therapeutic services for the children in the local community. The intermediaries did not take part in the challenge ranking as they were not participants. It is important to acknowledge that the inclusion of intermediaries had 290:10 Toshka Coleman et al.

an impact on our research activities, however, this is beyond the scope of this paper and discussed in detail in a separated publication reflecting only on methods [97].

3.6.2 Understanding Challenges and Ranking. The CBCD workshops consisted of a challenge ranking activity, followed by co-design and prototyping activities. As far as possible, the same participants who were interviewed and subsequently invited to attend the workshops were included as participants. The majority of the interviewed participants availed themselves for the workshops. Eleven participants attended the workshop in Limpopo. The participants constituted four fathers (two of which were community leaders), two CHWs (who were also mothers), and five mothers. The two community leaders were from the local royal family and sent by the tribal office. In Soweto eleven participants attended the workshop. All participants were female and included young mothers and a grandparent, as well as a community health worker. The workshop in Sweetwaters had eight participants of this eight, seven were female and represented mothers and other caregivers and one was a father. Two children accompanied their mothers: a one-week-old baby and a 23-month-old toddler. Finally the Cape Town workshop consisted of eight mothers.

The challenge confirmation and ranking sessions started with the intermediaries using the challenge cards for an ice breaker activity. This was done by asking the participants what they saw depicted in the cards and to reflect by providing an example of where they have faced similar challenges in their daily lives. The intermediaries facilitated discussions while the participants at each site confirmed the challenges depicted on the cards. The cards were then displayed on the walls and then we asked the participants to rank the challenges in order of how prevalent or important the challenges were in their lives. Each participant was given ten stickers with different colour representing the numbers 1-10 and asked to rank the challenge cards one by one. The researchers asked the participants to take the sticker representing the number 1 (most important) and place it on the card that they believed represented the most important challenge. This was done for all ten cards. Researchers then tallied the votes to identify the top two or three challenges as ranked by the community. This process was followed in all of the research sites except the Kwa-Zulu Natal site, where the first workshop took place. The participants at this site voted for the priority of each challenge card by raising their hands, resulting in many cards receiving equal votes and necessitated another round of voting for the cards that could not easily be ranked in order of priority. The participants at each site were then asked to choose the top two health challenges from the cards that they believed to have the highest priority in their current situation.

3.6.3 **Prototyping activities.** We next asked participants to make use of the design cards and craft material to create low fidelity prototypes of possible digital solutions to their chosen digital MCH priorities, leveraging all the elements represented by the cards (stakeholders, places, technology, resources). We divided the participants into two or three groups (depending on the size of the group) and first handed them the design cards, poster boards and markers. We briefed the groups to brainstorm as many solutions as they could come up with and to initially use the design cards to help them during the ideation process. We next asked the participants to select one idea from their brainstorms with the design cards and create a more in depth prototype by utilising craft materials. The participants presented and discussed these prototypes with each other at the end of the session. These sessions were voice recorded, and photographs were taken, only after we reaffirmed consent to do so. One researcher also took detailed research notes of the comments the community made as well as the overall observation of the sentiment and atmosphere in the rooms. Reports on the workshops including the top ranked MCH challenges, lessons learned the created prototypes and photographs of the prototypes were written at the end of each community engagement and shared with research team via email.

3.7 Data Analysis

The audio recordings were translated and transcribed and stored on a secure data cloud storage along with the research reports, photographic images of the prototypes and scanned copies of the research notes. This data cloud is only accessible by members or the research team. We crossreferenced the ranked challenges between each site in order to identify the top three challenges faced by all the communities. We next analysed the transcripts of the audio recordings, as well as the research notes and reports. We then made use of a reflexive thematic analysis [9] to start the coding process and identify and generate the themes which we discuss in the relevant sections in the findings of this paper. The project researchers cross-referenced, discussed and verified each generated theme against each other and made sure to agree on the themes or new codes that were generated during the analysis. We further drew on the experience and multidisciplinary expertise of network members with extensive experience in qualitative data analysis and methods to comment on the final themes. In line with the recommendations of Castleberry and Nolan [13], this method of constant communication, cross-checking for validity and leveraging the combined experience for the research network while we iteratively analysed the collected data, was followed to ensure the validity and rigor of the themes. We made use of reflexive TA as described by Braun and Clarke (2019) [9] by implementing an inductive analysis without the use of a code book.

4 FINDINGS

Through our CBCD workshops, we gained a better understanding of the priorities these communities have for digital MCH, and collaboratively brainstormed potential digital initiatives to address the selected challenges as their community priorities. The findings consist of four main sections. Firstly, we present the top-ranked MCH challenges prioritized by the communities. These were the outcomes from the ranking sessions across the four community research sites. Second, we discuss the community interpretations and experiences surrounding these chosen MCH priorities. Third, we describe the contextually-situated co-designed ideas and prototypes that the community participants created to address the identified MCH priorities. Finally, we provide a reflection on how the use of intermediaries and design cards influenced the facilitation of community engagement in the co-design workshops' reflections.

4.1 Community-contextualised Priorities for Maternal and Child Health in South Africa

The top three MCH challenges that participants selected as their priorities across all research sites were *Parent's emotional well-being, Building parenting skills in early life, and Accessible and affordable health information.* These were selected from the ten challenges coming from the community interviews and the researcher's input, listed in section 3.3. We next discuss the top-ranked challenges for each research site.

