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RESEARCH ARTICLE

Perceptions of preconception health messaging and responsibility: engaging with 'health helpers' in the Healthy Life Trajectories Initiative-South Africa trial

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Abstract

Premised on the Developmental Origins of Health and Disease theory and on the limited effectiveness of antenatal interventions, interventions in the preconception period are being conducted to potentially improve intergenerational health and non-communicable disease burdens. The Healthy Life Trajectories Initiative (HeLTI) is an international health research consortium primarily investigating the intergenerational effects of behavioural interventions on obesity via a complex four-phase intervention initiated preconceptionally, through pregnancy, and into early childhood. HeLTI, in partnership with the World Health Organization, aims to generate evidence that will shape health policy focused on preconception as part of a life course approach to population health. It is necessary to ensure that a renewed public health focus on preconception prioritises justice and equity in its framing. This article presents collaborative interdisciplinary work with HeLTI-South Africa. It applies a feminist bioethics methodology, which is empirical, situated, intersectional, and fundamentally concerned with justice, to investigate what South African HeLTI community health workers, or 'Health Helpers', who deliver the complex behavioural intervention, think about preconception health and responsibility. Seven semi-structured interviews were conducted with HeLTI-SA Health Helpers, and data were analysed using reflexive thematic analysis. Our findings show that Health Helpers' perceptions of preconception health and related responsibility were significantly gendered, heteronormative, and concerned with child-bearing intentionality and desires. These themes were inflected with Health Helpers' perceptions about how attributions of responsibility are shaped by culture, demonstrating the situated nature of epistemologies. Their ideas also highlight how preconception health knowledge can distribute responsibility unjustly. Understanding the contextual impact and relevance of values around responsibility is critical to prospectively design preconception health interventions that promote equity and fairness. This understanding can then be used for effective policy translation, with the goal that public health policy is founded upon contextual responsivity and justice for the public it aims to serve.

Keywords: Birth cohort studies; Feminist bioethics; Health messaging

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Introduction

In the last decade, global efforts to reduce rates of childhood obesity have been focused on a life course approach (WHO, 2015). Premised on the Developmental Origins of Health and Disease (DOHaD) theory and the limited effectiveness of interventions starting in pregnancy (Heslehurst *et al.,* 2019), there has been a shift to test interventions beginning in the preconception period. This is with the view to potentially improve intergenerational health and reduce the burden of non-communicable disease (NCD). Alongside the interest in preconception, a life course focus prioritises a continuum of care that follows during pregnancy, infancy, and early childhood.

A complex life course trial is required to test integrated, complex interventions that comprise components in multiple stages of the life course. The Healthy Life Trajectories Initiative (HeLTI) is a unique example of this. HeLTI is an international health research consortium developed in partnership with the World Health Organization (WHO) with cohorts in India, China, Canada, and South Africa. It primarily investigates the intergenerational effects of behavioural interventions on obesity by testing a complex, four-phase intervention initiated prior to conception, through pregnancy and infancy, and into early childhood. The primary outcome is Fat Mass Index in subsequent offspring at age 5; secondary outcomes relate to a range of indicators of parental and child health (HeLTI, 2019b; Norris *et al.,* 2022). A biosocial perspective, which recognises and investigates the complex, 'dynamic, bidirectional interactions between biological phenomena and social relationships and contexts' (Harris and McDade, 2018, p.3), is necessary for such a complex life course trial. This perspective will be critical to achieve HeLTI's aim of generating evidence that will shape a health policy focus on preconception health as part of a life course approach to population health (HeLTI, 2019a).

Existing alongside this is a need to ensure that a renewed public health focus on preconception prioritises justice and equity in its epistemic framing. There is a significant body of sociological and bioethical critique of the dominant Euro-American framing of preconception health. These highlight several epistemic issues around race and racism (Chadwick and Foster, 2014; Valdez, 2021; Meloni *et al.,* 2021; Mansfield, 2012; Mansfield and Guthman, 2015), Western nuclear family norms (Scheidecker *et al.,* 2023; Burman, 1996; Reynolds, 1993; Spiegel and Mehlwana, 1997; Ross and Pentecost, 2021; Bodin, 2018), and pronatalist ideals (Greer, 1993; Consoli, 2014; Waggoner, 2013, 2017; Thompson *et al.,* 2017; Valdez, 2021). A central critique of early life interventions is that a focus on pregnancy has produced a highly gendered discourse of responsibility for health outcomes (Lappé *et al.,* 2019) and that the expansion into the preconception period as a target for intervention could expand gendered allocations of responsibility. There is also the risk of reproducing heteronormative assumptions in preconception interventions and of furthering the biomedicalisation of female bodies (Valdez, 2021; Waggoner, 2015, 2017; Bodin, 2018). A feminist bioethics (Scully, 2008, 2021; Lindemann Nelson, 2003; Sherwin, 2008) lens is thus particularly useful to investigate these ethical issues, as it attends to issues beyond gender, including power dynamics and justice, as well as the relational and situated nature of the production of knowledge and the allocation of responsibility.

This article presents collaborative, interdisciplinary work in the HeLTI-South Africa team that applies a feminist bioethics lens to investigate how preconception health messaging in this context interacts with local cultural scripts and norms. To do this, we interviewed the community health workers (known as 'Health Helpers'), who deliver the complex behavioural interventions during the preconception phase of the trial, about what they think about preconception health and responsibility. Trial interventions have their own 'technoscientific scripts' which are the set of practices, protocols, and routines followed in a technological and scientific activity that is inscribed with particular values (Akrich, 1992). The HeLTI-South Africa trial also follows a technoscientific script which has been explicitly adapted to account for socioeconomic realities, family dynamics, and participant priorities (Draper *et al.,* Draper, 2020; Draper, Thwala, *et al.,* 2023; Draper, Motlhatlhedi, *et al.,* 2023). The Health Helpers' (HHs) reflections show further that

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there are implicit sociocultural assumptions around gender, heteronormativity, intentionality, and attributions of responsibility that are in dialogue with these technoscientific scripts. HHs' perceptions offer lessons for how we might ensure that preconception health interventions and messaging can be designed to enhance equity and justice.

