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Master Thesis

A Qualitative Study of the Role and Lived Experience of Community Health Workers within the HIV Treatment Interventions in Eswatini

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This thesis has been written as a study assignment under the supervision of an Utrecht University teacher. Ethical permission has been granted for this thesis project by the ethics board of the Faculty of Social and Behavioral Sciences, Utrecht University, and the thesis has been assessed by two university teachers. However, the thesis has not undergone a thorough peer-review process so conclusions and findings should be read as such.

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Abstract

Introduction

Community Health Workers (CHWs) are recognized as an essential global workforce to address the gap in healthcare services, especially in resource-constrained countries. However, they often lack structural support and formal recognition. They are also found to undertake multiple roles in their work and perform extra responsibilities. Existing public health literature focuses mainly on evaluating CHWs' performance and effectiveness and tends to neglect the importance of investigating their experiences. As CHWs in Eswatini face similar challenges as those of other countries, this thesis adopted a phenomenological approach and the role theory to understand how RHMs experienced their work and practiced their multiple roles.

Methods

This thesis used existing data collected as part of the HIV treatment interventions, the MaxART program, in Eswatini to investigate Community-Based Volunteers' (CBVs) experience implementing the study. 27 semi-structured and in-depth interviews were conducted with CBVs using a topic list covering various aspects of their roles, perceptions of HIV, and involvement in implementing the EAAA project. Only 17 interviews with Rural Health Motivators (RHMs), the largest represented group of CBVs, were eventually analyzed. Inductive thematic analysis and a phenomenological approach were adopted for data analysis.

Results

This study added new understandings of RHMs' lived experience and how they practiced their roles. Informed by the role theory, the findings revealed RHMs’ various role problems, such as

role ambiguity, role overload, role identity, and role insufficiency, while performing their duties. The findings indicated that RHMs did more than their formal obligations, including providing food and following up on patients' medical records. The findings also highlighted RHMs' emotional work, such as providing support and handling negative reactions from the community. Generally, despite challenges, RHMs were recognized by community members for their efforts.

Conclusion

This study underscores a need for further research on RHMs' overlooked emotional work and advocates for increased diversity within RHM programs. Policy implications include providing psychological support and training on interpersonal relationships to support RHMs better. Ultimately, the study emphasizes the importance of considering RHMs' perspectives and experiences to construct a more sustainable healthcare system and support RHMs effectively.

List of Abbreviations

Abbreviation	**Definition**
ART	**Antiretroviral Therapy**
CBV	**Community-Based Volunteer**
CHW	**Community Health Worker**
EAAA	**Early Access to ART for ALL**
HIV	**Human Immunodeficiency Virus**
LMICs	**Low- and Middle-Income Countries**
MaxART	**Maximizing ART for Better Health and Zero New HIV Infections**
MoH	**Ministry of Health**
PHC	**Primary Healthcare**
RHM	**Rural Health Motivator**
WHO	**World Health Organization**

Introduction

Problem Statement

Who are community health workers?

The notion of community health workers (CHWs) as a particular cadre of health workers in primary health care (PHC) could be traced back to China in the 1920s (Perry et al., 2014). However, it was not until the 1960s that the concept of CHWs gained more recognition globally and became one of the approaches to filling the gaps between the unmet health services needs of patients in the rural and resource-constrained regions and the lack of a trained health workforce (Perry et al., 2014).

Following the Alma Ata Declaration on PHC, countries worldwide were inspired, directed, and further funded to develop and implement larger-scale CHW programs (Perry et al., 2014). Moreover, to relieve the strain on healthcare systems, the World Health Organization continued encouraging task-shifting and started to fund and actively encourage countries to further develop CHW workforces (Perry et al., 2014; WHO, 2018).

In recent times, CHWs have played a crucial role in the healthcare system of resource-constrained countries and are often the frontline personnel of primary health services in rural areas (Laurenzi et al., 2021; Mhlongo et al., 2020; Walker et al., 2020). Studies have shown the positive contributions of CHW to the reduction of the prevalence of child malnutrition, mortality and the improvement of women's health in low- and middle-income countries (LMICs), as well as the delivery of HIV-related services (Perry et al., 2014; Mwai et al., 2013). Research also shows that in addition to their contribution to health, CHWs play an essential role in providing

emotional support to the communities they serve (Glenton et al., 2013; Mhlongo et al., 2020; Mukherjee & Eustache, 2007).

What is the problem?

Some challenges faced by CHWs reported by previous studies include a lack of training, being under-resourced (e.g., a lack of uniforms and first aid materials), and low remuneration (Ballard & Montgomery, 2017; Glenton et al., 2013; Oliver et al., 2015). These challenges result from a lack of recognition by higher authorities (Mwai et al., 2013). Other studies have also found that CHWs are often expected or perceive themselves to do more than their official responsibilities and take on multiple roles (Laurenzi et al., 2021; Schneider et al., 2008). These different roles and work CHWs are doing are reported to cause tension among them and the communities (Mlotshwa et al., 2015). Moreover, studies demonstrate that CHWs sometimes fulfill extra responsibilities beyond their emotional and physical capabilities (Mlotshwa et al., 2015; Oliver et al., 2015), which could be energy-draining and stressful (Haq et al., 2008; Oliver et al., 2015). Lastly, some previous studies indicate that one of the factors that could impede CHWs' work is a lack of credibility within their communities (Adam et al., 2022; Kane et al., 2010; Mhlongo et al., 2020), which could result from insufficient structural support, including necessary equipment, training, and authority supervision (Adam et al., 2022; De Neve et al., 2017; Kane et al., 2010).

A focus on Rural Health Motivators in Eswatini

Similar to other resource-constrained countries, the Ministry of Health (MoH) of Eswatini founded a national CHW program in 1976 to tackle various health issues and the shortage of PHC providers, which is referred to as the Rural Health Motivator (RHM) program (Geldsetzer

et al., 2017; Walker et al., 2020). Being the most long-standing and the largest cadre of the CHW program in Eswatini, as of 2017, approximately 5230 RHMs were employed, according to Geldsetzer et al. (2017). Their tasks focus mainly on delivering health education, visiting households, and providing community health referrals (Walker et al., 2020).