In Soweto, one of the semi-urban sites, community participants ranked the 10 research-based challenge cards and *Parental Emotional Well-being* and *Building Parenting Skills in Early Life* emerged as the top maternal and child health challenges selected as priorities to address in their community. The challenges were ranked similarly in the second semi-urban site in Cape Town, with the *Parental Emotional Well-being* card receiving the most votes, followed by the *Accessible and Affordable Health Information*.

In the more rural research sites in Limpopo, the selected priorities appeared to partly align with the previous sites, ranking the *Parent's Emotional Well-being* as their highest priority, followed by *Parental Skills in Early life*. The participants from the second rural site, Sweetwaters, ranked *Accessible and Affordable Health Information* and *COVID Misinformation* as top priorities to address in their communities during the workshops.

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Overall, Building Parenting Skills in Early Life and Access to Affordable Health Information were both given top priority in two of the four sites. In addition, emotional health was prioritised in all four sites with Parent's Emotional Well-being being highest ranked in 3 out of the 4 sites and Health Worker Emotional Support ranked as a top priority in Sweetwaters. While it is evident that there are common community priorities among the four sites, the community participants call for greater attention to emotional health and well-being. In addition, community participants also highlight the need for more accessible MCH resources and improved parental abilities to implement early childhood development (ECD) practices with their children at home.

In Figure 2, the highest-ranked priorities discussed in this section are shown.



Fig. 2. Highest-ranked Challenge Cards: a) Parent Well-being, b) Accessible and Affordable Health Information and c) Building Parenting Skills in Early life

4.2 Community Experiences of Contextually-situated MCH Priorities

In general, the community interpretations of the top priorities depicted in the challenge cards were accurate, triggering discussions among the participants and several community experiences.

4.2.1 **Community Experiences with MCH information and Services**. When the *Accessible and Affordable Health information* card was presented to the participants across the sites, they first related themselves to the situation while referring to the visual representation of a clinic with a long queue, and the poor affordability of data was also mentioned as major challenges in these communities. For example, a mother participant from Cape Town stated:

"There is a mom holding a baby with a problem. She can't find help on her phone and medicine is too expensive."

All participants agreed that the challenge card showed mothers not being able to access to MCH information as well as not being able to access healthcare services and therapists in the community. The mothers in all sites lamented that data for accessing online MCH content is often too expensive and prevented mothers in their communities from accessing MCH information. Parents also expressed their lack of access to appropriate and useful content in the four sites, expressing that MCH information is usually too text-heavy and provides information that is too generalized, not in their local language, and not suited to their children's individual needs. In addition, community participants also stated that they often struggle to understand advice and guidelines provided from doctors and current MCH information due to the unfamiliar jargon used. For example, a mother from the Cape Town site stated:

"We need personalised information for our children, their conditions are different, even children with the same conditions are different."

Socio-cultural practices also appeared to play a role in the prioritization of challenges as participants from the two rural community expressed that they often opt for traditional healers instead of doctors as they are more accessible (closer to where they live), usually speak their home language, and parents are desperate and seek any possible help. Participant responses supporting this include:

"There are no hospitals in rural areas and parents need help, they are willing to try everything to help their child - there is no taxi needed to take to a traditional healer, they are in your neighbourhood and sometimes some of their herbs do help"

"Traditional healers speak the same language as us, at the same level as us, which is sometimes helpful."

In most African cultures, although child-rearing is the women's responsibility, women will defer conversations and decision making to men [42, 97]. We found that turn-taking can be used to improve the participant of women in conversations.

4.2.2 Shifting the Focus from General Health Services to the Providing Parental Emotional Support. Participants from every research site highlighted the lack of emotional support available in their communities for parents, and mothers in particular. Mothers expressed how difficult it is to balance their every day activities and responsibilities with motherhood. In addition, many mothers touched on the fact that they have struggled with postpartum depression and often felt alone and overwhelmed. In Soweto, mothers provided comments on their emotional experiences such as:

"It is emotionally draining to become a mom, I ended up with depression. Our people do not care about emotions, I ended up losing my milk".

Another mother from Soweto stated:

"This goes back to involving fathers [another challenge card], people think mothers are strong, they think we can multi-task, they say women are sent from God and then they treat us like we do not have feelings."

In addition, mothers also explained that it is not always easy to leverage support from family members as stated by a mother from Soweto:

"You cannot complain to your mother, she will tell you, you are ungrateful and spoiled."

In urban Cape Town, mother participants expressed that they very much resonated with this challenge and have felt emotionally overwhelmed, especially after hearing the news that their child had disabilities. Participants agreed that having someone to talk to, especially someone in the same situation can be very helpful and comforting. They voiced their emotional concerns and how they felt like they always needed to be strong in order to be a good parent to their children. Some comments from mothers in Cape Town included:

"There is a lot of depression, I had an unexpected baby and I needed to see a professional, I needed to work through a lot of fear".

Another mother shared the positive role of the situated community network as "It is good to share with other mothers, my baby was in hospital for 4 months, I was crying every day. I met a mom who told me, don't cry, sing or scream or do something else, crying is not going to change where you are, your child will be the same when you are done crying".

It was also evident that parents do not receive the necessary emotional support from healthcare workers, nor are they referred to specialists who can assist them. A mother in Soweto explained

"Nurses are mean, we end up with more depression. One nurse told me...don't ever have another child."

