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Women's Empowerment Among Women Living with HIV in the Kasungu District of Malawi

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EMPOWERMENT AMONG WOMEN LIVING WITH HIV
IN THE KASUNGU DISTRICT OF MALAWI

by
Victoria L. Scheer

A Dissertation Submitted in
Partial Fulfillment of the
Requirements for the Degree of

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ABSTRACT

EMPOWERMENT AMONG WOMEN LIVING WITH HIV IN THE KASUNGU DISTRICT OF MALAWI

by

Victoria L. Scheer

The University of Wisconsin-Milwaukee, 2020
Under the Supervision of Professor Mkandawire-Valhmu

Background: Women's empowerment is recognized as a goal in major development discourses globally. Interventions seeking to empower women are often focused on women living in the Global South. However, the perspectives of women located in the Global South are less represented in literature compared to the dominant narratives of women located in the Global North. This is especially true for women living at the intersections of national and local poverty, racism, and patriarchy, such as is the case for women living with HIV in Malawi. Women in this context stand to gain from empowerment interventions, though there exists a gap in knowledge of how empowerment is experienced in this population. To address this gap, this qualitative study was conducted to explore women's definition of empowerment and to construct a substantive theory of empowerment among women living with HIV in the Kasungu District of Malawi.

Methods: Using grounded theory methodology and informed by a postcolonial feminist perspective, 25 individual in-depth, semi-structured interviews were completed over three months in the Kasungu District of Malawi. Interviews were completed in the local language, Chichewa, transcribed and translated into English.

Results: Findings reveal how women described empowerment in the form of receiving encouragement, strength, and courage from others, and through normalizing of their experiences of living with HIV. Women emphasized how receiving encouragement, as well as material assistance, caused them to work hard in taking their medications and to develop their home. This framework of empowerment, constructed through women's perspectives, guided the development of a theory of empowerment. This theory, *Putting Your Life in the Front*, demonstrates how women experience empowerment through *Protecting Health*, *Working for Household Development*, and *Giving and Receiving Encouragement*. These findings contribute to new knowledge about the nuanced experiences of empowerment among women living with HIV in rural Malawi and provide guidance for developing interventions for improving the health and wellness of women in similar contexts.

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CHAPTER I: INTRODUCTION

Introduction

Women's empowerment has increasingly become something of a "buzzword" linked to global efforts to improve the status of women and achieve gender equality. In the extensive discussions of how to empower women, the stories of individual women are often left out. This is especially true for marginalized women, such as women living with HIV/AIDS in low-income countries. This study seeks to describe empowerment from the perspectives of women in the context of HIV/AIDS, embracing the stories of women who are underrepresented in the literature, explore the factors that hinder and facilitate empowerment, and how empowerment relates to health among women living with HIV/AIDS.

Background and Significance

Women's empowerment is linked to gender inequalities, which are a major contributor to the spread of HIV (Lindgren, Rankin, S., Rankin, W., 2008). In Malawi, a country located in southeastern Africa with a population of 16.36 million people (World Bank, 2013), gender inequalities are pervasive. More women are infected with HIV, and at younger ages, than men (Malawi Demographic and Health Survey 2010 (MDHS), 2011). Overall, 12.9 percent of women in Malawi are living with HIV compared to 8.1 percent of men (MDHS, 2011). In Malawian society, women experience marginalization as a result of gendered institutional practices that lead to limited formal education and employment opportunities for women. The Malawi Demographic and Health Survey (2011) reported differences between women and men in literacy (68 vs. 81%) and employment (55.5 vs. 82%). Additionally, one in four women reported ever having experienced sexual violence, and four in ten ever-married women reported

having experienced emotional, physical, or sexual abuse by their partners (MDHS). Little or no formal education, poverty, and experiences of violence increase a woman's risk of becoming infected with HIV (Andersson, Cockcroft, & Shea, 2008; Dunkle et al., 2005; MDHS; Pronyk et al., 2006).

Exploring experiences of empowerment among women living in Malawi has significance for the health of women, children, and communities, and holds potential for directing future nursing research and practice. Women in Malawi are often the primary caregivers of children and those who are ill (MacIntyre et al., 2013). Throughout sub-Saharan African countries, women often focus on subsistence farming, growing foods for cooking and feeding families and communities, compared to men, who often focus on growing cash crops (Kondylis, Mueller, Sheriff, & Zhu, 2016). When women are ill, they are less able to participate in caregiving and farming activities; in these situations, children, particularly girls, often drop out of school to become the main caregivers for their parents and siblings (Foster & Williamson, 2000). When women suffer, the health and wellbeing of children, families, and communities do as well.

In order to best inform empowerment efforts, it has been suggested that research should focus on those most at risk and most vulnerable. Women living with HIV experience intersections of marginalization. In addition to gender inequalities; women living with HIV may endure violence, neglect, and isolation as a result of the stigma surrounding HIV (Chilemba, Van Wyk, & Leech, 2014). As such, women living at these intersections are at high risk for poor health outcomes. Few studies of empowerment have been conducted among women living with HIV. Lessons learned from exploring empowerment in these contexts may help to inform future research and practice among women living with HIV in Malawi, as well as women in other contexts who have similar experiences of marginalization.

Women's empowerment is significant to nursing as nurses aim to study human responses, promote health, and provide culturally safe care. Women's empowerment holds potential to strengthen women's ability to promote change within their lives, and the environments in which they live (Carr, 2003; Kim et al, 2007, Mosedale, 2005; Zimmerman, 2000). Doing so could have implications for women's mental health by increasing self-efficacy and perceptions of self, as well as physical health, by promoting healthy relationships with men, reducing sexual risk behaviors, and reducing the spread of HIV (Kim et al., 2007; Pronyk et al., 2006). Understanding women's empowerment in the context of HIV would lend vital information for developing and facilitating future interventions aimed at improving health outcomes.

The empowerment of women is deeply political. Empowering women is not only morally and ethically significant, according to the World Bank (2012), it holds huge economic potential. Women's empowerment and gender equality are goals of the current Sustainable Development Goals, the global agenda for sustainable development outlined by the United Nations (2015), and were also included as targets in the previous agenda, the Millennium Development Goals (World Bank, 2012). These international agendas have influence over gender policies and programs developed at international and local levels, and where international efforts and monies are allocated. Where health statistics were often used, women's empowerment is now being used as an indicator of a country's development. Women are directly impacted by how women's empowerment is conceptualized.

Uses of Empowerment

Empowerment has a long history of use in academic research and literature, as well as policy, especially in the contexts of health, workplaces and organizations, and development. Within health research, empowerment has been included in a wide range of studies focused on

both psychological and physical well-being of individuals, families, and communities. Studies on empowerment and health have been conducted in the context of reducing intimate partner violence (IPV) (Dalal, 2011; Kim et al., 2009) and health promotion related to HIV and STD prevention (Swendeman, Basu, Das, Jana, & Rotheram-Borus, 2009). Empowerment has also been linked to decreases in depression (Rahman et al., 2012), increases in self-efficacy (Grabe, 2012), self-worth (Swendeman et al., 2009), and autonomy (Hunter, Jason & Keys, 2013). Across several disciplines including community psychology and nursing, empowerment is used in the context of work environments, focusing on organizational structures of power, team empowerment of co-workers, empowerment of individual employees, and leadership development (Laschinger, Read, Wilk, & Finegan, 2014; MacPhee, Skelton-Green, Bouthillette, & Suryaprakash, 2012; Seibert, Wang, & Courtright, 2011). In the development arena, empowerment has been used as an indicator for gender equality, and levels of country development (United Nations, 2008). Often, the concept of empowerment is used specifically in relation to women and may be used interchangeably with women's empowerment. In this study, I will focus specifically on empowerment among women.

Definitions of Empowerment

A multitude of definitions of empowerment currently exist. According to the Merriam-Webster dictionary, to empower is defined as “to give power to (someone); to give official authority or legal power to (someone); to enable; to promote the self-actualization or influence of” (n.d.). The Merriam-Webster thesaurus defines empowerment as “the granting of power to perform various acts or duties” (n.d.). Conversely, disempower is defined as “to cause (a person or group of people) to be less likely than others to succeed: to prevent (a person or group) from having power, authority, or influence; to deprive of power, authority, or influence: make weak,

ineffectual, or unimportant” (Merriam-Webster, n.d.). While dictionary definitions imply empowerment is inherently the giving, taking, or denial of power from one person to another, definitions in the literature focus on individual developments of control, capacity, and agency, as well as empowerment beyond individual contexts.

Between the 1970s and 1980s, many definitions of empowerment still used today emerged out of community psychology, development, and community participatory research. In his often cited 1984 work, Kieffer defined empowerment in terms of development as the achievement of “multidimensional participatory competence”. As a community psychologist, Kieffer’s definition of empowerment centered on individual empowerment in the context of affecting broader community and societal change. His definition of empowerment was developed through in-depth interviews with grassroots activists and did not focus solely on women as targets of empowerment. Other definitions of empowerment during this time reflected similar ideologies and centered on empowerment in relation to the social and political environment; for example:

Empowerment is an intentional, ongoing process centered in the local community, involving mutual respect, critical reflection, caring, and group participation, through which people lacking an equal share of valued resources gain greater access to and control over those resources (Cornell Empowerment-Group, 1989 as cited in Zimmerman, 2000, p. 43).

During this time, other community psychologists like Rappaport acknowledged empowerment as a process through which not only individuals gained control and mastery of their lives, but also organizations and communities (1984). Again, these definitions of empowerment were targeted not solely on women, but on communities and groups. In the context of social change, it was believed that marginalized groups, including women, were in need of empowerment. However, this could not effectively be achieved without acknowledging

the broader social and political contexts that played a role in creating environments that sustained marginalization.

Over time, definitions of empowerment in the literature began to primarily focus on the empowerment of individuals or groups of individuals, separate and without relation to the broader contexts of change reflected in earlier definitions. In social psychology, scholars tend to separate individual, group, or community empowerment. When focusing on individual psychological empowerment, definitions are mostly conceptual in nature, and included constructions of empowerment in terms of self-efficacy, self-determination, and competence (Spreitzer, 1995).

The development literature has also seen a change in definitions of empowerment over time. During the 1990s and 2000s, the concept of women's empowerment became a central focus in development. Generally accepted definitions of empowerment during this time included implicit and overt references to concepts of control, choice, and decisions. For example, in 2005, empowerment was defined as “a process of increasing capacity of individuals or groups to make choices and to transform those choices into desired actions and outcomes” (Alsop & Heinsohn, 2005). However, new definitions appear to reflect shifts toward older definitions rooted in broader political change. A recent definition of empowerment released by the United Nations states:

“Empowerment . . . is an iterative process with key components including an enabling environment that encourages popular participation in decision-making that affects the achievement of goals like poverty eradication, social integration and decent work for all as well as sustainable development” (2013).

In nursing, definitions of empowerment reflect conceptualizations that include patients and the role of the nurse and relate to health behavior change. For example, “empowerment is a social process of recognizing, promoting and enhancing people's abilities to meet their own

needs, solve their own problems and mobilize the necessary resources in order to feel in control of their own lives”, including their own health (Gibson, 1991).

Conceptual, Methodological, and Theoretical Challenges

Assumptions

The unique definitions across disciplines help to illuminate some of the conceptual, methodological and theoretical challenges to studying empowerment in relation to health. Working with the concept of empowerment is complicated by the fact that there are many different types of empowerment, including economic, social, psychological and political empowerment. In the literature, these different types of empowerment are sometimes described specifically, for example, ‘economic empowerment’, while other times they are described as an overarching ‘empowerment’. In the literature, there is no clear consensus on an overarching definition of empowerment, let alone more specific definitions of types of empowerment, or a conceptualization of how all the components of empowerment are linked.

Some similarities exist across disciplines. Generally, individual empowerment is accepted as an increase in ability to control one’s life. Throughout the literature, definitions of empowerment mainly agree on several assumptions:

1. Empowerment is an ongoing, non-linear process rather than an outcome. Persons can be empowered or disempowered in relation to others, or in relation to themselves over time.
2. Persons can only empower themselves. Others may facilitate empowerment, but cannot directly empower another
3. Empowerment includes components that are both internal (psychological) and external (resources)

These general agreements have risen out of a history of critique and debate in the empowerment literature. However, these assumptions may be problematic in the context of studying empowerment among women living with HIV/AIDS. I will discuss each of these assumptions in turn.

Empowerment has been conceptualized as both a process, an outcome, and both (Zimmerman, 2000). Even though empowerment can be considered an increase in one's level of personal power, it is logical that it be considered a process (Narayan, 2005). Processes allow for growth, development, and change in a non-linear fashion that captures how different people may experience empowerment uniquely. Persons may experience a process over time, proceed forward in the process, and take steps back in the process. Conversely, viewing empowerment as an outcome, being either empowered or not empowered is limiting. The concept of power, interwoven with empowerment, is dynamic and ever-changing; one does not simply gain or possess power in an absolute sense.

The assumption that persons can be empowered or disempowered in relation to others is not without problems. Measuring a process such as empowerment can only be done by measuring phenomenon of the process (Narayan, 2005). If a broad operationalization of empowerment is applied, women in unique contexts may be compared using measurements that may not be appropriate across all contexts. Additionally, if empowerment is a process through which one increases their ability to control their *own* life, it is not logical to compare people's level of empowerment to anyone other than themselves.

Comparing relative power is different from comparing relative empowerment, as people who have always been in power, such as those in the most dominant social groups, may not have experienced an increase in power, and thus, would not be empowered. Additionally, carefully

discussing the constructs of empowerment and power is necessary to differentiate empowerment from connotations and constructs of power that are rooted in domination and control. A critique of empowerment often cited in feminist scholarship is that the object of empowerment is not to have power *over* others (Oxaal & Baden, 1997).

The assumption that persons can only empower themselves has arisen from debates as to how to differentiate empowerment from similar concepts, such as gender equality, and philosophical debates over whether power is internal, external, rooted in structures and/or constructed. To differentiate empowerment from similar concepts, empowerment assumes women must be participatory agents. Meaning, an improvement in empowerment outcomes does not reflect empowerment if women did not participate in the process that brought about an improvement in empowerment outcomes (Malhotra & Schuler, 2005). In other words, as Malhotra and Schuler explain, women must be agents of change in empowerment, not solely beneficiaries (p. 72, 2005).

Any conceptualization that centers solely on individual empowerment has the potential to be problematic. Such a definition is reminiscent of a neoliberal agenda pushed by western ideology toward individual achievement and responsibility, rather than collective growth and development. This conceptualization may also be used to focus on individuals being at fault for their lack of relative empowerment, rather than the social and institutional structures that might impede empowerment. Historically, these conceptualizations have been used in development agendas and policies and have been criticized by feminist scholars. For example, the Development Alternatives for Women in New Era (DAWN), a collective of women researchers and activists, have challenged agendas of development programs that target women's lack of participation as the main barrier to women's development (Sen & Grown, 1988). While

individual empowerment is important, it must be considered within the greater context of broad factors that impact women's lives.

Conversely, the assumption that persons can empower others also raises questions. Can people who are not empowered themselves, empower others? If persons empower others, do they themselves lose power?

A feminist perspective holds that empowerment is not the transfer, denial, or withholding of power between persons (Oxaal & Baden, 1997). Rather, individual empowerment is a process of realizing personal power. Empowerment may be better thought of as the removal of external and internal barriers that impede our ability to make use of our own inherent power. Thus, external persons *can* facilitate empowerment by assisting in the removal of such barriers, and in many ways people can be thought of as empowering one another. In this way, even individual empowerment can be thought of as relational. Defining empowerment in terms of the collective more closely aligns with black feminist scholars, such as Patricia Hill Collins who writes, "while individual empowerment is key, only collective action can effectively generate lasting social transformation of political and economic institutions" (2002).

Across disciplines and perspectives, most agree that empowerment has both internal and external components. Meaning, the process of empowerment cannot be limited to increasing access to external resources, nor increasing psychological internal aspects. These constructs function together and should not be ignored in any conceptualization of empowerment. Improving one's internal self-efficacy, for example, may not result in an individual changing how they control their life if external factors, such as lack of economic resources, create significant barriers for them. On the other hand, increasing access to external resources may not automatically create change in one's life if internal barriers exist. For example, one may choose

not to participate in formal education opportunities if they do not feel confidence that they can achieve the outcomes they want (Diener & Biswas-Diener, 2005). As with the last assumption, describing empowerment as both internal and external must be done carefully. Internal barriers, such as internalized racism or sexism may exist, and can impact the health of women, including women of color (Smedley, 2012). However, these particular concepts tend to construct women as victims of oppression, as well as perpetrators of their own marginalization, rather than focusing on the external structures that create and perpetuate such conditions.

Although there is some consensus among the assumptions of empowerment, these assumptions have not been verified across all populations and contexts and have the potential to inappropriately represent women living in low-income countries. There continue to be additional areas that complicate empowerment research. These challenges can be lumped into three categories that are conceptual, methodological, and theoretical in nature: Who needs empowerment? How is empowerment measured? What does empowerment do?

Who needs empowerment? Conceptual disagreements across and within disciplines continue to exist regarding whether disempowerment is an antecedent to empowerment. Does one have to be disempowered to experience empowerment? This definition can be problematic when used in the context of international development, where empowerment efforts often target women living in low-income countries. Applying a conceptualization of empowerment where disempowerment is an antecedent in this context misrepresents women living in low-income countries and assumes all women in these contexts are inherently disempowered and without power or capacity (Mohanty, 1988). Definitions that generalize to large groups of people, particularly women, without attention to context are often the center of critiques by Third World feminist scholars, such as Chandra Mohanty. Beyond rhetoric that constructs women as

disempowered, requiring one to be disempowered to experience empowerment has the potential for missing persons who could benefit from empowerment interventions. For example, if disempowerment is defined in terms of economic poverty, policies and interventions for empowering persons would in turn target those who are poor. However, this does not help to address populations who feel disempowered as a result of factors other than poverty.

Naila Kabeer, a feminist scholar who focuses on topics of gender, poverty, policy and economics, engaged this discussion and attempted to ameliorate some of the issues created by assuming disempowerment as an antecedent of empowerment. In her conceptualization, she defines empowerment as, “the process by which those who have been denied the ability to make strategic life choice acquire such an ability (1999, p. 437). To Kabeer, someone who has lived their entire life always having the ability to make choices about their own life would not be *empowered*. Rather, one would first have to be disempowered and then gain the ability to make choices to be *empowered*. Here, choices are strategic life choices, such as where to live, whether to have children, and freedom to work and associate outside the home. This definition is useful as it makes sure those who are most in need are targeted in empowerment interventions; however, it uses a predefined framework of disempowerment, which may not be appropriate. In other words, it continues to blanket populations with a definition of disempowerment with which individuals may not agree. While some women, for instance, may feel disempowered by gender roles or religious ideologies that are perceived as restrictive, other women may feel empowered by such roles.

