



Maternal mental health research in Malawi: Community and healthcare provider perspectives on acceptability and ethicality

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ABSTRACT

Maternal mental health (MMH) is recognised as globally significant. The prevalence of depression and factors associated with its onset among perinatal women in Malawi has been previously reported, and the need for further research in this domain is underscored. Yet, there is little published scholarship regarding the acceptability and ethicality of MMH research to women and community representatives. The study reported here sought to address this in Malawi by engaging with communities and healthcare providers in the districts where MMH research was being planned. Qualitative data was collected in Lilongwe and Karonga districts through 20 focus group discussions and 40 in-depth interviews with community representatives and healthcare providers from January through April 2021. All focus groups and interviews were audio recorded, transcribed verbatim (in local languages Chichewa and Tumbuka), translated into English, and examined through thematic content analysis. Participants' accounts suggest that biopsychosocial MMH research could be broadly acceptable within the communities sampled, with acceptability framed in part through prior encounters with biomedical and public health research and care in these regions, alongside broader understandings of the import of MMH. Willingness and consent to participate do not depend on specifically biomedical understandings of MMH, but rather on familiarity with individuals regarded as living with mental ill-health. However, the data further suggest some 'therapeutic misconceptions' about MMH research, with implications for how investigations in this area are presented by researchers when recruiting and working with participants. Further studies are needed to explore whether accounts of the acceptability and ethicality of MMH research shift and change during and following research encounters. Such studies will enhance the production of granular recommendations for further augmenting the ethicality of biomedical and public health research and researchers' responsibilities to participants and communities.

1. Background

Globally, maternal mental health (MMH) has become an object of professional and policy concern; perinatal anxiety, for instance, has been regarded as a public health threat requiring urgent attention (Dennis et al., 2017; Falah et al., 2017). Depressed mood, too, has become a key focus; in Low- and Middle-Income Countries (LMICs), not least given

quantitative research indicating high levels of antenatal and postnatal depression (as measured by the Edinburgh Postnatal Depression Scale) (Cox et al., 1987; Fisher et al., 2012). Such studies and measures have energised and shaped a problematisation of MMH that helps render the distress of millions of women worldwide more visible, even as the biomedical framings within it might not always accord with lived experiences and community perspectives.

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Advocacy and research on mental health are growing in Malawi as part of a response to promote mental health policy and access to quality and affordable mental health care (Deitz et al., 2020; Ng'oma et al., 2019; Stewart et al., 2014). Research by Stewart et al. (2010, 2014) on antenatal and postnatal depressed mood has demonstrated, for instance, the implications of structures of poverty and precarity for the experiences of women and their babies (see also Ng'oma et al., 2019). The relationship between economic issues and individual experiences in Malawi underscores how legacies of colonialism and contemporary geopolitical processes can contribute to psychological harm (Johnson et al., 2022; Kanougiya et al., 2021; Serpa Pimentel et al., 2021).

'Generation Malawi' (GM) is a cohort study exploring the impact of mental health on families (amongst other objectives). It is a 4.5-year longitudinal examination of family, maternal, and childhood mental health, funded by the UK Medical Research Council [MR/S035818/1] and Wellcome Trust [217073/Z/19/Z]. It seeks to establish a population cohort of mothers, fathers, and their children to understand other environmental and genetic factors associated with mental ill-health, including any impacts of parental mental health (and its economic and other underpinnings) on infant development. Paper author AM is the principal investigator of this project, and MP, LMT, RS, and EU are co-investigators.

One of the objectives for GM is to collect biological samples from individuals in several communities in Malawi's central and northern regions for subsequent genotyping to contribute to knowledge on mental health genomics. The project also entails a public and community engagement component, under the aegis of which the data for this paper is drawn. This includes focus groups and individual interviews with a range of community stakeholders to understand better concerns and expectations about the processes and implications of the cohort study. The intent is for these forms of qualitative data and consultation to iteratively inform how biomedical and public health researchers undertake GM in socially appropriate and ethically robust ways.

This paper builds on formative work exploring community priorities for and concerns around MMH research in Malawi through a public (town hall) discussion event (Manda-Taylor et al., 2021) conducted in Blantyre (in the southern region). This research found that household and community consultations are essential to inform research proceedings, especially where a pregnant woman is involved. Here, we investigate community engagement and acceptance of biopsychosocial research into MMH, exploring issues relating to its acceptability and ethicality (particularly about consent). Our study is informed by the needs of GM yet is not restricted by those - nor is it an evaluation of the ethicality of GM specifically. Instead, our qualitative data collection sought to inform GM and to provide a further understanding of MMH and research around it through broader discussion. Accordingly, our data and analysis have implications beyond the study setting.