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4.2.3 **Progressing towards Becoming Better Parents Beyond Meeting their Children's Basic Needs**. Across all the sites, participants agreed that this was a priority often neglected in their communities and expressed that they were never taught how to "be a good parent". For example, a participant from Cape Town stated:

"We woke up as parents, but no one taught us to be parents, we had no idea how to raise a child, we all needed lessons. We want to raise good children".

In addition, the concept of "play", as depicted on the *Building Parent skills in Early Life* card, was discussed in Cape Town, where a mother stated that she learnt through experience that playing with children while they are young is crucial for a healthy development of their children, as parents can only send their children to the nursery from the age of six. Another mother voiced that nutrition is a prominent challenge for her due to her child's inconsistent eating habits and needs. While participants recognized the need to improve their parenting skills and that some information is available, the information does not meet the needs of their children as one mother participant from Cape Town expressed:

"There is information in the road to health book about milestones, nutrition etc – but it is not for our babies. It does not help for children with special needs."

In Limpopo, the interpretations were slightly different, with both father and mother discussing and focusing more on what their responsibilities regarding ECD for their children are. A father started the discussion on this challenge by stating:

A mother must choose the best way to raise a child, another father joined the conversation by adding "Yes, it is the way in which we much raise children, children could touch dangerous things and get hurt, we must be responsible for them".

Other mothers soon joined the conversation by expressing:

"Mothers should raise their children close to them, making sure they eat well, watching how the child is playing" and "It is important to be present while your child grows, to use toys to identify the talents of our children, to make sure they eat and learn well"

4.3 Co-designing Contextually-situated Solutions to Community Priorities in MCH

4.3.1 **Re-designing and Adjusting Community Spaces to Enhance Parental Involvement.** All of the community participants considered community spaces as an overarching strategy to co-design digital MCH initiatives that address the identified community priorities. In this section, we introduce the communities' co-created solutions that integrated and adapted community spaces in the potential community-based solutions.

Central community structures and places, such as community halls, faith-based centres, and clinics appeared as an important contextual consideration for the co-created interventions proposed by the community participants. When communities generated ideas for possible interventions, these were usually associated with communal spaces, rather than personal ones, such as in their homes. A caveat is the use of community radio, which is accessed personally, but its use is distributed across the communities. At the communal locations, participants envisioned central access to resources and technology that could assist them with their MCH needs.

In the rural community of Ga-Dikgale in Limpopo, the community hall was a central meeting point for many community meetings. These meetings often involved providing updates on community events, news and information sessions on COVID-19 safety and vaccinations. The multi-purpose centre lends itself to different ways in which health needs and well-being can be supported, especially as the community prioritises gatherings over individualised engagements. As such, this community space aspect was valued by the participants while co-creating ideas and prototypes

during the workshops, highlighting the importance of group communication and understandings of maternal and child well-being. While collaboratively discussing topics of concern with community members appeared strongly in this community, much of the participation in such community gatherings were largely led by the men in the community. In the co-design activities in our workshops conducted in Limpopo and Sweetwaters, this also manifested as women participants were less active in the discussions than the men in the room.

Even when physical common shared spaces were not a dominant feature in the community, such as that of communities in Kwa-Zulu Natal and the Western Cape, the importance of a communal space remained relevant for designing support with and for mothers. Despite being more physically distant within the larger communities, community ideas centred around the facilitation of spaces, be it online or in-person, to provide avenues of support. Part of this was due to the context of COVID-19 and its potential risk of infection, but another, was the socioeconomic challenges associated with travelling and meeting up to provide or receive support. Support can thus be interpreted in various ways but it fundamentally focuses on fostering a community which intends to help each other. The nature of design ideas, including leveraging radio and online spaces such as social media platforms and mobile applications. Pairing this with the regular visits to the community clinic made the use of "community spaces" a significant consideration for designing for MCH in low-resource settings.

Overall, the role of the community leaders and members as a support mechanism for initiatives addressing the priorities was evident. The participants from Soweto brainstormed solutions that combined the community with nursing professionals, such as home visits from nurses, as well as community spaces for nurses engaging with mothers needing assistance. In Limpopo, participants also stressed the role of the community and community leaders. These communities offered comments such as:

"The nurse needs to connect to the community. The community can then mobilise to support mommies who are not coping" and "Mothers can talk to the community for help, the community needs to be informed and they can help mothers."

This blending of community spaces, community citizens and leaders, and in some cases government resources, presented as a common theme throughout all the prototyping sessions and is elaborated on in the next sections.

4.3.2 Co-designing to Facilitate Access to Health Information and Support Parental Skills.

The use of a wireless network was received as an effective way to combat the major challenges communities face across all workshop sites, a desire for a community wireless network (CWN) was prominent for improving access to information. In addition, CWN and internet-in-a-box associated solutions often involved placing these in a central community spaces, thus leveraging the aforementioned community spaces highlighted by community participants. In all sites, the inclusion of either the church leaders, community leader or traditional healers was suggested as part of the implementation of a digital development to facilitate access to health information and support parental skills. During the workshops, participants considered WhatsApp groups with leaders involved, and the inclusion of leaders in mediums such as CWNS to connect resources across communities.