Preconception trials will influence global health policy on maternal and child interventions. Intervention design must explicitly attend to the impact and relevance of values around responsibility. This is required to *a priori* build preconception health interventions that promote equity and fairness before they become translated into and established within public health policy. This is also applicable to all birth cohort research, and for shaping preconception health and birth cohort studies in future.

Beyond birth cohorts: expanding the life course approach

Birth cohorts are an essential methodological tool for life course epidemiology. They generate longitudinal and intergenerational data that offer unparalleled insights into the biosocial dynamics of time, place and kin, and indeed how cohort research infrastructures are themselves a part of this dynamic (Gibbon and Pentecost, 2019). Birth cohort studies provide an ideal setting for life course research, in which the preconception period is gaining an increasingly important focus.

The term 'preconception health' encompasses a range of purposes around the improvement of parental, foetal, child, and intergenerational health. It targets both individuals and populations and can refer to varying periods of time: from days to weeks, to months or even years before conceiving, to the entire life course and beyond (Barker *et al.,* 2018; Fleming *et al.,* 2018; Stephenson *et al.,* 2018). While preconception health practices have traditionally focused on a period of weeks to months before conception with the predominant aim of improving maternal and foetal outcomes, new insights into the transgenerational inheritance of health risks have reorientated the preconception health agenda towards addressing the burgeoning global problem of NCDs (Mandy and Nyirenda, 2018; WHO, 2022). Since 2018, there have been efforts for preconception health to be framed more broadly as the general health of all people with reproductive potential and aims to improve the health of subsequent generations (Stephenson *et al.,* 2018; Schoenaker *et al.,* 2022). To support the framing of preconception health more broadly, Hall et al. (2023) recommend a holistic life course model to include school-based education, social media, and national campaigns, and training and system-level support for the range of healthcare professionals who can deliver it.

The concept of preconception health, especially as it exists within DOHaD, has significant historical links to birth cohort studies. In the 1980s, a United Kingdom (UK) retrospective birth cohort found that a group of adults with cardiovascular disease was underweight at birth and that this was related to maternal gestational nutrition (Barker and Osmond, 1986; Barker *et al.,* 1989; Barker, 1990, 1995). This finding sparked the beginnings of the initially controversial 'Fetal Origins Of Adult Disease' hypothesis, where the development of adult NCDs was thought to be attributable to 'programming by the environment in *fetal and infant* life' (Barker, 1990, p.171, own emphasis) based on adaptive developmental plasticity (Gluckman *et al.,* 2009). DOHaD thus hypothesises that exposures at certain critical developmental points can significantly affect the trajectory of one's health over their entire life course, and beyond (Barker and Osmond, 1986; Gluckman *et al.,* 2009; Hanson and Gluckman, 2014).

Since the early 2000s, DOHaD scientists have been interested in epigenetics as an explanatory mechanism for their observations (Gluckman *et al.,* 2010). Epigenetics theoretically explains how environmental exposures in preconception and early life influence how genes are expressed (phenotype), without changing genetic makeup (genotype) (Gluckman *et al.,* 2011).

While early DOHaD research focused on observational studies, including birth cohorts, in the last decade, DOHaD researchers have turned towards interventional studies. One key focus of DOHaD research is obesity prevention. The LIMIT trial (Dodd *et al.,* 2014, 2018) and the

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UPBEAT trial (Poston *et al.,* Poston, 2015), for example, investigated the effects of lifestyle interventions on overweight and obese women antenatally, and, after demonstrating no significant effects in their children, concluded that the antenatal period is too late for targeted interventions and that 'ideally, women should be counselled prior to conception' (Dodd *et al.,* 2018, p2). Along with the World Health Organization's (WHO) Commission on Ending Childhood Obesity Report (WHO, 2016), this research informed the milestone Lancet 'Preconception Health' series (Lancet, 2018), which cites 'compelling' evidence for the DOHaD logic of '[p]ericonceptional development conditioning' (Fleming *et al.,* 2018, p1842). A systematic review and meta-analysis by Heslehurst et al. (2019) found that women who are obese prior to conception have children with a 264% increased odds of obesity themselves. This finding further buttressed a focus on preconception health as a crucial component of life course interventions for childhood obesity and NCDs. Testing interventions that begin before pregnancy require complex life course trials that have links to, but extend beyond, traditional birth cohort models. The HeLTI trial is uniquely designed to address this challenge.

Healthy life trajectories Initiative-South Africa

HeLTI was commissioned by the research councils of Canada, China, India, and South Africa in collaboration with the WHO to develop four linked and harmonised intervention cohorts that are designed to determine whether a four-phase complex intervention trial (in preconception, pregnancy, infancy, and early childhood) impacts on child adiposity age 5 (primary outcome) alongside other childhood and development outcomes.

The HeLTI-South Africa randomised controlled trial is called *Bukhali. Bukhali* is (isiZulu for 'smart' and 'powerful') launched in 2019, and is the first intervention in South Africa to include a preconception health component (Draper *et al.,* 2022). *Bukhali* is an adaptable and pragmatic intervention which uses an explicitly biosocial approach to continuously respond to complex dynamics in the field, for example, navigating diverse and substantial participant priorities, needs, and health literacy levels (Soepnel *et al.,* 2022; Norris *et al.,* 2022; Draper *et al.,* Draper, 2020, 2022; Pentecost *et al.,* 2024).

Bukhali is located in Soweto. Soweto (derived from the term 'South Western Township') is a large urban-poor township in Johannesburg that is densely populated by predominantly Black South Africans (98% (Stats, 2011)) and is otherwise highly demographically, socioeconomically, and linguistically heterogeneous (Phadi and Ceruti, 2011; Stats, 2011; Mpondo *et al.*, 2022). It is an area characterised by high inequality, with many of its 1.27 million inhabitants (Stats SA, 2011) experiencing unemployment, food insecurity, and high levels of stress and adversity (Bosire *et al.,* 2021, 2020; C. Draper, Motlhatlhedi, *et al.,* 2023). It is also a well-established research location for previous birth cohort research, namely, the Birth to Thirty birth cohort study, which, since its inception in 1990, is the 'largest and longest running birth cohort study in Africa' (Bt30, n.d.).