How to measure empowerment? Measuring empowerment is difficult as it is a process and can only be measured by its outcomes. There is little consensus about what these outcomes should be. Across disciplines, conceptualizations of empowerment often include a component

that centers on decision-making and making choices regarding one's life. However, what types of decisions empowerment refers to are often ambiguous and poorly defined. In the development literature, these decisions have focused on decisions made within the home regarding how monies are spent, the ability to leave the home when desired, and decisions about whether or not to have children. Some have contended these definitions are inaccurate for application across populations as not all women desire having complete power over making all decisions in the home (Zimmerman, 2000). Additionally, there is a value-laden aspect implied in some empowerment definitions and operationalization. When empowerment is measured by whether or not women make their own decisions, there is a standard by which women are being compared, there is a *right* answer. There is little room for women to define their own empowerment by their own standards. For example, some women may not want to make decisions themselves, but rather, in conjunction with their spouses.

In regard to health, nursing literature may aid in pushing empowerment definitions toward conceptualizations that are more appropriate across populations. In her 1991 concept analysis of empowerment, Gibson emphasized the need for nurses to acknowledge patients' capacity to make decisions about their health, and to respect what those decisions might be, regardless of content. Meaning, patients may be considered as having experienced empowerment if they have increased their ability to make decisions about their health or healthcare, regardless of whether healthcare providers agree with those decisions. Taking this same idea and applying it to other contexts in which empowerment is used, may allow more contextually appropriate measures of empowerment.

When measuring empowerment, it is important to separate individual empowerment from that of family, community, government, or broader areas of empowerment. In the development

literature, empowerment is often conflated with goals for social justice, reform, and equality. However, having equal representation of women in government, or having land laws that are equal for both men and women does not capture the entirety of empowerment. These measures are significant, as they relate to structural realities that impact women's lives; however, they do not measure whether women's personal power has increased or whether women have greater control over their lives. Thus, these measures fail to provide specific data related to individuals and contexts that would be useful for designing empowerment interventions. Without specific measures for empowerment, appropriate interventions for supporting women cannot be designed, and empowerment cannot be better understood. Individual empowerment must be conceptualized and operationalized by context. As empowerment is an individualized process, it must be understood through the realities and perspectives of individuals.

What does empowerment do? Empowerment is indeed a complex, dynamic concept, and thus difficult to conceptualize and operationalize. In turn, it is difficult to determine causative associations and to utilize in theory and praxis. It is unclear if empowerment should be used as an intervention, a means to an end, or an outcome. It is also still unclear what exactly empowerment *does* and what impact it has. To explain, I will use empowerment in relation to health, in the context of intimate partner violence (IPV) and HIV among women. Women experience IPV, which increase their risk for sexual abuse, rape, and subsequent HIV risk, through controlling behaviors that inhibit negotiation for safe sex (Andersson, Cockcroft, & Shea, 2008). The empowerment of women has been suggested as a means to decrease IPV and HIV risk among women (Kim et al., 2007). Much of the literature exploring the relationship between women's empowerment and IPV has focused on economic and financial empowerment, women's capacity to earn money and to control how money is spent.

Although some authors have found financial empowerment as being a possible protective factor against IPV (Kim et al., 2007), others have found that women's monetary access may threaten men and lead to increased IPV against women (Balasubramanian, 2013). Several studies have also demonstrated a limited interaction between economic empowerment, IPV, and HIV infection, suggesting the need to explore additional factors, which could be thought of as dimensions of empowerment, such as education and social support (Dalal, 2011). The Intervention with Microfinance for AIDS and Gender Equity (IMAGE), conducted in South Africa, was designed to offer economic interventions, in conjunction with methods to reduce IPV and HIV. After two years, researchers found that these interventions positively affected women's empowerment, IPV and HIV risk behaviors, such as condom use and communication about HIV with partners (Kim et al., 2007; Pronyk et al., 2008). Another study conducted in Côte d'Ivoire integrated an economic empowerment savings program with gender dialogue groups offered to women and male partners and found significant reductions in economic abuse among women (Gupta et al., 2013). These studies demonstrate possibilities for successively impacting IPV and HIV risk behaviors through empowerment interventions. However, there is limited evidence to support causative relationships between empowerment, IPV and HIV risk, and it is unclear whether these interventions could be successfully replicated across populations without harm.

Across the literature, empowerment is discussed as necessary to improving health and wellness among individuals and groups; however, models of empowerment have been under tested and its mechanisms of action are poorly understood. Few theories of empowerment have been presented in the literature. Most discussions surrounding empowerment do not go beyond conceptual frameworks. For example, decision-making power, communication skills, personal strength, self-efficacy, mobilization, education and financial stability are all concepts often

considered in relation to empowerment, though it is unclear whether these are facilitators or outcomes of empowerment. Factors that impact empowerment, such as gender norms, structural and institutional inequalities, are often discussed as barriers that negatively impact women's lives; however, these have also not been tested as barriers, moderators, or mediators. Empowerment itself has been used in research as an intervention (Swendeman et al., 2009), tested as a moderator (Rahman et al., 2012), and used as measurement of developmental success (United Nations, 2008). In order for empowerment to become a more useful tool for nurses and healthcare providers, a formal theory of empowerment is needed.

Philosophic Orientation

Empowerment Through a Feminist Lens

Studying women's empowerment through a feminist lens is recommended (Carr, 2003; Mosedale, 2005). A feminist perspective assumes that lived experiences are unique, and seeks to describe and explore empowerment as perceived by women. By putting women's perspectives at the forefront, the social, economic, and political contexts in which they live are not ignored; and the risk of inaccurately portraying women and woman's experiences is reduced.

As mentioned earlier, many studies involving women's empowerment focus on control. However, Zimmerman (2000) states that this is an inherently westernized view of empowerment, which may not be appropriate for all women. Not only does this perspective assume empowerment can be measured by levels of control, it also assumes control is a desire of all women. In developing interventions to empower women, it must first be known what empowerment means to women, and what they hope to achieve through empowerment.

Decontextualizing women's empowerment can have negative consequences. In 2010, Anyidoho, and Manuh reviewed how women's empowerment was framed by several

organizations working toward women's rights in Ghana. These organizations focused on economic empowerment and education while ignoring the political and social environments in which the women lived, thus assuming financially wealthy women were not disempowered, and that women who were educated would automatically be equipped to enter the political arena and become empowered (Anyidoho & Manuh, 2010). Microfinance or economic empowerment programs in other countries led to women being less empowered and at risk for violence, as the women did not maintain control of their earnings, or gave loans to their husbands, which were then not repaid (Balasubramanian, 2013; Goetz & Gupta, 1996). In countries where gender inequalities are deeply rooted in social and institutional structures, MacIntyre and colleagues (2013) state, "It would be naïve to assume that women should simply stand up, speak for themselves, and confront situations that challenge their power" (p. 112).

It is necessary to acknowledge the political, economic, and social environments which oppress women, but that is not to say that women are always victims of this oppression. Postcolonial feminism arose out of critiques of feminisms that often-depicted women in low-income nations as victims of patriarchal societies and culture, who are in a state of development, lacking knowledge or capacity (Mohanty, 1988). Through their work in Kenya and Malawi, Mkandawire-Valhmu, Kako, Kibicho and Stevens (2013) challenge these notions and demonstrate women living with HIV in low-income countries are not victims, but rather are women who have the capacity to overcome obstacles and promote change.

Postcolonial Feminism and Empowerment

Postcolonial feminisms lend a framework through which to study and explore women's experiences of empowerment. Postcolonial feminists argue that many feminist perspectives often disproportionately represent women in western or European nations and cannot be

generalized to women in all countries (Mohanty, 1988; Mosedale, 2005; Narayan & Harding, 2000). The environment of oppression as experienced by women in postcolonial nations is unique from that of the gender and class oppression experienced by women in western nations (Mkandawire-Valhmu & Stevens, 2007), and in terms of empowerment, using a western feminist perspective risks applying inaccurate notions of “female liberation” (Mosedale, 2005, p. 245).

A postcolonial feminist perspective has both strengths and limitations. By applying a postcolonial feminist perspective to empowerment research, conceptualizations of empowerment may be produced that are contextually rooted and stem directly from women’s experiences and include dimensions of women’s situatedness. Such definitions may be more appropriately used for designing empowerment research and interventions focused on improving health. Further, a postcolonial feminist perspective focuses on the experiences of the world’s most marginalized women, whose stories have been underrepresented in the literature. Increasing our understanding of the lives of these women can assist in broadening existing knowledge and more effectively and efficiently targeting the factors that prohibit women’s empowerment.

Critics of postcolonial feminism have questioned the utility of building a feminist knowledge base that is divisive and separate from that of existing western feminisms (Tong, 2013). Some feminist scholars believe that rather than separating feminist movements, feminists around the world should be finding common ground to combat global injustice as a united front (Tong, 2013). Postcolonial feminist scholars have responded with criticism regarding the agendas of some western feminists seeking to unite feminisms only to push their own ideas for liberation, rather than finding commonalities that unite all women globally (Mohanty, 1988). Still other feminist scholars have questioned whether there is enough common ground that unites feminist movements across the world at all (Tong, 2013). Ultimately, postcolonial feminists

such as Mohanty contend that any interpretation or criticism that postcolonial feminists are seeking to divide feminist movements is misguided (2014). Rather, postcolonial feminists seek to join feminist forces across the world through careful contextualization. The fight for liberation in the lives of women living in the world's top one third, as Mohanty describes, will not look the same as the fight for women living in the world's bottom two-thirds. Thus, using a postcolonial feminist lens to study the concept of women's empowerment in the lives of the world's most marginalized women is appropriate and useful.

Nursing Paradigm and Philosophy

Nurses' approach to healthcare is guided by a metaparadigm, an overarching theory that provides a definition of the global view of a profession, the focus of a discipline, and how that focus is distinctively addressed (Kuhn as cited in McEwen & Wills, 2011). The four major concepts pertinent to the metaparadigm of nursing are: person, health, environment, and nursing. The profession of nursing is further guided by connections between these concepts that demonstrate areas of interest relevant to nursing. These connections include: person and health; person and environment; health and nursing; and person, environment, and health (Fawcett & Malinski as cited in McEwen & Wills).

Throughout history, empowerment has been utilized as a concept related to social justice and equality in terms of social, institutional, and structural inequalities. Empowerment has also been used in health research with the purpose of increasing mental and physical health outcomes. Thus, empowerment is relevant to nursing as it has the potential to play a role in the relationships between people and their environments, and people and their health. It may also be possible for nurses to facilitate the empowerment of others, in turn enhancing social justice, gender equality, and positive health outcomes through nursing intervention. In order for empowerment to be a

useful concept within nursing, we must understand its relationship to health, and how nurses might be able to facilitate empowerment.

Nursing has historically been described as an “art” and has struggled to ground itself in the scientific community. Although often criticized for the use of concepts such as “hope”, nurses contend that these concepts are integral and significant to nursing, which is inherently both a “caring” discipline, and truly, an art. Nurses have been challenged to find methods of concretely articulating our unique approach to health, research, and intervention that holds its own within the context of the “harder” sciences and medicine. Empowerment must be understood in terms that can be explained, and the role of nurses in empowerment must be articulated. One way nursing care can be explained is through empirically measuring the impact of our interventions; however, by their nature, concepts such as “caring” and empowerment cannot be measured empirically.

As empowerment cannot be seen empirically, it can be difficult to explain how it manifests. To begin considering how one might study empowerment, it must be noted that empowerment cannot be exhibited itself as a phenomenon, in the traditional sense of the word. Johnson and Weber (2009) define phenomena as “observable connections or relationships between objects, events, people, or ideas”. Empowerment is a social process, relational to one’s environment; it is not observable. In this way, empowerment may be described as latent phenomenon, or noumena. Noumena, much like phenomenon, represent relationships between objects, though this connection is not observable and is instead implied or perceived (Johnson & Weber). Although the terms noumena and phenomena are often used interchangeably, I believe the differentiation is helpful in considering how a study of empowerment might be approached

uniquely from something that can be measured empirically, such as a change in a patients' perfusion based on the color of their skin.

Manifestations of noumena can be described and identified by constructions of observable phenomenon. In terms of empowerment, it can be beneficial to consider instances in which one has felt the experience of empowerment, as well as instances in which there is an absence of empowerment.

Empowerment might be experienced by women living with HIV who have taken part in a support group. Through normalizing their experiences with other women, women might experience an increase in self-confidence, which ultimately increases their self-esteem. Women in a support group may also experience material gains through monetary support, which could impact their quality of life. Sharing collective stories within a group may impact the way a woman views her relationship with her husband and may prompt her to try new strategies of asserting her sexual desires. Women who have been a part of a support group may be more inclined to regularly take their antiretroviral medications, and to help educate others about HIV prevention.

In contrast, a woman living with HIV who has not experienced an instance of empowerment may not believe there is hope for quality of life while living with HIV. They may blame themselves for the disease and feel they in some way deserved the illness. Women living in the absence of empowerment might have poor mental health, exhibiting signs of depression and anxiety, or feelings of having little control over their life and their health outcomes. They may be less motivated to participate in treatment and adhere to a medication regimen. Within the household and community, women may not actively participate in combating stigma or changing norms and beliefs that marginalize women living with HIV.

By comparing instances in which some empowering process has taken place, it is possible to draw a clearer picture of the relationships associated with empowerment. For example: empowerment guiding community action, empowerment improving mental health, and empowerment improving medication adherence. Using these relationships, it may be possible to operationalize empowerment through the measurement of its effects. The identification of the effects of empowerment are useful for nurses and healthcare providers interested in exploring to what extent empowerment plays a role in promoting health, and how best to support empowerment efforts. Understanding these relationships is essential to building a theory of empowerment for women living with HIV.

The above instances of empowerment and absence of empowerment are biased, as they were constructed through my own perspective, which was informed by predefined conceptualizations of empowerment as identified in empowerment literature. The examples and relationships drawn from them are not based in women's personal realities or experiences and are not in line with a postcolonial feminist perspective. The above examples begin to explain how phenomena that cannot be seen empirically can be studied and understood. However, in order to truly define empowerment and understand it through women's perspectives, a study must be conducted without applying preconceived notions of empowerment. By asking women what empowerment means to them and hearing stories of empowerment through their perspectives, nurses may be able to identify outcomes of empowerment within specific contexts. This could be useful for future nursing research and intervention focused on improving specific outcomes through empowerment.

Before embarking on creating empowerment interventions, it should first be identified how the empowerment process works, what it looks like, and how it might be facilitated. Asking

these questions before intervention development is essential to creating research and intervention that is context specific, appropriate, and rooted in women's experiences and personal desires. Thus, it is necessary to look more specifically at the process of empowerment, which was a focus of this study.

Assumptions and Limitations

Personal Perspective

My desire to explore empowerment began my first year of graduate school. I was given an assignment of performing a literature review on the concept I thought I might use as a focus for my future dissertation. At the time, I only roughly knew what I wanted to focus on; I had a better idea of the population. I knew I wanted to conduct my research in Malawi, Africa, working with women. This decision was made after having traveled to Malawi during a study abroad trip my senior year of undergraduate school. During this trip, I learned through readings and first-hand experiences the gender inequalities women in Malawi faced. I also learned the troubling ways some of my peers viewed and spoke about people in Africa. This led me to research language and media representations of women in Africa, which often described women as victims of gender oppression. Even work that discussed women's empowerment framed women in this manner, as victims who were to be given power by some other powerful agent. This is not how I view empowerment.

To me, everyone has power and agency. It is not something that is given or taken away. However, I understand the feeling of being powerless and having no control over one's life. Thus, while everyone may inherently have power, the perception of one's self, and one's ability to make changes in their lives plays a role in whether one may use this power in action. Additionally, one's ability to use their power may be impacted by their environment, the

resources that are available to them, and their social support system. In my perspective, empowerment is the realization of power and putting that power into action to make change. Through this lens, I see women in Africa not as victims, but as powerful women who have yet to realize their power or are constrained by external forces that inhibit their ability to use said power.

While completely unlearning, or erasing, one's bias is impossible, being cognizant of your bias is essential. Throughout the research process it was vital that I checked in with myself as to whether I was unduly applying my own beliefs about power, agency, and empowerment. For example, while I believe all women inherently have power, this may not be how women in this study viewed themselves. My assumptions challenged my ability to approach this study unbiasedly, though, my perspective also be beneficial. My beliefs allowed me to better identify with women who see themselves not as victims, despite significant barriers in life.

An unintended and unexpected influence of my positionality became apparent during interviews when one woman seemed to believe she was being interviewed to be a part of a program that would provide microloans for starting businesses. In this way, it is possible my positionality could have influenced the women's decision to participate in the study or the way woman discussed experiences of development projects.

Empowerment in Chichewa

This study was conducted in Chichewa, one of the formal languages of Malawi; English is the other. Translating the word empowerment between English and Chichewa has some limitations. Empowerment may be translated to either *kupatsidwa mphamvu* or *kulimbitsa*. *Kupatsidwa mphamvu* back translated into English means, to be given power. Rather than inherently having power, this translation assumes women must be given power, presumably from

another powerful agent. This limitation may have focused the current study more on external power, such as economic or social resources, rather than internalized power. To help mediate this limitation, *kulimbitsa* was also used, which translates into being strengthened. In Chichewa, strength, rather than power, is more often used when discussing internal, mental, or emotional subjects. Decisions made regarding translations are discussed further in chapter V.

Research Questions

1. How do women living with HIV in rural Malawi who attend an HIV clinic describe their experience of empowerment?
 - a. What factors contribute to empowerment?
 - b. What factors lessen empowerment?
 - c. What do women perceive as outcomes of empowerment?
2. How do women living with HIV in rural Malawi who attend an HIV clinic describe how they manage HIV?
 - a. What factors contribute to management of HIV?
 - b. What factors are barriers to management of HIV?
3. How do women living with HIV in rural Malawi who attend an HIV clinic describe the role of empowerment in the management of HIV?