In the case of Sweetwaters, the participants stated that the CWNs would provide greater opportunities for affordable access to health information, especially at vital communal spots such as the clinic or religious sites. In the semi-urban areas, Soweto and Cape Town, the desire to access videos and educational content via a CWN was more evident. For example, Soweto's community participants brainstormed ideas for addressing *Building parenting skills in early life* (see Figure 3) showing a centrally located community centre that housed an Internet-in-a-box, supported by a CWN. Using the cards, participants considered that the content on the Internet-in-a-box would

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include a digitised "Road to Health booklet" (RTHB)¹⁰, a government resource that assists mothers in the first 1000 days of childcare, and educational videos by doctors and nurses. Community participants expressed that these educational videos would also include video content for babies, with a caution that babies and toddlers should not spend more than two hours each day in front of a screen. People with smartphones would access these resources by connecting to the CWN from their homes, and those who do not own smartphones can access the resources at the community centre, using tablets that can be provided by community leaders.



Fig. 3. Brainstormed solution for Building Parenting Skills in Soweto

Similarly, in Cape Town, community participants brainstormed solutions focusing on *Access to MCH information* as shown in Figure 4 and included a digital ECD platform whereby videos related to early childhood play, care, nutrition, and well-being would be made available with no bandwidth costs. Community participants discussed that ECD information and videos should be made accessible through CD-ROMs, flash drives, internet-in-a-box and shared throughout the community through community wireless networks.

At both semi-urban sites, Soweto and Cape Town, digitising the national "Road to Health booklet" was a priority, with many mothers requiring more education on and exposure to the resource. Participants expressed that the booklet is often neglected in their communities and a mother indicated that she had not previously considered the details of healthy nutrition as it is presented in the booklet.

In the rural communities of Sweetwaters and Limpopo, community radio was the most prominent choice for information sharing, and more community and religious leaders were included in their brainstorming activities. In Sweetwaters, it was suggested to use community radio that could be used to share information regarding child rearing and maternal health. One participant stated the following:

"Moms need information over the community radio or on her smartphone. She can also talk to the community for help".

For example, Figure 4 illustrates one of the brainstormed solution for addressing *Access to MCH information* from the Sweetwaters workshop. This solution depicts a community, a mobile clinic and a community wireless network which provides the community with access to the clinic nurse and the church via a mobile phone from their homes. Finally, in Limpopo, community participants suggested that information should be shared over community radio to strengthen parental skills and support mothers on how to manage their money, time, and other resources.

 $^{^{10}} https://www.westerncape.gov.za/first-1000-days/files/atoms/files/ROADTOHEALTHBOOKA4GIRLS.pdf$



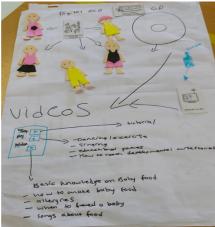


Fig. 4. Brainstorming ideas to Facilitate Access to MCH Information in Sweetwaters (left) and Cape Town (right)

4.3.3 Co-designing Strategies to Provide Emotional Support for Caregivers. As with the previous examples, the involvement of communities, and community and religious leaders was prioritised in the ideas and prototyped solutions to enhance emotional support across the research sites. Additionally, community members from Soweto emphasised that local clinics should be integrated into solutions for emotional support, to assist in distributing clinic-facilitated, maternal mental health information. The solutions largely included social media spaces and the use of CWNs to share experiences and advice between mothers, religious leaders and clinic members. It was emphasised across the sites that community support was important for relieving their stressors. Interestingly, the mothers in Cape Town expressed that talking about their challenges in the workshop was therapeutic, and decided amongst themselves to create a WhatsApp group to continue to support each other.

In the two urban sites, the solutions for parent well-being typically involved a smartphone, CWN, community radio, and community members and leaders. In Cape Town, group chats and chatbots were part of their brainstormed ideas whereby mothers would have 24/7 access to chat with other mothers and use the chatbot to acquire advice about their experiences. As presented in Figure 5 below, an example of a solution for addressing parent emotional well-being in Cape Town was an application that connects mothers who experience similar situations and stressors. The home page includes a list of stressors in which a mother can click on. All mothers who click on the same stressors would be connected and will be able to chat, and share experiences and advice. It was also mentioned that a professional in each chat be included to ensure correctness in advice and to provide additional support.

In Limpopo, community participants designed a solution comprising a Wi-Fi network with community radio providing mothers with mental health information as a form to support *Parental emotional well-being*. It includes social media networks so that the mother can receive help while managing their home.

4.4 The Use of Facilitators to Support Community Participation in CBCD Workshops

4.4.1 **The Key Role of Intermediaries to Encourage Community Participation**. The presence of intermediaries played a significant role in increasing community engagement of the reflection of

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Fig. 5. Brainstorm of Parental Well-being in Cape Town: chatroom application for mothers with similar stressors

MCH priorities. Along with facilitating language translations, integrating tribal and local leaders in the research space facilitated engagement of the community members. Furthermore, the cultural leaders in the rural sites created a familiar and culturally safe space for community members to feel comfortable and supported by their community leaders when expressing themselves. For instance, the community leaders often initiated the more sensitive topics when the other community participants were more quiet and shy to speak about them. For example, the male community leaders in Limpopo started the conversation about "Involving Fathers" by stating:

"This is a problem in our community. Fathers get bored with their children at home and go to the tavern. They are like visitors in their own homes. We need to teach men about raising children."

The community leaders also paved the way for discussions of taboo topics such as the Headsman in Limpopo openly addressing the Postpartum Care card by stating:

"This is a mom, who should be taken care of at home."