2. Literature review

Acceptability in health research is complex, with definitions in healthcare and health research varying in application and interpretation. Operational definitions of acceptability, for instance, might specify procedures used to measure a more conceptual definition (Sekhon et al., 2017). To an extent, distinctions can be made between social acceptability and treatment acceptability. The former "refers to patients' assessment of acceptability, suitability, adequacy or effectiveness of care and treatment" (Staniszewska et al., 2010). Treatment acceptability refers to "patients' attitude towards treatment options and their judgement of perceived acceptability before participating in an intervention" (Sidani et al., 2009). However, as these definitions indicate, different forms of acceptability are not necessarily demarcated but can instead blur together.

Importantly, 'acceptability' is socially situated (Parkhurst et al., 2015). Qualitative research has explored the barriers, facilitators and needs in relation to perinatal mental health (Nakku et al., 2016), barriers

and facilitators for adolescents to accessing mental health care (Field et al., 2020), and maternal mental health priorities, and what is sometimes termed 'help-seeking behaviours' (Tol et al., 2018) in sub-Saharan Africa. However, there is currently limited evidence on the acceptability of studies investigating environmental and genetic factors associated with MMH, particularly how this is situated against wider social concerns and experiences (including prior community and interpersonal encounters with biomedicine).

The perceived acceptability of any study is also influenced by people's understanding of its nature, aim and goals - including presumed risks and benefits. Of particular concern is how therapeutic misconceptions (TM) might influence acceptability. TM "denotes the phenomenon in which research participants conflate research aims, protocols, and procedures with clinical treatment" (Thong et al., 2016: 17). This is a crucial concern in (mental) health research because TMs can lead to miscalculation or misestimation of the specifically health-related risks and benefits of participating in research. These misestimations can subsequently impact and affect the informed consent process and generate unrealistic expectations of benefits, or what Horng and Grady have described as therapeutic optimism (TO) (Horng and Grady, 2003). TO refers to the research participant hoping for the best outcome while participating in research (Horng and Grady, 2003). Researchers have responsibilities in relation to TM/Os, in terms of - for instance - improving processes of informed consent (Meurer et al., 2012). It is strongly recommended that qualitative research methods be used to investigate and potentially contribute to addressing the disparities between community members' health-related expectations, hopes, and desires and the scientific goals and anticipated/likely outcomes of research so that the participant autonomy can be enhanced (see, relatedly, Swidler and Watkins, 2017).

Community engagement (CE) is a valuable - and normatively significant - component of global health research and is today commonly required by funding agencies alongside regulatory and ethics bodies (Black et al., 2022). Researchers should engage with participants and communities transparently, culturally sensitively, and respectfully to earn trust and demonstrate trustworthiness (Cunningham-Burley, 2006; MacIntyre et al., 2013; Nyirenda et al., 2019). Developing trust between communities and researchers is often understood as supporting the aims of CE (Anderson and Solomon, 2013; Dunn, 2011; Kamuya et al., 2013; Molyneux et al., 2005; Phiri et al., 2018). CE is often used instrumentally rather than dialogically, however; for instance, "to gain community 'buy-in', increase study enrollment, or to ensure smooth research operations (Pratt et al., 2020: 43; see Reynolds and Sariola, 2018; MacQueen et al., 2015; Nyirenda et al., 2019). On the other hand, more intrinsic goals of CE include showing respect and ensuring inclusion to establish solidarity in the co-production of knowledge (Pratt et al., 2020: 43; see Participants in the Community Engagement & Consent Workshop, 2013). In potentially contentious areas such as MMH, there is a clear need for substantive and thoughtful CE that will contribute to ensuring that MMH research is undertaken in ways that are sensitive to the hopes and concerns of Malawian communities.

3. Methods

3.1. Study design

We undertook a cross-sectional qualitative study employing 20 focus group discussions (FGDs) and 40 in-depth interviews (IDIs) to explore how communities discussed mental (ill-) health in general, MMH specifically, and MMH research (including but not limited to the GM project). This study sought to establish the most acceptable and ethical ways of engaging communities and to obtain culturally appropriate and respectful consent for MMH research in general and the GM project in particular.

3.2. Study setting

Malawi is a land-locked, low-income country in eastern sub-Saharan Africa with a rapidly growing population of around 19.9 million and a life expectancy of 64 years (World Bank Group, 2020). Malawi continues to be impacted by the legacies of colonial violence. Today, a large proportion of the population lives in poverty, with over 70% living on less than 2.15 USD/day (World Bank Group, 2020). Malawi’s population predominantly reside in rural areas, with rural poverty at 70% (National Statistical Office, 2021).

Important to note is that the study was conducted in two districts in Malawi: Area 25 in Lilongwe and Chilumba in Karonga. Lilongwe is Malawi’s capital city and has experienced a high urbanisation rate since the government under the late president, Bingu wa Mutharika, relocated all government head offices from Blantyre to Lilongwe. Many residents live in informal settlements and in conditions of poverty. Chilumba is a small town in the Northern Region of Malawi and is located along the western shores of Lake Malawi in the predominantly rural Karonga District. Our findings, therefore, cover perceptions of community members from both the rural and urban settings in the Malawian context. Aside from these community characteristics, these two Districts were selected because community members have long been involved in large-scale, long-term, population-based studies conducted by the Malawi Epidemiology Intervention Research Unit (MEIRU) (the director of which is also a co-investigator of GM and is where authors MKN, CB, and MN were based). Consequently, they could generate diverse and considered perspectives on establishing the most acceptable and ethical ways of conducting MMH research with Malawian communities.