Bukhali recruited 6360 Sowetan women, aged 18–28 into a 2-arm randomised trial. The complex behavioural intervention's key message is 'Living your best life' (Norris *et al.,* 2022, p5) and integrates four optimising principles concerning health, nutrition, mental health, and early childhood development. Interventions delivered during the preconception, pregnancy, early infancy, and childhood phases are delivered using 'Healthy Conversation Skills' (Draper *et al.,* 2022) – a standardised technique to maximise healthcare practitioners' skills to support and empower patients through the process of behaviour change. It was developed by the MRC Life course Epidemiology Unit in Southampton, UK (Lawrence *et al.,* 2016) and was 'specifically developed and tested for use with socioeconomically disadvantaged participants' (Norris *et al.,* 2022, 6). In the preconception phase, women receive an 18-month intervention or until pregnancy (whichever comes first). Formative qualitative research with women in Soweto illustrates a range of challenges related to mental health, safety, and material and relational constraints (Ware *et al.,* 2019; Draper *et al.,* 2019; Cohen *et al.,* 2020; Ware *et al.,* 2021; Kehoe *et al.,* 2021).

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HeLTI-SA's pilot trial demonstrated that preconception health trials must attend to socioeconomic context, particularly high levels of poverty, food insecurity, and limited employment and education opportunities (Draper *et al.* Draper, 2020). Preconception health messaging thus needs to be delivered alongside interventions focused on these priorities. Adaptations to *Bukhali* in light of pilot findings thus included community social messaging campaigns and expanding contact time with participants to increase rapport and allow for discussion of values and priorities beyond health alone (Draper *et al.,* Draper, 2020).

The *Bukhali* intervention is delivered by "agents of change" (Norris *et al.,* 2022, p5) called 'Health Helpers' (HHs). These are women between the ages of 23 and 43 who have a similar educational background to community health workers (CHWs), such that the trial models 'real world' implementation is applicable to the South Africa public health sector (Draper *et al*., 2022). The HHs are specifically recruited from Soweto and surrounds, and thus have personal insights into the kinds of backgrounds and challenges participants might face (Ibid.). They are thus the mediators, interpreters, and translators of the HeLTI ideas that underpin the preconception intervention to population, of which they are also a part. Language is nevertheless one of the main challenges HHs cite for delivery intervention given the multilingual nature of Soweto (Ibid.). The HHs' role includes providing and explaining health literacy materials, supporting behaviour change through individual sessions with participants, and offering health feedback and services including free HIV and pregnancy testing and free curriculum vitae printing services (Norris *et al.,* 2022; Draper *et al.,* 2022). However, qualitative research and process evaluation have led to key adaptation to the HHs' role in shifting emphasis from focusing on participants' health behaviours to focusing more broadly on offering support over the prolonged period of the trial (Draper *et al.,* 2022).

Previous engagement with the HHs indicated that their own backgrounds may impact the extent to which they might discuss difficult life circumstances with participants (Ibid.). The HHs must, by necessity, take the scientific research in the intervention, itself value-laden, and (re)package and translate it in ways that make sense to themselves and to participants. In this way, scientific ideas are imbued with contextual, cultural, and personal values. In this article, we examine how the *Bukhali* HHs think about preconception health messaging and responsibility.

Methodology and methods

This qualitative study employed a feminist bioethics approach (Scully, 2008, 2021; Lindemann Nelson, 2003; Sherwin, 2008) to examine HHs' understandings of preconception health messaging and responsibility. Feminist bioethics is empirical, situated, and intersectional; it recognises the relational nature of humans and knowledge; and it is inherently concerned with power dynamics and justice. The approach was operationalised by prioritising the views of people who come from similar backgrounds to the Sowetan *Bukhali* participants but who must translate preconception health messaging by paying attention to themes concerning power and justice. We conducted once-off semi-structured interviews with HHs to facilitate 'purposeful conversations' (Braun and Clarke, 2013). The topic guide was developed using the relevant literature on reproductive and preconception health responsibilities, while remaining open to direction from the participants. Topics of discussion included, but were not limited to, who should have responsibility, what responsibilities these are, and when responsibility for preconception health should begin. Interviews were conducted by CVG in May 2023 at the MRC/Wits Developmental Pathways for Health Research Unit (DPHRU) – the same unit out of which *Bukhali* runs – and lasted between 56 minutes and 1 hour 42 minutes (mean = 1 hour 9 minutes). Interviewees were provided with information about CVG, the research team, and the research prior to interviews. Interviews were conducted in English (spoken by all HH interviewees), were audio-recorded using a secure laptop, and transcribed and de-identified by CVG. Fieldnotes were made before and

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during interviews. Transcripts were not returned to participants, and there was no participant checking or feedback.

Seven convenience-sampled HHs were recruited via voluntary response to electronic email invitations. They fulfilled the inclusion criterion of being currently employed as a *Bukhali* HH, providing the study intervention to participants in the preconception phase of the trial. Nil of the 7 invited HHs refused or withdrew their participation. Although there are more than 7 HHs, this number was sufficient to reach data saturation, likely as a result of the homogeneity of the group.

Data was analysed using reflexive thematic analysis (Braun and Clarke, 2006, 2013, 2019), with themes being primarily constructed inductively. Data was coded using NVivo software, and data reliability was enhanced using intercoder triangulation with CVG and LH, and themes were iteratively reviewed and discussed with the co-authors. We used the COREQ checklist (Tong *et al.,* 2007) to ensure quality in research reporting.

We, the author group, are a highly interdisciplinary team coming from differing epistemological backgrounds including biomedicine, psychology, anthropology, social work, and bioethics. Our credentials and employment titles include project coordinator, research assistant, PhD student, postdoctoral researcher, senior lecturer, professor, and principal investigator. This has allowed us to strive for 'a stretchable epistemic space in which to be curious with researchers from other disciplines as well as with study participants' (Behague, 2020). Much of the fieldwork and data collection were, however, conducted by CVG. As such, her positionality as a White South African medical doctor and PhD student supported by a UK university, and a woman in the preconception phase of life influenced by feminist ideals, will have influenced the research and results. An example of this is her shifting 'insider/outsider' status with the HHs, with whom she had no prior relationship before study commencement. On the one hand, being a similar-aged woman insider with a medical background may have helped the HHs to talk openly with CVG about sexual and reproductive issues. On the other hand, she was very obviously an outsider as a White, culturally South African-European, English-speaking person with little experience of the contextual and sociocultural realities and predominant languages of Black Sowetans. While this may have caused the HHs to perhaps feel more suspicious or mistrusting of CVG and the interview process, it had the unexpected positive effect that HHs, instead of assuming any implicit knowledge on CVGs part, would explicitly verbalise and describe their experiences to her.