This is with the exception of Limpopo community workshop, where mothers often would moderate their voice and participation out of respect for the male participants.

The inclusion of the NGO intermediaries in Cape Town also promoted a sense of ease and comfort for the mothers of children receiving early childhood development interventions. The presence of the NGO members in the session encouraged the participants to open up about their experiences as they were familiar and comfortable with them. The NGO members were also able to refer to events and experiences in the participants lives that they were aware of that related to the challenge cards and identified priorities.

4.4.2 The use of Challenge and Ideation Design Cards for Initiating Conversations and Establishing a Shared Understanding. In all the sites, the Challenge Design Cards initially assisted as an ice breaker for the participants to open up about their challenges and relate their personal experiences to the illustrated challenges represented in each card. In this way, the cards initiated a conversation between the community participants and enabled them to feel more comfortable by sharing their interpretations and parenting experiences. Community participants would often point at a mother in the figure, and say, "That's me!", relating themselves to the

challenges depicted in the cards by stating "I know that feeling" or "I have been there" and other mothers would agree and join the conversation, expressing their personal experiences with the priorities.

The majority of the participants were able to easily recognize and describe what was happening in each illustration, as well as who and what the different stakeholders, places and resources were. We see this in their accurate interpretations of the cards presented in Section 4.2. We found that the use of familiar family roles, places, items, and emotions informed by the previous community interviews helped facilitate this understanding and perception of what what happening in the cards. Using the Challenge Design Cards as a medium to communicate the challenges helped ensure that each participant had a shared understanding of what the challenge represented. Language and cultural barriers were mitigated using illustrations as opposed to text or reading the challenges aloud. This was apparent in the affirming responses from the participants across all the sites, with varying backgrounds and cultures.

The Ideation Design Cards were effective in introducing and incorporating technology concepts that were foreign to the participants and otherwise would have been discounted as possible elements for a solution, consequently extending the capacity of the prototypes. For example, the illustrations of the community wireless network and internet-in-a-box were initially unknown to most participants but were used in many of their solutions across all four sites. This highlights the significance of awareness of available resources as a tool to empower low-income communities, whereby they would otherwise not even be aware of the possibilities and opportunities for their communities. We found that the field of digital MCH was unknown to most of the participants and one of the facilitators stated, "Had we not had the Ideation Cards, the participants would have really struggled and we would not have had the ideas that we have." However, it should be noted that some participants were overwhelmed by the craft materials. The participants who assumed leadership roles in initiating the activities were normally associated with cultural norms in rural areas (Limpopo and KZN) but not in urban areas. Working in groups allowed for the comfortable association of roles for the participants – some crafted, some were presenters and some just participated in the discussions of the designed prototype.

Finally, no new ideas were created by the participants outside of the design cards presented. However, they sometimes drew and crafted their own recreations of the existing cards e.g., a smartphone would be drawn but with their mobile application idea displayed on it (shown in Figure 5), or their personal depiction of a house (shown in Figure 4)

5 DISCUSSION

In this paper we have engaged with community participants to further explore the community priorities across different regions of South Africa, in the context of maternal and child health. Based on the identified community priories, we explored the use of co-design methods with community participants to assess the potential role of technology to address the identified priorities, and what ideas would be welcomed by the communities according to their perspectives. We have highlighted how the intermediaries and the design tools we used in the workshops have supported and enhanced the community participation of low-resourced communities in South Africa. Here, we discuss the existing design tensions and opportunities to co-design digital MCH in South Africa.

5.1 Reconsidering and Advancing HCI and MCH research to Support Parental Well-being

5.1.1 Bridging the Gap to Enhance Parental Emotional Well-being in South African Communities. All of the research sites in our study highlighted mental and emotional well-being above physical health priorities such as postpartum care. Yet, the MCH research for the Global South

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conducted in the HCI space largely focuses on physical needs around nutrition and breastfeeding [69, 88, 106], postpartum care [59, 74], and healthcare monitoring [5, 110]. A study by Pendse and Karusala et al. [79] investigating mental health and HCI in the Global South found that "little work has been done in HCI4D addressing mental health directly" and further states that other issues such as diabetes [81] and HIV [67] are prioritised.

We believe that this is potentially due to the prominence of expert-led health sciences-based research performed in the MCH field, as opposed to more research work co-designing with actual parents on a more in-depth, qualitative level. Previous research [1] in MCH discovered that there is a definite shortage in community engagement and formative research to ensure that cultural practices are considered in this space [1, 17]. Based on our research [98], studies on digital MCH predominantly employ top-down design that did not involve the community [47, 89], leading to at least one MCH project failing as a result of not considering the current community realities and experiences [88]. Thus, it is probable that in previous studies, the community's evident demand for mental well-being interventions did not appear as a prominent priority.

In South Africa, there are very few digital mental health and well-being projects for mothers, though there are current innovations that provide mental MCH resources, such as Messages for Mothers¹¹ from the Perinatal Mental Health Project (PMHP)¹². Such platforms provide important MCH information to mothers about maintaining healthy mental healthcare habits to help mothers manage their mental health. However, while some are zero-rated (i.e. no data costs are charged for accessing the website), access is limited by network coverage and device compatibility. Also, content is typically only available in limited languages e.g. usually English, Afrikaans, isiZulu, isiXhosa but not usually in other low-resourced community languages such as isiNdebele and Setswana. This was also evident in our co-design workshops, as mothers expressed frustration in not being able to access MCH resources because they were not available in their local language.