Chapter Summary

Women's empowerment has been widely studied across a variety of disciplines and utilized within many contexts and populations. Despite the existence of a substantial body of literature on empowerment, theoretical, conceptual and methodological issues surrounding the study of empowerment continue to exist. Gaps in existing literature include limited studies of empowerment specifically among women living with HIV/AIDS using a feminist perspective, and a lack of formal theories of empowerment focused on health and wellbeing among women living with HIV/AIDS. A postcolonial feminist perspective is used to guide this study, providing a framework through which to situate empowerment in the context of social, political, and

institutional systems that impact the lives of women. Grounded theory methodology is applied with the aim of developing a substantive theory of empowerment in the lives of women living with HIV/AIDS.

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CHAPTER II: REVIEW OF LITERATURE

Introduction

Using classic grounded theory approaches (Glaser & Strauss, 1978), the researcher attempts to do little research prior to the study. This is done with the goal of keeping the researcher unbiased to current research on the subject. Rather than completing a literature review before the study, a literature review is conducted during the time of data analysis and while preparing to write up one's findings. At this point, the researcher compares existing literature to their own findings, helping to further develop the emerging theoretical framework.

As Charmaz points out (2014), this practice may be possible for seasoned researchers, but it is often unrealistic for novice researchers who are required to demonstrate their own understanding of topics and theories prior to conducting research. Rather than attempt to ignore the knowledge a researcher brings into a study, Charmaz suggests to remain ever critical of it; “. . . remain alert as to whether, when, and to what extent earlier ideas and findings enter your research, and if so, subject them to rigorous scrutiny” (p. 307). That said, Charmaz still holds that the full literature review should be written after data analysis and should serve as a discussion between existing literature and your findings.

In this chapter, I will demonstrate my understanding of topics integral to conducting my dissertation research. Firstly, I will present a small review of current literature related to the concept of women's empowerment among women living with HIV in Malawi, Africa. Secondly, I will include a manuscript demonstrating my knowledge of feminist theory, and ability to relate research and policy.

Review of Literature

Purpose and Aims

The purpose of this review of relevant literature was to explore and describe empowerment in the lives of women living with HIV in Malawi. The aims of this review were to: 1. Identify facilitators and outcomes (or indicators) of empowerment; 2. Describe barriers and strategies for overcoming barriers to empowerment; 3. Describe the capacity of women to empower themselves and others.

Evidence of the agency of women living with HIV in Malawi (Mkandawire-Valhmu et al., 2013) provides the rationale for choosing this group to study empowerment. Women living with HIV may have already overcome barriers in their lives, such as leaving an abusive husband (Mkandawire-Valhmu et al., 2013), or found methods of overcoming barriers, such as forming support groups, and can provide insight to what may traditionally be described as empowerment. Women living with HIV and women living without HIV are assumed to have differing perspectives of empowerment; these groups should be studied separately. This review assumes women's empowerment is an ongoing and cyclical process, with both internal and external factors that can facilitate or hamper progression.

Design

Studies were analyzed and synthesized using strategies adapted from Polit and Beck (2012); and were guided by a postcolonial feminist perspective. In using a postcolonial feminist perspective, special attention was paid to experiences of women within a historical, cultural, and political context as well as epistemology used by researchers. Major concepts were identified iteratively, compared for similarities and differences, and synthesized for meaning.

Search Methods

An initial search of four major databases was conducted in November 2013: CINAHL (EBSCO), PsycINFO (EBSCO); Social Sciences (EBSCO); and Medline (PubMed). Searches

were limited to studies published between 2003 and November 2013; peer-reviewed journals, articles available in English, and qualitative studies. Keywords included: empowerment; women; HIV; “women’s empowerment”; and qualitative. A secondary search was conducted in August 2015 for updated sources and missed evidence; the same search methods were used. Titles and abstracts were reviewed for inclusion and exclusion criteria.

Inclusion Criteria:

- Quality qualitative research papers using interviewing methods
- Peer Reviewed
- Study population of adult women (studies including men and/or male partners were included)
- Studies specifically focused on the concept of women’s empowerment, the context of empowerment, and/or the capacity for empowerment

Exclusion Criteria:

- Quantitative research, dissertations, discussion or opinion papers
- Study population of adolescent and/or young women or older adults
- Studies conducted in the context of sex work, chronic disease and/or mental health excluding HIV/AIDS

Search Outcome

The initial search yielded 737 articles. Searches were further limited with major subject headings or MESH terms for power or empowerment; studies pertaining to populations living with chronic diseases such as diabetes or mental health disorders (not including HIV/AIDS), drug-users, or sex workers were not included. The resulting 149 studies were reviewed by title and abstract for inclusion and exclusion criteria; final inclusion decisions were made by relevance based on the study purpose and aims. From the initial search, 9 references were chosen for review. The secondary search yielded 268 articles for title and abstract review. After removing duplicate studies, an additional 3 references were included for review. Search strategies and review of articles was limited by time and resource constraints; pertinent sources may have been missed.

Quality Appraisal

There is a lack of consensus around accepted methods of assessing quality of qualitative research, and to what extent quality should exclude qualitative research from meta-ethnographies (Polit and Beck, 2012). In the current review, general guidelines by Walsh and Downe (2006) were used; however, no formal procedure for exclusion based on quality was determined prior to quality appraisal. Articles were deemed acceptable if there was logical consistency between the research question and methods used and limitations were described; all articles were included in the final review.

Data Abstraction

Articles were read in full and relevant data was abstracted into an evidence table. This included the study aim or goal, theoretical or methodological orientation, sample characteristics, key findings, and strengths and weaknesses.

Synthesis

Themes were developed through an iterative process; articles were read in full and key points and concepts were recorded. Similarities and differences were compared throughout the articles until three major themes emerged. These themes: empowerment; the role of culture and society; and the capacity for empowerment are described below, followed by a discussion of the implications of these findings for future nursing research and practice.

Results

The eleven studies included women and men from ten countries: Bangladesh, Egypt, Iran, India, Kenya, Pakistan, Rwanda, Uganda, South Africa, and Malawi. All countries varied in terms of GDP per capita and HIV prevalence (Table 1). Participants were heterogeneous in education, employment, and socioeconomic status, and came from both rural and urban areas.

Four studies were guided by a postcolonial perspective; five discussed results in the context of the HIV/AIDS epidemic and three included women living with HIV. All studies discussed the context of social, gender, and structural norms that impacted women's lives.

Empowerment. Definitions of empowerment differed throughout all studies. Seven of the eleven studies either explicitly stated or implied the definition of empowerment of women in terms of decision-making, power, or control (Bhengu, 2010; Henry, 2011; Kako & Dubrosky, 2013; Kohan, Simbar, & Taleghani, 2012; Mbweza, Norr, & McElmurry, 2008; B. Nyanzi, S. Nyanzi, Wolff, & Whitworth, 2005; Skafté & Silberschmidt, 2013). In all of these studies the definition of empowerment was established prior to data collection and was not derived from the present findings. Though, it is important to note that in four of these studies, the purpose was to explore power relations or the outcomes of empowerment, and thus providing an established definition of empowerment was appropriate (Bhengu, 2010; Mbweza et al., 2008; Nyanzi et al., 2005; Skafté & Silberschmidt, 2013). Only two studies specifically aimed to explore women's experiences of empowerment (Henry, 2011; Kohan et al., 2012), and of these, neither was conducted in Malawi or with women living with HIV. A clear definition of empowerment for women living with HIV in Malawi is needed.

Definitions of empowerment varied based on the theoretical or conceptual framework used by the authors. Some articles, which defined empowerment in terms of decision-making and power, were guided by theories that may be contextually inappropriate in Malawi and do not reflect feminist values. For example, Henry (2011) integrated principles based on the work of Paulo Freire (1972 as cited in Henry), which asserts oppressed persons can be empowered through education and knowledge. This perspective perpetuates a western stereotype of women being victims of oppression who lack knowledge and are in a state of development (Mohanty,

1988). Other studies lacked theoretical or conceptual support, and may have been based on author bias, or definitions from political agencies; it is unclear whether these definitions reflect women's experience. In contrast, studies that used a feminist or grounded theory approach found unique definitions of empowerment. Women discussed empowerment in terms of personal strength, relationships with family (Bustamante-Gavino, Rattani, & Khan, 2011; Skafté & Silberschidmt, 2013), education for themselves and their children (Bustamante-Gavino et al., 2011; Schuler & Rottach, 2010), and respect, recognition and social standing in the community (Bustamante-Gavino et al., 2011; Gnauck et al., 2013; Kako & Dubrosky, 2013). However, none of these studies were conducted the context of women living in Malawi, and only two were conducted with women living with HIV. Souza (2010) studied women ($n=2$) living with HIV through a postcolonial feminist perspective and demonstrated women's empowerment through learning and accepting their status, redefining their identities, and showing strength in the face of stigma. These studies demonstrate the important findings that come from studying empowerment through a feminist lens while the findings by Souza highlight the unique experiences of empowerment in women living with HIV. A postcolonial feminist perspective would be useful in studying experiences of empowerment in women living with HIV in Malawi.

Descriptions of the empowerment process, facilitators, barriers, and outcomes were inconsistent across studies; although there were some overarching themes. In nearly all studies, empowerment was discussed by women as a process that occurred both psychologically, and as external skills, recognition, and support were acquired (Bhengu, 2010; Bustamante-Gavino, Rattani, & Khan, 2011; Gnauck et al., 2013; Henry, 2011; Kohan, Simbar, & Taleghani, 2012; B. Nyanzi, S. Nyanzi, Wolff, & Whitworth, 2005, Schuler & Rottach, 2010; Skafté & Silberschmidt, 2013; Souza, 2010). Decision-making power, communication skills, personal

strength, education, and financial stability were all identified as contributing to empowerment; though it is unclear whether women considered these parts of the empowerment process or if they were facilitators, or outcomes. Women often met barriers to empowerment that were attributed to cultural gender norms, society, stigma, religion, education, or economic status. These results demonstrate the cyclical nature and complexity of the empowerment process and demonstrate a need for a clear understanding of empowerment that is contextually rooted. However, none of the studies were conducted with women living with HIV in Malawi and may not fully capture the experiences of these women. An exploration of the process of empowerment, facilitators, barriers and indicators of empowerment of women living with HIV in Malawi is needed.

The role of culture and society. All the studies found that the empowerment of women was affected by cultural, societal, religious, and institutional factors. Women reported how expected gender roles placed barriers on their empowerment; women struggled to balance pursuing work or education with the roles they were expected to perform at home such as childcare, cooking, and cleaning (Henry, 2011, Schuler & Rottach, 2010). Women discussed how society expects women to stay in the home and not question men's behavior or authority; these normative expectations were reflected in women's ability to refuse sexual advances or insist on condom use (Gnauck et al., 2013; B. Nyanzi, S. Nyanzi, Wolff, & Whitworth, 2005). Even when women became economically empowered, societal norms hindered women from maintaining control of their earnings, and this empowerment did not translate into expressing more power in relationships with men (Gnauck et al., 2013). In this review, gender norms were a reflection of a patriarchal society, religion, or institutional factors such as land laws or unjust judiciary systems (Bhengu, 2010; Bustamante-Gavino, Rattani, & Khan, 2011; Mbweza, Norr, &

McElmurry, 2008; Skafté & Silberschmidt, 2013; Schuler & Rottach, 2010). Women's empowerment cannot be studied effectively without acknowledging the complex effects of social gender norms.

Women living in the context of the HIV epidemic and a society of stigma have additional and unique pressures placed on them (Gnauck et al., 2013; Souza, 2011). For women living with HIV, the disease itself can be disempowering; women experience stigma, violence from male partners, and isolation from their families and communities, which decrease their opportunities to negotiate desires and participate in decision-making processes (Kako & Dubrosky, 2013; Mkandawire-Valhmu et al., 2013). Stigma surrounding HIV also affect women's economic empowerment, women who depend on piece meal work and the selling of goods reported a loss of customers after their HIV positive status became known (Kako & Dubrosky, 2013).

Women's empowerment can have unexpected consequences related to societal norms. In Bangladesh, women often are married and begin having children before the age of eighteen; women's empowerment, in terms of education and attending school, led to men pressuring women to become pregnant quickly (Schuler & Rottach, 2010). Men, particularly those who were uneducated themselves, did not support their wives pursuing education as they believed this would lead to the women leaving them; while becoming pregnant would ensure them staying in the marriage (Schuler & Rottach). This created negative and unforeseen barriers for mothers trying to empower their daughters to pursue education and delay childbearing at young ages. In Kenya, social empowerment also had consequences (Gnauck et al., 2013). Women who participated in an economic empowerment group felt they became a more recognized and valued member of the community; however, others in the community felt these women were too proud and arrogant. Husbands in the community remarked they would not agree with their wives

participating in such a group as they felt this would encourage the women to become unruly and misbehave (Gnauck et al., 2013). In the context of the HIV epidemic, women who gained recognition in their community may have been less likely to be tested for HIV or disclose their status as they would be at increased risk for stigma (Gnauck et al., 2013). In Uganda, economically empowered women working in a market received the unwanted masculine label of *kiwagi*, meaning independent and disobedient (B. Nyanzi, S. Nyanzi, Wolff, & Whitworth, 2005). In the context of living with HIV, and in Malawi, where marriage and childbearing is highly valued, these potential negative consequences of empowerment should be explored.

Capacity for empowerment. Women demonstrated capacity to become empowered, empower themselves, and to empower others. In several studies women developed income generating activities and successfully managed their finances either on their own, with support of other women or through an intervention sponsored by an outside donor (Bhengu, 2010; Gnauck et al., 2013; B. Nyanzi, S. Nyanzi, Wolff, & Whitworth, 2005). Women came together and empowered one another through sharing experiences and gaining an understanding of the nature of their disempowerment (Bhengu, 2010; Mkandawire-Valhmu et al., 2013; Skatfe & Silberschmidt, 2013; Souza, 2010). In all studies, women were aware of the environment of gender inequalities and the cultural and institutional factors that affected their lives. At times, women saw themselves as role models and sought to educate others in the community (Bhengu, 2010; Souza, 2010). Many women encouraged their children to recognize the effects of gender inequalities and saw this as a method to change future generations through empowering both boys and girls to challenge societal gender norms (Henry, 2011; Schuler & Rottach, 2010).

Several studies demonstrated women's capacity for empowerment through the innovative ways they negotiated their desires. At times, women used established social values and

traditions to do so. For example, when negotiating sex, women reported being unable to directly refuse relations, but would fake illness or lie about having their menses to avoid unwanted intercourse (B. Nyanzi, S. Nyanzi, Wolff, & Whitworth, 2005). In Rwanda, women used fear of unwanted pregnancies and intolerance of alternative birth-control methods to negotiate condom use in sexual relationships (Skatfe & Silberschmidt, 2013). When negotiating with men over household decisions, women found it was beneficial to focus on maintaining harmony in the home and keeping the children safe and healthy, rather than asserting their rights (Bhengu, 2010; Mbweza, Norr, & McElmurry, 2008; Skatfe & Silberschmidt, 2013). Women are aware of the shared family values of men and women, while understanding that at times, fighting against gender norms is less successful.

In other instances, women demonstrated direct resistance against social and gender norms that negatively impacted their lives. Some women reported actively refusing sexual relations with their partners or insisting on HIV testing if their desires were not met, despite the possibility of violent repercussions from their male partners (Skatfe & Silberschmidt, 2013). Women living with HIV defied stigma through disclosure and making their status public on their own terms (Kako & Dubrosky, 2013). Others turned away from the normative institution of marriage following personal experiences of abuse and neglect from their partners (Mkandawire-Valhmu et al., 2013). Women realize empowerment through acts of resistance.

Collectively, these studies establish that women are not ignorant of their status in society and are not only capable of realizing empowerment but have already found methods of empowering themselves and others. However, women in some of these studies had opportunities for education, employment, and support that women in Malawi may not have. Although two of these studies contributed to the understanding of how women living with HIV experience

empowerment, they focused specifically on experiences of violence, and negotiations between male partners; there is still much to be known about additional situation and context specific empowerment processes.

In many ways, women paradoxically felt empowered by the same gender roles that created barriers for them. Women's roles as caregivers gave them power in making decisions about purchases in the home, food, contraception, and pregnancy within relationships (Mbweza, Norr, & McElmurry, 2008). Being the primary caretakers of children also allowed women to empower their children, which in turn made the women feel more empowered (Bustamante-Gavino, Rattani, & Khan, 2011). For some women, being able to fulfill expected duties in the home produced feelings of empowerment (Bustamante-Gavino et al., 2011). These studies show that although gender norms create barriers for women, they are also sources of empowerment. This is an important finding that contradicts many notions that view gender inequalities as purely oppressive. One study with women living with HIV in Malawi shows marital relationships to be problematic and a source of disempowerment; it is unclear to what extent women's normative roles may continue to be sources of power for women living in this context, and thus this should be studied further.

Discussion

This review of relevant literature aimed to explore what is currently known about experiences of empowerment in women living with HIV in Malawi, Africa. A search of four major databases found no current qualitative research on the specific topic of empowerment in this population. The search was expanded and eleven studies, which discussed the topic of women's empowerment or women's power, and were qualitative in nature, were reviewed. Although this review only yielded one study with women living with HIV in Malawi, there are

important lessons to be learned from the synthesis of the included references and the experiences of women living in diverse contexts.

Women in many countries face barriers to empowerment. These barriers are far more complex than simple gender inequalities and include HIV stigma, violence, poverty, and social and gender norms. Although unequal opportunities for education and employment may exacerbate women's disempowerment, these are not necessarily the root of the problem. Rather, barriers to empowerment are deeply rooted in the cultural, societal, religious, and political environments in which women live. Women living with HIV have unique challenges and barriers to realizing empowerment, but also share similar experiences with women who are not HIV-infected, as well as women living in different countries and contexts. These same social and structural factors that create barriers for empowerment, may also be sources of power.

Women in the articles reviewed were not powerless and demonstrated the capacity to empower themselves and others. These women were often knowledgeable and aware of the environment that impacts their empowerment and had developed innovative ways to negotiate their desires. These findings not only contest several western notions of the capacity of women in "developing" nations, but also highlight the importance of context in studying the complex process of women's empowerment (Mohanty, 1988).