Results

The group of 7 HHs interviewed had broadly similar demographic backgrounds. Participants ranged in age from 23 to 32 years, all were living in Soweto, most identified as female (with one participant identifying as non-binary), most had at least one child, and all were of reproductive age and self-reported to be currently in the life stage of preconception themselves. Most had worked in health or community work before, and all reported no prior formal knowledge of preconception health, with *Bukhali* forming the foundation and reference point for their preconception health knowledge. Durations worked as a HH ranged between 11 months and 4 years (mean 2 years 2 months).

The results of our analysis reflect what a group of HHs in the *Bukhali* trial thought about, and how they engaged with, responsibilities for preconception health. While the topic guide was aimed towards collecting data about ideas around responsibilities and preconception health more broadly, all HHs interviewed had no prior knowledge of preconception health prior to *Bukhali*, which meant that it was frequently used as a reference point in HHs' answers and by the interviewer to challenge or clarify certain points. This 'preconception knowledge gap' is unsurprising given that prior work with young women in Soweto has shown that preconception health is not a familiar concept (Bosire *et al.,* 2021).

We found that the HHs' raised issues around how the messaging and information framing around preconception health can influence the attribution of responsibility. This refers to the ways that established knowledge and practice, as known to, and experienced by the HHs generally

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within their lived realities and in the broader healthcare setting, can tend to circularly reproduce existing norms and responsibilities within the framing of preconception health. These existing norms shape *who* is currently thought to have responsibility for preconception health, as well as *what* these responsibilities look like. The three prominent themes from this analysis are related to gender, heteronormativity, and child-bearing intentionality and desires.

Gender

Health Helpers frequently discussed issues around gender in relation to expectations and responsibilities for preconception health. For example, when asked about who preconception health messaging should target, or what its purpose is, it was often talked about in reference to women and girls and in relation to pregnancy: 'It's mostly for women who wanna be pregnant' (HH4). When explicitly asked about gender in preconception health, though, for example, 'do you think men have a role in preconception health?', most HHs expressed, to varying degrees, that men ought to be involved, and that their lack of involvement perpetuates their exclusion. This exclusion of men from health-related activities, reproductive or otherwise, seems to have implications for apportioning of responsibility and blame:

> *I think already we do know that men have a perception that only women need to take care of themselves, and not them, and that if you've got a healthy woman then you'll have healthy children, and I believe that men tend to pass on the blame to women most of the time, so they don't see themselves as the problem. So, as we are excluding them, already they feel that okay, they also not part of the preconception health … I think maybe it's because they don't get the same attention that we give to women … the material also focuses on the mother and the baby, not the father. (HH4)*

HHs also noted the disproportionate focus on women's sexual and reproductive health, with the suggested result that women are then framed as barometers of health for men, and that men become subsequently released from responsibility regarding their health behaviours. This is described by HH5, who theorises that an inclusive approach to men could remedy this:

> *We are looking after the woman, the HIV test, everything, everything, so the women will look after themselves, but what about the men that they sleep with? I wish there was a study for the men as well. I think that would make a difference because you find even with the girls that come here, their partners don't test. They'll tell you that "Once I've taken an HIV test then that means my partner also knows his status" - so they [men] they never go to test for HIV, if the girl comes there and she tests negative, automatically the guy is also negative. (HH5)*

Not only did preconception health *practice* and *status* appear to be responsibilised by gender, but also the passing on of preconception health information and traditions. This is through the expectation on women to disseminate preconception health knowledge. HH4's reflection below suggests that, in the Soweto context, women are not only made responsible for preconception health because of the physical reality of pregnancy, but that they are also expected to become responsible for shaping the 'culture' around preconception health societal norms and expectations:

> *The reason why I said it's mostly for women who wanna be pregnant is because I feel they have a responsibility in a way of like practicing a certain culture, especially to pass it on to someone else, but … I also agree that men need to be able to take care of themselves for themselves, even when they not gonna have babies, but they should be able to take care of themselves so that they can live a healthy life, they can live longer for themselves. (HH4)*

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Some HHs also perceived that men are often uninvolved and lack a personal sense of responsibility for a child once conception has occurred. For example, HH6 made the explicit link between being present during pregnancy and the subsequent ability to 'care' about the child. Notable was the racialised framing of paternal absence and lack of responsibility, with the implicit suggestion that men of other races do not 'run':

> *With us Blacks, they [men] tend to run (laughs), they don't have a sense of responsibility, they were not there during the pregnancy, right, how are they gonna care. So, if the baby's there and they suffered with you through the whole thing, they gonna have a sense of responsibility to this child: "No ways, I suffered to get you here." (HH6)*

As can be seen, the HHs' link between involvement and care led to their speculation that when men are actively involved and invested in a pregnancy, this may enhance their sense of responsibility for the child through a sense of having sacrificed. While this quote explicitly mentions pregnancy, it relates to preconception health in that the man's investment, caring, and sacrifice would simply begin earlier.

Heteronormativity

Heteronormativity was also a prominent theme in this research, and refers to the notion that 'there are only two genders, woman and man, and these two are each other's opposites and are expected to desire each other' (Bodin, 2018, p9). This theme highlights how the exclusion of those not fitting the cis-gendered, heteronormative ideal are often excluded from sexual and reproductive health, including preconception health, and that this is often based on precedent within the healthcare system.

