Community Participation in Maternal and Perinatal Death Surveillance and Response (MPDSR) in Kenya

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Declaration

“I, Mary Wangechi Mbuo, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.”

Dedication

For Tavi Maina: Fly with the angels my little man, till we meet again.

Abstract.

Community participation in Maternal and Perinatal Death Surveillance and Response (MPDSR) is expected to support the aims of the MPDSR process by generating data for quality improvement and resource mobilisation. The policy guidelines and literature do not articulate the theoretical underpinnings and practical realities of implementing community participation in MPDSR. This thesis adopts a critical approach to understand how community participation works in practice. I conceptualised the collaborative processes expected between community members and health workers during MPDSR sessions as knowledge co-production.

I conducted this qualitative study in two counties in Kenya. I used in-depth interviews, observation of MPDSR sessions, focus group discussions and facilitated a co-production workshop with MPDSR participants.

The participation process is characterised by rhetoric, contradictions between what MPDSR participants say and what happens. Rhetoric is created by challenges in the health system and the wider context in which MPDSR is implemented. Health workers talk about the importance of community participation but also about the lack of competence and credibility of community members as knowledge producers. This results in the exclusion of community knowledge from the MPDSR process.

Despite health workers' discourse of no blame in the MPDSR process, health workers and community members associate MPDSR participation with scrutiny of their actions. Health workers avoid scrutiny by *re-engineering'* MPDSR reports, while community members avoid MPDSR sessions where 'bad' deaths are reviewed. This makes it difficult to co-produce knowledge for quality improvement.

The MPDSR policy puts a lot of faith in community representatives’ capacity to mobilise resources for MPDSR implementation with little regard for the socio-political context that MPDSR is implemented.

Examining MPDSR participatory spaces uncovers the disconnections between the policy expectations and the practical realities of implementing MPDSR. These findings could strengthen the global policy and our understanding of community participation in quality improvement and resource mobilisation.

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[1] To keep the locations of this thesis anonymous, I have to give you pseudonyms, but you know yourselves.

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List of Acronyms

ANC	Antenatal Care
BTN	Beyond the Numbers
CBHIS	Community Based Health Information Systems
CHEW	Community Health Extension Worker
CHV	Community Health Volunteer
CoiA	Commission for Information and Accountability for Women and Children's Health
CSO	Civil Society Organization
CVA	Community Verbal Autopsy
CVRS	Civil and Vital Registration Statistics
CU	Community Unit
DHIS2	District Health Information System
EOC	Emergency Obstetric Care
FANC	Focused Antenatal Care
FP	Family Planning
IDSR	Integrated Disease Surveillance and Response
LMICs	Lower- and Middle-Income Countries
MDR	Maternal Death Reviews
MDSR	Maternal Death Surveillance and Response
MOH	Ministry of Health
MPDSR	Maternal and Perinatal Death Surveillance and Response
PHC	Primary Health Care
PPH	Post partum haemorrage
RCT	Randomized Control Trial
TBA	Traditional Birth Attendant
TWG	Technical Working Group
SA	Social Autopsy
SDG	Sustainable Development Goals
UHC	Universal Health Coverage
VA	Verbal Autopsy
WHO	World Health Organization
WRA	Woman of Reproductive Age

Glossary

Clinical audit: a quality-improvement process that seeks to improve patient care and outcomes through systematic review of aspects of the structure, processes, and outcomes of care against explicit criteria and the subsequent implementation of change. Where indicated, changes are implemented at an individual, team or service level and further monitoring is used to confirm improvement in health care delivery (1,2)

Confidential Enquiry: A systematic multi-disciplinary anonymous investigation of all or a representative sample of maternal or perinatal deaths occurring at an area, regional (state) or national level. It identifies the numbers, causes and avoidable or remediable factors associated with them (1,2)

Facility based maternal and perinatal death review: A qualitative, in-depth investigation of the causes of and circumstances surrounding maternal and perinatal deaths occurring at health facilities. Deaths are initially identified at the facility level but such reviews are also concerned with identifying the combination of factors at the facility and in the community that contributed to the death, and which ones were avoidable (1,2)

Maternal mortality: the death of a woman while pregnant or within 42 days of the termination of pregnancy, irrespective of the duration and site of the pregnancy, from any cause related to or aggravated by the pregnancy or its management but not from accidental or incidental causes. Maternal deaths can be categorized into direct obstetric deaths and indirect obstetric deaths (3)

Neonatal mortality: death of a newborn baby at any time from birth to 28 days (2)

Pathway to survival: a guide that distinguishes between prevention behaviours, such as breastfeeding, that can be implemented entirely in the home and those, such as vaccination, that require more direct support from the health system. Pathway to survival was initially developed for community management of childhood illnesses and can be adapted for maternal morbidity and mortality (4,5).

Perinatal mortality: stillbirth or death of a newborn baby within the first seven days of life. The definition has been expanded to include late neonatal deaths upto 28 days of life (2)

Social Autopsy an interview process aimed at identifying social, behavioral, and health systems contributors to maternal and child deaths. It is often combined with a verbal autopsy interview to establish the biological cause of death (6). Social autopsy can also refer to public meetings where community members, health professionals and other stakeholders discuss the contributing factors to maternal and perinatal deaths (7).

Stillbirth: A baby born with no signs of life, weighing more than 1 000 g or with more than 28 completed weeks of gestation. Stillbirths are grouped as either antepartum i e occurring before the onset of labour or intrapartum i e occurring after the onset of labour and before birth (2,8)

Three-delay model: proposes that pregnancy-related mortality is usually due to delays in: (1) deciding to seek appropriate medical help for an obstetric emergency; (2) reaching an appropriate obstetric facility; and (3) receiving adequate care when a facility is reached (9).

Verbal Autopsy: A method of finding out the medical causes of death and ascertaining the personal, family or community factors that may have contributed to the deaths in women who died outside of a medical facility(1)

Introduction

This thesis has focused on community participation in Maternal and Perinatal Death Surveillance and Response (MPDSR) in Kenya. Global policies and guidelines have suggested that community participation in MPDSR could support health systems to provide people-centred care and ensure accountability for preventing maternal and perinatal deaths (10–12). In theory, community participation in MPDSR is expected to contribute to the overall goal of the MPDSR policy process, which is to establish accountability for the prevention of deaths by generating data and using the data for quality improvement and resource mobilisation (3,13,14). A Cochrane review on the effectiveness of maternal, perinatal and child death audits recommended that there was a need for more research on community participation in MPDSR to explore how discussions between community members and health professionals could contribute to improving the quality of care and overall accountability for maternal and newborn health (15).

The research question for this study is '**How does community participation in MPDSR contribute to the MPDSR goal of accountability for preventing maternal and perinatal deaths in Kenya?**

In this thesis, I examine how participation happens at different levels of the health system and in different participatory spaces to understand how different contexts shape participation. The participatory spaces include physical spaces such as health facilities and community sites, homesteads of bereaved community members, political spaces, and policy spaces. I explore the participation experiences of health workers, bereaved family members and community representatives to understand their perspectives on participation in MPDSR. This PhD contributes to our understanding of how community participation in MPDSR works in practice.

Organisation of the thesis

This thesis consists of eight chapters that are organised as follows:

Chapter one provides a background of the MPDSR process in general, describing the historical beginnings of the process and how MPDSR has evolved. I describe how the MPDSR process is expected to work. I also describe how the MPDSR policy is implemented in Kenya and explain how community participation in MPDSR is expected to work at different levels of the health system in Kenya.

Chapter two is divided into two parts. In the first section, I summarise some relevant debates on community participation in health and identify relevant concepts in the literature, such as power, knowledge, and social accountability, that I have used to analyse community participation in MPDSR. In the second section, I summarise and critique the literature on community participation in MPDSR by drawing on the wider community participation in health literature. I identify relevant themes covered in the existing literature and the gaps this PhD has addressed. I then present my study rationale and conceptualisation in response to the research question and study objectives.

In **chapter three**, I present the methodology for this study and provide a detailed account of the methods and tools I used, the decisions I made when generating data and the rationale for those decisions. I used an interpretivist grounded theory approach in this qualitative study to explore the experiences and perspectives of the health workers and community members as MPDSR participants. I sought to understand how community participation in MPDSR works in practice and the meanings health workers and community members associate with the participation process.

In **chapters four to six**, I present descriptive and analytical findings addressing the research question and study objectives. I describe the context in which community participation in MPDSR happens, what people do and how they interact during MPDSR sessions. I also critically analyse the findings by focusing on study participants' talk throughout their interviews and focus group discussions (FGDs) to understand how they construct meaning about their experiences of MPDSR participation and how this shapes the participation process. I analyse the participatory process at micro, meso and macro context in which participation happens for a more nuanced understanding of how MPDSR is implemented in practice.

In **chapter four**, I describe the micro-level interactions between health workers and community members during MPDSR sessions in the community and at primary care health facilities. I pay attention to the different forms of knowledge that health workers and community members bring to MPDSR sessions. The forms of knowledge are (i) experiential knowledge based on the lived experiences of community members, (ii) health workers' clinical knowledge of maternal and newborn health and (iii) health workers' tactical knowledge of how the MPDSR policy is enacted. I critically examine health workers and community members perspectives on the different forms of knowledge and the value that MPDSR participants accredit to the different forms of knowledge.

I interrogate the contradictory nature of study participants' talk about the importance of community participation in MPDSR and what happens in practice. On the one hand, health workers and community members use vocabularies of hope to describe the MPDSR process and the role that community members are expected to play in generating knowledge. On the other hand, health workers and community members use other vocabularies that contradict the vocabularies of hope. Health workers use vocabularies of incompetence and lack of credibility to question the role of community members as knowers in the MPDSR process. Health workers also use the vocabularies of incompetence to rationalise using the MPDSR process to educate the community members. Community members use vocabularies of exposure to question the intentions of the MPDSR process as a way of uncovering community practices that the community members prefer to keep hidden. I examine the contradictions between these vocabularies and demonstrate that, in practice, health workers and community members do not collaborate when producing knowledge through the MPDSR process. I have labelled this lack of collaboration despite positive talk as the rhetoric of knowledge co-production that is characterised by epistemic injustices that diminish community members' value and relevance in the MPDSR process.

In **chapter five**, I focus on the meso-level context in which MPDSR is implemented by analysing the relationships among MPDSR participants in the health system. I show that there is a rhetoric of “no blame” which shapes the participation process. Despite repeated claims among health workers that MPDSR is implemented in a blame-free context, in practice, blame permeates the interactions of health workers and community members, which influence the participation process. I examine health workers' framing of the MPDSR process as a way of scrutinising and penalising their actions, which affects their decisions to exclude community members from MPDSR sessions. I show that these meanings of scrutiny have a temporal dimension, which shapes the actions of health workers as they manage or avert blame before MPDSR sessions, during MPDSR sessions and after MPDSR sessions. I pay attention to how health workers use health system tools such as the three-delay model or the MPDSR proceedings to cope with the meanings of scrutiny and blame. I interrogate community members’ meanings of the no-blame discourse in MPDSR and show how community demands for accountability for perceived negligence by health workers shape the MPDSR process.

I also pay attention to the material context within the health system in which MPDSR is implemented and have shown that the lack of adequate resources demotivates both community members and health workers from participating in MPDSR.

In **chapter six**, I focus on the macro-level context, such as the political economy and socio-cultural environment in which MPDSR is implemented. I examine the roles of community representatives as they navigate different MPDSR participatory spaces as intermediaries between the community and the health system. I explore the different hats that community representatives wear in different MPDSR participatory spaces, and the balancing acts involved as they support the needs of community members on the one hand and fulfil health workers' demands on the other.

I question the discourse that community representatives are trusted and respected to channel information, advocate for resources and mediate between community members and the health system in light of the socio-political barriers they face. I pay attention to the wider context of MPDSR implementation to uncover the contradictions between how study participants construct community representatives' roles and the practical challenges they face when performing these roles, which influences community participation in MPDSR.

In **chapter seven,** I return to my research question and study objectives and show how this thesis has addressed them. My first study objective explores the experiences and perspectives of study participants as they produce knowledge. I argue that there are epistemic injustices in the knowledge production process and that community members’ experiences and knowledge are left out of the MPDSR process. The second objective examines the social interactions and symbolic meanings that MPDSR participants associate with MPDSR participatory spaces. I demonstrate that health workers and community members associate MPDSR participatory spaces with meanings of social and political control, scrutiny of their actions and negative meanings of social and professional risk and stigma, which affects how they participate, and the knowledge produced (in the form of MPDSR recommendations).

I also examine the different forms of rhetoric or contradictions on how community participation in MPDSR is expected to work and how it works in practice. I draw from anthropological theories on policy processes and health system functioning to explain how structural barriers contribute to the rhetoric. Several structural barriers influence community participation at the policy level, within the health system and the broader socio-political context in which MPDSR is implemented. For instance, an overemphasis on quantitative indicators in the global MPDSR policy could contribute to the epistemic injustices and the lower status that community members’ knowledge is given in the MPDSR process. The lack of material and symbolic resources and the hierarchical nature of the health system could account for disrespectful maternity care and health workers’ negative strategies for dealing with the scrutiny associated with MPDSR participation. I show that community participation in MPDSR is a sensitive process that requires careful attention to socio-cultural meanings associated with deaths, and the MPDSR process can be disruptive to existing social norms and cultural practices. I also show that MPDSR is a political process involving negotiations for resources, and those with power control the MPDSR process. I then discuss the theoretical contributions that this PhD has made and reflect on the study's limitations.

In **chapter 8**, I conclude the study by discussing the implications of the study findings and propose some areas for future research. By highlighting the barriers and contextual factors that limit knowledge production in the MPDSR process, we can better understand the rhetoric associated with community participation in MPDSR and the challenges of establishing accountability for preventing future mortality.

1.0 Background

The 2022 global data for maternal and perinatal mortality show that 800 women died daily due to complications of pregnancy and childbirth (16). In the same period, there were approximately 2.3 million neonatal deaths and 2 million stillbirths globally (16). Yet, 75% of neonatal deaths, 80% of maternal deaths, and most intrapartum stillbirths are preventable by identifying and addressing the modifiable social and clinical factors that contribute to maternal and perinatal mortality (2,3,12). With the sustainable development goal (SDG) target to reduce the global maternal mortality ratio to <70/100000 livebirths and a global neonatal mortality rate of 12/1000 livebirths more needs to be done to accelerate progress and improve survival rates for women and babies (17–19). A Cochrane review on maternal and perinatal death surveillance and response (MPDSR) reported that implementing MPDSR could reduce deaths by 35% and contribute to achieving the SDGs (15).

The primary goal of MPDSR is to prevent avoidable maternal and perinatal deaths by systematically collecting, analysing and aggregating information on maternal and perinatal deaths to guide decision-making (14). The underlying mechanism of how MPDSR is expected to work is that by reviewing each maternal death and a proportion of perinatal deaths, health professionals at all levels of the health system can learn and take action to prevent future deaths of a similar nature (14,20–22). The information that is reviewed can include patient records and interviews with relatives of the deceased to understand the social and clinical factors that may have contributed to the death. The review process should also be used to analyse the wider non-health system barriers (e.g., poor road network and low status of women) to maternity care and either act to address them or advocate with policymakers for change (21,23).

MPDSR is a complex process that involves many interventions or activities taking place all at once by different actors at different levels of the health system (24). At the national level, the MPDSR process is expected to collate data (from death reviews) from sub-national levels to guide national level priority setting (24,25). At sub-national (district/county) the MPDSR process reviews data or reports at that level and makes recommendations on the changes needed to address the modifiable factors within the district. The national and sub-national levels of the health system rely on the information generated at primary care facilities during death review meetings to prioritise their actions (24). It is also expected that MPDSR committees at primary care facilities will develop their own action plans to address modifiable factors within the facility and in the communities that they serve (24,26)

The current approach and guidelines on how to implement MPDSR builds on existing strategies for reviewing maternal and perinatal deaths in health facilities and communities (3,14). These strategies are confidential enquiries, maternal and/or perinatal death reviews, and community-based reviews through social and/or verbal autopsy (3,14,24,27). *See the glossary for a detailed description of each strategy.* In practice, different countries use the term MPDSR to describe programmes that link surveillance data to response for prevention of maternal and/or perinatal deaths regardless of the strategies used for review (i.e. confidential enquiries, facility death review or community-based reviews) (24,28,29).

Regardless of the strategies used to review deaths, the ultimate purpose of the MPDSR process is to act on the data and findings of the review by bringing together different stakeholders who can play a role in preventing future deaths (13,14,21). These stakeholders include community members, health professionals, civil society, the private sector, and professional associations (e.g., midwifery councils). In some contexts, the MPDSR process only involves health professionals with no community engagement (30–32), while in other contexts, community members participate in either facility death review meetings or community-based review processes (29,33).

Community participation in MPDSR is often framed as a means of supporting health systems to meet the MPDSR goal of preventing maternal and perinatal deaths (3,13,22,34,35) This PhD has focused on community participation in MPDSR in Kenya. I will briefly describe the history of the MPDSR process and how it is expected to work before describing the context of community participation and MPDSR implementation in Kenya.

1.1 History of MPDSR

MPDSR evolved and built on progress through several global strategies, policies, and action plans. In 2004, WHO launched Beyond the Numbers (BTN) guidelines for conducting maternal death reviews (1). BTN sought to "*tell the stories behind maternal deaths and put faces to the numbers"* and provide explanations on why maternal mortality persisted despite the availability of evidence, resources and political commitment to prevent deaths (1 :5). The BTN guidelines provided a framework for health professionals to generate the "*right kind of information to prevent future deaths*" (36 :27). While the BTN guidelines provided direction for conducting maternal death reviews in health facilities and in communities (through community-based reviews), in practice most countries implemented maternal death reviews only in health facilities with no community involvement (37).

In 2012, WHO and other partners proposed a shift from BTN to Maternal Death Surveillance and Response (MDSR) (3). MDSR was introduced as a systematic process that documents and reviews all maternal deaths to identify the associated circumstances and contributing factors (including health systems barriers) and uses the findings to prevent future deaths (3). MDSR is a continuous action cycle that involves death notification and reporting, i.e. collecting information on when, where, and why women die (3). Death reporting is followed by a review of the information and making and implementing recommendations to prevent future deaths of a similar nature *(ibid.*). Implementing MDSR allows the health system to "*hear women's personal stories*" and use this information to review deaths in health facilities and in the community (34:1). The MDSR policy emphasises the need to strengthen accountability throughout the MDSR cycle by using data to monitor if the recommendations are effective at different levels of the health system (such as primary care facilities, referral facilities and health policy actions at national level) (3). The difference between BTN and MDSR is the explicit reference (in the policy guidelines) to MDSR as an accountability process for preventing deaths by using surveillance data to drive decision-making, improve quality of care and mobilise resources, which was not explicitly stated in BTN (3,13,22,25).

Following the launch of the Every Newborn Action Plan (8) and Making Every Baby Count guidelines (2), perinatal death surveillance and response was added to the MDSR process in 2017 to leverage the gains made through BTN and MDSR (2,14). The MPDSR process inherited the policy and strategies that were used in MDSR. In practice, countries have transitioned from BTN to MDSR and MPDSR at different rates; some countries have MPDSR policies, but some aspects of the process, such as perinatal review and response, remain aspirational (24). I will briefly describe how the MPDSR cycle of active surveillance and response is expected to work and show how community members participate in surveillance and response.

1.2 How the MPDSR process is meant to work.

MPDSR is implemented through an action cycle of surveillance and response (3,14). Active surveillance is a process of proactive identification, notification, reporting and review of maternal and perinatal deaths in real time (13,23,28). The response component links data from the surveillance processes of identification, reporting and review to actionable recommendations to address the modifiable factors that contribute to maternal/perinatal deaths (14). Response also includes establishing accountability through monitoring progress on the implementation of recommendations and advocating with duty bearers to support the implementation of recommendations (*ibid*.).

An active surveillance system can generate data on where and when deaths occur, which is an essential first step to counting every maternal/perinatal death (12,38,39). Surveillance builds on existing mechanisms for reporting births and deaths, such as civil and vital registration systems (CVRS) and public health and disease surveillance programmes (23,40). In high-income countries, there are well-established mechanisms for using vital registration data to understand maternal and perinatal mortality trends (41). This is not always feasible in Lower and Middle-Income Countries (LMICs) as vital registration regimes are not as robust, which leads to a tendency to use global or regional retrospective estimates of maternal and perinatal mortality rates that are less reliable (23).

In contexts where CVRS is not well established or where a significant proportion of births and deaths occur in the community, as is the case in many parts of Asia and sub-Saharan Africa, it is envisaged that MPDSR could facilitate active surveillance for identification and notification for maternal and perinatal deaths in the community (41,42). This is done by working with community volunteers or groups who identify and report all suspected maternal and perinatal deaths to health professionals (41,43). In many contexts, identification is followed by reporting of deaths using verbal autopsy (VA) questionnaires that are used to assign a cause of death (44). In some contexts, the verbal autopsy questionnaire also includes key informant interviews with immediate family members or community members to explore the woman’s pregnancy journey before the adverse outcome (45,46).

In theory, the surveillance process should include reviewing the information collected on maternal and perinatal deaths in the community and health facilities, though this varies in practice (3,14). Review of deaths involves identifying modifiable clinical and social factors (such as lack of necessary drugs or community delays in seeking health care) throughout the continuum of care in the antepartum, intrapartum and postpartum period (21,28,47). Maternal/perinatal death reviews are analytical processes that use frameworks such as the three-delay model (9) or the Pathway to Survival tool (4) to explore the underlying factors that contributed to deaths in health facilities as well as in community settings. The two frameworks are used to review a pregnant woman's journey from the household to a health facility and the emerging delays or issues that contributed to an adverse outcome. In practice, the three-delay model is more widely used during the review process (5,47,48). See the glossary for a more detailed description of the three-delay model and the pathway to survival framework.

Successful death review meetings (in health facilities) can produce a "*maternity conscience*" among the health professionals attending the review, as participants can use the review discussions to learn and make changes to their future clinical practices (49:27). Death reviews can generate information to explore quality of care issues and uncover the reasons behind maternal and perinatal mortality in facilities and in the community. Some studies have suggested that community-based reviews can create opportunities for community members to discuss the deaths and make community-level recommendations on preventing future deaths (7,33,46).

The response phase of the MPDSR cycle involves making and implementing recommendations[2]. The MPDSR guidelines emphasise that recommendations should be Specific, Measurable, Assignable, Realistic and Timebound, i.e. SMART recommendations (3,14). The recommendations can relate to changes that are required within the different levels of the health system or in the community (3,14). For instance, death review meetings or verbal autopsy data can uncover delays in community referral, requiring responses to improve referral systems and community knowledge on the need for prompt health facility attendance during an obstetric emergency (50,51). Recommendations may also be targeted to policymakers and political leadership for resource allocation to support maternal and newborn health efforts (45,47,52). Other recommendations could target health workers to improve clinical practice and quality of care within health facilities (33,53).

Figure 1 summarises the MDSR/MPDSR cycle (3)

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[2] Recommendations are also referred to as actions in the literature. I will use the term recommendations but acknowledge that some other literature may use the word actions to refer to the same thing.

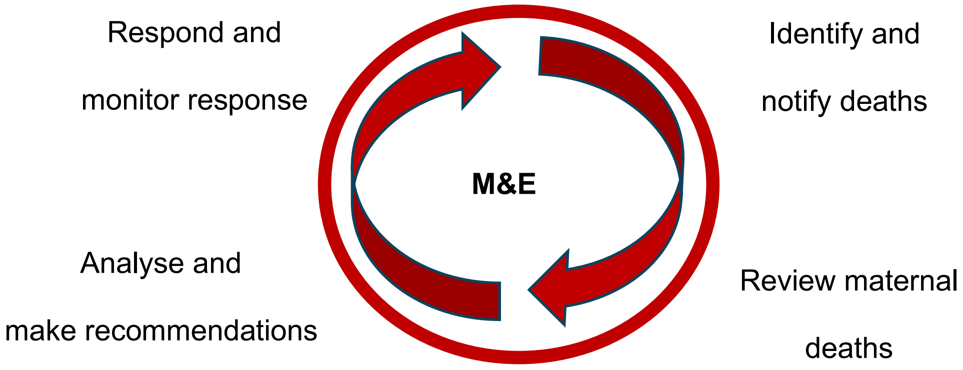

Figure 1 MDSR cycle

Research on MPDSR has shown that health workers can feel threatened to participate in death reviews if they are blamed for deaths during the review process (54–56). The WHO guidelines and other research have explained that the purpose of death review meetings should be to learn from the deaths under review rather than apportion blame (14,27). As such, the MPDSR process is supposed to be guided by a "*No Name, No Blame and No Shame environment, which is grounded in three ethical principles of confidentiality, anonymity and respect*" (56: 840). WHO guidelines and other researchers have argued that there is need for countries to establish legal frameworks that can protect health workers from the legal risks that are often associated with the MPDSR process (14,25,27). Despite these guidelines, blame culture remains a significant challenge in MPDSR implementation. I will discuss this further in chapter two when I review the literature on community participation in MPDSR.

At the global level, MPDSR is coordinated and led by WHO through a technical working group (TWG) that provides global guidance and tools to support countries implementing MPDSR (57). In 2020, the TWG developed a work plan and identified priority areas for more research to support countries implementing MPDSR (57). The priority areas are (i) blame culture and community engagement, (ii) MPDSR implementation in fragile and humanitarian settings, (iii) capacity building and mentoring health professionals, (iv) strengthening monitoring and reporting and (v) strengthening communication among global partners implementing MPDSR (*ibid)*. Through its members, the TWG develops and disseminates tools and guidance to support the implementation of MPDSR in different contexts (e.g. 14,56).

1.3 Establishing accountability in MPDSR.

MDSR/MPDSR is considered *"a cornerstone of MCH accountability"* because it supports a comprehensive reporting process on collecting, analysing and monitoring data related to maternal and perinatal deaths (13: 5). At inception, MDSR (before addition of 'P' in the guidelines/policy) was expected to establish accountability by: (i) generating **results** by improving death notification, review and response, (ii) mobilising **resources** through advocacy and (iii) realising **rights** for women and children by using the data from the process to improve quality of care (13). After the additional of perinatal death surveillance and response to the MDSR process, WHO provided additional guidance that reiterates the goal of MPDSR as a process of generating results, improving quality and mobilising resources (14,58). Different actors in the health system (frontline health professionals, health managers, policy makers and community leaders) are responsible for ensuring that the data generated through the MPDSR process is used for quality improvement and resource mobilisation (3,13). Later on in this chapter, I will describe how the MPDSR process works and the decision making/accountability arrangements in the Kenyan context.

Five arguments have been proposed on why community participation in MPDSR can help establish accountability for resources, results and rights for women and children (13,23,34). First, MPDSR is expected to improve surveillance of where deaths have happened in the community and health facilities to provide valid and accurate data to guide decision-making (13,22)**.** Accountability can be established by ensuring that death notification for all deaths is mandatory to optimise opportunities to count the dead at sub-national levels (23). In an éditorial on MDSR, Danel *et al.* (21) suggest that MDSR could improve estimates for maternal mortality and contribute to accountability by providing reliable data on maternal deaths at sub-national levels**.** MPDSR is also expected to improve CVRS by ensuring coordination of death notification between the health system and CVRS departments in countries (13,21,22). Bandali *et al.* (59) have shown that countries such as Ethiopia have used MDSR as a framework to improve death notification and reporting using facility death reviews and verbal autopsy data as a form of accountability in MPDSR.

Secondly, accountability in MPDSR is established by closing the action cycle loop, i.e. linking surveillance data to response (22). Closing the cycle loop involves analysing data generated from death reporting (from community and facilities) and making recommendations to address gaps identified in the review process (14,23). Recommendations should be implemented at every level of the health system, where information on deaths is collected and analysed, and relevant recommendations are made (10,14,23). A project in Nigeria showed that data from maternal death reviews can be used to improve health practices at the local level as well as for advocacy at the national level by increasing the visibility of maternal deaths to policy makers and leaders (59).

The third way in which accountability in MPDSR can be strengthened is by monitoring the submission of MPDSR reports (13,22). MPDSR reports should be generated at different levels of the health system, from the community to subnational and national levels (14,24). The reporting process should involve collating reports from lower levels of the health system and reporting them to higher levels (23). In an ideal situation, all the reports from sub-national levels of the health system should be collated, and the data from the reports should be aggregated and used to guide policy decisions and mobilise resources for the prevention of future mortality (13). Mathai *et al.* (22) argue that a good MDSR process is only as good as the quality of the reports that are generated from all levels of the health system. The authors further argue that quality reporting requires the involvement of family members, community members and health professionals to explore social and clinical circumstances surrounding the deaths (*ibid*.). Other scholars have claimed that involving community members in death review processes can improve the quality of MPDSR reports generated through the reviews (34,60).

Fourth, MPDSR is expected to improve quality of care by using results from review sessions to improve healthcare practices (23,58). WHO and others have argued that ensuring good quality of care for maternal and newborn health is a marker of accountable health systems (13,58). The MDSR process was formalized towards the end of the Millennium Development Goals (MDGs) in 2015 (3). The goal of MDG 5 was to improve maternal health by reducing maternal mortality ratio (MMR) by increasing skilled attendance at birth (61). While some progress was made by increasing coverage of skilled birth attendance, effective coverage remained a challenge (62,63). At inception, MDSR was expected to address this challenge by providing real-time data to health workers to learn from review sessions and improve the quality of care (22,62). In more recent publications, WHO has proposed that community members can participate in MPDSR and contribute to accountability efforts on quality improvement by giving feedback on their experiences of care before an adverse outcome (14,58).

Finally, the implementation of MPDSR is expected to establish accountability through advocacy for the rights of women and newborns (13). Data generated from review sessions can make death more visible to policymakers and mobilise resources to support action (53,59,64). Scot and Danel (13) argue that community members have a responsibility to participate in death reviews to provide information to health workers on the circumstances surrounding maternal and perinatal deaths. The authors further argue that community members should hold themselves to account by identifying ways that the community can support pregnant women and families to prevent maternal and perinatal deaths (*ibid*.). Community members can also hold duty bearers accountable by using data from the MPDSR process to advocate for resources and promote the rights of women and newborns (52). For instance, Jat *et al.* (47) have used data from maternal death reviews at health facilities to hold sub-national and national leaders to account for failures to protect the lives of women and uphold the right to health for communities.

While the MPDSR policy recognises that community participation in MPDSR is critical to the accountability process (3), many countries do not include community members in their MPDSR processes, e.g. (30,31,65). Several studies on MPDSR implementation within health facilities have recommended that further research on the role of community participation in MPDSR could strengthen the MPDSR process (60,66–68). A Cochrane review on the effectiveness of maternal, perinatal and child death audits recommended that there was a need for more research on community participation in MPDSR to explore how discussions between community members and health professionals could contribute to the quality of care efforts (15). Even though global policies and guidelines such as the Ending Preventable Maternal Mortality Partnership (12) and the WHO Commission for Accountability Framework for Women and Children (11) identify community participation in MDSR[3] as a critical component for improving data collection on maternal deaths and empowering communities to engage in social accountability for maternal/perinatal mortality prevention, there is a paucity of research on community participation in MPDSR.

Towards the end of the MDGs, the WHO led Commission for Accountability Framework for Women and Children (11) collated progress reports on strengthening national accountability for women and children. Kenya was among the 68 countries globally that developed a Country Accountability Framework, which prioritised implementing MDSR as one of the strategies for strengthening accountability to prevent deaths (11). Kenya developed an MPDSR policy that explicitly includes community members as key stakeholders in

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[3] This document was produced before perinatal surveillance, and the response was added to the MDSR cycle. However, in practice, MPDSR inherited all the policy and strategy documents that were related to MDSR because even after adding the 'P,' there are no fundamental changes to the policy, strategy, or guidelines.

implementing MPDSR (69). In this PhD, I have examined how community participation in MPDSR in Kenya works by exploring the experiences and perspectives of MPDSR participants (at selected sites in Kenya) in generating data to improve quality of care and mobilise resources, i.e., strengthening accountability for the prevention for maternal and perinatal deaths.

1.4 Kenya Country Context

Kenya is a lower-middle-income (LMIC) country with the largest economy in East and Central Africa (70). Kenya is among the countries in the world with the highest burden of maternal mortality, losing between 5,000 and 6,000 mothers every year due to pregnancy and birth complications (16,69,71). Most maternal deaths in Kenya are due to direct obstetric causes, i.e. haemorrhage, severe preeclampsia/eclampsia, sepsis, obstructed labour, and unsafe abortion (70,72). The leading causes of perinatal mortality in Kenya are preterm labour, preterm birth, infections, and birth asphyxia (70,72).

Despite an increase in institutional childbirth, maternal and perinatal mortality remains high, with more maternal and perinatal deaths occurring in health facilities than in communities (73). In 2020, 67.5% of all deliveries in Kenya were conducted by a skilled birth attendant (70). The national MPDSR annual report for 2019/20 found that most maternal deaths occurred among women who had received antenatal care (72%), with the majority of the women attending ANC at least four times as recommended by WHO (70).

Kenya has a devolved health system; the national government is responsible for policy articulation, while county governments are responsible for (i) the adoption of policy guidelines to suit the local contexts, (ii) the implementation of health programmes/ interventions, and (iii) allocation and management of health budgets (74). The County Assembly comprises politically elected officials responsible for managing devolved health activities, approving health budgets, and holding health workers accountable for implementing health activities at the county level *(ibid)*. The county assembly appoint County Executive Committee (CEC) members who serve as equivalents of cabinet secretaries in the county; typically, the health CEC is a health professional who is politically appointed and responsible for signing off on all MPDSR reports.

Kenya adopted the WHO guidelines on maternal death reviews (MDR) in 2008 and updated the guidelines to include perinatal deaths in 2016 (69). MPDSR is entrenched in the Kenya National Health Policy (2014-30) as a critical strategy for reducing maternal and perinatal mortality (69). The national MPDSR guidelines provide a roadmap for conducting reviews for stillbirths and maternal and neonatal deaths at the community and facility levels (69,70). Notification of maternal deaths is mandatory in Kenya and is anchored in the law; maternal deaths must be notified within 48 hours and reviewed within seven days (69). Data on maternal and perinatal deaths is uploaded to the District Health Information System 2 (DHIS2), with a requirement for zero reporting of maternal deaths (70).

The Kenya Community Health Policy's (2020-30) goal is to empower individuals, families, and communities by strengthening community health services at all levels of the health system (75). In addition to the policy, Kenya has a Community Strategy that provides a framework for enacting the policy (76). The Community Strategy outlines how communities can participate in health activities through community representatives and volunteers (76). The Community Strategy is used to support the implementation of all community health projects/programmes in the country; in this thesis, I reflect on how the strategy is used to support MPDSR implementation during MPDSR sessions and the work of community health volunteers and other community representatives.

Community Health Volunteers (CHVs) are responsible for pregnancy surveillance, promoting antenatal care (ANC) and family planning (FP), providing health education on newborn practices such as thermal care, cord care and exclusive breastfeeding, referring and/or supporting referral of mothers and newborns and promoting immunisation (75). The Community Health Policy and Strategy outline how community volunteers and representatives are expected to support community-based health information systems (CBHIS) (75,76). CHVs also collect public health information at the community level, such as the number of households with latrines or households they have visited to promote childhood immunisation, among other public health issues.

The CHVs also collect information on maternal or neonatal deaths in their villages (75,76). Due to the difficulty in explaining intrapartum and antepartum mortality to non-medical staff, CHVs only collect information on neonatal deaths (i.e., 0-28 days of life). The information/data CHVs collect is displayed on a community chalkboard (as part of CBHIS) in a public place so that people can see their progress on key indicators (75,76). CHVs use data recorded on the community chalkboard to facilitate health education discussions with community members and to set community-level priorities relating to community health (*ibid*). The Community Health Policy also requires that the CBHIS data be uploaded on the DHIS2 (75). Each community unit is assigned credentials allowing health workers from that catchment area to upload community-related data (such as maternal deaths and verbal/social autopsy reports) onto DHIS2 (75).

Community volunteers and representatives are supervised and supported by Community Health Extension Workers (CHEWs) (75,76). CHEWs are salaried staff with training and qualifications in community public health (75). Community volunteers receive stipends from county governments as compensation for their time on community activities (75). In practice, every county adapts the Community Strategy to their local context, forming a basis for how community participation is organised in that county (76).

CHVs and other community representatives such as chiefs and elders are supported by health workers from their catchment health facilities to organise Community Dialogue Days. The Dialogue Days are envisioned to be spaces where community members, community volunteers and health workers can discuss the health problems/issues they face based on the CBHIS data displayed on the community chalkboard (76). In some counties, the dialogue day incorporates social autopsy to discuss any maternal or neonatal deaths that have occurred in that community. The social autopsy sessions that I describe in this thesis were implemented as part of Community Dialogue Days.

1.4.1 Structure of MPDSR committees in Kenya

Kenya has a 5-tier committee structure for MPDSR with committees at community, facility, sub-county, county, and national levels. At the national level, there is a national Technical Working Group (TWG) on MPDSR that is made up of government representatives, donors, some NGOs and civil society organisations (CSOs) that support the Ministry of Health (MOH) to implement MPDSR at community, facility, sub-county and county levels (69,72). The technical working group also provide technical and administrative support to the national MPDSR committee. The national MPDSR committee is made up of representatives from the Ministry of Health, such as the Director of Medical Services who chairs the committee, representatives from professional organisations (such as Kenya Obstetrical and Gynaecological Society and Kenya Paediatric Association and Kenya Medical Association), development partners, the inter-religious council of Kenya, representatives of private health care institutions and the Kenya Human Rights Commission, among others (69).

The national MPDSR committee meets bi-annually to conduct confidential enquiries; the process begins with anonymisation of all MPDSR reports that all 47 counties in Kenya upload on the DHIS2 (also referred to as KHIS platform) (70). The committee conducts confidential enquiries into maternal and perinatal deaths with the support of volunteer obstetricians, midwives, paediatricians and other relevant health professionals who produce an annual report on their findings (70). One of the main challenges identified by the national MPDSR committee is the low quality of review reports, with many of the reports missing crucial information or incorrect completion of the forms, e.g. misclassification of WHO ICD-10 classifications for cause of death (70). This makes it difficult for the national MPDSR committee to formulate responses because of the weaknesses in the data uploaded (*ibid.*). Another challenge is that while the national MPDSR committee receives a lot of technical and administrative support from donors and academic and professional institutions, there is less support provided to county, sub-county, facility and community MPDSR committees (26).

There are several MPDSR committees in the counties that are organised to correspond with the health system structure in the county. These are the county MPDSR committee, sub-county MPDSR committee, facility MPDSR committee and community MPDSR committee (69). A complete list of the members of the different committees and their terms of reference is included in the national MPDSR guidelines (69).

The county MPDSR committee comprises senior health professionals who handle the overall implementation of health (including MPDSR) activities (69). This includes a Community Strategy focal person responsible for providing leadership and facilitating community participation in all health activities. The county MPDSR committee are supposed to meet quarterly to review the MPDSR reports that have been uploaded from the different sub-counties. The county MPDSR committee also aggregates the findings from MPDSR reports and uses the information for budgetary allocation and advocacy (69).

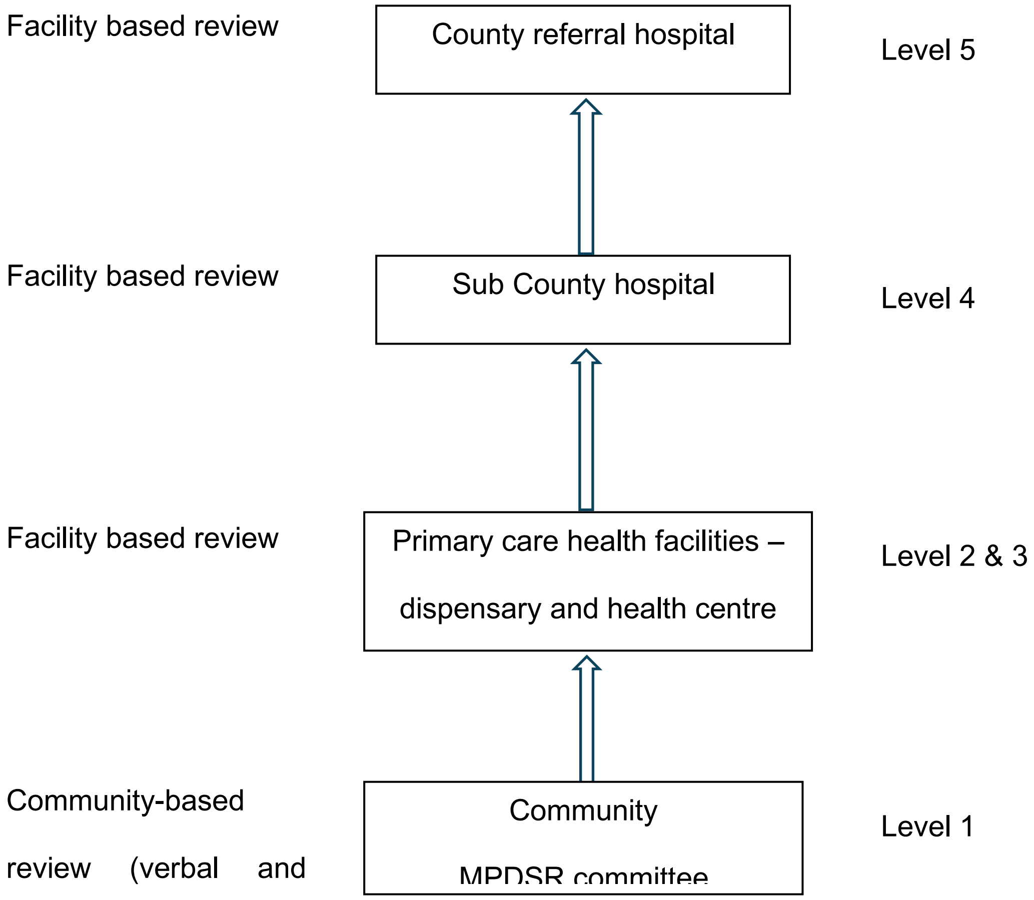
The sub-county MPDSR committee is supposed to meet monthly (69). The committee is responsible for collating all MPDSR reports from level 2 health facilities and the community MPDSR committees and uploading these reports on DHIS2 for the county MPDSR team to aggregate. The sub-county MPDSR committee is also responsible for implementing/supporting the implementation of recommendations made by the health facility committees (69).

The facility MPDSR committees conduct maternal and perinatal death reviews for deaths occurring in level 2 and 3 facilities (health centres and dispensaries). The facility committee is supposed to meet weekly to ensure that all maternal deaths and some perinatal deaths are reviewed as required by law (i.e. within seven days of a death) (69). The health workers at these facilities are also responsible for supporting community representatives such as community health volunteers (CHVs) to conduct community-based death reviews using verbal and/ or social autopsy (69,76). The referral hospitals also have a facility MPDSR committee that meets weekly and submits their reports to the county MPDSR committee.

Community MPDSR committees are chaired by chiefs/sub-chiefs responsible for registering births and deaths in the community (69). Other members of the community MPDSR committee include community volunteers such as CHVs, village elders, religious leaders, members of the county assembly (or their representative) and members of health facility committees (69). The community MPDSR committee collaborate with health workers to conduct community verbal autopsy and social autopsy sessions. In some counties (e.g. the ones included in this study), community representatives are also members of facility MPDSR committees (69,76).

Figure 2 shows a flow diagram of how the MPDSR process works in Kenya (69).

Figure 2: Structure of MPDSR committees in Kenya



2.0 Literature Review: Community Participation in MPDSR

Chapter outline

In this chapter, I have summarised some of the leading debates in the literature on community participation in health as a first step to identifying relevant concepts for understanding the literature on community participation in MPDSR. Later in the chapter, I use relevant concepts from community participation in health literature to critique the literature on community participation in MPDSR. I have identified some of the theoretical and methodological gaps in the literature that this thesis will address. I also present a conceptual framework that I have used to guide this study.

2.1 Aims of Community Participation in Health

Researchers, policy makers, health planners and practitioners promote community participation in health as a key strategy that could address poverty and reduce health inequalities (77–80). Notably, maternal and perinatal mortality is highest in the poorest countries globally (10,16,81) and among poorer segments of the population in high-income countries (65).

Community participation in health was first articulated at Alma Ata when primary health care (PHC) was introduced as a community health strategy (82). At Alma Ata, policy makers, health planners and practitioners expected that community participation would give community members the right to make decisions about their health (83). Policymakers and health planners also argued that community participation would widen the scope of health beyond biomedical descriptions of disease to addressing the social determinants of health (84).

Over time, several aims of community participation have emerged. Scholars see community participation in health as a process that can facilitate people-centred health services that are responsive to the needs of community members (78,83,85). Community participation has been shown to support the delivery of health programmes at the local level, such as supporting the implementation of primary health care (PHC) and increasing coverage of services such as immunisation and health promotion (84,86,87). Some studies and global policies have also suggested that community participation could ensure that health systems are accountable to community members (10,11,59,88–91).

The literature has shown that community participation can lead to social change and improvements in health outcomes; for instance, a randomised controlled trial (RCT) on participatory action learning cycles with women groups reported improved neonatal health outcomes (92). Other studies have demonstrated that community participation can (i) promote acceptability of health services (93), (ii) improve maternal and newborn health (MNH) survival (94), (iii) increase accountability for maternal health (95) and (iv) promote positive behaviour change among community members (92,96).

2.2 Defining community participation in health.

There is no consensus on how community participation in health is defined in the literature (97,98). Community participation has been described as complex, elusive and difficult to measure (77,85,99). Scholars use different phrases to describe community participation in the literature in seemingly interchangeable ways; for instance, community mobilisation (100), community participation (97), community engagement (101), community involvement (102), patient or public engagement (103,104) and health co-production (105). I have used community participation in this thesis but acknowledge that other literature has used different terms to describe approaches to involving community members in healthcare.

Several typologies exist for unpacking community participation in the literature e.g. (77,91,106,107). Some typologies describe community participation as a progressive continuum that denotes the extent to which community members are involved in the project, ranging from consultation on one end of the spectrum to shared decision-making and collaboration at the other end; for example, Arnstein's ladder of citizen participation (108) and the AI2 Participation spectrum (109). These typologies present varying degrees of community involvement and decision-making power in the participation process (109,110). Tritter *et al.* (110) argue that typologies such as Arnstein's ladder assume that as participants go up the ladder, they gain more decision-making power without a critical reflection on who participates, who benefits from this process and the decisions participants can make in light of the barriers they may face.

Morgan (111) has argued that the literature on community participation presents the participation process as either (i) utilitarian/instrumental or (ii) an empowerment approach. The two forms of participation are not mutually exclusive and can be at work within the same health programme or intervention (85,111,112). In the next section, I will summarise the arguments from the literature on these two approaches.

2.2.1 Instrumental approaches to understanding community participation.

Instrumental approaches have been described as participatory processes where community participation in the intervention is a means to achieving a particular goal, such as ensuring more efficiency in delivering health goods or services (e.g. immunisation campaigns) (83). Community members are expected to participate in health programmes or interventions, but they (community members) do not decide what the goals of the programme/intervention are or how to achieve them (83,100). Instrumental approaches have also been associated with meeting the bureaucratic requirements to involve the community in healthcare, e.g. government or donor policies that mandate community participation as a prerequisite for accessing donor funds (77,113,114).

From the 1980s, the World Bank began to promote and institutionalise community participation in its policy frameworks by linking participation to issues of social justice, social accountability and economic growth (115). Critiques argue that institutionalising participation can be a means through which programmes meet the strategic interests of funders or policymakers by associating participation with community development (79,111,115). Participation projects that are donor-driven can be affected by what Mosse refers to as '*Weberian routinisation'* (116 :32), resulting in participatory processes that are largely top-down because they are driven by policymakers and funders who may be primarily focused on ensuring that programmes are delivered efficiently and in line with donor mandates (86,111,115).