The shortage of available mental healthcare platforms within these South African communities may also be associated with cultural norms since expressing negative experiences and depressive emotions are considered inappropriate, and mental healthcare is largely undervalued in these communities [38]. From what we have observed in our workshops, mothers are expected to handle their emotions and balance motherhood demands on their own, despite experiencing mental distress. It was also evident that health professionals share this attitude toward community members, failing to provide mental health services, or refer them to experts, or have difficulties expressing sympathy for their mental concerns and experiences, which often leads to mothers not getting the support they need. A plethora of research on mental illness and health in South African supports this notion of poor attitudes of community health workers towards mental and emotional well-being [44]. South African studies have explored the perceived levels of stigma in the community toward people with mental illnesses. Studies that have looked into this topic have all found high levels of stigmatizing views against people with mental illnesses in their communities. Three additional studies [50, 56, 57] looked at the attitudes of mental health nurses working in public hospitals and discovered that a large number of nurses had negative and stereotypical attitudes toward mental health care users [44].

During the co-design workshops, participants also expressed the need for inclusion of community stakeholders such as community leaders while brainstorming their potential solutions and placed great value in them as having potential to help alleviating stressors and providing support. Parental well-being ideas frequently incorporated communal institutions such as churches, and social digital media such as chatbots and group chats, as well as a combination of both. However, healthcare

¹¹ https://messagesformothers.co.za/

¹² https://pmhp.za.org/

professionals cannot be included in initiatives if they do not develop empathetic engagement skills. Therefore, before we shift our focus to collaborating digital initiatives with community and religious leaders, training for empathy such as the Secret History Strategy [37] should be considered, in order to reduce the stigma associated with mental well-being and mental illness in these communities. The Secret History Strategy's objective is "to engender an ethos of care and compassion within maternity settings, so as to ultimately prepare these environments for mental heath task shifting initiatives."

Taking all of the above into account, our findings show that communities are favorable to and would welcome digital interventions for MCH but they have not yet been exposed to nor experienced many useful ones. In addition, socio-cultural practices and norms need to be considered as they could influence community willingness to participate in co-design initiatives. Therefore, future research and design of interventions should not only prioritize expanding the digital space for mental well-being in MCH in South African contexts, but also consider the assimilation of them within community structures when doing so, to create contextually-suited and cultural-relevant interventions that collaboratively address mental health and well-being challenges and stigma within the local communities and beyond.

5.1.2 **Contextually Addressing Access to Relevant MCH Information**. The second and third highest priorities highlighted were *Parental Skills in Early Life*, with three out of the four research sites prototyping solutions to this challenge, and *Affordable and Accessible Health Information* with two out of four research sites (and highly prioritised in the other two sites). These two challenges coincide in terms of the priority of expanding mothers' knowledge and their ability to apply that knowledge in their parenthood. However, current research in HCI and ECD in South Africa is limited [104]. We observed that mothers also expressed that they are unable to use the existing MCH information they have access to because it is not available in their home language, not relevant nor applicable to their culture or uses unfamiliar jargon.

Community participants sought for community familiarity, and because of this, often opted for community-based solutions such as asking help from family, religious leaders or traditional healers. We believe that we should be working with this sense of familiarity, and not working away from it. This ties in with the idea of designing for community spaces presented in our workshops and designing for connectedness (see next section). With that being said, the community participants' co-created prototypes not only included these community connections but also opted for maintaining already-available resources, for example, the digitisation of the RTHB and incorporation of CD-ROMS and social media. Furthermore, the mothers in the workshops also largely opted for community radio and community spaces as opposed to mobile apps for MCH education and awareness, as they proposed that this would be more accessible for many mothers in their communities. In this way, we recognise that digital approaches should not negate communities' available resources when incorporating technology into developments, as these are often more appropriate and sustainable in low-resourced communities, specially in rural communities.

In our workshops, we saw that community participants from the rural communities prioritised design elements that they feel more comfortable with, such as the community radio and church structures. Whereas, the participants from the more semi-urban communities prioritised smartphones, mobile applications and videos, due to being more familiar with these because of their increased access to technology (this was also highlighted in the community interview findings that informed the design of the challenge cards). It should also be noted that participants rarely used technology items such as wearables, Internet of Things, and sensors, probably, because they were newly introduced to these items and were unfamiliar to them without knowing how they can be used. Their lack of familiarity with these technology examples is likely due to the shortage of ICT

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infrastructure within low-resourced regions in South Africa. This digital divide is evident in ICT research in South Africa. According to [4], the integration of ICT infrastructure in post-Apartheid South Africa varies across the country. Rural communities have limited access to ICT services and infrastructure, putting them at a considerable disadvantage in comparison to urban areas. The majority of ICT infrastructure users in these rural communities are likewise novices, mostly using phone calls, SMS, and social networking. Furthermore, previous research [77] supports the notion that supplying technologies does not inevitably result in skills, partially because the educators available lack the necessary digital skills to teach individuals. Therefore, when implementing digital initiatives for South African communities, we do not need to develop holistically; rather, our design should take into account all the differences within the settings and prioritize contextual approaches that communities are familiar with and have more potential to access, as this may increase the viability and sustainability of the designed intervention. In addition, there is increasing research supporting asset-based approaches, especially in digitally divided regions like South Africa [10, 22]. In their research, Brooks, and Kendall proposed that asset-based interventions are beneficial because they focus on the capacities, skills, and assets within the social system and improving the inherent assets in a system.