Most HHs noted that the preconception health information they were delivering tended to focus on heterosexual women to the exclusion of queer women. Notably, this HH perceived this exclusion of queer-relevant information, especially when the HH was not able to provide this 'extra' information in their interaction, to have left the participant feeling unhappy and with a sense of injustice:

> *The other day we had to do contraceptives and being prepared for pregnancy and that participant wasn't happy because she feels like we didn't add anything with regards to same sex, we were only speaking about different sexes like a male and a female, there was nothing regarding and they felt that was really unfair cause she feels like it would be interesting for her to read it, to share with her partner. (HH2)*

The HHs also perceived this exclusion of queer persons within the wider healthcare sector, with the HHs' perceived result that queer persons may subsequently exclude themselves. It appears that this may, at least in part, stem from the misconception that because health information, for example, around HIV, is not geared towards queer persons, then HIV and other health issues are not considered to be relevant to them:

> *I think it [preconception health] only talks about male-female, it does not really include them, that's why they also exclude them themselves from thinking that they also at risk of getting such diseases, cause when you take a pamphlet from the clinic it only talks about a man and a woman, how you contract HIV with unprotected sex with a man, so that's why they also feel that it does not include them. (HH4)*

HHs also noted this heteronormative frame in preconception health and research when they were asked about if and how they navigate preconception health information with queer persons in the

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trial. This is highlighted by HH3 who reports also not knowing queer-relevant information herself, and then proposes that there ought not to be *separate* materials for queer persons, but a single message for all regardless of gender and sexuality. This would ensure full inclusion of all sexualities and identities, and would require the inclusion of queer-relevant preconception health information that's 'not in the book', so to speak:

> *I'd say our material basically concentrates on the straight females cause there's certain things that lesbians and tomboys would ask us, and it's not in the book. Things that we don't ever know about, but it's also preconception that we also should be giving out, because of even if when they come to you, some would come dressed like me so you don't know whether they lesbian or tomboy cause they just like me, so I think we should be giving information both sides, but in a more understanding way, we shouldn't just categorise it as 'this is information for lesbians or gays' or stuff like that, but it should be preconception basically that we should understand on both sides that it benefits a straight woman and a woman that is gay. (HH3)*

Intention and desire for children

This theme centres on what HHs thought about child-bearing intentions and desires, and how this relates to responsibility and contextual realities in this Sowetan and South African setting. Firstly, HHs contemplated the terminology of 'preconception' health in its potential capacity to exclude persons not wanting, able to have, or actively intending to have children. When explicitly asked if they thought terminology that centred on 'conception' could be exclusive of these groups, it was clear that most of them had not previously considered this, but could see theoretically how it might exclude some groups, or send the message that it's 'not for them':

> *The name, I haven't thought about it in terms of 'pre' as in before you have a child, I didn't put it in that aspect of what about women who don't want to have children, and then we still call it 'preconception' . . . but now since you're saying it, it looks like we are focussing on women who want to have kids, not women who don't want to have kids, so I think the name slightly goes a bit offish. (HH3)*

> *'Preconception health', I think yes, it will make them feel that it's not relevant for them because they can't have children because the 'preconception' term comes across as if now you are preparing for that conception at some point, to have a baby at some point so I think it might make them feel like it's not relevant for them because they already know that they cannot have children. (HH4)*

The terminology of 'preconception' health did not, however, appear to be *actually* exclusionary in this context. This seems to be due to the way that HHs frame or 'advertise' the *Bukhali* trial, as well as language and health literacy barriers for this population. This is illustrated in the following:

> *We don't really advertise that way, even when they are recruited, they are being told, "*we *just coming up to check on your health, the study's an 18-month* study*" . . . I don't think majority of the participants understand what the word 'preconception' means, because basically they just came here for a 'health study'. Does the word matter? I don't think it does to them, they just there to make sure that their health is correct everything is fine, I don't think it matters to them that the study's 'preconception' under* Bukhali*. (HH6)*

The HHs also suggest that in this context, high levels of poverty and precarity create tensions between the desire to bear children and the structural issues that constrain their choices. They thus can not necessarily act intentionally in accordance with their desires. When asking HHs about if

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the women in the community and trial tend to not want or want children, the HHs felt that poverty and precarity obstructed reproductive desires:

> *So, growing up in a township, where I'm from, in most families you'll find that there's ten people in this house, one person works, the other nine depend on this one, if you gonna be bringing in a child, who's gonna be responsible for that child? A lot of people in their 20s in a whole lot of townships, they don't work, and if I'm gonna have a child it means I'm gonna need to find a job, and it's not something that's easy to find. It's not that, deep down, they don't wanna have kids, but it's because of the environment that they in, they can't afford to have a child. (HH6)*

HHs perceived that even if women in this community want children, they do not feel they have the means to do so. This is to some extent based on their sense of responsibility, and who will have to take responsibility for, a child in precarious circumstances. This precarity, as discussed by the HHs, seems to highlight a further tension between intentionality and responsibility. As HH6 says, precarity often means that it becomes infeasible for Sowetan women, including the HHs themselves, to take responsibility for and be intentional about having children:

> *Interviewer: Do you think a woman should feel the same level of responsibility for a child that doesn't exist yet versus one that is here now?*
>
> *HH6: For the young women in Soweto, me myself included, we don't see the need to think about a future that we are not certain of … for a Black woman, most of us consider things when we see them – they have more effect when it's happening than when it's me thinking about it, so it's easier for them to consider the child now than the child in the future, because most first pregnancies are accidental, we don't want those babies … now you are pregnant, you are gonna consider the child's health. (HH6)*

This quote also emphasises why HHs think many pregnancies, at least the first ones, are 'accidental' or unintended, by suggesting that participants feel that the sheer uncertainty around the future forecloses the feasibility of planning ahead. Future children, or reproductive outcomes, appear to therefore not be considered or actively pursued, and thus, responsibility is not ascribed for them in the same way that it is for existing children.

Interestingly, the HHs saw their provision of preconception health information to trial participants as having a positive effect on pregnancy intentionality. For example, when asking about the effect of preconception health information on participants' childbearing desires and intentions, some HHs thought it made participants feel more intentional in having children:

> *The trial will make them now feel that they are doing something right, they are being healthy and that will make them feel, I think, like they are ready to have children. They'll feel that they are healthy now, more prepared to now have children. (HH5)*

While some HHs perceived that the provision of preconception health information might allow their participants to feel more prepared, empowered, confident, and thus, intentional about having a healthy child, some HHs also conversely noted that for some participants, their increased awareness of the realities and responsibilities that might come with parenthood increased their intention to avoid pregnancy:

> *We have some [participants] actually go then "If I have to do so much to fall pregnant then I don't want to do it at all, it's fine" … "It's too much work, if I have to go through all of those*

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hurdles, then I don't want it, keep it" (laughs), so ya, you do find that "No I'm good, if it wants all of it, then I'm fine, thank you." (HH5)

Thus, it seems that by HHs increasing their participants' awareness of preconception health information and its entailing responsibilities, the HHs perceive that their participants were able to better know their child-bearing desires, and thus make actively intentional decisions to have or avoid having children.