Instrumental approaches to participation exist on a continuum with more or less community involvement (111). With some forms of instrumental participation, community members can be passive recipients of health goods and services, e.g. monologic[4] health education sessions at community sites (79,91). In other instances, community members may be consulted during the needs assessment stage of an intervention to ensure that community members are involved, but community members have little or no say in how the intervention is designed or managed (111,117). In other cases, community members may be asked to contribute their time, labour or material resources but the community is not part of the decision-making process regarding deploying these resources (107,117). For instance, in many contexts, community health workers or volunteers (CHW/CHV) participate in health interventions as a means to improve coverage because it is cheaper than using health professionals for mobilisation activities, but CHWs are not always included in decision-making processes (40,86). Other forms of instrumental participation can involve appointing some community members to decision-making forums such as health committees (85,118).

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[4] Monologic health education refers to techniques of delivering health information where health professionals educate community members but do not provide community members with opportunities to share their knowledge or lived experiences e.g (120).

However, the appointment process can be tokenistic because the community members may have no influence on the decision-making process of those committees, or the committee members serve the interests of the elite in the community (114,119).

Scholars criticise programmes that use instrumental approaches for failing to acknowledge the role that socio-structural barriers such as gender, race, and economic status play in health inequalities (111,120). The underlying assumption that providing biomedical technologies, products, or information to community members would improve health outcomes has not held up because of the underlying socio-structural barriers (79,83). Nevertheless, some authors suggest that instrumental participation can still be helpful because, over time, community members could use their presence in participatory processes to negotiate for decision-making opportunities- turning '*presence into influence'* (121:163).

2.2.2 Empowerment approaches in community participation

Scholars have defined community empowerment as a social and political process involving community members' active participation as agents of change, e.g., to improve health outcomes (100,120). Wallerstein (122 :73) has defined community empowerment as "*a social action process by which individuals, communities and organisations gain mastery over their lives in the context of changing their social and political environment to improve equity and quality of life. It embraces political change and an understanding of […] relationships*." In other literature, empowerment has been described as a process through which communities gain control over their circumstances by increasing their opportunities to make decisions about their lives (86,111,120,123).

Empowerment approaches to participation have been conceptualised and implemented using community psychology approaches that borrow from Paulo Freire's work on conscientisation, i.e. "*the process of constructing critical awareness about oneself and the* *world”* (100: 264). Community awakening or conscientisation is a political process that can enable community members to become more self-reliant and confident to take actions that can transform their circumstances by, for example, addressing inequalities that contribute to poor health (120,124,125). Proponents of the empowerment approach to participation argue that conscientisation is not something that communities are given; instead, community members achieve it through social processes of dialogue, which empowers them to learn from the process (79,120,126). The process by which conscientisation leads to empowerment involves several stages that, over time, produce social change (79).

I will describe the conscientisation process and then use an example from the literature to show how empowerment has worked in practice. Campbell and Jovchelovitch. (79) posit that the participation process can create an arena for community members to collectively develop an awareness of the challenges they face and the resources they need to address them. The authors further argue that as part of the conscientisation process, community members think about who they are and what they want, which can empower them to challenge self-limiting beliefs about their social conditions, e.g. that individuals are to blame for poor health (79). As community members participate and engage in critical reflection, they can develop skills such as confidence to speak up and recognise the value of their existing knowledge (120,126). Community members can also use participatory processes to build relationships with other community members or external actors (such as health professionals or CSOs) and mobilise resources such as finances or access markets for their produce (100,120). Scholars argue that when community members feel that they have the resources and skills to act in one area of their lives, they gain confidence and can be empowered to act in other areas, such as addressing circumstances that contribute to social deprivation (120,127). Guareschi and Jovchelovitch (120) argue that community members can be empowered through participation, noting that over time, they can exercise their rights by expressing their views and defending their interests. I will now give an example of a case study of a youth empowerment programme as described by Wallerstein (122) to illustrate the points I make in this paragraph.

In the case study, the author describes an intervention in New Mexico among youth aged 12-21 years (122). The youth faced severe deprivation, with poor health statistics, high levels of drug use and high levels of school dropout rates. In the first two years of the programme intervention, the programme implementors focused on providing health education to the youth on the dangers of drunk driving and setting up youth centres. The author notes that the youth saw the programme *as "ambiguous and too abstrac*t" (122:75). A year and a half into programme implementation, a town hall meeting brought together youth to critically reflect on their social circumstances. The youth identified issues such as systemic racism, discrimination, lack of adult support and poor policy environment (e.g., youth expulsion from educational institutions and selling alcohol and tobacco to minors) that played in perpetuating the risks that the youth faced. Over time, the youth held several town hall meetings where dialogue and critical reflection continued, which built confidence among the youth to "*believe in themselves*" (pg. 76) and identify specific actions they could take to address the barriers they faced. The youth had a long list of actions they proposed and acted on. For example, they used the skills they gained in confidence and public speaking and their relationship with programme implementors to campaign for state health and education departments. The campaigns were aimed at changing laws on retailers selling tobacco products to minors and reviewing the education policy to deliver sex education to schools as a way of curbing teenage pregnancies *(ibid*).

This example describes the empowerment process and illustrates several stages of the conscientisation process of the marginalised youth. At the initial stages of the programme implementation, the youth did not see the links between the policy environment and the problems they faced, and the intervention seemed ambiguous to them. The youth held collective discussions during the town hall meetings and critically reflected on their problems.

As the youth participated in the town hall meetings, they developed the skills and confidence to identify their problems and unpack the factors that contributed to these problems. The youth also leveraged their relationships with programme implementors to challenge policy decision-makers.

While there is yet to be a clear consensus in the literature on how to define community participation or the rationales for community participation, there is consensus in the literature that understanding the role of power and knowledge is critical to understanding community participation in health. The literature has also demonstrated that the environments where participation happens can facilitate or limit the community participation process. I will summarise some debates on power, knowledge and enabling environments in community participation literature.

2.2.3 Power in participatory processes

Rowlands (123) argues that power is at the root of the participation process and that understanding how power is distributed in society is central to understanding the role of power in community participation. This means that by understanding how power works in society, i.e. who has power and who does not and how those with power use it, we can better understand how issues of power affect the participation process (123,128).

Campbell (100) explains that power in society can be understood using either a materialist lens influenced by Marx and Freire or a social constructionist lens influenced by Foucault. Following Freire on the materialist conception of power, Campbell notes that society is structured in ways that enable one group to dominate and exercise power over another and perpetuate inequality through structures such as race, gender, age or social class (100). The goal of participation should be to enlighten marginalised, powerless groups through conscientisation to address these structural barriers that affect their life circumstances and their interactions with the powerful (79,120,128,129).

Foucault has influenced an alternative conceptualisation of the role of power in society and sees power as socially constructed and fluid (100). With the social constructionist view of power, scholars argue that power is not held by one dominant group; instead, it is embodied in relationships and can be created and shared during everyday interactions (100,128). Community members can manipulate their social relationships to exercise quiet power in ways that benefit them without necessarily changing the social structures in which they live (107,116,130).

Feminist theorists of power such as Collins (131) argue that there is need to understand the complex and intersectional nature of power and how this perpetuates disadvantage during social interactions. Collins (ibid) reflects on issues of race and gender and notes that while power relations are often seen as one dimensional such as through a lens of race- where one race dominates others (such as white over black), a feminist analysis of power is more nuanced and reveals how gender and race intersect creating multiple arenas of disadvantage for both white and black women. For instance, a feminist analysis of power in the context of MPDSR participation could reveal the multiple ways that unmarried adolescents participating in MPDSR sessions can be affected by power relations as their experiences may be shaped by their age, their gender, social status as unmarried and pregnant and their relative economic disadvantage.

Kothari (2001) suggests that we can understand how power influences community participation by analysing social interactions during participation. The participation process brings together different actors, such as health professionals and community members. By observing how different participants interact, e.g., how they communicate with each other or whose views are prioritised and considered legitimate during the participation process, we can better understand the role of power in the participation process (103,104,128). The literature has described different forms of power in community participatory processes based on an analysis of how power affects social interactions during the participation process as follows: (i) power over, (ii) power from within, (iii) power to, and (iv) power with (123,126,128,132). I will describe each of these conceptualisations and give examples to explain.

First, power in community participation can be conceptualised as dominion over others- where one group of participants has power and uses their position to dominate other groups (100,129). Ansell (132) describes this form of power as *'power over'*- where one group is seen as powerful and exercises power over other powerless groups of people. Powerful groups can also exercise power over the marginalised by "*setting rules of the game*" that exclude marginalised groups from being part of the participation process (123:10). These forms of '*power over'* relationships can be characterised by silencing the voices of less dominant groups by for example controlling the invitation process to participatory spaces thus systematically excluding the marginalised from decision making (128,133,134). In other instances, community members may be invited to participate, but they have no control over how their inputs are used during the participation (134–136). The literature has shown that forms of '*power over'* during participatory processes can be seen in relationships such as between health workers and community members, as health workers' biomedical knowledge dominates over community members' experiential knowledge (120,137). Other examples of '*power over'* interactions during participation can include the power to determine acceptable norms during the participation process, such as excluding participants because they are too emotional (138,139) or setting norms on acceptable dress or talk during participatory meetings (103).

Power issues during community participation can also be understood as a transformational process where community members exercise "*power from within"* by critically reflecting on the social and political circumstances that contribute to inequality (123). Scholars argue that '*power from within'* is an internal transformational process, where community members undo negative social meanings and beliefs and are empowered with skills such as confidence, self-determination and self-awareness to address the inequalities they face[5] (123,126,132). When community members develop power from within (through critical reflection), they can define their needs and priorities and identify ways of addressing them rather than relying on external agents such as NGO workers or health professionals to propose solutions (123). The processes by which community members develop power within is a precursor for community members' engagement in collective or political action for social transformation (100,123).

Power is also conceptualised as a process that increases the capacity of marginalised groups in terms of skills or leadership development, which Ansel (2014: 24) has labelled as "*power t*o." Community empowerment can take the form of capacity building to equip community members with technical skills to address health problems (85). This form of empowerment involves the transfer of skills or knowledge from health workers to community members to address a specific issue and within a particular context, e.g., training women on hygienic practices for newborn care (78,83,85). Cornish (140) has argued that the empowerment process can increase community members' or other marginalised groups' power to act in one domain. However, the marginalised group can remain powerless in other domains. As such, she argues that when describing empowerment processes, programme leaders (or those describing the intervention) need to clarify the context in which community members are empowered and what they are empowered to do (*ibid*).

Marston *et al.* (78) also argue that empowerment approaches should not just focus on addressing community members' capacity gaps; rather, empowering participatory processes can also support health professionals and health systems by building their capacity to

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[5] This is part of critical reflection, as described by Freire.

participate. This form of empowerment includes participatory action and learning cycles with women groups to address maternal and child health issues (94). In these learning cycles, health workers and local facilitators were trained to engage with local women groups, thus building their capacity as the dominant group to enable them to work effectively with the women groups (94,141).

The final dimension of conceptualising power in participatory processes is "*power with*" (132: 24). Scholars who argue for this conceptualisation of power say that power issues are inherent in participatory processes and cannot be avoided; as such, an analysis of how marginalised (powerless) people work with the powerful in participatory processes is necessary (142). Community participation can also empower marginalised groups to create alliances or networks with external actors who may have access to more power or resources that they can leverage and use to address health challenges (104,119,128). Rowlands (123) describes a gender and development project that used a *'power with'* approach, using tools such as dialogue and awareness raising to address issues of inequality between men and women. The author maintains that the use of dialogue between men and women who participated in the programme empowered women to acquire new information and skills to identify and prioritise activities such as income-generating activities without jeopardising gender relations in the community (*ibid*). When power is conceptualised as collaborative rather than dominating (i.e., power over), the voices and lived experiences of the marginalised/powerless group are respected and understood and the powerful try to find common ground between their views and those of marginalised groups (126).

2.2.4 Knowledge production in community participation.

Kothari (2001) argues that participation is a mechanism through which community members can utilise and acquire knowledge. For instance, community members can use knowledge by sharing information with external agents, including health providers, who may consult them about their experiences or needs (79,116,143). Studies have shown that community members have knowledge based on their lived experiences that can make a valid contribution to the outcomes of participatory processes (135,136,144). There is also an increasing emphasis on the value of lived experience knowledge of patients, service users, and communities; for instance, in the context of MPDSR, health professionals acknowledge that understanding the experiences of the pregnant woman or her newborn before an adverse event is helpful because it can be used to understand why the death happened (14).

The literature has shown that there are different forms of knowledge during participatory processes. There is technical knowledge or expertise based on academic training; this form of knowledge is characterised by certification, professional norms and standards, e.g. clinical training that different health professionals hold (117,136). Experiential knowledge is based on people's lived experiences (whether lay people or professionals), e.g., how people cope with health challenges or the experiences of health professionals as they deliver services (120,137). Renedo *et al.* (137) argue that knowledge is hybrid and relational, noting that health professionals' knowledge combines their lived experiences and clinical or technical training. The literature on community participation in health has recommended that an analysis of participatory processes should focus on how different forms of knowledge are perceived and used for decision-making during the participation process (105,120). In the following few paragraphs, I will summarise the debates on how different forms of knowledge influence the participation process.

The process of producing knowledge during participation is contested, as different knowledges compete for legitimacy (120,136,137). The dominance of biomedical approaches for addressing health inequalities has created a dichotomy between health experts and lay people (111,117). Biomedical knowledge is seen as scientific, evidence-based and objective, while experiential knowledge is seen as individual, irrational and not scientific (136,137,145). Biomedical knowledge is also considered valid and valuable, e.g., it can be used for decision-making (145). Health professionals often label community knowledge as local, indigenous, and experiential, perceiving the knowledge as lacking rigour or certification (83,103,106,120,136). Health professionals can perceive community knowledge as lacking value and less useful for decision-making because it is seen as unrepresentative or subjective (79,120,146,147).

Jovchelovitch (148) disputes the idea that any form of knowledge is detached and pure (i.e., unadulterated by the social world and human experiences), noting that knowledge is influenced by the personal, interpersonal, and socio-cultural context in which it is produced. She further argues that defining who holds rational knowledge is a political act, and those with power to control the participation processes can determine if one form of knowledge is considered superior to another form of knowledge (148,149). For example, where health workers position community members as less capable of producing knowledge during participation, knowledge production can be top-down, where the powerful use participatory processes to educate the community (120).

There are differences in how knowledge production during participation is described in the literature depending on whether the participatory approach is instrumental or an empowerment approach (120,150). Instrumental approaches focus on knowledge transfer, where practitioners or external agents use participatory spaces to educate community members based on assumptions that the external agents are more knowledgeable (111). Proponents of empowerment approaches argue that participation can create spaces for different forms of knowledge (i.e. that of community members and practitioners) to dialogue and for the mutual benefit of community members and practitioners (79,120). In practice, dialogue and mutuality between different forms of knowledge are rare, and often, one form of knowledge tends to dominate participatory processes (150).

Some authors have acknowledged that some forms of technical knowledge transfer are necessary during the participation process to empower community members to acquire new skills, e.g., educating community members on pregnancy danger signs (120,142). Guareshi and Jovchelovitch (120) also argue that providing technical knowledge during participatory processes is not enough to generate transformative social change (i.e. address structural barriers that contribute to health inequalities) because knowledge transfer does not create opportunities for the marginalised group to critically reflect on their circumstances and challenge the existing forms of knowledge. When the participation process creates opportunities for dialogue, different actors in the participation process can be legitimate partners who can contribute to knowledge production in more transformative ways (79,120,135). Participatory processes that provide opportunities for dialogue can mean that participants can bring different forms of knowledge to participatory spaces, which could produce new forms of knowledge or correct misconceptions in existing local knowledge (119,120,137).

Several studies have suggested that understanding how emotions influence the process of producing knowledge during participation is necessary (138,139,151). However, there is no consensus in the literature on whether expressing emotions among community members in participatory processes hinders or fosters knowledge production. Some studies have shown that health professionals prefer that patients share knowledge with health professionals using disembodied frames that are devoid of emotion so that the knowledge is perceived as less subjective (137,146). In other instances, emotional displays during participation are perceived to be beneficial, e.g. a study on patient involvement in the UK demonstrated that participatory spaces where displays of emotion were encouraged enabled the participants to bond better, promoting cooperation among participants (139). Other literature has shown that participatory spaces that encourage emotional displays still need to be balanced so that the participation process does not exclude those who prefer a more emotionally measured approach (138).

2.2.5 Creating enabling environments for community participation in health.

The literature on community participation in health has also shown that socio-structural barriers (i.e. norms, practices or policies that systematically marginalise some community groups based on social characteristics such as age, income, or gender) can limit community members agency to act during participatory processes (85,111,119,140,152). Structural barriers can affect community members' agency to act because the community may lack the material resources; for example, a lack of finances to pay for healthcare may limit community members' capacity for improving their health-seeking behaviour (79,85,111,119,152). The community may also face symbolic barriers, e.g., the marginalisation of women because of patriarchal rules, which can also affect their ability to act during participatory processes, e.g. women are not allowed to speak, or they have no control over decisions that affect their health such as the use of contraception (95,119).

Campbell and Cornish (119) argue that for participatory processes to be transformative (i.e. support community members in addressing the challenges that contribute to health inequalities), there is a need to create an enabling environment. Enabling environments are participatory spaces where community members are supported to voice their demands to decision-makers, and decision-makers are supported to respond to the demands of community members (119). Other literature has referred to this process of building voice and supporting duty bearers to respond to community demands as social accountability (153,154). I use the concept of social accountability rather than transformative communication but acknowledge that the two concepts refer to giving voice to community members and enabling duty bearers to respond to voice.

The underlying assumption is that social accountability could mediate power relationships between unequal partners, such as health providers and community members, to ensure transparency in service delivery (121,153,155). Social accountability has two domains: (i) giving or building community voice to demand change or accountability, and (ii) strengthening the capacity of duty-bearers or decision-makers to respond to the demands of community members (153,155,156). I will summarise the debates on the two domains and give examples.

Building voice

Building community voice involves a sequence of activities comprising critical reflection, capacity building, and building relationships (157). Building voice begins with critical reflection that enables community members to recognise their challenges, e.g., high maternal mortality rates (95,119). As community members interact during participatory processes, they can leverage their relationships with external actors such as health professionals or NGO workers for capacity building, e.g., training on the danger signs of pregnancy and the importance of giving birth in a health facility (95,119). Capacity building also involves giving community members information about their rights and entitlements relating to maternal and newborn health (e.g., good quality care with standards of quality explained to the community). Next, with the support of other actors, community members can identify issues they want to change and develop strategies to voice their demands, e.g., demand for respectful maternity care (95). Most of the projects that are geared towards building community voice are initiated with the support of external actors, such as NGOs, who invite community members to participatory spaces where they can exercise voice (115,158). Nevertheless, in some contexts, community members can mobilise themselves and demand change without the involvement of external actors, e.g. (159).

Programmes can use different strategies to build community voice or create opportunities for communities to voice their demands. Some strategies aim to build community members' capacity to monitor or evaluate how services are provided or whether duty bearers meet agreed targets (160). Examples of this form of accountability are using scorecards and citizen report cards to monitor health system performance. Other forms of community monitoring are feedback meetings where community members provide feedback to duty bearers on services provided (e.g. 90,95,161). Another strategy through which community members voice their demands is by appointing or selecting community representatives to decision-making bodies, e.g., health facility management committees (162,163). It is often assumed that the community representatives who participate on behalf of their communities bring community voices into decision-making spaces (162). Another strategy is working through civil society organisations (CSOs) so that the CSOs can represent community members in decision-making arenas (164,165). CSO members are not selected or appointed by the community but are an external resource they can leverage to support their efforts in voicing their demands.

There is evidence that some of the strategies above can support community members by building voice, e.g. (89,90). However, some scholars have argued that some strategies and tools for giving voice have depoliticised social accountability, robbing it of its transformation potential (166). Other scholars disagree that community representatives can bring community voices to decision-making spaces, noting that community representatives can be at risk for elite capture rather than represent the interests of the poor (154,167).

Strengthening the capacity of duty bearers to respond to community demands.

Establishing accountability mechanisms at the community level without supporting duty bearers to respond to the issues raised by the community members has shown no difference in health outcomes (32,115,153). Londenstein *et al.* (168) argue that health professionals’ receptivity to community voice is shaped by (i) the extent to which interventions or health systems provide health professionals with support and (ii) the perceived legitimacy of the community voices by duty bearers. I will discuss the two issues in turn.

As community members exercise voice to duty bearers, some of their demands have material dimensions, i.e. duty bearers would need to respond by meeting the material needs expressed by community members (119,153). Material demands can include deploying more health workers or improving drug supplies. Enabling environments for participation should support duty bearers with the material capabilities to address the supply side of community demands (119,153). In many contexts, material support to duty bearers is the responsibility of governments and may be supported by donors, financial institutions or NGOs (115,169). Projects that support community voice and provide support to duty bearers to respond to material demands have reported positive outcomes for health, e.g. (89). For example, CARE-an international NGO, conducted a cluster randomised evaluation on a social accountability project in Malawi (89). The project created participatory spaces for dialogue between community members and health professionals to discuss reproductive health services (*ibid*). Community members were trained in advocacy using a scorecard where they allocated points to health facilities based on their experiences of care. As part of project implementation, the health system capacity was strengthened by training health professionals and material support to pay for family planning commodities. The evaluation results showed that uptake of reproductive health services improved (89).

Duty bearers may also have relational or symbolic needs that can influence how they respond to community demands (119,168). For instance, Lodenstiein *et al.*'s realist review (168) has shown that health professionals can associate community voice and advocacy with personal attacks, which limits their willingness to participate in participatory processes where community members exercise voice. In some instances, health professionals may want to respond to community demands but are limited by health system hierarchies because health professionals who attend participatory processes tend to be more junior and lack the power to make decisions on behalf of the health system (168,170). Cleary *et al.* (171) argue that health systems seeking to increase responsiveness to community voice should strengthen interpersonal relationships among health professionals and improve the health system's organisational culture. This can provide health professionals with the symbolic resources they need to support community participation processes.

Duty bearers may hold limiting beliefs about the status of the community groups (e.g., perceiving them as undeserving of being heard), which can minimise their responsiveness to community demands (156). For instance, duty bearers can be unwilling to accept community members' analysis of the problems in the health system or victimise community members who speak up (95). Participatory processes are laden with contentions about whose power and knowledge are considered legitimate (120,169). Enabling environments can be created if duty bearers such as health professionals acknowledge the legitimacy of the community members exercising voice during participatory processes (119,168). Marginalised groups can use participatory processes to build relationships with powerful external actors such as NGOs or the media and leverage the power of the external actors to gain legitimacy with duty bearers (95).

Thus far, I have summarised some of the arguments in community participation in health literature, showing that community participation is a complex process that could help address health issues. In the next section, I will focus on the literature on community participation in MPDSR. I intend to use the arguments I have presented here (on community participation in health) to summarise and critique the literature on community participation in MPDSR.

2.3 Approach to Literature Review

I used a systematic approach to search and review the community participation literature in MPDSR. The literature search included published and grey articles focusing on community participation in MPDSR in all countries globally. I searched six databases (Medline, Embase, Scopus, Global Health, CINAHL Plus and Web of Science) for papers published between 2004, when WHO launched ‘Beyond the Numbers’ (1), and August 2022. I also contacted members of the WHO MPDSR technical working group[6] to help identify additional published and grey literature on community participation in MPDSR. I contacted non-governmental organisations (NGOs) implementing MPDSR projects at the community level to source for other grey literature (with the support of the WHO technical working group). In addition, I hand-searched reference lists to identify additional literature that could be relevant to the topic.

I used three broad terms and their variations for the search- ‘community participation’, ‘maternal and perinatal death’, and ‘surveillance and response.’ I used search terms that have been used in a previous systematic review on community participation (97) and (ii) a scoping review on MPDSR implementation (172). See appendices for my search terms and inclusion/exclusion criteria.

I had the support of an MSc student to screen the articles on title and abstract. One of my supervisors (LPK) and a community engagement expert from WHO double-screened 20% of the titles and abstracts for additional rigour. The protocol for the literature review is registered on Prospero (Reg. num: CRD42022345216). A detailed protocol of the methodology for the literature review has been published separately (173).

A scoping review of factors that affect MPDSR implementation reported that only 27% of the included studies closed the MPDSR loop from surveillance to response (24). The scoping review found no differences in implementation factors, whether articles were reported on MDSR, perinatal death reviews/audits, maternal death reviews, or MPDSR *(ibid.)*. As such, I included any papers that said any of the components of MPDSR, i.e., death surveillance, verbal autopsy, social autopsy, or death review meetings for either maternal deaths and/or

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[6] The WHO technical working group is a global team made up of academics, health professionals, NGO representatives, policy makers and WHO staff working in MPDSR globally. I am a member of this working group.

perinatal deaths (stillbirths, neonatal deaths). I also included papers that reported community participation in any part of the MPDSR cycle, even if the surveillance and response loop was not closed.

2.4 Findings from the literature search

I identified 7,896 articles from different databases, Google Scholar and reports from non-state actors such as NGOs. 2,919 of these were duplicates. After screening for relevant inclusion criteria, 45 papers (both published and grey literature) were included for data extraction. Most (88%) articles reporting any form of community participation were from low- and middle-income countries (LMIC). 33 articles reported community members' involvement in the identification and notification of maternal and perinatal deaths in the community. 19 articles reported some form of community participation in the review and response steps of the MPDSR cycle, e.g., death reviews through social autopsy and community members participating in the process of implementing solutions to prevent deaths. 9 articles reported community participation in monitoring the implementation of actions to prevent maternal and/or perinatal deaths.

2.5 Who is the community in the MPDSR context?

The concept of community is not always well defined, and there are inconsistencies in how the different literature on community participation in health describes community members (85,91). In the context of MPDSR, community members are defined as follows:

People with shared geography and social systems

WHO guidelines and studies focusing on community participation in social or verbal autopsy have defined community members based on shared geography (7,33,46). The term community participation in the broader community participation in health literature tends to focus on people living in the same geographical area (77). It is often expected that people with shared geography share some social systems such as language, values and practices, though this is not always the case (83).

Bereaved family members or relatives:

Studies on patient involvement in healthcare have defined community members based on shared experiences from a health condition or experience using services (Martin, 2008a). In the context of MPDSR, parents and other family members participate in maternal or perinatal death reviews in health facilities (46,174). Other studies have included relatives of deceased persons as critical informants for verbal and social autopsy because of their shared experiences with deceased mothers or newborns before an adverse outcome (5,28,175).

Community health workers/community health volunteers (CHWs/CHVs):

Community health workers are community members trained to carry out some health-related activities (not necessarily MPDSR) but do not have tertiary qualifications in healthcare (176). Community health workers/volunteers (CHWs/CHVs) are typically selected by other members of their communities in collaboration with health professionals to support the implementation of community-level health activities (176,177). CHWs/CHVs are expected to bridge communication between the health system and community members (177). In some contexts, CHWs/CHVs are paid and are considered part of the health workforce, while in others, CHWs/CHVs are expected to work in a voluntary capacity (40,178). In the context of MPDSR, studies have shown that CHWs/CHVs are involved in the identification and notification of deaths e.g.(28,53) and facilitating community death review sessions (33).

Community representatives:

Community representatives are appointed or selected to participate on behalf of other community members in community-level health activities (not just for MPDSR) (167). The selection or appointment process is often based on some established criteria, such as the roles that the individuals play in the community or perceived level of community influence or social networks in the community (76,179,180) In the context of MPDSR, community representatives can include village elders, local authorities, members of health facility committees or other community groups, parent advocates, traditional birth attendants and healers (28,33,46,53,60,181).

Civil society groups (CSO)/grassroots organisations

These are non-state and not-for-profit actors who are formally organised to represent or advocate on behalf of community members on social development issues (115). The literature on community participation in MPDSR has shown that CSOs and other non-state actors can participate in MPDSR processes, primarily to support community advocacy with decision-makers and health workers to implement MPDSR recommendations (14,45,47,182).

2.6 Summary of the Literature

In this section, I summarise and critique the literature on community participation in MPDSR. I have drawn on the wider community participation in health literature described in the previous section to critique how community participation in MPDSR has been conceptualised in the literature. My main arguments in critiquing the literature on community participation in MPDSR are centred on differentiating between instrumental and empowerment approaches and understanding the role that power, knowledge, social interactions and enabling social environments play in the participation process.

As presented in the background chapter, community participation in MPDSR is expected to contribute to the aims of the MPDSR process of preventing maternal and perinatal deaths (3,14). The aims are: (i) using active surveillance for notification and reporting of deaths to generate data on where, when and why deaths happen, (ii) using surveillance data to improve quality of care by reviewing deaths and making recommendations, and (iii) using information from surveillance and death reviews to advocate for resources for supporting implementation of recommendations (3,13,14,22,32). I have organised the review of the literature on community participation in MPDSR based on the three aims of MPDSR as described by WHO and some scholars.

2.6.1 Surveillance for identification, notification, and reporting of deaths.

Most of the literature on community participation in MPDSR shows that the participation process is largely instrumental (111). Researchers and programme implementors see participation as a means of improving coverage of death surveillance or improving the efficiency of the tools used for death notification. Most of the literature on community participation in MPDSR has focused on community members' roles in counting the dead through identification, notification, and reporting. In contexts such as LMICs where childbirth still happens outside the health system, health workers rely on community volunteers or representatives to inform them on where and when births and deaths have occurred e.g. (25, 39–41,181,183,184). In addition, most studies have focused on describing or improving the tools used for notification and reporting e.g. (28,39,185,186). Some studies have explained that community members are selected as informants because of their social networks and knowledge of their communities e.g. (33,53). However, these studies have not analysed how the interactions between community representatives and bereaved families influence the notification and reporting of deaths. For instance, we do not know the experiences of community representatives and bereaved relatives during death notification and how they make sense of their involvement in death notification and reporting process.

The literature has focused on how community members support the health system to identify and report deaths to understand mortality trends and improve estimates of mortality, e.g. (5,41,44,181). Studies have shown that community members can participate in the implementation of community-based health information systems (CBHIS) to improve surveillance of maternal and perinatal deaths in the community (39,40,53). For instance, a study from Malawi showed that engaging community members in notification and reporting deaths improved data on maternal deaths because the community volunteers identified deaths that the health system would have otherwise missed (33). In India, community health workers reported 62% of the expected maternal deaths in health facilities and in the community; most of these deaths had occurred in health facilities but had still been missed by the health system (187).

Some studies on community participation in MPDSR have focused on testing the efficacy and validity of different verbal autopsy tools to determine how well the tools work in assigning the cause of death e.g. (188,189). Health workers use verbal autopsy to interview community members or family members of a deceased woman or newborn to establish the symptoms the deceased had before an adverse outcome (190,191). Verbal autopsy data is used to assign the cause of death as well as explore non-medical circumstances surrounding a death (3,5,43). Even though the literature has described verbal autopsy as a form of community participation, e.g., (14,43), the literature has not shown how community members participate during verbal autopsies or explored their perspectives and experiences in knowledge production during verbal autopsy.

Some scholars have conducted cost-effectiveness studies to compare different approaches of working with community volunteers for purposes of notification and reporting of deaths with other approaches such as household surveys (39,44,185,192,193). For instance, an RCT in India demonstrated that community members can support death notification and reporting, leading to a better understanding of mortality estimates (44). The authors also noted that working with community members for notification and reporting is cheaper than using household surveys and other approaches that are used to generate mortality estimates (*ibid*.).

Other studies have compared the use of different technologies, such as mobile phones, tablets and GIS mapping, to support the notification and reporting of deaths (5,64,186). Mobile phones and tablets have been shown to improve timely reporting of deaths in contexts where the terrain is rugged and travel complicated for community informants (40,53,186,194). GIS mapping was shown to raise the visibility of maternal and neonatal deaths at community sites, triggering community involvement in the review process by providing information on the circumstances surrounding the death and making recommendations to prevent future mortality (64).

2.6.2 Community participation in death reviews and quality of care improvement

WHO has reiterated that community participation in MPDSR during the review process could improve the quality of maternal and newborn health care and ensure that services are centred on the needs of community members (10,11,58). The literature on community participation in MPDSR has shown that community members participate in the review[7] process in health facilities and communities using verbal and social autopsy (33,46,52,96,182). Willcox *et al.* (195) have argued that while verbal autopsy tools can help health professionals establish the cause of death, the verbal autopsy questionnaire on its own is not sufficient to identify modifiable factors during the review. The authors further argue that community participation in the review process could allow health professionals to get information from community members that the verbal autopsy tool[8] does not cover (195). Yet, few studies show how this works in practice.

Sri (196) notes that the rationale for engaging community members in MPDSR is to provide opportunities for health professionals to understand the social circumstances that could have contributed to a maternal or perinatal death. Social autopsy sessions are public forums intended for health professionals and the community to discuss the problems that contribute to deaths and propose solutions to address them (6,64). Yet many of the studies on community participation in MPDSR describe the participation process as an instrumental

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[7] The review process involves using data collected in the surveillance phase to make recommendations that if implemented would prevent future mortality.

[8] Verbal autopsy tools are designed at global level by WHO and then countries adopt them to fit their context.

process geared towards the transfer of information, such as health education from health workers to passive community members (25,30,45). Campbell *et al.* (157) argue that participation forums geared towards change should facilitate an exchange of ideas among participants through dialogue. However, many of the studies that describe community participation in the review process (either in the community or within health facilities) have not analysed how dialogue happens as different forms of knowledge (i.e., experiential knowledge and clinical/biomedical knowledge) interact during MPDSR sessions.

Some studies have suggested that power hierarchies between health workers and community members could affect their interactions during reviews e.g. (33,46). However, these studies do not describe how this might influence participation in the review process. Most of the other studies on community participation in MPDSR do not acknowledge the role of power relations in participatory processes. In addition, none of the studies on community participation in MPDSR have analysed how power issues among those participating in the review can affect the types of knowledge (in the form of recommendations) produced during the review sessions. For instance, Willcox *et al.* (46) note that community members did not speak during the confidential enquiries held at health facilities and attribute this to a lack of knowledge among community members. Later in the paper, the authors note that community members gave suggestions during community meetings on how deaths could be prevented (ibid). The authors do not analyse how power differences between community members and health professionals during confidential enquiries may have constrained community voice, rather than the assumption that community members lack the knowledge to contribute to the sessions.

Studies have demonstrated that health workers can feel blamed by other health workers and community members for deaths which limits opportunities for using MPDSR sessions for quality improvement (54,66,197,198). A study exploring the possibilities of including parents in perinatal death reviews reported that health professionals were unwilling to allow parents to participate in the reviews due to the potential risk of litigation (199). Sri *et al.* (63) suggest that blame culture in the review process results from power hierarchies entrenched within the wider health system, noting that senior health professionals avoid taking responsibility for maternal deaths by blaming junior health professionals and community members. Some studies have proposed strategies that can support health workers in overcoming blame culture, such as establishing legal frameworks to protect health workers (25) and strengthening the leadership of MPDSR committees to facilitate review sessions effectively (56).

There is evidence that health workers use MPDSR sessions to blame community members for deaths by attributing deaths to the actions of community members, e.g. delays in seeking care (96,197,198). For instance, a paper from Bangladesh reports that social autopsy sessions provide opportunities for health workers to tell the community "*the mistakes they [community members] make that lead to deaths*" (184:3). Other studies have reported that community members can be unwilling to participate in reviews if the death is associated with a socially stigmatising event (e.g. mothers with HIV) (33,46). Willcox *et al.* (46) demonstrate that family members can be unwilling to participate in social autopsy sessions after perinatal deaths because the mothers felt blamed by other community members. There are limited studies that have looked at how blame culture affects community members or how community members can manage blame culture.

Some researchers have argued that in contexts where community members participate in the notification and reporting of deaths to health workers, community members are also motivated to participate in the review process (33,53,64,182). For instance, an RCT on participatory community-based health information systems showed that when community members collected data on the deaths, they were more willing to participate in discussions on how deaths could be prevented (53). Other studies have suggested that making surveillance data visible to community members using tools such as GIS maps or community noticeboards encouraged community members to attend social autopsy sessions (53,64). Some studies have shown that community members would like health professionals to make data on deaths that happen in health facilities more visible, e.g. by presenting data to community members and explaining why the deaths occurred (60,200). However, only a few studies report on health workers giving feedback to community members on the details relating to adverse outcomes in health facilities e.g. (33,46). Only one study from my literature search has shown that community members can participate with health professionals jointly in a facility-based confidential enquiry (46). In this study, the authors conclude that community members lacked knowledge because they (community members) did not contribute during discussions (46).

There have been recommendations that involving community members in the review process could improve the quality of care within health facilities (15,58). Some authors have suggested that community members could provide additional information on their experience of care before an adverse outcome to facility review teams, but there is limited evidence on how this would work (60,201). Willcox *et al.* (46) have argued that involving community members in reviews contributed to a better understanding of the issues that contributed to the deaths, which enabled the review team to make better recommendations. Other studies have suggested that involving parents in death reviews could help assure them that health systems are accountable for dealing with negligent health workers e.g. (60). Still, there are no studies in LMICs that describe how this would work in practice.

Scholars acknowledge that policymakers and health professionals face tensions between allowing community members into facility-based reviews and managing the risk of litigation for health providers (174,201). Some studies have piloted different approaches that could allow feedback from health workers about deaths within health facilities without community members participating in facility-based reviews (33,174,175,202). The different pilot studies describe participatory review meetings that use a sequential approach that involves an average of 3 meetings[9] to discuss one death (33,175,199). Two studies (33,175) reported that community members could participate in reviews and recommend community-level actions (e.g. addressing harmful traditional norms or improving community transport). Bayley *et al.* (33) also report that health workers provided feedback to the community on the recommendations they (health professionals) made at death review meetings in the health facility. However, none of the studies demonstrated how community members can share their experiences of care before an adverse outcome as part of the review process or provide a critical review of how issues of knowledge and power influence the process of generating MPDSR recommendations collaboratively.

Some of the literature on verbal and social autopsy acknowledges that family members' grief can affect the MPDSR process and the quality of data collected through verbal and social autopsy (53,175). The WHO guidelines and some studies have recommended that community members are allowed time to observe burial rites and grieve before conducting verbal or social autopsy (14,203). Some studies on perinatal death reviews from high-income settings have suggested that involving parents and parent advocates in the review process could be part of bereavement care for families (60,201). The authors suggest that involving parents could help them manage self-blame and cope better with future pregnancies (60). To the best of my knowledge, none of the literature in LMICs has focused on bereavement care as part of the MPDSR process.

2.6.3 Advocacy for mobilising resources to support the implementation of recommendations.

Several studies have demonstrated that community members can participate in implementing low-cost community-level recommendations to address the modifiable factors

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[9] The pilots propose an approach where community members meet on their own, and health workers meet separately on their own and then third meeting where community representatives' feedback to health workers what they discussed at the meeting with community members. Health workers can also give feedback on what they discussed at their meeting.

identified through the review process (182). For instance, some studies have shown that community members can respond to the findings of review sessions by improving health-seeking behaviour, such as attending antenatal care or giving birth in health facilities (182) Other studies have reported that community members committed themselves to addressing harmful traditional practices that contribute to maternal and perinatal death, e.g. traditional practices of umbilical cord care could contribute to neonatal deaths (33,46,175).

Other studies have reported that community members do not necessarily participate in review processes where MPDSR recommendations are made (31,200). However, there is often an expectation that community members should support the proposed recommendations even if they were not involved in making the recommendations (31). A study from Senegal reported that the maternal death review (MDR) committee made a recommendation to upgrade and expand emergency obstetric care (EOC) services as a way of preventing future deaths (31). Community members had not participated in the review process, but community representatives agreed to the proposal that community members should meet 80% of the financial cost to upgrade the EOC services (31). Dumont et al (31) do not provide any details on how community input was sought in deciding that community members would bear the financial burden and how power issues may have constrained community voice (204). More research on the interactions of community representatives and health professionals when making recommendations on behalf of community members could be useful.

Some studies have shown that CSOs can participate in MPDSR as community representatives (47,52). Most studies that report on CSO participation in MPDSR have shown how CSOs engage in advocacy with decision-makers on behalf of the community (47,52). However, we do not know how social and power hierarchies between community members, CSO representatives and decision-makers shape advocacy efforts in MPDSR.

A key component of advocacy in MPDSR is monitoring to see if the recommendations generate the expected changes (22). The MPDSR guidelines recommend that community members and other stakeholders participate in monitoring to establish accountability for preventing deaths (3). Some authors have suggested that community participation in monitoring could strengthen the response aspects of MPDSR (13,59). From my literature search, only one study showed how community members and health workers were involved in jointly monitoring MDR recommendations (33). More research is needed to understand how this works in practice.

Some of the literature has shown that while community members can propose solutions in response to review findings, they can be constrained in implementing the recommendations due to a lack of financial resources (182). For instance, a study in Bangladesh reported that transport difficulties contributed to maternal deaths as women delayed getting to health facilities, but no support was provided to community members to address these barriers (96). Only one study was identified from the literature search where community members received financial support to implement their proposed recommendations (64). Most of the other studies expected that community members would contribute the required resources to implement their recommendations (33,182,205).

In most studies, community members' recommendations tend to focus on what individuals can do and not the broader social structural issues that can contribute to deaths. (46,53,175). For example, a common recommendation during MPDSR sessions to address the first and second delay is advising pregnant women to have birth preparedness plans where they put aside money that they will use to access services at the time of delivery (35,96). However, in many contexts, women have limited control over household financial decisions or other decisions related to health-seeking behaviour (83). This would make it difficult for women to actualise their birth preparedness plans because they do not have control over how resources in the household are used. Campbell *et al.* (127) argue that programmes that target changes in individual behaviour without analysing how the wider social context (e.g. gender norms) affects individual agency to act can be ineffective in facilitating transformative change. The authors further argue that focusing on an individual's actions rather than the wider context fails to recognise how structural issues can obstruct behaviour change interventions *(ibid)*.

2.7 Study Rationale

In this thesis, I have used the community participation literature to critique the current literature on community participation in MPDSR. I focus on the critical concepts of power, knowledge and enabling social environments to understand how community participation in MPDSR works in practice. I hope to provide new theoretical insights and suggest approaches that MPDSR interventions can adopt when engaging community members in MPDSR and other quality improvement initiatives that, of necessity, require collaboration between community members and health workers.

The existing literature on community participation in MPDSR has not critically examined how issues of power, knowledge, and the wider context shape the participation process, e.g., how health professionals perceive the contributions from community members during MPDSR sessions and the role the wider context plays in knowledge production. The existing literature has not explored the experiences and perspectives of community members as participants in the MPDSR process. In this section, I present my arguments on the gaps in the literature as follows:

(i) Existing literature on community participation in MPDSR does not adequately theorise the participation process and we do not know how community participation in MPDSR works in practice.
(ii) The experiences and perspectives of community members as MPDSR participants have not been adequately explored in the literature. We do not know how the wider

context in which MPDSR is implemented shapes the participation experiences and perspectives of MPDSR participants.

2.7.1 How does community participation in MPDSR work in practice?

While some of the literature has suggested that there is a strong rationale for community participation in MPDSR (14,15), most studies have not analysed how the participation process works in practice.

Most studies that describe community participation in surveillance describe the roles that community members play in counting the dead using positivist framings that suggest that the data is neutral and generated through a seemingly objective process (5,22,40,43,181). The literature has described the MPDSR process as '*opening up the black box'* (37:1). The idea of opening the black box on maternal/perinatal mortality uses a metaphor from the aviation industry as an objective way of unpacking the issues that contributed to a plane crash; in the case of MPDSR, it relates to uncovering the contributory factors that led to maternal and/or perinatal deaths (37,72). In the aviation industry, opening the black box is a mechanical and possibly objective process, which may not necessarily be the case with a health system process such as MPDSR. Gilson (206) has argued that the health system is a social system that is characterised by interpersonal relationships (e.g. among community members or health professionals) and institutional relationships (e.g. between health professionals and community members). These interpersonal and institutional relationships can be characterised by power hierarchies and mistrust influencing how health professionals and community members interact (206). Earlier in this chapter, I showed that an analysis of how issues of power and knowledge affect interactions during community participation is critical to understanding the participation process. Yet, most of the existing literature has not focused on understanding how the social aspects of the MPDSR process, such as power dynamics, relationships among participants, and knowledge, influence the participation process and the data that is generated during MPDSR sessions.

Some literature has suggested that engaging community members in social and verbal autopsy are forms of community empowerment (45, 49,50), but research has not explored these claims. Several WHO guidelines suggest that community participation in MPDSR can empower community members to co-produce healthcare while ensuring that health systems provide people-centred care (3,35). However, the global guidelines have not shown how this works in practice. Earlier in the chapter, I described the empowerment approach as presented in the literature, indicating that it involves critical reflection, dialogue, and action among community members with/without the support of external agents (119,120). But despite claims in some of the literature that verbal and social autopsy are forms of empowerment, authors do not describe how critical reflection and dialogue happen during verbal and social autopsy. Studies have also not shown how the MPDSR process facilitates or inhibits critical reflection among participants (health professionals and community members).

Most of the studies on community participation in MPDSR do not acknowledge the political nature of the participation process. Literature on community empowerment has shown that empowerment is a political process and the importance of analysing how power relations affect interactions during the participation process (120,128,155,157,204). Studies have shown that understanding power hierarchies during participation is critical to empowerment because power influences how knowledge is produced and interpreted (103,114). Most of the studies on community participation in the review process have not addressed the role that power plays in influencing community participation, e.g., how community members share their experiences and perspectives during death reviews with health professionals who have more power in the participation process.

Community participation for deaths that happen within health facilities has not been well understood in the literature. Some literature on community participation in MPDSR suggests that community participation is only appropriate in contexts where most deaths are in the community, not health facilities (51,200). In these studies, community participation in MPDSR is seen as a strategy to educate the community by promoting childbirth in health facilities to prevent future deaths (7). Yet, there is an increase in the number of women giving birth at health facilities in LMICs, and increasingly more deaths occur in health facilities and not in the community (19,47,62,207). With this shift (i.e., more deaths occurring within health facilities), community participation in reviewing facility-based deaths could contribute to improvements in the quality of care, which is one of the goals of the MPDSR process, but there is a paucity of research in this area.

Some studies have shown that community members want to understand why deaths happen within health facilities and that engaging community members in facility-based reviews could improve the quality of care (14,28,60). However, few studies have explored how health professionals provide feedback to community members on deaths that happen in health facilities. Some authors have recommended that additional research on strategies that could facilitate feedback between health professionals and community members is necessary (33,175).

Quality of care in maternal and newborn health literature (of which MPDSR is a subset) is analysed using two domains- provision of care and experiences of care (14,208). The indicators for measuring provision of care are based on technical or clinical criteria, while those for experiences of care are based on the feedback from community members about their lived experiences of receiving care in health facilities (14,62,208). We do not know how community members' experiences of care shape their participation in MPDSR. We also do not know how discussions to improve the quality of care during review sessions shape future care provision among health workers.

Most of the literature on MPDSR as an accountability process for the prevention of deaths is formulated at the global level with the expectation that countries would adopt it to their local context (3,13,14,22,23). The WHO-led Commission for Information and Accountability for Women and Children's Health (COiA) noted that accountability for the prevention of deaths was hampered by a lack of data on births and deaths (209). The Commission also noted that MDSR[10] could support collecting timely, reliable, and accessible data on births and deaths, which would mobilise political will to provide the necessary resources to support MDSR (*ibid*). The underlying assumption in the CoiA findings appears to be that improving the availability of data on maternal and perinatal deaths is sufficient to mobilise political will to support the implementation of the recommendations. The MPDSR policy (and other supporting guidelines) do not problematise the political nature of participation and how issues of power influence resource allocation by policymakers. There is a paucity of studies on the political nature of community participation in MPDSR. In addition, more research on how community members use the MPDSR process to advocate for resources could help understand the role of community participation in supporting the accountability goals of the MPDSR process.