In 1999, when a national HIV emergency was declared, the RHM program added responsibilities for HIV and tuberculosis (TB)-related issues (The Government of the Kingdom of Eswatini, 2018; Walker et al., 2020). The Eswatini MoH launched the MaxART[1]project from 2011 to 2017 to improve the health outcomes of people living with HIV and reduce new HIV infections by implementing various HIV treatment interventions, including the facilitation of immediate access to HIV treatment for HIV-positive people, which refers to starting HIV treatment as soon as possible upon diagnosis instead of based on disease progression and the status of the immune system. (MaxART consortium, 2018). RHMs played a vital role in the so-called 'community mobilization' during the implementation of Early Access to ART for ALL (EAAA), the second phase implementation study of the MaxART project aiming to evaluate the acceptability of providing HIV treatment for people with HIV immediately after diagnosis (MaxART consortium, 2018). This thesis aims to contribute to the existing literature on the roles of RHMs in international global health programs by investigating the experiences of RHMs in the MaxART research project in Eswatini. I draw on existing qualitative data collected by social science researcher working in the MaxART project to assess how RHMs experience their work and practice their roles throughout the implementation of the MaxART EAAA program.

[1] Short for "Maximizing ART for Better Health and Zero New HIV Infections". The MaxART program was an international partnership between the government of Eswatini, the Dutch non-governmental organization Aidsfonds (previously called Stop AIDS Now!), and the American agency Clinton Health Access Initiative (CHAI), and several other implementing partner organizations, and was funded by the Dutch Postcode Lottery (Vernooij, 2022)

Overview of Existing Research

Roles and responsibilities of CHWs

CHW programs have become an essential component of many countries and are acknowledged explicitly for improving primary healthcare services, especially in LMICs (Austin-Evelyn et al., 2017; Perry & Zulliger, 2012). In LMICs, CHWs' roles and responsibilities vary across different settings. These generally include connecting people to medical resources, raising awareness of health issues through outreach, visiting homes, acting as a bridge between the public and medical personnel, and aiding in the care of patients in their communities (Mhlongo et al., 2020; Olaniran, 2019). Other research also finds that CHWs, in some contexts, have to distribute contraceptives and other goods, provide first aid, support child health, and manage uncomplicated work (Glenton et al., 2013; Sanders et al., 2017).

In addition to their officially outlined duties, previous studies have found that CHWs tend to undertake multiple roles in the community and fulfill tasks outside of their scope of work and training. For instance, in Schneider et al. (2008)'s study in South Africa, CHWs were delegated clinical duties that were originally performed by nurses. South African CHWs in Loeliger et al. (2016)'s research reported taking care of patients in their homes, cooking and fetching treatments for them. CHWs working beyond their official roles could be mainly due to their sense of obligation to help and the unclear national definition of their roles, which could be emotionally and physically demanding (Laurenzi et al., 2021; Mundeva et al., 2018). In studies by Laurenzi et al. (2021) in South Africa and Ahmed et al. (2022)'s review across 33 LMICs, CHWs reported providing food and monetary support, sometimes even emotional and social support, to their service recipients. Glenton et al. (2013) found evidence that this phenomenon is more often

reported in LMICs, which could potentially be explained by their limited access to other general services. The same authors also argued that the high demand for CHWs' training in areas outside of their regular duties, such as dealing with sexual assault, domestic violence, and housing concerns, indicates the strenuous situations and emotional difficulties CHWs have to face in their work (Glenton et al., 2013).

CHWs' experiences and challenges

CHWs experienced positive and negative aspects of their work, and their responses varied across different contexts. In the analysis of Glenton et al. (2013) reviewing 53 studies of CHWs in high-income countries and LMICs across Asia, Africa, Oceania, America, and Europe, it was summarized that CHWs experienced being socially acknowledged by communities they served, and that they expressed a sense of altruism doing their work. Studies of CHWs in South Africa and Guatemala found their participants content with their job and thought of it as purposeful, seeing themselves as capable of facilitating change and respected health workers (Austin-Evelyn et al., 2017; Ruano et al., 2012). Another group of South African CHWs received respect from their communities and considered this a reward for their work (Laurenzi et al., 2021). They were motivated by the appreciation from the community and were willing to work beyond their work hours so that they could always be available for community members (Laurenzi et al., 2021).

Despite positive experiences, other studies also reveal challenges CHWs face, including inadequate training, lack of structural recognition, lack of supplies, and low remuneration. For example, in a review of HIV care in sub-Saharan Africa by Mwai et al. (2013), it was discovered that although skill training is needed for CHWs to perform their tasks effectively, it is often not

sufficiently provided. Multiple studies around the world echo this view, and CHWs have been calling for more relevant, adequate, and refresher training for them to address the community's needs properly (Nxumalo et al., 2016; Olaniran et al., 2022; Perry & Zulliger, 2012; Smith et al., 2014). CHWs are also in need of financial assistance and material resources. They are found to receive limited structural support, including supplies and transportation, which hampers their capacity to provide comprehensive care (Aseyo et al., 2018; Scott et al., 2018). Austin-Evelyn et al. (2017) and Glenton et al. (2013) highlighted that the lack of this official support in the form of signifiers could result in decreased credibility and legitimacy of CHWs in the communities.

The 'work' of RHMs in Eswatini

The Eswatini MoH officially defines that RHMs are responsible for: 1) visiting households; 2) providing health education; 3) referring ill patients to clinics or other appropriate healthcare facilities; 4) monitoring child growth in the community; 5) delivering first-aid for minor sickness (Geldsetzer et al., 2017; Walker et al., 2020).