3.3. Study population

The study population included healthcare providers, traditional and religious leaders from these districts who served the study sites or health facilities (Area 25 Health Centre and Chilumba Rural Hospital), and broader community members (men and women) in existing MEIRU research sites in Lilongwe and Chilumba.

3.4. Data collection procedures

From January through April 2021, we conducted 20 FGDs and 40 IDIs across a rural site in the northern region and an urban area in the central region of Malawi. We used convenience sampling by recruiting participants from a database of people who participated in previous MEIRU research and consented to be contacted about future studies (Crampin et al., 2012). The first author (MKN) made appointments with the participants through phone calls, ensuring that FGD participants were distinct from IDI participants. All participants in Chilumba accepted the invitation to participate in this study. At the same time, 24% of those we approached in Lilongwe declined to participate (generally citing their busy schedules).

Ten FGDs were conducted per site in Karonga and Lilongwe. Six FGDs were held in each area with community representatives, two FGDs with healthcare providers, one FGD with traditional leaders, and one FGD with religious leaders. There were six to eight participants per FGD (Table 1). 20 IDIs were also conducted at each site. These IDIs comprised ten community representatives, two traditional leaders, two religious

Table 1
Focus groups conducted.

	Lilongwe (LLW)		Karonga (KA)	
	M	F	M	F
Community members (COM MEM)	19	23	26	22
Community leaders (COM LEADS)	13	3	14	3
Healthcare providers (HCPs)	6	10	8	6
Total	38	36	48	31

leaders, and six healthcare providers (Table 2). The total participant sample size was 153 for FGDs and 40 for IDIs (N = 193). While demographic data has been differentiated by gender for illustrative purposes, we did not undertake a specifically gendered analysis; rather, we sought to understand community concerns and perspectives more generally. The FGDs were conducted to explore community-level narratives and accounts of MMH and MMH research. The IDIs were used to generate more sensitive, individual information that participants may have been reluctant to raise in a group, such as interactions with the health facilities and local leaders. Informed by debates around triangulation in social science, we also used FGDs and IDIs as a methodological approach to sense-check between data sets and to minimise the researcher bias that could, for instance, result from IDIs alone.

We used a single semi-structured interview and discussion guide for IDIs and FGDs (see ‘supplementary materials’) to elicit rich data on how MMH, in general, and GM specifically, should be designed to be ethical and acceptable to communities. The guide was piloted on eight MEIRU field workers to check for clarity, relevance, comprehensiveness, and question flow. Questions that we identified as ambiguous were amended. MKN and one research assistant, MN, from MEIRU, conducted IDIs and FGDs separately and together. FGDs and interviews were conducted in a private space and were audio-recorded. The IDIs lasted 35 min each, and the FGDs 90 min each on average. Debriefing was undertaken after every IDI and FGD, and saturation was reached within the planned sample size. The broad topics covered in the IDI and FGD guides included understanding (maternal) mental health, the most suitable community engagement approach for MMH research, and the most appropriate process to obtain informed consent from participants and community assent.

We developed participant information sheets (PIS) and informed consent forms (ICFs) in English, Chichewa (local, national language) and Chitumbuka (local dialect or vernacular language in Karonga) for IDIs and FGDs. Each participant was invited to read the PIS, or this was read to them, before agreeing to participate. Written consent was obtained where possible; otherwise, a thumbprint was provided. Participants were assured that their details would be omitted from transcripts to ensure confidentiality. Participants were also told that any data generated by the study might be published but that confidentiality would be maintained, and no personal details would be shared. Lastly, participants were told that their involvement in the study was voluntary and that withdrawal was permitted at any time without personal consequence.

The IDIs and FGDs were undertaken in Chichewa in Lilongwe and Chitumbuka in Karonga, the dominant languages in each location. All data collection was conducted face-to-face yet “socially distanced” in compliance with Coronavirus Disease (COVID-19) mitigation protocols issued by the College of Medicine Research Ethics Committee (COMREC). The study was approved by COMREC protocol number P.11/19/2865 and conducted following the Declaration of Helsinki guidelines and regulations (World Medical Association, 2001). Participants were reimbursed for their travel costs to the venue (MWK2000).

3.5. Data analysis procedures

Recordings were transcribed verbatim and translated into English by

Table 2
In-depth interviews conducted.