Four of the studies in this review used a postcolonial perspective, which specifically seeks to contextualize the experiences of women within social and institutional structures. In this review, a postcolonial perspective was useful for identifying the unique challenges, barriers, and strategies for empowerment of individual women. Despite some similarities across populations, individual differences remained in terms of empowerment processes, how women negotiated desires, and overcame barriers. Exploring empowerment through women's

experiences allows for a nuanced understanding of the factors that impact women's lives, and adds to the body of knowledge of how women uniquely meet these challenges. Women's empowerment is different across all contexts and within individual women.

Conclusion

In 2015 the Millennium Development Goals will be renewed, including goals specifically focusing on increasing gender equality and empowering women, and addressing HIV/AIDS. As the global community continues to work in these areas, special focus on individual experiences of gender inequalities and empowerment for women living with HIV may provide insight. Future research and policy development should focus on continuing to build a body of knowledge of empowerment rooted in women's experiences, developing conceptual and operational definitions of empowerment, and seeking to support interventions and strategies for empowerment women have already identified or implemented. Nurses are in a position to affect research, interventions, and policies that may directly impact gender inequalities, empowerment, and the health and wellness of women globally.

Table 1.

Country	HIV Prevalence % 2013 estimates	Population Below National Poverty Line (%)	GDP per capita 2013
Malawi	10.25	53% (2004 est.)	237.3 USD
Egypt	0.02	25.2% (2011 est.)	3,314.46 USD
Iran	0.14	18.7% (2007 est.)	6,375.9 USD
India	0.26	29.8% (2010 est.)	1,486.9 USD
Pakistan	0.07	12.4% (2011 est.)	1,275.30 USD
Kenya	6.04	43.4% (2012 est.)	1,238.5 USD
Rwanda	2.85	44.9% (2011 est.)	638.67 USD
Bangladesh	0.01	31.5% (2010 est.)	957.82 USD
South Africa	19.05	35.9% (2012 est.)	6,886.3 USD
Uganda	7.44	19.7% (2013 est.)	657.4 USD

Sources:

The World Factbook; World Bank

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CHAPTER III:

Manuscript I: Raising Questions About Capitalist Globalization and Universalizing Views on Women

This manuscript serves as one of my manuscripts to fulfill the requirements of the manuscript option for my dissertation. This article was published in the June 2016 edition of *Advances in Nursing Science*. In this article, I challenge the philosophical underpinnings and language used in the *World Development Report: Gender Equality and Development*, demonstrating my knowledge of feminist theories, as well as how research ties into policy.

Raising Questions About Capitalist Globalization and Universalizing Views on Women: A Transnational Feminist Critique of the *World Development Report: Gender Equality and Development*

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Abstract. Nursing in the United States has embraced global health primarily from a clinical perspective, with emphasis on care delivery to populations in underserved, resource-poor settings. Less attention has been devoted to developing policy expertise about social, economic, and political contexts that produce ill health around the world. The purposes of the articles are to offer a transnational feminist critique of the *World Development Report: Gender Equality and Development* and to illuminate implications such reports may have in the lives of the world's most marginalized women and girls. We examine the political economy idealized in the report, raising questions about the capitalist framework underpinning its agenda. Second, we examine the assumptive language used in the report, suggesting that it discursively constructs a problematic representation of women in low-income countries. We contend that the report perpetuates a hegemonic discourse of patriarchy and inequality for women in the Global South through the use of an uncontested economic framework and universalist reasoning. We conclude the article with discussion about a transformative policy making that could be more inclusive of the wisdoms, values, and everyday experiences of women living in the Global South and about the vital role nurses can play in advancing gender equity through their active collaboration in policy critique and policy formulation.

Nursing in the United States has embraced global health primarily from a clinical perspective with emphasis on care delivery to populations in underserved, resource-poor settings. Less attention has been devoted to developing expertise on the social, economic, and political contexts that produce ill health around the world. Without acumen in the analysis of political

economies of health and a comprehensive understanding of the structural issues that create health problems, nurses are hampered in providing leadership at the highest levels to affect positive changes in global health. In this paper, we take up the challenges of economic globalization and ever-expanding development efforts as they affect the well-being of women and girls by examining a major policy document intended to direct actions reducing gender inequities, the World Bank's 2012 *World Development Report: Gender Equality and Development*.¹ We offer this analysis as a modest contribution to a nursing literature that can ground global health nursing practice in policy arenas. The purposes of the paper are to offer a transnational feminist critique of the *World Development Report: Gender Equality and Development*, and to illuminate implications such reports may have in the lives of the world's most marginalized women. To make our argument, we draw substantially from the work of feminist scholars in the Global South, voices that have not been well represented in nursing theory and research, and may be new even to U.S. nurses who approach the world from a feminist point of view.

In September, 2015, United Nations Member States adopted *Sustainable Development Goals*,¹ replacing the Millennium Development Goals that had guided worldwide anti-poverty efforts from 2000 to 2015. A major emphasis in the new Goals is to make measurable improvements in the health, safety, prosperity, human rights, and dignity of women and girls who have been left behind by prior development initiatives and the progress of globalization. For example, those who were pushed off their smallholder farms and into extreme poverty because their land was destined for more profitable uses, or those who were forced to migrate to cities for low-wage sweatshop jobs or no-wage domestic work because traditional livelihoods no longer supported their families, or those who fell immediately into hunger because of global fluctuations in basic food prices.³ Globalization does not operate neutrally, creating well-being

for all; rather, it tends to be a fiercely competitive process with winners and losers. Success is achieved by taking advantage of investment opportunities, cultivating untapped markets, and lowering production costs. In the wake of this success, gaps between the rich and poor are widened with particular disadvantage to low-income women.

Recognizing the gender inequity made apparent by globalization, feminist scholars have made the case that gender equality is the basis for accomplishing all development goals.⁵⁻⁷ The World Bank, arguably the world's largest and most influential development institution, has strived to address gender inequity as well. The motivations and consequences of World Bank actions have long been under scrutiny,⁸⁻¹² with critics questioning whether or not development agendas can ultimately support an egalitarian society.¹⁴ Nevertheless, the World Bank's standpoint on women and girls is well communicated in the *World Development Report: Gender Equality and Development*. According to the World Bank, the key message of the Report is:

Gender equality matters for development: it matters because it is a core development objective in its own right, and because gender equality is smart economics—gender equality can raise productivity, improve other development outcomes, including prospects for the next generation, and contribute to more representative decision making in societies.^{13,pi}

The argument we build about the Report is organized in the following fashion. We provide background about the World Bank and the Report, and clarify our theoretical use of the terms Global South and Global North. Then, we describe the approach we took in our transnational feminist critique, defining the worldview that situates transnational feminism. In presenting our case, first, we examine the political economy idealized in the Report, raising questions about the capitalist framework underpinning its agenda. Second, we examine the assumptive language used in the report suggesting that it discursively constructs a problematic representation of women in low-income countries. We contend that the Report perpetuates a

hegemonic discourse of patriarchy and inequality for women in the Global South through the use of an uncontested economic framework and universalist reasoning. We conclude the paper with discussion about a transformative policymaking that could be more inclusive of the wisdoms, values, and everyday experiences of women living in the Global South, and about the vital role nurses can play in advancing gender equity through their active collaboration in policy critique and policy formulation.

Background

The World Bank

The World Bank is a transnational institution, like the World Trade Organization and the International Monetary Fund. Formed in 1944, it has since become the global leader in providing monetary assistance to low-income countries. The vision of the World Bank is twofold: to eliminate extreme poverty around the world, and to bolster development through sustainable globalization. Its major strategy is to provide loans, credits, and grants to countries in economic crisis. The World Bank also supports research and analysis, and provides advice to governments and non-governmental organizations (NGOs) about socioeconomic policy development and implementation. Employees of the World Bank include economists, social scientists, and experts in public policy and international affairs.

The World Bank is predominately run by a small number of wealthy economic powers, including the United States and the European Union. To what extent these powers can appropriately represent and advise others on the needs of those in low-income countries is debated. Critics of the World Bank have identified adverse effects its policies have had on low-income countries and marginalized populations.¹⁴ During the 1980s and 1990s, for example, the World Bank pushed structural adjustment policies wherein countries receiving loans were forced

to accept conditions meant to make them more market oriented. These conditions usually involved a combination of free market policies such as privatization of government owned infrastructure, fiscal austerity, reduction of trade barriers, and deregulation. Implementing these structural adjustments often resulted in dramatic fiscal losses to education, public health, and other social safety nets in under-resourced communities, which are still being felt today. New loans continue to compel countries to reduce public spending and social provisioning to the detriment of education for girls, maternal health services, and childcare; which would seem to be at odds with a goal of gender equality.¹⁵ Countries lacking a sociopolitical framework in line with the World Bank's capitalist stipulations have been most adversely affected, including many in sub-Saharan Africa, where development continues to be a large challenge. Skepticism about sweeping policy endorsements made by the World Bank remains high, particularly among women's advocates.¹⁰

The World Development Report

A significant event in the World Bank's complex and equivocal history was its 2012 release of *World Development Report: Gender Equality and Development*. Because these annual *World Development Reports* comprise the flagship publication of the World Bank and carry weight in international development policy, research, and programming; the choice to focus on gender equality and implications for women is not inconsequential. In making its recommendations to governments, NGOs, and private development partners, the institutional author of the Report pays particular attention to low-income countries that have disproportionate rates of gender disparities compared to high-income countries. Evidence is provided for how gender inequality puts women and children at risk for gender-based violence and abuse, poverty, and stigma; with associated psychosocial effects. The central argument made is that not only is

gender equality morally and ethically imperative, it is also “smart economics”.^{1,pxiii} Four priorities are identified: reducing gender gaps in human capital; closing gaps in economic opportunities; reducing gender differences in voice and agency; and limiting gender inequality across generations.¹

Terminology for Specifying Difference and Explaining Connections

Various terms have been used to distinguish between affluent, privileged countries and economically and politically marginalized countries, including: first world/third world, developed/developing, Western/non-Western, high income/low-income. All these terms have been contested as dichotomizing, and critiqued for setting up problematic comparisons that fail to address the complex similarities and differences in people’s lives. While we acknowledge these difficulties and the limitations imposed by imperfect categorizations of groups of people, we agree with Global South feminist scholar, Chandra Mohanty,¹¹ that there is a political need for language differentiating the world’s “haves” from its “have-nots.” She chooses to use the terms Global North/Global South as a means for specifying the difference. We use Global North/Global South in this paper, as well; not as rigidly determining, but as a means for centering our analysis on women living in resource-poor communities.

Global North/Global South are terms of recent relevance in the humanities and social sciences literature to indicate that there are two major economic worlds on the globe, roughly situated north and south. The Global North is dominated by economic powers in North America, Europe, and Japan. It is characterized by massive wealth, technological advancement, and relative political stability. The Global South, including countries of South America, sub-Saharan Africa, and southern Asia, has a history of colonization by the North.¹⁶ It is more agrarian based, much poorer, lacks adequate technology, transportation, and communication infrastructure, and

suffers more political turmoil and conflict. Five-sixths of the world's population lives in the Global South, while only one-sixth lives in the Global North. According to one Nigerian scholar, "The unequal strength between the two is manifested not only in the dominant power of the Global North to control the pattern of international trade and agreement regulating it, but also in their ability often to dictate the terms whereby technology, foreign aid, and private capital are transferred to the Global South".^{17, p343} The terms Global North/Global South refer to affluent and resource-poor nations, respectively, but also extend beyond geographical location. As Arif Dirlik states, "North connotes the pathways of transnational capital, and South, the marginalized populations of the world, regardless of their location--".^{18, p351} Feminists choosing these terms wish to shape global politics by specifying the differences between women from the North and South, addressing the issues especially affecting women, explaining the connections in women's issues across national boundaries, and forming solidarities drawn from many parts of the world.^{19,20}

Approach

Transnational Feminism

A shared aim among feminisms is to center women's experiences, particularly in contexts where such experiences have been underrepresented. For instance, until recently, global development efforts have tended to underestimate women's perspectives and realities. Even when gender is "mainstreamed" into policy and interventions in an attempt to secure equal benefits for women and men,²¹ experiences of the *most* disadvantaged women, like many in the Global South, are often overlooked. In today's globalized reality, it is imperative to consider women's health, safety, prosperity, human rights, and dignity on a transnational scale.

Deriving insights from Marxism, poststructuralism, and postcolonialism; transnational feminism is a contemporary feminist paradigm that focuses on intersections among gender, nationhood, race, ethnicity, sexuality, and economic exploitation on a world scale. Like postcolonial feminism, transnational feminism is a response to earlier feminisms that were formulated by and about women in the Global North. Like postcolonial feminists, transnational feminists remain concerned about the long-lasting effects of colonialism on non-white, non-Western women in the postcolonial world. The goal of transnational feminism is to develop understanding of gender within a globalizing context. Comprehending social structures, politics, and economic conditions of women's everyday lives are key to this worldview. Beginning with a critique of globalization, transnational feminists problematize the hegemony of Western scholarship and dispute the theoretical assumption that power and progress inevitably move from Global North to Global South.¹⁴

Transnational feminist analysis is particularly well-suited to interrogate contradictory consequences of the expansion of global capitalism by transnational institutions like the World Bank. Using this approach in our critique of the *World Development Report: Gender Equality and Development*, we were able to rethink the complexities of globalization- identifying uneven impacts on marginalized groups such as poor women, and imagining solutions to the inequalities that are produced by flows of capital and geopolitics. We chose the works of Global South feminists to guide our critique because these scholars have witnessed and demonstrate a deep understanding for how institutions, economic systems, social structures, and universalizing ideals from the Global North impact low income women in the Global South. They are also the ones “on the ground” who can envision real-life social, economic, and political transformations to

generate well-being for women and girls. As feminists, Aguinaga, Lang, Mokrani, and Santillana suggest:

After several decades in which feminist thinking was mainly formulated in the North, it is the feminist movements of the South that are reviving and refreshing the debates linking patriarchy, the crisis of civilisation, the prevailing production and development models, and alternatives to this paradigm. Today, women in the South are productive and reproductive workers and subjects who are sustaining humanity and establishing different links with the planet.^{3, p.57}

Critique of the Report

Uncontested Capitalist Framing of Development and Globalization

In the *World Development Report: Gender Equality and Development* an unquestioned capitalist framework is imposed on an agenda for producing gender equality. While all women are included in this agenda, little attention is paid to women in high-income countries where inequalities are deepening, particularly against poor and immigrant populations.¹⁴ As viewed through an historical materialist lens, an economic system such as capitalism creates and perpetuates inequalities; setting up a dichotomy between the haves and the have-nots.²² Those who have economic power within the context of capitalism stand to gain considerably by continuing this system in which a select few at the top of a hierarchy control the means of production, while those at the lower end of the hierarchy must provide the labor to produce. As long as this system is in place, there is opportunity to gain materially by keeping a segment of the global population at the lower end of the hierarchy. Thus, it stands to reason that scholars interested in gender equality and social justice would be skeptical of an organization touting an agenda of equality that is centered within an inherently unjust economic system.

The central premise of the Report is that unrestricted markets will lead to economic growth, improving living standards for all in the Global South. Multinational corporate business expansion and poverty elimination are unproblematically linked in a vision for the future in

which women in the Global South constitute a vast untapped market and corporations benefit from women's growing labor market participation and purchasing power.¹⁵ Throughout history, however, capitalism has been a driving force behind the exploitation and discrimination of women, the working poor, and racial and ethnic minorities around the world.^{11,18} Capitalism has also been a driving force in the imperialist, colonizing, and neoliberal agendas of Global North nations that have kept Global South nations disenfranchised.^{18,23,24} The critiques of capitalism and globalization in feminist scholarship are abundant, and focus on the continuing politics of economic inequality, and the implications of global politics that impact the lives of women in the global South.^{11,25,26}

From a transnational feminist perspective, the makeup of an economic system can be seen as creating social norms and beliefs. The Report presents an account in which those in the higher ruling class are portrayed as superior to those in the lower class. The authors of the Report discuss how “market signals”^{1,p21} and political representation drive gender norms and beliefs. They specify that imbalance between women and men in the economic sphere feeds societal norms that prejudice women. While this tenet opens the possibility for a feminist analysis within the Report, a discussion about alternative ways to correct imbalance in representation is not taken up. Capitalist economic strategies are idealized as the means to shift societal norms. Authors make the “business case for gender equality”^{15, p.954}. Their reasoning suggests that in order for women and men to be seen as equals, women must enter into the work force, be visible in the political sphere, and operate more fully as consumers and entrepreneurs in the free market. As women's representation in the economic system becomes more equal to men's, social norms will naturally progress to embrace ideologies of gender equality. From a feminist perspective, this shift in gender representation is not likely to be adequate to eradicate inequalities.

Women becoming part of the working class, in and of itself, is unlikely to change gender norms; a reality Marxist feminists found while observing the continued oppression of women in communist Russia.²⁶ In order to achieve true gender equality, there must be a change in the balance between reproductive and productive work in the lives of women.²⁶ The balance of reproductive and productive work cannot be effectively equalized if the reproductive work women are doing, generally in the home, is not simultaneously socialized as women move into the formal job market. Without this equalization, women remain responsible for both realms of labor, creating more opportunities for exploitation. The authors of the Report encourage women to enter the work force, while acknowledging a need for men to adopt more responsibility within the home. On a global scale, however, it is precisely the type of development encouraged by the World Bank that transnational feminists often criticize. Globalization has continued to push women into predominantly “feminine” jobs, for instance, in sweatshops such as Mexican *maquiladoras* (owned by wealthy businessmen from the Global North), where women are subjected to long work hours and poor wages.^{26,27} Across the globe, countries are eliminating socialized opportunities for childcare for women entering the workforce. Instead, the use of migrant women as private childcare workers is reinforced. These low or no wage domestic positions are insufficient to support the families of these migrant workers.²⁵

Inherently, capitalism perpetuates inequalities. Without a fair economic system, the strategies suggested in the Report will continue to create social contexts that foster exploitation of women, particularly in the Global South. Gender biases are not the only discriminatory views that function through capitalism; women suffer the intersection of many –isms: sexism, racism, classism, ableism, as well as hegemonic norms that negatively impact persons who are situated outside gender binaries, or a heteronormative lifestyle. Additionally, there are those who occupy

spaces in society where they experience marginalization, for example, people living with HIV, persons whose religious practices are outside the national norm, persons who do not conform to dominant beauty standards, etc. Within an unfair economic system; social beliefs will always be constructed that proliferate hierarchies of power. If the World Bank does indeed have an agenda for gender equality, working exclusively within a context of capitalism is flawed.