Recent studies focusing on RHMs have similar findings to other international research on CHW programs, such as an absence of recognition and high-level support (De Neve et al., 2017; Geldsetzer et al., 2017; Walker et al., 2020). Walker et al. (2020) also identified gender as a significant but overlooked factor that could influence the community's acceptance of RHMs.

In a study focused on understanding the role of RHMs and its relation to their recognition in Eswatini, RHMs were found to have poor training, guidance, and many forms of support from the national system (Walker et al., 2020). While the studies of De Neve et al. (2017) and

Geldsetzer et al. (2017) discuss RHMs' performance, program effectiveness, and position in the Swazi healthcare system, results observed in these studies could still support Walker et al.'s (2020) research in terms of the challenges faced by CHWs in Eswatini. Additionally, RHMs experienced vague definitions of their roles and high expectations from community members that they undertook extra responsibilities (Walker et al., 2020). As reported in other countries, RHMs in Eswatini received low salaries and considered themselves more volunteers than salaried workers (Geldsetzer et al., 2017). Regarding recognition, it was evident in De Neve et al. (2017)'s analysis that, similar to CHWs in other countries, RHMs also lack structural recognition on an organizational level.

It appears that most existing literature on the (volunteer) work done by CHWs in Eswatini is focused on assessing their performance and effectiveness. A gap exists in qualitative research which seeks to understand how CHWs value their 'work'. In this thesis, I seek to contribute to filling this gap by focusing on RHMs' experiences within an HIV intervention study.

Theoretical Framework

A phenomenological approach

This thesis adopted a phenomenological approach. Phenomenology is a type of research that aims to understand the essence of a phenomenon by looking at it from the viewpoint of those who have experienced it (Teherani, 2015; Neubauer et al., 2019). Phenomenological analysis endeavors to investigate someone's own experience and focuses on a person's understanding of an occurrence or object (Smith & Osborn, 2003). Therefore, adopting a phenomenological

approach is appropriate since this research aims to understand and describe RHMs' experience of their work in the community.

Role theory

Role theory, as described by Hardy & Conway (1981), is a set of ideas and potential explanations which suggest how a person will act in a specific role or environment. Additionally, role theory is often used in sociology and social psychology to explain the behaviors, features, expectations, and beliefs of an individual or a specific job (Major, 2003; Thomas & Biddle, 1966).

Role theory can also function as a conceptual framework for relating the characteristics of the organization and the individual, according to Schuler et al. (1977). Building on Schuler et al. (1977) 's premise, role theory can be used to analyze the perceptions and experiences of those who work in healthcare to provide relevant services to people in the community. Brookes et al. (2007) adopted this theory to explore how individuals perceive their roles within healthcare organizations and looked at how community nurses perceive their roles as they interact with patients in their community. Taylor et al. (2020) investigated how health professionals viewed the role of rural community pharmacists in expanded pharmacy practice using the Role Theory.

Concepts and role problems in Hardy and Conway's (1988) framework, which will be discussed in the next paragraph, have been further adapted to understand individuals' experience and role navigation. For instance, previous role theory research has indicated that individuals typically cope with role conflicts by mentally changing their roles and informing others that they have exceeded their assigned roles (Ashforth et al., 2000; Shumate & Fulk, 2004). Hooper (2020) used

the role theory framework to understand the experiences of home-based childcare providers in the United States of America and their strategies to manage the multiple roles they undertook. Another research by Lipsky et al. (2017), also informed by the role theory, indicated that organizational communication between teachers and parents could possibly help with their role conflicts.

This study will be guided by the key role problems identified in Hardy and Conway's (1988) role theory framework while considering the most relevant ones identified by Brookes et al. (2007) and Taylor et al. (2020), as both studies recognized this framework to examine community healthcare professionals (e.g., rural community pharmacists and community nurses) views of their positions within the healthcare system. The five role problems and their definitions are presented in Table 1. These role problems are interrelated. For example, role ambiguity has been found to contribute to role conflict (Brookes et al., 2007; Taylor et al., 2020). Role overload is noted to be a type of role conflict when giving individuals too many duties (Burke et al., 1991). Role identity and role insufficiency can be affected by difficulties such as ambiguity, conflict, and overload, as these affect an individual's sense of their own capabilities and the significance of their roles (Sayers et al., 2015; Taylor et al., 2020).

Table 1: Definition of role problems (Hardy and Conway, 1988)

Role problems	Definition
Role ambiguity	Disagreement on role expectation associated with a lack of clarity of those expectations.
Role conflict	The focal person perceives existing role expectations as being contradictory or mutually exclusive.
Role overload	Inadequate resources relative to possibly excessive demands.
Role identity	The individuals' interpretation of role expectation, that is, position specific norms, identifying the attitudes, behaviors and cognitions required and anticipated for a role occupant.
Role insufficiency	Disparity in fulfilling role expectations, obligations or goals as perceived by self or significant others.

Existing literature has shown that CHWs, including RHMs, encounter challenges, such as meeting expectations and navigating the ambiguity in their role (Kok et al., 2017; Schneider et al., 2008; Walker et al., 2020). Furthermore, RHMs interact with and voyage through a complex system and therefore find themselves in situations similar to those of the research subjects of Brooke et al. (2007) and Taylor et al. (2020). Role theory offers an approach to comprehending the behaviors, anticipations, and connections linked to particular roles and how they affect individuals' feelings, behavior, and actions. Therefore, the Role Theory offers a potentially useful framework to investigate and understand better RHMs' perceptions of their roles and how they navigate multiple roles and their role problems within the community.

The interdisciplinarity of this study lies in integrating the above-mentioned theoretical frameworks. This study will use a phenomenological approach to gain insights into RHMs' lived experiences doing their work. Furthermore, informed by the role theory framework, drawing on sociological and social-psychological perspectives, my thesis will investigate the role problems RHMs encounter within their work environment and how they manage or balance their role(s). RHMs' work involves various interactions with their organizations, such as their communities, local healthcare professionals, and the MoH. As the role theory takes these external factors (e.g., expectations from people they interact with) into account, it is thus possible for this thesis to explore how they shape RHMs' role(s) when examining their lived experiences through a phenomenological lens.