The existing studies on community participation in advocacy have focused on reporting on the efficacy of the tools that CSO representatives use in their advocacy work, e.g. scorecards (59) or social movements and campaigns (45) and less on the relationships between the actors and the role of power between community members, duty bearers and external agents such as CSOs or NGOs who support community advocacy. Joshi and Houtzager (166: title) warn that social accountability processes that focus primarily on building tools for advocacy, such as scorecards without addressing the political nature of accountability relationships, risk reducing the accountability process to 'widgets', i.e. impressive but meaningless accountability processes. Researchers have recommended that enabling

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[10] COiA was in place before perinatal deaths were added to the MPDSR process, hence COiA statements refers to MDSR rather than MPDSR.

environments for building community voice should strengthen the relationships between community members and the external agents (such as CSOs) who support community members in advocacy with powerful decision-makers (119,155). To the best of my knowledge, none of the existing studies on community participation in advocacy for MPDSR have analysed how relationships between the CSOs and the community members influence the participation process. For example, none of the studies explain how CSOs interact with community members to identify the priorities that the community members want the CSOs to advocate for.

2.7.2 Not documented experiences and perspectives of community members as MPDSR participants.

Implementing MPDSR involves interaction between health workers and community members (54,66,197,198). Yet, most studies focus on interaction among health workers or how the MPDSR policy affects health workers, not community members. A scoping review on MPDSR implementation factors noted that there are gaps in the literature on how relationships among MPDSR participants affect the implementation process (24). The analysis in that scoping review only focused on interactions among health professionals, not community members (*ibid.*). To the best of my knowledge, none of the existing literature on community participation in MPDSR has described how community members interact with other MPDSR participants during MPDSR implementation and the meanings they attach to the participation process.

Most studies in MPDSR are based on research done with health professionals as the study participants. These studies describe the experiences of implementing MPDSR primarily from the perspective of the professionals with less focus on community experiences in MPDSR. For example, there are studies on blame culture (56,66,198), improving the efficacy of verbal autopsy tools based on the feedback of health professionals (188,189), comparing the tools used for death notification and reporting (39,44) and the challenges that health workers face during MPDSR sessions (54,66,197,198). While some papers describe the roles that community members play in supporting MPDSR implementation (53,181), there is limited focus on community members' experiences as participants in MPDSR (i.e. their perspectives on the MPDSR process). For example, we do not know the experiences and perspectives of the community informants as they support data collection using different verbal autopsy tools or facilitating social autopsy sessions in the community.

Several studies in MPDSR acknowledge that grief associated with maternal/perinatal deaths can affect community members and their involvement in verbal and social autopsy (53,175). A few studies from high-income countries have demonstrated that bereavement care can be an essential part of the MPDSR process (60,174). To the best of my knowledge, there are no studies in LMICs on issues of bereavement care in MPDSR. We also do not know how other emotions (such as anger or shame) influence participation in death reviews both in health facilities and in the community.

2.8 Research Question and Study Conceptualization

Community participation in MPDSR is expected to support the accountability goals of the MPDSR process by generating data on when and where deaths happen and using that data to improve quality of care and mobilise resources (3,13,14,22). In this study, I explored how community participation works in practice in two counties in Kenya to support the health system in meeting these three aims of the MPDSR process. I examined the interactions, perspectives, and experiences of MPDSR participants (community members and health professionals) to understand the participation process. This PhD has addressed the following research question:

How does community participation in MPDSR contribute to the MPDSR goal of accountability for the prevention of maternal and perinatal deaths in Kenya?

The study has two objectives:

1. To understand how health workers and community members co-produce knowledge throughout the MPDSR cycle.
2. To explore interactions among MPDSR participants and the meanings that MPDSR participants associate with the participation process.

2.8.1 Understanding how knowledge is co-produced during participation.

It is widely accepted that social factors contribute to maternal and perinatal mortality and that community members can play an essential role in the prevention of maternal and perinatal deaths (7,14,15,182). The MPDSR process relies on the cooperation of health professionals and community members to identify and review deaths and propose remedial actions to prevent future mortality (15,58). I have conceptualised the information generated during MPDSR sessions in any part of the MPDSR cycle as forms of knowledge. This includes the clinical/biomedical knowledge that health professionals use in the MPDSR process and the lived experiences of community members that are used to provide information on the social circumstances surrounding a maternal or perinatal death.

In this thesis, I have also conceptualised these interactions and collaborations that are expected to facilitate knowledge production during MPDSR as a form of knowledge co-production and examine how this (knowledge co-production) works in practice. By knowledge co-production, I mean the ways in which health workers and community members are expected to work together throughout the MPDSR cycle to collect and analyse information and then make and implement the recommendations to prevent deaths. Filipe *et al.* (105) have argued that co-production is an exploratory space where interactions between different people occur, which could lead to the production of new forms of knowledge. I have explored the interactions of MPDSR participants, health workers, community members and community representatives to understand how knowledge is produced or co-produced during the participation process.

In my conceptualisation, the knowledge co-production process is an action cycle adapted from the MPDSR cycle. I argue that the surveillance and response in MPDSR are socially constructed processes that involve interaction between health professionals and community members. The knowledge co-production cycle has three phases- (i) gathering knowledge, (ii) knowledge utilisation, and (iii) knowledge translation. Gathering knowledge and knowledge utilisation involves the same activities as the surveillance part of the MPDSR cycle. Knowledge translation involves the same activities as the response part of the MPDSR cycle, as I explain below. See: Figure 3

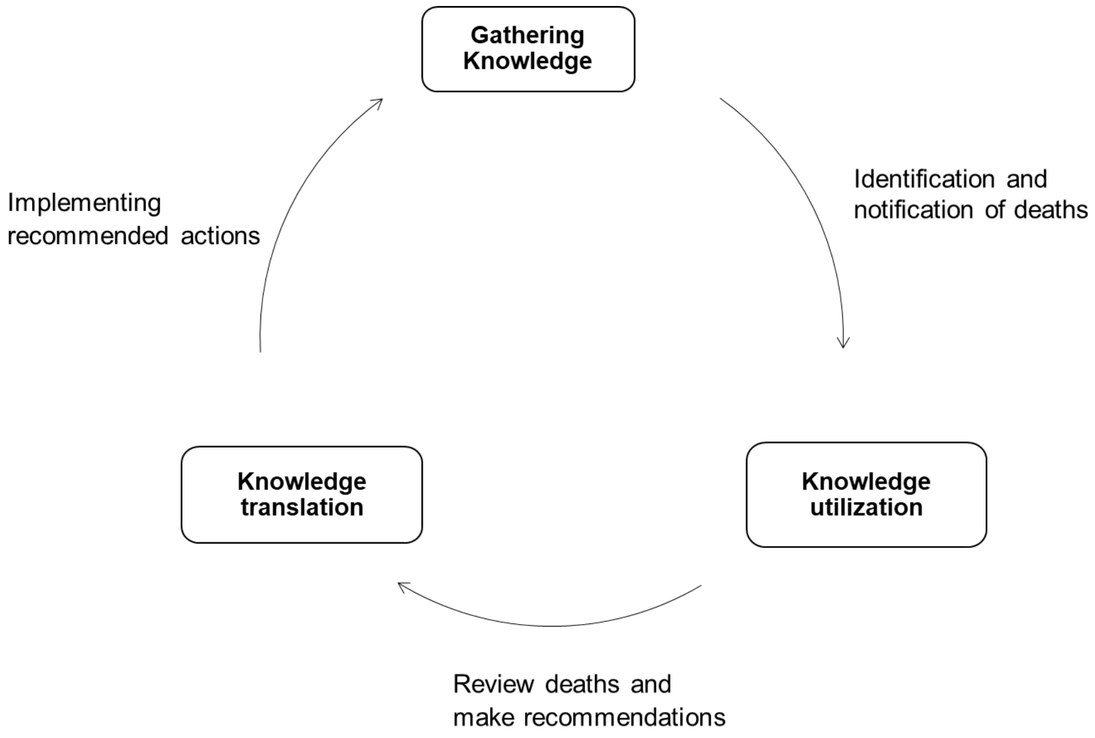

Figure 3 Knowledge co-production cycle.

The gathering knowledge phase involves the identification, notification, and reporting of deaths in health facilities and in the community. The information collected and reported includes:

(i) **who** died, **where** they died and **when** they died.

(ii) **how many** mothers and/or neonates died and assigning the cause of death to know **what they died from**

In this study, I have analysed the perspectives of health workers, bereaved family members and community representatives as they gather knowledge to understand how their experiences in death notification and reporting influence the participation process, e.g., which types of death are they willing or unwilling to report and why?

The second phase of the knowledge co-production cycle is knowledge utilisation. This involves reviewing cases and making recommendations using information generated through the gathering knowledge phase. Knowledge utilisation involves reviewing the deaths and making recommendations in health facilities or the community using tools such as facility death reviews or community-based reviews using verbal and social autopsy. The review process explores **why** the deaths happened by examining material aspects of the participation process, such as patient notes and the three-delay model. During the knowledge utilisation phase, community members can be invited to share their experiential knowledge on the circumstances that could have contributed to a maternal or perinatal death. I have examined the interactions between health professionals and community members to understand how MPDSR participants perceive different forms of knowledge (i.e., clinical and experiential) and how this influences the participation process. The knowledge utilisation phase also includes making recommendations that could prevent future deaths of a similar nature. I have also examined how the knowledge is used to make recommendations for quality improvement.

The third phase of the knowledge co-production cycle is knowledge translation. This involves implementing recommendations made during the knowledge utilisation phase and ensuring that responses are implemented. Knowledge translation also includes advocacy for mobilising resources to support the implementation of recommendations. Knowledge translation happens in health facilities and community sites where MPDSR participants can discuss their progress in implementing previous recommendations. Knowledge translation also occurs in other spaces, such as policy spaces where decision-makers allocate resources to implement MPDSR recommendations. I have explored the experiences of community members as they engage with CSO representatives and decision-makers to advocate for resources.

2.8.2 Exploring interactions among MPDSR participants and the meanings MPDSR participants associate with the participation process.

The MPDSR policy process in Kenya creates multiple participatory spaces in the community and within health facilities for community members and health workers to interact and possibly collaborate throughout the MPDSR cycle to produce knowledge that can be used to prevent future mortality. In their theory on the dimensions of participatory spaces, Renedo and Marston*.* (134) argue that participation occurs in spaces with several dimensions that frame how the participation process happens. For instance, participation in MPDSR happens in material spaces such as health facilities, community sites or the homes of bereaved relatives. Material dimensions can also include policy documents, minutes of MPDSR meetings and frameworks (e.g., the three-delay model) that participants draw on during the participation process to make decisions (114). Participatory spaces also have social and symbolic dimensions (134). Symbolic dimensions are the meanings or connotations that participants associate with the participation process, and these can influence what participants do in the participatory space (*ibid*). By exploring these participatory spaces, we can understand how the different dimensions of the spaces shape the participation process and the outcomes of the process e.g. the types of recommendations that are made during MPDSR sessions.

In this thesis, I use the term participatory spaces to describe the material/physical, policy, social and symbolic arenas where community members and other actors, such as health workers and decision-makers such as politicians, deliberate issues relating to MPDSR. I have explored how MPDSR sessions are organised to understand issues such as:

(i) who attends MPDSR sessions (and who does not and why), as well as who controls the invitation process into MPDSR spaces.

(ii) the experiences, interactions and perspectives of health professionals and community members during participation (e.g. how are the contributions from community members perceived by health professionals),

(iii) the meanings that MPDSR participants associate with the participation process (e.g. perceptions of community members about socially stigmatised deaths such as those resulting from abortions).

(iv) The documentation practices associated with the MPDSR process; for instance, how do the experiences of health professionals shape how MPDSR proceeding reports are written and how information from the MPDSR process is used.

I have examined how power differentials between health professionals and community members influence the participation process. By examining power relationships among different MPDSR participants, we can understand the barriers and facilitators that community members face when attending MPDSR sessions or advocating for resources. For example, I have analysed the interactions between MPDSR participants at death review meetings to understand how power dynamics influence the MPDSR recommendations that are generated during the review process. I have also focused on the role of power in facilitating or constraining community members' agency to act during the participation process, e.g., community members being allowed to speak during MPDSR sessions. I have also sought to understand how community members and their representatives interact and advocate for resources to implement MPDSR recommendations with powerful decision-makers such as politicians.

I have examined how power influences the knowledge production process, such as how health professionals use their positions to control the forms of knowledge they think are relevant to the MPDSR process. By focusing on the role of power and knowledge during MPDSR participation, we can better understand the types of knowledge that are produced during MPDSR sessions. I have sought to understand how the relationships between community members and community representatives influence the kinds of knowledge that community members gather and bring to MPDSR sessions. E.g., the types of maternal or perinatal deaths that community members are reluctant to report to health workers and how community representatives manage the reporting process. I have explored how health professionals use tools such as the minutes of MPDSR sessions to record and report clinical forms of knowledge (e.g., data from patient notes) and how this differs from the approaches to report non-clinical knowledge (e.g., bereaved relatives’ narratives of what happened before an adverse outcome) forms of knowledge.

I have explored the relationships between health professionals, community members and community representatives and the meanings the different groups associate with community participation in MPDSR. By understanding the social and symbolic meanings that MPDSR participants give to the participation process, we can better understand what the barriers and facilitators to knowledge co-production in MPDSR are. For instance, the literature on MPDSR has acknowledged that blame culture affects the willingness of health professionals to engage in MPDSR sessions (14,24,198). I have explored the meanings that health professionals and community members associate with participation in MPDSR, such as blame culture among health professionals. For instance, how does blame culture influence community participation in MPDSR? What are the implications of blame culture on the recommendations generated during the review process?

I have explored how interpersonal and institutional relationships shape how knowledge is gathered for the MPDSR process and how it is used, e.g., to improve the quality of care. Interpersonal relationships refer to the interactions that individuals have with each other, while institutional relationships refer to the relationships between community members and the health system (defined as organisations, people, policies and resources involved in delivering healthcare (210). In this study, I looked at how health workers use health system tools such as verbal autopsy questionnaires, DHIS2, and minutes of death review meetings during the participation process to report and interpret community members' knowledge. I also focused on interpersonal relationships and their influence on the participation process. For example, I have explored how disrespectful maternity care before an adverse outcome can affect the interactions between health workers and community members as they participate in MPDSR sessions. By exploring the different dimensions of the MPDSR participatory spaces, we can better understand how the community participation process works in practice.

This is a qualitative study where I have critically examined the experiences and perspectives of community members as they interact with other actors, such as health professionals and decision-makers, during MPDSR implementation. In the next chapter, I will present the study methodology.

3.0 Methodology

Chapter Outline

As explained earlier in the thesis, I have conceptualised community participation in MPDSR as a process of knowledge co-production where health workers and community members are expected to collaborate in gathering and producing knowledge (in the form of recommendations). In my critique of the literature, I argued that MPDSR is both a social and clinical process, but studies have not adequately theorised community participation in MPDSR as a social process that involves interactions between health workers and community members. The research question is: **how does community participation in MPDSR contribute to the MPDSR goal of accountability for prevention of maternal and perinatal deaths in Kenya?**

I begin the chapter by reflecting on how my experiences and positioning have shaped my interest in understanding community participation in MPDSR. Next, I describe the study rationale and describe the context in which I conducted the study. I then describe the data generation methods and tools and explain why these tools are best suited to answer the research question. Finally, I describe my analytical approach and reflect on how the Covid-19 pandemic affected the research process.

3.1 Getting to where I am: positionality.

Before I began my PhD, I had spent 20 years working with international NGOs and bilateral donors implementing and advising on public health and social policy programmes in sub-Saharan Africa. This influenced my interest in understanding community participation as a means for social justice and emancipation (79,115,211). At the same time, my understanding of community participation is also influenced by my experiences implementing community participation programmes in a context of donor-driven frameworks and mandates that rationalise community participation as a strategy for improving efficiency in programme delivery, i.e., what Morgan (111) describes as instrumental participation.

In developing my research question and study objectives, I was aware of this tension in understanding community participation, i.e., as a potential means for emancipation, but the practical realities of how community participation is implemented (e.g., to fit donor mandates). This influenced my choice of data generation methods and analysis. I used in-depth interviews to explore first-hand accounts from study participants about their experiences and perceptions of community participation in MPDSR. I did not seek to establish a single truth about community participation in MPDSR (212,213) or impose my perception of what 'good' community participation looks like. Rather, I sought to generate empirical findings and develop theory on the participation process.

During my PhD, I was invited to join the WHO Technical Working Group (TWG) on MPDSR, a team that supports the implementation of MPDSR globally. Being a member of the TWG has helped me appreciate the need for a clearer understanding of how community participation in MPDSR is conceptualised and implemented. During our TWG meetings, I have realised that at global level, the TWG members have assumptions on community participation in MPDSR that are not written up in the literature. For instance, some people feel that community members should not participate in facility death reviews, while others do not agree, yet these debates are not articulated in the literature. My aim in this PhD is to produce findings that can be applied in the real world and provide some clarity for actors such as the TWG and those implementing MPDSR at different levels of the health system. As such, my approach to presenting the findings is pragmatic. e.g. I have written up the findings to reflect different participation experiences at different levels of the health system. Chapter 4 focuses on interactions and experiences between health workers and community members at the micro-level, i.e. primary care facilities. Chapter 5 focuses on meso-level health system factors and their influence on how community participation in MPDSR is enacted. Chapter 6 focuses on the macro-level socio-political factors such as budgeting allocations for health activities and how this shapes community participation in MPDSR.

My past experiences working with health workers and knowledge of the health system hierarchy (national level to community level) were useful in helping me negotiate access to the study sites. MPDSR sessions (death review meetings in particular) can be sensitive spaces because there is a potential risk that the information discussed at the review meeting could be used for legal action. I relied on my social and professional connections to build trust with my study participants. The people I worked with as research assistants were local and known to community members, and this also helped in identifying bereaved relatives, especially in cases where deaths were 'hidden' from the formal health system. I provide more details in this chapter and the findings chapters to illustrate how my past relationships supported this study.

Valentine (214) has noted that researchers enter the study site as human beings with previous personal experiences, which can affect the research process. Before doing this study, I had experienced a perinatal loss and a near-miss incident (17 years ago). During the study, I was aware of my own bereavement experience and its influence on my interactions with study participants. While my bereavement experience was not my primary motivation for choosing this research topic, I have reflected on how it shaped my thinking during the design and implementation of this study. My experience with bereavement and coping with the health consequences of a near miss influenced my interview practices (215). When I interviewed bereaved relatives who had suffered perinatal losses, I could relate to their experiences, and I had genuine compassion for what they had been through. I felt that this was a strength that helped me during data generation not just to build rapport but to communicate with empathy based on personal experience rather than "textbook" empathy (215:1694).

3.2 An Interpretivist grounded theory approach

My aim in conducting this study is to understand how community participation in MPDSR works in practice. I sought to understand how study participants make sense of their experiences and interactions by examining and interpreting their accounts of the participation process (216,217). MPDSR sessions are held in different physical spaces such as health facilities and homesteads of bereaved relatives and policy spaces at sub-national and national level where decisions on quality improvement and resource allocation for MPDSR implementation are made (7,14,46). I have used an interpretivist approach (216) to analyse the different participatory spaces and the interactions and perspectives of MPDSR participants (health workers, community members and community representatives) as they co-produce knowledge throughout the MPDSR cycle.

Charmaz (218) notes that a grounded interpretivist approach uses participants' own framing of their experiences to make sense of social processes such as MPDSR. The author further argues that an interpretivist approach sees knowledge as situated and interpreted in context because as researchers construct meanings about study participants' actions they are not necessarily seeking an ultimate truth (218). I recognise that the data generated through this study is co-constructed between myself as a researcher and the study participants (218–220). While I sought to preserve the firsthand accounts of study participants, my past experiences working in community participation (described in my positionality statement above) shaped my approach to framing the research problem and study design (221) and the analytical process. This means my research findings are contextual and, at some level, subjective (222). But as Sword (223) and Corbin et al. (224) argue, I can show that some of the findings can be relevant to similar contexts through critical reflection and clear documentation of how I conducted the research. Throughout this chapter, I will critically reflect on how I think my background and experiences before this study shaped my interactions with study participants and my approach to data collection and analysis (214,223).

3.3 Study approach and rationale

Qualitative methods are useful for understanding people's experiences, the context in which action happens, and the meanings people associate with their experiences (225,226). Qualitative methods are also useful for exploring social interaction and how interactions shape what people do (222), e.g. how the interactions of health workers during MPDSR sessions influence how health workers interact with community members in health encounters such as ANC. I used qualitative data generation methods: interviews, focus group discussions and a co-production workshop with health workers and community members. I will describe the data generation methods and study participant recruitment later in the chapter.

3.4 Study setting

This study was conducted in two counties in Kenya. Due to the sensitive nature of some of the accounts in this thesis, I have anonymised the counties and referred to them as counties A and B. I purposively sampled these two counties for several reasons. First, counties A and B are among the 17 counties (out of 47 counties) that have a functional MPDSR committee, defined as a county that uploads MPDSR reports on the DHIS2 on a routine basis (70). Secondly, the national MPDSR guidelines (for Kenya) recommend a 5-tier approach to MPDSR committees, with committees established at all levels of the health system ranging from community MPDSR committees to the county MPDSR committee (69). While some counties in Kenya have MPDSR committees that actively review deaths within health facilities in line with the guidelines, most counties do not conduct community-based reviews, but counties A and B do (70). Both counties are implementing the Community Strategy and include community members in the MPDSR process (70,75). While overall reporting for MPDSR data from all counties in Kenya is not optimal, both counties are ranked as 'good' because they send reports to the national MPDSR committee for maternal and perinatal deaths (70). The third reason for selecting the counties was pragmatic and related to negotiating access to the study sites. Confidentiality in MPDSR meetings is critical because of the sensitive nature of the information discussed (14); the invitation to MPDSR sessions is controlled to protect the deceased and their families and health workers (49). I selected the two counties because I could negotiate access to study sites. I have previously worked in county B and am known by some health workers and community members. I had contacts with another NGO that has worked in county A, who helped me negotiate access.

3.4.1 Socio-demographic description of county A and B

I provide socio-demographic information and some maternal and newborn health indicators for counties A and B to give some study context without compromising anonymity.

County A is in a rural part of Kenya; the population in this county are largely homogeneous regarding ethnicity and socio-cultural practices such as language, culture, and religion. County B is also in rural Kenya, with a largely homogenous population in terms of ethnicity and socio-cultural practices. While there is homogeneity within the counties, there is heterogeneity between them. For instance, county A is predominantly Christian while County B is Muslim; the people in County A are Bantu who speak one language, while those in County B are Cushites who speak a different language from those in County A.

3.4.2 Community Groups participating in MPDSR sessions in the two counties.

In Chapter 1 of this thesis, I presented a broad overview of MPDSR implementation in Kenya by describing how MPDSR committees are supposed to function at the county level. In the two counties, community members participate in different MPDSR sessions (referred to as participatory spaces in this thesis) as expected in the national MPDSR policy. Both counties have MPDSR committees responsible for conducting MPDSR sessions and are organised in a similar hierarchy to that of the health system. The health system has six levels which are: (i) community health services (level 1), (ii) primary care provided by dispensaries, (level 2) health centres (level 3), (iii) county referral services, i.e. sub-county hospitals (level 4) county hospitals (level 5) and tertiary or teaching hospitals (level 6)[11] (69).

Participants of MPDSR sessions at different levels of the health system

Before going to the field, I collected the information I present in this section as part of my preliminary work. I spoke with health workers and NGO representatives in the two counties to understand how MPDSR is implemented. I used this information to guide my decisions when recruiting study participants.

i. **Community health volunteers (CHVs)**: CHVs are selected per the Community Strategy and guidelines (76). CHVs identify and report maternal and perinatal deaths that occur in the community (level 1) to health facility staff. CHVs also support health workers conducting community-based reviews using community verbal autopsy (CVA) and social autopsy.

   CHVs are also responsible for organising and facilitating Community Dialogue Days with the support of health workers and community leaders such as chiefs and village

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[11] The two counties do not have a level 6 health facility.

elders (76). In each community, CHVs monitor public health indicators and report them to health workers, e.g., households with adequate sanitation or bed nets (76). CHVs also report on indicators relating to maternal or neonatal deaths that have happened in their communities (*ibid.*). Health workers support CHVs in organising social autopsy sessions during Community Dialogue Days. The purpose of the social autopsy session is to discuss deaths that occur in the community and identify strategies that could prevent future deaths. Before any social autopsy session, health workers collaborate with CHVs and village elders to obtain consent from the family of the deceased so that the maternal/perinatal death can be discussed during a Community Dialogue Day.

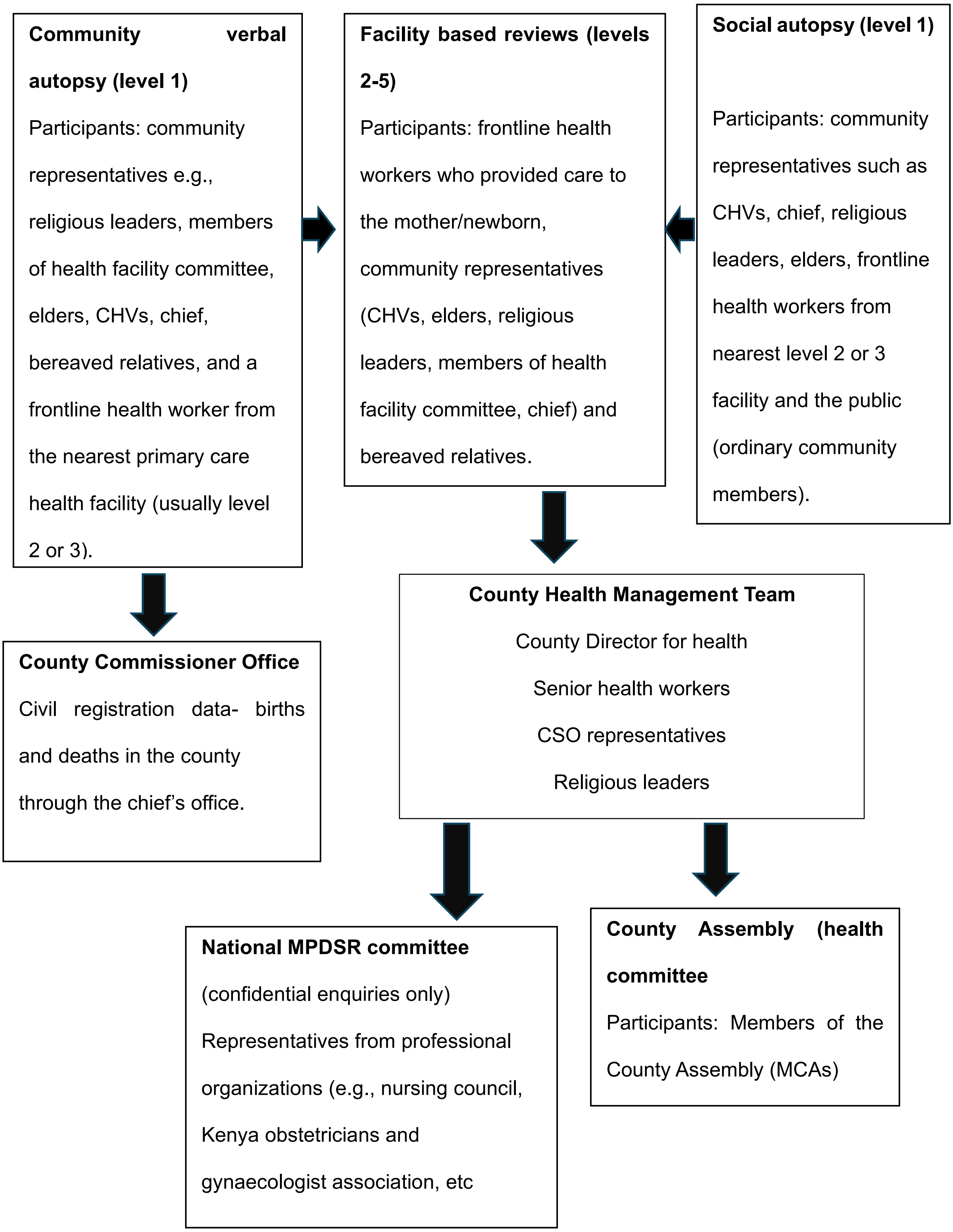
ii. **Community representatives:** community representatives such as members of health facility management committees, village elders, religious leaders, grassroots civil society organisations (CSOs) and CHVs are included as members of the health facility MPDSR committee at primary health care facilities (levels 2 and 3). Community representatives participate in maternal and perinatal death reviews at health facilities at all levels of the health system (levels 2-5) and at community-based reviews, i.e., verbal and social autopsy sessions (level 1).

iii. **Relatives of a deceased woman or newborn**: bereaved family members participate in MPDSR in two ways. First, where a death occurs in the community, and a CVA session is held, bereaved family members provide information to health workers and CHVs. The information provided includes a description of the deceased symptoms before their demise, which enables health workers to establish a probable cause of death. The relatives also describe the circumstances that the mother faced before her demise or that of her newborn. This provides information on social aspects of the pregnant woman’s life. The second way through which bereaved family members participate in MPDSR is through attendance of death review meetings at health facilities where they engage with health workers in reviewing the maternal/perinatal death at a death review meeting.

iv. **Ordinary community members**: community members participate in MPDSR by attending social autopsy sessions during Community Dialogue Days. Ordinary community members are members of the public who attend Community Dialogue days but they are not community representatives or bereaved relatives.

v. **Members of the County Assembly (MCAs)**: The provision of health services in Kenya is devolved to county governments and managed by the County Assembly (74). The County Assembly is made up of elected political leaders responsible for allocating resources for social development initiatives in the county. Within the County Assembly, a health committee oversees the health workers and implementation of health-related activities (work plans and budgets), including MPDSR. MCAs are also accountable to their electorate, i.e., the public who elect them so that they can represent the community at the County Assembly. MCAs or their representatives are also members of MPDSR committees in primary health care facilities (levels 2 and 3). In practice, most MCAs do not attend MPDSR sessions.

Figure 4 summarises information on MPDSR participatory spaces and shows participants and the reporting structure at different levels of the health system.



Community verbal autopsy (level 1)
Participants: community representatives e.g., religious leaders, members of health facility committee, elders, CHVs, chief, bereaved relatives, and a frontline health worker from the nearest primary care health facility (usually level 2 or 3).

Facility based reviews (levels 2-5)
Participants: frontline health workers who provided care to the mother/newborn, community representatives (CHVs, elders, religious leaders, members of health facility committee, chief) and bereaved relatives.

Social autopsy (level 1)
Participants: community representatives such as CHVs, chief, religious leaders, elders, frontline health workers from nearest level 2 or 3 facility and the public (ordinary community members).

County Commissioner Office
Civil registration data- births and deaths in the county through the chief's office.

County Health Management Team
County Director for health
Senior health workers
CSO representatives
Religious leaders

National MPDSR committee
(confidential enquiries only)
Representatives from professional organizations (e.g., nursing council, Kenya obstetricians and gynaecologist association, etc

County Assembly (health committee
Participants: Members of the County Assembly (MCAs)

Figure 4; MPDSR Participatory Spaces

3.5 Participant Eligibility and Sampling

I used a purposive sampling approach (220) to select study participants who had participated in MPDSR sessions at different levels of the health system. This allowed me to explore a range of experiences and perspectives from the participants. The following groups of people were eligible as study participants:

i. Community representatives who had participated in an MPDSR session either in a health facility or the community.
ii. Health workers who had participated in an MPDSR session either at the health facility or in the community (through verbal and social autopsy).
iii. Community members whose close relative had experienced a maternal or perinatal death. For clarity, in this thesis, I refer to family members who have experienced a maternal or perinatal death as bereaved relatives. I included bereaved relatives who had participated in MPDSR and those who had not participated to explore different perspectives between those who had participated and those who had not.
iv. Ordinary community members who had participated in social autopsy sessions held in their communities.

I used a theoretical sampling approach (219,224). Theoretical sampling is iterative and involves selecting study participants based on an initial analysis of the issues that could be relevant for generating theory (219,224). I began preliminary data analysis after my first three interviews, which allowed me to identify some codes, e.g., “community representatives relationships with bereaved relatives,” that study participants discussed in their interviews. I then tailored the next phase of sampling and recruiting study participants to include study participants who could provide rich accounts of their experiences (218–220). For example, I noted that study participants described their relationships with community representatives differently; bereaved relatives seemed to interact much more with CHVs compared to other community representatives, such as CSO representatives and elected leaders. Therefore, when recruiting study participants for the second phase, I included other groups of community representatives (not just CHVs as I originally planned) and explored how the interaction between CSO representatives and community members was similar or different to that of CHVs and how this affected the participation process. I will provide additional examples of how I used theoretical sampling in the data generation and analysis section, as my sampling decisions are closely related to the data analysis process.

3.6 Participant recruitment and planning for data generation.

I conducted fieldwork in three phases between February 2021 and February 2022. I used a phased approach to recruit study participants. This allowed me to use theoretical sampling and iteratively recruit study participants who gave me a richer understanding of participant experiences and confirmed or refuted preliminary categories that I had begun to generate in my analysis (219).

The first phase of the study was conducted virtually during the Covid-19 pandemic in county B. I worked with a local non-governmental organisation (NGO) based in county B, which supported me with the material requirements (office space, computer, internet connection) to make online interviews possible. I had ethics approval to work with two research assistants who would help me with the study's logistical aspects, such as recruiting study participants and setting up the interviews, because I could not travel.

I worked with the research assistants to identify health facilities in county B that had recorded maternal and perinatal deaths. The research assistants would visit the health facilities, talk to health workers about this study, and give them a study information sheet I had prepared. The research assistants would also request health workers for information about community members (either community representatives or bereaved relatives) who had participated in death reviews in the health facilities and the community. The research assistants would use the information provided by health workers to get in touch with the community representatives or bereaved relatives and recruit them on my behalf.

At the level 2 and 3 facilities, i.e., primary health care facilities, the research assistants would also inquire about any deaths in the community to identify potential study participants (bereaved relatives) who had not participated in any MPDSR process. The research assistants would then request health workers to refer them to the CHVs responsible for those households that had experienced an adverse outcome even though they had not participated in any review process. The research assistants would visit bereaved households with the CHV to invite their (bereaved relatives) to participate in the study. The research assistants would then request any CHV we had already identified if they knew other CHVs who had supported families with an adverse outcome and would be eligible to participate in the study. Through this snowballing process, we identified and recruited additional bereaved relatives.

I travelled to Kenya for the second and third phases of fieldwork and recruited study participants in County A with the help of my research assistant (county B was on lockdown due to COVID-19). I followed a similar approach to the one described above to recruit study participants. All the health workers from the different levels of the health system (and different cadres) who were requested to participate in the study agreed to participate. The community representatives also agreed to participate. Among bereaved family members, only one bereaved relative refused to participate in the study.

3.7 Ethics

I received ethics approval from the National Commission for Science, Technology, and Innovation (NACOSTI) in Kenya (ethics ref: NACOSTI/P/21/9486) and from the London School of Hygiene and Tropical Medicine (ethics ref: *22511*).

I provided information sheets to all study participants describing the purpose of the study and how the data generated would be used and managed. I obtained written consent from all study participants (interviews, FGDs, observation of MPDSR sessions and co-production workshop). The information sheets and consent forms were in English[12]. Only one of my study respondents was illiterate; I provided an audio recording of the information sheet in their mother tongue (with prior ethics approval). I also had an impartial witness who countersigned the consent form of the participant who could not write.

Valentine (2007) explains that researchers need to continuously negotiate ethics and consent with study participants for research topics such as bereavement because of the emotional nature of the study. When conducting interviews with health workers, many would describe their participation experiences in MPDSR and talk about sensitive issues relating to blame culture or potential negligence among health workers. Study participants would pause mid-way through the interview to reaffirm that the data would be anonymised and that their identity would remain confidential. I observed that despite providing an information sheet where I explicitly indicated that data would be anonymised and kept confidential and affirming the same at the beginning of interviews, study participants needed additional reassurance throughout the interview about anonymity and confidentiality of the research process, which I provided. While I did not know any of the study participants personally before this study, I had connections to other health workers and NGO representatives who helped me negotiate access for data generation. I sensed that the health workers who participated in the study trusted me because of my past relationship with other health workers. It is possible that health workers felt it was safe to share their experiences with me because they were aware that other health workers trusted me.

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[12] English is the language of instruction in Kenya, people learn how to read in English.

Given the emotional nature of the topic, I informed study participants of their right to withdraw consent at any point in the interview. I made provision for referring any study participants who would experience emotional distress to community support services, such as religious leaders living in these communities. I was also aware of the support that LSHTM could provide me to manage any emotional distress due to the study.

Each study participant (interviews, FGD, observation and co-production workshop) received KES 1,000 (approx. £7) as compensation for their time participating in the study. I also reimbursed transportation costs for community participants who attended the co-production workshop in county A during the third phase of data collection. Participants were informed about the compensation after their interviews or FGDs to avoid undue influence on participation.

In line with good research practice. (e.g. 227); I have anonymised the study sites and given pseudonyms to all study participants. I refer to health workers in general terms rather than by cadre to enhance anonymity. In addition, where there is only one study participant who fits a specific criterion (e.g., there is only one elected official whom I interviewed from the County Assembly), I do not use their pseudonym but only refer to the category they belong to (e.g., community representative) when presenting that specific quote as an additional layer of anonymity. Similarly, there are instances where the health worker's rank (hierarchy in the health system) is useful for understanding the quote[13], but there is a risk of compromising anonymity; I do not use a pseudonym for the health worker but label the quote as either junior or senior health worker.

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[13] E.g., there are specific roles in MPDSR that are carried out by senior health workers especially related to MPDSR implementation at county, (usually one person in the county), so when presenting quotes I do not use the pseudonym I have given the study participant.

My PhD is funded by Wellcome Trust Doctoral Studentship for Social Science and Bioethics grant number 217748/Z/19/Z. Wellcome Trust paid for my fees at LSHTM, a living stipend, and the research costs associated with this study, including travel international and local travel), accommodation and subsistence, research assistants, transcription of interviews and focus group discussions, and the co-production workshop. I also received a six-month (January to June 2023) living stipend from LSHTM to cover my expenses after the Wellcome studentship ended.

3.8 Data management

Before my fieldwork, I put together a data management plan in line with LSHTM requirements. In the plan, I provided details on how data collected would be stored and managed. I followed this plan during the fieldwork phase by, for instance, transferring all my recorded interviews onto the LSHTM servers (using one drive) at the end of each day. I also deleted audio files after transcription and reviewing transcripts for accuracy.

All interviews and FGDs were audio recorded and transcribed verbatim, noting non-speech cues such as laughter. I worked with a local (Kenyan) transcriber to transcribe the interviews, FGDs and discussions from the co-production workshop. I used LSHTM's guidance on working with transcribers to ensure that the person kept the transcripts and audio files confidential by having them sign a confidentiality agreement. I then cross-checked the quality of the transcription by listening to the audio while reviewing the transcripts. I did this for all the interviews, FGDs and co-production workshop round table discussions.

The interviews, FGDs and workshop were done in English, Swahili, and Sheng[14]; almost all interviews have a mix of languages (it is a typical way of how Kenyans speak). When analysing the data, I did not translate the Swahili or Sheng on the transcripts. Only one

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[14] A Kenyan dialect that is a mixture of local languages, English and Swahili

interview was in another language, i.e., not Swahili, Sheng, or English. I had the support of one of my research assistants, who speaks that local language, to help with translation during the interview. I present the quotes verbatim, but when presenting them in the findings section of this thesis, I have removed some utterances such as “uhs” to make it easier to read. I have translated the quotes used in this thesis from Swahili/Sheng to English where relevant; I have retained non-verbal communication, such as laughter, and noted it when presenting quotes.

During fieldwork, I kept a research journal where I would write down my initial impressions and ideas after each interview or FGD. Sutton et al. (2015) posit that research journals or field notes are useful tools during data analysis as they allow researchers to recall salient situational issues about specific interviews that may not be included in the transcript. I will give an example; my intention here is not to present findings but to illustrate a methodological point. During an FGD with community representatives, the participants said that there were no maternal or perinatal deaths in their village because no one was allowed to use a TBA for delivery. After the FGD, some community representatives (CHVs) helped me recruit bereaved relatives from the same village. All the bereaved relatives reported that TBAs had been involved in delivery or adverse outcomes, but these deaths had not been reported. I wrote these thoughts in my journal, and during analysis, the transcripts and the notes related to how I recruited study participants were useful in identifying a theme about TBAs and hiding deaths. I present findings on this in chapter 6.

3.9 Data generation methods and tools

I conducted 37 in-depth interviews and 5 FGDs and facilitated a co-production workshop to generate data. I also observed one CVA session and the interactions between health workers, community representatives and bereaved relatives at the co-production workshop. As mentioned, I collected data in three phases; phase one was done virtually in county B because of the COVID-19 pandemic, while phases 2 and 3 were conducted in person in county A.

Summary of data generation methods and tools

Study participant	Data collection method	Number of interviews/FGDS	Content of the topic guide
Frontline Health providers	10 Interviews	6 n=males 4 n=female	• Narrative description of previous MPDSR sessions they have participated in. • Perceptions of what works/does not work during MPDSR sessions. • Any contributions they made during the MPDSR session. • How action points related to reviews are decided and implemented
Frontline health providers and health managers	1 FGD (10 health workers different cadres)	Health managers, n=2 Frontline workers, n=8	• How knowledge produced MPDSR sessions at lower health system levels flows to county and national MPDSR sessions. • Support provided to both health workers and community members participating in MPDSR sessions. • Advocacy for resources to implement MPDSR recommendations.

Study participant	**Data collection method**	**Number of interviews/FGDS**	**Content of the topic guide**
			• Barriers and opportunities that people face when participating in MPDSR sessions
Health Managers (senior health workers)	4 interviews	Female, n=1 Male, n=3	• Narrative description of previous MPDSR sessions they have participated in. • Support provided to both health workers and community members participating in MPDSR sessions. • Advocacy for resources to implement MPDSR recommendations. • Perceived barriers and opportunities faced by health workers and community members during MPDSR participation.
Community representatives: elders, community health volunteers (CHVs), members of the health facility committee	11 Interviews	CHV, n=5 Other community representatives, Village elder =1 MCA =1 CSO representatives =2	• Narrative description of one or more MPDSR sessions they have participated in and their experiences participating in the session(s). • Perceptions of what works/does not work during MPDSR sessions.

Study participant	**Data collection method**	**Number of interviews/FGDS**	**Content of the topic guide**
members, Members of the County Assembly (MCA) and CSO representatives		Health facility committee members =2	• Any contributions they made during the MPDSR session. • How action points related to reviews are decided and implemented.
CHVs and health workers FGD	1 FGD (10 people CHVs and frontline health workers)	Frontline health workers n=4 CHVs n=6	• Perceptions on what community participation in MPDSR sessions means to them. • How their work in the MPDSR committee links to the community members they represent. • Perceptions of what works/does not work during MPDSR sessions. • Any contributions they made during the MPDSR session. • How action points related to reviews are decided and implemented.
Community representatives	FGD (8 people, different categories of	Village elders n=2 Chief, n=1 CHVs, n=5	• Experiences participating in MPDSR- the roles they play in the process.

Study participant	**Data collection method**	**Number of interviews/FGDS**	**Content of the topic guide**
	community representatives)		• Challenges and opportunities of their participation in MPDSR and how they manage the challenges. • Perceptions of what can be improved about the participation process in MPDSR.
Relatives of deceased mother/baby (stillbirths and neonatal) who participated in a review	6 Interviews	Males, n=4 Females n= 2	• Narrative description of an MPDSR session they have participated in. • Any contributions they made during the MPDSR session. • Barriers experienced and opportunities that their participation in the MPDSR provided.
Relatives of deceased mother/baby (stillbirths and neonatal) who had not participated in a review	6 interviews	Female, n=4 Male, n=2	• Reasons for not participating in MPDSR sessions or perceived barriers to not participating. • What can be done to encourage community members to participate in MPDSR sessions?

Study participant	**Data collection method**	**Number of interviews/FGDS**	**Content of the topic guide**
Relatives of deceased mother/baby (stillbirths and neonatal) who had not participated in a review	1 FGD (with 10 people)	FGD- 10 pax female, n=8 males, n=2	• Reasons for not participating in MPDSR sessions or perceived barriers to not participating. • Perceptions of trust in the health system, disrespectful maternity care, and the influence on MPDSR participation.
Ordinary community members	1 FGD	10 pax female, n=7 male, n=3	• Narrative experiences of their participation in a social autopsy session. • Instances when community members made. Contributions/suggestions during the social autopsy session. • How health workers and other community members received suggestions at the social autopsy. • Recommendations made at the social autopsy session to prevent maternal/perinatal deaths.
Community verbal autopsy (CVA) session	Observation (maternal death)	1 health provider 2 CHVs 1 elder	• Observe interaction and talk among CVA participants as they

Study participant	**Data collection method**	**Number of interviews/FGDS**	**Content of the topic guide**
		deceased's husband	discussed circumstances that led to the death. • Observe how different participants at the CVA perform their roles during the CVA session.
Co-production workshop participants (health workers, community representatives and bereaved relatives)	Round table discussions and plenary presentation	25 people (health managers, health workers, village elders, CHVs, CSO representatives, traditional birth attendants, bereaved relatives	• Present preliminary findings of the study. • Collectively propose recommendations on how to improve participation in MPDSR.

Table 1: Summary of study participants, data generation methods and tools

3.9.1 In-depth interviews

I used in-depth interviews to elicit first-hand accounts from health workers and community members on several issues in line with the study objectives. In-depth interviews allow researchers to explore a topic by prioritising the respondent's perspectives during the interview (220,228). An in-depth interview allows study participants to tell their story and express multiple perspectives, realities and emotions on the research question in ways that are relevant to them (212,220,228).

Using in-depth interviews allowed me to understand how study participants who had participated in MPDSR sessions framed their participation experiences- such as why they felt community participation in MPDSR matters and descriptions of the MPDSR sessions they attended, e.g., who spoke and what they talked about. I sought rich descriptions (212) of the interactions between MPDSR participants. The interviews lasted between 60 and 75 minutes. I was also interested in understanding the perspectives of bereaved relatives who had not participated in any MPDSR sessions. With this group, I explored their perceived barriers to participation and what they thought could be done to encourage community participation in MPDSR sessions. I recruited participants from both counties for in-depth interviews as follows:

1. Different cadres of health workers from the different levels of the health system (n=14)
2. Community representatives (n=11)
3. Bereaved relatives of a deceased woman or baby who had participated in a review (n= 6)
4. Bereaved relatives of deceased woman or baby who had not participated in a review (n=6).

In all my interviews with health workers, community representatives and bereaved relatives who had participated in an MPDSR session, I began by asking them to describe their experiences participating in an MPDSR session. This gave participants the flexibility to tell their story and focus on the issues they felt were important to them (212). It also helped me build rapport with the study participants as they had control over the issues in the story they wanted to prioritise and talk about (220,228). After listening to the study participants' narration on their experiences participating in MPDSR, I followed up by tailoring my questions to the narration the respondents shared and probing for more details to explore the perspectives further. For instance, when respondents said they had appreciated being at the MPDSR session, I would follow up with questions on what they felt had worked well or had not.

In the interview with bereaved relatives who had not participated in any MPDSR session, I asked them if they were aware of the MPDSR process and if they had been invited to participate. For the bereaved relatives who had been invited to participate and chose not to attend the MPDSR session, I got their perspectives on why they had not participated. For the bereaved relatives who had not been invited to participate in an MPDSR session, I asked them to share their perspectives on perceived benefits and barriers for community members participating in MPDSR sessions.

I used a topic guide to prompt interviewees (225) to explore the study respondents' experiences and their views on community participation, perceived opportunities, and barriers to community participation in MPDSR. At the initial interviews, I had very few prompts to follow up the broad question on people's experience participating in MPDSR sessions. After the initial interviews, I adjusted the topic guide iteratively to include issues that I had not initially included in the topic guide to incorporate issues that came up in the interviews (229,230). For instance, in my initial interviews with bereaved relatives, the respondents talked about their mistrust of the health system and how this affected their participation experiences. In subsequent interviews with health workers, I explored issues on community perceptions of the health system regarding trust and how these affected the MPDSR participation process. This meant the interviews I did in phase 3 were more focused as I built on what I had learnt from previous interviews and asked questions that allowed me to compare and contrast how different study participants made sense of the themes that were already emerging (212,218).