	Lilongwe (LLW)		Karonga (KA)	
	M	F	M	F
Community members (COM MEM)	5	5	4	6
Traditional leaders	1	1	2	–
Religious leaders	2	–	2	–
Healthcare providers (HCPs)	4	2	2	4
Total	12	8	10	10

translators/transcribers. The transcripts were anonymised, and each participant was assigned a participant identity (ID) number. Data analysis was conducted in four phases. Firstly, three sampled transcripts were deductively coded manually by two researchers (MKN and LMT) in MS Word to identify codes that were in line with study objectives and create a code book (Burnard et al., 2008; Tong et al., 2007). During this phase, codes were recorded separately on the margins of the transcripts. This exercise was conducted independently to minimise researcher bias (Braun and Clarke, 2008). The second analysis phase involved MKN, LMT, and EU, where the codebook was discussed and any discrepancies reconciled. During the third phase, MKN transferred all the translated transcripts into NVivo 12 for data management using the consensually agreed code book.

The NVivo file was shared with the core analysis team for data familiarisation. During the fourth phase, MKN, LMT, and EU regrouped again to review the codes and identify patterns. These codes were summarised, and the content was used to develop a statement that described a significant theme (Braun and Clarke, 2008). The core team agreed on the themes (Burnard et al., 2008). Participant quotes to support the analysis outlined in this paper (Burnard et al., 2008; Tong et al., 2007).

4. Results

The main content themes constructed in this study were: community perspectives on MMH, community perspectives towards MMH research, willingness to participate in MMH research, community engagement and consent, and broader concerns about MMH research and research conduct. The themes are described in detail below.

4.1. Community perspectives on MMH

Participants were asked if MMH is a familiar concept in their communities, and many expressed that they were unfamiliar with this terminology:

Where I am coming from, we do not know maternal mental health, but we perceive mental health in general. When we see people unusually handling themselves, we think the head is not functioning properly or say they are mad. **KA-FGD COM MEM- 08**

Although there was a limited reference to MMH specifically, participants described the presence of people in their communities whom they regarded as living with mental ill-health:

Yes, mental problems are known because we see people through what they do in the villages where we stay. We wonder what it is, but we do not know the exact problem. **KA-FGD CHIEFS-03**

Participants' accounts of the causes of mental ill-health reflected social, behavioural, and biomedical notions of distress. Community members often described mental ill-health through the idiom of madness, commonly as the effects of witchcraft or resulting from smoking cannabis, excessive beer drinking, epilepsy, and psychological distress:

It will not be easy for people to accept that mental problem is a diseases because they think it is because of drugs or marijuana, excessive beer drinking due to stress and witchcraft manifested through epilepsy or madness ... However, for those who believe that mental problem is related to being bewitched, it will be challenging for them to understand. You need to convince them for them to understand. **LL-FGD HCW-09**

Some community members and healthcare providers presented hereditary understandings of the development of ill-health:

Sometimes we link mental health to heredity. We say the grandparent was like this, so maybe this disease is running in the blood ... **KA-FGD COM-05**

In my view, I think mental disorders can come in following family history, meaning that if someone in the family ever suffered from a mental disorder through blood (inheritance), you can also suffer from the same. **KA-FGD-HCW 01**

In sum, participants indicated knowledge of the existence of unusual behaviour or subjective distress in general, which were considered mental ill-health, whilst the concepts of MMH grounded in the discourse of Anglophonic psychiatry (which underpin GM, for example) were less familiar. A perception that mental ill-health can be recognised and potentially comprehended is suggestive of the potential acceptability of MMH research. However, where this is grounded exclusively in the concerns and categorisations of practitioners in the Global North, this might not align with pre-existing community perspectives of the nature of ill-health and distress in Malawi – and misaligned perspectives may compromise the autonomy of potential research participants (Pickersgill, 2021).

4.2. Community perspectives on MMH research

Some community participants described a range of matters that they accounted for as affecting people's perspectives in relation to MMH research. These included the language, terminology, and the approach used by researchers to communicate it:

The issue here is the word mental. There is a need to explain cautiously. Otherwise, someone will say, do you mean I am mad? So yeah, you need to be careful when handling that aspect. **KA-FGD COM MEM-07**

Researchers consequently need to be mindful of the language used when interacting with prospective participants; for instance, when translating data collection tools, avoiding language that would disappoint or alienate study participants and which might contribute to discrimination and stigmatisation.

Another participant echoed the above sentiment when providing advice to the study team about the framing of the GM project:

Do not personalise the message when coming back with feedback. Package the message in a respectful manner. For instance, make it general when presenting results so that the client should not feel offended. Please do not say we are here because your head is not functioning properly, and we want to help you. The client may not cooperate. **KA-FGD COM MEM-09**

Use of offensive words and community memories of a lack of respect in prior studies shape perspectives regarding the acceptability of MMH research. Participants said if researchers carefully calibrated their approaches, MMH research could still be rendered acceptable:

The most important thing is to inform them that mental health illness is like any other disease that can affect anyone. They should be told not to feel ashamed of mental illness. They will feel free to participate if they know about that. **LL-IDI COM MEM-15**

Ah, the way I feel, it is about building trust. People will look at your history to see what you did in the past and how it benefitted them. Mistakes made in the past can disturb the current study. **KA-IDI PASTORS-12**

Forms of conduct that usually underlie the concept of trust include being competent, open and dependable (Phiri et al., 2018). As Wilkins (2018: S6), for instance, notes, research participants "rely on researchers' honesty and willingness to protect them from harm". Continued establishment of trust by researchers – and continued demonstration of trustworthiness - through building good relationships with study participants and providing the appropriate, relevant, and

required information can consequently be regarded as critical to enhancing the acceptability of MMH research.