5.2 Addressing the Tensions of "Connectedness vs Access" in South African Communities to Achieve Sustainable Interventions

In terms of the participants' choices of technology elements to incorporate into their solutions, the co-created prototypes in each site included Wifi, Internet-in a-Box, a Community network or Community Radio. It is clear that community participants are looking for access to information, but, also to connect to each other in different ways. This can be seen by looking at the stakeholders the communities considered for each of the challenges they focused on. For example, the solution for parental emotional well-being included an application that connects mothers, community leaders and therapists together to support and engage with one another going beyond conventional therapy. We also observed this in their choice to create a WhatsApp group to continue connecting with one another to access and provide support to each other. This aligns with a study on bandwidthconstrained mothers by Dsane and Densmore [21] which found that WhatsApp groups could help maintain cohesion and fostered mutual support between mothers. The consideration of religious and community leaders, and members of the community itself within the maintenance of their solutions aligns with the findings of Lodges and Young [53] who explain that access to networks that enabled communication between members of the community does not automatically lead to connectedness. This connecting access needs to be supplemented with a degree of connectedness to the system and to the community.

With regards to connectedness, Van Bel et al. [101] describes connectedness as relationship salience and closeness which relates to a sense of belonging, knowing others life experiences, and establising shared understanding. This connectedness is an important concept in African cultures. Perhaps the most pertinent example is "Ubuntu" which states "I am, because we are" [71] or another well-known Africanism: "It takes a village to raise a child" [95]. Elements of community connectedness were manifested in every single prototype and was discussed at great length during the workshops. The communities further touched on the fact that connectedness can be empowering. In line with this, Baron and Gomes [7] explain that access, and in turn connectedness, lead to stronger personal connections that can translate into strong community development, societal inclusion and empowerment. Putnam et al. [83] echoes these findings by stating that social capital and community cohesion can be fostered from the following four features: 1) The existence of a dense range of local community networks and organizations, 2) high levels of civic engagement, 3) the presence of a strong local identity, a sense of equality and belonging with other community

members, and 4) generalized norms of trust, all of which was exhibited by the communities in this study. Perhaps, considering the work of Donner [20] in his book, *After Access* we can now see indications that South Africa no longer requires just access to internet connections, but are also starting to consider what happens after the communities in this country are connected to the Internet. Overall, the community participants highlighted the needs and opportunities to make use of connectedness to address their own MCH problems, create their own solutions and to empower themselves and their communities to sustain the solutions. We propose that researchers and experts should apply this by involving communities, community structures, and figures such as community leaders and traditional healers, as opposed to moving away from them towards traditional health solutions and structures.

5.3 Facilitating Effective Communication Strategies and Co-design in South African Community Research

5.3.1 Supporting Community-Engaged Research through Intermediaries. Throughout our workshops, the use of intermediaries played a significant role in communicating the MCH challenges with community participants, and making them feel comfortable in the research space. This includes facilitating language translation and a sense of familiarity that allows them to open up more about their experiences. Especially in Cape Town, when working with mothers of children receiving early childhood development interventions, it made it easier for them to open up and engage with us through their therapeutic providers (NGO members). Furthermore, the community leader participants in the other regions played a role in creating a familiar and culturally appropriate space for community members to feel comfortable and supported by their community leaders in expressing themselves, and additionally, not feeling any feelings of shame or guilt in doing so. Many participatory design studies support this [94] for example DePaula et al. echo this by proposing that the use of intermediaries in their ICT participatory design sessions encouraged participation from community users and addressed language or cultural gaps [18]. With that being said, intermediaries should be considered in community-engaged research in different contexts with different cultural backgrounds when co-design researchers are not familiar with the language nor the socio-cultural practices of the local communities [97].

5.3.2 Use of Appropriate Language, Dialect and Vernacular in Communities. The use of language within digital health innovations has often been a concern when designing for marginalised groups [40]. In South Africa, a country with eleven official languages, it has become even more challenging to offer accessible support with digital health technologies. To design for all languages requires extensive resources not often available, which needs to be balanced with the goal of easy and affordable access to health care [43]. The alternative is to design resources based on a particular context, accounting for the local language as the main mode of communication used in these technologies. While not initially a transferable technology, prioritising local dialects and languages can generate helpful information on access and usability that may make an intervention easier to adjust and transfer to a different context.

Language usage, both in the way co-design was conducted and in the co-created prototypes, played an important role not only for improving access but to solidify ways of connecting to each other. While a common language may be spoken in a community, for example Sepedi in Ga-Dikgale, within the community, there exist particular linguistic nuances and vernacular that are contextually unique. Incorporating these nuances in the design of interventions and allowing for greater control over how information is communicated could provide both a sense of connectedness as well as a way to sustain the intervention with localised ownership of the community. Participants in the communities we engaged with felt more comfortable to communicate and collaborate when using

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their local language, of course, but what this implied is that co-design activities and co-design objects need to accommodate local languages throughout, and that dialects and localised verbiage would influence how the objectives of interventions are met. In many cases, however, the prioritisation of African languages in the co-design of health technologies has remained challenging for many years. Besides direct language, communication via local gestures and humour also played a role in our research, whereby our local facilitators were able to make participants feel more comfortable in the research space in this way. Thus, we again recognise the importance of involving local intermediaries in community-engaged research space.