The interview process is a form of social interaction that builds rapport and trust between the researcher and study participants (212,230). When interviewing bereaved relatives, I noticed differences in how male bereaved relatives interacted with me compared to females. While I built rapport with both male and female interviewees (bereaved relatives), I sensed that interaction with female interviewees flowed more easily, and the women shared more intimate details about their pregnancies, adverse outcomes, and their views on participating in MPDSR. For instance, some women would participate in the interview while breastfeeding and our conversation would ebb and flow onto other aspects of maternal and newborn health, such as breastfeeding. I felt it was okay for me to share some aspects of my life, e.g., I had children and breastfed them and what that was like for me (231). As a Kenyan female, I was also aware that there is no social expectation to halt the interview because the woman is breastfeeding; because we consider breastfeeding a routine task that women undertake as they do other things, such as talk to others. This made the interviews more like a conversation between two women and potentially minimised some of the power imbalances that may have existed because of my position as a researcher. During these interviews, some female bereaved relatives would link MPDSR participation to other healthcare encounters with health workers. This gave me a more comprehensive view of participation in MPDSR, even for participants who had not attended an MPDSR session. I noted in my journal that for most study participants, MPDSR is not a specific event, i.e., the MPDSR session; rather, they associated participation in MPDSR with narratives of the pregnancy, the adverse outcome and other interactions with health workers and community members. I then used this new understanding of the MPDSR process to adjust the topic guides for subsequent interviews to explore the temporal nature of participation in MPDSR. This is not to say that I could not have conducted this research if I was male or had no experience breastfeeding; I highlight these issues to show the gendered aspects of the interview and how I used these aspects to enrich data generation.

I also built rapport with health workers, community representatives and male bereaved relatives, but the sense of shared intimacy of personal details was less than with female bereaved relatives. I presented myself as a learner to the study participants (223). I told study participants that as I could not observe MPDSR sessions in real time (because of COVID-19), I hoped that study participants could “paint me a picture” of their participation experiences and share their perspectives on participation in MPDSR. This may have allowed participants to shape their interviews and share their views without feeling that I had preconceived ideas about what participation in MPDSR sessions was like. It may also have shifted some of the social differences between the study participants and me as they were in the position of a knower (231).

During the first phase of data collection, I conducted the interviews virtually using Skype. I will reflect on how the virtual interviews compare to face-to-face interviews in the second and third phases of data collection. I will also reflect on conducting emotional and sensitive interviews.

3.9.2 Generating data virtually.

I conducted 12 interviews virtually (3 with bereaved relatives, 3 with community representatives, 2 with senior health workers and 4 interviews with frontline health workers from different levels of the health system). I had the support of a research assistant to conduct online interviews using Skype. The interviews were held at the local offices of the NGO because the office has the resources, internet connection, computers, and technical skills to set up Skype. The research assistant would set up the room for the online interviews, explain to the study participants how Skype works and give the study participants consent forms to read through. The research assistant would sit in a different office and be available to help the study participant if the internet connection dropped or if there were other issues, such as if the study participant inadvertently muted themselves. Online data collection requires a good internet connection and access to online software such as Skype, Zoom or Teams (232). While I could pay for data bundles, I could not guarantee the quality of the internet connection. As a precaution, I procured internet modems from different service providers in Kenya so that when the internet from one provider was not working well, we could switch to another provider. As I was in the UK, I did not have challenges connecting to the internet.

I did not conduct any focus group discussions (FGDs) virtually for two reasons. First, to set up FGDs at the local NGO, we would have needed to either set up several computers/smartphones for each FGD participant and physically separate the participants to minimise feedback and echo during transmission/call. The NGO did not have enough computers or smartphones to support this. It would also require a stronger internet connection than the NGO had. An alternative would have been for several participants to share one device during the FGD, but this was not feasible due to Covid restrictions.

Carter et al. (2021) have argued that conducting online interviews requires different preparation and execution techniques from face-to-face interviews. The authors further suggest that it can be harder to establish rapport for in-depth and personal interviews when using online platforms because of a lack of “embodied care”, such as a pat on the shoulder if a participant is distressed (233: 741). To build rapport with online study participants, I would spend the first few minutes chatting with the study participant on general topics before beginning the formal interview. This also allowed study participants to familiarise themselves with the online technology. In almost all interviews, study participants and I kept our cameras on, but when internet connectivity was problematic, and participants began to freeze, I would switch off my camera. I only switched off the participants' cameras as a last resort as I wanted to observe non-verbal cues as part of the interview experience (232,234).

Another critical issue to consider when conducting online interviews is the extent to which some study participants are excluded from the process because of a lack of access to technology (232,234). I did not face this problem as study participants went to the local NGO’s office for the interviews, and I reimbursed the study participants for their transportation costs from their homes to the NGO. However, this arrangement relied on the willingness of study participants not just to be interviewed but also to travel to the offices of the NGO; for most study participants, that was an additional hour of travel in addition to the time spent at the interview (about another hour). This meant that both the research assistants working at the NGO and I had to be flexible in the timings of the interviews to suit the study participants' availability (233).

When planning for online interviews, researchers need to think about the ethical issues of the General Data Protection Regulation (GDPR) and the use of personal data such as user profiles (233). I did not ask any study participant to set up a separate profile; instead, all study participants logged onto the research assistant's Skype profile (with his consent). I also relied on my research assistants to print consent forms and scan and email them to me once study participants had signed them. I set up Skype or Zoom connections using a license provided by LSHTM. I did not use the recording function provided by technologies such as Zoom to record the interview. Instead, I used an encrypted mobile phone to audio record the interviews offline from my end, which ensured additional security (233).

I experienced challenges using a virtual approach despite the arrangement and contingency plans I made for using an online approach. For example, there were instances where the interviewee would freeze, and we could not communicate. This meant that there were times that I asked study participants to repeat what they had said. Typically, the response they gave the second time round was shorter than the original response, and I may have lost some “data richness” because of the interruptions (234).

Some study participants (particularly health workers) were uncomfortable participating in online interviews because they were unsure who else could access the information. Some health workers expressed mistrust about sharing sensitive information over the internet. I discussed my challenges with my supervisors, and we agreed that I could wait and conduct face-to-face interviews when international travel resumed (later in 2021). I used face-to-face interviews during the second and third phases of data generation.

There were some advantages of conducting online interviews compared to face-to-face ones. For example, after an online interview, I would bid a study participant goodbye and log off from the call, but I did not need to leave my seat immediately after the interview. This meant that I could spend some time reflecting on the interview and making notes immediately after the interview. In the latter phases (phases 2 and 3), I conducted interviews at peoples' homes and health facilities. At the end of those interviews, I had to leave the space physically to go to another location where I could reflect and write notes about the interview. As I was travelling with a driver and research assistant, my reflection and note-taking did not happen immediately after the interview but later in the day.

Some authors have noted that while online interviews can allow for a wider geographical reach, it is not necessarily cheaper to conduct online interviews than face-to-face ones (234). This was also my experience; conducting online interviews was not cheaper than it would have been if I had travelled to Kenya in person because of the cumulative costs of the logistics to get study participants to the NGO office for the interviews.

3.9.3 Emotional and sensitive interviewing

Dempsey et al. (235) have defined sensitive research as potentially affecting those who participate in ways that could harm them or evoke negative emotions. The research topic of this thesis focuses on issues that are sensitive and laden with emotion. The MPDSR process revolves around narratives about maternal and perinatal death, which are known to elicit emotions such as grief and anger among participants (175,196). Literature on MPDSR has documented the sensitive nature of the process because of blame culture and the risk of legal action against health workers (56,198). As such, in preparing for the interviews, I was aware of the ways that this could affect me and the study respondents.

Some authors have reported on the dilemmas researchers face trying to balance between being empathetic to study participants and maintaining professional boundaries as researchers without appearing to be emotionally detached (214,236). I found myself walking this line in many of my interviews with bereaved relatives. I was empathetic and could relate to some of the participants' emotions. However, I maintained an emotional distance between myself and the study participants. e.g. I chose not to disclose my own experience with the near miss or the perinatal loss with the study participants. Dempsey et al. (2016) argue that researchers must guard against burdening study participants with self-disclosure and recommend that researchers maintain an empathetic distance so that the focus remains on the participants' experience rather than shifting it to the researcher. This was my first reason for non-disclosure; I did not want to burden my study participants or risk an emotional breakdown (my own) during the interviews. Secondly, while I had experienced a perinatal loss, I had no experience participating in any form of MPDSR (as a bereaved relative) because the MPDSR policy did not exist 17 years ago.

Some literature on interviewing study participants on sensitive and emotional topics has recommended several strategies to manage the interview process. For instance, having a clear ethics statement to minimise harm to participants (235,237) and creating empathetic boundaries between study participants and researchers (214,236). Other studies have recommended building rapport with study participants by using a conversational approach to the interview and memorising the interview guide so that the interview process is not interrupted by researchers looking at their notes (235). I found all of these recommendations helpful; I had a clear plan for safeguarding by referring study participants who required support to community services provided by religious leaders. I also memorised the topic guide and used a conversational approach with interviewees, enabling interviewees to tell their stories with minimal interruptions. I would probe for details or use follow-up questions to guide the interview at appropriate times without overtly looking at the interview guide.

Many bereaved relatives shared that they had experienced disrespectful maternity care before adverse outcomes. When I initially planned my fieldwork, I suggested to the ethics committee that I would refer any bereaved relatives who needed psychological support to health workers in their communities. When I realised that many bereaved relatives did not consider health workers as a safe space for psychological support, I discussed it with my supervisors, and we agreed that I would refer any community members who needed support to religious leaders. None of the bereaved relatives required additional support during the interviews.

Some studies have reported on the role that gatekeepers can play in controlling access to study participants when the research topic is deemed to be sensitive or study participants are deemed to be at risk due to their involvement in a study, e.g. if participant accounts can be used as legal evidence (235). In addition to obtaining ethics approval from NACOSTI in Kenya and LSHTM as part of standard good research practice, I also got permission from relevant gatekeepers, mainly the County Directors for health in both counties. These are the most senior health workers in the county. The County Directors did not control which health workers I could interview, but they provided support in the form of official letters that I gave to health workers during the recruitment phase. Even though it was not strictly necessary for me to obtain the permission of the gatekeepers (i.e., County Directors), having their support in writing seemed to assure health workers that it was okay to participate in the study and talk about sensitive issues.

Another emotional dimension of the study relates to the analytical process that happens soon after the interviews. Open coding requires reading and re-reading transcripts to familiarise oneself with the data (218). I found this aspect of the study emotionally draining as each time I reread a transcript, the experience took me back to the interview and the narratives of bereavement that study participants shared. While I had found some literature on preparing for an emotional interview and conducting one, I could not identify literature on providing emotional support for researchers during the analysis phase. In retrospect, I could have been better prepared had I anticipated that re-reading the transcripts would be distressing. I relied on my social relationships (other PhD students and conversations with my supervisors) for support.

There are ethical debates in bereavement studies regarding harm done to participants as they talk about their experiences (214,237). Some studies have shown that providing study participants with opportunities to talk about their bereavement experience as part of the research study can be cathartic (235,238). When doing this study, bereaved relatives said they appreciated the opportunity to talk about their experiences. Health workers also said that they were rarely asked to reflect on their emotions during MPDSR and felt that the study allowed them to share their perspectives on how their feelings influence their participation in MPDSR.

3.9.4 Focus group discussions (FGDs)

I moderated five separate focus group discussions (FGDs) as follows:

(i) frontline health workers and health managers (10 people)
(ii) frontline health workers (different from I above) and community health volunteers (CHVs) (10 people)
(iii) community representatives (8 people)
(iv) bereaved family members who had not participated in any MPDSR session (10 people)
(v) ordinary community members who had participated in a social autopsy session where a maternal or perinatal death was discussed (10 people)

I conducted all the FGDs in county A because it was difficult to arrange for virtual FGDs in site B because of the technological difficulties and COVID restrictions described above (section on virtual interviews). I moderated all the FGDs with the support of a research assistant who took notes and recorded the discussion. I obtained written consent from each FGD participant. I informed FGD participants that while I would treat the discussions at the FGD in confidence and anonymise the locations and participants of the FGD, I could not guarantee complete confidentiality because of the group setting because I have no control over how FGD participants treat the discussion such as sharing with other people outside the

FGD (225,226,239). I encouraged FGD participants not to share information they considered sensitive at the FGD to minimise the risk of broken confidentiality.

FGDs explore interactions among a group of people to understand how participants co-construct meanings as they share their perspectives and experiences on an issue (225,226,239). FGDs provide an opportunity to explore what people say during the discussion, how they say it, and how others in the group interpret the issue under discussion (240). For example, participants in FGDs share, compare and challenge each other as they interact and agree or disagree on an issue, generating a rich discussion (239,240).

I facilitated two FGDs where the group composition was heterogeneous: (i) FGD with frontline health workers and health managers and (ii) FGD with frontline health workers and CHVs. Heterogeneous FGDs can clarify ideas on a topic by exploring views both groups share and those unique to one group (241). From the initial interviews that I had conducted in phase one, I noticed differences in how health managers and frontline health workers frame accountability in MPDSR. I used the FGD as an opportunity for the two groups to interact and discuss accountability in MPDSR- for example, what accountability means and the role of community members in establishing accountability. How do the views of frontline health workers converge with those of health managers, and why did they have divergent views?

At the FGD (heterogenous group) with frontline health workers and health managers, I explored how their roles within the health system shape their understanding of community participation during MPDSR sessions. Frontline health workers interact closely with pregnant women during their pregnancies, for instance, when attending antenatal care (ANC) and during delivery (for women who give birth at health facilities) (14). Health managers are responsible for ensuring that MPDSR sessions are held and following up on the implementation of action points made during MPDSR sessions, i.e. accountability for the process (3,14). By bringing these two groups into one FGD, I explored how the different health professionals make sense of community participation and their perceptions of the opportunities and barriers of community participation.

The other heterogeneous FGD was with frontline health workers and CHVs, who both have relationships with pregnant women but interact differently with the women. I wanted to understand how these groups perceived community participation and how the views of CHVs were received and debated by health workers and vice versa. Frontline health workers interact closely with pregnant women before an adverse outcome, for instance, during ANC visits, but typically in an official capacity as a healthcare encounter (76). CHVs also interact closely with women during their pregnancies but with stronger social ties, for instance, visiting women in their homes and interacting with the woman’s family in ways that health workers do not (76). Bosco et al. (241) argue that bringing heterogeneous groups together in an FGD can allow a diverse group to discuss topics they would not usually talk about during other interactions. CHVs and frontline health workers often interact at MPDSR sessions and other encounters to discuss maternal and newborn health issues in the community (76). However, the two groups would not typically discuss their participation experiences in MPDSR because the objective is to review deaths when they meet at MPDSR sessions. By bringing the two groups together at the FGD, I explored their interactions, perceptions, and experiences of having community members at MPDSR sessions.

I also facilitated three FGDs where the composition of the group was homogeneous. These were FGDs with (i) community representatives, (ii) bereaved relatives who had not participated in any MPDSR session, and (iii) ordinary community members who had participated in a social autopsy session in their community. FGDs leverage on interpersonal communication among research participants to explore issues of importance to the group as participants build rapport and share experiences (242,243). By having a homogeneous FGD with bereaved relatives, the participants could share their bereavement journey and empathise with other bereaved relatives who shared their bereavement experiences. At the end of the FGD, many of the bereaved participants said they found the FGD helpful because they could talk about their loss to other people who understood what they had experienced. The FGD participants also said they felt a sense of camaraderie with other bereaved relatives because of their interaction with health workers before an adverse outcome, which influenced their decision not to participate in MPDSR. Other studies have documented that the research process can be therapeutic for study participants, e.g. (214,235,237). My experience facilitating the FGD with bereaved relatives aligns with this view; by bringing the FGD participants together, the participants were able to talk about their bereavement journeys and from their accounts, they found the discussions beneficial.

Pope et al (226) posit that FGDs are useful for exploring the interaction among participants to understand which perspectives the group agree or disagrees on. With the homogeneous FGDs (iii to v above), I explored how participants in each group interacted within the group to see what participants agreed on and the issues they disagreed on regarding community participation in MPDSR. I also wanted to understand how the group dynamics would shape participants' views (226). For instance, at the initial stages of the FGD with ordinary community members who had participated in a social autopsy session, the community members talked about how useful social autopsy sessions were and how the community attended the session and contributed to the discussions. As the discussion progressed (at the FGD), some participants began to give contradicting accounts describing their difficulties at the social autopsy session. At this point, there was a shift in the discussion as participants described their positive and negative experiences during social autopsy sessions, possibly because some FGD participants were willing to discuss the negative aspects of their experiences.

3.9.5 Observation

During the second phase of data collection, I observed a CVA session for a maternal death that had happened four months prior to the date of my observation. Ordinarily, health workers and CHVs should organise the CVA in the community about a month after the death (69), but because of COVID-19, there had been delays in conducting the CVA. The CVA took about 2 hours and was held at the home of the deceased woman. The participants at this CVA were a health worker from a level 2 health facility, 2 CHVs and a village elder. I negotiated access to observe by speaking separately with the health worker and community representatives (CHVs and elders) and then with the bereaved relative (the deceased woman's husband).

At the CVA meeting, I was a non-participant observer (244), I did not play an active role in the discussions between the husband and the other CVA participants. But, as Walshe et al. (245) argue, I was part of the social interaction that shaped how the CVA was conducted because the participants were aware of my presence and that I was observing them. I had interacted with all the CVA participants before the session began as I requested their permission to observe the event (i.e., CVA). I chose not to record the discussions during the CVA to make my presence less intrusive, but with the participants' consent, I wrote field notes.

Observation is useful for inferring meaning about people's actions and the context in which the action takes place to understand what people do rather than what they say (213,245). Pope et al. (226) note that observation enables researchers to see the world in which study participants live, to make sense of the perspectives that study participants hold on an issue. By using observation, I was able to see how participants at this CVA interacted with each other as they participated in the CVA. I observed how CHVs and health workers perform their roles during MPDSR sessions rather than what they say they do, as is the case in the interviews (244). The observation helped me notice some nuances in how health workers use the three-delay model during the participation process. I used these new insights (on the three-delay model) to adjust my interview topic guide for subsequent interviews so that I could get additional insights on how health workers use the three-delay model during MPDSR sessions. I recorded the conversations and notes about what happened at the CVA in my fieldnotes, which allowed me to explore how the CVA participants interpret the actions and construct meanings about participation in MPDSR (213,245).

My field notes are not a verbatim transcript of what the participants said; rather, I made interpretations of what I had observed, e.g., nonverbal cues and how I perceived a participant's reaction to something that was said. In this sense, I was involved in co-constructing meaning during the CVA. I wrote field notes describing the actions and interactions based on my interpretations of the actions related to my research question (245). For example, I was interested in how participants used materials such as the CVA questionnaire[15] to guide the discussion and interaction during the CVA. So, I paid attention to how the health worker asked questions from the CVA questionnaire and how the husband and the other participants reacted (non-verbal cues) and responded (verbal cues) to the questions. For instance, in my field notes, I wrote: "The *bereaved husband looks frustrated with the health worker.*"-this is my interpretation of the husband's facial expression and his gestures, but the husband did not actually say that he was frustrated.

I could not take detailed field notes during the CVA as I had to multi-task, listen to the discussions among the CVA participants, observe for non-verbal cues, interpret (mentally) and write down what I considered to be relevant for my purposes (245). So, after the CVA session ended, I relied on memory to expand my field notes and additional thoughts and phrases from the participants I had just observed.

The CVA was the only opportunity I had to observe an MPDSR session directly because the pandemic changed how MPDSR was conducted. I reflect on the impact of Covid-19 at the end of this chapter.

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[15] A CVA interview is moderated by a health worker using a standard verbal autopsy interview guide to collate information relating to symptoms of the patient and then using more open-ended questions to explore social contributors for the death (43,282).

3.9.6 Co-production workshop

During the last data generation phase, I organised a one-day co-production workshop with 25 people drawn from health workers, community representatives, bereaved family members, and ordinary community members. All the participants of the workshop had previously participated in the study either at interviews or FGDs. The purpose of the co-production workshop was to disseminate preliminary findings from the study and to co-produce recommendations on improving the participation process in MPDSR.

During the co-production workshop, I presented my preliminary findings and then used anonymised vignettes to illustrate the main study findings; I leveraged on the skills of my previous employment, such as facilitating workshops with a diverse group of people. I was able to moderate the workshop so that health workers and community members could participate jointly and have rich discussions on what the preliminary findings meant.

I asked participants to reflect on the issues that each vignette illustrated. I separated the participants by their roles in MPDSR, having health workers at one round table, community representatives at another, bereaved relatives, and ordinary community members at their round table in the same room. I worked with three research assistants who were responsible for audio-recording the round table discussions. I moved between the tables, listening in on the conversations and responding to participants' questions. Each round table session lasted an hour, and then each group presented their ideas in plenary. The plenary presentations focused on how each group thought about the preliminary findings and how participation in MPDSR could be improved. I audio-recorded and transcribed the round table and plenary sessions for analysis.

3.10 Data analysis

As mentioned at the beginning of this chapter, I used a grounded theory approach in conducting this study (218) and detail the process I followed in the next section. Even though

I have presented the analytical process as a step-by-step process, in reality, the process was not linear and involved moving from using inductive approaches to deductive reasoning with a lot of back and forth of thinking, reviewing literature and re-organizing the data (229).

3.10.1 Coding, analytical memos and categorisation of data

I imported all anonymised transcripts and field notes to NVivo 12 to help manage and organise the data. I began the data analysis process by familiarising myself with the data by reading and re-reading the transcripts. This process started immediately after my first interview in phase one. I then began to inductively code the transcripts using line-by-line coding (218) of all the interviews conducted in phase 1. During the coding phase, I focused on how study participants described their experiences during MPDSR, noting the actions, feelings, and interactions they described in their interviews. For community members who had not participated, I had codes on the reasons they did not participate and their perceptions of barriers or missed opportunities.

I followed the principles of grounded theory in my analysis, using both deductive and inductive approaches to generate codes from the transcripts (218). As I explained in the theory chapter (section on study conceptualisation), MPDSR is a process of knowledge production during surveillance and response. I was interested in the concept of knowledge before I began coding. I was also interested in exploring the dimensions of participatory spaces (134). e.g. the invitation process to MPDSR sessions. Having identified the concepts of knowledge and participatory spaces a-priori, I used inductive coding using a line-by-line approach (218). For example, when coding, I looked through the transcripts for phrases that relate to knowledge, such as “learning,” “gaining skills,” “being competent,” “labelling community members as ignorant” and “lacking the right knowledge” “giving health education” “teaching the community” among others and coded them as issues “relating to knowledge.”

I also used inductive open line-by-line coding to develop a coding framework for the interviews, FGDs, fieldnotes and discussion from the co-production workshop to explore other issues beyond knowledge. To create the coding frame, I compared talk among the different participants; for instance, what health workers said about community members attending MPDSR sessions and how study participants described their experiences and interactions with each other during MPDSR sessions. I also noted how participants talk changed over time, usually within the same interview, and the contradictions that seemed to appear in their talk.

I used line-by-line coding for the first 12 interviews, including interviews with health workers, community representatives and bereaved relatives. From this exercise, I generated 60 codes covering various issues. For example, I had separate codes for "abortion-related death", "deaths that are associated with bad luck," "disclosing that a woman delivered with a TBA", "women feeling shame", and "relatives afraid of discussing the death." I combined this into a more focused code of "bad deaths" to describe deaths that community members consider to be problematic during MPDSR sessions.

Another example to illustrate my coding decisions relating to blame culture. Here, I had codes such as "health workers blaming other health workers," "health workers blaming community members", "community members blaming health workers," "health workers avoiding MPDSR sessions", "community members going to the police", and "what health workers write as part of MPDSR proceeding." I developed several focused codes from these by looking at the interconnections between the initial codes (238). From the example on blame, I had several focused codes, such as "how blame flows among MPDSR participants." Another was "tactics MPDSR participants use to manage blame" and "consequences of blame."

After the focused coding, I began to group the codes by comparing them codes and putting them into separate, distinct categories. Constant comparison involves assessing the codes for similarities within a case and how the codes vary across cases (224). After identifying initial categories, I wrote analytical memos describing the categories and illustrating these with some quotes from the data. I then shared the memos with my supervisors. My supervisors and I had many discussions exploring the categories I had developed, questioning how the different codes fit into that category and looking at participant quotes to ensure that the categories were grounded in the data.

I will illustrate how I moved from coding to more focused coding and then to categories using some open codes relating to knowledge. This is not a complete list of all the knowledge-related codes; I have selected a few to demonstrate how I conducted my analysis.

Example of opening coding and developing categories

Open codes	**Focused coding**	**Categories**
Community members are ignorant.	Health workers describe community members as lacking knowledge.	How study participants position each other about knowledge production in MPDSR
Community members do not know the right thing to do		
Community members are incompetent.		
Health workers have the right knowledge.	Health workers' perception of their own knowledge	
Health workers know what to do.		
Community members say health workers think they know everything	Community members' perceptions about health workers	
Community members say health workers ignored some details of their lived experience about the pregnancy and circumstances before the death that they shared at MPDSR sessions.	How health workers perceive contributions of community members’ lived experiences of pregnancy and circumstances before the death	Privileging biomedical knowledge above community knowledge
Health workers describe community members' contributions during MPDSR sessions as stories.		

Health workers refer to tools such as partographs as valuable forms of knowledge.	Health workers' perception of knowledge that is valid during MPDSR sessions	
Health workers rely on what is written in the patient file, not what people say at MPDSR sessions.		
Community representatives need to teach community members.	Physical spaces where community members receive health education	Using MPDSR sessions for health education and encouraging uptake of MPDSR recommendations
Health workers teach community representatives and bereaved relatives the right thing to do		
Visiting pregnant women at home to inform them of MPDSR recommendations	Ensuring community compliance with MPDSR recommendations	
If someone does not follow what we teach, we report them to the chief.		
Community participation is good because health workers and the community learn together.	Shifts in how health workers talk about community participation in MPDSR	Contradictions in the talk of health workers
We are opening a wound so that we learn together		

Table 2: sample of coding tree

3.10.2 Developing themes.

Ezzy (246) argues that themes are generated through thinking and talking about the research, i.e., they don't emerge mechanically. By using constant comparison between the codes, writing analytical memos, and discussing the memos with my supervisors, I began to identify themes related to knowledge production in MPDSR. I generated a theme on the rhetoric of knowledge co-production in MPDSR from the categories described above. See Box 1 below.

Rhetoric of knowledge co-production

Knowledge co-production in MPDSR is embedded in rhetoric. Study participants explained that community participation in MPDSR is important because it allows health workers and community members to learn and work together to prevent future mortality. But, in practice, health workers disparage the types of knowledge that community members bring to MPDSR sessions describing the knowledge as anecdotal. Health workers position community members as ignorant and uneducated, while positioning themselves (health workers) as having the right knowledge. Health workers frame community participation in MPDSR as opportunities to educate the community. Community members say that health workers are unwilling to listen to community members on how deaths can be prevented during death review sessions both in the community and in the health facility.

Box 1: Example of theme development.

3.11 Data saturation

During the last phase, I noticed that the study participants described issues I had previously coded, and no new issues came up in the data. I also presented preliminary categories of the data to study participants at the co-production workshop. I asked them to reflect on additional issues that they felt were relevant to understanding community participation in MPDSR. As I did not identify any other issues or topics in my analysis and from the co-production workshop, and I also had funding and time constraints, I made a pragmatic decision not to continue with data collection. It is possible that I may have reached data saturation, which has been described as the point in data analysis where no new themes are emerging (229,247).

3.12 Data quality

There are several aspects of the methodology. By using inductive coding, I have ensured that the categories and themes I have developed are supported by quotes in the data and not my preconceived ideas (218,223). I have systematically documented my assumptions and the process that I followed in developing codes, categories and themes to produce my findings (213).

I wrote analytical memos on all the categories that I generated from the coding and discussed these with my supervisors. My supervisors and I discussed how each category fit the themes I identified. This has ensured that the categories and themes that I present in the findings chapter are grounded in the data. Secondly, I shared anonymised transcripts (9 out of the 37 interview transcripts) with one of my supervisors so that she could see how I had done the analysis and how I moved from the initial codes to generating the categories and themes.

I used theoretical sampling to select cases that allowed me to explore the topics of interest. By iteratively sampling future study respondents based on my initial analysis, e.g., including national-level MPDSR participants, which was not in my initial plan[16], I brought additional perspectives on community participation into the study. In my analysis and write up,

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[16] As described in the study context section of this chapter, there is no provision for community members to participate in MPDSR at national level. Therefore, at the beginning of the research project, I did not anticipate having interviews with people from the national level of MPDSR implementation.

I present dominant codes and outliers to show where there was variation and offer explanations for why variations exist, for instance, of the 16 bereaved participants who did not participate in any MPDSR process (6 from interview and 10 from FGD), 14 described experiences of disrespectful maternity care and framed their unwillingness to participate around issues of the disrespect. I also present findings on the two bereaved relatives who did not relate their unwillingness to participate with disrespectful care. In developing my categories and themes, I have paid careful attention to the differences and reported this in my findings for a more balanced approach (222,224).

I facilitated a co-production workshop where 25 study participants who had previously participated in either interviews or FGDs attended. At the workshop, I presented the preliminary findings of the study by showing the participants the categories I had generated. I asked the workshop participants to reflect on how the categories resonated with their experiences and perspectives. I incorporated this feedback into the study as part of my findings. Study participants agreed that I had identified the issues and experiences related to community participation in MPDSR.

Corbin et al. (224) note that researchers should be transparent and make their analysis open to scrutiny by providing sufficient details on how they conducted the analysis and the decisions they made along the way. I have provided a step-by-step explanation of how I conducted the study and described how I made decisions on sampling and recruitment of study participants. As previously explained, I used deductive and inductive analysis by going back to my conceptual framework on knowledge co-production but also embedding my analysis in the data.

Researchers who use qualitative approaches recommend using a variety of data generation methods and tools as a way of triangulation (229,246). By triangulation, I do not mean that the different methods that I used, i.e., interviews, focus group discussions, observation, and the workshop, confirm that my findings are true. Instead, using different methods, I could get comprehensive accounts of study participants' construction of community participation in MPDSR (222,244).

3.13 Effects of COVID-19 on the Study

As explained earlier in this chapter, I conducted online interviews during the first phase because of the pandemic, as it was not feasible to travel. In addition, I had initially intended[17] to use observation of MPDSR sessions in health facilities and the community as my primary data generation method. I had to revise this plan during the pandemic and conduct more interviews and FGDs for several reasons. First, because of the pandemic, many health facilities in the study areas (and elsewhere) stopped having MPDSR sessions because health workers prioritised dealing with COVID-19 in the population. Secondly, due to rules on social distancing, no community meetings were happening as a preventative measure against Covid-19. This meant I had no opportunities to observe social autopsy sessions in real-time. Eventually, when COVID-19 cases began to subside, MPDSR meetings resumed. Still, health workers said they had to reduce the number of people who could attend a review session because of social distancing rules.

Once international travel resumed, conducting interviews and FGDs face-to-face was easier. Maternal deaths are a rare event (epidemiologically), and even in high maternal mortality settings, the absolute numbers of maternal deaths are quite small (248). This meant that it was difficult to have many cases of MPDSR sessions that I could observe, but I left the option to attend any MPDSR sessions open. It was only feasible to observe one community verbal autopsy session for a maternal death. While there are a lot more perinatal deaths, the MPDSR policy recommends that health workers only review a sample of the perinatal deaths

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[17] I began my PhD in 2019, before the pandemic; in my study proposal I had indicated that I would observe MPDSR sessions to generate data.

(69). When there are no maternal deaths to be reviewed, health workers do not organise a meeting only to review perinatal deaths.

4.0 Knowledge Processes in MPDSR

Preamble to the chapter

This preamble aims to describe the different forms of knowledge relevant to the MPDSR process and show how the MPDSR process is expected to work (as described in the policy). These descriptive details will clarify the findings I present in this chapter.

Earlier in this thesis, I explained that I have conceptualised community participation in MPDSR as a form of knowledge co-production, i.e., the ways in which community members and health workers are expected to collaborate throughout the MPDSR action cycle. Knowledge co-production in MPDSR involves generating data through death notification and reporting, improving quality of care by reviewing deaths and making recommendations, and mobilising resources to support the implementation of MPDSR recommendations. Both health workers and community members are expected to bring different forms of knowledge to MPDSR participatory spaces.

Community members bring knowledge based on their lived experiences by reporting deaths or participating in death review meetings in the community and in health facilities. Lived experience refers to a woman's personal story of her pregnancy, her interactions with the health care system (e.g., ANC attendance) and social factors in the community that could have contributed to the adverse outcome (e.g., lack of finances to pay for transport to go to a health facility). Lived experiences refer to a continuum of events and interactions the pregnant woman had over time and space. Lived experiences in MPDSR begin when a woman becomes pregnant and continue to the postpartum period (42 days after delivery). For perinatal mortality, lived experience is based on the mother's pregnancy journey and the newborn's interaction with health services (e.g., time spent in a neonatal intensive care unit) up to 28 days after birth. Another form of lived experience is the collective knowledge that community members have on community social life, e.g., culture, beliefs, and community practices.

Health workers have biomedical or clinical knowledge of maternal and newborn health based on their professional training as either nurse-midwives or doctors. Health workers have experiential knowledge of using tools such as partographs, or patient case notes to obtain relevant information that can be used during death review meetings. Health workers also have tactical knowledge about the MPDSR policy and guidelines, i.e., objectives of MPDSR and, how MPDSR sessions should be organised and the expected outputs from the MPDSR process (e.g., acceptable formats for submitting MPDSR reports). Having given this background information, I now focus on study findings.

4.1 The rhetoric of knowledge co-production in MPDSR

In this study, the rhetoric of knowledge co-production is characterised by four contradictory vocabularies that health workers and community members use simultaneously to describe the value of community participation in MPDSR. Study participants used positive language to describe their expectations of using MPDSR sessions for co-learning between health workers and community members. I refer to the positive language used by study participants as the vocabularies of hope, which are expectations that all study participants have about MPDSR sessions being conducive spaces for knowledge co-production. By using vocabularies of hope, study participants paint a picture of a positive, participatory process that is characterised by collaboration between health workers and community members. But as I will show, this is mere talk; in practice, health workers and community members do not co-produce knowledge during MPDSR sessions.

Study participants use other vocabularies that contradict their initial descriptions of hope for knowledge co-production as follows: (i) vocabularies of (in)competence, (ii) vocabularies of credibility, and (iii) vocabularies of exposure to describe community participation in MPDSR. I will present findings on how study participants use these vocabularies to describe their interactions and experiences at MPDSR participatory spaces in ways that contradict the vocabularies of hope for knowledge co-production.

4.2 Vocabularies of hope.

Health workers and community members use vocabularies of hope to explain that community participation in MPDSR allows both community members and health workers to collaborate and learn together (i.e. co-produce knowledge) about the causes of deaths and how the deaths can be prevented. At the start of their interviews, health workers and community members described participation during MPDSR as a process where the knowledge of both health workers and community members is complementary. Study participants talked about the importance of health workers and community members working collaboratively in the hope that they could learn together and from each other and prevent future mortality. From their interviews and FGDs, study participants' use of vocabularies of hope is more than wishful thinking; rather, study participants associate hope with co-learning between health workers and community members.

Health workers use normative language citing policy documents such as the MPDSR national policy (69) and the Community Strategy (76) that associate community participation in health with positive outcomes for preventing maternal and perinatal mortality. For example, a health worker explained: "*we are using the Community Strategy to implement MPDSR. We know that in all our national policies, community participation is critical. […]. We [health workers] must involve the community if we want to succeed in preventing maternal and perinatal deaths*" (Gavin, health worker).

Another health worker used a metaphor to illustrate that collaboration between community members and health workers is necessary to prevent deaths. By describing the MPDSR process using the metaphor of wearing shoes and walking together, the health worker implies that community members and health workers can cooperate during MPDSR sessions to co-produce knowledge. He commented:

> When we do this work [implement MPDSR], the community wears one shoe, we as health workers wear the other shoe, and we walk together in this journey of preventing deaths. We learn from one another. We must cooperate with each other (Oliver, health worker).

Health workers talked about the rationale for community participation in MPDSR sessions as opportunities to gather knowledge about the lived experiences of pregnant women and newborns. Health workers explained that by understanding the lived experiences of the deceased, there is hope that MPDSR participants can learn and prevent future deaths. An interviewee commented: "*when we have community members at MPDSR sessions, it helps us [health workers] piece together information about what happened before the maternal or perinatal death. With every death, we can learn […]*. Another health worker also reiterated:

> […].so, during the MPDSR review meetings, […] we [health workers] pick on a case […] We try to look at where we did well as a unit and where we have gaps, we work upon those gaps. Sometimes, we talk to the family about what happened before the mother came to the facility. We want to see what we can work on or what was not done well, and we hope it doesn't happen again (Jackie, health worker).

Community members described their rationale for participating in MPDSR sessions with health workers using phrases of learning and hopeful futures. Community members also explained that they participated in MPDSR sessions because it helped them understand what had contributed to the deaths and how future deaths could be avoided. Bereaved relatives talked about the changes they hoped to see in health facilities and the community because they participated in MPDSR sessions. For example, Gabriel, a bereaved relative, said:

> […]. At the meeting, I heard what led to the death of my son. We [people at the death review meeting who included health workers, community representatives and himself] said that the health workers should learn and not repeat what they did so that this [death] should never happen again […]. (bereaved relative).

Community representatives used vocabularies of hope to describe MPDSR sessions as opportunities to propose changes that can prevent future maternal and perinatal deaths. A community representative said: "*the meeting [death review meeting] is like a post-mortem. We discuss what happened […] we want to learn how to change […] what we can do differently […] because we don't want this [other maternal/perinatal deaths] to happen again*" (Robert, community representative).

Community representatives such as community health volunteers (CHVs) use vocabularies of hope to encourage bereaved relatives to participate in MPDSR sessions. In the vignette below, I use my observation of a community verbal autopsy (CVA) session to show how CHVs used vocabularies of hope to encourage a bereaved relative to share his painful experience of a maternal death by using an image of opening a wound.

> *The setting is a homestead where a community verbal autopsy (CVA) to discuss a maternal death has just begun. The participants at the CVA are a health worker, 2 CHVs, a village elder and the deceased woman's husband. The CHV talks to the husband to explain why the CVA session has been organised. She says to the husband, "[…]. We are opening a wound. Please allow us to open this wound so that we can all learn […], and we hope we learn, and this doesn't happen to another man…"* (field notes, CVA observation).

The CHV in the excerpt above uses words of hope that his participation (the husband) is useful for learning that would benefit the CVA participants and the general community.

A CHV described her experiences facilitating several social autopsy sessions in the community using vocabularies of hope for the community members to learn together. The CHV explains that social autopsies are opportunities for the community to give ideas to health workers on how deaths can be prevented. In her comments, the CHV explains that community members hope things will change because they participated in the social autopsy session. She explained:

> During social autopsy sessions, I sit with the community, and we discuss why a woman or newborn died. We go deeply, deeply [discuss in detail] and say what we [community members and health workers] can do to prevent other deaths. Health workers know that we [community] are stakeholders on issues of health and we come to these meetings [social autopsy] because we want things to change (Rebecca CHV).

Both health workers and community members described a few instances when they collaborated to make recommendations during MPDSR sessions. In counties, A and B, study participants gave examples of social autopsy sessions where health workers and community members recommended improving transport for pregnant women to minimise delays in reaching health facilities. For example, a CHV in county B talked about facilitating a social autopsy session where health workers and community members decided to pay for transporting mothers using motorcycles. Health workers and members of the health facility management committee (who are also part of the MPDSR committee) agreed that some of the cost-sharing[18] funds that health facilities are entitled to would be used to pay for motorcycle fare when pregnant women need to travel to health facilities for delivery.

In county A, health workers and CHVs described how they had collaborated to address blood shortages after several MPDSR review sessions. At an FGD with CHVs and health

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Health facilities in Kenya charge a nominal fee for some health services as a form of cost-sharing. The health facility is allowed to use a proportion of cost-sharing funds to support improvements within the facility. The health facility management committee and the health workers in charge are responsible for managing these funds.

workers, health workers explained that most maternal deaths were related to postpartum haemorrhage. They also explained that the county had a shortage of blood. The health workers explained that they had used social autopsy sessions to raise the issue with community members. Health workers explained that they had worked with CHVs and other community representatives, such as village elders and CSO representatives, to mobilise community members for a blood donor recruitment drive. The FGD participants (CHVs and health workers) described the experience of working together to address a problem identified during MPDSR sessions as encouraging and positive. The two examples of improving referral for pregnant women and addressing blood shortages were the only instances in which study participants described collaboration between health workers and community members.

Despite using vocabularies of hope to describe study participants' expectations of the community participation in MPDSR, knowledge co-production in MPDSR is rare. Study participants (health workers and community members) faced multiple barriers limiting the potential for knowledge co-production during participation. For the rest of this chapter (sections 4.3-4.5), I will present the contradictions between the vocabularies of hope to co-produce knowledge and what happens in practice.

4.3 Vocabularies of (in) competence

The vocabularies of (in)competence among MPDSR participants refer to how different MPDSR participants position themselves and others in relation to their perceived abilities to co-produce knowledge to prevent future mortality. Study participants used vocabularies of competence to describe the perceived level of performance of MPDSR participants, i.e., how well or poorly people are perceived to perform tasks associated with knowledge processes (e.g., give suggestions on potential recommendations). All the health workers in this study labelled community members as incompetent in the knowledge co-production process. At the same time, health workers described themselves as competent and having the right skills and experience that can be used to produce knowledge. Health workers also used vocabularies of incompetence to rationalise using death review meetings as opportunities for educating community members.

4.3.1 Health workers use labels of (in)competence.

Health workers felt that community members lacked the inherent capacity to co-produce knowledge for improving the quality of care. Several health workers used strong language such as "*ignorant*," "*incompetent*" or "*negligent*" to describe community members. For instance, Jane, a health worker, described community members as *"uneducated and ignorant, and they [community members] don't know the right thing to do."* Other health workers described community members using negative labels such as *"incompetent and negligent*" (Jacob, health worker) or "*community members cannot participate in review sessions because they don't understand what health workers talk about during review sessions*" (Charles, health worker). Health workers participating in an FGD shared their views on community incompetence to participate in review meetings. An FGD participant commented: *"community members are disempowered, they are ignorant […] some of them cannot even talk even if you invite them to come for a review meeting. Community members do not know the right thing to do to prevent maternal/perinatal deaths"* (FGD, health workers).

Some health workers used vocabularies of incompetence to describe the perceived lack of proactiveness by community members during MPDSR sessions. A health worker explained that community members could not take the initiative to give suggestions during MPDSR sessions. Other health workers explained that community members lack the capacity to participate in review meetings because they do not have good ideas on how deaths could be prevented. In an interview with a health worker, I asked if community members gave suggestions on how deaths could have been prevented during MPDSR sessions. The respondent had a dismissive tone and said:

> Community members lack good suggestions that we can use during the meetings, so they come to listen to us [health workers]. Even when we asked them if they have any suggestions, they sometimes talk but their ideas are not good, they don't have good suggestions (Joseph, health worker).

Health workers described bereaved relatives' failure to manage their emotions during MPDSR as incompetence, which hampered knowledge co-production. A health worker described her experience at a review meeting where a community representative was angry about the discussions during the review session. The health worker described the community representative as "*unreasonable and angry […] he made the review session so volatile we [MPDSR committee] could not discuss the death or make recommendations*" (Jackie, health worker). Another health worker described a CVA session as tense because the deceased's husband was angry and emotional. The interviewee (health worker) explained that the CVA had to be postponed because the bereaved relative could not manage his emotions and kept blaming health workers for the maternal death. Another health worker explained that community members were often unable to cope with their grief and could not provide information that could be used to co-produce knowledge. The health worker explained:

> In most cases, health workers don't get enough information because the relatives are still grieving, and some are angry. We don't really get a full picture of what happened before the mother came for delivery because the relatives don't talk (Peris, health worker).

A health worker described bereaved relatives as irrational and linked this behaviour to blame during MPDSR sessions in the facility. The interviewee explained that blaming health workers interferes with the review process. He commented:

> Community members are very emotional and irrational yeah, and they only come to meetings to blame health workers. This makes it difficult for the review meeting to be productive because we must deal with the accusations. They say you [health worker]

> killed my person instead of the critical issues on what caused the death (Solomon, health worker).

Conversely, health workers described themselves as competent to co-produce knowledge. Health workers described themselves as having the right skills and experience to review deaths and make recommendations. A health worker compared the competence of health workers with that of community members. In his comparison, the interviewee perceives health workers as having the right knowledge and being proactive in giving suggestions on how to prevent deaths at review meetings. This contrasts with the perceptions health workers have of community members as lacking the right knowledge, not being proactive and being unable to give suggestions at review meetings. The interviewee explained:

> From the review sessions, we know community members do not have the right knowledge. […] Health workers are trained, and they know what to do to address maternal deaths. We [health workers] have the right knowledge […] health workers give suggestions on what needs to be done…. we discuss and make recommendations during review sessions (Gavin, health worker).

Some health workers interpret the MPDSR guidelines and policy in ways that validate the perceived competence of health workers above that of community members. At the co-production workshop, health workers commented on the MPDSR policy and how they perceived its implementation. The health workers participating in the co-production workshop argued that the MPDSR policy could be implemented successfully by health workers without the participation of community members.

> So, I think the people who formulated the MPDSR policy did it from the top [...] from the perspective of the big people. I think the policy gives us [health workers] the monopoly to go through the issues raised at a meeting [death review session] and make proper decisions on how to avoid future deaths without talking to the affected people (health workers, co-production workshop).

Some health workers acknowledge that there are instances where some health workers do not have the right knowledge. The health workers explained that facility review meetings are useful for peer learning because those health workers lacking the right skills can learn from their peers. When health workers described the lack of capacity and necessary skills among other health workers, they did not frame it as a lack of competence or ignorance. Rather, health workers described the lack of knowledge among other health workers using seemingly positive phrases such as "*some health workers have gaps in their skills*" (Felistah, health worker) or *"the review is a great learning opportunity for health workers*" (Solomon, health worker). A health worker described the lack of knowledge among other health workers.

> We know that not all health workers are equal […] some have more skills and experience than others. Through MPDSR, we can identify the gaps that some health workers have; that way, they can learn and rectify them. It usually helps, with every review, health workers gain knowledge (Julius, health worker).

From these comments, the health workers perceive their lack of knowledge through a different lens from community members' lack of knowledge. Health workers use vocabularies of incompetence to label the lack of knowledge among community members using negative framings such as negligence and ignorance while labelling the lack of knowledge among health workers as a "*skills gap."*

Health workers position themselves as competent with respect to managing their emotions during MPDSR sessions. In several interviews, health workers explained that they sometimes experienced strong emotions, such as grief after an adverse outcome, as well as at MPDSR sessions. A health worker explained that many frontline health workers had an emotional connection with the bereaved relatives because they knew the pregnant woman before an adverse outcome, e.g., interacting during ANC visits. Some health workers explained that they had even attended the funerals of some of the deceased women. Health workers explained that despite experiencing negative emotions (such as grief, guilt, and anger), they manage their emotions and participate in death review meetings. A health worker described the emotional difficulties that health workers face, commenting, "In *some instances, health workers cry […], but you still have to go to the review meeting because it is your job […]*" (Oliver, health worker).

4.3.2 Using labels of (in)competence to rationalise health education during MPDSR sessions.

Health workers explained that MPDSR sessions are useful for highlighting the lack of knowledge among community members and the necessity of using MPDSR sessions to disseminate information on the MPDSR recommendations. A health worker explained:

> From the review sessions we know community members need a lot of health education because they are ignorant. We have realised that in some cases, in fact, in all cases, the death is attributable to the delays in community decision-making. It falls in the community. […] We [health workers] make MPDSR recommendations, such as the importance of timely delivery at a health facility, and we educate the community (Gavin, health worker).