In sum, the HHs offer three points for reflection around preconception health information and messaging related to gender, heteronormativity, and child-bearing intentions and desire.

Discussion

This research draws on the perspectives of *Bukhali* Health Helpers to consider how the framing of preconception health messaging may have implications for assigning responsibility. To our knowledge, this is the first bioethical empirical research on health messaging in relation to preconception health and responsibility in and from South Africa. That these data come from South Africa's first trial with a preconception health intervention is of incredible value, as it sheds light on how contextual values interact with this scientific area. Our findings show that HHs' perspectives around preconception health messaging have three key characteristics: they are gendered, tending to situate women as central and men as more peripheral in preconception health responsibilities; they are heteronormative, often excluding non-cis gendered or queer persons; and, they tend to be inclusive of all people regardless of childbearing desires or intentionality. These three findings are discussed in turn.

Gender

Gender has been noted to be a major factor in the distribution of preconception health and reproductive responsibilities (Waggoner, 2013; Richardson, 2015; Pentecost, 2021). This has also been a finding in the limited empirical research from Euro-America (Almeling and Waggoner, 2013; Chiapperino and Panese, 2018; Mello *et al.,* 2019, 2020). For example, Mello et al. (2020) found in their analysis of online survey results from the USA that, when considering responsibility for preconception health, women commonly perceived preconception health behaviours as the 'duty of a good mother', and men tended to rely on gender stereotypes of the women's primacy in children's health and rearing. Notably, the authors highlight that because 'most interventions and messages focus primarily on women, [this] may contribute to existing normative beliefs that women are more responsible for protecting children's health' (Mello *et al.,* 2020, p374).

Our research reveals some similar findings, for example, that HHs tend to frame, and acknowledge the framing of, men as secondary or auxiliary in reproductive and preconception health, with differing opinions on the fairness of this framing. The underpinning logic for this appeared to rest on the idea that preconception health is 'mostly for women who wanna be pregnant' (HH4), even though preconception, by definition, precedes conception and pregnancy.

Some HHs noted that a disproportionate focus on women had gendered implications for the apportioning of responsibility and blame. This is highlighted by the sentiment that 'if you've got a healthy woman then you'll have healthy children' (HH4), which suggests that women are framed as the sole vectors for children's health and disease (Richardson and Stevens, 2015). This normative view of gender and reproduction is not unique to HHs, however, but seems to pervade many reproductive health norms and spaces. Cynthia Daniels (2006) described this framing (albeit from a Euro-Western perspective) as 'reproductive masculinity', including features where men are seen as 'secondary in biological reproduction', and that 'men's own conditions do not "affect both pregnancy and the children they father"' (Daniels, 2006, p6-7, in; Mohr and Almeling,

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2020, p166), thus framing them as more distant from their children's health problems than women. Similar norms exist in South Africa, where the roles of pregnancy and women-as-caregiver are given primacy in children's health (Penn *et al.,* 2010; Nesane and Mulaudzi, 2024; Makusha and Richter, 2016), and are compounded by sociohistorical circumstances resulting in men being less present in their (biological) children's lives after conception (Morrell *et al.,* 2012; Richter *et al.,* 2010; Makusha *et al.,* 2013). Such gendered normative framings are also potentially embedded and reproduced in science, and then implicitly translated into policy. The consideration of values needs to be actively addressed in preconception health messaging and information to avoid implicit assumptions of female bodies as singularly reproductive and thus primary sites of intervention.

Importantly, this work shows how HHs perceive that women in this context are positioned as responsible for other people by disseminating certain health 'cultures' and knowledge. This was seen firstly through the statement 'I feel they have a responsibility in a way of like practising a certain culture, especially to pass it on to someone else' (HH4), where it is suggested that women must actively pass on the information and shape health norms to and for others. It is secondly shown in the HH statement where '[men] never go to test for HIV, if the girl comes there and she tests negative, automatically the guy is also negative' (HH5), where women are positioned as more passive reflections of, or windows into, the health status of men. Thus, insofar as HHs are interpreting cultural and technoscientific scripts in relation to preconception, women are considered as not only vectors for health but also vectors of health knowledge for many people. Conversely, where 'men need to be able to take care of themselves for themselves' (HH4), it seems that they are positioned as needing to be responsible for preconception health only insofar as it benefits themselves over their life course.

What was emphasised by many HHs, however, was that a disproportionate focus on women appears to be self-reinforcing, where men become increasingly uninvolved in reproductive and general health (by structures and themselves), and women are increasingly made responsible and blamed. This is in line with sociological and bioethical critiques of the broader Euro-American technoscientific preconception health script (Chiapperino and Panese, 2018; Mello *et al.,* 2020, 2019; Gentile, 2013; Hays, 1996), which makes '[pre]maternal sacrifice a master cultural frame' (Waggoner, 2017, p27). A recommendation from the HHs was that enhancing men's involvement with, and sacrifice (or 'suffering') around, reproduction would increase their sense of investment into and caring for a child, with subsequent increased feelings of responsibility. This is consistent with Draper and colleagues' (2023, p1) findings from qualitative research with partners of women enrolled in HELTI who had become parents, who indicated that their involvement and connection with their child was associated with their feelings of responsibility for the child. These findings support the need for reducing the structural and informational barriers for fathers' involvement in pregnancy and childhood (Drysdale *et al.,* 2021), thus allowing for more involvement, connection, and responsibility. As noted by Lorber (1993), gendered epistemic resources (being structures or materials from which knowledge is gained), or exclusion from such resources, are also gendering in effect. The findings from our research thus support the need for a rebalancing of gendered inclusion within preconception health messaging and practice in order to balance preconception health responsibility.