Low-resource languages, or often neglected languages, are challenging to design for, considering the dominance of English in the status quo of digital health intervention design [68], isiZulu, the most spoken language in South Africa, does not represent a proportional representation in the modes of communication through digital health technologies [40]). Designing for isiZulu because of its prominence in South Africa will come with its own challenges and easy, direct translation is in the best case, and in the worst, inaccurate, with sophisticated automatic translation services such as Google translate unsatisfactorily translating African languages to provide the intended meaning. Co-designing for MCH and parents-centered perspectives requires a prioritisation of preferred languages, and not as a second alternative to English. In South Africa, this would mean adjusting the design approach for each context to take into account the local language and the intended users of the intervention e.g., mothers, healthcare workers, or other caregivers. This consideration should be present during the engagements, which may mean the co-ordination and leadership of a first language speaker, as well as the design and presentation of any artefacts that will lead to an intervention. While it is unlikely to accommodate all users, language, and its role in the design, needs to be contextually applied and adjusted, so as to maximise the adoption of any intervention, as well as contextually relevant and centered on the identities and preferences of the users in the local communities.

5.3.3 Using Design cards for Communicating New Technology Concepts for Low-resourced Communities. As presented in our findings, the inclusion of unfamiliar technology concepts in the design cards enabled brainstorming of ideas and solutions that would have been discounted to be considered by the community participants. However, in doing so, there are some points to take into account. Firstly, ensuring the participants' understanding of the concepts depicted on the cards was challenging but important. We spent more time explaining the technology cards and using them in examples than the other cards. We also asked the community members questions about them such as "How would you see this helping in your community?", to help ensure their understanding. For future workshops, we would preferably include more transferable mediums such as videos of the technology in use in order for participants to gain a better visual understanding of the technology concepts more practically. Research also supports using videos over text and images for more effectually educating and conveying, new concepts to individuals [12, 52, 84]. Studies suggest that videos widen participation, and support emotional engagement, contextual understanding, and overall knowledge transfer [12].

The importance of the participants' comprehension was highlighted in our study, as another issue to consider when using new technology cards. We found that using technology cards that were newly introduced to the participants was sometimes potentially insufficient in helping them understand the feasibility and related costs of implementing the solutions in their community. Hence, they would often opt for the most "modern and new" options. Furthermore, they would often choose the technology that we spent the most time explaining as it may have seemed to be what we would want them to choose, introducing researcher-participant bias. Palleson and Rogers [78] considers this in their study on co-design for health, and proposes that facilitators

of co-design initiatives should be mindful of developing and sustaining a true relationship with the participants as equal partners and co-creators. They accomplished this during their co-design process by continuously using feedback, letting the participants guide the workshop, and minimising the amount of input from the researcher. In this way, the participants can feel more comfortable expressing their genuine concerns and opinions as they build a relationship with you and feel less judged and also more valued. In future workshops, we would spend more time asking the participants to explain their ideas and personal choice of cards, and use video as mediums, to ensure they understand the use and value of the technology concepts in their life - not because of the cards influence. We would also reiterate more that community participants are the experts in their everyday situations and that we cannot do the research without their input. Furthermore, we would give participants enough time to familiarise themselves with the cards before asking them to incorporate them into a solution.

6 CONCLUSION

In this paper, we present the top priorities for digital MCH according to four South African communities. These were identified as: 1) Parental well-being, 2) Building parental skills in early life, and 3) Accessible and affordable health information. We found that the conversations and reflections around these topics mostly aligned across the communities but differed between rural and semi-urban settings. Although the community participants across the sites all expressed the desire to enhance their parenting knowledge and skills, they commented about the barriers to this such as poor internet access, inadequate healthcare facilities and contextual barriers (such as language and jargon). Moreover, the rural communities experienced more socio-cultural nuances such as opting for health information via traditional healers as they are more accessible. This should be noted by future researchers to move towards including traditional healers and other community structures in the design of interventions, as opposed to only working with standard healthcare structures. In terms of emotional well-being, the parents across the sites expressed that mental well-being is underdeveloped in their communities.

In relation to co-design outcomes, the design elements incorporated in the solutions also varied between semi-urban and rural settings, with rural sites prioritising community radio, community and traditional leaders and community structures such as ECD centers and clinics, whereas the semi-urban regions leaned more towards advance mediums such as mobile applications and videos. We believe that this should be considered when designing digital-based initiatives for communities, also proposing asset-based approaches for such contexts. To support emotional well-being, we recognise the importance of including community participants in the design of any intervention aimed to address MCH stigma and to contextualise resources, according to community needs and preferences. Based on the co-created prototypes across all the sites, community participants seek more than just access to information, and look for meaningful connectedness with each other and their community leaders. This may manifest through social media, community spaces or places of worship.

Finally, we learned the importance of intermediaries in communicating effectively with participants, not only through speaking the same language but through their vernacular, humour and cultural awareness. This led to participants feeling more comfortable and opening up more about their experiences with less fear. Additionally, we discovered that design cards are effective as co-design aids, but incorporating video mediums was suggested as well that may be beneficial for giving participants a more in-depth contextual understanding of unfamiliar technology concepts. Future work in this field should consider these priorities and the design tensions and opportunities we have presented in this paper.

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7 DATA AVAILABILITY

The CBCD workshop data from the co-design sessions generated and analyzed during this study are not publicly available due to ethical concerns.

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