Health workers use MPDSR sessions to educate bereaved relatives when they (bereaved relatives) participate in review sessions at the health facility. Bereaved relatives explained that the health workers emphasised the need for community members to comply with the advice given by health workers without question. An interviewee described his experience receiving health education during a facility review meeting as follows:

> At the review session, health workers told us [bereaved relatives] to stop being ignorant and listen to what health workers say. We [bereaved relatives] should not argue with health workers […] because health workers know the best way to prevent deaths. […] this arguing with health workers is what causes deaths (Kevin, bereaved relative).

In the excerpt below, a bereaved relative explains how health workers used the review session to warn other community members about the dangers of not listening to health workers. The interviewee commented:

> When I attended the death review session, health workers had the chance to tell me what caused my son's death. Health workers told me that because I have heard the reasons why my child died, I should go and tell others in the community to listen to what health workers say. […]. Health workers said that deaths happen because people do not listen to them (Gabriel, bereaved relative).

Health workers drew on the Community Strategy (76) to describe the approaches they use to educate the community on issues related to MPDSR. Health workers explained that they relied on community representatives whom they invited to MPDSR sessions to go back and educate the community. A health worker explained that the county health management team had successfully advocated with members of the county assembly (MCAs) to allocate funds for implementing the Community Strategy. The interviewee further explained that the county health team had money to pay CHVs so that they (CHVs) could give health education to community members. Another health worker reiterated that health workers leverage the implementation of the Community Strategy to support health education. He commented:

> We are implementing the Community Strategy so that, as health workers, we can reach every household. We have a budget to give stipends to CHVs to do their work. We invite community representatives to review meetings so that they can support us in giving health education and supporting households in matters of health especially maternal and child health. CHVs are our representatives in the community. Health workers make recommendations during MPDSR sessions. […] We task CHVs to discuss these recommendations during social autopsy sessions and when they visit pregnant women at home (Solomon, health worker).

Health workers use MPDSR sessions to educate community representatives. In the excerpt below, the interviewee frames the MPDSR session as an opportunity to address the religious leader's perceived ignorance by educating him. Health workers also expect the religious leader to pass on the knowledge (i.e., MPDSR recommendations) he acquires from the review meetings to others in the community.

> This community believes in the happenings of God and that death was God's will. But we [health workers] invite the religious leader to the review meeting so that they can stop this ignorance. We [health workers] want religious leaders to see that it is not up to God. God does His part, and we do ours […] We want the community to know that they can do something to prevent deaths. […]. We educate the religious leader so that when he is preaching, he can talk about what we discuss at the meeting [the MPDSR recommendations] to others in the community (Jane, health worker).

Health workers expect community representatives to transfer information on MPDSR recommendations from health workers to community members. Health workers explained that they invited different community representatives, such as CHVs, religious leaders, chiefs, political leaders and CSO representatives, so they could use different spaces to educate the community. A health worker explained:

> We [health workers] invite community representatives to MPDSR sessions so that we can expose community representatives to the discussion at review meetings, and they [community representatives] can listen to us. We want them [community representatives] to go back to the community and educate them [community members] (Joseph, health worker).

Community representatives described their positions in MPDSR as competent intermediaries who transfer health education from health workers to community members. A CHV described herself and other CHVs as more knowledgeable than others in the community. She explained: "*as a CHV you must know more than other community members […] you must be able to teach the community and tell them what health workers have said […]* Rebecca, CHV.

The flow of health information relating to MPDSR recommendations is uni-directional, moving from health workers to community members via community representatives. In their interviews, community representatives gave many examples of their experiences giving health education to community members during social events such as funerals and religious meetings. Community representatives described health education sessions, where they told community members about MPDSR recommendations they had received from health workers. This excerpt is typical of the comments by different community representatives regarding educating the community. See excerpt:

> At the social autopsy session, we [CHVs] explain to the bereaved relatives and other community members about the causes of the deaths and how to avoid them in future. For example, if a mother loses her newborn, we talk to her and teach her so that she can change her behaviour and enter her into the system[19] she needs to do the right thing […]. We [CHVs] want the bereaved relatives to follow our advice [the MPDSR recommendations] that we are giving... (FGD, CHVs).

Health workers leverage the social positions of some community representatives, such as elected leaders, because they (elected leaders) can reach more people than health workers can. In an interview, an elected leader explained that he uses his position to support health workers to pass on MPDSR recommendations. The elected leader explained that because of his social position, his presence at social events attracted more community members than those attending health education sessions organised by health workers. The interviewee described social events as opportunities for community members to listen to him as he transferred health information he had received from health workers.

> Most times, we raise these issues on occasions when members of the county assembly (MCAs) are attending, and we have a ready audience […]. MCAs are respected, and many people don't get a chance to see them [….]. We use social events where elected leaders are invited because many people will come to listen to the

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[19] The exact translation of this phrase "*kuinigiza mtu system*" is sheng for forcing someone to do something or coercion. The phrase is also used to mean manipulation and has notions of getting people to do something without the choice to opt out.

> elected leaders. You find that if there are open days [maternity open days] at the health facility, the community attendance is very poor. You can get a day that the facility is conducting sensitisation or health education, and you only get 20 people. We [elected leaders] use forums like funerals to tell community members what health workers want them to know. For example, we tell women to deliver in a health facility (elected leader community representative).

Community representatives position themselves as being responsible for ensuring that community members comply with MPDSR recommendations. CHVs use persuasive techniques such as household surveillance, soft coercion and threats of reporting community members who fail to comply with the recommendations. During interviews, MPDSR committee members (both community representatives and health workers) explained that the most common recommendations from MPDSR sessions are (i) to encourage women to give birth at health facilities and (ii) to encourage the uptake of ANC services. The MPDSR committee expects CHVs to ensure community members comply with these recommendations. At an FGD, CHVs described how they go beyond providing health education to checking the pregnant woman's health records (i.e., ANC booklet) to ensure she is not defaulting. The ANC booklet shows how many ANC visits a pregnant woman has attended. Every pregnant woman is expected to go for ANC services at least four times during pregnancy. CHVs are expected to encourage pregnant women to attend ANC by providing health education.

CHVs (at the FGD) explained that when women failed to comply with these recommendations, they (CHVs) use social pressure of powerful people in the community to encourage compliance. For instance, the CHVs threaten to report the non-compliant woman to health workers, village elders or the chief, who then coerce the woman to comply, e.g., threats of arrest. See excerpt:

> As CHVs, we identify the households where there is a pregnant woman. We visit households every month and keep a record of health data, like if there is a pregnant woman, has she gone for MCH [ANC]? Then we check her ANC attendance booklet

> to see if she is defaulting and ensure she attends clinic. We also mark her expected date of delivery and will follow up to remind her to go to the facility for delivery. […] If she refuses to comply with our advice, we [CHVs] can inform the village elder or the chief and health workers to help us talk to her and make sure she goes (FGD, CHVs).

Health workers explained that community representatives can enforce compliance with MPDSR recommendations if community members are perceived as uncooperative. The interviewee (health worker) gave an example of a maternal death review session where the MPDSR committee concluded that the death had occurred because a husband had delayed consenting to a caesarean section. The interviewee explained that the community representatives (part of the MPDSR committee) insisted that a recommendation be made to allow community representatives to consent on behalf of women whose relatives delayed or were unwilling to consent to medical procedures. See excerpt:

> Community representatives are very committed to preventing deaths. […] We had a maternal death review here last week. We [the MPDSR committee] looked at the patient's case notes, and there was a delay in the family giving us consent for a caesarean section. So, the religious leader and the chief who were attending the meeting on behalf of the community asked why we didn't call them before the woman died because they would have consented on her behalf. They [chief and religious leader] said next time a husband refuses to consent, call us, and we will give consent (Joseph, health worker).

4.3.3 Community members using vocabularies of incompetence.

Community members also used vocabularies of incompetence to label health workers as incompetent listeners because even though community members share their lived experiences, health workers do not seem to actually hear what community members say during MPDSR sessions. Community members described instances where they had suggestions they could share during review sessions, but they (community members) held back because they did not think health workers would actively listen and understand what they were saying. At the co-production workshop, community members participating in the round table discussions shared their perceptions of health workers, describing them as *“[health workers] cannot listen to you, so why bother telling them what you think?”* Community representatives such as CHVs described their participation experiences primarily as opportunities to listen to health workers and relay the information to community members. As I will show in chapter 6 of this thesis, while health workers expect community representatives to channel feedback about services from community members to health workers, in most cases, they disparage the feedback and do not act on it.

In some of their comments, community members position health workers as arrogant and people who do not consider the suggestions from community members to be important. In an interview, a community member described health workers as “*people who cannot listen because they think they are always right…you can’t tell them what to you think*.” (Orpah, bereaved relative). At an FGD with community members who participated in a social autopsy session, I asked the FGD participants if they felt that they could make suggestions on how to prevent maternal/perinatal deaths. One FGD participant reckoned “*you know, they say a health worker is always a health worker, they think they are the only ones who know, so you can’t come to the meeting [social autopsy] to tell them…” (community members, FGD).* The comments from the community members could mean that the FGD participant positions health workers as people who disregard the possibility that community members can contribute to discussions during MPDSR sessions and that community members hold back from sharing their perspectives.

Community members also frame incompetent listeners as health workers who allow community members to speak during review sessions but ignore the contributions that community members make. I had an interview with a bereaved relative who had been invited to a review session, but he chose not to participate. The bereaved relative explained that health workers disparage the knowledge contributions from community members by pretending to listen but not valuing the suggestions that community members give. When I asked him if health workers listen to suggestions from community members, he laughed and said:

> [laughter] it may be possible for health workers to listen to suggestions from community members because it is the polite thing to do. But you know the system here [study locations] health workers will listen and still ignore the suggestions. They may know that people have useful suggestions, but they [health workers] will not necessarily listen. Most of the time, health workers won't take the suggestion even if it is a good one. It is their nature to ignore people (Simon, bereaved relative).

4.4 Vocabularies of credibility

At the beginning of this chapter, I explained that health workers and community members bring different forms of knowledge to MPDSR sessions. One form of knowledge is held by health workers and is characterised by clinical knowledge of maternal and newborn health and tactical knowledge of how the MPDSR policy process works. The other form of knowledge is based on community members' lived experiences of the pregnant woman's community life and her interaction with the health system before an adverse outcome.

Health workers use vocabularies of credibility to position and value different forms of knowledge based on perceived usefulness, reliability, and relevance for reviewing deaths and making recommendations. Health workers use their positions and tactical knowledge of the MPDSR process to determine the credibility of different forms of knowledge. The ways in which health workers interpret the value of different forms of knowledge influence how they document and report the different forms of knowledge to higher levels of the health system as part of the MPDSR process.

Community members also use vocabularies of credibility to question the relevance of some of the MPDSR recommendations they receive from health workers because the recommendations do not align with their (community members) lived experiences. In the sections below (4.4.1 and4.4.2) I present excerpts from interviews and FGDs to illustrate study participants' use of vocabularies of credibility.

4.4.1 Health workers use vocabularies of credibility to question the value of community members' knowledge.

Health workers used vocabularies of credibility to question the lived experiences of community members as a valuable form of knowledge that could be used to make recommendations during MPDSR sessions. Health workers label community members' knowledge based on lived experience as *'stories'* while describing biomedical knowledge as evidence-based '*data.'* The labels have notions that some forms of knowledge are more useful for generating MPDSR recommendations than others. In the excerpt below, the health worker explains that inviting community members to a death review meeting is an opportunity for health workers to gather knowledge about the lived experience of community members. This comment is quite typical of how health workers describe experiential knowledge from community members. Health workers described experiential knowledge using phrases such as "*the community tell us A to Z of what happened before she died, […] they tell us the whole story"* (Oliver, health worker) or "*we want to hear their side of the story […] we want to know what happened before the death*" (Solomon, health worker). From their comments, health workers frame knowledge based on lived experience as stories and opportunities to fill in gaps in the information that health workers already have. A health worker commented:

> We [health workers] invite community members to MPDSR sessions so that we can get a full picture of the woman's pregnancy journey. As health workers, we may not know what happened before the woman came to the health facility. […] CHVs and birth companions [TBAs] have more details, and we talk to them, and we get more information (Peris, health worker).

Health workers describe the proceedings of facility death review sessions using labels such as "*data"* and "*evidence"* to describe biomedical knowledge. A health worker explained that the MPDSR committee has data from facility review sessions that they (the MPDSR committee) use for "*evidence-based advocacy*" (Solomon, health worker). At an FGD, health workers discussed how they use health records to review deaths and prevent future mortality. The FGD participants talked about using the data for learning during MPDSR sessions. One FGD participant said:

> When MPDSR was introduced, we [health workers] went back to the records in maternity ward. […] We realised we had data on so many maternal and perinatal deaths already. But we had never sat down to look at the data and understand what it means. Through MPDSR, we can now look at our data and understand what is contributing to the deaths (FGD, health workers).

Health workers use biomedical tools to account for the higher status they give to their knowledge compared to community members' knowledge. Health workers felt that the records they kept before an adverse outcome (such as patient notes and partographs) were reliable sources of information that could be used to produce knowledge during MPDSR sessions. In the excerpt below, the health worker accounts for the reliability of the evidence based on what is written in the file and not what participants say at the meeting. See excerpt:

> At the review, we [the MPDSR committee] use what is written down in the patient case notes. […] There was a review where a CHV said that the mother [maternal death] was a sickler [suffered sickle cell anaemia], but it was not written in the file […] I tell the MPDSR committee we can't discuss things not in the file. The file tells us what happened, so we need health workers to make sure they write down everything (Felistah, health worker).

Health workers also account for credibility of knowledge based on the tools used to report the findings of MPDSR sessions to higher levels of the health system. In the background chapter of this thesis, I explained that Kenya has a six-tiered health system ranging from level

1 to level 6 (74). Community-based reviews through verbal or social autopsy are held within the community (level 1) with the support of health workers based in primary care facilities (levels 2 and 3). Primary care facilities (levels 2 and 3) are also expected to conduct death review sessions for any deaths that happen in the primary care facilities. The national MPDSR guidelines state that reports from the community up to level 3 health facilities must be submitted to the sub-county MPDSR committee (level 4). The sub-county MPDSR committee collates all MPDSR reports from community-based and facility-based reviews and submits them to the county MPDSR committee (level 5). The county MPDSR committee is also expected to collate all sub-county MPDSR reports plus the MPDSR reports from the referral hospital and submit these to the national MPDSR committee.

This reporting structure serves two purposes. One is performance accountability, by ensuring that MPDSR meetings are held and reported as mandated by the MPDSR policy. Secondly, the MPDSR reports are used by decision-makers for policy direction, improving quality of care, resource allocation and reporting to global offices such as WHO. Health workers in this study use this structure to submit MPDSR reports based on biomedical knowledge but leave out community members' knowledge from the process as I illustrate below.

Health workers explained that MPDSR committees use different reporting structures when submitting MPDSR proceedings or reports[20]. Health workers describe knowledge produced from facility-based death review meetings as authentic data they upload onto the DHIS2. An interviewee explained that data uploaded on DHIS2 is accessible to anyone who can log on to the system. The interviewee also describes how health workers use data from

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[20] MPDSR reports are also referred to as MPDSR proceedings, they contain details of what was discussed at an MPDSR session plus any recommendations that were made in light of the deaths reviewed at that session.

the DHIS2 to lobby decision-makers for resources to implement MPDSR recommendations. See excerpt:

> Yes, we [the MPDSR committee] have data. It is not something we have cooked. […] The data is there […]. Anybody can log onto the DHIS and get the information. We upload data from facility review meetings […] we have examples of how we use the data to lobby decision makers in the county like members of the county assembly to allocate funds to implement our recommendations. […] (senior health worker).

Health workers explained that reports from community-based reviews are treated informally, and the reports are not submitted to higher levels of the health system. In several interviews with health workers, I asked how the information from CVA questionnaires is used. Interviewees (health workers) informed me that the CVA questionnaires and reports are kept in a file at the primary care facility (usually level 2 or 3) but are not uploaded on DHIS2 as expected.

At another interview with a national-level MPDSR committee member, the interviewee confirmed that the data on the DHIS2 was only from facility death review meetings but not community-based reviews such as CVAs. The interviewee explained that the national MPDSR committee uses the data uploaded on DHIS2 to conduct the national confidential enquiry into maternal and perinatal deaths. The national MPDSR committee also uses data on DHIS2 to compile national and global reports on MPDSR to bodies such as WHO for accountability. The interviewee (national MPDSR committee member) commented that the national committee worked on the assumption that CVA sessions were not being conducted anywhere in the country because the data was not available. However, as I have shown in this chapter, community members and health workers shared their experiences as participants in CVA sessions. I also observed a CVA session for a maternal death in real time, but there appears to be a difference in how reports from these MPDSR sessions are reported and used.

4.4.2 Community members questioning the credibility of knowledge processes

Community members used vocabularies of credibility to question the validity of some of the MPDSR recommendations they received during community health education sessions. A community representative described his experience giving health education to community members at a social autopsy session. The community representative explained that there were instances when community members doubted or questioned the notion that following the MPDSR recommendations could prevent deaths. He commented:

> At social autopsy meetings, we [community representatives] tell community members that it is important for women to give birth at health facilities. But the community members ask us if we are [MPDSR committee] are 100% sure that if the mother had come to the hospital she would not have died. […] some community members even say so and so went to the health facility, but they still died […] (David community representative).

Community members do not necessarily accept all the health education messages they receive from health workers. Community members felt that health workers had not taken their lived experiences into account when making MPDSR recommendations. In some instances, community members questioned and contested some of the MPDSR recommendations by not adopting them. Community members use vocabularies of credibility to filter out parts of MPDSR recommendations that do not align with their lived experiences. At an FGD, I sought to understand the experiences of community members attending a social autopsy session in their village. A FGD participant narrated her experience of giving birth at a health facility. The FGD participant questions the recommendations because of her lived experience of losing a child due to perceived poor care at a health facility. For this participant, her lived experience contradicts the recommendation that giving birth at a facility is necessary to prevent deaths. The FGD participant questions the recommendations provided by CHVs and health workers and draws her own conclusions based on her lived experience. See excerpt:

> Speaker 1: Two years ago, I went to deliver at the health facility. When I was in labour there was only one nurse, and we were five women giving birth that night. The nurse delayed, and my baby died during the birth. So, after that, I decided that I will go to the clinic [for ANC] but I will deliver with the help of a birth companion [TBA]. Because having one nurse at the clinic made me lose a child, the birth companion is only focusing on me, but the nurse has to look after several women. So even when I went to the meeting [social autopsy session] and the CHVs say that women should deliver at the health facility, I will not do that. But you know you can't say that at the meeting. You cannot start disagreeing with the CHV and health workers at the meeting. I gave birth to this healthy baby [pointing at her child] with the help of a TBA (FGD, community members).

Community members cannot contest the credibility of MPDSR recommendations openly. From the excerpt above (FGD, community members), the speaker does not agree with the recommendation on the importance of giving birth at health facilities. Despite having knowledge based on her lived experience, the FGD participant reports that she cannot share this knowledge and contradict the recommendations CHVs and health workers provided.

At the same FGD, other community members explained that they cannot contradict health workers even if they disagree with the MPDSR recommendations. Another FGD participant (community member) explained that contradicting health workers could have future repercussions. The FGD participant commented: "*if you are going to disagree with what health workers are saying or say something negative about the health facility during the meeting [social autopsy meeting], you had better be sure you are done giving birth because if the health worker takes note of you, you will be in trouble."* (FGD, community member). The comments show that community members feel they have to be careful about what they say at MPDSR sessions. The remarks of the FGD participant above show that even when community members question the relevance of MPDSR recommendations, it is difficult for community members to openly contest MPDSR recommendations given by health workers.

Some community members question health workers' competence in delivering health services, which shapes community members' trust in the credibility of the advice provided by health workers. At the co-production workshop, three husbands whose wives had died during childbirth narrated how they had tried to comply with MPDSR recommendations regarding giving birth at health facilities. The three husbands explained that before their wives decided to go to TBAs, the women had gone to a health facility but had been sent back home because they were not in labour. The husbands then explained that their wives had each gone into labour that same day and had decided to go to TBAs because they felt that health workers were incompetent. One of the husbands commented: "*It is like they [health workers] are confused […] they don't know what they are talking about* (John, bereaved relative). Another bereaved husband contributed to the round table discussion and said:

> Health workers do not seem to know what they are doing […] they do not know when a woman is in labour, you use your money and go to the health facility, then they send your wife back home […] on the same day, the baby came and we went to the TBA and when she died, they came to my home [for the CVA], and they [health workers] said it was my fault for taking her to a TBA (Irvin, bereaved relative).

Community members question the credibility of some of the MPDSR recommendations made during MPDSR sessions because they felt that health workers filtered out some details of community member's lived experiences during the discussions at the review. Some bereaved relatives had doubts about the relevance of some of the MPDSR recommendations because of the filtering process. A bereaved relative described how health workers selectively chose parts of her narrative and ignored others when she participated in a death review meeting at the health facility. In her interview, the bereaved relative, whom I shall call Rachel, narrated her experience after the death of her baby. Rachel described her experience at the health facility where she had delivered her baby and where the review was done. She explained that at the review meeting, she was asked to describe her pregnancy and birth experience, which she did. At the interview, Rachel described what she narrated to health workers during the death review meeting. She explained that she had gone to the hospital before labour progressed, and she was admitted. She had prolonged labour, but she eventually delivered a live baby. Rachel said that health workers recommended that the baby stay in the neonatal unit for observation. On the day that her baby died, there was a power blackout at the hospital. While the hospital has a generator to provide backup power, it was not switched on, and the electrical equipment in the nursery went off. When Rachel checked on her baby, she found one health worker looking after many babies that night. According to Rachel, five babies died that night. Rachel was later invited to a review meeting at the health facility. At the interview, Rachel commented that the health workers ignored the parts of her story that she thought had contributed to the death. Rachel explained that health workers did not discuss the issues to do with (i) power failure, (ii) the failure to switch on the generator, (iii) the overworked health worker or (iv) the other four babies who died that night. She explained:

> Health workers told me that my baby died because I had prolonged labour. This was four days after my baby was born. On the day my baby died, four other babies died, and I don't think all the mothers had prolonged labour […]. I know my baby died because of the power blackout. It is also very difficult for one person to look after so many babies. I know women who have twins, and they say looking after two babies is hard, so how can one person look after many children? (Rachel, bereaved relative).

Later in the interview, Rachel questioned the credibility of the records from the review meeting because of her perception that health workers filtered out some details. She commented "*these meetings [death reviews] are important, but only if health workers look at what happened and write in the file. So that if another case happens, they can know. But if they [health workers] write what they want, and nobody looks at the file […], how will they [health workers] learn*? (Rachel, bereaved relative).

4.5 Vocabularies of exposure

Community members used vocabularies of exposure to question the intentions of health workers during MPDSR sessions. Community members described MPDSR sessions as opportunities for health workers to expose or uncover community practices that they (community members) prefer to keep hidden. Community members associate disclosing some forms of information or practices with social and legal risks. The notion that MPDSR sessions are spaces where hidden community practices can be exposed is problematic for community members because of the perceived public disapproval and loss of social esteem. Community members and bereaved relatives described some forms of death as a social disgrace and dishonouring to the bereaved family. Interviewees expressed feelings of shame when describing people in the community who had died after abortions or those who were suspected to have HIV. Bereaved relatives explained that they did not want to participate in MPDSR sessions if their relative had died due to a socially stigmatising event, such as an abortion, because of the shame the family would experience.

Conversely, health workers framed this exposure as positive by explaining that uncovering hidden practices is necessary for knowledge co-production. Health workers felt that the MPDSR process creates opportunities for open discussions between community members and health workers, which could facilitate co-learning. The comment from a health worker below is typical of how health workers used vocabularies of exposure. The comment illustrates that for health workers, exposing hidden community practices is a positive thing that could improve the process of knowledge co-production. See excerpt:

> MPDSR sessions have helped me in my role. Sometimes, there are things that community members do in the village, and as health workers, we may not know about them. […] having MPDSR sessions has helped me to understand, for example issues of abortions, teenage pregnancies […] or teenagers who are pregnant, but we don't know where the babies go […]. All these things are happening in the community, and we [health workers] don't always know about them. Community members hide some of these things. […] But now, with MPDSR, we have a system of tracking and reporting births and deaths in the community and forums such as social autopsy sessions […], and these hidden things are brought out. The issues become clear to us (Oliver, health worker).

Study participants described how community members manage the risks associated with exposure. In some instances, community members refuse to attend MPDSR sessions. In other instances, health workers described community members as disruptive or felt that community members withheld information during MPDSR sessions.

I had an interview with a community member whose relative died after abortion-related complications. Early in the interview, the interviewee distanced himself from the deceased woman, casting doubts on the legitimacy of the woman's marriage to his brother. He explained:

> [speaking hesitantly] You know that girl [the deceased] was not even really my brother's wife because he had not stayed with her for very long; we [the family] didn't know her very well. We just heard she got sick and went to hospital. It is very shameful to die like that. […] Health workers wanted to talk to us [the family] about the abortion. They wanted to know who in the village does abortions, but we could not talk about it. Her husband was away at the time, so he didn't know anything. Her parents refused to talk to anybody. Health workers called me, but I said I didn't know anything. […] We just buried her and finished that story (Mike, bereaved relative).

Community members described MPDSR sessions as opportunities for health workers to investigate some community practices, such as providers of abortion services. For instance, in the quote above, the speaker describes the family's sense that health workers wanted information on where the abortion was procured. The interviewee insists that none of his family members can provide the information that health workers are looking for.

Health workers at the co-production workshop talked about the difficulties of obtaining information from community members on issues relating to abortion. Health workers described different MPDSR sessions where they sensed that bereaved relatives were withholding information on where the deceased had procured an abortion to avoid arrest. A health worker commented: "*abortion is very sensitive for the family […] usually when we [health workers] ask questions, the community is quiet, they don't want to talk […] the family would prefer if we* *let the matter die quietly because there is fear that the police will be involved*" (health workers, co-production workshop).

Community members said that health workers can use information revealed during MPDSR sessions to sanction bereaved relatives or community members. A community representative explained that bereaved relatives refused to disclose the identity of traditional birth attendants (TBA) if an adverse outcome is associated with a TBA delivery. The community representative commented: "*you find that families will notify health workers about a death, but they will be careful so that in the process health workers don't unearth the TBA who helped the mother, because that can cause problems for the TBA*" (Zack, community representative).

Health workers explained that they use MPDSR sessions to identify TBAs who provide birthing services in the community. While childbirth with TBA support is not illegal, health workers and community leaders such as chiefs discourage the practice because of the perceived risks associated with TBA services. In several interviews, health workers made comments of unspecified threats to TBAs who provide childbirth services, such as *"if at a review we hear of a TBA providing services, we will deal with that TBA"* (Charles, health worker). Some community representatives also commented on how they would deal with TBAs by "*reporting the TBA to civil administration."* (Robert, community representative).

Health workers and community representatives described social autopsy sessions as open forums where community beliefs and practices can be debated publicly to co-produce knowledge. However, some bereaved relatives associate the public discussions during social autopsy sessions with public humiliation. Health workers explained that they anonymise information on a maternal or perinatal death before a social autopsy session. However, according to CHVs and community members, those attending a social autopsy session tend to know the families that have experienced maternal and perinatal deaths. Some health workers acknowledged that anonymisation did not always work because people in the village know each other and the information on maternal and perinatal/neonatal death is displayed on the community chalk board[21]. An interviewee (health worker) explained that community members labelled health workers as "*malicious*" for the perceived broadcasting of the details of a maternal or perinatal death. A bereaved relative explained that she had not attended a social autopsy session to discuss the death of her newborn because she wanted to avoid public humiliation. She commented: *"I would not want people to discuss my case at a social autopsy session. People will talk about me and say that I am not a competent woman because I didn't look after my baby well. I don't want people to talk about me"* (FGD, bereaved relatives).

The perceived risks of exposure during MPDSR sessions create tensions among MPDSR committee members. At the co-production workshop, a health worker shared an experience of a community representative disrupting a review session because the review was about his (community representative) relative's abortion-related death. The relative is also a community representative and sits on the facility MPDSR committee. According to the health worker, the community representative was very hostile during that review session and would not accept the health worker's accounts of what had led to the death of his relative. According to the health worker, the bereaved relative had previously participated in other maternal death review sessions without showing hostility to health workers. The health worker explained that the community representative disrupted the review meeting because he (the community representative) felt that the discussion at the review meeting exposed his relative.

> That review session was very volatile. In the end, we did not make any recommendations or action points on how to address illegal abortions because of the arguments that arose during that review session. Even though the health workers at the review had seen the patient's file and knew that the girl had an abortion, her relative [community representative who is also on the MPDSR committee] would not accept that the girl had been pregnant. The relative was uncooperative, and in the end, we

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[21] In chapter one, when describing MPDSR implementation in Kenya, I explained that community level data is displayed on a community chalkboard. CHVs use that information to facilitate community dialogue days and social autopsy sessions.

> [health workers] just left the case alone because it was getting very bitter (co-production workshop, round table with health workers).

This chapter shows how study participants use different vocabularies to describe the knowledge production process. There are contradictions between the vocabularies of hope on the one hand and the vocabularies of (in) competence, credibility, and exposure on the other hand. Using these contradictory vocabularies shows that while community members and health workers feel that the MPDSR process could support knowledge co-production, in practice, the opportunities for co-producing knowledge are limited.

5.0 “*We participate, but nothing changes*”: Factors within the health system that affect the participation process.

Chapter Overview

Study participants described two significant challenges in the MPDSR process that affect the participation of health workers and community members in MPDSR. I will present each of these challenges as a separate theme. The first theme focuses on the *principle of no blame and no shame* among health workers participating in MPDSR sessions. The principle of *no blame*[22] among health workers states that the MPDSR process should not be used by anyone to blame or shame health workers for the deaths reviewed during MPDSR sessions. The *no-blame* principle is articulated in the MPDSR policy, and health workers are trained to avoid blame during death review meetings (69,70,72). All the health workers who participated in this study had been trained on MPDSR implementation as part of national government plans to roll out MPDSR throughout the country. In theory, no health worker should have legal action taken against them based on the discussions held at MPDSR sessions neither should other health workers blame a health worker who is linked to an adverse outcome (because they cared for the patient). I will show that the use of the *no blame, no shame* principle is rhetorical, and despite all health workers saying that MPDSR participation is guided by this principle, in practice, MPDSR participation is infused with blame. I will then show how health workers use different strategies, tactics, and tools to manage or avert blame and how this affects community participation in MPDSR.

The second theme focuses on the health system's challenges when implementing MPDSR and how these challenges influence community participation. I will show that the failure to implement recommendations made during MPDSR sessions demotivates health

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[22] While the principle states no blame no shame, in practice literature and practice (e.g., study participants) simply refer to it as no blame. I will use this phrase in this chapter but acknowledge that the term refers to the full phrase of no blame no shame.

workers and community members from participating in MPDSR sessions. Study participants described the opportunity cost of participating in MPDSR sessions, often describing it as a waste of time. Community members described some of their previous interactions with health workers in negative terms, citing disrespectful maternity care or a lack of transparency in how health services are provided. I will show how these past histories of care affect the willingness of community members to participate in MPDSR.

5.1 The rhetoric of no blame among study participants during MPDSR sessions

Health workers explained that the principle of *no blame* is meant to encourage them to participate in review sessions without worrying that what they said would be used to apportion blame. Health workers primarily referred to facility-based reviews when talking about the importance of blame culture. Blame culture in the MPDSR process shapes the actions of health workers before MPDSR sessions and during MPDSR sessions. The flow of blame among MPDSR participants is multidirectional, i.e., health workers blame each other, health workers also blame community members, and community members blame health workers.

The excerpt below is a comment from a health worker. This comment is typical of all health workers who participated in this study. A health worker explained:

> Of course, the essence of the review is not fault finding, at the beginning of each session we assert that this is not a fault-finding mission. We want to establish what the gaps are and how they may have contributed to the death. The review is not meant to punish anyone or blame anyone. We need to reassure everyone so that we can identify the factors that have contributed to the death and address them if they are avoidable (Solomon, health worker).

Community members did not refer to the no-blame principle during their interviews or FGDs. This could be because the *principle of no blame is part of the MPDSR implementation guidelines and policy that* community members would not necessarily know about.

Despite repeated affirmations on the importance of no blame, health workers gave examples of MPDSR sessions they had participated in where blame was evident. In some instances, health workers blamed other MPDSR participants (both community members and health workers) attending the same MPDSR session, while in other cases, health workers blamed people (health workers and/or community members) who were not at the session.

A health worker described MPDSR sessions as opportunities for fault-finding by senior consultants (obstetricians and paediatricians). A health worker explained that most junior health workers (mainly nurses) feared what the senior consultants would say at the review. The health worker described the MPDSR sessions as opportunities to point out junior health workers' mistakes. The interviewee described the consultants as "*super medics"* who told off junior staff during the MPDSR session with other people present. The interviewee further explained that junior health workers avoided attending MPDSR sessions when more senior consultants were participating to avoid the embarrassment of being called out during the meeting. He commented:

> Sometimes, the super medics [consultants] come to the review meeting to listen, and they tell us [junior health workers] what we did wrong. […] The consultants can lecture you [junior health worker] in front of everybody. People [junior health workers] do not want to attend the review if consultants are coming (Julius, health worker).

Another health worker commented:

> We have problems with people [nurses] attending review sessions, and even getting a quorum for the MPDSR meeting is hard. Especially when senior health workers [consultant obstetricians and paediatricians] attend the review session. The frontline junior health workers fear what the consultants will say. In case they say the nurse caused the death. People [nurses] are afraid to come. Even when we say that the meeting is not meant to be punitive, it can be punitive […] (Jackie, health worker).

In the following sections (5.1.1-5.1.4), I will show how blame culture affects the participation of both health workers and community members in MPDSR. I will then describe the study participants' tactics and strategies to manage or avert blame.

5.1.1 Blame culture affects interactions during MPDSR sessions.

Health workers explained that blame during MPDSR sessions affects them professionally and personally. Health workers described their participation experiences in facility review meetings as difficult and unfair, while others said they felt harassed due to issues relating to blame. Health workers rationalised their decisions not to invite community members to facility review meetings because of the potential risk that community members would blame health workers for the death.

Some health workers explained that apportioning blame during participation was unfair for some cadres, such as nurses, compared to doctors. I facilitated an FGD with nurses who had previously participated in health facility review meetings at different levels of the health system, ranging from level 2 dispensaries to the county referral hospital. In their discussions, the nurses shared their perceptions that doctors blamed nurses during MPDSR sessions. The FGD participants described how MPDSR participants filter the recommendations in ways that protect doctors from being blamed. See excerpt:

> Nurse 1: on the issue of blame game. I think it is very central because whenever we have these MPDSRs, you will see from the discussions each cadre of health staff is trying to look for a way out of the review […]
>
> Nurse 2: in most cases, you will find that the doctor is delayed in coming [to provide care for a mother/newborn] or unavailable. The nurse can say everything she did to try and help the mother, but when you go to the recommendations, they hardly mention what the nurse did [to manage the situation] or that the doctor delayed. Which means the doctor is presumed to be perfect. Anybody else can be blamed, but not the doctor (FGD, health workers).

In an interview, a nurse explained that doctors would attend review meetings and blame nurses for mistakes doctors had made. The interviewee explained that being blamed for the death during a review session can have professional repercussions such as receiving warning letters or disciplinary action for the nurse. She explained:

> Yes, it [blame] happens. Mostly, when doctors make a mistake, they say nurses made the mistake. At the review meeting, doctors will say the patient's vital signs were not taken properly, which resulted in the death. If the nurse did not monitor the patient, you are given a warning. If you repeat a mistake, you are given a show cause letter by the management of the facility (Jane, health worker).

Some health workers interpret the no-blame principle as a way of accepting negligent actions from health workers, but some nurses seem to struggle with this view. The FGD participants perceive that some doctors are negligent but cannot be dealt with because of the no-blame principle. At the FGD, the nurses discussed their previous experiences at MPDSR sessions, where the review sessions had identified delays in providing care as the contributing factor to the deaths. In their discussions, the nurses talked about the perceived negligence of a doctor who had been mentioned at several MPDSR sessions for failing to provide care. The FGD participants questioned the no-blame principle and perceived no-blame as a way of overlooking the perceived negligence of some health workers. See an excerpt from their discussion.

> Health worker 3: […] I also have issues with this no-blame approach and the process not being punitive. I think sometimes people [health workers] should be blamed and dealt with especially if it is obvious negligence […].
>
> Health worker 2: We have several reviews, and the problems come back to the same doctor [mention doctor’s name]. I have had several cases where you call the doctor, prepare the patient for theatre and the doctor does not come […]. We have a review meeting [….] but we are not addressing the issues within the health facility that contribute to the death. We do not talk about why the doctor is called and he does not

> come or does not pick his phone […]. I think there should be blame (FGD- health workers).

From the comments of the health workers in the excerpt above, even when nurses thought that doctors had been negligent, the participants at the review meeting did not discuss the perceived negligence of the doctor. There was no indication from any of the interviews and FGDs that I conducted that doctors were blamed or ever faced repercussions based on the proceedings of a review meeting, but several nurses/midwives were blamed or had faced repercussions.

Health workers also struggled with emotions such as anger during review meetings because they felt blamed by other health workers at the review sessions. A health worker explained that he was angry during a review session because other health workers were "*malicious"* and blamed him for contributing to a death (Joseph, health worker). Another health worker described her experience during an MPDSR session as "*acrimonious"* because the participants of the review session blamed her. In the interview, the nurse described how she had cared for a pregnant woman and recommended a caesarean section for her. The nurse explained that she had then called a doctor, but the doctor delayed in coming. Much later, the mother was taken to theatre, but she succumbed. A maternal death review was organised. The doctor leading the review session (not the one who did not attend to the mother in distress) blamed her for "*wasting the doctor's time and not doing her job properly and was then told to give a formal apology to the doctor for her actions [….*]." At the interview, the nurse commented:

> At the review meeting, I felt very angry and humiliated. Even though I did my work well, I called the doctor on time, the people at the review meeting still blamed me instead of the doctor who delayed in performing the caesarean section. I was also upset that I had to write a letter to apologise to the doctor for wasting his time […]. But I do not think I did anything wrong (health worker).

Some health workers experienced self-blame- even though other health workers at a review meeting did not blame them, they blamed themselves. In an interview, one health worker described how the review process had shown that some clinical errors had contributed to a death. At the interview, the health worker said she recognised that if she had done things differently, the death could have been prevented. The health worker explained that she felt remorse and guilt over the death. She commented:

> There was a time I attended a review of a mother to whom I had provided care. During the review, I realised what went wrong and what I should have done. I started asking myself questions- now, what did I do? I felt bad [...] even if the other people at the review meeting did not blame me. I asked myself questions. I blame myself. But I must live with it. (health worker)

At the co-production workshop, health workers talked about how they struggled with self-blame for some maternal or perinatal deaths. The health workers also described the emotional difficulties they face due to blame (from others or themselves) and the lack of support for health workers to cope with the guilt arising from self-blame.

A senior health worker explained that senior management recognised the emotional difficulties frontline health workers face because of having to participate in frequent MPDSR sessions related to the high number of deaths in the county. The interviewee explained that while it was unfortunate that health workers struggle emotionally, MPDSR sessions still need to be held because health workers have an obligation to submit MPDSR reports on time.

Health workers also felt blamed by community members. Study participants (both community members and health workers) described instances where community members had taken legal action against health workers. None of the community members who participated in this study had taken legal action against health workers, though several respondents (bereaved relatives) said they had considered going to the police. Several interviewees were aware of instances in the community where health workers had either been arrested, or legal action had been taken against them after maternal/perinatal deaths. Some health workers explained that some community members had launched court cases against a health facility (mainly the referral hospitals) after maternal or perinatal deaths.

Bereaved family members blamed the health workers for adverse outcomes, and this resulted in community members' unwillingness to participate in the review sessions. CHVs explained that bereaved relatives would sometimes be angry with health workers because of the death and would refuse to participate in the review sessions despite being invited. Some bereaved relatives who had been invited to review sessions had chosen not to participate because they did not want to interact with health workers whom they blamed for the death. For instance, Simon, a bereaved relative, was invited to a review meeting at the health facility after the death of his son. From his accounts, even though he was invited to attend the death review meeting at the health facility, he chose not to attend. He explained: "*I did not go to the meeting because it would mean sitting down with health workers and listening to them […] and I do not trust them* (Simon, bereaved relative).

Some community members did not use blaming language when describing their interactions with health workers. Instead, community members talked about holding health workers to account for perceived negligence. Bereaved relatives attending the co-production workshop spoke about the importance of establishing a process for dealing with negligent health workers. Bereaved relatives (round table co-production workshop) felt that MPDSR sessions could be useful for pinpointing negligent health workers, but health workers at the workshop disagreed. The co-production workshop participants did not reach any consensus on reconciling a no-blame discourse that health workers insisted on with the need for accountability that community members wanted.

5.1.2 Tactics that health workers use to avoid or manage blame.

Most study participants who had participated in a facility review session explained that after an adverse outcome, the health workers who had provided care would be in the spotlight. For example, Gabriel a bereaved relative talked about nurses who had provided care before an adverse outcome ‘’*being questioned by the MPDSR committee”* (Gabriel, bereaved relative). Another interviewee talked about health workers at a review session “*deflecting questions to avoid the spotlight”* (Zack, community representative). Health workers also spoke about how the health workers who had provided care would *“avoid attending the review meeting or taking responsibility for the patient”* (health worker, referral hospital).

Some community representatives in the MPDSR committees also described how health workers would avoid attending or contributing during MPDSR sessions. A community representative described health workers' unwillingness to participate in review meetings. He said: “*I feel like some health workers who could shed more light on what happened before a maternal/perinatal death chicken out of attending meetings…” (*Frank, community representative).

In some instances, health workers would attend review meetings but would try to hide in the background during the discussions. A community representative who had participated in several MPDSR sessions described the behaviour of health workers as “*evasive*.” He commented: “*The meetings are sort of punitive, and you can see some health workers deflecting questions and being evasive in their answers so that the discussions spotlight another health worker”* (Zack, community representative).

Some health workers suggested that they can avoid blame by not inviting community members to health facility review meetings. Health workers explained that while the MPDSR policy in Kenya encourages community participation, not all health workers are comfortable with this policy. In practice, community members (bereaved relatives and community representatives) attend facility review meetings (e.g., from this study, the bereaved relatives who participated include Gabriel, Irvin, Sue, Rachel, and Kevin; community representatives: Joan, Rebecca, Frank, David, Robert, Zack). There are also instances, where health workers did not inform or invite bereaved relatives or community representatives that review meetings, had been organised, and bereaved relatives such as Nickson did not know if his wife's death was reviewed.

A health worker explained that some health workers worry about community members attending review meetings because it can cause problems in the community for health workers. The interviewee explained that community members would go back to their villages and tell others in the community about what they had heard during review sessions. Most health workers live within the same communities they serve, while others have relatives living in the same villages. The interviewee rationalises not inviting community members to avoid the risk of negative social consequences for health workers or their relatives.

> If there are community members at the review meeting and we [health workers] talk about how a particular health worker was not available to provide services on time, the community member will go back to the village and say so, and so's son [referring to the health worker who is perceived to be negligent] is the one finishing us in this village because he does not do his work properly. This can create social problems for health workers because some health workers live in the same villages. And some have relatives in the same communities. […] We prefer that community members do not attend the review… (Jackie, health worker).

In their interviews, health workers explained that they did not want to invite bereaved relatives to MPDSR sessions to reduce the perceived risk of legal action. A health worker commented:

> We [health workers] do not want bereaved relatives attending MPDSR sessions and listening to the review. […] there is a risk for health workers […] and the process of going to court to defend yourself or being threatened with legal action or being taken to the police is tiring (Solomon, health worker).

Health workers use the MPDSR session agenda to shape their decisions on whether to attend a review or not as a way of avoiding blame. At an FGD with health workers, they discussed how some of them would opt not to attend the meeting after looking at the meeting agenda. The participants at the review meeting are guided by the set agenda to determine which health workers would be scrutinised as the patients they cared for are discussed. Another FGD participant explained that health workers were sometimes vague when describing the circumstances that led to a death. The FGD participant felt that the contributions of health workers at review meetings are not authentic because there is a risk of punishment if one shares the perceived facts of the events before an adverse outcome.

> Health worker 4: On the issue of blame […], health workers do not want to attend [review meetings]. You find that if a health worker knows that their patient's case [maternal/perinatal death] is on the agenda for the review meeting, they do not want to attend. Getting a quorum for the meeting can be difficult […]
>
> Health worker 2: people [health workers] look at the MPDSR meeting as if it is punitive; maybe if you get the health worker who was involved with the patient, he thinks you want to punish him, and people are not willing to give the information of exactly what happened (FGD, health workers).

Health workers from peripheral facilities (levels 2 and 3) disassociate themselves from the patients they refer to referral health facilities to avoid scrutiny of their actions before referral. Health workers explained that death reviews are conducted at the health facility where the adverse outcome happened. In cases where a patient was referred to the referral facility from the peripheral one, the participants at the review meeting looked back at the peripheral health facility, the care provided prior to referral, and the referral process to understand what happened. Health workers from referral facilities felt that staff from peripheral facilities hid some details of what happened before the referral. A health worker explained that staff from peripheral facilities refused to be identified as the person in charge of the referred patient. Health workers from peripheral facilities also considered some review meeting discussions as harassment. A health worker from a referral hospital explained:

> At the referral hospital we find we do not have a full picture of the patient. Maybe the information that is on the referral letter doesn't provide details. You have to probe more so that you can get the right information. Health workers from peripheral facilities sometimes do not want to take responsibility for the patient they are referring so they say I was just called upon to come and refer. So, we at the referral hospital tell them that you cannot just be called upon from the market to refer patients that you do not know. Staff from peripheral health facilities also do not like referring clients here because they feel sometimes, we [at the referral hospital] do not handle them well. This is because we ask them questions during the review meetings. They hide information, so we have gaps, but we keep probing, and they say we are harassing them (health worker).

Health workers shift the focus of the discussion at the review session to avoid scrutiny of their actions before an adverse event because they associate the recommendations made during a review meeting with blame. Health workers participating in an FGD explained that they do not want the recommendations to target their individual actions for something they had either done or failed to do. By shifting the focus of the review so that the recommendations target others (such as community members), a health worker can avoid blame. See excerpt:

> Health worker 1: And then also some health workers run away from having a spotlight on them during the review. Like if the discussion shows that it was a health worker who delayed, and all the people at the review can see it was a delay, each cadre tries to move away from being responsible. […]
>
> Health worker 1: […] Then, at the recommendation, they say the mother should have come to the health facility on time. Or that the CHV should have given health education to the mother […] So, in the end, everything goes back to the CHV and the community. […] the blame remains on the mother and the CHV.
>
> Health worker 2: When you look at the conclusions of the discussions, […] in most cases and very often, you will end up having some broad kind of recommendations that do not really address the issues that led to the death (FGD, health workers).

Health workers rationalised their seemingly harsh treatment of pregnant women during childbirth as a tactic to avoid blame by preventing adverse outcomes. Health workers explained that, in some instances, they faced a lot of challenges when providing care, and this meant they were sometimes harsh during their interactions with pregnant women (before adverse outcomes). Health workers described some patients as "*uncooperative and refusing to push" during labour,* which could lead to an adverse outcome *(*Jane, health worker). Other health workers also explained that the best strategy to avoid being blamed was to avoid being associated with an adverse outcome (Jackie, health worker). The health workers at the co-production workshop described how they avoid blame by being harsh with pregnant women during childbirth. For the workshop participants, the need to avoid blame shapes how they provide care in seemingly harsh ways to pregnant women in the future (i.e., after MPDSR sessions). One health worker commented:

> You have seven women labouring, and you have only two birth couches, so some women are labouring on the floor […]. A mother is in active labour but won't push […], and other women need to use the birthing couch. You find health workers becoming harsh because if that baby dies in your hands […] you will be the one to explain at the review meeting. People say health workers are bad… but this job is very difficult (health workers, co-production workshop, round table).