4.3. Willingness to participate in MMH research

Participants described motivations for and concerns about participating in general MMH research and GM. As explained below, motivations included the perceived benefits of the MMH research, including improving community health and well-being, and receiving support, treatment, and health care:

Benefits are there because we talk of the people in Malawi. So, Malawi is dead when Malawi is full of mentally disturbed people with few normal people. So, the fact that this study will minimise maternal mental illnesses means Malawi will be uplifted. **KA-FGD PASTORS-04**

You hear cases of suicide. Those cases are there because of mental problems. It may be related to being stressed and depressed. Therefore, death related to mental problems will decrease if this research is conducted. **LL-FGD HCW-10**

People will be interested to know what causes this disease. Is it curable and preventable, so people should practice a good lifestyle to avoid getting disturbed mentally. I am also interested to know what causes this pregnant woman to suffer from this disease. **KA-IDI COM MEM-20**

These extracts also underscore how morally inflected participants' understandings of (M) MH and its substrates (e.g., practising "a good lifestyle") were, raising questions about the role of MMH research – and the responsibilities of researchers - in processes of (de) stigmatisation.

Participants also described their perceptions of community members' willingness to accept and participate in MMH research to learn more, obtain treatment, and receive material incentives. This is illustrated by the quote below, where the participant cites expectations generated through encounters with previous public health projects in the area:

Community members have different expectations. Sometimes, they expect that they will have access to medication when they participate in a study. Sometimes they expect to receive information through leaflets and the like. Another expectation is that researchers will help them with their household needs. **KA-IDI COM MEM-02.**

However, participants also indicated some dissatisfaction with their engagements with researchers in the past:

In our communities, people tell us that you, health workers, use us as tools for your education. It is what people think and makes many people withdraw from studies. So, there is a need to give people information and enlighten them. People want to know from start to end how the study was conducted, and they should see real benefits that the study has ended here so that they should remove that thinking of being used as tools for education by researchers. **LL-FGD COM MEM-02**

Some people think that when there are studies, the researchers benefit from the samples of blood taken. They think that they are selling them and getting paid. Many times, people have participated in studies, but results are not communicated back to them, so people start doubting; hence they think that maybe they sell the specimen and get money. **KA-IDI COM MEM-15**

The FGDs and IDIs indicated that community members have concerns about researchers, and particularly about the collection of biological samples (e.g., for genotyping). These cautions and concerns are important to consider, not least because of the perception of scientists as 'using' research participants. There is a considerable duty for researchers to engage closely with potential participants and not simply dismiss or assuage these concerns. MMH research must instead be

undertaken in a way that delimits the possibility that such concerns will emerge in the first place, with close engagement and communication between researchers and communities being essential.

Despite the participants' dissatisfaction, the data suggest that participants regard the benefits of conducting MMH research as potentially outweighing the perceived burdens of participating in longitudinal research (including that which will collect biological samples). The only requirement and request participants made was the need to be kept informed about the use of their samples to avoid people being used solely as educational tools. This request links to the desire to reap health-related benefits from the knowledge generated through community participation in research. Such therapeutic misconceptions - or therapeutic optimism - need to be addressed right at the onset of the research during community involvement to enhance autonomy and avoid later dissatisfactions.

4.4. Community engagement and consent

We asked participants to suggest acceptable ways of engaging the community and contextually appropriate ways of consenting. The participants suggested consultations with chiefs (community gatekeepers) as one appropriate way to gain community buy-in and entry. Participants noted that community members easily accept an invitation to participate in research if their chief (traditional leader) approves it. Most participants recommended that MMH researchers consult community gatekeepers before recruitment, considering the sensitivities intrinsic to research with pregnant women. For example:

I feel like the best way is to consult chiefs. You and us, the health care providers, might meet the chiefs before going into the villages. When the chief agrees, he mobilises people to come together for a meeting. So the fact that the "big boss" has accepted, there will be no problems at all. **KA-FGD HCW-02**

The key gatekeepers were described as local leaders, including chiefs, pastors, and political leaders (members of parliament). Participants placed different weight on the relative importance of consulting with different gatekeepers:

I feel like there will be no challenges since you have involved us pastors. Pastors meet many people, and those people trust us a lot when we preach to them and give them instructions. Yes, the chief is important, but they are also our church members, and we preach to them and follow the instructions we give. If I am at the altar, the chief is my child also. So the obstacles are very slim. **KA-FGD PASTORS-04**