Scientific and Social Relevance

Whilst some research has been conducted previously regarding RHMs' work in the Swati context, they mainly adopted from an evaluation perspective using a quantitative approach to evaluate RHM's performance and develop suggestions for strategies to improve the RHM program's effectiveness. There seems to be a gap in qualitative research analyzing RHMs' personal experiences and perspectives on their efforts in HIV prevention. It is important to listen to the voices of CHWs/RHMs and understand their experiences because of their importance to international global health interventions and provide insights about the personal experiences and challenges RHMs may face to improve their working environment (Musoke et al., 2022). Looking at it on an even broader level, the vast body of public health research on CHWs in LMICs and the problems they face daily tends to concentrate on performance improvement and

program effectiveness (Ballard & Montgomery, 2017; Laurenzi et al., 2021), ignoring the perspectives of CHWs themselves (Laurenzi et al., 2021; Maes et al., 2014).

This study could help to address the scientific gap as it adopts a qualitative approach to explore how RHMs experience their work and perceive their role within the MaxART EAAA program. As Austin & Wright (2014) suggested, qualitative research helps researchers think from another person's perspective and gain insights into their experiences. Moreover, since CHWs are clearly used to fill the human resource gaps (Kok et al., 2017). To create long-term, viable solutions to address the difficulties facing LMICs in healthcare delivery, it is thus vital to understand their involvement, experiences and how they can be better capacitated. Lessons learned from this study could be further used as a reference for policy recommendations for CHW programs worldwide, especially in LMICs.

Research Questions

This thesis seeks to address this research question: **How do Rural Health Motivators experience their work and practice their role during the implementation of the MaxART EAAA program?**

Methods

Study Design

This study utilized existing data collected as part of the MaxART program in Eswatini. The MaxART Social Science Research adopted a mix-method approach to study people's experiences with HIV and (community) health providers implementing the EAAA project (MaxART

Consortium, 2018). Data collection was done by Swazi researchers in the local language, siSwati, during the implementation of the MaxART project, more specifically, the Social Science Research component conducted from 2014 to 2017 in Eswatini (MaxART Consortium, 2018). The data set used for this thesis consisted of 27 in-depth interviews done with what are referred to in the MaxART program as 'Community-Based Volunteers' (CBVs).

All interview voice data was recorded digitally and transcribed verbatim after a session's completion. The siSwati transcripts were further translated into English by translators experienced in translating qualitative interviews and familiar with the relevant terms used.

Study Sample

The study population in this study is CBVs who participated in implementing the MaxART study in Eswatini, including CHWs, RHMs, caregivers, support group members, and community police (MaxART Consortium, 2018). Social scientists working alongside the implementation study team randomly selected CBVs from a contact list provided by the MaxART team, who led the community engagement study team. The social science team selected every fifth participant on this list, considering different cadres of workers and different community locations involved. Participants were contacted by phone by the researchers and invited for an interview to talk about their experiences in the MaxART project. Participants were interviewed at a preferred location close to their locality, which included local health facilities or the inkhundla center (constituency headquarter) (MaxART Consortium, 2018).

After familiarizing myself with the 27 interviews, I decided to select the largest represented group of CBVs, the RHMs, with whom 17 interviews were done. Other types of CBVs

interviewed were community police and HIV support group members. Another reason for focusing on RHMs' experiences was to limit the focus of the analysis to CBVs who were performing health-related tasks and who were most involved with the implementation of the EAAA study. Furthermore, RHMs are the Swati CHW program's oldest and largest cadre (Geldsetzer et al., 2017). They are likely to continue to exist as a health workers cadre, hence understanding their experiences also bears relevance for future research and policy development.

Data and Measurements

A topic list was developed to conduct semi-structured, in-depth interviews with CHWs during the study. The interview questions consist of two parts: Introduction and EAAA experience. The introduction part aims to obtain general knowledge of CHWs in the community and their work in the HIV context. It includes questions about their roles, self-identification, the perception of HIV, leadership, and involvement with people living with HIV in the community. The section on EAAA experience investigates CHWs' knowledge of EAAA. It encompasses questions such as existing EAAA-related activities, materials used, people's responses to EAAA, dialogues, training, and their role in implementing EAAA.

Data Analysis

All interviews were previously transcribed verbatim from siSwati to English by the MaxART research team. This study adopted an inductive thematic analysis as well as a phenomenological approach to analyze the transcripts. Inductive thematic analysis was proven useful for comparing different transcripts and pinpointing the main topics (Braun & Clarke, 2006). This method was also used by Walker et al. (2020) in similar qualitative research on CHWs' role and experience in the HIV/AIDS context. As described in the theoretical framework chapter, the

phenomenological approach aims to delve into an individual's lived experience and is therefore used to guide this analysis. Prior to the coding, I familiarized myself with the data by summarizing all 17 interviews, highlighting interesting phrases to identify potential themes, and discussing my initial insights with my supervisor. The coding was done using the qualitative data analysis software – NVivo 14. Informed by Nowell et al. (2017), the data was coded without attempting to fit it into an existing coding framework or my own analytical preconceptions. Emerging themes were then organized and reported.

Results

By carefully examining 17 RHM interviews and categorizing their quotes into relevant codes and themes, I examined RHMs' official responsibilities according to previous research and distinguished how they experienced their work and managed their role(s) in practice. My analysis also highlighted the challenges faced by RHMs and how they navigated the negative incidents during the implementation of the MaxART EAAA program.

Rural Health Motivators' official responsibilities and expectations

According to my analysis, the number of households to visit per month that each respondent was tasked ranged from 22 to 45. Most interviewees reported spending 2 to 3 days a week on RHM duties, and a small number of them said to visit the homesteads of their responsibility whenever they had time.

Generally, interviewees visited homesteads and educated people about health issues, such as HIV and child immunization, and environmental hygiene, as part of their work. Some participants

also indicated that if people they visited complained about discomfort, RHMs would distribute painkillers (Panadol) as first aid and encourage them to visit health facilities.