In the next section, I will show how health workers use health system tools such as minutes or proceedings of MPDSR sessions to shift blame to community members.

5.1.3 Health workers use health system tools to deal with blame

Health workers use health system tools such as patient case notes, partographs[23], proceedings/minutes of MPDSR sessions and the three-delay model (9) to avoid blame. In some instances, health workers used the tools before MPDSR sessions; in others, they used the tools during the sessions to avoid blame by shifting responsibility to community members.

Health workers control the tools used to bring knowledge to MPDSR sessions, such as the patient case notes and partographs before MPDSR sessions. In chapter 2 of this thesis (study conceptualisation section), I explained that gathering knowledge is a process through

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[23] a partograph is a graphical record of key data (maternal and foetal) during labour entered against time to track progress of labour.

which health workers and community members bring different forms of knowledge to MPDSR sessions. Gathering knowledge happens before a review session as health workers and community members provide information about the medical and lived experiences of the mother/baby before an adverse outcome. In an interview, a community representative who is part of the MPDSR committee explained that health workers control the process of gathering knowledge by altering the details in patient case notes, which shifts blame from health workers to community members. He explained:

> You find that health workers normally manipulate the patient case notes, […] yeah, and on the documentation that is available, including the partographs. You find that there is a way they change the information on the partograph so that people do not notice when the delays happen, which makes it easy to blame the community […] (Zack, community representative).

Study participants (health workers and community representatives) explained that health workers are responsible for writing or documenting what happens at the review meeting. Despite having community members at MPDSR sessions, community members have no control over how their contributions or inputs are used or reported in the review meeting proceedings. One health worker described the process:

> At the meeting [maternal/perinatal death review], health workers read the patient file. They say what happened and how to improve, they put the point down in the minutes. So, there is little chance for community members at the meeting to add anything to what is written (Jane, health worker).

In the excerpt below, the health workers describe how they change or filter patient details to avoid blame. See below:

> We [health workers] sometimes have a review. The patient's case notes say that the death was a macerated stillbirth, but the truth is if you follow up and ask questions, you realise the death was a fresh stillbirth. However, in the review documentation, it will show that it is a macerated stillbirth. If the proceedings of the review meeting conclude

> it was a macerated stillbirth, the recommendation will target the community because it implies that the mother is delayed at home. The action point will be to give health education in the community. Sometimes, the MPDSR documentation is changed [during the review] so that health workers can avoid many questions (FGD, health workers).

The comments from a senior health worker show that senior management was aware that health workers manipulated the proceedings of review meetings. The senior health worker explained that when reviewing MPDSR minutes from the different health facilities at the county review meeting, the county MPDSR committee could see how details had been changed. The interviewee (senior health worker) perceived that MPDSR proceedings are not authentic because of the changes that health workers make during review sessions. The interviewee further explained:

> If you look at the MPDSR proceedings, they are written in a way that totally exonerates staff, and if you look keenly, you can see how they have cooked the details. […] So that when the action points from that review session are made, what they [MPDSR committee at health facilities] have discussed happened in labour ward is quite different from what could have contributed to the death […] almost always the action point is to provide health education and to action CHVs to do their work better (Senior health worker).

Health workers filter the details of the patient’s lived experience (i.e., what happened to the pregnant woman or her newborn before an adverse outcome) during a review session by documenting some parts of the patient’s story and leaving out others. At an FGD, a CHV described her experience participating in a health facility review meeting after a maternal and perinatal death for a woman the CHV had been supporting. From the CHV accounts of the review meeting, the health workers at the MPDSR session changed the details of what happened to the pregnant woman before the adverse outcome to cover up the details of what could have contributed to the death. During the review meeting, health workers explained to the CHV that they needed to change the details of what had happened to avoid professional repercussions for health workers. The CHV commented:

> I know what happened to the mother because she is my client. I left her at the hospital, waiting to be seen. […] when I attended the review meeting, the health workers told me that we cannot write what happened before the woman died in the report [MPDSR proceedings]. The health workers said it is much simpler to say the woman was delayed in coming to the hospital […]. That way, no questions will be asked. […] If we say she was told to sit at the bench [for six hours] and that she died on the bench, it will bring complications for us with senior managers (FGD, CHVs).

Health workers also use the three-delay model during review sessions to shift blame to community members. The three-delay model[24] (9) is a framework for analysing barriers that pregnant women may experience along the continuum of care during delivery from the household to health facilities. Most health workers referenced the three delays at some point during their interviews and FGDs as a starting point for analysis of what contributed to the death. For example, a health worker explained that they reference the three-delay model during review sessions to understand what happened in the community before a woman came to a health facility. She explained "*we are looking at the three delays, we want to know what caused the death*." (Jane, health worker).

Health workers use the three-delay model to frame how lived experiences from community members (on the pregnancy and care seeking before adverse outcomes) are recorded and used to make recommendations. At the co-production workshop, health workers talked about how they often had review sessions where they identified the first delay as a contributor to a death. One health worker commented: "we *lump everyone in the delay boat […] even though not everybody delays"* (health workers, co-production workshop). During the workshop, the health workers explained that the most common MPDSR recommendation from

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[24] For more details on the three-delay model and how it is used see glossary

MPDSR sessions (in health facilities and community-based reviews) is the need for community health education to address the first and second delay.

A senior health worker explained that in her experience, MPDSR committees sometimes applied the three-delay model incorrectly. At the interview, the senior health worker said that MPDSR committee members would sometimes recommend health education to address the first and second delay even when the details of the maternal/perinatal death did not reflect community delays. The health worker gave an example of a recommendation that did not correspond with the cause of death as described in the MPDSR meeting proceedings. From her example, the health worker noted that the MPDSR committee that had reviewed the death had concluded that a fresh stillbirth had resulted from delays at the household. She said that from the patient's case notes, when the mother had arrived at the health facility, there was a foetal heartbeat, but she had a fresh stillbirth 24 hours later. Yet the MPDSR committee recommended that health education to address the first delay was necessary. The senior health worker disagreed with this recommendation because, in her opinion, it was more likely that delays had occurred at the health facility. The senior health worker concluded that the MPDSR committee conducting the review had applied the three-delay model incorrectly, which shifted responsibility for the death away from the health system to the pregnant woman.

I will draw on my field notes from observing a CVA session to show how health workers used the three-delay model to control the discussion and shift blame to community members. The CVA session was held after a maternal death at the deceased woman's home. The participants at the session included the deceased's husband, a village elder, 2 CHVs and a health worker. The husband of the dead woman narrated the events that had happened before his wife's death. During this CVA session, the health worker and CHV encouraged the husband to share what had happened to his wife by telling him*: ". it is good for us to discuss what happened so that we can learn from this experience.*" (health worker). And so, the husband began to share his experience:

> *The husband [of the deceased woman] began by relating how his wife had decided to deliver with a traditional birth attendant (TBA) who lived nearby, and after the safe delivery of the baby, there were some complications. The TBA advised that the family seek care from a health facility, which was about 2 km from the deceased home. Unfortunately, there were no health workers at the nearby health facility. The family then had to travel to the next health facility, which took about 2 hours. Upon arrival at the health facility, they were informed by health workers that she needed a blood transfusion, and as such, they had to go to the referral hospital. They were not provided with any support for referral, such as an ambulance. The family then travelled to the referral hospital, but unfortunately, the mother succumbed just before arriving at the referral health facility.*
>
> *After the narration, the health worker asked the deceased husband what he thought had led to his wife's death. The husband replied that it was the absence of health workers at the first health facility and the subsequent delays in getting to the referral hospital that led to the death. According to the husband, if his wife had received health services at the initial health facility, her life could have been saved despite going to a TBA. The health worker disagreed with the husband's assessment and maintained that the death occurred because the woman had delivered with a TBA rather than at a health facility. After trying to explain to the health worker and maintaining that his wife's death was not only because they went to a TBA, but rather the ensuing health system delays also contributed, the bereaved husband gave in and said, "If that's what you have decided." The husband looked frustrated and resigned.*

At this CVA, the health worker insists that the woman died because of her family's delays in decision-making by choosing to go to a TBA. Even though the husband disagrees that going to the TBA was not fully responsible for the death, and he explains this to the health worker, the health worker maintains that his analysis is the correct one. Throughout the discussion at the CVA, the health worker uses the three-delay model to control the discussion on why the woman died.

The health worker documented the first and second delays and identified them as the contributors to the death. However, from my observations, the health worker did not consider the additional information the husband gave that points to health system failures, which are third delay issues. The decision to go to a TBA may have contributed to the death, but from the husband's analysis, that was not the whole story. The husband's narration during the CVA highlights several issues related to the third delay. For instance: (i) absence of health workers at the health facility, (ii) no ambulance to transfer the mother are third delay issues that contributed to the death and (iii) the family's decision to go to a TBA despite having a health facility within walking distance of the family home[25].

Health workers are strategic in documenting the proceedings of MPDSR sessions and patient case notes. A senior health worker commented that health workers do not include many details in patient case notes. The interviewee further explained that this could protect a health worker in the event of legal action. He commented: *"health workers do not write detailed case notes [when providing care to a patient before an adverse event]; you find details are missing in the patient case notes […] even if the court summons the health worker to provide case notes to the court as evidence, it would be difficult to have sufficient evidence based on the case notes"* (health worker).

In another interview, a health worker described how health workers manage potential risks of litigation during the MPDSR session. The interviewee explained that health workers kept records of the patient file and MPDSR proceedings to use them as part of one's defence in the event of legal action. The interviewee explained:

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[25] When analysing delays using the three-delay model, one should also reflect on how issues in the 3rd delay can contribute to the 1st delay. E.g., if community members do not expect to find health workers at a health facility, they can decide not to bother going to the health facility. While this is seen as a first delay issue, the underlying reason for the first delay are third delay issues such as no staff at health facilities.

> The minutes of the meeting are filed, and in case of a legal case, the minutes can become part of the legal proceedings. Fortunately, so far, we have not seen people being taken to jail. A few months ago, a maternal and perinatal death happened at the hospital and the family went to court. The case has not come up for mention. We keep the patient records and minutes of the review meeting as a means of defending yourself [health worker] in case you are called to court, the minutes will show what happened. You can use the file to defend yourself (health worker).

5.2 How shortcomings and challenges in the health system affect MPDSR participation.

The healthcare encounters between health workers and bereaved relatives prior to an adverse outcome affect the willingness of bereaved relatives to participate in MPDSR sessions. Bereaved relatives associate their negative histories of care with a range of negative emotions such as anger, disappointment, bitterness, and resentment, which made it difficult for them to participate in review sessions willingly. Some bereaved relatives explained that they do not trust the health workers because they feel that health workers are corrupt. Bereaved relatives described previous healthcare encounters where they perceived that health workers were charging patients for services that are supposed to be provided free of charge. Bereaved relatives explained that the perceived corruption among health workers shaped their (bereaved relatives) unwillingness to associate with health workers during MPDSR sessions.

. Health workers and community representatives explained that the failure to implement MPDSR recommendations demotivated them, but they still attended MPDSR sessions because they had a professional obligation to participate.

5.2.1 Histories of care shape participation in MPDSR sessions

Study participants reported that their experiences of care before an adverse outcome shaped their willingness to participate in MPDSR sessions. Four of the six bereaved relatives who did not attend any MPDSR session reported previous negative healthcare encounters, during ANC or childbirth, with health workers before an adverse outcome. Two bereaved relatives who did not report negative encounters in the past said that they had not attended the review sessions because health workers had explained to them that the deaths could not have been prevented. The two interviewees explained that early on in their pregnancies, health workers had told them about the high-risk nature of their pregnancies and had referred them to a higher facility. The two interviewees felt that health workers tried to prevent adverse outcomes, and the interviewees accepted the two deaths were unavoidable. However, for the four other interviewees and the 10 FGD participants who had not participated in a review, their accounts show that they attributed their unwillingness to participate to their previous negative care and the strong emotions associated with those encounters.

Bereaved relatives explained that negative experiences during past healthcare encounters also shaped their decisions on how they used health services after an adverse outcome. A bereaved relative explained that she was unwilling to participate in the review process, where the death of her baby was discussed. At the interview, the bereaved relative recalled that she had been mistreated throughout her ANC experience. The interviewee said that there were gaps in her clinical care, which resulted in the death of her baby. She had not been invited to participate in the perinatal death review meeting. But at the interview, she was also clear that she would not have participated even if she had been invited. The interviewee also explained that she and other members of her household had stopped going to that health facility because of her negative experiences of care during her pregnancy. She said:

> I would not be comfortable attending a review session. Maybe other people can go but not me. Because of the pain I felt. Not even about losing my baby during delivery. It is the way they took me round and round earlier -go here- go there, shouting at me [during her ANC visits]. I felt very bad. I would never want to meet those people again. For me to meet with them, sharing what I went through […] I do not see myself doing it. […] I do not go to that hospital […] recently my husband was unwell, and he refused to go to that hospital [...] I have never forgiven them (Nia, bereaved relative).

Other bereaved relatives echoed the interviewee above by describing how health workers had mistreated them during their pregnancies or childbirth. At an FGD, bereaved relatives (who had not participated in any MPDSR sessions) shared their frustrations and anger with health workers during their pregnancies. The FGD participants associated their negative histories of care with their unwillingness to participate in any MPDSR processes. One FGD participant explained that when she was pregnant and due to give birth, she arrived at the health facility, and the health workers shouted at her, saying she had delayed. The woman felt blamed by the health workers for causing the death of her baby. Yet, according to this FGD participant, the health workers did not give her a chance to explain what had happened, and as such, she felt misunderstood and angry. She had a stillbirth and was later discharged from the facility. When contacted by CHVs to attend the review session at the hospital, she did not avail herself because "*she did not want to talk to those people [health workers] again*." (Bereaved relatives, FGD).

Some bereaved relatives felt that it would have been more beneficial for health workers to discuss with the relatives about what was happening and the treatment plan before an adverse event rather than discussing why their relative had died at a review meeting. Some bereaved relatives explained that health workers ignored their pleas and suggestions, e.g., referring mothers or newborns to a higher facility for treatment. At the FGD with bereaved relatives (who had not participated in MPDSR), participants discussed how health workers did not listen to the requests of the relatives or communicate with the families on how treatment was progressing. One bereaved relative described how health workers had ignored her pleas to refer newborn twins to the referral hospital, where the relative felt the babies would have received more advanced care. At the FGD, the bereaved relative said that despite asking for explanations from health workers on what was happening, she had not been given any information. The neonates died several days later. When I inquired about her willingness to participate in a review session for those deaths, she said she had not been invited and would not have participated even if she had been invited. She wondered why health workers would want to talk to her after the twins had died. She commented in an angry *tone "where were they [health workers] when I needed someone to tell me what was going on […] before my grandchildren died […] I have nothing to say to them." (Bereaved relative, FGD).*

In some instances, bereaved relatives felt that by attending MPDSR sessions, they would be going back to the spaces they (bereaved relatives) associate with harm. For some bereaved relatives, participating in MPDSR sessions meant that they had to interact with the same health workers they felt had contributed to the adverse outcome. A mother whose baby had died after a home delivery described her experience of participating in a community verbal autopsy (CVA) session. At the interview, the bereaved relative reported suffering disrespectful maternity care during her pregnancy and then being subjected to participating in a CVA facilitated by the same health worker. The bereaved woman explained that despite being upset with the health worker, she still had to participate in the CVA because social norms require her to be polite to people visiting her home (especially in an official capacity such as a CVA).

Bereaved relatives explained that they did not trust health workers because of the perceived corruption in previous interactions between health workers and community members. A bereaved relative gave examples of how health facilities sold drugs and other supplies, such as gloves, to patients despite public knowledge that these drugs and supplies should be provided for free. The interviewee explained that even though he had been invited to attend the review session after his son died, he chose not to attend because he does not trust health workers. At the interview, the bereaved relative talked about his perceptions and those of other community members about the health system, describing instances of perceived misconduct among health workers. The interviewee associates participating in an MPDSR session with cooperation between the community and health workers. He explains that it is difficult for community members like himself to trust health workers who are not providing good services. He explained:

> If you ask people in the community if they think the health system is doing enough to prevent deaths, most people will tell you about their negative experiences at the health facility. People talk about how health workers tell them to buy medicine or gloves, but we know these things are supposed to be free. How can you cooperate with people you don't trust? […] If I had attended the review session, it means sitting down to listen to health workers. And I don't trust them […]. Health workers must improve services and then seek community cooperation […]. You cannot tell a community whose mothers and children are dying to trust the same health workers who are not giving a good service (Simon, bereaved relative).

Other bereaved relatives also talked about a lack of consistency in the information that health workers give at CVAs and social autopsy sessions. A bereaved relative described his experience. Irvin's first wife had died during childbirth, and he had participated in a CVA. At the interview, Irvin described the CVA as a difficult experience for him. Irvin said that the health worker and community representatives facilitating the CVA had blamed him for allowing his wife to give birth with the help of a TBA. At this point in the interview, Irvin had remarried, and his new wife was pregnant. In the interview, Irvin talked about his frustrations with the health system because health workers asked him to pay for services his new wife needed. Yet, from his accounts of the previous CVA, health workers had told him that his first wife should have attended ANC and given birth at the facility because health services are free. When his new wife went to the health facility for ANC, the health workers told her to buy some drugs from a private pharmacy that is owned by a health worker instead of being provided with free medication from the facility, which is the policy. At the interview, Irvin was upset and commented:

> So now, they [health workers] said my other wife died because of not going to the hospital. […] this one [new wife] has started going to the hospital, and they are mistreating her […] and making me pay for medicine even if I know it's free at the hospital. If she stops going to the hospital and goes to a TBA and dies […], will they say it is still my fault? (Irvin, bereaved relative).

Here, the interviewee is concerned that his wife may discontinue using health services during her pregnancy and risk another maternal death which he will then be blamed for in another review session.

Study participants (both health workers and community members) explained that when health workers are on strike and services are disrupted, trust is broken between the community and health workers. In an interview, a health worker described how a strike that lasted four months (before phase 2 of this study) had affected the relationship between health workers and the community. The interviewee explained that at the time of the strike, there had been a higher-than-usual number of maternal and perinatal deaths as health services were unavailable. After the strike, health workers began to organise CVA sessions to review the deaths during the strike. The interviewee explained that many bereaved families were unwilling to participate in the CVAs. An interviewee described his experience facilitating a CVA for a maternal death that had happened during the strike.

> The community was not happy to see us […] The family did not want to talk to us. Why had we [health workers] been on strike? Trust was completely broken. We [health workers] are trying to rebuild trust […] we wanted to use the verbal autopsy to encourage the family to come back and use services because even though the mother is dead, her newborn still needs services like immunisation. But building trust is a process that will take time (Oliver, health worker).

5.2.2 Health system's failure to implement MPDSR recommendations demotivates people from participating in MPDSR sessions.

Study participants discussed the lack of accountability in the MPDSR process because recommendations are not implemented. Community members and health workers explained that the failure to implement the recommendations made after MPDSR sessions affects the participation process in two ways. In some instances, study participants (mainly community members) said that the failure to implement recommendations discouraged them from future participation. Other study participants mainly (health workers and community representatives) explained that while they still attended MPDSR sessions, they were demotivated because the recommendations of previous sessions were not implemented. Health workers also explained that attending MPDSR sessions is a professional requirement, which they adhered to even when they felt demotivated about the process.

Community members said they did not attend review meetings or social autopsy sessions because of the perceived opportunity cost of attending the sessions. Bereaved relatives and community representatives described participating in MPDSR sessions as losses in terms of time and money. In an interview, a community representative explained that some bereaved family members consider attending social autopsy sessions as a waste of time. He commented:

> When you call people to a meeting [social autopsy], they say it is a waste of time where one goes to sit down and listen. You will be hungry with a dry mouth, and no one will feed your family in the evening. […] You just sit there, and people talk, but nothing will change (Walter, community representative).

A bereaved relative explained that while he had heard about social autopsy sessions in his community, he had never attended any. The interviewee (bereaved relative) explained that he has competing priorities for his time. He added that he does not consider attending social autopsy as a valuable way of spending his time because there is no accountability. He commented:

> I have heard about the meetings [social autopsy], but I have never attended any meetings. I am a busy man; my wife died [maternal death] [….] am raising my children, […] the meetings don't have an agenda […] nothing will change after the meeting. People just talk. Who is going to make sure that the things we say at the meeting are done? […] I cannot sit down to just listen; I have things to do (Nickson, bereaved relative).

Another bereaved relative who had not participated in any MPDSR session also explained that he did not participate because it meant he had to choose between earning a living or attending the MPDSR session at a health facility. The interviewee feels that the discussions at the health facility review will not change anything because no one is responsible for instituting changes. He explained:

> If I attend the MPDSR meeting, it means I stop working so that I go to a meeting instead of going to look for food. My family rely on me for livelihood [he describes what he does for a living]. I cannot go to listen to people just talking […], and nobody will do the things that are discussed (Simon, bereaved relative).

Bereaved family members also expressed their exasperation with what they perceived to be a futile participation process because the recommendations made at previous MPDSR sessions did not help prevent future deaths. A bereaved woman had two adverse outcomes- an intrapartum loss and a neonatal loss in 36 months. Health workers invited her for the neonatal death review, which was her more recent loss. In her interview (as part of this study), she talked about her experience participating in the neonatal death review meeting. After describing her participation experience, I asked her if she felt the review process had been useful. She was doubtful. She commented:

> The meetings would be helpful if the things health workers record actually help women. Like me, this is my second loss, and I wonder if I get pregnant again, will something else happen? Does anyone look at the things they [health workers] write in these files [at the review meeting]? It would help if they checked the file then If they see me again, they know my case. But if no one reads the file […] how will they know? How do I have confidence for another pregnancy? (Rachel, bereaved relative)

The interviewee above wonders how health workers document and use her individual patient case notes and if the review can help her future pregnancies. In her comments, she recognises the potential value of review meetings in documenting what contributed to a death. But for her, the real benefit of review meetings is in addressing the identified contributors.

Health workers and community representatives are frustrated because most MPDSR sessions produce the same recommendations but are not implemented. A CHV commented: *"the social autopsy sessions are the same [….] people just talk and talk and just repeat that we should do the same things but nothing change*s" (Rebecca, *CHV).* In another interview, a community representative suggested that bereaved family members do not perceive the meetings as critical for initiating change that could prevent mortality "*because it's the same people who talk at these meetings. Nobody follows up to see if things are done."* (David, community representative). His comment implies that social autopsy sessions are dominated by the same people who speak at every session, which could suggest that other community members do not have opportunities to contribute to the discussions.

Health workers perceive participation in MPDSR sessions as time-consuming and demotivating because the MPDSR recommendations are not implemented. Health workers described the effort involved in organising review meetings and the difficulties in getting other health workers to attend the meeting. An interviewee (health worker) explained that health workers made the same recommendations repeatedly, but the recommendations were not implemented. A health worker said: "*these meetings are exhausting because we meet and repeat the same action points and nothing is done* (Peris, health worker). Another health worker explained:

> The recommendations are the same: we say the same things need to be done, but none of them are done […] it can be tiring to say the same things, and nothing happens […] we do not get the supplies we need. Delivering a mother in the health facility is the same as do it in a banana plantation because we do not have the supplies we need" (Jackie, health worker).

A health worker explained that despite following the guidelines on how to frame the recommendations to meet the policy guidelines' standards, the recommendations are still not acted on. Health workers acknowledged that even when they had followed the MPDSR guidelines on making recommendations to ensure they were specific, measurable, attributable, realistic and timebound (SMART), there was no guarantee that the recommendations would be implemented. She said:

> Attending these meetings [MPDSR sessions] is demotivating due to delays in implementing action points. At each review meeting, we make SMART recommendations. [….] we follow the guidelines because we were told that good recommendations must be SMART. But if the recommendations are not acted on, then we have another meeting and make other SMART action points even before the other ones have been implemented… […] In the end, we have pending recommendations for more than a year. […] but we [county MPDSR committee] must file returns [proceedings of facility-based reviews on the DHIS2] to Nairobi (senior health worker).

In the quote above, the senior health worker questions the assumption that following the guidelines to make SMART recommendations is sufficient to ensure that action points are acted on. The interviewee further talks about the professional obligations of county MPDSR committees to submit reports to higher levels of the health system as a form of accountability even if the recommendations are not acted on.

At the co-production workshop, health workers discussed how the lack of resources to implement MPDSR recommendations discouraged them from doing their work. The health workers spoke about the workload associated with MPDSR sessions because of the high volume of deaths and the amount of time they were required to spend attending review meetings. During their discussion at the round table, there was a general sense of frustration among health workers because of the lack of implementation of the proposed changes. Most of the health workers framed participation in MPDSR sessions as an obligation. Some health workers referred to participation in MPDSR as "part of the job" (Peris, health worker), and others admitted it was frustrating but "*what can you do […] "you want flour [to retain a job]"*" (Oliver, health worker).

A CHV who is also a member of the MPDSR committee at the health facility expressed frustration participating in MPDSR sessions because the recommendations were not implemented. In the excerpt below, the CHV expresses her frustration with health workers and community members for not acting on the recommendations made during MPDSR sessions.

> Sometimes I feel like we discuss something at the facility or at these social autopsy sessions and nothing is done. We [CHVs] give our feedback to health workers […] the actions we propose are not implemented. We [CHVs] teach the community. […] nothing changes. So, it is very discouraging to come to meetings where people talk and talk, but nothing happens. But we must continue because one-day, things will change (Rebecca, CHV).

While the CHV quoted above (Rebecca, CHV). did not stop attending MPDSR sessions or facilitating social autopsy sessions; her tone at the interview was one of discouragement and frustration with the process.

In this chapter, I have shown how interactions and experiences of MPDSR participants at the meso level, i.e. the health system, shape community participation in MPDSR. Despite a health system discourse on no blame and no shame, I have demonstrated that blame culture is pervasive during MPDSR participation. I have also shown how study participants use different tactics and tools to manage blame. I have shown how people's histories of care affect their willingness to participate in MPDSR sessions. Finally, I have shown how challenges and failures in the health system demotivate participants from engaging in MPDSR sessions.

6.0 Navigating MPDSR participatory spaces: The role of community representatives

Chapter overview

In this chapter, I examine community representatives' roles in the MPDSR process. There are several categories of community representatives who are involved in the MPDSR process, including village elders, religious leaders, grassroots political leaders referred to as members of the county assembly (MCA), CHVs and CSO representatives. While each of these representatives has a role in MPDSR, the most prominent community representatives are CHVs, CSO representatives and MCAs.

Community representatives navigate different MPDSR spaces such as bereaved family members' homes for purposes of death notification and CVAs. Community representatives also participate in death reviews at health facilities or community sites for social autopsy sessions. Community representatives also represent community members in political spaces where resources to support MPDSR implementation are allocated.

I begin by briefly illustrating how study participants use a discourse of trust and respect to describe community representatives and then focus on the different roles that community representatives are expected to play in MPDSR. Then, I will show how community representatives navigate different participatory spaces, the challenges they face as they perform their roles, and how these challenges shape the participation process.

6.1 Using a discourse of trust and respect to describe community representatives.

Health workers said they invited community representatives to MPDSR sessions to represent community members because they trust them. Health workers used phrases such as: *"people trust the community representatives because the community choose them"* (Oliver, health worker) and "*the community have a lot of respect for the religious leaders*" (Charles, health worker). Another health worker commented: "*people in the community respect village elders, they will not hide what happened and will tell the elder everything […] we talk to elders during the review meeting to learn more about a death* (Peris, health worker). These comments were typical of how health workers described community representatives.

Community members also explained that they trusted and respected community representatives. At an FGD, a community member described CHVs and village elders as *"people whom we know well, and we trust them, and we can tell them our problems."* A bereaved relative described the relationships CHVs have with women in her community as follows: "*We trust the CHV [mentions CHV by name] she knows about good health, and she teaches us [community members] about pregnancy and other things [gave examples on immunisation and ANC]"* (Sue, bereaved relative).

Community representatives described themselves as people whom the community trusted. A community representative explained that community members trust community representatives such as religious leaders, village elders and members of the health facility committee to participate in MPDSR sessions on behalf of the community. In an interview, a CHV explained, "*People in the community know that I am there to help them; they trust me because I am always available. I am here to help the community because I know all the pregnant women under my care"* (Joan, CHV).

All health workers and most community members maintained the view that community representatives are trusted and respected. Only one community member (interviewee) disagreed with the notion that community representatives such as CHVs are trusted and respected. The interviewee (bereaved relative) felt that health workers do not really value what CHVs say. The interviewee perceives the interaction between health workers and community representatives as unequal. Her comments show that while CHVs are willing to volunteer and participate in MPDSR, health workers can choose not to listen to their contributions. She commented:

> CHVs are good-hearted people who have time on their hands to volunteer. But I do not think health workers really respect them or listen to them because they are not at the same level. I think health workers put them at a lower class compared to themselves. I don't think they can tell health workers anything and they are taken seriously (Nia, bereaved relative).

While her views (above excerpt) were not expressed by others, her comments in many ways better reflected the practical realities of the relationships between community representatives, health workers and community members. Despite most study participants' explanations that community representatives can perform their roles in MPDSR because they are trusted and respected, in practice, community representatives' relationships with health workers and community members are complicated as I illustrate in section 6.2.

I will present findings on participants' views on the roles that community representatives play in MPDSR in sections 6.1.1 to 6.1.3 after which, I will show that that community representatives have a complicated relationship with health workers and community members in section 6.2.

6.1.1 Community representatives are channels between community members and health workers.

Community representatives act as channels between the health system and the community by providing information to health workers about deaths in the community, i.e., gathering knowledge. According to health workers, community representatives such as village elders and CHVs were best placed to support them in the identification and notification of maternal and perinatal deaths because they know the families who may have suffered an adverse outcome. A health worker commented that *“community representatives could be trusted to give health workers the relevant information that health workers need to conduct verbal autopsies*” (Peris, health worker). At an FGD, health workers explained that CHVs and TBAs often accompany pregnant women to health facilities at the time of childbirth. If a death happens, health workers rely on the CHV or TBA who had accompanied the mother to the health facility to provide additional details to health workers on the circumstances that could have contributed to the death. See excerpt:

> Health worker: CHVs and birth companions [TBAs] spend a lot of time with mothers in the village, and they know how a mother’s pregnancy went. That’s why it is important to involve them in these review meetings. They know the mothers well, and they tell us what happened in the village before the mother came to the health facility (FGD, health workers).

Community representatives are also expected to channel community members’ feedback on their healthcare experiences back to health workers. Health workers explained that the MPDSR process is linked to other quality of care initiatives in the county for maternal and newborn health. These quality-of-care initiatives include maternity open days and community dialogue days where community members can attend and give feedback on their experiences of care. An alternative approach, which was more favoured by the interviewees (health workers and community members), is using feedback provided through CHVs.

Health workers’ interactions with CHVs during feedback sessions show that they do not take the feedback from community members seriously, and the sessions are tokenistic. At an FGD, health workers explained that feedback reports from CHVs are read out during a staff meeting for health workers, but there was no follow-up to see if any of the feedback had been acted upon. One health worker described how she dealt with feedback from CHVs at the facility where she was in charge:

> I come and read the report [from CHVs] and all the complaints CHVs have collected from community members. I tell staff at the meeting to listen and if you think that the report is talking about something negative you did […] then you can decide to correct yourself and amend your behaviour (FGD, health workers).

Later at the same FGD, health workers talked about suggestion boxes placed in all health facilities so that any community member could put in their suggestions or complaints anonymously. One of the health workers commented: *"community members can write their suggestions or complaints in the suggestion boxes, but no one opens the suggestion boxes* [said while laughing]." (FGD, health workers). From their description of the feedback process, it seems that health workers treat the feedback sessions casually or as a tick-box exercise.

At the co-production workshop, health workers accounted for their tokenistic approach to feedback from community representatives by highlighting their difficult working environment and multiple demands on their time. The health workers talked about the different expectations for timely reporting, provision of health services, and meetings with senior health officials and NGOs working at the county, all of which had huge demands on their time. Health workers acknowledged that they are expected to meet with CHVs, and other community representatives monthly as stipulated in the Community Strategy, but these meetings were largely perfunctory.

There were a few instances where health workers reported that they had acted and made changes based on feedback from community representatives. Two interviewees (health workers) described how CHVs had spoken to the health workers in confidence about their concerns relating to specific health workers who were linked to several maternal and perinatal deaths. The health workers in charge of those facilities reported that they had reviewed the maternal and perinatal death reports. They confirmed that those specific health workers had been on duty when most maternal and perinatal deaths occurred. The interviewees (health workers) explained that they had transferred the health workers associated with the maternal and perinatal deaths from the maternity ward to a different ward but had not reported the cases to senior health workers at the county as a way of protecting the ‘accused’ health workers.

6.1.2 Community representatives mediate between community members and health workers.

Community representatives mediate between community members and health workers in instances when either group feels distressed or aggrieved. Community representatives also participate in MPDSR sessions on behalf of bereaved relatives when bereaved relatives are either unable or unwilling to participate in MPDSR sessions, e.g., because of their (bereaved relatives) previous negative experiences with health workers. Community representatives also participate in MPDSR sessions on behalf of the community when health workers are uncomfortable having bereaved relatives at review sessions, e.g., when health workers feel that bereaved relatives are too emotional to participate in MPDSR sessions. Most of the community representatives involved in this study (except the elected leader) had participated in MPDSR sessions, either social autopsy sessions or facility death review meetings on behalf of community members.

Health workers rely on community representatives to support bereaved relatives by helping them (bereaved relatives) regain composure and avoid disrupting MPDSR sessions. A health worker commented: “*community representatives help community members to calm down during MPDSR sessions […] When community members are emotional and feel aggrieved, they blame health workers. They [bereaved relatives] become difficult saying we killed their person* [relative] (FGD-health workers).

A bereaved relative explained that having community representatives with him at a review meeting had helped him to restrain himself and not report health workers to the police. He commented: “*it was good to have the CHV and religious leader at the meeting [MPDSR* *session]. They helped me to calm down. During the review, I became angry, and I wanted to go to the police*" (Gabriel, bereaved relative). The bereaved relative described how he had listened to the discussions at the facility review meeting and realised that the perinatal death was due to errors that health workers made. The interviewee explained that the religious leader (who is part of the MPDSR committee as a community representative) helped health workers avoid potential arrest.

Health workers also rely on community representatives to explain to bereaved relatives that health workers are not culpable because some deaths are unavoidable. At the co-production workshop, a CHV described how health workers had invited him to attend a review meeting after a health worker was arrested following a maternal death. The CHV explained that he was responsible for the household where the deceased woman lived. According to the CHV, the hospital management organised a maternal death review as a way of providing clarity to the bereaved family on why the death happened. At the workshop, the CHV commented: "*the health workers invited me to the meeting [maternal death review]. They said that from the meeting it will be clear what happened and why the mother died, which would help with the release of the health worker who had been arrested*" (CHV, co-production workshop). According to the CHV, the discussions that were held at the review meeting determined that the maternal death was unavoidable; and health workers asked the CHV to inform the family of the same. After the review meeting, the CHV described how he helped the family of the deceased to accept the death and drop charges against the health worker. The CHV said:

> I had to explain to the family that sometimes death happens, and it is no one's fault. The family know me [CHV]; if it was the first time I was interacting with them, and they did not know me, they would not have listened to me. They trust me because I had walked with this woman throughout her pregnancy […] things settled down, and the matter ended (co-production workshop, CHVs round table discussion).

Community representatives also represented bereaved relatives at health facility review meetings if (i) relatives were either not invited or were unwilling to participate or (ii) health workers felt that it was not appropriate for the relatives to attend. A health worker commented that sometimes health workers invite community representatives to participate on behalf of the family instead of the bereaved family members. The interviewee implied that this would protect family members from undergoing further trauma as discussions on their loved one's death are held. He said:

> It had been suggested that bereaved participants come to referral hospital reviews, but the review committee has requested that relatives of the deceased not to attend because they are aggrieved and traumatised. We felt that the discussion would result in more trauma for the family. We requested that the religious leader and the chief attend on their behalf and relay what has been discussed. (Jacob, health worker).

Community representatives also attend meetings on behalf of bereaved family members when bereaved relatives are unwilling to attend a review because of their past negative experiences with health workers. Simon, a bereaved relative, explained that health workers had invited him to a review after his son's death, but he chose not to attend. At a different interview with a health worker, I asked him how health workers ensured that the experiences of bereaved relatives were included in the review. The health worker explained that health workers encourage bereaved relatives to attend, but if they choose not to, community representatives such as religious leaders and CHVs participate on behalf of the bereaved relatives (Solomon, health worker).

6.1.3 Community representatives advocate on behalf of community members.

Community representatives act as advocates at the MPDSR sessions by speaking on behalf of community members who are unable to speak for themselves. Community representatives also advocate on behalf of both health workers and community members with duty bearers such as elected officials for the implementation of MPDSR recommendations.

Some bereaved relatives explained that they relied on community representatives to challenge or confront health workers if the bereaved relatives could not voice their concerns for themselves. A bereaved relative explained that she trusts the CHV attached to her village to intervene on her behalf. She commented: "*if you are unhappy […] you could talk to a CHV if you are treated badly during an ANC visit and they will intervene with the health workers*" (Sue, bereaved relative).

A bereaved relative (see excerpt below) suggested that health workers were more likely to listen to community representatives rather than bereaved relatives or ordinary community members. Earlier in the interview, Simon had explained that health workers generally ignore community members' contributions during healthcare encounters (not just MPDSR). Simon suggested that if several community representatives work together and advocate on behalf of community members, they are more likely to succeed because health workers would listen to the group of community representatives. He suggested:

> Community representatives may be a better force to communicate and talk to health workers. A single community member may not be well listened to. First, if the problem was in a certain health facility in the village, the chief, the elders, and religious leaders can go to the local health facility and talk to the health worker in charge. They [health workers] will have to listen to the community representatives (Simon, bereaved relative).

Some bereaved relatives said they expected community representatives to use their positions on MPDSR committees to advocate and confront health workers for perceived negligence. A bereaved relative commented:

> It is up to the health facility committee chairman [community representative] to deal with negligent workers by reporting them to the highest office. Because even if there are deaths that happen, there are also issues of negligence from health workers (Nia, bereaved relative).

Another bereaved relative said: “*the meeting should not just end with health workers saying sorry for causing deaths […] they need to be dealt with […]. Otherwise, if health workers say sorry [apologise] and nothing is done, deaths will continue”* (Simon, bereaved relative).

In some instances, community representatives supported bereaved relatives to seek redress from higher authorities. Some community representatives explained that as members of the MPDSR committee, they also review health workers' mistakes. If a health worker makes mistakes repeatedly, they will deal with the negligent health worker. A community representative explained:

> When we think a health worker is negligent […], we can report the health worker to the civil administration because if a health worker says they made a mistake and it is the first time, we can understand. But if they keep repeating the same mistakes, we do not accept that explanation” (Robert, community representative).

It is unclear how the reports that community representatives send to civil administration to report health workers for perceived negligence are dealt with. None of the study participants (community representatives) knew how complaints were dealt with and if any actions were taken against health workers.

Some bereaved relatives said that they relied on community representatives to ask health workers questions on their behalf. Some community members explained that they had wanted to know more about why deaths had happened in health facilities. In an interview, Kevin, a bereaved relative, explained that he expected community representatives to get answers from health workers about why deaths were happening in the health facility.

Another bereaved relative explained that having a CHV accompany him to a health facility review meeting was good because the CHV had asked health workers questions during the review session, which helped clarify to the bereaved relative why his son had died at birth. See excerpt:

> The review meeting helped me because I heard the nurses being asked questions by the CHV to understand why the delay occurred in maternity in delivering the baby. Why didn't they conduct a caesarean section on time? If the nurses had referred my wife for the caesarean section early, the baby would have been saved. Even the chief took the nurses to task. The nurses did not give a clear reason for why there was a delay in delivering the baby or conducting the caesarean section. The nurses committed to ensuring this mistake was not repeated (Gabriel, bereaved relative).

Health workers expect community representatives such as CHVs to advocate for implementing MPDSR recommendation sessions with community leaders and decision-makers. Health workers expect community representatives to use other forums where the community representatives interact with community leaders to advocate for financial resources and support for implementing MPDSR recommendations. A health worker explained:

> We [health workers] believe that if a person is given the right information, they will make the right decision […] they will do the right thing. We are implementing the Community Strategy so that we give community members and CHVs the right information […] This will empower them to advocate with their leaders to implement the MPDSR action points they raise [during social autopsy] (Gavin, health worker).

Simon, a bereaved relative, also said that he expected community representatives participating in MPDSR sessions to advocate for the community. The interviewee (Simon) explained that many community members complain about the lack of adequate drugs or supplies at health facilities, which contributes to the deaths. He commented:

> If you ask people about the health services provided, most of them will say the health facility does not offer a good service […] it is up to the community representatives [on the MPDSR committee] to complain to the highest office about these things (Simon, bereaved relative).

While there are instances when community representatives perform their roles as expected, there are other instances when they do not. In the next section, I will show that there are contradictions in the notion that community representatives are trusted and respected to consistently perform the roles of channelling, mediation, and advocacy in MPDSR.

6.2 Study participants' rhetoric that community representatives are trusted and respected to perform their roles in MPDSR.

Study participants described some of their experiences participating in MPDSR in ways that contradict the view that community representatives are trusted and respected to perform the roles described above consistently. Study participants also explained that challenges in the wider socio-cultural, political and health financing context shape how community representatives perform their roles. I will use three sub-themes to show how community representatives negotiate the challenges in the following contexts: (i) cultural, (ii) social, and (iii) political.

6.2.1 Navigating cultural tensions associated with channelling information.

Community representatives perform their roles in a messy middle, balancing meeting their obligations to health workers and supporting community members in culturally appropriate ways. As I have shown, there are many instances when community representatives channel information about deaths from the community to health workers. However, community members have some cultural beliefs (e.g., discussions about perinatal deaths are a bad omen) that make it difficult for community representatives to report these types of deaths because of the cultural implications. Health workers expect community representatives to support them by reporting these deaths to improve health records on births and deaths (and the goal of MPDSR as an accountability process for generating data). Yet, this expectation means that the requirements of health workers and those of community members are at cross-purposes and community representatives are caught in the middle.

Community representatives are selected from other community members who share social norms, cultural values, and beliefs with the rest of the community members they represent. I will show how community representatives negotiate these contradictory aspects of their roles while striving to maintain their cultural beliefs and their social bonds with community members by not reporting “bad deaths.” Bad deaths include early neonatal deaths, deaths where a TBA was involved, deaths among pregnant teenagers and abortion-related deaths.

The culture in the study areas is that perinatal deaths are associated with a bad omen for the woman. As such, the cultural norm when dealing with stillbirths and early neonatal deaths (up to 7 days of life) is to bury the baby on the same day without any burial rituals or discussions. In interviews, bereaved relatives and community representatives explained that it was important for people in the community to maintain the cultural practice of burying babies without rituals or discussions. For instance, a bereaved relative explained why she had not attended a perinatal death review because it could result in misfortune for the family. The relative commented, *“I did not want people to talk about it [social autopsy for perinatal death]. The discussions can bring bad luck to my family”* (FGD, bereaved relative). A health worker also commented “*the community believe that these discussions [death reviews and social autopsy] can bring misfortune to the family* (Peris, health worker).

CHVs are sometimes conflicted between performing their roles of identifying and reporting perinatal deaths to health workers and maintaining their socio-cultural views about holding discussions related to perinatal deaths. At an FGD, CHVs talked about the complications associated with reporting perinatal deaths. The CHVs said, *“[…] we know that even if it were you [referring to the other CHVs], you would not want people to talk about the death; it can bring issues [….]. We believe that the mother might not conceive [again]” (*FGD, CHVs).

A community representative who had participated in several MPDSR sessions at health facilities and in the community explained how CHVs negotiate this contradictory aspect of their roles.

> You find that when mothers lose their babies, especially younger mothers, they may not want to participate in a review because they don’t want the issue to be discussed or followed up. The culture here is that we believe if a newborn dies, that is a bad omen [….] CHVs will have an informal visit with these families. They will talk, but nothing will be reported officially. CHVs also know the customs here and they know we don’t talk about those kind of deaths […]. It is different for mothers [maternal deaths]. You can’t hide a maternal death because she is an adult who needs a burial permit […], so CHVs report maternal deaths happening in the community. But it [reporting maternal deaths] also creates problems because the process can unearth some information like the TBA who helped that mother, and that is also a problem (Zach, community representative).

Community members and some CHVs collaborate not to report deaths to health workers if TBAs are involved. As mentioned earlier, it is not illegal for TBAs to assist women during childbirth, but health workers and civil administration discourage the practice. During my fieldwork, I learnt of several perinatal deaths in which TBAs were involved; even though the CHVs were aware of these deaths, they had not reported the deaths. Some health workers explained that they knew that CHVs do not always report deaths occurring in the community. A health worker commented:

> We know that some deaths are not reported, like if a newborn is born at home and dies, the family will bury that same day but there will be no official record […]. CHVs do not want to expose the TBA […] the TBAs are from the [same] community so that it will create problems […] health workers can’t always follow up (Joseph, health worker).

Even though community members said they trust community representatives (as shown earlier in this chapter), there are instances when community members hid information about deaths from community representatives. For example, community members do not want to disclose information about abortion-related deaths to community representatives. CHVs said that when community members hide information, it makes it difficult for them (CHVs) to fulfil their role of channelling information to health workers. CHVs described instances where they suspected that a teenager had died from abortion-related complications, but the family were unwilling to provide the CHVs with details about the pregnancy or maternal death. At an FGD, CHVs explained that some teenagers hide their pregnancies from CHVs so that there is no official record of the pregnancy. CHVs explained that typically, when teenagers do not want CHVs to have a record of their pregnancy, they are likely considering having an abortion. An FGD participant explained:

> We [CHVs] visit some homes, and when we ask if there is a pregnant woman in the home, the family is evasive. […] These are the girls who intend to have an abortion, and they don't want us to know they are pregnant, so there is no record […]. Later, you hear that the girl went to visit her relative in another town and unfortunately, she died […] you can't be sure, but people in the village say she was procuring an abortion and it went wrong…When you go to the review meeting or to report the death to health workers, you can't be 100% sure that it was abortion-related, but as a CHV, you will have heard the talk in the village. (FGD, CHVs).

Health workers described situations when CHVs are unwilling to cooperate with them (health workers) to discuss socially and legally difficult deaths such as abortions. Health workers explained that in some instances, community representatives would side with community members and refuse to participate in social autopsy sessions where health workers wanted to discuss an abortion-related death. At an FGD, health workers discussed a previous teenage maternal death that had resulted from an unsafe abortion. The teenager died at the hospital. In their view, the health workers thought that this case would have been a good opportunity for a social autopsy so that they could have a meeting with community members to discuss unsafe abortions. Health workers said they faced challenges in getting the support of CHVs to organise a social autopsy session because community members and CHVs were unwilling to accept that the death resulted from an abortion. A health worker commented:

> Everyone in the village knew that the teenager was pregnant and had an abortion […] even the TBAs and CHVs knew she was pregnant. But no one was willing to discuss it. It would have been great to have a social autopsy session to discuss this case, but we didn't have anywhere to start because if no one will publicly accept that the death was due to an abortion what can we say at the meeting (FGD, health workers).

6.2.2 Negotiating social norms and power hierarchies associated with advocacy.

Health workers and community members expect community representatives to use their positions for advocacy with decision-makers. However, some community representatives such as CHVs found it challenging to fulfil their advocacy role because of social norms that direct relationships with people in authority (e.g., what is considered a socially acceptable way of talking to authority figures in public places). Study participants explained that while CHVs are constrained by social norms around being respectful in relation to advocacy and talking to those in authority, CSO representatives are not constrained. I will show that CHVs struggle to fulfil their advocacy roles because of social norms about respectful behaviour in relation to people who are in authority, such as decision-makers, in ways that CSO representatives are not. Yet, there are complexities in how this is enacted during MPDSR participation.