Notably, the sentiment around men's lack of involvement expressed by HH6 was also racialised. This is where she said, 'With us Blacks, they [men] tend to run (laughs), they don't have a sense of responsibility'. This statement explicitly talks about Black men and is implicitly in comparison to men of other races. This racialised framing of father absenteeism is frequently seen in media portrayals of Black men both internationally (Coles and Green, 2010) and nationally with media headlines such as 'Too many black children don't have fathers at home' (Mndende, 2021) and 'Where are black fathers in South Africa?' (Majozi, 2021). These are set alongside statistics asserting that while 80% of White children live with their biological fathers, only 32% of Black children live with theirs (StatsSA, 2019). While family fragmentation and father absence

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are a reality in South Africa, such configurations of 'absent' Black fathers in South Africa render several key factors invisible. This is, firstly, that absenteeism is not an essential feature of Blackness, but that Blackness might be a proxy identifier for an array of sociopolitical factors that Black people are disproportionately affected by. These factors include legacies of apartheid that removed many fathers from the home to be migrant labourers, as well as ongoing and heavily racialised poverty and disadvantage, and family fragmentation as a result of the HIV epidemic (Mabula, 2020; Makusha and Richter, 2014; Manderson *et al.,* 2016; Mkhwanazi and Manderson, 2020). Secondly, the severity of father absenteeism amongst Black families in South Africa is perhaps overblown as a result of pervasive Western ideologies and norms that emphasise the nuclear family model as the standard (Scheidecker *et al.,* 2023; Burman, 1996; Reynolds, 1993; Spiegel and Mehlwana, 1997; Ross and Pentecost, 2021; Bodin, 2018). In South Africa, Western nuclear family configurations are not the norm; instead, more extended family models apply, where the *role* of father is not restricted to the *biological* father, and where not cohabiting does not equate to a lack of involvement (Makusha and Richter, 2014; Makusha *et al.,* 2019; Sonke Gender Justice *et al.,* 2021; Draper, Motlhatlhedi, *et al.,* 2023; Hall and Mokomane, 2018; Makusha and Van Den Berg, 2018). Because such sociohistorical and normative constructs are made invisible by media and pervasive stereotypes, however, it becomes easy to essentialise the reason for absenteeism as related to race, and continues to reinforce unjust perceptions that frame Black men and fathers as irresponsible and neglectful (Hosegood *et al.,* 2016; Prinsloo, 2006). This stereotype appears to have been internalised by HH6 who, in turn, verbalised this normative assertion around Black men.

Heteronormativity

Heteronormativity was another theme of HHs' discussions around preconception health information and responsibility. Heteronormative framings of preconception health have been critiqued for the tendency to conflate gender, sex, and sexuality and diminish their complexities and differences (Waggoner, 2015, 2017; Ekstrand Ragnar *et al*., 2018; Bodin, 2018; Valdez, 2021). The HHs in this research noticed this tendency, with precedent set within the wider healthcare context. For example, some HHs perceived that a cis-gendered, heteronormative framing of their materials left some of their participants with negative emotions, such as a sense of injustice, especially when the HH was not able to provide this 'extra', queer-relevant information during their interaction. This lack of information was related back to the wider healthcare context in South Africa which has also been noted by previous research to exclude queer persons in health promotion and intervention messaging (Müller, 2017; Luvuno *et al.,* 2019; Templeton, 2022). HHs perceive that this exclusion in health messaging causes queer persons to exclude themselves from certain health-related activities or to develop misconceptions about what is relevant for them.

A HH recommendation is that there ought to be a single, fully inclusive, and integrated preconception health intervention that is relevant to all persons regardless of gender or sexuality, and not fragmented and separate bodies of information delivered to people depending on how they identify. One way to do this, as recommended through public engagement on preconception health messaging in the UK, is to use gender-neutral language (and perhaps imagery) where possible (Schoenaker *et al.,* 2021). Another way to ensure queer-inclusivity is through sex- and gender-based analysis (SGBA) and reporting. This is important for acknowledging the distinction between sex (a biological variable) and gender (a socially constructed, continuous variable), and the complex ways that these are understood, experienced, expressed, and institutionalised (CIHR, 2023). One way to achieve this is via 'gender mainstreaming' (under which SGBA is categorised), which refers to the 'internationally accepted strategy that aims to institutionalize gender equality across sectors' (WHO, 2011, p7). The WHO, for example, has especially emphasised the importance of this approach given the significant role of gender on people's health (Ibid.). Our findings feed back to the HeLTI consortium's own 'HeLTI Sex- and Gender-Based Analysis Plan',

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based on the Canadian Institute for Health Research (CIHR) practice guide (CIHR, 2021), which aims to 'generate, understand, and apply evidence related to sex/or gender-related factors and interactions' (HeLTI, 2023) that is integrated across all its programme domains, including intervention materials and knowledge translation and implementation. In line with this plan's key goal of informing policy and decision-making that is sensitive to and inclusive of diversity in sex and gender, considering how gender and sexuality will be reflected in the preconception health messaging will be imperative.

Inclusivity and intentionality

Preconception health messaging, in particular the terminology of the name itself, also has the potential to exclude some groups' involvement. This is through centralising fertility and 'conception', and risks framing preconception health as targeted towards persons only insofar as they have positive reproductive potential, intentions, and desires (Thompson *et al.,* 2017). Such rhetoric may embed 'the neglect of all other non-fertile or non-reproducing women along the gender/sex spectrum' (Consoli, 2014, p45), as well as those not desiring or actively intending to have children. This all raises questions around how preconception health should be defined (for example, focused on reproduction specifically or general health across the life course), what it means for planning for children, and if it inadvertently frames 'a *planned* conception as a *good* conception' (Pentecost and Meloni, 2020, p8, original emphasis). This lattermost point is reflected in exhortations around '*normalizing* conversations about pregnancy intention' (Stephenson *et al.,* 2019, p2264) during routine clinical encounters, with the normative implication that child-bearing intentionality is or ought to be a responsibility. The Lancet Series framing of preconception health, as well as the CDC, take the position that preconception health is important for all persons, regardless of their child-bearing intentions (Stephenson *et al.* 2018, CDC, 2023), and in the South African context the HHs' reflections point to a positive framing of preconception health for all people.