The participants weighed infants and children in the community as an activity to monitor their growth. RHMs also used this opportunity to preach to the mothers about child vaccination and the EAAA program, integrating their ‘role’ as promotors of early ART within their officially expected activities of weighing children.

> *“Yes, we weigh children. We weigh children under trees…When we get to the tree where we weigh the children, we greet the mothers and then we start teaching. We remind them about HIV and inform them about this new program where people are allowed to start pills before they get bedridden or have diarrhea regardless of the CD4 count. This program encourages anyone who test HIV positive. We teach them and add to what they already know.” [A female RHM who was trained in 2010 at Ntfonjeni]*

Lived experiences of doing RHM work

This section will discuss themes regarding RHMs’ lived experiences that emerged during the analysis, such as recognition, credibility, and the challenges they face in their work. RHMs in this study generally felt a sense of recognition and interacted well with community members. However, when conveying health-related messages in the community, they sometimes seemed not credible in people’s eyes. Challenges were also identified, including the lack of resources and engaging certain groups in the community.

Recognition

"I feel like I do good." This was mentioned by a female RHM who just started her position 9 months prior to the interview. Most of the interviewees had high self-recognition and took pride in their work. They believed that RHMs played a crucial role in health education and HIV-related efforts.

Many respondents commented that they had a good relationship with community members and that they were willing to confide personal information, such as their HIV status, with RHMs.

> *We work very well together. Very well because if someone disclose to me and say "I take these pills" I am able to visit them and say "hey my child how is it going with your clinic issue." [A female RHM with 14 years of experience]*

Patients in the community sought help from RHMs. When referred to RHMs by health facilities, they called or went to RHMs for consultation. One interviewee was registered at the clinic as a patient's reference, which is usually someone to whom patients have disclosed their HIV status and who can be contacted in case they miss an appointment to pick up medication. The interviewee followed up on the patient until s/he recovered. *"I registered your name that I want you to be my motivator,"* said the patient.

> *"We do get along just fine because if there are problems, they call on me and tell me that there is a problem which they cannot address may I help them, that there is a problem that I cannot fix. They give themselves the opportunity to consult with me." [A female RHM leader]*

One female interviewee who had been a RHM for 14 years also indicated the recognition of their work from community leaders: *"…elders usually say, "we rely on rural health motivators, we want a report on how you worked". They encourage us to work."*

Only in one case, a respondent mentioned that she had heard previous incidents of RHMs being insulted and was frightened when she was selected a RHM because she perceived herself being insulted as well. However, no situation of such was reported by the interviewees.

> *"I was also surprised since rural health motivators get insulted a lot. I used to hear one of them being insulted before I became a rural health motivator in many different ways, people would say that she does not give people pills and keeps them for her children, that meant I would also be insulted. I cried as if someone had died on the day I was selected and I was instructed to pack and leave for training the following day. I woke up and prayed with difficulty from all the crying the following day."*

Credibility

RHMs' credibility emerged as another theme from the interviews. Interestingly, despite recognizing their importance in the community, an overwhelming majority of interviewees seemed to lack credibility in the community. People had the attitude that "*they already knew everything*" or "*they don't care,*" indicating that RHMs were telling them nothing new and indirectly questioning their knowledge and skills. A male RHM felt that this was something that was "not going well" with his work: *"What I feel is not good it's the time when people tell you they know…I feel that is not good because what I talk about is a message that I was sent to pass on to the community…then people seem to know everything."*

Despite being selected and going through training to work as a health worker, RHMs seemed to still lack credibility in medical authority compared to clinical staff. As one participant described, when trying to discuss the EAAA program, she realized people would rather be told about HIV by healthcare professional from the hospital, and not RHMs.

> *"They say they want to get it from the hospital that they should start treatment, and not to get that from us, they want to be told at the hospital." [A female RHM who had been in the position for 4 years]*

Another quote worth highlighting is from a female RHM who shared that people did not find what she said credible because she was not HIV-positive herself. This shows they were lacking credibility in terms of biosocial identity.

> *"It is difficult especially because sometimes you talk to a person then they tell you what can you tell me have you started the treatment when you try to explain that I have not started but I have tested then my blood is not reached that level (meaning negative) then they say what can I talk with you because the joys of taking treatment you do not know them the sorrows of taking treatment you do not know them." [A female RHM who just started her position 9 months prior to the interview]*

To improve credibility, many informants expressed keenness to receive continuous training and adequate materials, stating that those might help with their work.

> *"There may be no questions what I can point out is that if they can continue because after some time….that you just continue and feed us with more knowledge about the program because even though we have learnt maybe after two, three years it is then absorbed by the*

brain and that if there is something new that has been added keep on adding it to us so that we are able to go and give it to the people." [A female RHM who just started her position 9 months prior to the interview]

"(the teaching materials) It does help because it reminds me what kind of a thing is the early start program so that I can be able to explain to people." [A female RHM who said she started from when the salary was only E100]

Some participants also felt the need to involve more stakeholders, such as community leaders and other cadres of CBVs (e.g., caregivers and community police), in increasing awareness about HIV and the EAAA program. Community leaders could potentially be a bridge between community members and RHMs, as they could advocate and support the messages RHMs tried to convey.

"I think you if can come with us our meetings and then leaders will tell the community that together we have come with such a program to the community and how do they feel about it so that people can see what we talk about is legit…yes they do know that its legit but to have you present in the meetings with the community will be good because it will show that we are one in this." [The only male RHM among all interviewees]

"I would suggest that you must also ask to them (community workers), so that you can sometimes teach them because as a rural health motivator you have this pressure when you approach them they do not care it but if you can also set aside time to summon community elders to give them lessons and tell them that they must also work along with rural health providers." [A female regional RHM leader from Piggs Peak]

An interesting approach to engaging people in conversations, indicated by one interviewee, was to pretend she was HIV-positive herself. Another informant also shared that she would invite a patient already under HIV treatment to visit homesteads with her to help engage people in conversations. Linking this back to the lack of credibility of one HIV-negative RHM, it could perhaps be explained why this strategy would be useful when RHMs tried to talk to people.