CHVs have a lot of first-hand experience engaging with community members (e.g., during household visits with pregnant women and during community-based reviews such as CVAs). CHVs are aware of the challenges the community faces regarding maternal and newborn health (including MPDSR participation) because of their routine contact with pregnant women and their families.

Conversely, CSO representatives have limited direct contact with community members. From their accounts, CSO representatives are less aware of the issues community members face in relation to MPDSR and maternal and newborn health services generally. However, study participants felt that CSO representatives are not constrained by social norms about respectful behaviour. I will show that social norms influence how CHVs and CSO representatives perceive their advocacy roles. CHVs who interact closely with the community said they are unable to advocate on behalf of community members. At the same time, CSO representatives who are more removed from the daily life of community members (and their involvement in MPDSR) are responsible for advocacy on behalf of community members.

CHVs explained that they risk being perceived as disrespectful by other MPDSR participants if they speak up and advocate for community members during MPDSR sessions. A CHV explained that if one tried to advocate with their elected leaders during social autopsy sessions, the leaders could see it as being disrespectful and causing trouble for the elected leader. The CHV explained: "*if you start asking the leaders questions about providing resources to implement recommendations, the community will think you are confronting the leader. People will say you have no respect for the leader [MCA]. It will look like you are attacking the leader by saying the leader is not doing his work [e.g., advocating for adequate drug supplies for the health facility]." (*Joan, CHV).

The perception among some community members and CHVs that advocating on behalf of bereaved family members can be rooted in malicious intent and disrespect, makes it difficult for CHVs to fulfil their expected advocacy roles. A community representative described advocacy and demands for accountability from their leaders negatively. He said: *"if a CHV does advocacy it is seen as being malicious and having ulterior motives to finish the political leader. People will say you have become Okiyah Omtatah*[26] *that you are given money to cause problems*" (Zach, community representative).

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[26] Okiyah Omtatah is a long-time activist (not from the study area) who presents himself as an advocate of the people. He often sues government as part of his advocacy and accountability campaigns. He is seen as a controversial and confrontation person because of his advocacy work. At the time of the interviews, Okiyah was not an elected leader, but he has since been elected to the National Senate.

In other interviews, CHVs and community members talked about advocacy with decision-makers as *"…risky because people say you are a busybody*" (Rebecca, CHV) or *"lacking respect for the elected official"* (FGD, community members).

While CHVs are constrained by social norms on respectful behaviour and advocacy, CSO representatives are not constrained. A CHV explained CSO representatives, can engage in advocacy without breaking social norms or being labelled as malicious because community members accept that CSO representatives are "*just doing their jobs*" (Joan, CHV), and it is acceptable for CSO representatives to challenge or advocate with decision makers.

Health workers expect CSO representatives to advocate with decision-makers on behalf of the health system. Health workers explained that they invited CSO representatives to MPDSR meetings because the CSO representatives were better placed to advocate with decision-makers, unlike health workers or community members. A senior health worker described herself and other health workers like herself:

> We [health workers] are just lowly workers[27] [we have no power] who provide health services. […] we do our work, but we don't really have a voice with the county government because they are our employer…but these people from CSOs they can talk about our issues for us (Senior health worker).

Another health worker commented:

> We have invited some representatives of CSO to be part of the MPDSR committee. We want them to take the issues we discuss at death review meetings and run with them, discuss them with decision makers and politicians so that they [decision makers] can support MPDSR action plans (Felistah, health worker).

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[27] The word used here is mtu wa mkono- which translates directly to those who do menial work and have no influence in the decision making process.

Health workers also expect CSO representatives to advocate with decision-makers on behalf of community members. However, CSO representatives do not consult or interact with community members to understand the issues that community members face regarding MPDSR. In an interview with a CSO representative, I sought to understand how the CSO collected information on the experiences of community members relating to maternal and perinatal deaths. The CSO representative notes that while he and other CSO representatives participate in MPDSR meetings on behalf of the community, they do not get information from community members on what to advocate for on behalf of the community. The interviewee explained that there was no need to consult the community members on their priorities because community members would not grasp the issues that CSO representatives wanted to advocate for. The interviewee said:

> We [CSO representatives] are invited to MPDSR meetings as representatives of the community. […] our work is very complicated. [….] community members would not understand about the things we talk about. […]. We do not have meetings with the community […] we advocate with decision makers on behalf of the community (CSO, representative).

However, CSO representatives also faced challenges in their advocacy work when challenging the actions of powerful actors such as private health providers. CSO representatives and health workers (from public facilities) feel that private health facilities contribute to maternal and perinatal deaths, yet CSO representatives are unable to advocate with decision makers to address the perceived challenges posed by private health providers because private health providers are powerful. By way of background, the national government supports the implementation of a health financing strategy called *’Linda Mama’* (translates to protect mothers). *Linda Mama* aims to reduce maternal mortality by removing financial barriers associated with institutional delivery. The funds are given to any health facility that provides maternity services, whether they are public facilities, facilities run by religious institutions or private health facilities (i.e., facilities that are not owned by the government).

The national government reimburses the costs of childbirth for each woman who gives birth at that facility regardless of the outcome (i.e., whether mothers survive or not). Health workers described how CHVs and TBAs use their reputations as trusted community representatives to influence pregnant women to choose private health facilities for childbirth. CHVs receive financial incentives from private health providers to encourage mothers to give birth at private facilities. This allows private facilities to increase the reimbursement claims they can get from the national government. Health workers felt that by encouraging pregnant women to deliver in private health facilities that are ill-equipped to provide safe maternity care, CHVs inadvertently put women's lives at risk because private facilities are associated with more adverse outcomes.

The CSO representatives also expressed frustration with CHVs and TBAs for the role they play in getting mothers to obtain maternity services from private health providers and the challenges this presented to the MPDSR committee. His comments suggest that members of the MPDSR committee can sometimes work at cross purposes because while health workers and CSO representatives see the challenges presented by private providers access to *Linda Mama* Funds, CHVs (also part of the MPDSR committee) benefit from how the funds are used. The CSO representative commented:

> We [the MPDSR committee] are working in a context where some people [private health facilities] are just doing business with people's lives. […] and we can't really ask questions because you don't know who you could be dealing with…some of the people involved are powerful and it would not be wise to challenge them. […] and then there is this issue with TBAs and CHVs […] women trust them, and they [CHVs and TBAs] are the ones sending women to private facilities to die" (CSO representative).

Health workers described the difficulties they face when advocating with decision makers to deal with private health institutions for their unwillingness to participate in MPDSR sessions. Health workers also explained that the national health guidelines and MPDSR policy require that every health facility (public or private) should conduct death review meetings for maternal and perinatal deaths in their facilities. Yet, private health facilities do not always comply with these guidelines, and CSO representatives cannot advocate so that policymakers can compel private health facilities to conduct or participate in MPDSR sessions. Health workers explained that the referral process from the private facility to the public facility is often problematic because the private facility staff give very few details on what happened. This makes it difficult for the MPDSR committees (at public facilities) because they do not have all the details they need to review the death.

A health worker commented:

> The [MPDSR committee] cannot have a meaningful discussion because we have no details [….] but also as a health worker in a public facility, you have to be careful because some of these facilities are owned by powerful people in the county […] we would desire to have action points that address these private facilities, but you can't point fingers (health worker).

6.2.3 Navigating political spaces where resources to implement MPDSR are allocated.

I begin this section with a brief description on how financial resources to support implementation of MPDSR recommendations are allocated through a public participation process. The public participation process is meant to ensure that the budget approval process (for health and other sectors) is transparent and that community members have opportunities to contribute to debates on how resources are allocated.

The public participation day or forum is provided for in the Kenyan constitution as a space for citizens to engage in discussions on how county governments plan, manage and allocate resources (249). The public participation process is guided by the principles of transparency, accountability, inclusivity, and public participation (*ibid*.). The participation forums are held quarterly at every ward, sub-county, and county. Public officials and elected leaders are expected to meet with the public to discuss and approve the budget and workplan for the different administrative levels i.e., ward, sub-county, or county. This public participation process is enshrined in the constitution and elected leaders are duty bound to ensure that public participation forums are held; otherwise, the budgeting process can be challenged in a court of law. By Kenyan law, participation in public participation forums are not meant to be a political process, however, in practice, participation is political.

Health workers expect community representatives to advocate for resources on behalf of the community during public participation days. A health worker explained that health workers "*have also empowered the CHVs so that they can attend public participation forums and advocate for their communities*" (Gavin, health worker). Later in the same interview, the health worker explained that community members could use the information they get from the social autopsy sessions to lobby their elected leaders to allocate funds for some of the recommendations e.g., providing ambulances to improve referral for pregnant women. But as I will show from several other interviews with health workers, community representatives and elected leaders, the advocacy process is complicated.

CSO representatives explained that most ordinary community members are excluded from attending public participation days, even though they are meant to be open to anyone. A CSO representative explained that politicians pay some community members to attend the forums and leave out others as a way of controlling the invitation process. The CSO representative explained that once community members knew that some people were being paid and others were not, those who had not received payment would no longer be interested in attending the forums. The CSO representative explained*:*

> Politicians have hijacked the public participation process […] they have made it an invite only process. […]. They [politicians] invite the people they want to come to the forums, and they pay them […]. When some community members come [to a public participation forum] and see that some people are signing an attendance sheet and being given money, and they are told they cannot get money because they are not on the attendance list. [….] they stop attending other meetings […] (CSO, representative).

Elected leaders justified their approach to managing the invitation process by saying that it was the only way they could get community members to participate. At an interview with an elected official, he explained that community members are reluctant to participate in the participation forums because they would miss out on work and loose wages. The elected leader explained that he and other leaders give money to some community members as a compensation for lost wages. He further explained that because resources are limited, the number of people whom he could pay to participate was limited.

CSO representatives felt that politicians also control the participation process by selecting community members who rubber stamp what the politicians say. Later in the interview with the CSO representative, the interviewee described the type of community members who were invited by politicians to attend the public participation forums. From his comments, the interviewee perceives the community members who have been invited as lacking capacity to engage politicians in debates about the budget proposals that are presented for public debate and feedback. The interviewee describes the public participation process as a tick-box exercise because the community members who are invited to participate cannot discuss the written contents of the workplans and budgets because they are illiterate.

> And you find that the community members who have been invited by the elected leaders are illiterate, people who can’t even write their names. […] so, they come to the public forum and just agree with what the politicians say. After all they will still get their allowance for participating in the forum and the politicians will pass what they want. […] (CSO representative).

The CSO representative also described other tactics that politicians use to discourage CSO representatives from participating in public participation forums. The interviewee explained that he and other CSO representatives attend the forums without expecting payment from politicians. But the interviewee felt that politicians deliberately withheld important information that CSO representatives would need as part of their (CSO representatives) preparation to attend the forums. According to the interviewee, this is meant to frustrate him (and other CSO representatives and discourage them from asking questions because they have had very little time to review the workplans and budgets.

> You find that the politicians are supposed to give people the documents that will be tabled at the public participation forum early so that people can review the documents and prepare for the forum. […] We [CSO representatives] normally demand to get the workplan but the politicians don't give it in time. […] we [CSO representatives] are given a 50-page document on the proposed workplan and budget the night before the public participation day. […] it is like the leaders don't want us to ask questions of the proposed work plan and budget […] it is difficult to go through the details of the proposed plan in such a short time (CSO representative).

CSO representatives described how they cope with the challenge of limited time to review proposals that are presented during public participation forums. The CSO representative explained that he would leverage on skills gained to support advocacy as part of his involvement in MPDSR in the county. The CSO representative explained that several CSOs in the county had received training on developing advocacy briefs from an international organisation as a way of supporting MPDSR implementation. The interviewee explained that he (and other CSO members) could use the advocacy briefs to lobby decision makers for resources during public participation days. For instance, the interviewee described how the CSO had developed advocacy briefs for a blood bank as part of MPDSR recommendations. The CSO representative explained that while the issues of constructing a blood bank were not in the proposed plan that the politicians had included, the CSO members had enough data (given to them by health workers) from MPDSR sessions to make a case for inclusion of the blood bank onto the workplan and budget. According to the CSO representative, over time and after attending several public participation forums and presenting the same advocacy briefs, the proposed blood bank was included in the budget.

Politicians control how resources to support MPDSR implementation are allocated and distributed. An elected political leader explained that as a member of the county assembly (MCA) he (and others in the assembly) are responsible for allocating and approving the health budget for the county. He explained that as leaders they approve a lump sum for the health department, and it was up to the county health team to have a broken-down budget so that they could finance action points relating to MPDSR as they (health workers) saw fit. The elected leader's comments imply that health workers have the leeway to decide how to prioritize the items on the approved health budget. But according to health workers, the budget allocation process is political and contested because the politicians want to control how the resources are distributed.

A health worker explained that the MPDSR committee had recommended that several ambulances be purchased to support timely referral for pregnant women in the county. This was presented to the elected leaders at the county assembly (health committee) and the elected leaders agreed and approved the budget. The health worker commented:

> We [county MPDSR committee] were allocated funds [by the county government] to buy some ambulances. But it has become difficult to make them operational. Each MCA wants the ambulance positioned in their ward because it gives them political mileage. […]. It is not necessary or possible to buy an ambulance for each ward [..] this makes it difficult for us as health workers to allocate resources (health worker).

According to health worker (above quote), it became very difficult to agree on where to position the ambulances because each leader wanted the ambulance in their ward. In the end the ambulances had still not been provided at the time of my field work more than a year after the budget had been approved.

To summarize this chapter, I have described the multiple roles that different community representatives play during MPDSR participation. I have shown how community representatives navigate different participatory spaces and the different barriers they face as they fulfil their roles in MPDSR.

7.0 Discussion

Chapter overview:

In this chapter, I return to my research question and study objectives to combine the three findings chapters that explore how community participation in MPDSR works in practice. I conceptualised community participation in MPDSR as a potential process for knowledge co-production, that requires the collaboration of health workers and community members throughout the MPDSR cycle. The MPDSR process relies on the cooperation of health workers and community members to pool together clinical and lived experience forms of knowledge by gathering knowledge, analysing it and translating it into recommendations to prevent future mortality. The study has examined the participatory spaces (134) where MPDSR-related activities are implemented by exploring the experiences, perspectives and interactions of health professionals, community members and community representatives as they participate in knowledge co-production.

I have summarised the findings of the study to demonstrate how I have responded to the two study objectives and the overall research question. This thesis has addressed the research question: **How does community participation in MPDSR contribute to the MPDSR goal of accountability for preventing maternal and perinatal deaths in Kenya?**

In the background chapter of this thesis (chapter 1), I stated that WHO and a number of studies on MPDSR have argued that MPDSR is an accountability process with three aims: (i) generating data on maternal and perinatal deaths to know the number of deaths, where, when and why these deaths happened, (ii) using review data to improve quality of care, and (iii) using data to mobilise resources to support implementation of MPDSR recommendations (3,13,22,23).

After summarising the study findings and situating them in the existing literature on community participation in MPDSR, I reflect on the implications of the study findings. I have organised the section on the implications of the study findings following the three stated aims of the MPDSR process.

7.1 Summary findings

7.1.1 Objective 1: To understand how health workers and community members co-produce knowledge throughout the MPDSR cycle.

I have described how MPDSR participants (community members, community representatives, and health workers) participate in knowledge co-production throughout the MPDSR cycle. I showed that community members are involved in gathering knowledge as they identify and report deaths to health workers. I also described the experiences of MPDSR participants as they used death review sessions to produce knowledge by discussing the clinical and social factors that may have contributed to a death. MPDSR participants also engage in knowledge translation as they mobilise resources to support the implementation of MPDSR recommendations or make changes to their practices (clinical or social) in line with the MPDSR recommendations.

I have shown that there is a rhetoric of knowledge co-production, i.e., the difference between what study participants say about the value of community participation in MPDSR and what happens in practice. All study participants used vocabularies of hope to paint a picture of collaboration and learning between health workers and community members during MPDSR sessions. Health workers used normative language when rationalising the value of community participation in MPDSR by referring to policy documents such as the Community Strategy (75) and the national MPDSR policy (69). Despite using vocabularies of hope on the value of community participation, health workers, community members, and community representatives reported multiple barriers which influence how knowledge is gathered and used for quality improvement and resource mobilisation in MPDSR processes. I showed that despite using vocabularies of hope to describe the knowledge processes as collaborative, in reality, knowledge is not co-produced as study participants face multiple barriers that make co-production difficult.

Study participants described these barriers using vocabularies of (in)competence and a (lack of) credibility. Health workers use vocabularies of incompetence to assign labels to community members as incapable and incompetent knowledge producers during MPDSR sessions. Community members labelled health workers as incompetent hearers because health workers ignore the knowledge contributions of community members during MPDSR sessions. The labels that MPDSR participants used to position each other separate health workers and community members into silos, and limit collaboration between them during the participation process.

Health workers used the vocabularies of incompetence to disparage community members' lived experience knowledge by describing community members as "*ignorant*," "*uneducated*", or "*incapable of giving good suggestions*." These perceptions among health workers influence their decisions on whether to invite community members to facility death review meetings or not. Health workers also filtered out community knowledge from the MPDSR process because they feel that community members' knowledge is unreliable because community members are perceived to be emotional and irrational.

Health workers use vocabularies of incompetence to rationalise the use of MPDSR sessions as opportunities to educate community members "*so that they can stop being ignorant*." The flow of health education is uni-directional and is channelled from health workers to community members via community representatives. Community members explained that they do not always agree with the MPDSR recommendations (in the form of health education) given by health workers because they do not align with their lived experiences. While community members question the relevance of the MPDSR recommendations, they cannot openly contest them because of power hierarchies. Community members' comments demonstrate that contesting the knowledge presented by health workers during MPDSR sessions could have repercussions on community members' use of health services in the future. As a community member at an FGD said: "*If you are going to disagree with what the health worker said [during social autopsy sessions], be sure that you are done giving birth, because […] it can cause problems for you*."

Health workers used vocabularies of credibility to stratify different forms of knowledge by questioning the legitimacy or value accredited to community members' knowledge. Health workers described the information generated from clinical processes such as review of patient notes and partographs as "*data*", which has implicit meanings of relevance and importance in MPDSR (MPDSR is described as a data-driven process (14,21,24)). According to health workers, "*data*" is gathered using biomedical tools such as partographs and patient case notes, while community members' narratives of their lived experiences before an adverse outcome are described as "*stories"* by health workers. The minutes of facility death review meetings are written up as MPDSR proceedings reports, uploaded onto the DHIS2 and submitted to subnational and national MPDSR committees for resource allocation and policy direction. Conversely, health workers do not upload reports from community verbal autopsy (CVA) onto the DHIS2 as required (in the health policy). Excluding CVA data from the DHIS2 means that information from CVAs cannot be used to guide decision-making or advocate for resources at subnational and national levels of the health system[28].

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[28] At sub-national (county) and national level, health managers and policy makers use the information on the DHIS to make policy decisions on maternal and newborn health.

Some of the findings from this study mirror other studies on community participation in MPDSR. Most of the existing literature on community participation in MPDSR has described how community members are just involved in identifying and reporting deaths to the health system (e.g. 40,51,53). Other studies have described community participation in community death reviews using verbal and social autopsy (7,33,175) and community engagement in facility-based reviews (33,46). Most of the existing literature on community participation in MPDSR has concentrated on the role of social and verbal autopsy as a tool for health education (7,33,50). I have shown that community members participate in death notification and reporting as part of knowledge gathering. I have also described community members' experience as participants in death reviews both in health facilities and in the community through verbal and social autopsy. In addition, some of the existing studies that have reported community participation in the implementation of recommendations have shown that community members support the implementation of local-level interventions to prevent deaths and to improve health-seeking behaviour e.g. (7,33,52,182). I also showed that community members in this study are involved in implementing local-level recommendations, i.e. knowledge translation such as community mobilisation for blood donation and providing transport to improve referral from the home to the health facility during childbirth.

As I explained in my critique of the literature (chapter 2), the existing studies have not focused on community members' experiences and perspectives as they identify and report deaths or participate in the review process. The existing studies have also not conceptualised the contributions of community members during death notification, reporting, and review as forms of knowledge or analysed how community knowledge is used in the MPDSR process. In this thesis, I have gone beyond describing the activities related to death notification and reporting by examining how the knowledge that community members gather is used and translated into recommendations that could prevent future deaths.

This PhD contributes to the literature on community participation in MPDSR by demonstrating how the theorised knowledge-production process is working in practice. The use of the vocabularies of incompetence and credibility to describe community participation in MPDSR demonstrates that there are epistemic injustices (250) that shape the participation process. I will briefly introduce epistemic injustice and show its relevance to understanding the study findings on knowledge co-production in MPDSR.

Epistemic injustice

Epistemic injustice was coined by Miranda Fricker and refers to wrongs and injustices done to people in their capacity as knowers (250). Epistemic injustice helps us understand the wrongs related to excluding some forms of knowledge from knowledge encounters because some knowledge producers are labelled as lacking the capacity to participate in collective sense-making (250–252). Epistemic injustice is understood in the context of unequal power relations where a dominant group's knowledge is deemed more credible (204,250,251). This is often the case in physician-patient interactions where biomedical knowledge is considered the more dominant and relevant form of knowledge relative to the lived experiences of community members (146,252). Epistemic injustice has been applied to understanding knowledge processes in global health research (253), patient-health provider relationships (252) and exploring health and illness (146).

Scholars argue that labelling knowledge processes as epistemically unjust does not imply that all forms of knowledge are always relevant for all circumstances (e.g., ill patients may lack the clinical knowledge necessary for treatment). Rather, epistemic injustices are context dependant; there maybe circumstances when an individual or group may lack the relevant knowledge for a specific context, but there can be other contexts where they have legitimate knowledge that is unjustly ignored. (146,252). In making my arguments about the forms of epistemic injustices that exist during MPDSR participation, I limit the claims for knowledge co-production to the forms of knowledge based on the lived experiences of community members that are required to analyse the contributors of maternal and perinatal deaths. There are limits to what community members can contribute in terms of knowledge of MPDSR because they do not have the biomedical training to suggest clinical recommendations (e.g., how to manage patients with PPH). Nevertheless, knowledge based on the lived experiences of community members is relevant to the MPDSR process for two reasons. First, it is well-accepted that understanding and addressing the social factors contributing to maternal and perinatal deaths is critical to maternal and perinatal mortality reduction (9,254). Secondly, understanding patients' experiences of care within health facilities is one of the domains of measuring the quality of care in maternal and newborn health, including MPDSR (58,62). As such, I argue that community members have relevant knowledge based on their health care experiences before an adverse outcome and their lived experiences of their social life before the death.

Health workers in this study do not question the importance of community members' lived experience knowledge to the MPDSR process, rather, health workers use vocabularies of incompetence and credibility to question the roles of community members as knowers in the MPDSR process. Using labels such as *negligent* or i*gnorant* to describe community members separates health workers as competent knowledge producers from incompetent community members during knowledge encounters (250). The labels of competence versus incompetence and credibility versus lack of credibility of knowledge that study participants use are epistemically othering (255) and have notions of 'us' versus 'them' during MPDSR sessions. This limits the potential for knowledge co-production in MPDSR.

While health workers use the labels of *"emotional*" and *"irrational*" to exclude community members as reliable knowers from MPDSR sessions (146,252), health workers do not question their positions as reliable knowers even though they also experience emotional difficulties. In their interviews, health workers explained they sometimes broke down during

MPDSR sessions or experienced guilt and self-blame. Yet, health workers still participate in MPDSR sessions despite these problematic emotional experiences without devaluing their (health workers') role in the knowledge production process.

Health workers use their positions of power over community members to control the invitation process to facility review sessions, which excludes community members from spaces where collective knowledge is produced (252). By controlling the invitation process (134), health workers limit the forms of knowledge and knowledge holders that are included in MPDSR participatory spaces. Participatory spaces may be physically accessible, as is the case with social autopsy sessions where, in theory, anyone from the community can attend because one does not require an invitation. Yet, despite being physically accessible, health workers and community representatives dominate the process by controlling what people are allowed to say in these spaces (99). I have shown that community members do not consider social autopsy sessions as safe spaces for dialogue. Community members moderate their interactions by not publicly disagreeing with health workers during social autopsy to manage potential negative repercussions to their future healthcare interactions. This limits the opportunities for community members to engage with health workers and contribute to framing MPDSR recommendations.

I argue that the three-delay model is not a socially neutral tool; rather, it can be manipulated or used incorrectly by those who control the knowledge production process. This can result in excluding some forms of knowledge from the MPDSR session, such as quality of care issues (3rd delay) or how the third delay contributes to the first and second delay. The three delay model is often used in MPDSR as an analytical tool to explain how social and clinical factors- contribute to maternal and perinatal deaths (48,256). I showed that health workers emphasise the role of the first and second delay in contributing to deaths and less on the third delay. The first and second delays are associated with community-level factors that contribute to deaths, such as a lack of knowledge of pregnancy danger signs (1st delay) or lack of finances to pay for transport (2nd delay) (9). By emphasising issues related to the first and second delay and not the third delay, health workers can shift blame and responsibility for deaths to community members.

When I observed a CVA for a maternal death, I noted that the health worker used the three-delay model to scrutinise the actions of the deceased woman's family before the death. During the CVA discussion, the health worker did not acknowledge the role that third delay issues may have played in contributing to the death. Even when the bereaved relative suggested to the health worker that there were health system delays, the health worker did not adjust his conclusions to consider the relevance of the bereaved husband's testimony. The health worker uses his position to determine how information about the death is analysed and reported. There are two forms of injustice here, first diminishing the place of the deceased husband as a knower (251). Secondly, the health worker at the CVA treats the bereaved relative as an epistemic other whose role in the CVA is only to contribute knowledge based on the boundaries set by the health worker (255). In this CVA (and from other study participants' accounts of their participation experiences), the bereaved husband is only expected to respond to the questions posed by the health worker, and there are no opportunities for him to contribute to the CVA beyond what the health worker allows him to do.

I have shown that health workers frame community participation in MPDSR as an opportunity to transfer health education in the form of MPDSR recommendations to community members. However, community members question the credibility of some of the MPDSR recommendations because the recommendations do not align with their (community members) lived experiences. Community members can struggle to give their feedback to health workers because of power hierarchies, as illustrated earlier in this section. Community members felt that health workers were arrogant, describing them as "*incompetent hearers"* who cannot listen to the views of community members. Pohlhaus (255) posits that when hearers (i.e. those in power) fail to recognise a speaker's capacity to generate ideas that differ from their own (i.e. the speakers), the speaker is reduced to a subject who is not expected to push the boundaries of knowledge. It may be that health workers use uni-directional methods for health education because they do not expect community members to have new or additional ideas for the health education sessions. By using monologic approaches to health education (120), community members are denied opportunities to use MPDSR sessions as spaces to contribute or contest the discrepancies between their lived experiences and the MPDSR recommendations they receive as health education. As Filipe et al (105) argue, the co-production process should create participatory spaces where different forms of knowledge are explored and debated so that new knowledge can develop, yet this opportunity to co-produce knowledge is lost as the role of community members as knowers is diminished.

7.1.2 Objective 2: To explore interactions among MPDSR participants and the meanings that MPDSR participants associate with the participation process.

Community members in this study use vocabularies of exposure to question the intentions of health workers during MPDSR sessions. Community members see MPDSR sessions as opportunities for health workers to investigate and expose community practices. Community members associate MPDSR sessions with meanings of shame and public humiliation from other community members, fear of arrest for deaths associated with illegal activities such as abortions and fear from God because of going against expected beliefs and culture. Community members deal with the associated risks of exposure by avoiding MPDSR sessions, disrupting sessions or withholding information that could be useful for producing knowledge to improve quality of care.

Health workers associate participation in MPDSR with scrutiny of their actions. I showed that health workers associate participation in MPDSR with blame from other health workers, professional risks from their employer and threats of legal action from community members. Despite repeated claims among health workers that the MPDSR process upholds a no-blame approach, health workers gave many examples of blame during MPDSR sessions.

In practice, blame pervades interactions among health workers and between health workers and community members. This is the rhetoric of no blame, i.e., the difference between what health workers say about blame in the MPDSR process and what happens in practice. I have shown that blame flows are hierarchical as doctors blame nurses, and frontline health workers (mainly nurses) blame CHVs and bereaved relatives. Health workers also described a hierarchy of blame between staff working at the referral hospital and those from peripheral health facilities (typically more junior health workers). Community members also blamed health workers for deaths, but rather than framing it as blame, most community members framed it slightly differently and talked about holding health workers accountable for perceived negligence which contributed to the deaths.

The study findings show that meanings associated with blame and its consequences shaped health workers' actions before, during and after MPDSR sessions. For instance, health workers were reluctant to have community members participate in facility death reviews despite the policy guidelines indicating that community members should participate. Health workers used different tactics to manage or avoid blame, such as deciding not to attend MPDSR sessions or manipulating documents such as partographs to "*cover up what happened"* before the MPDSR session. Both frontline health workers and senior health workers felt that the MPDSR reports were not authentic, with comments such as "*You can see how the health workers at the facility review meeting have cooked the data*." In other instances, health workers managed blame during the review session by ensuring that the recommendations made at the review meeting did not target them as individuals or as a cadre and shifting blame to community members. As one health worker explained, "*during the meeting everyone [health workers] does not want the recommendations to target them because it means you made the mistake, […] each cadre tries to run away […] in the end the recommendation targets the CHV and the community"*.

Health workers also filtered out knowledge contributions from community members either by not documenting what community members said during MPDSR sessions or using tools such as the three-delay model to shift blame from themselves (health workers) to community members. Some health workers attended death review meetings but chose not to speak during the meeting as another tactic for managing blame. Health workers also used the MPDSR proceedings to avoid the risk of blame in the future; for instance, health workers are strategic in how they record and file the proceedings of death review meetings by leaving out information that could be used to legally incriminate a health worker if they are taken to court.

From their accounts, health workers rationalised their seemingly harsh treatment of pregnant women during childbirth as a way of avoiding adverse outcomes and the associated risk of being blamed for the death. The healthcare encounters between health workers and bereaved relatives before an adverse outcome (e.g., previous disrespectful maternity care) affect the willingness of bereaved relatives to participate in MPDSR sessions. Some of the bereaved relatives who had not participated in a death review meeting associated their decisions not to participate with past negative experiences with health workers.

Both health workers and community members explained that participation in MPDSR involves negative histories of care that return community members to spaces that are associated with harm or trauma. Community members talked about the difficulties of narrating their lived experiences before an adverse outcome to the same health workers they felt had contributed to the death. Health workers explained that participating in death review meetings could be emotionally difficult because they felt that despite doing their best to prevent deaths, they were still blamed for the deaths at the death review meeting.

Community members and health workers leverage on their relationships with community representatives to manage blame and make MPDSR spaces more habitable. Community representatives mediated between health workers and community members when either party felt aggrieved. Community representatives (except CSO representatives) also spoke on behalf of community members during MPDSR sessions if bereaved relatives could not speak for themselves or were not invited to the review meeting.

Health workers and community members disengaged from the MPDSR process when they did not see how their inputs were used because recommendations were not implemented. Study participants described the opportunity cost of participating in MPDSR sessions, citing losses in terms of time and money. Health workers expressed frustration with participating in MPDSR amidst heavy workloads and other healthcare priorities with no visible changes because recommendations are not implemented. Community members also talked about the difficulties of sustaining participation in MPDSR sessions because "*people just talk, and nothing changes*."

Health workers and community members use normative language from the Community Strategy to describe the advocacy and mediation roles that community representatives are expected to perform in the MPDSR process. Community representatives live in a messy middle as they are sometimes conflicted between maintaining social-cultural values they share with other community members and meeting their obligations when reporting deaths that are considered culturally problematic, e.g., perinatal deaths associated with bad omens.

Community representatives are expected to advocate with decision-makers such as MCAs to allocate resources to implement MPDSR recommendations, but they face several challenges. As community representatives, CHVs are more aware of the challenges community members face in relation to maternal and newborn health, but CHVs are constrained by social norms on advocacy with decision-makers because they do not want to be seen as "*disrespectful" or* "*troublemakers*" for calling out people in authority. Conversely, while CSO representatives are not constrained by social norms on advocacy, the CSO representatives did not engage community members to understand what community priorities are, and the issues that advocacy should focus on.

Secondly, CSO representatives explained that the political class (MCAs) control the invitation process and the discussions during the public participation forums. This has implications for how resources to support the implementation of MPDSR recommendations are allocated and distributed. Politicians used public participation days to "*gain political mileage*" by controlling how health managers distribute the resources to support the implementation of MPDSR recommendations (within the broader health budget).

CSO representatives associated the implementation of *Linda Mama* funds with increasing the risks for adverse outcomes because of the involvement of private health facilities in maternity care. Health workers and CSO representatives felt that CHVs inadvertently contributed to maternal and perinatal deaths by using their influence on pregnant women to encourage them to give birth in private health facilities. Health workers and CSO representatives were unable to advocate and compel powerful private health providers to participate in MPDSR sessions for deaths that happen in private facilities as set in the national guidelines.

The findings in this study align with other literature that has shown that community members are reluctant to participate in death notification and review if the deaths are socially stigmatised, such as HIV-related deaths (33) or if mothers are blamed for the deaths during social autopsy (46). Some of the existing literature has also shown that health workers and community members are demotivated from participating in MPDSR sessions if the recommendations of the MPDSR process are not implemented (46,66,195). Other studies on community participation in MPDSR have shown that CSOs can support community efforts for advocacy (47,52,182).

The study findings on blame culture resonate with other studies in MPDSR on how blame culture affects health workers by avoiding MPDSR participation (54,56,66,195). Other studies have shown that blame culture influences how health workers document details relating to maternal deaths during MPDSR sessions to minimise professional risks (195,198).

This PhD contributes to the literature on community participation in MPDSR by analysing the meanings that study participants associate with the MPDSR process and how these meanings shape the knowledge production process. People make sense of their participation experiences based on the meanings they associate with the spaces, which can shape their unwillingness to participate (99). Health workers and community members also associate community participation in MPDSR with scrutiny of their actions, which shape the participation process, and the knowledge (in the form of recommendations) produced to improve quality of care and resource mobilisation as I will illustrate throughout this chapter.

Having summarised the study findings and situated these findings in the existing MPDSR literature, I will combine the findings from the two study objectives and discuss their implications on the practical realities of implementing community participation in MPDSR.

7.2 Rhetoric of community participation

In this PhD, I have used a grounded theory approach to explore how community participation as a strategy for supporting the accountability goals of MPDSR works in practice. In chapter 2 of this thesis, I explained that I have conceptualised community participation in MPDSR as an intervention that creates participatory spaces for health workers and community members to co-produce knowledge by gathering on where deaths have happened, using the knowledge to review deaths and translating knowledge into recommendations. The emerging theory from this study helps us understand the participatory spaces where knowledge is co-produced and the realities of the participation process.

The unifying thread for the three chapters is an underlying rhetoric that characterises community participation in MPDSR. The word rhetoric can be used in different ways, here I mean "*language designed to have a persuasive or impressive effect, but which is often regarded as lacking in sincerity or meaningful content*" (257). Each of the findings chapters begin by describing a prevailing discourse on community participation that is largely shaped by the aspirations of the MPDSR policy. At the micro-level (i.e. interactions between health workers at primary care facilities where deaths happen and community members), the prevailing discourse is that community participation is valuable for knowledge production. This view is inherent in the global and national MPDSR policies by linking community participation to the accountability goals of MPDSR (13,23,34) . Yet there are epistemic injustices in the knowledge production process that contradict the discourse on the value of community participation in MPDSR. At the meso level (institutional relationships i.e. relationships among health workers and relationships between health system and community members), the prevailing discourse that a no blame culture in the MPDSR process is necessary for participation in MPDSR to improve quality of care. At the macro level (socio-political context), the prevailing discourse in the Kenya Community Strategy (76) is one of trust and respect as a key ingredient that enables community representatives to perform their roles in MPDSR. Yet as I have shown, talking about trust and respect (without actually demonstrating it) is insufficient for enabling community representatives navigate the complex MPDSR participatory spaces. Another prevailing discourse at global level is the role of data in supporting advocacy and accountability(13), but as I have shown there are challenges navigating political spaces which contradict this discourse.

Figure 5 below summaries the emerging theory on community participation in MPDSR and illustrates the contradictions in the aspirations of the MPDSR policy that community participation could support its accountability goals of generating data, improving quality of care and mobilising resources to support MPDSR implementation.

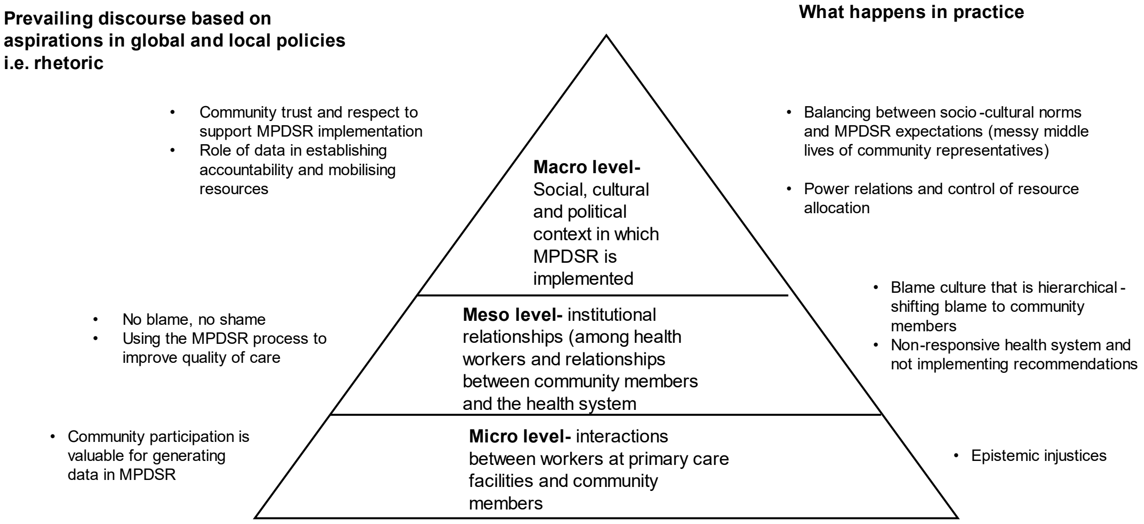

Figure 5: Emerging theory on community participation in MPDSR

Freedman and Schaaf (258) note that accountability processes or policies such as MPDSR need to be connected to the practical realities in which the policy is enacted. The authors further argue that while a policy may state the expected norms for health professionals and other actors and use the right language and indicators to demonstrate technical understanding of the problem the policy seeks to address, the policy can have no influence on those norms being enacted into practice (258). Sardan (259: 1) has described the dissonance or gap between formal rules as stated in policies and actual practices of actors such as health workers as ‘practical norms’. Practical norms are people’s (such as health workers, community representatives or other bureaucrats) responses to the contexts in which they perform their roles to cope with the opportunities and challenges they face. This can present itself as rhetoric- as people use policy language to show that they understand the rules or the policy while their actions are not aligned with the policy expectations.

Scholars have suggested that to understand why rhetoric exists, we need to examine how programmes are implemented on the frontlines and the everyday challenges that actors such as community members and health professionals face (258–260). From my summary of the findings, three broad realities are associated with MPDSR participation in the frontlines, i.e., during MPDSR sessions. These are epistemic injustices, the negative meanings of scrutiny associated with MPDSR participation and complex power relations. The epistemic injustices, negative meanings of scrutiny and power relations that characterise the interactions between frontline health workers and community members are othering (255), creating a binary view that pits health workers against community members in the MPDSR process. Yet, these challenges are influenced by the health system and the wider context in which the MPDSR policy is implemented. The findings and analysis of this study should not be understood as community members versus health workers. Rather, community members and health workers are constrained by upstream barriers in the health system and the wider socio-political context in which they work (146,250), as I demonstrate in the next section.

I have organised the section as follows:

(i) Global and national policies and guidelines.
(ii) Structural barriers within the health system.
(iii) Socio-cultural and political contextual barriers.

7.2.1 Policies and guidelines

I argue that the global MPDSR policy has been implemented using top-down approaches that are not necessarily suited to the context in which it is implemented. This influences how health professionals (both national level and frontline workers) interpret its implementation, which can result in rhetoric. Freedman *et al.* (258) posit that global health policies often risk rhetoric in their implementation because the "*problems and solutions are framed at the global level, rather than the reality on the ground*". I present several arguments to demonstrate the global MPDSR policy's role in creating rhetoric of community participation in MPDSR. First, the history of the MPDSR process could contribute to the marginalisation of community participation in MPDSR. Secondly, I show that the over-emphasis on quantitative indicators in global MPDSR reporting can marginalise community knowledge because community members do not supply their knowledge in ways that are recognised in the policy reporting formats. Thirdly, I argue that the MPDSR global principle of '*no blame and no shame'* is insufficient to address the rhetoric of no blame during MPDSR participation. Finally, I show that the MPDSR policy lacks conceptual and practical clarity on how some elements of the MPDSR policy, such as social autopsy, should be implemented. I will elaborate on each of the points I have listed here.

History of MPDSR

Historically, the MPDSR policy process grew from Beyond the Numbers (BTN), a strategy that did not explicitly recognise the role of community members in surveillance, review and response during maternal death reviews (1). There is a lack of clarity on the differences between BTN and MPDSR among health workers participating in this study. At the co-production workshop, health workers talked about the top-down nature of the MPDSR policy process and their perception that community members are not necessarily required to participate in MPDSR, which was the case in the BTN era, where maternal death reviews did not include community members. Health workers' views and practices may still be shaped by the principles in the BTN[29] strategy (i.e., community participation is not explicitly expected) while using the language in the MPDSR policy (where community participation is more explicitly described). Cornwall (261) posits that even when policies and concepts such as participation are re-invented, they can still maintain discordant meanings and interpretations, influencing how they are enacted. It is possible that while the MPDSR policy has changed over

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[29] In the BTN strategy, community engagement in the reviews is limited to verbal and social autopsy and maternal death reviews are purely a clinical process of audit.

time and encouraged more community engagement in the MPDSR process, health workers' perceptions about MPDSR and the role of community participation have not changed.

While the WHO guidelines indicate that countries should adapt the MPDSR process to ensure that it is relevant to their context (14), in practice, most MPDSR interventions rely on global standardised tools for implementation, as is the case for Kenya. Sardan *et al.* (262: 71) have conceptualised policies developed at the global level based on past success stories in one part of the world with the expectation that replication elsewhere will yield similar success as "*travelling models*". The literature has suggested that tools such a partographs and focused antenatal care (FANC) are travelling models that have been developed by global experts and implemented using standardised tools and protocols to facilitate managerial efficiency (260,262). In the case of MPDSR, the success of the UK confidential enquiries that have existed since the 1950s is often cited as the rationale for implementing MPDSR globally in the hope of yielding similar success (49). I would argue that the MPDSR policy is a form of a travelling model developed globally and disseminated to countries with standardised tools such as death notification forms, verbal and social autopsy tools and maternal/perinatal death review forms. The standardised approach does not account for differences in the professional norms of health workers who implement the policy or the social norms of community members who receive healthcare based on health workers' interpretations of what the policy means (262). This could account for some of the rhetoric in the MPDSR process as MPDSR participants use normative language of what the policy documents state about the importance of community participation in MPDSR. While study participants repeatedly used vocabularies of hope to explain that community participation is important for knowledge co-production, in practice, there are epistemic injustices in the knowledge co-production process, and the knowledge from health workers dominates MPDSR sessions.

Measurement in MPDSR

The MPDSR policy and some of the literature emphasise quantifiable data's role in decision-making MPDSR by defining it as “a data-driven process for tracking maternal deaths” (23: 3). This could perpetuate the notion that some forms of information generated are valid, measurable data while others, such as experiential knowledge, are not. WHO explains that MPDSR involves “*an in-depth qualitative interview to understand the circumstances that contribute to maternal/perinatal deaths”* (14: 1). Quantitative and qualitative information is necessary for decision-making in MPDSR, but global reports on MPDSR tend to focus on quantifiable data (e.g. 37). The emphasis on reporting quantifiable data could also contribute to the interpretive marginalisation of community members as knowers (252,253) because the format in which community members supply their knowledge as oral or spoken contributions is not used for reporting and submitting MPDSR data at global level.

Storeng *et al.* (263) have argued that maternal health programmes emphasise the role of data as a tool for ‘*evidence-based advocacy’*. The authors note that the data generated from project implementation is a political tool that programme implementors can use to negotiate for resources with bilateral/multilateral donors (*ibid*.). There is a push at global and national levels for countries to produce and report quantifiable MPDSR implementation-related data, which is often a measure of how well a country is performing regarding MPDSR implementation (e.g. 37) and Time to Respond Global Report 2024 (WHO upcoming).

The guidelines on the types of data that are relevant are articulated at a macro level (global and national), which can influence how micro-level knowledge production during MPDSR sessions happens. Health workers use vocabularies of credibility to describe the value of knowledge generated from patient files and tools such as partographs during death review meetings. Health workers only upload MPDSR proceedings for death reviews conducted in health facilities, not those from qualitative CVAs, as expected. This may influence how lived experience knowledge (text-based data from the in-depth interviews) is reported on the DHIS2.

Data uploaded on the DHIS2 is primarily numerical as it is a health information management system. From my interviews with senior health workers (national and county), I learned that there is a separate section on the DHIS2 where data from CVAs could be reported. Health workers were unclear about how to report CVA data with comments such as "I *am told there is a section on the DHIS2 where we can report CVAs*" (senior health worker). The Community Strategy describes how to report community-based health information (CBHIS) such as CVAs on the DHIS2. However, it is unclear from the interviews if health workers do not know or know and cannot upload CVA data on the DHIS2. In practice, the information from CVAs remains in paper files at level 2 health facilities and is not available at the decision-making table (county or national level).

Using structural frameworks such as DHIS2 to submit reports on facility death reviews and not those from CVAs means that we know less about community experiences in MPDSR. For example, in my interview with a member of the national MPDSR committee, he said that the committee assume that CVAs are not conducted because they are not reported. Byskov (251) has argued that the decision to exclude some forms of knowledge from decision-making arenas excludes the evidence from future debates. By excluding CVA data from the DHIS2, it is assumed that Kenya has no experience implementing CVAs. Taking this further, it can be assumed that if there are discussions on experiences implementing CVAs, Kenya would be excluded from the discussions because there is no evidence that the knowledge exists.

Burgess (264) challenges those designing global health interventions to reflect on the role that power plays in setting up the structures (such as the DHIS) that shape knowledge production. The author further argues for critical reflection on the theories of change that underpin health programmes to interrogate how power relations influence how an intervention is designed and implemented (*ibid*).

For instance, in this study, data is deemed credible because it is uploaded on the DHIS without questioning how power dynamics influence which forms of knowledge are deemed credible and therefore uploaded on the DHIS and which ones are left out.

No blame-no shame principle

The findings of this study suggest that the lack of a clear mechanism and framework for managing blame culture can affect how health workers and community members make sense of their participation in MPDSR sessions. The *no blame, no shame principle* is simply a statement that health workers repeat before any MPDSR session. The no-blame principle In Kenya[30] is not backed by any resources such as legal frameworks to support its implementation and assure health workers of their protection from legal or professional risks.

Junior health workers feel that the process of apportioning blame is hierarchical and unfair because senior health workers do not face the same professional risks that junior health workers face. This can affect how frontline health workers (typically more junior) use MPDSR proceedings to protect themselves by filtering out some forms of knowledge and shifting blame to community members who are lower in the health system hierarchy. The comments from frontline health workers also show that blame culture influences future healthcare practices, such as disrespectful maternity care as a strategy to avoid adverse outcomes and the associated meanings of blame. Some authors have argued that the lack of resources that participants can draw on to make sense of the negative meanings of scrutiny could result in epistemic injustices during micro-level interactions (250,253). For example, it could be that the lack of a legal framework to support the no-blame principle makes it difficult for frontline health workers to trust the MPDSR process to protect them from the legal and professional risks associated with MPDSR participation.

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[30] None of the health workers I interviewed at county or national level knew of if there is an explicit law that protects health workers. The MPDSR policy says that health workers should be protected against litigation, but there are incidences of legal action, mostly against the referral hospitals. But as I showed in the findings, some health workers have been arrested.