The HHs were concerned about the exclusionary potential of 'preconception' health terminology when explicitly asked about it. They noted, however, that it is only potentially exclusionary *in theory*, however, in their context, they did not find this to be the case. This seems to be due to the way that HHs frame or 'advertise' the *Bukhali* trial, as well as language and health literacy barriers for this population. Regarding the trial advertising, HHs avoid a framing centred on women's reproductive capacities, and instead characterise it as looking at their general health over their life course, as, unlike the other HeLTI cohorts, Bukhali did not recruit based on intention to conceive. The HHs' approach is thus consistent with having a preconception health strategy that addresses the wider determinants of general health (Stephenson *et al.,* 2018; Schoenaker *et al.,* 2022). Additionally, HeLTI-SA research has also found that the women in this environment were largely unfamiliar with the concept of preconception health, and had significant gaps in health knowledge more generally (Bosire *et al.,* 2021). The implication of this, along with language barriers and translation difficulties (Draper *et al.,* 2022), means that the way in which preconception health is framed by HHs may be more relevant than the terminology around conception in the English 'preconception health', thereby mitigating its potentially exclusionary effects. Though it may be purely pragmatic, this framing may be useful from a justice point of view if the preconception frame can similarly focus on health in such a way that it avoids a centring of individual women and their reproductive capacities in isolation.

The concept of intentionality, along with the ability to act on one's child-bearing desires, is also closely linked to the idea of reproductive autonomy. Autonomy is a prerequisite for intentionality, and includes having *knowledge* around available choices, as well as *ability to choose* from a suite of real and meaningful alternative options (Beauchamp and Childless, 1991). If a person does not have autonomy in a situation, they cannot, at least not fully, be held responsible. It thus follows that if a person is not autonomous, she cannot exercise intentionality in childbearing and thus

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cannot be held responsible for not being intentional. The normative assumptions and expectations surrounding intentionality in preconception health can therefore be problematic, because the structural constraints of poverty and precarity can preclude the ability for intentionality (Macleod, 2016; Bearak *et al.,* 2020). This is particularly relevant in the South African and Sowetan setting, where between 34% and 64% of pregnancies are unintended by women (SADHS *et al.,* 2019), and, despite being socioeconomically heterogeneous, many Sowetans face high levels of unemployment, food insecurity, limited access to health services and safe shared spaces, and relational difficulties concerning gender and intergenerational conflict (Cohen *et al.,* 2020; Draper *et al.,* Draper, 2020).

As the HHs suggest, these factors of poverty and precarity appear to translate into constrained reproductive autonomy, where people may want to have children *that they can effectively care for,* but might not feel able to realise this within their circumstances. Poverty and precarity thus diminish the suite of *real* choices available – a prerequisite for autonomy (Beauchamp and Childless, 1991; Kimport, 2021) – to many individuals in this community. As the HHs suggested, this structurally constrained reproductive autonomy also appears to foreclose intentionality, with the future so precarious that intentional planning is infeasible – essentially, that participants 'having control over the various facets of their lives that would be required to plan a pregnancy is not a realistic expectation' (Macleod, 2016, pe385, citing; Kendall *et al.,* 2005). This emphasises a possible disjuncture between a public health focus on preconception health that is forward-looking, and the lived realities of Black South African women in this context prioritising the 'now' (Draper *et al.,* Draper, 2020).

While preconception health messaging may create and reinforce responsibilities around intentionality which can be at odds with structural constraints on intentionality capabilities, the HHs perceive the provision of preconception health knowledge as potentially mitigating against some of these constraining effects. This appears to be via the empowering and confidence-building benefits of knowledge for their individual women participants, as well as by providing a realistic view of the burdens and responsibilities that preconception health and child-bearing entails. As the HHs implicitly suggest, this knowledge provision provides an opportunity for reflections on reproductive intentions, and if framed inclusively allows for women to reflect on both the desire to have children, or the desire to avoid having children.

Conclusion

The preconception period is fast becoming an important target for investigation in life course research. This includes within birth cohort studies (Woolcott and Dodds, 2022), with some now including this temporal expansion in their design. While there is a growing body of literature addressing how preconception health and its framing can affect and be affected by normative ideas around responsibility, it is predominantly theoretical and tends to be from or about Euro-America. Our research thus offers a novel perspective by empirically investigating health messaging in relation to preconception health responsibilities in and from South Africa. Using a feminist bioethics approach, we present the perceptions of HHs – the Sowetan CHWs who mediate, interpret, and translate the ideas that underpin South Africa's first trial with a preconception health intervention. We identified three main themes through our analysis of HHs' perceptions around preconception health messaging and responsibility, namely gender, heteronormativity, and child-bearing intentions and desires.

A feminist bioethics methodology has been crucial to the production of this research by allowing us to acknowledge and investigate the relational aspects of preconception health knowledge and its production. This knowledge is both partially shaped in the value-laden technoscientific scripts of birth cohorts (Behague, 2020) and HHs' own contextualised cultural scripts. A feminist bioethical approach is sensitive to context, power dynamics, and justice. We operationalised this approach by offering a platform to HHs to privilege and take seriously their

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thoughts and reflections about the preconception component of the *Bukhali* intervention. This is important because HHs' are themselves women from this Sowetan community and their personal sociocultural, moral, and political perspectives imbue and mediate the preconception health technoscientific script as it is translated and delivered to trial participants. This has implications for what will later be translated and delivered under a preconception health public health policy. While it remains to be seen whether preconception interventions will be the solution for intergenerational patterns of obesity, the appeal of this framework and the potential problems it may introduce are clear. This analysis thus allows us to prospectively imagine ways in which a focus on intergenerational health might be improved, such that it enhances justice from the outset.

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Competing interests. There are no conflicts of interest to declare.

Ethical standard. This research is fully compliant with the ethical principles set out in the World Medical Association Declaration of Helsinki of 1975, as revised in 2008 (http://www.wma.net/en/30publications/10policies/b3/17c.pdf). Ethical approval was granted by King's College London (LRS/DP-22/23-29682, approved 05/09/2022) and the University of the Witwatersrand (M210257, approved 17/06/2022). Prospective participants were electronically provided with an information and consent document, which included information about the primary researcher, research team, and research purpose, and given a minimum of 24 hours deliberation and enquiry time. Participants provided written informed consent prior to interviews. All participation was completely voluntary, and participants could withdraw consent without reason up until one month following their own interview. After this time their data became inseparable from the whole. Participants consented to de-identified data access being limited to the research team, and the low risk of their identification through quotes. Data protection and confidentiality will be maintained in line with the South African Protection of Personal Information Act 4 of 2013, and the UK General Data Protection Regulation (GDPR UK).

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