Universalizing Views on Women

We contend that the *World Development Report: Gender Equality and Development* provides an acontextual and ahistorical account of gender oppression. Through its language choices and lines of reasoning, the World Bank constructs women in the Global South as a monolithic group, differentiated from and inferior to women in the Global North. Three concepts ground our argument: universalism, gender essentialism, and cultural othering, which are elaborated in the following sections.

Universalism. Feminists have long critiqued the use of universalizing descriptions of women as they impose a degree of homogeneity and sameness on groups of people who are incredibly diverse and unique. For instance, if policymakers in the Global North assume that all women have similar experiences and aspirations, it is likely that the needs of women in the Global North, with whom they have some familiarity, will be privileged; leaving women in the Global South largely unheard. In her classic article, "Under Western Eyes: Feminist Scholarship and Colonial Discourse", transnational feminist, Chandra Mohanty,²⁸ asserted that when all women are grouped into a unitary category for analysis, and gender oppression is thought to be a global phenomenon; the realities of women's lives cannot be addressed. Such an analysis does not uncover the historical structures of oppression across unique populations of women. Further,

faulty “one size fits all” solutions can result when global policies are based on assumptions that women across the world are essentially alike and experience gender oppression in the same way.

In the Report, the World Bank authors describe “the evolution of gender equality”^{1,p1} as being similar across the world; progress is made when women participate more fully in the labor market and demonstrate their purchasing power. Population demographics are dichotomized: low-income countries are compared to high-income countries. Direct correlations are made between gender inequities and the status of a country’s success in the global economic market. In order to improve on gender inequities, therefore, countries must improve their economic productivity. Here, the implied liberation of women in rich economies of the North is set as a standard for women in the Global South, who are depicted as victims of poor economies as opposed to hegemonic masculinities in both the Global North and Global South.

Although improving one’s access to economic wealth and stability can be linked to improvements in quality of life, viewing gender equality solely through an economic lens is limited. Depending on capitalist economic solutions to gender inequality is problematic in that it lacks historical context and discounts the complexity and variability in gender oppression across the world. The Report fails to capture the nuanced ways in which women experience gender inequality differently based on their social location, and how these differences affect women’s desires and inform development of effective interventions.

In keeping with a transnational feminist perspective, it must be emphasized that the history of gender inequality is unique across nations, and differs even within countries based on women’s social situatedness. In seeking to support women’s empowerment and eliminate inequalities, interventions based on analyses that are acontextual and ahistorical will likely be ineffectual. Evidence from microfinancing interventions in the Global South, for example,

demonstrates differential impacts on women's economic empowerment across contexts;^{29,30} in some circumstances, microfinance is beneficial for women, while in other circumstances it has been shown to exacerbate gender-based violence against women.³¹

The universalism expressed in the World Bank's Report sets the capitalist economic system operating in the Global North as the implicit referent by which countries of the Global South are compared. Making a shift away from assumptions of universal experiences to a careful acknowledgment of the contextual realities of women's lives in various regions of the world may allow for more effective and efficient interventions that have a greater impact on improving the lives of women.

Gender Essentialism. While it should not be assumed that all women experience gender inequality similarly, it also should not be assumed that all women experience gender inequality. As in the case of universalism, categorizing women into predetermined gendered categories is problematic when they are conflated with reality.^{28,32} When *all* women are compared in totality to other groups, dichotomies are constructed that toe the line between what is descriptive and what is reality.³² When these binaries are constructed in terms of gender, social descriptions and reality can be conflated as inherent traits, or gender essentialism. Gender essentialism assumes *all* women are similar to other women, and *all* men are similar to other men, which implies that women and men are essentially different. When describing the characteristics of *some* women, these descriptions can discursively be understood as realistic characteristics of *all* women.

Essentialism is problematic as some women cannot represent all women, and typically only dominant groups are represented. Additional issues arise, however, when gender essentialism is used to deduce that the descriptive inequalities between men and women are in fact, a result of women's inherent inferiority to men. For example, in the Report, the World Bank

authors discuss agency as the ability to control one's life; they write, "Across *all* countries and cultures, there are differences between men's and women's ability to make these choices, usually to women's disadvantage" (emphasis added).^{1,p6} Here, the authors construct an essential binary between men and women that generally places women at a disadvantaged position. Later in the Report, the authors again construct a gender essentialist binary when discussing domestic violence. According to the Report, across the world, "violence knows no boundaries".^{1,p20} Domestic violence is posited as a blanketing phenomenon against all women, and implicitly places women in an inferior position compared to perpetrators (i.e. men).

There is substantial evidence that women experience violence on a global scale, and experience greater social disadvantages compared to men. This is therefore, not to suggest that such statements from the World Bank are entirely inaccurate. However, the Report lacks information that would help to contextualize the experiences of gender difference and domestic violence. Essentialist language perpetuates a discourse that has implications for interventions targeting women. If gender essentialism is accepted, women and men are assumed to have inherent traits that cannot be changed. Women are depicted as docile, maternal, emotional, and weak; whereas, men are depicted as violent, strong, leaders and providers. These patriarchal depictions do not allow room for empowering women or closing the gender disparities gap.

At present, the World Bank upholds patriarchal depictions of women. To avoid gender essentialism, the World Bank might need to articulate women's concerns while engaging in a contestation of hegemonic patriarchal discourse. For example, while women experience marginalization and violence, evidence also demonstrates women's capacity and agency to resist and persevere.³³ By demonstrating counter narratives, a more holistic picture of gender inequality can be developed, thus avoiding the danger of a "single story".³⁴ Coined by

Chimamanda Ngozi Adichie,³⁴ a single story is problematic when one story about a group of people becomes the only story that is heard, perpetuating a one-dimensional view of people in the group. By telling multiple stories, individual differences are acknowledged, and interventions to empower women and promote gender equity are not limited by essentialist ideologies that constrain the possibilities for change.

Cultural Othering. Cultural essentialism occurs when all people within any given geographic region are assumed to hold the same beliefs, customs, and values.³² From such a perspective, individual differences are often glossed over, and marginalization of subgroups is made invisible. Uma Narayan,³² a prominent feminist scholar from the Global South, offers an example of cultural essentialism. She points out that in the works of Global North feminist, Mary Daly (1978, as cited in Narayan), Daly discusses “Indian culture” and *sati* as though this now outlawed Hindu practice (whereby a widow immolates herself on the funeral pyre of her husband) was practiced by *all* Indians. Daly does not acknowledge contradictory examples as to the extent of *sati* practice, nor does she acknowledge the groups in India that resisted the practice.

Cultural essentialism exists when characteristics of some are generalized to an entire population.^{28,32} The World Bank authors avoid essentialist language about particular cultural groups. In the Report, cultural norms and traditions are discussed in ways that highlight fluidity; that within cultures, traditions and beliefs are constructed over time. There is, however, emphasis on differentiation between Global North and Global South, which leaves room for cultural othering.²⁹ Othering is a form of social representation that consists in the objectification of another person or group, ignoring their complexity and subjectivity. Like stereotyping, othering is a process by which people construct sameness and difference to affirm their own identities.

Those who are in the same group (e.g., country of origin, race, religion, etc.) are believed to be part of the right way to be human, whereas others outside the group, are not. If unexamined, this human tendency to categorize can prompt hostility toward those who are not in the same group. Taken to a transnational scale, cultural othering can be seen to facilitate colonizing agendas.²⁸

In the Report, countries of the Global South are referred to as “developing” countries; countries of the Global North are referred to as “developed” countries.^{1,p36} Discursively, persons in developing countries are put in the position of being under-developed and in need of an implied standard of development set by those in developed countries. Gender roles in developing countries are “othered” as persistent cultural phenomena that are “traditional”^{1,p33} and “old problems”.^{1,p7} The message appears to be that in order to be considered “developed,” persons in Global South cultures must adapt gender norms and beliefs to reflect those in the Global North.

Gender roles in the North or South may have negative implications for both women and men; for example, when beliefs about gender are used to justify violence against women, or to keep men from pursuing interests that are considered “feminine”.¹ Gender roles may also be a source of women’s empowerment and serve to promote gender equality; for example, women’s position as caregivers may permit them control and power in the home, allowing them to educate and influence their children, and alter gender norms positively.^{35,36} Contextual understandings of cultural gender norms are needed; it cannot be assumed that all women and men in the Global North, the Global South, or within individual countries, share similar cultural beliefs. Cultures should not be based on othering, or discursively defined as under-developed. Rather, critiques of cultural practices should be grounded in deep understandings of the experiences of cultural insiders and outsiders.³⁷

Conclusion

Feminism provides a powerful political and theoretic point of view from which to evaluate efforts to redress the oppression and exploitation of women, particularly if feminist ideas are enlarged to embrace transnational realities. In this paper, transnational feminism has provided an alternative analytical frame from which to critique capitalist globalization and universalizing discourses about women. Using the World Bank's *World Development Report: Gender Equality and Development* as the impetus for our discussion, we have argued that reducing gender relations to a matter of economics that can be exported to the entire world is neither just nor adequate. For emancipatory change that equalizes opportunities for women, inequities cannot be eradicated in only one sphere of social life. Literally and figuratively, social structures that allow wealth for the few to be accumulated at the expense of the many must be dismantled.³⁸ Unfair, unabated capitalism is inconsistent with such an egalitarian agenda.

In this era of globalization, the challenge for policymakers seeking to promote gender equality is to more fully consider contextualized and historical accounts of women's experiences so as to gain a deeper knowledge of the richness and range of women's lives in the Global South and the Global North. And, major players, like the World Bank, might do well to bring contrary voices to the table, engaging their critics in creative solutions for sustainable development. The challenge for feminists is to cultivate inclusion and understanding among diverse groups of women. With new information and communication technologies, the possibilities for organizing transnationally and creating solidarities across vast differences in women's lives are exponentially increased.

Transnational feminist theorizing can help nursing bridge the local and the global as well. Nurses bring a unique holistic perspective on global health. While we hone our skills in the assessment and treatment of physical and mental health problems, and innovate services and

structures for care delivery around the world, we must always seek to understand the root causes of problems. To be leaders in global affairs, nurses need what Mohanty¹¹ calls an analytic framework that is attentive to the micropolitics of everyday life, as well as the macropolitics of global economic and political process. She says that a transnational feminist analysis “that is anchored in the lives of marginalized communities of women provides the most inclusive paradigm for thinking about social justice”.^{11,p.510} Her advice is particularly apt for the nursing profession as we strive to have influence in the global policy sphere:

If we pay attention to and think from the space of some of the most disenfranchised communities of women in the world, we are most likely to envision a just and democratic society capable of treating all its citizens fairly. Conversely, if we begin our analysis from, and limit it to, the space of privileged communities, our visions of justice are more likely to be exclusionary because privilege nurtures blindness to those without the same privileges.^{11,p.510}

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CHAPTER IV: METHODS

Introduction

This study sought to answer the question of how women living with HIV/AIDS in rural Malawi, Africa, who regularly attend an HIV clinic, describe their experiences of empowerment. To fulfill the aims of this study, a qualitative approach using grounded theory, and a postcolonial feminist perspective was chosen. In this chapter, I will elaborate on the research design that allowed me to carry out this study.

Methodology

A qualitative approach to inquiry is appropriate for gaining knowledge about subjective concepts, personal desires, and individual realities (Ritchie & Lewis, 2003). Using observation, in-depth individual interviews, focus group interviews, videography, photographs and more, qualitative methods facilitate the collection of rich data describing how individuals view and interpret the world, and make meaning of their interactions (Ritchie & Lewis). In comparison, quantitative methods are limited in the data that may be gathered. Limitations in quantitative research stem from research methods that do not allow participants to express their subjective views. Instead, the participants answer questions based on a series of potential answers that may or may not fully represent the participants' views. A qualitative approach is appropriate when seeking to gather rich data about the subjective perspectives of individuals.

Grounded Theory

Grounded theory is a qualitative methodology developed by Barney Glaser and Anselm Strauss (1967) in their book, *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Grounded theory has its roots in sociology and seeks to generate a theory to explain patterns of behavior which are relevant and problematic for those involved (Glaser, 1978, p 91).

Grounded theory is inductive, contextual, and emergent. While there are many qualitative approaches to research, grounded theory was selected for this study based on its usefulness for studying complex phenomena, providing direction for nursing research and practice, and its congruence with feminist thinking.

Grounded theory is useful for studying complex phenomena (Brown, Stevens, Troiano, & Schneider, 2002), such as empowerment. Unlike phenomenology, which focuses on a concept, such as pain, experienced by a group of individuals, or an ethnography, which focuses on describing patterns of social behaviors or cultural experiences of a group, grounded theory focuses on a specific process or action that occurs over time, and seeks to develop a theory to explain that process (Creswell, 2007). As Strauss and Corbin (1998) explain, grounded theory brings into data *process*, which is the difference between “a snapshot and a moving picture” (p. 179). In doing grounded theory, the researcher seeks to raise data to an abstract level to capture the overarching process being studied. Grounded theory aids the researcher in moving beyond a descriptive level of analysis into a theoretical level of analysis (Glaser, 1978).

In literature focused on the nursing discipline and qualitative research, grounded theory is recommended for theory development (Creswell, 2007; Ritchie & Lewis, 2003; Walker & Avant, 2011; McEwen & Wills, 2011; Meleis, 2012; Polit & Beck, 2012). Since the 1970s, nursing researchers have used grounded theory to inform nursing practice (Doering, 2013; Häggström, Asplund, & Kristiansen, 2012; Kylmä, Vehviläinen-Julkunen, & Lähdevirta, 2001; Larsson et al., 2007; Morse, 2001). Theories unique to nursing are necessary for pragmatically guiding nursing practice and research, and for assisting in articulating nurses’ roles in facilitating health outcomes. Rather than adopting a “top-down”, deductive strategy using existing theories, grounded theory methodology allows for the development of theory that is inductive and rooted

in qualitative data (Glaser & Strauss, 1967). This strategy is particularly useful when existing theories fail to fully describe the phenomenon of interest. Empowerment has been studied in relation to HIV prevention (Kim, Pronyk, Barnett, & Watts, 2008), and models of health care empowerment could be applied to patients living with HIV (Johnson, 2011); however, there are no current, specific theories of empowerment among women living with HIV. Grounded theory has often been used in nursing research and is recommended for developing theories rooted in qualitative data.

Grounded theory is also congruent with feminist thinking, making it not only appropriate for the study of empowerment, and useful for nursing science, but also consistent with my own philosophical views. Grounded theory is underpinned by pragmatism and symbolic interactionism (Corbin & Strauss, 2008; Milliken & Schreiber, 2012). Pragmatism holds that truth and meaning is created through social and physical interactions with the world, while symbolic interactionism is based on the tenets that people act toward objects based on the meanings those objects have for them, and that these meanings are constantly modified and changed through interpretative processes (Schreiber & Stern, 2001, pp. 193; Blumer, 1969). Consistent with feminist thinking, the tenets of grounded theory assume there is no single universal truth, but rather, knowledge is constructed, impacted by social, structural, and institutional context, and is fluid and changes throughout history. Participants are considered experts of their own realities and sources of knowledge (Wuest, 1995). Grounded theory is consistent with feminist thinking in that both ideologies seek to gain knowledge through the study of women's subjective experiences.

Principles of Grounded Theory. Grounded theory methodology rests on two central principles: constant comparative analysis and theoretical sampling (Glaser & Strauss, 1967).

Constant comparative analysis is the continuous comparison of data by incidents, which may include individual words, phrases, or stories. When comparing data, the researcher looks for similarities and differences and seeks to find patterns that fit into conceptual categories. Through comparing these incidents, the researcher is able to understand and articulate the properties of a category. Constant comparison also serves as a method of verifying the analysis, as the researcher continuously checks emerging codes and categories against other data. Finally, constant comparison allows for raising data to an abstract, theoretical level.

The purpose of theoretical sampling is to broaden the range of experiences reflected in the theory, guide the emerging theory development, and to test it against similar or different incidents (Glaser & Strauss, 1967). Theoretical sampling occurs simultaneously with data collection and analysis; as the researcher collects and begins coding data, she may seek out additional groups of participants that may either confirm or challenge the emerging theory. For example, in a study of medication management in adults the researcher would begin by sampling a wide range of participants by factors such as age, gender, education, religion, etc. As the study and analysis continues, the researcher may find many of the participants appear to have easy access to healthcare and medication, and do not seem to have any financial constraints in terms of medication management. The researcher may then want to collect additional data with participants who are low-income to see how this data compares with emerging codes and categories from other participants.

Traditions in Grounded Theory. While grounded theory was originally introduced by Glaser and Strauss (1967) in their book, *The Discovery of Grounded Theory: Strategies for Qualitative Research*, the authors' approaches to conducting grounded theory fragmented as the years went on. In 1978, Glaser wrote *Theoretical Sensitivity*, which elaborated on the steps of

doing the grounded theory described in *Discovery*. By the late 1980s and early 1990s, Strauss's writings, particularly those co-authored with Juliet M. Corbin began to demonstrate the differences of Strauss's approach to that described by Glaser in 1978. *Basics of Qualitative Research*, by Strauss and Corbin was first published in 1990 and provided step by step instructions for conducting grounded theory; the manual quickly became a fundamental textbook for novice researchers. However, the book was criticized by Glaser (1992) as being overly structured and predictive, forcing the data and theory into preconceived frameworks, rather than sticking closely to the data and allowing a theory to emerge. The two traditions to grounded theory were labeled: Glaserian and Straussian.

The traditions can be difficult to untangle for new researchers embarking on a study using grounded theory; much has been written on where the two converge and diverge (Heath & Cowley, 2004; Duchscher & Morgan, 2004). Over time, new approaches to grounded theory emerged, such as Kathy Charmaz's "constructivist grounded theory" (2014), which puts the role of the researcher in constructing theory at the forefront. There is little consensus on how to label and identify all the different approaches to grounded theory.

Adeline Cooney (2010), in her adeptly titled article, "Choosing between Glaser and Strauss: an example", identified five different approaches: a classic approach as described in *Discovery*, a Glaserian approach, a Straussian approach, a constructivist grounded theory, or a combination. However, a Glaserian approach has been used interchangeably with a classic approach (Heath & Cowley, 2004), raising questions as to whether a Glaserian approach and a classical approach are in fact unique. Further, according to several authors (Glaser & Strauss, 1967; Crooks, 2001; Milliken & Schreiber, 2001), grounded theory as it was originally introduced, rooted in symbolic interactionism, fits within a constructivist paradigm, raising

questions as to how newer constructivist approaches to grounded theory differed from the original. Glaser himself called Charmaz's 'constructivist grounded theory' a "misnomer" (2002), explaining that grounded theory has always acknowledged the role of the researcher in the construction of theory. To be sure, a combination of approaches is not recommended, as doing so could violate philosophical underpinnings of the methods (Heath & Cowley, 2004).