Even though health workers use the rhetoric of no blame to describe the MPDSR process, they have developed strategies to manage or avoid blame. For instance, health workers felt that the information they documented in the MPDSR proceedings was sometimes "cooked" to avoid or shift blame. Health workers' accounts also suggest that they write very few details in the MPDSR report so that the information on the report would be insufficient for legal purposes if legal action against a health worker is sought. These same MPDSR proceedings or reports are then uploaded onto the DHIS2 for policymakers to allocate resources and give policy direction on quality of care. This could suggest that the MPDSR reports lack sufficient detail that could guide the decision-making process.

Sardan *et al.* (2017, p. 74) have used the term 'social engineering' to refer to tools or policies (such as partographs) whose use and effectiveness are dependent on how frontline workers use (or do not use) the tool or policy. In other words, the actions of frontline health workers and the health system shape the utility of the tool or policy. I would argue that the MPDSR proceedings or reports are instruments of social engineering (262) because their effectiveness for decision-making is shaped by what health workers document (or leave out) during MPDSR sessions as a tactic for managing blame.

Social Autopsy as a tool for knowledge co-production

The study findings suggest that using social autopsy to generate knowledge can be problematic and is not necessarily fit for purpose. Kalter *et al.* (2011) define social autopsy sessions as public community meetings where community members collectively discuss the issues that contributed to death and make recommendations to address the issues. Social autopsy sessions are conducted in the villages where the deceased person lived so that those people who know more about the circumstances relating to the adverse outcome (i.e., lived experience) can share it in a public space (e.g. 7,64) The guidelines for conducting a social autopsy require that health workers anonymise the details of the deceased before the social autopsy session (14). Community members use vocabularies of exposure to show that there are some types of deaths that they perceive as “bad” deaths, e.g., abortion-related deaths, maternal deaths among teenagers and deaths associated with a TBA delivery. Community members associate social autopsy sessions where bad deaths are discussed with public humiliation, risk of being investigated and fear of arrest.

There appears to be a lack of congruence in how social autopsy is expected to work. The process is meant to draw on community members’ collective knowledge of the details relating to the death of a fellow villager but also requires the anonymisation of personal details before the session. In the Kenyan setting where the research was done, anonymisation does not seem to work, as community members know the family who experienced the loss as social autopsy sessions are held among deceased relatives and neighbours. Bereaved relatives also do not consider the social autopsy as a safe space where others in the community can discuss their relative’s death if the death is considered a ‘bad’ death. Additionally, community members feel that health workers are “*malicious”* for organising social autopsies to discuss ‘bad’ deaths. Health workers felt that community members were uncooperative during social autopsy sessions for ‘bad deaths’. This suggests that during social autopsy, health workers and community members “labour under inadequate tools” (250:7), which affects the kind of knowledge produced during social autopsy because of the negative connotations and perceived scrutiny of community members’ actions.

Having focused on how global policies can contribute to the rhetoric on community participation in MPDSR, I will now focus on national-level policies and how they shape participation in MPDSR.

Kenya Community Health Policy and Strategy

The Kenya Community Health Policy and Strategy documents (75,76) recognise community representatives' roles as gatekeepers who support the health system to gain access to the community. Yet, the Policy and Strategy documents do not provide guidance on how community representatives should manage or navigate the complicated nature of their roles in the messy middle. The Strategy promotes working with community representatives such as CHVs, village elders and religious leaders to support community health activities. Most study participants described community representatives as trusted and respected individuals who link the community to the health system. I showed that community representatives perform a bridging role (177), responsible for channelling information, mediating and advocating on behalf of community members. Yet the study findings also show that community representatives limit access to the community where the MPDSR process involves ‘bad’ deaths. Community representatives hold the same cultural and social meanings about perinatal deaths, deaths linked to TBAs, deaths among pregnant teenagers and abortion-related deaths, and this seems to shape how they participate when these kinds of deaths are discussed during MPDSR sessions. I also showed that community representatives support families by not reporting ‘bad’ deaths to health workers as stipulated in their roles. The lack of guidance on how community representatives should handle these contradictory aspects of their roles could account for the perception that community representatives can be disruptive of the MPDSR process.

Community members are also constrained by social norms relating to confronting people in authority during participatory events in public spaces. CHVs and community members explained that engaging in advocacy could be perceived by others in the community as causing trouble, which CHVs were keen to avoid. As such, despite the expectation from health workers and the Community Health Policy that CHVs can advocate for resources, in practice, they are unable to do so.

CHVs have no power or tools to ensure that health workers hear them. Most study participants described CHVs as trusted and respected, and many community members felt that CHVs can channel information to health workers on their behalf. But as I also showed, health workers do not take the feedback from CHVs seriously, and health workers do not act on the feedback. This could suggest that the Community Strategy is an imperfect conceptual tool (253) for guiding community engagement activities in MPDSR because it defines responsibilities for CHVs but does not provide them with the tools to perform their roles adequately. In practice, community representatives have limited voice and "*no teeth*" to perform their advocacy roles (153: 346). For instance, community members felt that the health system lacks an accountable process for managing negligence and complaints relating to adverse outcomes. For community members, going to the police or resorting to legal action could result from a lack of a framework for addressing grievances related to adverse outcomes (54). Community members' accounts show that they expected community representatives to use MPDSR sessions to hold health workers accountable for deaths. While community representatives used their positions as community intermediaries to mediate between health workers and community members to reduce tensions associated with blame culture, community representatives lack the power to hold health workers to account.

7.2.2 Health system barriers

The findings of this study show that there are multiple health system barriers and challenges that affect community participation in MPDSR. For instance, there are tensions between public and private health providers regarding MPDSR participation and the perception that while private health providers are responsible for some maternal and perinatal deaths, the private providers are unwilling to participate in MPDSR processes. I also showed that the health system faces challenges such as health workers' industrial action, lack of material resources such as equipment and supplies, perceptions that health workers are corrupt and disrespectful maternity care. These challenges contribute to the rhetoric associated with the vocabularies of hope, where community members and health workers expect to use the MPDSR process to prevent maternal and perinatal deaths. Instead, participation in MPDSR is characterised by a loss of trust among MPDSR participants (such as disrespectful maternity care) and a loss of trust in the MPDSR process (e.g. failure to implement recommendations).

Disrespectful maternity care is shaped by structural factors in the health system, such as overworked health workers and lack of adequate supplies and equipment to provide a safe and respectful maternity experience (265–267). Disrespectful maternity care does not only refer to verbal or physical abuse of women during childbirth but also includes corrupt practices among health workers and provision of poor quality care such as delays in giving care, i.e. too little, too late (268). Community members in this study gave examples of different forms of disrespectful care, such as verbal abuse, health workers selling health commodities and delays in receiving care despite going to a health facility on time. Some bereaved relatives associated their negative experiences of care with their unwillingness to participate in MPDSR processes. Health workers in this study explained that they are harsh with women as a way of motivating them to "*cooperate during childbirth"* in the face of difficult birthing environments because of limited resources.

Study participants indicated that one of the main recommendations from MPDSR sessions is giving health education geared towards promoting institutional childbirth. But some bereaved relatives question the validity of this recommendation, linking their lived experiences of an adverse outcome to disrespectful maternity care, e.g., some bereaved relatives felt that health workers were too overworked to provide adequate care, which contributed to stillbirths and neonatal deaths). Studies have shown that disrespectful maternity care is associated with women's reluctance to give birth at health facilities (267). This could explain why community members are unwilling to comply with MPDSR recommendations that promote institutional childbirth. Some community members explained that they pick and choose the MPDSR recommendations they will practice; for instance, several women participating in an FGD explained that they are happy to attend ANC services as advised during health education sessions but not give birth in a health facility. These demonstrations of community members exercising quiet power (107,116,130). Even though community members cannot use participatory spaces such as social autopsy sessions to openly confront those in power, they have agency to decide what works best for them even though it contradicts the messaging of those in power.

Health workers also described the lack of supplies and equipment as a barrier to skilled attendance at birth. The lack of materials and supplies for respectful maternity care shapes health workers' practical norms, i.e., the practices of health workers that are contrary to the official rules or stipulated policies (259). Health workers use practical norms not because they do not know what they are expected to do (i.e. the rules or the policy) but their actions are shaped by the contexts in which they work (259,260). For example, some community members felt that health workers were guilty of double-speak because while health workers publicly promoted childbirth in health facilities, there were instances when they quietly advised women to go to TBAs to avoid caesarean sections. Global and national health policies prohibit TBAs from conducting childbirth, and while health workers may not publicly disagree with the regulation, they recognise that the lack of adequate supplies and equipment for respectful maternity care means that the services provided at health facilities are no different from the services provided by TBAs. As one health worker commented: "*we don't have even the basic supplies and there is no difference if the woman is giving birth at the hospital or in a banana plantation […]*." It is beyond the scope of this thesis to discuss the merits and demerits of TBAs and their role in childbirth. I highlight these issues with TBAs to show how health system barriers and relational issues between health workers and community members shape community members' reluctance to adopt MPDSR recommendations for institutional childbirth.

Despite using vocabularies of hope to reiterate the importance of participating in MPDSR sessions, health workers and community members also expressed frustration with a futile participation process. Study participants perceived participation as a waste of time for both health workers and community members because recommendations were not implemented. All study participants explained that participating in MPDSR sessions involved opportunity costs because they had left their other priorities, such as earning a living (community members) or engaging in other healthcare duties (health workers), so that they could participate in MPDSR sessions. Other studies on MPDSR have reported similar findings, e.g. (24,26,66,195,197) who have noted that the failure to implement recommendations results in health workers disengaging from the process. Some of the literature on health system challenges in LMICs has noted that governments do not allocate sufficient resources to health systems, affecting healthcare delivery (269,270). Oleribe *et al.* (269) found that health systems in Africa face challenges related to workforce, leadership, governance, health financing and health service delivery. These challenges contribute to problems such as burnout and corruption among the health workforce, an increase in industrial action and health worker attendance to private practice (269). The authors also argue that these challenges are related to a lack of political will and poor policy legislation and regulation at the national and global level (e.g., poor working conditions for health workers in LMICs are a huge motivator for health worker migration to the global north (*ibid.*). These wider health system challenges relating to lack of resources could explain why study participants felt that the health system is unresponsive and many MPDSR recommendations are not implemented.

Community members felt that health workers were corrupt because they charged for services that were supposed to be provided free of charge. Health workers also felt that CHVs use their positions to benefit from Linda Mama funds because CHVs are paid by private health providers when they refer pregnant women, despite the maternity risks associated with private health providers. The seemingly corrupt or unfair practices of both CHVs and health workers could be a response to their working conditions. Private health providers aim to maximise the opportunities for profit created through Linda Mama funds by paying CHVs to refer pregnant women to their facilities, hoping to increase the number of women who give birth in private facilities. As the reimbursement for caesarean sections is higher than that for vaginal childbirth, health workers from public health facilities felt that private health providers perform unnecessary caesarean sections as a response to the potential for more income from the national government. The literature on health systems and the health workforce has shown that the working conditions for health workers influence their actions, such as demand for informal payments (265,269) or maximising opportunities such as output-based financing (271).

Bereaved relatives associated their negative histories of care, either through corrupt health worker practices or disrespectful maternity care, with their unwillingness to participate in MPDSR sessions. A bereaved relative who had not participated in a death review despite being invited by health workers wondered: "*how can you co-operate with people [health workers] you do not trust*?" illustrating the mistrust some bereaved relatives associate with the MPDSR process. Renedo *et al.* (272) have shown that a community's past experiences with health professionals, other officials, and bureaucrats shape how they engage with policy processes or interventions. This could explain why community members and health workers in this study felt that despite their engagement with the MPDSR process, "*nothing changes, because people just talk.*"

7.2.3 Social and political economy of MPDSR participation

Despite having a legal framework entrenching community participation through public participation days and the assumption in the MPDSR policy that community members can use the MPDSR process to advocate for resources, in practice, this is rhetoric. The underlying assumption in the MPDSR policy is that community members and CSO representatives can use the data they produce through the MPDSR process (in the form of recommendations) to advocate for resources (23). However, as I have shown, some of the community social norms make it difficult for community members to advocate for resources to support the implementation of MPDSR recommendations. Additionally, the political context in which

MPDSR is implemented also shapes participation in MPDSR and community efforts for advocacy.

Health workers explained that they invite CSO representatives to MPDSR sessions so that the CSOs can advocate for resources on behalf of the community. Yet, CSO representatives do not consult community members on the issues to advocate for; rather, CSO representatives attend public participation days to advocate on behalf of the health system. Some of the existing literature on community participation in MPDSR have shown that CSOs play a crucial role in advocating for the resources to implement MPDSR recommendations (e.g. 182). As I explained in my critique of the literature (chapter 2), the studies that have reported CSO involvement in advocacy have not described how CSOs interact with the community members they represent. From their accounts, CSO representatives do not think that community members have the cognitive capacity to understand what they want CSOs as their representatives to advocate for with duty bearers. This could mean that community members are even more removed from the political process of advocating for resources because they are silenced (204) by the political class who control the invitation process and by CSO representatives who do not consult them before advocating on their behalf as I showed earlier.

The study findings show that the meanings that community members and representatives associate with advocacy constrain their agency during MPDSR sessions. Health workers framed the involvement of community representatives in MPDSR as opportunities for community members to speak up for themselves and be heard by politicians (MCAs primarily) who are responsible for allocating resources at the county level. Community members and community representatives such as CHVs found it difficult to advocate with politicians and others in authority because they associate advocacy with disrespect and/or revolt. As one CHV commented "*people will say you have become Okiyah Omtatah*"- a man who is associated with taking on government to advocate for different causes in ways that are not always socially acceptable[31]. Knowledge is interpreted within social and symbolic structures that people use to make sense of their world, e.g. social norms on acceptable behaviour and symbolic resources such as confidence to speak up during participatory encounters (79,146). This would suggest that the MPDSR participatory spaces do not enable participation (119) because of the negative social meanings associated with advocacy.

Campbell and Cornish (119) have argued that the wider context in which participation happens can influence the participation outcomes. By analysing the interactions between MPDSR participants, we can uncover the different ways in which the health system, the socio-cultural context and the political structures intersect (131) to create environments that limit community participation. While health workers in this study appear to have power e.g in determining what is the MPDSR recommendations that are documented in MPDSR reports are, they do not have power to allocate the resources needed for implementation. Similarly, CSO representatives have power to silence the community by not consulting them on their priorities, yet, they too are constrained and their exercise of power is limited in the political spaces where they present ‘evidence’ to the political class. CHVs may not have power to ensure that health workers take their feedback on board but by choosing not to report ‘bad’ deaths, they exercise quiet power which shapes the MPDSR process by excluding some forms of knowledge. Understanding these dimensions of power could help those planning interventions to create enabling environments for participation.

7.3 Implications of study findings

I return to my research question and ask, what do the study findings tell us about community participation in MPDSR and how it works in practice to support the stated aims of the MPDSR policy? Earlier on in the thesis, I explained that MPDSR is considered an

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[31] At the time of the interviews, Okiyah Omtatah was not an elected politician, he has since been elected as a political leader in another part of the country. The general perception among study participants (and Kenyans in general) is that he was a ‘gun for hire’ and used to be paid for his advocacy work.

accountability mechanism for producing knowledge (or data) that can be used for quality improvement and mobilising resources to support the implementation of MPDSR recommendations (13,21,23,34). There is a push from policymakers at the global and national levels to generate data on maternal and perinatal deaths, and policy actors argue that community participation could improve that process (23). I reflect on the implications of the study findings against the three stated aims of the MPDSR process and how community participation contributes to these aims.

7.3.1 Community participation in generating knowledge.

The findings of this study suggest that the quality of MPDSR data that is produced during MPDSR sessions at primary care facilities is at best questionable because health workers perceive the data as "*cooked"* and at worst incomplete because community knowledge is left out of the process. The findings suggest that the MPDSR process should not just focus on what is reported as data; rather, we should also understand how and why certain forms of knowledge are deemed as credible data and others are left out. Earlier in this chapter, I argued that the MPDSR proceedings report is a socially engineered tool (262) that is shaped by the practical norms (259) of health workers who choose what to document or leave out. By exploring the dimensions of the participatory spaces (134), such as how the powerful (health professionals and politicians) control access to the physical MPDSR spaces and the meanings that MPDSR participants associate with the MPDSR process, e.g. scrutiny of actions, we can understand the underlying mechanisms that shape how data is generated in MPDSR.

The MPDSR process is promoted by WHO and others as a form of performance accountability (32) that is used to measure health system performance in producing data at subnational, national and global levels. The quality of national reporting and the results generated from the process can only be as good as the individual reports that come from the micro-level MPDSR sessions, i.e. primary care facilities. The MPDSR reports that frontline health workers produce during MPDSR sessions are the backbone of MPDSR data generation; the information in the MPDSR reports is collated at the national level and used for in-country decision-making. The reports are also submitted to global bodies such as WHO to demonstrate Kenya's performance regarding MPDSR implementation. The 2021-22 national MPDSR report for Kenya highlighted that MPDSR reports from the counties (not just study areas) are of poor quality, which limits their utility for decision-making at the national level (70). This has implications for how county and national-level MPDSR committees use the data for decision making, such as improving the quality of care and allocating resources.

7.3.2 Using the MPDSR process to improve quality of care.

Quality of care in maternal and newborn health (which includes MPDSR) is measured using two domains- (i) provision of care and (ii) experiences of care (58,62). Provision of care is measured using clinical indicators, while experiences of care indicators focus on users' experiences of health services (62,208). While it is plausible that health workers could make recommendations on the provision of care without the input of community members, it would not be possible to understand experiences of care without the knowledge of community members because they are the service users. As such, when health workers exclude community knowledge from MPDSR sessions either because they do not invite them or they filter out and ignore community knowledge, opportunities to explore experiences of care to improve quality of care are lost. Community members' fear of exposure and disclosure about bad deaths could also limit their willingness to provide feedback on their experiences of care.

Health workers and community members associate MPDSR participation with negative meanings, shaping how they act during MPDSR sessions. Rather than asking "what can we learn from this death to improve quality of care? which is the expectation of the MPDSR process, study participants (both health workers and community members) seem to ask other questions such as: 'whose fault is it?' or 'how can I protect myself from the associated professional, legal or social risks that could arise?' The difference in how study participants frame these questions, whether publicly or privately, influences their interactions during MPDSR sessions and the knowledge generated to improve the quality of care. For example, the meanings associated with blame culture influence people's willingness to attend MPDSR sessions, how tools such as the three-delay model are used to seemingly shift blame to community members and how recommendations are framed.

A *'successful'* MPDSR process (49: title) relies on teamwork between health workers and community members as they bring clinical and social knowledge together to prevent future mortality. The need for dialogue is implicit in the MPDSR process so that health workers can use the information (knowledge) they receive from community members to improve their quality of care in health facilities (34,196). Yet, health workers treat the feedback from community members casually, e.g., by not opening the suggestion boxes that community members use to give feedback. Londenstein *et al.* (2018) conceptualise feedback sessions between community representatives and frontline health workers as informal accountability arrangements that can be used as forums where community members can exercise their voice and improve the quality of care. By treating feedback from community members in a perfunctory manner, health workers could miss out on valuable knowledge of community members' experiences of care, which, if used, could improve the MPDSR process and possibly contribute to maternal/perinatal mortality prevention.

There is an expectation (in the MPDSR policy) that community members can share their experiences of care during death reviews. Community members do not consider facility death review meetings or social autopsy sessions as safe spaces for making knowledge contributions. I question the assumption that social and verbal autopsy are forms of community empowerment that provide community members opportunities to participate in quality of care discussions as some of the existing literature has suggested e.g. (7,33). I have shown that the relationships and interactions of health workers, community members and community representatives during MPDSR sessions hamper collaboration and dialogue that are critical for empowerment (119,144).

Community members explained that they do not always agree with the MPDSR recommendations given by health workers because the recommendations do not align with their lived experiences. But while community members question the relevance of the MPDSR recommendations, they cannot openly contest them because the MPDSR sessions are not conducive for dialogue. Pohlhaus (255) posits that pooling and sharing of information is a basic epistemic practice necessary for human survival. That is, human survival is dependent on learning from each other, which requires that different knowledge bearers are given opportunities to share their knowledge. Study participants cite multiple barriers within the health system, such as blame culture and macro-level barriers, which make it difficult for health workers to hear and engage community members so that they can pool knowledge together. I argue that health workers are not simply poor hearers as community members perceive them; rather, their poor hearing is shaped by structural issues in the health system and the wider political and socio-economic environment where MPDSR is implemented.

MPDSR sessions are not discrete events; rather, they have a temporal nature (134) that affects the interactions among participants and the outputs of the process, i.e., making and implementing recommendations. This has implications on our understanding of how the MPDSR process is organised to collect information that can improve quality of care. While the MPDSR session is organised as an event (e.g., CVA session or death review meeting), the session is influenced by past interactions between health workers and community members and the meanings people associate with the interactions. The experiences of community members with the health system, such as during ANC attendance, influence community members' trust of health workers and the health system in general. This, in turn, can shape their willingness to participate in MPDSR and co-operation with health workers during MPDSR sessions. Community members' histories of care, such as disrespectful maternity care, can silence community members, and they choose not to participate in MPDSR sessions.

7.3.3 Community participation in mobilising resources for MPDSR implementation

This study demonstrates the need to reconsider the rationale that community members can use evidence generated through the MPDSR process for advocacy in the context of health system and socio-political barriers. The MPDSR policy aims to combine performance accountability, i.e. how well the system performs in collecting data (32,152,160), with social accountability, i.e. using evidence as a tool that gives voice to community members to advocate for resources (59). The MPDSR policies (global and national) state that CSOs and community members can support health systems to mobilise resources for implementation of MPDSR recommendations, but as the study findings suggest, this can be problematic as I illustrate below.

The MPDSR policy frames participation in MPDSR as a way of generating data that can be used for evidence-based advocacy. Yet, the study findings show that despite having 'evidence' in the form of MPDSR recommendations, the wider context limits how CSO representatives exercise agency when advocating for resources. The study findings also show that the powerful (such as politicians) can also use 'evidence' to serve their own interests. For example, CSO representatives and health workers explained that even when politicians approved budgetary allocation to support the implementation of recommendations such as the purchase of ambulances, the politicians wanted to control where the ambulances were deployed because it gives them political mileage with the community. This study demonstrates that understanding the political economy in which MPDSR is implemented is important as it influences how knowledge (such as MPDSR recommendations) is translated and implemented.

While CSO representatives describe themselves as community representatives, their advocacy work appears to be driven by the needs of the health workers rather than the community members they ostensibly represent. Aveling and Jovchelovitch (150) posit that the priorities of local grassroots organizations (such as the CSOs in this study) are shaped by the organizations who finance the CSOs activities, which influences how they interact with the community members they represent. When describing the study context in the methodology chapter, I explained that in county A, the CSO representatives who participate in MPDSR are also supported by an international organisation working in the county. It could be that the approach that the CSO representatives use for advocacy (i.e., not consulting community members) is influenced by the priorities of the international organisation. The study findings suggest that understanding how material power e.g. who funds the CSO (150) shapes the activities of CSOs participation in MPDSR is important. We need to understand whose interests CSOs represent; if the assumption is that CSOs represent community members in MPDSR, we need to examine how CSOs are funded and how the knowledge CSOs use as evidence for advocacy is generated.

Study participants can mistrust the MPDSR process because it does not produce the changes they hope for. I showed that study participants use vocabularies of hope to describe what they expect of the MPDSR process i.e., as an opportunity to learn and prevent future deaths. Yet in practice, community members and health workers felt that the failure to implement recommendations resulted in unfulfilled hope. Study participants talked about the opportunity cost of participation and the demotivation because "*nothing changes*." Health workers in this study felt pressured to submit MPDSR reports to the national MPDSR committee regardless of the emotional toil associated with death reviews for both health workers and community members. Both health workers and community members frame their emotional difficulties in the context of a failure to implement recommendations describing the MPDSR process as "*a waste of time*." This could mean that both health workers and community members can lose confidence because their inputs are not used in knowledge encounters (251). It could also mean that both health workers and community members could disengage from the MPDSR process because of unfulfilled hope.

7.4 Theoretical contributions

To the best of my knowledge, this is the first study on community participation in MPDSR that has systematically applied theory to understand how participation works in practice. I used the theory on the dimensions of participatory spaces (134) to uncover the rhetoric in the discourse on community participation and its value to the MPDSR process. I analysed how MPDSR participants use of material aspects such as physical access to MPDSR participatory spaces and tools such as the three-delay model and MPDSR proceedings reports contribute to epistemic injustices. I also looked at the social and symbolic meanings that MPDSR participants associate with the MPDSR process such as scrutiny of their actions and how this shapes the participation process. I have also explored the temporalities in the MPDSR process to illustrate that community members past histories of care influence the participation process and the forms of knowledge that are produced.

My analysis of the study findings brings conceptual clarity into the practice of community participation in MPDSR. In the study rationale section of this thesis, I noted that community participation in MPDSR has not been adequately theorized. I explained that scholars have argued that the concepts of knowledge, power and social interaction are important in analysing community participation processes (e.g. 114,119,120,128,273). I have examined the role that power, social interaction and knowledge play in the MPDSR process and generated findings to show the realities of community participation in MPDSR. These empirical findings are anchored in existing theories on community participation which could increase the utility and generalizability of the study findings beyond the study sites.

Community participation in health is generally associated with social justice and emancipation e.g. (79,115,117,211). Policy makers and global health experts also frame prevention of maternal and perinatal mortality as an issue of human rights and social justice (8,11,274). Fricker (275) argues that engaging in knowledge encounters and contributing to the process of sense making is a basic human capability, a mark of dignity and a matter of moral importance. The findings of this study help us understand epistemic injustices that characterize the micro-level interactions between health workers and community members. By disparaging or filtering out community knowledge from MPDSR processes, community members could be denied opportunities to exercise their rights (275) to participate in knowledge encounters. This can rob community members of opportunities to contribute to prevention of maternal and perinatal deaths.

By looking at community participation in the context of what it is theorized to do in the MPDSR policy, I uncover the ambiguities and rhetoric in study participants' understanding of community participation in MPDSR. The rhetoric of knowledge co-production in MPDSR suggests that study participants may consider community participation as a "buzz" word that legitimizes the MPDSR process (158: 1043). By using the phrase that 'community participation is useful, the MPDSR process in the study areas can be deemed as inclusive, bottom-up and arguably a good thing (276). Health workers in this study could be using normative language by acknowledging that community participation is useful and inclusive without examination on how community participation works to contribute to the goals of MPDSR. I show that the rhetoric of community participation in MPDSR is created by the wider context in which MPDSR is implemented. As such, it maybe that the rhetoric is not just limited to the study areas but could also be relevant in other similar contexts e.g. LMICs.

7.5 Study limitations

My original study design included using observation of death review meetings in health facilities and in the community. The Covid-19 pandemic affected this plan because of the social distancing rules that were enforced in Kenya. Practically, this meant that there were no social autopsy meetings held during my fieldwork. I had one opportunity to observe a community verbal autopsy session. I also observed the interactions of health workers, community members and community representatives at the co-production workshop. I was not able to observe facility death review meetings. Health workers explained that only a limited number of health workers could attend a death review meeting to ensure that social distancing rules were maintained. Instead of observation, I used in depth interviews and analysed the accounts of people who had participated in MPDSR sessions as they shared their perspectives on MPDSR participation. I missed the opportunity to use observations and develop more insights of what people do during MPDSR sessions; as such, my analysis is primarily based on what people say happens during MPDSR sessions rather than observing what they do.

I conducted my study in two counties only, due to time and financial constraints. I could not spend a lot of time in the field because of the Covid restrictions that were changing rapidly and impacted my decisions on how long I could stay at a study site. It is likely that if I had included more counties or spent more time in each location, I could have observed more interactions and generated more data on the experiences of MPDSR participants. In the methodology chapter, I highlighted some of the challenges I faced while conducting online interviews. I also noted that I was unable to conduct FGDs in county A because I could not travel to that county at any time during the study period. These challenges could mean that I may have missed useful insights that could have contributed further to my analysis.

Kenya has institutionalized public participation in decision making and community participation is a legal requirement. While the global MPDSR policy promotes community participation in MPDSR, many countries do not include community members in the MPDSR process particularly in facility death reviews. As such, some of the findings may be contextual, which could affect their applicability in contexts where community participation is not institutionalized.

In the next (and final) chapter of this thesis, I present my conclusion of the study by reflecting on the implications of the study findings on the health system beyond MPDSR. I also give some recommendations for future research.

8.0 Conclusion

In this thesis, I have demonstrated how rhetoric in community participation in MPDSR is created. I have argued that the epistemic injustices, negative meanings of scrutiny of actions and power relations associated with community participation in MPDSR are shaped by upstream factors such as the global MPDSR policy, the challenges in the health system and the socio-political context in which MPDSR is implemented. In this closing chapter, I outline some recommendations on how community participation in MPDSR can be strengthened and suggestions for future research.

8.1 Implications for MNH and health system functionality

There is need to think about the temporalities during community participatory processes and their role in shaping how knowledge is produced for purposes of improving quality of care. I showed that previous histories of healthcare influences how community members engage with health workers and affects their willingness to co-operate when sharing experiences. The findings also show that failure to act on feedback or recommendations or treating feedback in superficial ways can demotivate both health workers and community members. This could result in community members disengaging from programmes that are associated with past histories of inaction because they perceive the participation process as futile. This could be applicable to other aspects of healthcare (not just MPDSR), where community feedback is sought as part of health service delivery.

I have demonstrated that rhetoric in policy implementation can result from barriers in the context in which the policy is enacted. We can apply the idea of '*travelling models* (262) to other global health policies such as Universal Health Coverage (UHC) which are articulated at global level and the extent to which countries like Kenya can adopt them without risking rhetoric because of the social-economic barriers that such a policy would face. The experiences of health workers and community members in the implementation of *Linda Mama*, which is a form of social health insurance hint at how health financing models can reshape the practical norms of private providers and CHVs. The findings from this study could be useful in examining how global health policies ‘travel’ from global institutions such as WHO to countries and how frontline health professionals interpret the policy and implement it.

The health system barriers I highlight in this thesis do not only affect MPDSR implementation but maternal and newborn health (MNH) more generally. This reflects the importance of overall health system strengthening because the gains made by a having a functional health system could potentially improve community participation in MPDSR. The health system barriers such as disrespectful maternity care, corrupt practices, and the failure to provide the necessary supplies and equipment that are recommended during MPDSR sessions influence the future practices of both health workers and community members. For example, the unwillingness to attend MPDSR sessions, participation fatigue and the unwillingness to accept MPDSR recommendations. Literature on reducing maternal and perinatal mortality have highlighted the importance of an enabling environment for skilled attendance that includes trained and motivated health workforce, adequate supplies and equipment and building trust between community members and the health system (277–280). This suggests that community members and health professionals are more likely to participate and support MPDSR (and quality of care improvement interventions) in contexts where adequate resources that are fit for purpose are deployed to strengthen the health system functions.

8.1 Recommendations

This findings from this study show that that MPDSR participatory spaces in Kenya where the research took place are not conducive for community participation despite national and global policy promoting community participation. Study participants (health workers and community members) understand the rules or policy aspirations of the MPDSR process but the spaces where they enact the policy are challenging which reduces the potential of the MPDSR process to achieve its goals. Some recommendations to improve the participation process are:

1. Recognize the role of power in the knowledge production process; the forms of data that are valued, recorded and written up shapes people's perceptions of the value of community participation in MPDSR.
2. Recognise the role that global health experts and organisations such as WHO play in legitimising some forms of knowledge.. Such an analysis could potentially lead to designing more equitable health programmes.
3. Strengthen and sufficiently fund health systems to provide skilled attendance at birth to ensure that the basics of the health system are functioning. Lack of adequately trained staff and their deployment, drug and equipment shortages and power cuts are all problems that need to be addressed higher up the health system and the political system that allocates resources. The challenges of an unresponsive health system that as currently resourced cannot prevent mortality-makes it difficult for community members and health workers to collaborate without resorting to blame and shifting accountability.
4. Work with community representatives and equip them with the material and symbolic resources to support both the health system and community members to make sense of the MPDSR process and to mediate the spaces.
5. Challenge CSOs and their funders on the power dynamic between them and how this shapes community participation and priority setting.
6. Recognise temporalities in the MPDSR participation process and how these temporal aspects influence trust in the participation process. Health workers and community members come to the MPSDR participatory spaces with experience and previous interactions that make MPDSR sessions unconducive for learning.
7. Create enabling environments by addressing barriers in the different dimensions of the spaces (physical, social, symbolic and temporal). Understanding the different dimensions

of participatory spaces can ensure that regardless of the physical locations where MPDSR sessions are held (community sites or health facilities), the participatory spaces promote dialogue and allow for community members to share their knowledge.

8.2 Future research

There is need to balance a no blame approach to MPDSR with accountability for perceived negligence that contributes to maternal and perinatal deaths. This is useful for practice because increasingly more maternal/perinatal births and deaths occur in health facilities rather than in the community (17). The earlier assumptions in the literature that community participation in death surveillance is primarily useful for identifying and reporting deaths in the community (e.g. 186) may lose relevance over time. One of the main arguments of excluding community members from MPDSR sessions in this study and other literature e.g. (60) is that health professionals are afraid of the legal repercussions that could arise. Community members' accounts in this study show that the failure to explain why deaths happened and the lack of a clear complaints mechanism increases the likelihood of community members considering litigation. Several questions arise- first, can MPDSR sessions in health facilities remain closed to community participants given the shift in places where deaths happen? Gaventa (128) describes closed participatory spaces where some views are excluded from the process and notes that participation can be a way of broadening inclusion of previously excluded voices in decision making. Secondly, what are the potential repercussions of excluding community members from the MPDSR process considering the demands by community members for more accountability and transparency of the health system? Thirdly, what mechanisms could facilitate community participation while recognizing the real risks that health workers could face from increased community participation? In this study, community representatives reported some success in mediating between health workers and community members to manage or avert blame. We need to better understand how community representatives or intermediaries can be supported through training and an enabling environment to play a mediation role.

Community members and CSOs require an enabling environment to perform their advocacy roles (119,281). Yet as the findings show, despite institutionalizing community participation and entrenching participation in the constitution, community members can still be excluded from decision making spaces. More research on how stakeholders and community members can use the MPDSR process to claim their rights from seemingly unresponsive political actors is needed.

The MPDSR process can be an emotional process because discussions that held focus on death which is associated with emotions such as grief or anger. Health workers and community members in this study talked about the emotional difficulties they experienced while participating in MPDSR. Yet the existing policy and guidelines do not adequately address the emotional burden of participation. Bakhbakhi *et al.* (60) noted that parents felt that being engaged in perinatal death reviews could support them cope with future pregnancies better and manage the self-blame parents felt after the perinatal deaths. While there are few studies in high income countries that have included bereavement care in the death review process e.g. (174), studies in LMICs have not addressed bereavement care. More research on the emotional burden of participation for both community members and health workers and the role that MPDSR could play in bereavement care would be useful.

In conclusion, examining the dimensions of participatory spaces uncovers the disconnections between what community participation in MPDSR is expected to do, and the socio-political realities in which MPDSR is implemented. These findings could strengthen the global policy and our understanding of community participation for quality improvement and resource mobilization.

As I bring this thesis to a close, I reflect on an African proverb that says, "*a pregnant* *woman has one foot in the grave*”. My grandmother repeated this proverb often, my mother said it to me when I was pregnant. My hope is that I do not have to repeat this proverb to my daughter when her time comes because pregnancy is not supposed to kill you. The findings of this study show that community members want to contribute to discussions on mortality prevention and those of us working in global health should think about how we can ensure that community voices and knowledge is part of the debate on preventing maternal and perinatal deaths.

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Appendices

Literature review search terms

Table 1: Search terms for community engagement, maternal and perinatal deaths and surveillance and response

Community Engagement terms	“Collective or community or community intervention” or “community action” or “community mobilisation” or “capacity building” or collaboration or conscientization or engagement or intervention or outreach or involvement or consultation or “shared leadership” or “community network” or “community participation” or leadership or “health program” or “community initiative” Empower* or “Health Promotion” or “Maximi? ing access” or “Participatory intervention” or “Participatory approach” or “Social mobilization” or “Social movement” or “Social capital” or “Social participation” or “Village health worker” or “Women group” or “community capability” or “collective efficacy” or “patient public involvement” or PPI or “patient public engagement” “Consumer participation” or engagement or involvement or “community representation” or “community accountability” or “community W3 accountability” or representation or “social accountability” or “community advocacy” or “community health worker” or “community representative” or “health facility committee” or “health management committee” or “Stakeholder participation” or “stakeholder engagement” or “health co-production”

Maternal or Perinatal death	“Maternal death” OR “mother death” OR maternity OR fetal OR perinatal OR pregnancy OR "child-birth" OR birth OR "labo?r W/3 mortality" OR death* OR fatality* OR “pregnancy complication” OR “f?etal death” OR “still-birth” OR “still-born” OR “sudden infant death” OR sids OR “cot death” OR “crib death” or “saving mothers lives” OR “making pregnancy safer” OR “making childbirth safer” OR “new-born death” OR “intrapartum death” OR “intrapartum mortality”
Surveillance and Response	"maternal and perinatal death surveillance and response" or MPDSR or “maternal death surveillance and response” or MDSR or audit or surveillance or response or "death audit" or “maternal death review” or perinatal death review” or "death surveillance" or "death review" or "surveillance W3response" or "confidential enquir*" or "confidential inquir*" or "death* meeting" or "death enquir*" or "death inquir*" or "confidential enquir* into Maternal and Child Health" or CEMACH or "Confidential Inquir* into Maternal and Child Health" or CIMACH or "Cent* for Maternal and Child Enquir*" or CMACE or "Cent* for Maternal and Child Inquir*" or CMACI or "Confidential Enquir* into Maternal Death" or CEMD or "Confidential Inquir* into Maternal Death" or CIMD or "Cent* for Maternal Death Enquir*" or CMDE or "Cent* for Maternal Death Inquir*" or CMDI or "verbal autops*" or "social autops*" or "communit* W3 death audit" or "death review" or "death meeting" or "verbal autops*" or "social autopsy"

MOH Verbal Autopsy Tool (blank form)

Verbal Autopsy Tool (maternal death)

MINISTRY OF HEALTH

MNDF form number										Sub-County MDR Comm. no.								

INSTRUCTIONS

1. ***This form must be completed for all deaths, including abortions and ectopic gestation related deaths, in pregnant women or within 42 days after termination of pregnancy irrespective of duration or site of pregnancy***
2. ***The verbal autopsy tool to be filled by trained Community Health Nurse or CHEW, in consultation with the village health committee and the Chief***
3. ***The forms should be filled in quadruplicate. The original is sent to the RHFMSU (uploaded to DHIS) one copy to CRHC, one copy sent to the facility MPDRS committee and one copy remains with the designated person (CHEW) in the Community Team***
4. ***The forms should be filled within 14 days of occurrence of death***
5. ***These are confidential documents and should not have names, or any other identification details of the deceased or the persons who provided care to the deceased.***
6.

1. Locality where death occurred

No.	***Question***		
1.1	In which locality did death occur?	County	
		Sub-County	
		Division	
		Community	

2. Selecting participants for interview

No.	***Possible answers***	***Comments / Remarks***
2.1	☐ Husband ☐ Co-wife ☐ Mother ☐ Mother-in-law ☐ Father ☐ Sister	

	☐ Daughter/son ☐ TBA ☐ Other, specify_______________	
2.2	☐ Husband ☐ Co-wife ☐ Mother ☐ Mother-in-law ☐ Father ☐ Sister ☐ Daughter/son ☐ TBA ☐ Other, specify _______________	
2.3		
		Relationship to woman
	☐ Present when ill ☐ Present when died	
	☐ Present when ill ☐ Present when died	
	☐ Present when ill ☐ Present when died	
	☐ Present when ill ☐ Present when died	
	☐ Present when ill ☐ Present when died	
	☐ Present when ill ☐ Present when died	

3. General background

No.	***Question***	***Possible answers***	***Comments / Remarks***

3.0	Was she pregnant at time of death or 42 days prior to her death?	☐ Yes ☐ No ☐ Not Known	
3.1	How long ago did she die?	☐ ☐ days ☐ Not Known	
3.2	How old was she when she died?	☐ ☐ days ☐ Not Known	
3.3	Where did the death occur?	☐ Home ☐ TBA ☐ On transit to HF ☐ Health facility ☐ Other, specify ______________________	
3.4	Was the death due to an accident?	☐ Yes ☐ No ☐ Not Known	
3.5	Do you know the cause of the death?	☐ Yes ☐ No ☐ Not Known If yes, specify	
3.6	Do you know if before she died she had any long term medical problems?	☐ Yes ☐ No ☐ Not Known If yes, specify _________________	
3.7	Was she on treatment for this illness?	☐ Yes ☐ No ☐ Not Known If yes, specify _________________	
3.8	What was her educational level?	☐ None ☐ Primary ☐ Secondary ☐ Technical ☐ University ☐ Other, specify ______________	
3.9	What was her occupation?		
3.10	What was her marital status?	☐ Married ☐ Single ☐ Widowed ☐ Divorced ☐ Other, specify ___	
3.11	If married, specify for husband the following		
	Educational level	☐ None ☐ Primary ☐ Secondary ☐ Technical ☐ University	

		☐ Other, specify	
	Occupation		
	Age	☐ ☐ years	
3.12	How many times has she been pregnant in total (including the one during which she died)	☐ ☐ times ☐ Not Known	
3.13	How many live births did she have?	☐ ☐ live births ☐ Not Known	
3.14	How many still births did she have?	☐ ☐ still births ☐ Not Known	
3.15	How many abortions / miscarriages did she have?	☐ ☐ abortions ☐ Not Known	
3.16	What was her age at first pregnancy?	☐ ☐ years ☐ Not Known	

4. Family's account of events around the woman's death and illness

Give an introduction explaining that we would like them to tell us what happened:

1. around the woman's death (final hours)
2. from the time the woman started to feel ill to her death

Try to create a chronology (timeline) based on what they say if story is complicated

Enter text data

5. Deaths during pregnancy, labour or within 6 weeks after of end of pregnancy

Only ask the questions in this section when the woman died **during pregnancy, labour or within 6 weeks after of end of pregnancy**

No.	***Question***	***Possible answers***	***Comments / Remarks***
5.1	How long has she been pregnant for?	☐ ☐ months ☐ Don't know	
5.2	Did she have swelling of the legs?	☐ Yes ☐ No ☐ Don't know	
5.3	Did she have swelling of the face?	☐ Yes ☐ No ☐ Don't know	
5.4	Did she complain of blurred vision?	☐ Yes ☐ No ☐ Don't know	
5.5	Did she have any fits?	☐ Yes ☐ No ☐ Don't know	

5.6	Was she pale?	☐ Yes ☐ No ☐ Don't know	
5.7	Was she short of breath when she carried out regular household activities?	☐ Yes ☐ No ☐ Don't know	
5.8	Did she lose weight?	☐ Yes ☐ No ☐ Don't know	
5.9	Did she have her blood pressure taken?	☐ Yes ☐ No ☐ Don't know	
5.10	Did she tell you what her blood pressure results were?	☐ Yes ☐ No ☐ Don't know If yes, ☐Normal BP ☐ high BP ☐ Low BP	
5.11	Did she bleed from the vagina before pregnancy ended during her final illness?	☐ Yes ☐ No ☐ Don't know	
5.12	Did she bleed more than usual from the vagina immediately after pregnancy ended during her final illness?	☐ Yes ☐ No ☐ Don't know	
5.13	Did she bleed more than usual from the vagina 2 days after pregnancy ended but before 6 weeks during her final illness?	☐ Yes ☐ No ☐ Don't know	
APH5.14	Was she ever transfused blood or given drugs to increase her blood during or after this pregnancy	☐ Yes ☐ No ☐ Don't know	

Mal5.15	Did she have high fever during her final illness?	☐ Yes ☐ No ☐ Don't know	
Seps5.16	Did she have foul-smelling vaginal discharge during her final illness?	☐ Yes ☐ No ☐ Don't know	
5.17	Did her skin or eyes turn yellow at the time of her death?	☐ Yes ☐ No ☐ Don't know	
5.18	Had she been ill with any other illness during this pregnancy?	☐ Yes ☐ No ☐ Don't know If yes, specify _______________	
5.19	Did she have a miscarriage 6 weeks before her death?	☐ Yes ☐ No ☐ Don't know	
5.20	Where did the delivery take place?	☐ Home ☐ Health facility ☐ On the way to health facility ☐ During referral ☐ Died undelivered ☐ Don't know	
5.21	Who assisted her at the delivery?	☐ No one ☐ Relative ☐ TBA ☐ Community midwife ☐ Nurse/Midwife ☐ Clinical Officer ☐ Doctor ☐ Don't know	
5.22	What sort of delivery was it?	☐ Normal ☐ Instruments used ☐ Caesarian Section ☐ Don't know	

5.23	How many months pregnant was the woman when labour began?	☐ ☐ months ☐ Don't know	
5.24	Was she in good health when labour began?	☐ Yes ☐ No ☐ Don't know	
5.25	How long was she in labour for?	☐ ☐ hours ☐ Don't know	
5.26	Did she die before the baby was born?	☐ Yes ☐ No ☐ Don't know	
5.27	Was the placenta delivered?	☐ Yes ☐ No ☐ Don't know	
5.28	How long after the birth of the child was the placenta delivered?	☐ ☐ hours ☐ Don't know	

6. Contributing Factors

6.1: In your estimation, how long did it take from the time the illness started to the time it was decide she should go to the health facility? _____ hours / days

6.1.1: What is your collective opinion about the time taken? ☐ normal ☐ long

6.1.2: If in your opinion it was long, what contributed to the delay in deciding to go to health facility?

____

____

6.2: In your estimation, how long did it take from the time it was decide she should go to the health facility to the time she actually arrived at the health facility? _____ hours / days

6.2.1: What is your collective opinion about the time taken? ☐ normal ☐ long

6.2.2: If in your opinion it was long, what contributed to the delay in reaching health facility?

____

____

6.3: In your estimation, how long did it take from the time she arrived at the health facility to the time she received any treatment for the illness? _____ hours / days

6.3.1: What is your collective opinion about the time taken? ☐ normal ☐ long

6.3.2: If in your opinion it was long, what contributed to the delay in receiving treatment at the health facility?

____

____

6.4: Was she referred from the health facility she first visited to another facility? ☐ yes ☐ no

6.4.1 In your estimation, how long did it take from the time she was referred from the first health facility to the time she arrived at the destination health facility? _____ hours / days

6.4.2: What is your collective opinion about the time taken? ☐ normal ☐ long

6.4.3: If in your opinion it was long, what contributed to the delay in reaching the referral health facility?

____

____

6.5: In your estimation, how long did it take from the time she arrived at the referral health facility to the time she received any treatment for the illness? _____ hours / days

6.5.1: What is your collective opinion about the time taken? ☐ normal ☐ long

6.5.2: If in your opinion it was long, what contributed to the delay in receiving treatment at the referral health facility?

____

____

7. Summary of findings / conclusion

No.	***Question***	***Possible answers***	***Comments / Remarks***
8.1	Direct cause of death	☐ Haemorrhage	

		☐ Infection ☐ Eclampsia ☐ Obstructed labour ☐ Abortion ☐ Not applicable (indirect cause) ☐ Other, specify	
8.2	Indirect cause of death	☐ Malaria ☐ Anaemia ☐ HIV / AIDS ☐ Cardiovascular ☐ Not applicable (direct cause) ☐ Other, specify	
8.3	Contributing factors	☐ Failure to recognize danger signs ☐ Ignorance of available services ☐ Cultural / religious reasons / objections ☐ Poverty ☐ Lack of communication/transport from home to facility ☐ Lack of communication/transport between facilities ☐ Long distances / poor roads ☐ High cost of treatment ☐ Other, specify	
8.4	*Action points*	*Responsible Officer*	*Time frame*

Completed by:

Name: …………………………….

Rank: ………………………………

Tel: ……………………………….

E-mail ……………………………….

Date: ……………………………...

Signature: ………………………….