I believe that you meet people when you go into the communities. However, those people are under the leadership of certain people, so it is good to give leaders a priority, for instance, chiefs. These people have proper channels to communicate with the community members. Since this is about mental health, healthcare workers must also be involved. These are important stakeholders that we need to work with hand in hand on issues concerning maternal mental health. **KA-IDI COM MEM-02**

Participants recommended that researchers begin by consulting with local leaders to negotiate an approach to working in their communities. Community consultations were also suggested, involving door-to-door approaches so that community members can be provided with adequate information about the research, and have their concerns engaged with. Participants articulated that these approaches would minimise potential fears and rumours that they could have about MMH research - which themselves reflect "asymmetries of power" (Kaler, 2009: 1711) - and, more importantly, help researchers build community trust:

There is a need to explain to people in the community and give them detailed information about maternal mental health. When you have

visited a household, give people the necessary information so that people should be aware of your intentions. **KA-IDI COM MEM-04**

To ensure that people trust you in this study, it is necessary to inform people about the research before it starts because people will know what the research is all about. It will also help remove fears from those afraid of the research. It will also help to break bad rumours about the research. So, you need to find time to inform people about this research, and that will be helpful. **LL-IDI COM MEM-017**

Such accounts accord with the encouragements of some academics to build and demonstrate researcher trustworthiness or more generally to act ethically as part of community engagement (including several authors cited above; see, for instance, Nyirenda et al., 2019; Pratt et al., 2020; Wilkins, 2018).

However, some community members expressed their reservations about the role gatekeepers play in allowing or determining access to the whole community by researchers. Participants confirmed that once a chief has permitted researchers to recruit community members, people can feel they no longer have a voice to exercise their autonomy and decline an invitation to participate. Some participants viewed this as a form of coercion:

As I said initially, you should go through the chief. The chief sensitises the community and makes them convene at one place for a meeting. The chiefs even tell them that if they do not come, they will have to pay a fine ... They give them a penalty. **KA-IDI HCW -08**

[T]he chief sensitises people in the village to participate. So when they know that the chief has called them, they cannot refuse to participate. People find it very hard to refuse to say, "Eh, the chief has called us" **LL-FGD COM MEM-01**

Despite positively offering access in the community, these findings indicate that approvals from chiefs should not be taken on their own to represent community assent. Rather, MMH research must enhance autonomy through ensuring individual participants are content to participate, and carefully discussing wider participation with chiefs or other local leaders to help ensure that there are no ramifications for anyone who declines to participate. This might involve also reiterating that there are unlikely to be any immediate health-related benefits to communities from their participation.

Other concerns about consent were shared based on previous experiences and served as a reminder that communities should be adequately informed and engaged before starting a research project:

[S]ometimes you come with a study for maybe children, and then you do not tell us that the children should eat, or sometimes you give them treatment at school without our consent, and then children get sick right there at school. This creates opportunities for some conflicts. **KA-FGD COM MEM-06**

You go to the hospital for other things, but once you mention your name to them since they know that you participated in a study, they will go through their books and say, enter this room and undress, yet you are sick, and you went there for treatment. There was no privacy; they would look at you everywhere whilst you were naked. I believe that if this comes again, people will not accept it since we are now civilised. **KA-IDI COM MEM-20**

These concerns also underscore that unethical conduct can happen within research and public health activities, despite the best intentions, and must be carefully monitored and guarded against. In short, participants emphasised that participation in the study should be voluntary, such that the ethicality of obtaining permission from local authorities to research communities always needs to be complemented by individual consent.

4.5. Wider concerns about MMH research and research conduct

Participants expressed some specific concerns about the GM project and some general concerns about research practices. Participants' concerns were about the stigma and discrimination that a longitudinal study could generate, mainly because the research requires follow-up visits to a household that could attract unwanted, unnecessary, and suspicious attention:

You said this study is for four years and a half. In that period, how many visits will you make? Because you need to look into that. The community becomes suspicious when you visit a person more than two times. Most of the time, people rush to think there is COVID-19. People thought that it meant there was an HIV case there in the past. So since you will go several times, people tend to fear you and ask why people often come to your house. So you need to look into it and plan the best way to avoid such questions or bringing in some risks to the one taking part. **LL-FGD COM MEM-02**

It is important to note that participation refusals increase when study participation is linked to stigma and discrimination (Woodall et al., 2010). Researchers need to consider ways of managing follow-up visits during planning stages to minimise such implications during the implementation stage and prevent studies from contributing to wider social processes of stigmatisation and discrimination. One participant suggested that follow-up visits should not be undertaken at home to prevent arousing community suspicions or concerns about the health status of individual participants:

The other way is to use the hospital because it is safe, and no one would notice the results. Unlike at home, once the results are out, people can think that things are not okay. That is why people may not be willing to participate. **KA-FGD COM MEM-07**

Other concerns raised were about researchers' practices, such as health worker attitudes, poor time management, and inadequate feedback. Community members from Karonga and Lilongwe echoed each other's concerns on the attitudes of health workers more generally, providing insight into how researchers should approach communities. Participants mentioned selective treatment and poor care as reasons that were a cause for concern:

Sometimes, healthcare workers favour some people and leave out others. People get discouraged by that, giving the community members a negative attitude against participating in studies. Some do not know how to speak well with clients. They shout at them. Healthcare workers should have a good approach so that the clients should feel accepted. **KA-IDI COM MEM-04**

Being unsatisfied with the way health providers handle clients. Assuming a pregnant woman arrives at the hospital very early in the morning but is not being attended to up to 1 p.m. and then she is hungry, you come and say we want to conduct a study on you; this woman will refuse. **KA-IDI COM MEM-20.**

Health workers themselves supported the above views:

Let us say you treat them harshly, and they know your behaviour. This may be through meetings or even at the hospital. If someone has been treated poorly, they can go to the community and tell others you are bad. Sometimes people will hate you because of what they heard about you from other people. They will have a negative attitude toward you. It is because of the behaviour you show off to people, be it treating them harshly or showing favouritism. **KA-IDI HCW -10**

You will find some women complaining about a particular nurse that maybe they did not talk to them well during delivery. Seeing the same nurse enrolling them in a study, it is easier to say no. That is the problem that can be there. **KA-IDI HCW -05**

Managing time and respecting participants by keeping appointments was another expressed concern. Participants also pointed out that researchers sometimes use long question guides, disregarding their time:

You come with many questions, so people feel like you are wasting their time. Sometimes you will come at noontime when the woman is busy cooking; for the sake of respect, the woman will stop what she was doing to attend to you, and then you take longer to the point that children get hungry and start crying all over the compound. So they make up their mind never to participate again. They will say, 'when they come again, I will hide'. **KA-FGD HCW -02**

Another thing is keeping time. When you promise a client that you will come again tomorrow at 8 am, you should keep time and arrive at the promised time. In that way, people will trust you than lie to them that we will come at 8 o'clock and yet you come at 11 o'clock. **LL-FGD COM MEM-01**

Imagine arriving at the household at noon and then leaving at 4 pm. People complain that you take much time. They think you waste their time. Sometimes they go to the field and receive a message to come home and then ask questions for five hours. If you do not plan properly, people develop negative attitudes and make up their minds never to accept it again. **KA-FGD COM MEM-07**

Lastly, inadequate dissemination of research results was a concern, mainly in studies that collect biological samples:

Studies are good, but people want to understand more when you are taking samples. You need to explain well to convince people to give samples. If you have successfully taken the blood sample, please return the positive or negative results. Bring back the results. When you do not come with feedback, it raises many questions about what you do with our blood, so some will say you sell it. **KA-FGD COM MEM-08**

These concerns were echoed by health workers who observed their poor approach to providing feedback on samples collected and tested:

It is important to ensure that the results should be given once the samples are collected. People wait for the results, and there is a need to give the results of the samples collected. If you do not give the results, people lose trust in the community. **LL-FGD-HCW -10**

Healthcare workers thus emphasised the need to follow up with the participants from whom samples were collected and disseminate the study findings to the communities, including the health facilities that participated.

5. Discussion

Our study involved participants who would potentially be involved in a large-scale, longitudinal population-based research project - 'Generation Malawi' (GM) - in Lilongwe and Karonga. Through discussions with various stakeholders about this project specifically and MMH more generally, our study provides new insights into the acceptability and ethicality of MMH research in Malawi (and, indeed, population health research more broadly). Some of our findings reinforce and resonate with earlier studies on community perspectives around collecting biological samples in research, concerns around researchers' perceived intentions, and the need to strengthen community engagement to reduce stigma, discrimination, misconceptions, and misinformation (Manda-Taylor et al., 2021; Mfutso-Bengo et al., 2015; Nyirenda et al., 2019, 2020).

The broad acceptability of MMH research was confirmed by people's knowledge of the presence of people in their communities whom they regarded as living with mental ill-health. Furthermore, our findings indicated that participants would be willing to participate in MMH research because of its perceived benefits to the individual and to community well-being. However, this underscored the potential for

what bioethicists term the therapeutic misconception (Appelbaum et al., 1982; Burke, 2014) to compromise autonomy. Given the nature of a longitudinal study like GM, tangible and immediate benefits of the kind that participants might predict are unlikely to arise: while participation in the project could facilitate access to healthcare more generally, it will not directly generate new interventions for MMH.

The findings of this study highlight the need for researchers to understand and respectfully navigate the complexity of ethical challenges in the consent process because of the cultural and structurally embedded norms and values regarding hierarchy in our setting (Zulu et al., 2019). Our data suggest the need for research teams to consult with local leaders to negotiate an approach to working in their communities. Participants also suggested community consultations involving door-to-door approaches so that community members can be provided with details about the research, engage with any concerns, and dispel any therapeutic misconceptions. This suggestion resonates with the 3C model for participatory community engagement (Nyirenda et al., 2019). The model's participatory cornerstones - collaboration, consultation, and communication - respond to participant concerns in ways that can ensure GM and MMH research, more generally, are conducted ethically.