Despite the criticisms of Glaser, a constructivist grounded theory as described by Kathy Charmaz will be used in this study. I find the approach by Charmaz the most well-articulated and easy to follow for myself as a novice grounded theorist. Further, while constructivism underpins and is implied in the writings of Strauss (2008), I appreciate Charmaz's direct approach to constructivist grounded theory. While providing directions for conducting grounded theory, Charmaz also frequently discusses the role of the researcher in constructing the data, which is helpful for new researchers, such as myself, still learning how to be reflective and aware of my position throughout the research process.

Feminist Perspective

The theoretical perspective that guides this study was formed primarily through the works of postcolonial feminist scholars, such as Uma Narayan, Chandra Mohanty, and Oyewumi Oyeronke. Common themes in postcolonial feminist literature include critiques of hegemonic, universalizing and "Othering" (Mohanty, 1988) notions of Third-World women. Postcolonial feminists also seek to critically analyze the power inherent in research and knowledge production (Mohanty, 1988; Narayan, 2004). Such a perspective is useful in a study of empowerment among women living with HIV in Malawi as it acknowledges that men and women fundamentally experience the world differently, but there is also emphasis placed on

intersections of marginalization that go beyond that of gender, including race, class, and a history of imperialism.

It is necessary for feminist scholars to critically acknowledge one's positionality in relation to that of participants (Mohanty, 1988). Reflection on one's positionality is an act of reflexivity: engaging critically with the ways in which a researcher's own position influences research design, data collection, analysis, and synthesis (Sultana, 2007). Reflexivity is also "implicated in how one relates to research participants and what can/cannot be done vis-à-vis the research within the context of institutional, social, and political realities" (Sultana, 2007, p.376). In other words, reflexivity is the acknowledgement of subjectivity, the contextual limitations of a study, how power operates within relationships between the researcher and participants (Mohanty, 1988), how a researcher's personal position can both positively and negatively impact a study (Dowling, 2006), as well as how a researcher's personal position is impacted by the research (Dowling). Further, reflexivity is an attention to histories of colonialism and imperialism, including the discursive ways even feminist writing can be exploitative (Mohanty, 1988; Sultana, 2007). Reflexivity is then expressed in a variety of ways, through decisions made in conceptualizing and designing a study, through data analysis, the write up of findings, and dissemination of results.

My own social position was discussed at length in Chapter I. In short, I am an educated, white, Western woman, a nurse, and a scholar who comes from a middle-income background. Within a global context, these identities put me in a position of power compared to the women I will interview. Awareness of my position of power is significant because this position holds great responsibility to be ethical and emancipatory in my work (Mohanty, 1988) and to minimize power differentials when possible (Hesse-Biber, 2007). Positionality is not only about power;

my social positions also place me as an outsider to the women and communities with which I will be working. Being an outsider may limit my full ability to understand the experiences of participants. While being an outsider differentiates me from women in Malawi, it also has benefits. Being an outsider doing research, I may be seen as someone who has influence, so women may be motivated to talk with me. As a nurse, women may be more likely to trust and open up to me. As a scholar from a high-income country, I also have access to resources and knowledge from all around the world, which assists me in easily accessing information that would be beneficial to informing policy and future health interventions.

Sample and Setting

Setting

This study was conducted in conjunction with the non-governmental organization (NGO) K2 Tigwirane Manja (K2 TASO) located in the Kasungu district of Malawi. In English, *Tigwirane Manja* means, “Let us hold hands.” K2 TASO provides health services for women and men living with HIV/AIDS, including HIV testing and treatment, and palliative care services for those who are terminally ill (K2 TASO, n.d.). Partnering with a community based NGO served two beneficial purposes: firstly, staff working at the organization know and understand the population well and were able to assist in identifying potential participants; secondly, working with an NGO provided a connection to the community, which may have aided in establishing trust and rapport with those in the community. The staff of K2 TASO were vital in providing intimate knowledge of the community. Further, K2 TASO serves approximately 2,000 women and men in the community and provided a robust setting from which to recruit women living with HIV with unique experiences of empowerment.

K2 TASO is in a rural community in Central Malawi, where household incomes are more likely to be low-income compared to urban areas (Malawi Demographic and Health Survey 2015-2016 (MDHS), 2017). A postcolonial feminist perspective seeks to begin analyses with the world's most marginalized women, as these women are likely to have the best understanding of the factors that inhibit them (Mohanty, 2014). Chandra Mohanty conceptualizes the world's most marginalized women as "poor women of all colors in affluent and neocolonial nations; women of the Third World/South or the Two-Thirds World" (p. 510). Women living in the rural Kasungu district of Malawi would thus be considered some of the world's most marginalized women and are an appropriate sample for studying empowerment through a postcolonial feminist perspective. It is likely that knowledge of empowerment gained through the experiences of women in Kasungu, Malawi may be transferable to women living with HIV/AIDS in other contexts as well.

Sample

To fulfil the aims of this study, women were recruited using the principles of theoretical sampling and additional women were recruited for individual interviews until theoretical saturation is met (Corbin & Strauss, 2008). Women were recruited if they met the inclusion criteria: 1. Over the age of 18. 2. Diagnosed with HIV/AIDS. 3. Clients of K2 TASO. Additional inclusion criteria were based on characteristics to elicit a wide range of experiences including age, ethnicity, religion, relationship status, time since HIV diagnosis, economic comfort, number of children, if any, and participation in development projects and business. Due to time restraints, ideal theoretical sampling was not achieved in this study. All women who expressed interest in participation and met inclusion criteria were recruited into the study and completed an interview. Theoretical sampling did take place to recruit women with experiences

in business and who had been a part of programs in which they received microloans, fertilizer, or livestock.

Observational Data and Field Notes

Observational data was recorded in field notes immediately following interviews, as recording observations during interviews may have been disruptive (Rubin & Rubin, 2012). This observational data included information regarding the participant's geographical location, home and neighborhood, as well as verbal or non-verbal cues noted during the interview. A separate reflexive journal was also kept in which I recorded thoughts and reflections throughout the research process.

Other Sources of Data

In grounded theory, additional sources of data beyond interviews and observational data may be included to assist in reaching saturation of a category or its properties (Glaser & Strauss, 1967). These "slices of data" (Glaser & Strauss, p. 65) may include gray literature that specifically addresses part of the emergent theory or provides a unique perspective on the area of study. Other sources of data in this study included educational material and posters, government documents, and healthcare treatment guidelines for practitioners. Using multiple sources of data enhances the depth and diversity of the theory, allowing for better transferability (Glaser & Strauss).

Procedure

Consent

Ethical concerns have been raised regarding the consent process, particularly in studies conducted in low-income countries by persons from high-income countries (Krosin et al., 2006; Marshall, 2006, Strauss et al., 2001; Gikonyo, Bejon, Marsh, & Molyneux, 2008; Tamariz,

Palacio, Rober, & Marcus, 2012). Participants in such studies may have difficulty comprehending the informed consent process, including the rights of participants and potential risks (Krosin et al., 2006). Methods for ensuring informed consent include community engagement, conceptualizing consent as a process, giving information on various occasions, and assessing participant understanding prior to consent.

In this study, research was conducted in conjunction with an existing community organization, K2 TASO. Through this collaboration, the community and community leaders were informed of the researchers' presence and the purpose of the study. Participants heard details about the study first from staff at K2 TASO, and again when they met with me prior to interviews. In total, I spent three months in the community, volunteering at K2 TASO, as well as engaging with the community through attending church, political rallies, and weddings, for example. Prior to beginning recruitment or data collection, I met with both the Chief of Mtunthama, the village in which I was staying, as well as the Traditional Authority of the District of Kasungu to discuss the purpose of my study and to obtain permission to conduct research.

When meeting with women individually my research assistant and I had a conversation with them about the study and again offered to answer any questions at that time. We asked the women a few questions about the study and their rights and felt each woman had sufficient understanding. Consent to participate was then obtained verbally and either the research assistant or I signed the consent form demonstrating that consent was obtained. The consent agreement (**Appendix A**) was available in both Chichewa and English for participants upon request. None of the participants requested this documentation. The rationale for using verbal

consent is to reduce any potential discomfort that may occur from asking a participant who may be illiterate to read or sign a consent form (Mkandawire-Valhmu & Stevens, 2007).

During the interviews, breaks were offered, and at times we took short breaks if there were interruptions such as others needed to come into the space in which we were conducting interviews. We also prompted women if the interviews were approaching an hour long and asked if they wanted to continue after that point. If women opted to end an interview at any time, this would have been treated as removal from the study and any audio recordings with the participant would have been deleted at that time; this did not occur in any of the interviews. As the interviews at times elicited discussions of sensitive topics, additional time was spent with women as necessary. All women who participated in an interview were given a packet of salt and sugar, and four bars of soap for their time.

Data Collection

Prior to data collection, I visited K2 TASO to become acquainted with the staff and the facilities. Staff were briefed on the study, and procedures for identifying and inviting potential participants. Staff shared with women information about the study, and if interested in participating, women were asked to meet with the research staff. This most often took place while women were already visiting the health clinic and I was present to conduct the recruitment, consent, and interview process. Interviews lasted approximately one hour, were audio-recorded and guided by a semi-structured interview with potential probes. Additional probes and questions were included when appropriate. During interviews, everything I said was translated into Chichewa for the participant, and any responses from the participant were translated English for me, thus enabling me to further probe or change the wording of questions that may have been unclear or misunderstood. The interviews took place at a location preferred by the participants,

which included private offices or rooms, or outside at K2 TASO, a private office where women met for support groups, and at women's homes.

Prior to meeting with potential participants, the consenting process and interview guides were discussed with the research assistant, who also served as a translator, allowing interviews to be conducted in Chichewa. The purpose of this was to familiarize the translator with the study materials, answer questions, and clarify any items, as well as discuss study protocol and patient confidentiality. Throughout data collection, we continued to review the semi-structured interview guide to ensure English to Chichewa translations were clear and understandable; we also discussed collaboratively new probes and questions to ask participants. At times, questions were adapted for clarity, for example, questions regarding how women managed their health were simplified to ask how women cared for their health.

Data Analysis

Audio recorded interviews were transcribed and translated into English for data analysis. Recommendations for conducting qualitative research in languages other than the researcher's primary language include transcribing interviews verbatim and then translating the transcriptions (Lopez, Figueroa, Connor, & Maliski, 2008), identifying and following up with inconsistencies (Lopez et al.), and working closely side-by-side with professional translators (Lopez et al.).

In this study, interviews were first transcribed verbatim and then translated into English by a research assistant who also served as the translator during the interviews. Mrs. Carol Beya has previous experience serving as a translator and transcriptionist for research, particularly in healthcare setting. This is useful as translating medical terminology between English and Chichewa can be challenging at times. Data collection was paused temporarily after conducting the first three interviews. After being transcribed and translated, these interviews were reviewed

for accuracy by Dr. Mkandawire-Valhmu, who is fluent in both Chichewa and English. After her approval, data collection continued. In the final translated transcripts, all conversation between the translator, the participant and myself were recorded, which also allowed me to personally review the accuracy of the translations.

Coding

Coding serves as a link between data and theory (Glaser, 1978). Through coding and constant comparison of data, the researcher seeks to identify categories and their properties that eventually form the emerging theory (Glaser, 1978). Categories refer to groupings of incidents, while the properties of categories refer to theoretical properties, such as relationships to other categories, when a category may manifest or be absent, or major consequences (Glaser & Strauss, 1967). Coding in grounded theory is an iterative process and evolves through constant comparison, and continuously re-coding and sorting the data around the emerging theory (Glaser). All codes must be verified through the fit of data; in the end, if all data does not fit in an emergent theory, the theory must be modified (Glaser). While coding transcripts, codes were typed in the margins of documents; all codes were organized in electronic tables. In grounded theory, coding includes initial coding, focused coding, and theoretical coding.

Initial coding. Initial coding is the first level of coding and begins with line-by-line coding of the data (Charmaz, 2014; Glaser, 1978). While line-by-line coding can be time consuming, it forces the researcher to fully and richly develop a category, and it also minimizes the possibility of missing things in the data, or applying preconceived ideas (Glaser, 1978). Initial codes are often gerunds, describing actions or processes, or in vivo codes using participants own words (Charmaz). Constant comparison begins during open coding with the

comparing of incidents, which may include comparing specific words, phrases, sentences, or experiences within the data (Charmaz; Glaser).

Focused coding. Focused coding is the process of reviewing initial codes and identifying those that are being most consistently used, account for larger amounts of data, and hold greater analytic weight than less significant codes (Charmaz, 2013). Moving away from a descriptive level of coding and into a more conceptual level (Corbin & Strauss, 2008), focused codes are a way of categorizing data (Charmaz). During this phase, constant comparison is used to compare initial codes with the data, to determine similarities and differences, and to further sort and organize the data (Charmaz). Some data may be set aside, to come back to later in the analysis or for another project, while the focused codes become the center of the emerging analysis (Charmaz).

Theoretical coding. Theoretical coding is the highest conceptual level of coding. Theoretical codes provide a structure to focused codes and as Charmaz (2008) says, helps to tell an “analytic story” (p. 150). These codes link relationships between focused codes and categories, and form hypotheses about the data (Charmaz; Glaser, 1978).

Memoing

Memoing is an essential part of grounded theory. As Glaser writes, “Memos are the theorizing write-up of ideas about codes and their relationships as they strike the analyst while coding” (1978, p. 83). While memoing begins with initial open coding, it continues throughout the coding and theory development process, and occurs when the researcher is not actively coding. Memoing is where comparisons occur, ideas are deconstructed, focused codes move to conceptual categories, properties of categories are established, and theoretical hypothesizing takes place (Charmaz, 2013; Glaser; Corbin & Strauss, 2008). In this study, memoes were both

handwritten and typed and were labeled by date, time, and any categories or codes discussed within the memo.

Data Management

As the Principal Investigator, I was responsible for implementing data management. Throughout this study, data was generated in the form of audio recording, transcriptions, memos, and coding. At any point data may be shared between the Principle Investigator and consulting researchers including Dr. Mkandawire-Valhmu, Dr. Doering, Dr. Wilson, and Dr. Thongpriwan. Transcriptionists will have access to raw audio recordings. Before being shared with others, I used pseudonyms to change any names or personal identifiers in the raw data, and electronic files were labeled using coded numbers for each subject. All electronic data is stored on my own secured laptop, as well as backed up on a password protected external hard drive. Any printed or physical data was scanned to create an electronic copy and then destroyed.

Protection of Human Subjects

The process and procedures for conducting this study were approved by the UW-Milwaukee IRB and the Malawi Ministry of Health.

Enhancing Rigor and Trustworthiness

Rigor was enhanced in this study based on the criteria of grounded theory, which include fit and relevance; the theory must also *work*, and be modifiable (Glaser, 1978). Fit means that the categories of the theory must fit the data, if all data does not fit, the categories must be evaluated and changed. Fit is the antithesis of putting data into preconceived categories. To ensure fit, the strategies of refit and emergent fit may be employed (Glaser). Refit means to continuously modify and refit categories to the data to check whether new data does in fact fit.

Emergent fit is a strategy of carefully using existing categories provided data does fit them; this may include borrowing existing categories from the literature, or slightly modifying these existing categories to achieve fit.

In grounded theory, theories must be relevant, and they must work (Glaser, 1978). Researchers achieve relevance by allowing core problems and processes to emerge organically, rather than forcing preconceived theories onto the data. Theories that work are ones that are able to explain an area of interest; one should be able to use the theory to interpret what is happening, to predict what will happen, and to direct actions in that area. The final criteria for enhancing rigor in grounded theory is modifiability (Glaser, 1978), meaning that the researcher is always open to changing and modify the theory as new data and situations emerge over time. In addition to these four criteria used for enhancing rigor in grounded theory, trustworthiness will be used to demonstrate that the research is credible, transferable, dependable, and confirmable (Lincoln & Guba, 1985).

Credibility

Research is considered credible when the researcher's interpretations of the data closely match the participant's perspectives (Lincoln & Guba, 1985), as well as participant's interpretations of meaning that operate through language (van Nes, Abma, Jonsson, & Deeg, 2010). In this study, prolonged engagement, observation, and member checking were used to enhance credibility (Lincoln & Guba). I spent several months in Kasungu, Malawi, during which time I was able to observe the community and become accustomed to some of the nuances of the context, which enhanced my understanding and ability to credibly analyze the data.

Member checking was used informally during interviews; aspects of interviews were repeated back to a participant to check my understanding of both content and the meaning of

what was said, and emergent findings were at times included in questions. Credibility of data analysis was also enhanced through discussing emerging codes and categories, and working through analysis concerns with Dr. Doering, a member of my committee and an expert on grounded theory methodology. Interpretations of language were also discussed with my research assistant, clinician staff, and Dr. Mkandawire-Valhmu.

Transferability

Findings that are transferable are evaluated based on applicability in other contexts (Lincoln & Guba, 1985). The use of thick description in contextualizing the findings enables readers to judge the transferability of findings to other contexts. In this study, rich descriptions are included in the write up of findings and have been developed throughout the study through the use of constant comparative analysis, memoing, and field notes. These rich descriptions also pertain to the write up findings in terms of language used by participants; in order to convey meanings that could be lost in translation, interpretations of participant's words are also explained, rather than only providing word-to-word translations (van Nes et al., 2010).

Dependability and Confirmability

The dependability of qualitative research is demonstrated through logical and consistent decisions made throughout the design and implementation of a study, including dissemination of findings (Hall & Stevens, 1991; Lincoln & Guba, 1985). Confirmability of data is demonstrated through objectivity, the extent to which the researcher's interpretations of data is free from influence of bias (Lincoln & Guba). Both dependability and confirmability may be enhanced through recording decisions made, engaging in reflexivity, and using external audits. In this study, decisions made regarding the design of the study were included in my proposal and were reviewed by members of my dissertation committee. During the study, an audit trail of all data

collection and analysis have been compiled through electronic tables of all codes, and electronic and handwritten memoes. These documents, along with transcripts, audio-recordings of interviews, and field notes will be sent to two Malawian scholars who will conduct a confirmability audit of the data. At the time of this submission, this audit has not yet been completed due to complications concerning the COVID-19 pandemic; this audit will be completed prior to the publishing of any data.