RHMs adopted other strategies to elicit conversations with community members. One RHM who had just started the position 8 months ago said that she would switch among different topics when talking to people because *"people get tired somedays."* Another interviewee, when asked about how she could make people "hear her", thought visiting one household repeatedly would be a useful approach.

> *"… when you talk to someone for the first time, they might not hear you or understand you but maybe if you come again for the second time they might hear you but if you have talked to them once in passing…maybe if talk to them again they will hear what you are talking about."*

Challenges

<u>Engaging the community</u>

A few participants experienced difficulty engaging people in conversations, especially when talking about HIV topics and the EAAA program. As one interviewee put it, *"The challenge is the people; they don't want to listen anymore."* Some community members ran away to avoid RHMs and their "HIV talks." This view was echoed by other interviewees sharing their

encounters with community members. They were told by people that they were tired of RHMs talking about HIV and the EAAA program.

> *"…I have spoken to 3 people…because others will not let me speak to them…they run away." [A female RHM who was trained in 2010 at Ntfonjeni]*

The engagement issue appeared to be more prominent when respondents tried to reach the youth and men. When asked about their interactions with the youth, a participant commented: *"Some do listen whereas some say leave us alone you like talking too much."* Another interviewee considered the youth uninterested in the program, recalling that even when a community meeting was held and the youth was called, only very few showed up.

<u>The lack of resources and stipends</u>

The interviewees reported various challenges during their work and interactions with the community. A common view amongst interviewees was the lack of resources. Some participants indicated that having uniforms would allow people to identify them and further help with the engagement with household members. Furthermore, many informants reported not being provided sufficient leaflets and teaching materials to give to communities. Some also noted the lack of access to enough contraceptives and painkillers to distribute. Such issues reportedly affected the relationship between RHMs and the community because people expected RHMs to bring something to help them. For instance, several interviewees mentioned that people questioned RHMs for hiding the painkillers for themselves. It also caused the inability of RHMs to present themselves professionally.

"It's very difficult to visit the homesteads without carrying pills because people will want them and when you say you don't have them today, they think you are lying and you have just taken them yourself…and they will ask "why have you visited them without the pills?" [The only male RHM among all interviewees]

Another common view among interviewees was the lack of monetary compensation for RHMs. There were some negative comments from the interviewees that they needed more allowance for transport or a stipend for their work. The lack of support also appeared to affect their motivation to continue doing their work.

Undertaking different roles and doing different 'types' of work

Within the EAAA program, RHMs' specified tasks, such as door-to-door visits and delivering HIV education, aligned mostly with those outlined by the MoH but had more emphasis on conveying messages about EAAA.

Many of the interviewees attended the initial training intended for RHMs to deliver the EAAA messages more effectively. They described their role within the EAAA program as to encourage people to get tested for HIV and know their status.

"We emphasize and tell them that they must go check their HIV status so that they can start taking the treatment before they get sick and be bedridden." [A female RHM, years of work experience unclear]

They also urged those who tested positive to start the ART treatment early despite their CD4 count. Every month, RHMs were obligated to report their progress to community leaders.

During the analysis, I found that RHMs were actually performing a wide range of tasks that fell outside of their formal MoH and the EAAA program scope of work, including checking up on medical information and offering money and meals. From my analysis, it also became clear an important part of their work included what might be called ’emotional work’ which will be discussed in the next section.

Checking up on confidential medical information

For instance, some interviewees stated that following up on patients, checking their “patient booklet” and “treatment card”, and ensuring their treatment compliance were also their duties. The RHMs reminded patients to visit the clinic for a refill for their treatments. One respondent said she would visit those who “*become lazy*” and skipped their appointments, or even ask health workers to check on the patients, revealing her “policing” role in the community.

> *“I also tell them that for instance if in that homestead maybe there is a sick person in that homestead who is bedridden in a week I have to visit that person, or if there is a person who is on treatment I have to know their treatment card and see when that person is supposed to return for refills and then I remind them that you should remember that on this day you should go and get your refills.” [A female RHM who was also a first aider for the Red Cross]*

Lending a hand with money and meals

In this study, while discussing the interactions with people, an overwhelming majority of RHMs reported having to provide material support to community members. One respondent commented: *"…it's expected that you help out,"* indicating that as a RHM, they bore the expectations to meet the community's needs. Despite having few resources themselves, some interviewees described providing financial aid for transport to clinics as well as sharing their own food with community members.

> *"(RHMs' role) Is to meet people's needs yet you won't be able to…let's say the person is hungry…even if I don't have the food…but we did not have much because my husband died in 1993 and I stay with orphans…but the little I have…when the person comes asking for that something…if you do have it, you help." [A female RHM who was also a volunteer at the Red Cross]*

> *"Some people even come to my home for food and you find that I also don't have food. They say "madam rural health motivator I need to take my pills". Some people take other pills on top of these. Pills for high blood pressure and diabetes. They say they can't take their pills or their injection without eating. You find that I don't have anything but I give them what me and my kids are eating so that they don't die because we want everyone to get to vision 2022." [A female RHM with 14 years of experience]*

Besides supporting individual community members with food, if necessary, RHMs were also cooking during community events hosted by the MaxART study. According to one female RHM of 3 years, during the dipping tank dialogue organized by the MaxART study when health awareness talks were normally conveyed (MaxART Consortium, 2018), "*being busy with the*

pots" was also one of RHMs' extra responsibilities. She stated that the RHMs could not hear what was being taught because they were preparing food for the crowd.

These different types of work seemed to also occupy RHMs time outside of their working hours. One interviewee mentioned that she did not have enough time to visit all households. Most participants reported to work 2 to 3 days on average; however, several interviewees reported to talk to people they encountered in the streets about the EAAA program. Some received calls from patients at night and had to accompany them to health facilities, and some experienced community members coming to their houses outside of their work time.