However, our study also demonstrates some of the challenges of widespread engagement about its potential to act as a vehicle for power, authority, and even coercion. For instance, when leaders permit a particular study to be implemented, community members may view it as an endorsement, impacting autonomy. These findings mirror the results of a study conducted in Ghana to assess the informed consent process, which reported that chiefs are critical gatekeepers in research such that their endorsement in a study may influence participation (Tindana et al., 2006). In Malawi, Nyirenda et al. (2020) have reported how community engagement can create a conducive environment for community leaders to influence individuals to consent to research, which might result in compromised ethical conduct. Despite these concerns, community consultations and engagements are vital; however, the role of gatekeepers must not occlude the need for individual consent. We recommend that researchers take time to understand local structures, as part of reaching a goal of supporting community members to consent to a study in an informed manner (Walsh et al., 2018; Zulu et al., 2019).

Considerations and concerns around the ethicality of MMH research were also raised in our data. These concerns are highlighted in the participants' responses on applying appropriate community engagement practices, respecting individual consent and people's time, and ensuring that the benefits of participating in research outweigh the burdens. Urgent attention is required to interrogate measures that researchers put in place to ensure that the ethicality of research is upheld and to bear in mind the unintended consequences that could arise from ostensibly laudable practices (Kaler et al., 2016). Although prior experience with participation in research is a recognised determinant of willingness to participate, community concerns around past experiences with research and healthcare can also negatively influence an individual's experience with and willingness to participate in research (Lazovski et al., 2009; Trauth et al., 2000). Feasibly, some of our participants blurred together experiences with research and experiences with healthcare about their concerns around prior bad practices. However, this underscores rather than undermines the need for researchers to demonstrate trustworthiness so that participants are not discouraged from future encounters with research and, vitally, healthcare.

Regarding time, our findings suggest that individuals associated with research - whether they are, in fact, researchers per se or are instead healthcare workers - do not always adhere to appointment slots and that encounters can be over-long. This may affect the nature and quality of data collected as participants rush through so they can be freed to continue their work (with ramifications for future research participation). Literature supports this complaint, showing how poor timing is a barrier to research participation (Friedman et al., 2015; Isaksson et al., 2019; Mfutso-Bengo et al., 2008). Much as long distances and poor road networks might contribute to poor timekeeping, researchers must

understand the temporal rhythms and demands of the communities with whom they seek to work. During the farming season, for instance, people are busy in the fields, and it would be inconsiderate to seek to recruit them in studies which would demand most of their time. By demonstrating substantive understanding and respect for the constraints under which participants live, researchers might also help to demonstrate one salient dimension of trustworthiness (MacIntyre et al., 2013).

5.1. Limitations

The use of convenience sampling was a limitation in our study which could have resulted in selection bias since only participants who had previously consented to be contacted about future research were reached. Their views might not align with those of other community members. However, this study was conducted in two districts in Malawi with 193 participants, which ensured a broad range of perspectives. Since these were elicited from the communities where GM will occur, we also have reliable data to base future procedures in GM and any other MMH research conducted by members of the project team (or others).

6. Conclusion

This paper described community members' perspectives toward participating in MMH research in general and GM in particular. MMH research, such as that proposed by GM, is broadly acceptable. However, some of the expectations about its impacts could reflect therapeutic optimism or misconceptions about the immediate benefits of such research – which researchers must carefully engage with. Further, some concerns that could jeopardise the ethicality of research, including GM, have also been reported (e.g., the role of community coercion). Future studies should explore the acceptability of research interventions during and after projects such as GM to examine the experiences of people taking part and ultimately make recommendations for further augmenting the ethicality of research in biomedicine and public health. This includes the ways in which research articulates with broader processes of (de) stigmatisation about (mental) ill-health.

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Availability of data and materials statement

The dataset generated and analysed during this study is not publicly available. Even without identifiers such as names, the dataset could hold identifiable participant information in aggregate due to the catchment area. The involved districts are small, and with potential identifiers, it would be ethically inappropriate to publicly share the data that could reveal our participants' identities if read by someone within the district. The dataset or part of it could be available from the corresponding author on reasonable request with permission from the College of Medicine Research Ethics Committee (comrec@medcol.mw).

Credit authorship contribution statement

Lucinda Manda-Taylor: Funding acquisition, Conceptualization, Methodology, Formal analysis, Project administration, Writing – review & editing. **Myness Kasanda Ndambo:** Data collection, Formal analysis, Writing – original draft, Writing – review & editing. **Eric Umar:** Funding acquisition, Conceptualization, Formal analysis, Writing – review &

editing. **Christopher Bunn:** Conceptualization, Writing – review & editing. **Marty Pickersgill:** Funding acquisition, Conceptualization, Writing – review & editing. **Robert C Stewart:** Funding acquisition, Conceptualization, Writing – review & editing. **Andrew McIntosh:** Funding acquisition, Writing – review & editing. **Maisha Nyasulu:** Data collection – review & editing.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix A. Supplementary data

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