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CHAPTER V: RESULTS

MANUSCRIPT II: Women's Empowerment: Perspectives of Women Living with HIV in the Kasungu District of Malawi, Africa

Abstract

This study explores empowerment through the perspectives of women living with HIV in the Kasungu District of Malawi, a small landlocked country in South East Africa. The aim of the study was to develop a conceptual understanding of empowerment to guide the analysis of a grounded theory study. While incidence and prevalence of HIV has been decreasing and uptake of treatment has increased, Malawi remains at epicenter of the HIV epidemic with 8.8 percent of the total population living with HIV (MDHS, 2017). Illuminating women's experiences of empowerment within this context provides insight for healthcare professionals and those working in development to guide the construction of appropriate and effective interventions in an effort to improve the health and wellbeing of women. A qualitative approach was used, guided by a postcolonial feminist perspective and involving in-depth individual interviews with 25 women living in the rural area of Kasungu district in Malawi. Results highlight the capacities of women to support their own empowerment, bolstered by social support of others, and material assistance. Contextual factors that continue to inhibit women's achievements are discussed.

Introduction

Women's empowerment has increasingly become something of a "buzzword" linked to global efforts to improve the status of women and achieve gender equality. In the extensive discourse on women's empowerment, the perspectives of women are often left out. This is especially true for marginalized women, such as women living with HIV in low-income countries. In this study, we sought to describe empowerment from the perspective of women

living with HIV in rural Malawi in an effort to center the voices of women who are underrepresented in the literature in the discourse on empowerment.

Background and Significance

Women's empowerment is linked to gender inequality, which is a major contributor to the spread of HIV (Mkandawire-Valhmu, Wendland, Stevens, Kako, Dressel, & Kibicho, 2013). In Malawi, a landlocked country located in southeastern Africa with a population of 17.56 million people (National Statistical Office, 2019), gender inequalities are pervasive. More women are infected with HIV, and at younger ages, than men (Malawi Demographic and Health Survey 2015-16 (MDHS), 2017). Overall, 10.8 percent of women in Malawi are living with HIV compared to 6.4 percent of men (MDHS, 2017). In Malawian society, women experience marginalization as a result of gendered institutional practices that lead to limited formal education and employment opportunities for women. The Malawi Demographic and Health Survey (2017) reported differences between women and men in literacy (72 vs. 83%) and employment (63 vs. 81%). Additionally, 21 percent of women reported ever having experienced sexual violence, and more than two in five ever-married women reported having experienced emotional, physical, or sexual abuse by their current or, in the case of divorced women, most recent spouse (MDHS). In Malawi, women with higher education attainment have a better understanding of sexual behaviors that contribute to HIV risk compared to women with lower education levels (MDHS). It has been suggested that income can also play a protective role for women in negotiating safe sex practices with partners (Mugweni, Omar, & Pearson, 2015), while violence in the form of infidelity and unprotected sex within relationships can contribute to HIV (Mkandawire-Valhmu, Wendland, Stevens, Dressel, & Kibicho, 2013).

Exploring experiences of empowerment among women living in Malawi has implications for the health of women, children, and communities, and holds potential for directing future nursing research and practice. Women in Malawi are often the primary caregivers of children and those who are ill (MacIntyre et al., 2013). Throughout sub-Saharan African countries, women often focus on subsistence farming, growing foods for cooking and feeding families and communities, compared to men, who often focus on growing cash crops (Kondylis, Mueller, Sheriff, & Zhu, 2016). When women are ill, they are less able to participate in caregiving and farming activities; in these situations, children, particularly girls, often drop out of school to become the main caregivers for their parents and siblings (Foster & Williamson, 2000; Mkandawire-Valhmu et al., 2020). When women suffer, the health and wellbeing of children, families, and communities do as well.

In order to best inform empowerment efforts, it has been suggested that research should focus on those most at risk and most vulnerable. Women living with HIV experience marginalization at various intersections. In addition to gender inequalities, women living with HIV may endure violence, neglect, isolation and abandonment as a result of the stigma surrounding HIV (Chilemba, Van Wyk, & Leech, 2014). As such, women living at these intersections are at high risk for poor health outcomes. Lessons learned from exploring empowerment among women living with HIV may help to inform future research and practice among women living with HIV in Malawi, as well as women in other contexts who have similar experiences of marginalization.

Women's empowerment is important to nursing science as nurses aim to study human responses, promote health and provide culturally safe care. Women's empowerment holds potential to strengthen women's ability to promote change in their own lives, and the

environments in which they live (Carr, 2003; Kim et al, 2007, Mosedale, 2005; Zimmerman, 2000). Women's empowerment has implications for women's mental health by increasing self-efficacy and perceptions of self, as well as physical health, by promoting healthy relationships with men, reducing sexual risk behaviors, and reducing the spread of HIV (Kim et al., 2007; Pronyk et al., 2006). Understanding women's empowerment in the context of HIV would lend vital information for developing and facilitating future interventions aimed at improving health outcomes.

The empowerment of women is deeply political. Empowering women is not only morally and ethically significant, according to the World Bank (2012), it also has important economic implications. Women's empowerment and gender equality are goals of the current Sustainable Development Goals, the global agenda for sustainable development outlined by the United Nations (2015). These goals were also included as targets in the previous agenda, the Millennium Development Goals (World Bank, 2012). These international agendas have influence over gender policies and programs developed at international and local levels, and also determine how international efforts and monies are allocated. Women's empowerment is now used as an indicator of a country's development. Women are thus directly impacted by how women's empowerment is conceptualized.

Grounding conceptualizations of empowerment in women's experiences is essential to developing appropriate and effective interventions. How women define and experience empowerment is uniquely dependent on the contexts in which they live. For example, while a western view of empowerment may find gendered roles problematic, one study conducted in Malawi found that women's roles as caregivers gave them power in making decisions about purchases in the home, food, contraception, and pregnancy within relationships (Mbweza, Norr,

& McElmurry, 2008). For some women, being able to fulfill expected duties in the home produced feelings of empowerment (Bustamante-Gavino, Rattani, & Khan, 2011). As empowerment has not specifically been studied among women living with HIV in Malawi, there is utility for nurses and the development community in exploring empowerment in this context.

Study Purpose

The findings presented here are part of a study aimed at developing a substantive theory of empowerment in the lives of women living with HIV in rural Malawi. In this manuscript, a conceptual definition of women's empowerment will be presented through the perspectives of women living with HIV in rural Malawi. The development of a conceptualization of empowerment grounded in the experiences of women allows for the use of this framework as a lens through which to analyze data and construct a theory of empowerment. In so doing, the application of contextually inappropriate frameworks of empowerment is avoided. The research questions to be answered in this manuscript are: How do women living with HIV in rural Malawi describe their experiences of empowerment? What factors contribute to empowerment? What factors lessen empowerment? What do women perceive as outcomes of empowerment?

Design

Postcolonial Feminism and Empowerment

Postcolonial feminism provides a useful and valuable framework through which to study and explore women's experiences of empowerment. Postcolonial feminists argue that feminist perspectives and theorizing predominantly represent women in western or European nations that cannot automatically be generalized to women globally, particularly women situated in the Global South, as well as women in western nations who do not necessarily benefit from western capitalist states and have often been historically harmed by them through state sanctioned

genocide in the case of indigenous women or institutionalized slavery in the case of African American women (Mohanty, 1988; Mosedale, 2005; Narayan & Harding, 2000). For ethnic minority women in western nations, which include the two populations mentioned above, ongoing disinvestment in their communities along with harmful policies that impact health outcomes are among some of the issues central to feminist scholarship and activism.

The environment of oppression as specifically experienced by women in postcolonial nations is unique from that of the gender and class oppression experienced by women in western nations (Mkandawire-Valhmu & Stevens, 2007). Frequently, hegemonic feminist theorizing is also dismissive of the heterogeneity of women in the global south, as well as ethnic minority and indigenous women located in western nations. It is this type of theorizing that postcolonial feminist scholars seek to disrupt. In terms of empowerment, using a western feminist perspective risks applying inaccurate notions of “female liberation” (Mosedale, 2005, p. 245) leading to the development of interventions that are impractical and ineffective for advancing health outcomes for women who are situated differently from the women ordinarily dominating and represented within the spaces in which hegemonic feminist theorizing focuses.

Assumptions and Limitations

Personal Perspective

As first author, I gained an interest in exploring empowerment and working with women in Malawi after studying abroad during my time as an undergraduate nursing student. This experience sparked a desire to critically analyze language and media representations of women in African nations, which often described women as victims of gender oppression. These depictions did not fit my view of empowerment; rather, I see everyone as having power and agency, which is not something that is given or taken away. My view is that while everyone may

inherently have power, the perception of one's self and one's ability to make changes in their lives plays a role in whether one may use this power in action. Additionally, one's ability to use their power may be impacted by their environment, the resources that are available to them, and their social support system. In this regard, empowerment is the realization of power and putting that power to action in order to facilitate change.

In addition to having some a priori opinions regarding empowerment, I am an unmarried white, Western woman, a nurse, and a scholar who comes from a middle-income background. Thus, my positionality differs greatly from the study participants. While completely unlearning or erasing one's bias is impossible, I sought to be cognizant of my bias through continued exercises in reflexivity throughout the course of this study. The other co-authors include African immigrant women situated in the west as well as White feminist allies who along with the first author, have different life experiences from those of the women who participated in this study. Here again, reflexivity was key to confirming data analysis in a way that lent itself to the credibility of the study.

Empowerment in Chichewa

This study was conducted in Chichewa, one of the formal languages of Malawi; English is the other. Translating the word empowerment between English and Chichewa had some limitations. Empowerment may be translated to either *kupatsidwa mphamvu* or *kulimbitsa*. *Kupatsidwa mphamvu* back translated into English means, to be given power. Rather than inherently having power, this translation assumes women must be given power, presumably from another powerful agent. This limitation had the potential of focusing the current study more on external power, such as economic or social resources, rather than internalized power. To help mediate this limitation, *kulimbitsa* was also used, which translates into being strengthened. In

Chichewa, strength, rather than power, is more often used when discussing internal, mental, or emotional subjects. The decision to construct empowerment in this way for this study was based on the general accepted assumption in the literature that empowerment has both internal and external characteristics (Diener & Biswas-Diener, 2005; Zimmerman, 2000).

Method

A qualitative approach to inquiry was used in this study, guided by the theoretical perspectives of postcolonial feminist scholars such as Uma Narayan, Chandra Mohanty, and Oyewumi Oyeronke. Grounded theory methodology was selected for this study based on its usefulness for studying complex phenomena and providing direction for nursing research and practice. Feminist thinking and grounded theory are congruent in that both ideologies seek to gain knowledge through the study of women's subjective experiences. While utilizing works by Glaser, Strauss, and Corbin, a constructivist approach to grounded theory as described by Charmaz was utilized in this study. This decision was based on the practical descriptions of conducting research offered by Charmaz, which were particularly helpful for the first author, a novice researcher.

This study was conducted in conjunction with the non-governmental organization (NGO) K2 Tigwirane Manja (K2 TASO) located in the Kasungu district of Malawi. In English, *Tigwirane Manja* means, "Let us hold hands." K2 TASO provides health services for women and men living with HIV/AIDS, including HIV testing and support, and palliative care services for those who are terminally ill (K2 TASO, n.d.). To familiarize themselves with the context, the first author stayed in the Kasungu district while collecting data over the course of three months.

Following the principles of theoretical sampling, a purposeful sample of women was recruited for individual in-depth interviews. Women were recruited if they meet the inclusion

criteria: 1. Over the age of 18. 2. Diagnosed with HIV. 3. Clients of K2 TASO. Additional inclusion criteria were based on characteristics to elicit a wide range of experiences, which including age, ethnicity, religion, relationship status, time since diagnosis, economic comfort, number of children, if any, as well as any experience in conducting business or being a part of an empowerment project. A total of $n=25$ women were recruited. Consent for participation was obtained orally and women were offered a copy of the study consent in both English and Chichewa upon request. All women who were recruited participated in audio-recorded semi-structured interviews that were conducted in Chichewa through the use of a translator. Interviews were then transcribed in Chichewa and translated into English. Data were coded using initial, focused and theoretical coding. Constant comparison was utilized through comparing incidents, which included comparing specific words, phrases, sentences and experiences within the data (Charmaz, 2014; Glaser, 1978). Throughout the study, memos were kept as a record of data analysis decisions. The study protocol was approved by the Institutional Review Board of the University of Wisconsin-Milwaukee and the Malawi National Health Sciences Research Committee.

Results

Women ranged in age from 23 to 61, with the mean age being 42. Time since HIV diagnosis ranged from less than a year to 15 years, with the average of 6.7 years. All women reported having been married, with 14 currently married, 6 divorced, 3 separated, and 2 widowed. Only two women reported not having a source of income, with most women doing some form of farming, piece work, or business for money. Estimating income is difficult as it varies greatly by the time of year depending on the harvest; women were asked to approximate how much money they spent daily, which varied from MK500 ((Malawi Kwacha) less than \$1)

to MK1000 (\$1.33) daily. Of those who had an income, at the most, one woman reported earning MK200,000 (\$267) yearly and at the least, one woman reported earning MK500 (less than \$1) daily. In terms of formal years of education, ten women had zero to three years of schooling, seven women had four to six years, seven women had seven to eight, and two women had ten years.

When interviews first began, the researchers quickly recognized that the Chichewa phrase “kupatsidwa mphamu” may be difficult to work with as its meaning is very broad. Our first participant described power as being physical power and strength. To ensure this was not an isolated incident, we continued using this phrasing for three interviews. By this time, it was decided to explore different phrasing of power in order to broaden the responses we received. Through discussions with the staff at the health clinic, we changed our questions to use both phrases, “kupatsidwa mphamu”, and the phrase “kutukulidwa”, meaning empowerment. The latter phrase is often used by empowerment projects and programs in the area. Using these phrases, we continued to receive some answers focused on physical power/strength, but also received more varied answers to what empowerment meant to women and their experiences with empowerment.

The following includes findings from questions asked about women’s experiences of power, strength, and empowerment. Women were asked questions such as: What does power mean to you? Please tell me about a time you were given strength, if ever? Can you tell me about a time you felt you didn’t have empowerment? Data presented here represents initial findings of a larger grounded theory analysis. Here, focused codes are organized by power, strength, and empowerment, however, these words were often used interchangeably by women and these codes were identified across all data.

Power

Physical strength. Using the first iteration of questions with the translation, “kupatsidwa mphamvu”, meaning to be given power, women often discussed power as physical strength.

1006: [B]efore I was sick, I was very powerful and able to do a lot of farming activities without problems but when I started getting sick I saw the power in me was getting less (26-27).

1115: Power means you as a person you are well and not having a pain in your body and being able to do your activities without struggling, and in that way, you are able to know that this one, it has power (29-31).

Power to people. Another type of power discussed by women was “power to people”. While one woman described power to people in the context of receiving goats in a support group, another described it as receiving money from her relatives.

1004: [W]hen they say power to people, it means that working hard, capability of working hard, empowering each other when doing things (39-40) ... Like when they have given us the goats (short pause). After we have been given, we also need to give someone, so in that we are benefiting a lot from the [support group], if we have a problem, we just sell a goat and solve the needs of the house (91-92).

1009: Power to people it means there are people who are assisting you for you to have a healthy life (65) ... Power to people is like if I am sick and someone sends money to me, and at the same time, I will take the money, maybe I will come here to the hospital to receive the treatment, in that way, that money will end there (116-117).

In the former example, it appears this woman felt more powerful, potentially due to the sustainable nature of the help she received. When receiving goats, she was given a resource that she could continue to sustain through breeding. Comparatively, in the second example, this woman only received money that was quickly used and depleted. She was left still in need. When prompted about whether she felt empowerment and power to people were different she said of empowerment:

1009: If am given capital to start up a business so that I can be able to take good care of my children and in that way it means that person has empowered me and has assisted me

to have the needs of my home so that I should not suffer because am living a hard life (94-95).

While of power to people she stated:

1009: The only power maybe is that they send me money and that is the only power. And I use that money straight away (82) ... But in my life if there can be a chance for me to stand on my own and get my needs without begging from my relatives for help, that's what I wanted, to have a home that I will be able to do things by myself (117-119).

Power and strength walk together. Throughout data collection and analysis, descriptions of the three key words, power, strength, and empowerment, were compared to understand whether there were distinct differences. These could not be clearly separated as explained in a conversation with one participant:

1004: When we are given power, it affects us in the way that, it is like you have put your life in the front, they encourage us to be doing things that makes our life to be going very well (162-163).

When a follow up question was asked about how power and strength are related, the participant responded,

1004: Yes, they are related because to be given power and strength it walks together (202). . . Its related because when they have given you strength your life goes on well and you become a free person and this makes you to be doing your things at your house freely and also it is the same when you meet with your friends at the [support group] (207-209).

Strength

Giving and receiving encouragement. Many women described strength in terms of receiving encouragement from others. Encouragement came in the form of women receiving advice or instructions for caring for themselves, being encouraged to work hard, as well normalizing their experiences of living with HIV.

Receiving Advice or Instructions. Women often received advice or instructions about caring for themselves through counselling at health clinics or support groups.

1004: We are given strength in the way that we have met, they encourage us to be coming to the hospital to get our medicine, we should not forget to be taking our medicine every day and if we get sick, we should rush here to [health clinic] (101-102).

1007: There are many kinds of strength, people can encourage you on how you should be taking your medicine, and at also at the hospital, they give us a lot of advice and when we listen and apply it, with the encouragement we see that we are having a happy life (506-508).

Using Strength in Action. A few women pointed out that it was important to be an active participant in receiving advice or instructions. Meaning, it was not simply that women were being given encouragement to do something, but that women actively acted on what they were advised:

1119: People can tell you, do this so that it can help you, but you are not focused, not doing those things, it means you don't have interest. They tell you take this and do that, maybe it can help you in this way, but you are not doing it, are you showing your interest? (99-102)

Other women focused on the importance of receiving encouragement and working hard to achieve something:

1118: To be encouraged means working hard, not with absentism, doing a thing with strength (737-738).

1006: [I]t is like when you want to do something, but you are failing to do it by yourself, so someone comes and gives you courage of doing it, more like helping you to achieve that thing (105-106).