> *"If there is someone who is sick I they come to me if it is at night they wake me up and I accompany them to the health facility as a rural health motivator." [A female RHM with 14 years of experience]*

<u>Emotional work: Dealing with skepticism and negative reactions</u>

In addition to providing information about HIV and the EAAA program, and doing additional work such as cooking, a few participants responded that they had to address and clarify issues raised by community members. Several informants reported that upon learning about the EAAA program, patients often expressed their concerns about the stockout of the treatment. When asked by the patients what would the solution be if there was insufficient treatment for all HIV patients in Eswatini, RHMs tried to mitigate these fears and referred them to clinical health workers.

> *"Most of them were asking that since you are saying that we should start treatment we will be many. If it happens that the treatment runs out, what will we do because there will be many of us…I tell them that I do not think treatment will run out but they can get the*

assurance when they get to the clinic health providers would be able to tell them more about that." [A female RHM who was also a first aider for the Red Cross]

Some interviewees also indicated that while introducing the EAAA program to community members, they had to cope with people's misconceptions and worry that the treatment would cause premature deaths. This could arise from rumors in the community about people's death after starting early treatment, which resulted in the rising reluctance and fear for early ART initiation.

> *"She got tested…she came here for the early start program…she started with the treatment but then came across a problem…after that she became very sick until she died…and now people say the early start program came to kill them…someone also died because she started with the treat while they were still healthy." [A female RHM who said she started from when the salary was only E100]*

People sometimes responded negatively and thought that RHMs wanted them to "*die early*" or that the EAAA program would "*kill them*."

> *"They are excited about it even those some say, "it is the program for starting early, you want us to die early". We then provide clarity by saying no "you start ART early if you are diagnosed as HIV positive." [A female RHM responsible for Mashobeni area]*

RHMs were also faced with rejection sometimes as people were reluctant to accept the EAAA program. This could require a lot of emotional efforts.

"They don't like it when you tell them that they must go visit the clinic t check their status then would say… "You mean I have the virus, this this and that" …they don't like it…but we look at ways in which we engage them so that they can go to the clinic." [A female RHM who was also a volunteer at the Red Cross]

RHMs also had to cope with community members' negative reactions towards them, which could be considered a type of emotional work. Many interviewees reported receiving people's constant complaints about lacking food, and that they could not take the treatment without food. As one individual commented: *"…they say that our bags do not have anything… every day they are complaining that you do not bring us anything…"* RHMs had to share what they had at hand *"so that they don't die because we want everyone to get to vision 2022."* Some respondents even appealed to the interviewers on behalf of the community that RHMs should be provided food to bring during their outreach.

"…sometimes as we go around visiting homesteads, you find that they don't have food so that they can be able to drink the pills…so we are pleading if they could give us something like mealie meal so that people can eat and be able to drink pills on full stomachs and in the end, so that they could get well." [A female RHM who said she started from when the salary was only E100]

Discussions

Overview of the Findings

The initial objective of this study is to understand RHMs' lived experience of their work and how they practiced their divergent roles within the MaxART EAAA program and in their communities. Linking to the role theory, this study also found that RHMs encounter role problems, such as role ambiguity, role overload, role identity, and role insufficiency within their work. Furthermore, the overall results from my analysis indicate that on top of their official responsibilities, RHMs were, in fact, doing many different types of work, one of which was emotional work. Generally, RHMs were acknowledged for their contributions by their fellow community members and took up different strategies to navigate achieving recognition and credibility for their work, which could also be seen as their ways to try to cope with role insufficiency. Still, RHMs faced challenges, such as difficulty engaging the community, particularly the youth and men, and insufficient remuneration and resources.

Findings in Relation to Other Research

The role theory

The role theory framework can be applied to understand individuals' perceptions of their roles, their experiences, and how they manage these roles. Although the perceptions of RHMs about their roles did not appear to be a primary finding in this study, their experiences navigating different roles and role problems were recognized and will be discussed in this section. Role ambiguity was frequently identified in this study, as RHMs were found to do many different types of work. Even though the MoH outlined their official responsibilities, in reality, their roles had blurred boundaries, and they had to carry out tasks expected by the community. Role conflict

was, however, not observed in this study. In terms of role overload, which can be experienced by healthcare personnel in rural and isolated areas if the expectations of a particular job surpass the individual's ability to perform it (Brookes et al., 2007), was also distinguished in this study. Although RHMs wanted to meet the community's need for food to take with their medication, transport money, and painkillers, it was beyond their capabilities because they did not possess the resources. Role overload was also experienced when RHMs called for more stakeholders to be involved that as it was not enough when they were the only ones talking about HIV issues. Despite the role ambiguity, which generally contributes to role identity development (Brookes et al., 2007), RHMs in this study seemed to internalized communities' expectations towards them and act accordingly. For example, they commented that they were expected to provide help and were willing to do so. Lastly, RHMs in this study experienced role insufficiency when they realized they did not have the knowledge or skills to deliver new information and offer aid to community members, and yet their goals were to raise people's awareness about HIV and the EAAA program.

As my study finds that RHMs' experience of their work aligns with many role problems that could potentially lead to stress and low productivity at work, such as role conflict, role ambiguity, and role overload (Brookes et al., 2007; Taylor et al., 2020), it is, therefore, necessary to consider these findings carefully in future research on RHMs' work.

Going the extra mile: the emotional work of Rural Health Motivators

Aligning with the findings of Walker et al. (2020) and Laurenzi et al. (2021), my thesis highlights that RHMs work beyond their roles and that people in the community expect them to

lend a hand. One common view in Laurenzi et al. (2021) and this study is that CHWs feel obligated to help.

Another significant finding in this study is the emotional work that RHMs do, such as handling people's negative reactions, complaints, and being the community's emotional support. This echoes Glenton's systematic review, where many articles included showed evidence of community health workers dealing with communities' emotional needs and non-healthcare-related issues, which could be very energy-draining. Other forms of emotional work have been mentioned in previous research. A study by Pandey & Singh (2016) conducted in India investigated the emotional labor of CHWs, where they had to express appropriate emotions and emphasize when providing services, which caused them plenty of burdens from their close relationships with community members. Similar findings were found in Laurenzi et al. (2021) 's research, where CHWs had difficulty disassociating themselves from the clients' emotions. It appears this emotional labor is often an unofficial and overlooked aspect of CHW's work. Writing about the concept of 'emotional labor,' Hochschild (1983) explained this as the process where employees must manage their feelings to meet customers' emotional needs as part of their job responsibilities. In the context of nursing healthcare, the term' emotional labor' has been adopted to describe an "under-appreciated aspect of caring work" (Henderson, 2001, p. 130) and characterized as a battle of "being ordered to care in a society that refuses to value caring" (Reverby, 1987, p. 5). Occupations that require a lot of 'people work' are emotionally exhausting in the sense of emotional labor (Pandey & Singh, 2016). As most CHWs' work involves interacting with community members, sometimes even healthcare personnel, RHMs in this study also experienced similar types of 'emotional labor'; however, this type of work is often not

formally described in their responsibilities and, therefore, not evaluated or valued by their employees.

My analysis of RHMs' emotional work in providing caring services also supports Oliver et al. (2015) 's views that having to address community members' health and emotional demands could require more energy than imagined and that the challenge is often underestimated. Additionally, this study adds to existing literature that many RHMs went above and beyond to fulfill their "responsibilities," frequently at a personal sacrifice.

RHMs' emotional work demonstrated their dedication and commitment in Eswatini to the well-being of their communities. However, it is essential to note that these tasks were not formally assigned to RHMs and reflect their adaptability in responding to community needs.

Implications of the Study

As this thesis has shown, there is a need for further research on RHMs' emotional work, especially when it is discovered to be a part of RHMs' unofficial work and could be taxing, and yet CHWs, including RHMs in Eswatini, are generally referred to as volunteers and are heavily underpaid (Geldsetzer et al., 2017; Maes, 2014). Although the results observed in this study did not fit entirely into the definition of emotional labor by Hochschild (1983), they could be related to Henderson (2001)'s adopted explanation as RHMs in this study were indeed doing much caring and 'people' work but were sometimes feeling unappreciated. On top of this, previous studies also discover a lack of psychological support for CHWs when navigating their work and challenges in the communities (Mwai et al., 2013). Therefore, issues such as what the emotional

aspects of RHMs' work entail and how to better support them in the public health system should be comprehensively investigated.

A more practical and policy-oriented implication is to increase the diversity within RHM programs, which currently consists primarily of married women. As the participants in this study revealed difficulties engaging certain groups, namely men and the youth, it is thus recommended that increasing the number of male RHMs may help the tailored health messaging get more traction in the country (Jaskiewicz & Tulenko, 2012; Geldsetzer et al., 2017; Walker et al., 2020). People who share the same sociodemographic characteristics or are from the same generation may have more in common and know how to talk to one another. Therefore, recruiting or encouraging more males and the younger generation to become RHMs could potentially help address the engagement issue, as some community members may find them more relatable than female RHMs. Finally, RHMs' work involves daily interactions with the community. Consequently, policymakers and stakeholders must provide relevant training on interpersonal relationships and communication to equip them with skills that could help them better engage the community.

Strengths and Limitations of the Study

Strengths

Whilst there is currently a large body of research discussing or advocating for CHWs, there need to be more insights into CHWs' descriptions of their work, which raises concerns for those who support global health concerning power and participation in CHW programs (Oliver et al., 2015). As my analysis revealed the importance of emotional labor as part of RHM work, which was

relatively less discussed in previous studies, a critical strength of this study is its potential to fill the knowledge gaps in the existing literature.

Another strength of this study is that trained local researchers conducted all interviews in the local language siSwati. This means that they understood the social context and how to speak to interviewees in an appropriate manner, as HIV/AIDS is still a sensitive topic in Swazi society. Furthermore, compared to the scenario where I was the one interviewing RHMs, conducting interviews in siSwati by local professionals should maximize the chances of participants understanding the questions due to mistranslation.

Limitations

A few significant limitations need to be considered in this study. First, the interviews were conducted by the MaxART research team, and I did not have control over the data collection process. The researcher might have different research questions and approaches to interviewing the participants. In most cases, the interviewees were not guided to elaborate more about their responses because the interviewers might already have the needed answers. This made it challenging to gather more in-depth information about lived experiences, hampering a rich phenomenological analysis of my research question and potentially influencing my data analysis and interpretation. On top of that, I was also not able to interact directly with the interviewees and lacked access to the richness of participant perspectives, which could limit my understanding of the context and nuances surrounding the data. Nonetheless, throughout writing this thesis, I did my utmost to mitigate this limitation. For instance, in case of confusion or questions regarding the interview data, I often reached out to my supervisor, Eva Vernooij, for her

clarification, which provided me with more context about the MaxART EAAA program and helped me comprehend the transcripts better.

Additionally, the generalizability of the results is limited by the small sample size and the need for more diversity among the interviewees. Only 1 in 17 RHMs interviewed in this study is male; therefore, this study could only explore mostly female RHMs' perspectives. Furthermore, only the experiences of active RHMs involved in the MaxART EAAA program were investigated. This should be considered when interpreting the findings in the context of other literature.

Conclusion

Most existing public health literature focuses on examining the effectiveness of the CHW and RHM programs and tends to neglect what they genuinely have to say about their work. My research produced insight that sheds light on the lived experience of RHM work, how they practiced their many roles in the community and the challenges they faced. Moreover, as my study adds more insights into the less-noticed emotional work of RHMs, proper interpretation of and further research based on these results is needed to understand how policymakers could better support RHMs with their work and could potentially help global and local authorities build a more sustainable healthcare system.

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Appendices

Appendix 1: Code tree