1123: To be strengthened, it's like you are improving, if you were doing something less, you change and increase your effort to prosper in that thing (264-265).

In addition to working hard, some women felt receiving strength also was useful in overcoming challenges.

1124: Being given strength would mean that, say your business was going down and you decide to quit. So, when one advises you against quitting, and you don't quit, you have been given strength (208-210).

1125: Strength means giving you strength in how you do things. If things happen not in a good way, you don't have to be weak, don't get pushed back, but progress. So, I'm encouraged to work hard (428-430).

Normalizing. When discussing strength and receiving encouragement, many of the women spoke of others helping to normalize their living with HIV. Women were reminded that

they were not alone, that many others have the same diagnosis, and that this is not the end of their lives.

1003: When someone comes and gives us strength, saying that you are not the first one who is positive, there are a lot of people. Life goes on, and keep on taking your medication, it is when we feel better (282-283).

1124: The time my husband was sick, his sister came over from [village]. I told her about the illness, how it started and all. She said don't worry, it's not the end of one's life so long you know what you're suffering from. Just be competent with the drugs as advised at the hospital. There are lots of people you will find at the hospital with the same condition. Some park their cars and you can't even think that they are in the same program as you (218-222).

1007: I was given encouragement that you should not just look at us here hospital workers, we are also in the same situation just like you, this was like they gave me strength (273-275).

1004: Before coming here, that time I was worried and shy and when we went for the test, they started counselling me. They said that this illness is not the end of you and your life is going to continue sure, don't have worries, just keep on taking your medication properly (110-112).

The above excerpts indicate that women were empowered in the knowledge that there was nothing inherently the matter with them that led to their ending up with HIV infection. The excerpts also suggest that women were empowered in the knowledge that HIV is not an infection exclusive to poor women with limited formal education like themselves; rather, it is an infection that equally affects healthcare providers who have formal education as well as people who they deem to be better off like those who drive cars.

Empowerment

Overcoming discrimination. Women discussed both gender-based discrimination and stigma they experienced that was mitigated by empowerment:

1120: To me being empowered means different things; for instance, when we were at the [market] there was discrimination, but when I started being part of a group, I was empowered because I was being encouraged and I felt great. Right now, I am not worried

because when we come [to the support group], we learn a lot and we are given strength and are no longer discriminated, everything is fine (26-30).

1115: They tell us that we have all means for us to work hard and get our household needs. While in the past, other people thought that since I am on medication, it means I am already dead, so they didn't want to work. But now things are different, we are empowered to be able to do things by ourselves and now people do not discriminate us like in the past because we are able to do things by ourselves with the empowerment that we are given (40-43).

1120: I see a lot of change in my life in a sense that what I couldn't do back then, now I am doing because of my focus group participation. There is power in these groups because we are empowered, because they say we should not leave it all to men, but rather do it together equally. So right now, even if I am independent there is nothing I can't do. I can do it with all my heart, even if the man is not around, I know that I have power to do anything (98-103).

Developing the household. One woman, when asked what empowerment meant to her, stated:

1121: Of course, the word empowerment means household development (58).

This sentiment was reflected in the stories of several other women who brought up development in terms of community development activities, empowerment programs through which people are given micro-loans, fertilizer or livestock, and how these contributed to helping women develop their homes:

1114: The first thing is that you can be empowered through farming or maybe to be given like the livestock or other kinds of help (85).

1122: For me to say I have been empowered, I'll have to say that I have been given adequate fertilizer, which means things will be good in my home, which means I am ok if I am not lacking anything (89-91).

1124: I may say empowerment, as I said I do business. You had 10 thousand and you could loan from some organization and they give you 20 thousand. You had less and now it is more. When you add it up, it boosts your business. That's being empowered (75-77).

Not only was household development supported by programs that gave monetary and material assistance for women, but development was supported by the hard work and actions themselves:

1123: The word being developed means that if you had a little capital and we are given a top up like given loan from micro-loan. It happens like we are given a capital that help us to boost our business, we should be happy, we should eat at home, we should send well our children to school, buy them clothes well till all the necessary cares are available at home that's what it means to be empowered (40-44).

1119: To be empowered...it depends with the way your household is for example, maybe your household is very poor, so it needs you to work extra hard for your household to improve for better (41-43).

1118: The word empowerment means doing businesses, when doing businesses, it's like you are contributing towards helping the house by buying salt, soap and you work extra hard that the house has everything which is needed (426-428).

1115: Empowerment... to me I think it is like the when we have come to the group, we are told to be working very hard in our homes so in that way we cannot lack things in our homes. So in that way it means they are empowering us to work hard and get the needs of our households easily, it means if we are not working will not find the our needs it's like they support us to work hard even if we are on medication we need to be strong than just staying and that also makes the body to be weak (37-40).

One woman summarized these two facets of empowerment, the first in which women are given something that assisted them in developing their household, and the second in which women are actively working and participating in this development:

1116: To be empowered it is in two ways (Tr: umm), sometimes it happens that they could find you at your house and they will knock and you answer them, they greet you and you also greet them back. Then they ask you if you have eaten on that day and if you tell them that you haven't eaten anything, then you see them bringing food to you, then you just see them bringing a basin of flour to you. They also give you money and those people who do everything like this are not even your relations aah aah no. Sometimes they give you fertilizer, you should farm and sometimes they give you soya bean seeds for you to plant so that you could depend on yourself (50-54).

Power, Strength, Empowerment and Health

Taking medications accordingly. When discussing strength, several women brought up being encouraged to take their medication appropriately and working hard to do so:

1009: Strength is when someone has given me something to go and do. Something in life, for something that am given I will be working hard on it. If it is medicine, I will be working hard taking the medication accordingly like the way they tell us at the hospital, maybe to be taking the medicine to be taking it twice a day afternoon and evening. Yeah that is being given strength, only that there it has a lot of meanings (127-130).

Being without worries. Living with HIV naturally brought about stress and worry in the lives of women; however, women explored how strength helped to mitigate these worries.

1006: Strength, there are different kinds of strength, for example, there is a group of us who have this disease. Sometimes different people give us strength because sometimes we think of just killing ourselves, it happens. But when we meet with people that give us encouragement like every day, in that way, our life changes for better. We start living like we were in the past (97-99).

1117: Being encouraged means that when you are in social groups you feel supported and you throw your worries away (87-88).

1007: So you should not have worries, when I first started the medication, when I went to hospital I met a lot of women who started the medicine long time ago, they encouraged me that this is not a problem. I should just work hard taking my medication properly and everything will be fine. Sometimes when I stayed, I was thinking that am I going to get better or maybe I am going to die, so I was told that you are going to be fine when you have started the medication you will be okay, so I was encouraged in that way so sometimes it a good thing and it makes your life to be strong sure (521-525).

1120: Right now, when am living, I just live like a mere person and even saying things like you doubt yourself saying that the way I used to before. Well right now I see that being strengthened has changed my life every day. These days my life is changing because frequently I am always happy. There are no days when I am unhappy. There is no day that I have problems. I am always happy (125-129).

This point was reinforced when women were asked if they felt being without strength impacted their health:

1001: When I don't have strength I normally have bad thoughts. It is because I was not encouraged. When I have been given strength, I always have good thoughts (265-266).

1121: If I were not to be encouraged, I could have died with worries (210).

Discussion

The goal of empowering women is one that is common in the development literature. When conducting empowerment research among women living in low-income African countries, it is particularly important to avoid perspectives that perpetuate western stereotypes representing women as victims of oppression without capacity or agency (Mohanty, 1988). In the literature, women who are targeted through empowerment programs or interventions are commonly

referred to as being disempowered, uneducated, or in a state of development (Mohanty, 1988). A postcolonial feminist perspective assists in deconstructing these depictions by highlighting the strengths of women in the global south.

In this study, power, strength, and empowerment were used to construct interview questions and to guide the construction of a conceptualization of empowerment among women living with HIV in rural Malawi. An analysis of individual in-depth interviews with women demonstrates that women experience empowerment through encouragement from others and from within, through material assistance, and through their own hard work, bettering their households. Through empowerment, women's medication adherence and mental health outcomes may be positively impacted.

Empowerment is important in the lives of women as it contributes to the development of their households. Presently in the Kasungu district of Malawi, programs exist that provide goats, fertilizer or microloans to women. For example, in goat programs, a number of men and women within a support group are given a goat. Each person is expected to breed this goat and once it has offspring, pass the goat onto another member of the group. In this way, each household receives a goat that can continue to breed or be sold for income. Through these programs, women in this study had resources to buy food and goods for their homes or to send their children to school. When describing these experiences of empowerment, women described not only a single moment of receiving assistance, but a process in which they are assisted to create sustained improvements in their lives.

Women are active participants in this process; they spoke of having to work extra hard to improve their lives, a process that was facilitated by receiving outside assistance, but did not necessarily depend on it. Meaning, even if women did not receive material assistance in the form

of a loan, for example, women could still work hard to improve their lives, and this could be seen as empowerment. These findings are reflective of critical analyses of development literature in which access to resources as a source of change is overemphasized (Cornwall & Rivas, 2015), particularly when material resources are discursively assumed to be all women need to advance their lives. While material assistance is certainly important for women, particularly for women in low income communities, our findings demonstrate that sustained change and being able to depend on oneself were what women valued most.

Having the courage and motivation to work hard was bolstered by encouragement from healthcare professionals and support groups for women living with HIV. Women used this courage to continue working hard to improve their lives, even when faced with setbacks, such as businesses failing, stress and worry, or experiencing social discrimination related to their status. Empowerment is not as simple as having social support and counselling, but women actively taking in that support and acting on it. In this way, women play a dynamic role in their own empowerment. These findings are particularly useful in the context of women living with HIV in the Global South, as such women experience intersections of vulnerability, which inherently create a need for coping with hardships and the development of effective interventions that would enable them to cope.

While a postcolonial feminist lens assists in centering the capacity of women, it also allows for contextualizing women's experiences, rather than assuming a universalizing view of women in the global south. In so doing, the historical, political, and societal contexts that contribute to hardships in the lives of women are distinguished, revealing areas of improvement in developing interventions and policies. In the development literature, empowerment is often discussed in terms of economic independence, education, household decision making, mobility,

or political participation (Miedema, Haardorfer, Girard, & Yount, 2018; O'Hara & Clement, 2018). In the current study, we found that women focused on their own hard work and determination with the end goal of economic stability in mind as evidenced by being able to care for their home and children. These findings contribute to an analysis of empowerment that could lead to interventions and policy that best fit the current needs and desires of women living with HIV.

Critiques of the development literature often focus on economic empowerment as the sole method of arriving at gender equality (Cornwall & Rivas, 2015; Scheer, Stevens, & Mkandawire-Valhmu, 2016). This discourse emphasizes economic power in relation to empowerment, and women as an untapped market of monetary potential (Scheer, Stevens, & Mkandawire-Valhmu, 2016). Women in the current study demonstrated their desire and ability to work hard in becoming economically independent. Beyond capacity, it is important to consider the barriers that impede women's ability to advance economically. For example, in the goat program, according to study participants and staff of K2 TASO, there are many ways in which the program may not operate effectively. Having livestock in rural Malawi is difficult as goats are at risk for developing disease. While veterinarians and vaccines exist, these can be quite costly and difficult to obtain. There are instances in which a goat may have a stillborn and still, the woman must pass on the goat, so she does not receive any benefit. There are also instances in which someone is given a goat and then leaves town, delaying or inhibiting several people within a group from ever receiving livestock. Further, there are times when continuing to breed goats is simply not possible as they must be eaten or sold in order for families to eat, particularly when the goats represent the only asset that women and their families have for dealing with shocks or

other crisis such as illness or death. Projects focused on economic empowerment must take these contextual factors into consideration in order to achieve substantial and sustainable outcomes.

Taking into account that empowerment has implications for not only gender equality but also for women's health, nurses need to gain an understanding of this concept and to work across disciplines to determine effective interventions that are culturally relevant in empowering women in ways that are most meaningful and most impactful. Nurses can continue to support empowerment efforts among women living with HIV in Malawi by identifying resources that help foster women's strength, determination, and courage. Women mentioned counselling at health centers and support groups for people living with HIV as empowering through normalizing the experiences of living with HIV. In developing programs to empower women, bolstering access to existing social networks, or fostering new relationships should be considered. Previous studies have demonstrated the advantages of relationships between women (Mkandawire-Valhmu, Kako, Kibicho, & Stevens, 2013), women in the current study did not specifically mention relationships they had with other women. Rather, they spoke of support groups in general, which are open to both women and men. It is possible that support groups for women may provide additional levels of support, such as strategizing and problem-solving gender-based issues (Mkandawire-Valhmu, Kako, Kibicho, & Stevens, 2013), and this should be explored further.

Limitations

As Malawi has a free universal healthcare, all women in this study had access to healthcare and ART through a nearby health clinic. The clinic affiliated with K2 TASO, which is where women were recruited, is donor funded with the ability to provide resources to clients in the area, albeit limited as it caters to a large catchment area. Resources provided included

transportation assistance, food assistance during times lean or hunger seasons and palliative care for clients as needed. K2TASO is also responsible for coordinating the HIV support groups of which the women participating in the study were a part. This level of support is not ordinarily available to rural Malawians in the rest of the country especially taking into account that K2TASO provides support that is uniquely comprehensive in nature with most non-governmental agencies in the country focusing on a specific aspect of support like nutrition or health. It is important to review our findings with this perspective. Additionally, all but one of the women in this study were part of a support group for people living with HIV, and some of the women were recruited at the site of a support group meeting. For these reasons, discussions of support groups may be overemphasized in this sample.

Conclusion

The study showed how empowerment among women living with HIV in the Kasungu District of Malawi is fostered by relationships between women and others living with HIV in support groups as well as healthcare professionals, through encouragement and normalizing of their experiences. In discussing empowerment, women brought up a desire to be able to depend on themselves for economic stability. This challenges development and aid agencies to consider the sustainability of empowerment programs and interventions focused on solely providing material assistance to women. Based on our findings, receiving material assistance alone may not enable a woman to experience empowerment. Women in this study demonstrated a capacity and desire to work hard and to improve their own lives. Efforts focused on empowering women should seek to continue breaking down barriers to women achieving their goals, including the larger contextual factors that may inhibit sustained success.

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MANUSCRIPT III: Putting Your Life in the Front: A Theory of Empowerment Among Women Living with HIV in the Kasungu District of Malawi

Abstract

Women's empowerment remains a goal in development and gender equality discourse, though few studies of empowerment have been conducted among women living with HIV using a framework of empowerment developed with the same population. The aim of this study, informed by postcolonial feminism and utilizing a grounded theory methodology, was to construct a substantive theory of empowerment among women living with HIV in the Kasungu District of Malawi, Africa. This small landlocked country in southeast Africa is located within one of the hardest hit regions by the HIV epidemic. With a population of 17.56 million (National Statistical Office, 2019), 8.8 percent of the total population and 10.8 percent of women are living with HIV (MDHS, 2017). A theory of empowerment among this population informs efforts to support the health, wellness, and material assistance of women living with HIV in the global South. Findings include the process of empowerment women go through of *Putting Your Life in the Front*. Three core categories within this process are explained: *Protecting Health*, *Working for Household Development*, and *Giving and Receiving Encouragement*. Implications for policy, practice, and research are discussed in light of these findings.

Introduction

Women's empowerment has been widely studied across a variety of disciplines and utilized within many contexts and populations. Despite the existence of a substantial body of literature on empowerment, theoretical, conceptual and methodological issues surrounding the study of empowerment continue to exist. Gaps in existing literature include limited studies of empowerment specifically among women living with HIV informed by a feminist perspective. There is also a lack of theories of empowerment focused on the health and wellbeing among

women living with HIV. A postcolonial feminist perspective was used to guide this study and to provide a framework through which to situate empowerment in the context of social, political, and institutional systems that impact the lives of women living with HIV in rural Malawi.

Background and Significance

Empowerment has a long history of use in academic research and literature, as well as policy, especially in the contexts of health, workplaces and organizations, as well as in development discourse. Within health research, empowerment has been included in a wide range of studies focused on both psychological and physical well-being of individuals, families, and communities. Studies on empowerment and health have been conducted in the context of reducing intimate partner violence (IPV) (Dalal, 2011; Kim et al., 2009), and health promotion related to HIV and STD prevention (Swendeman, Basu, Das, Jana, & Rotheram-Borus, 2009). Empowerment has been linked to a decrease in depression (Rahman et al., 2012), increase in self-efficacy (Grabe, 2012), self-worth (Swendeman et al., 2009), and autonomy (Hunter, Jason & Keys, 2013).

Across several disciplines including community psychology and nursing, empowerment is used in the context of work environments, focusing on organizational structures of power, team empowerment of co-workers, empowerment of individual employees, and leadership development (Laschinger, Read, Wilk, & Finegan, 2014; MacPhee, Skelton-Green, Bouthillette, & Suryaprakash, 2012; Seibert, Wang, & Courtright, 2011). In the development arena, empowerment has been used as an indicator for gender equality, and to measure levels of national development, particularly in low and middle-income countries (United Nations, 2008). Often, the concept of empowerment is used specifically in relation to women and may be used interchangeably with women's empowerment.

Between the 1970s and 1980s, many definitions of empowerment still used today emerged out of community psychology, development, and community participatory research. In his often cited 1984 work, Kieffer defined empowerment in terms of development as the achievement of “multidimensional participatory competence”. As a community psychologist, Kieffer’s definition of empowerment centered on individual empowerment in the context of affecting broader community and societal change. His definition of empowerment was developed through in-depth interviews with grassroots activists and did not focus solely on women as targets of empowerment. Other definitions of empowerment during this time reflected similar ideologies and centered on empowerment in relation to the social and political environment; for example:

Empowerment is an intentional, ongoing process centered in the local community, involving mutual respect, critical reflection, caring, and group participation, through which people lacking an equal share of valued resources gain greater access to and control over those resources (Cornell Empowerment-Group, 1989 as cited in Zimmerman, 2000, p. 43).

Also, during this time, other community psychologists like Rappaport acknowledged empowerment as a process through which individuals gained control and mastery of not only their lives, but also organizations and communities (1984). Again, these definitions of empowerment were targeted not solely on women, but on communities and groups. In the context of social change, it was believed that marginalized groups, including women, were in need of empowerment. However, this could not effectively be achieved without acknowledging the broader social and political contexts that played a role in creating environments that sustained marginalization.

Over time, definitions of empowerment in the literature began to primarily focus on the empowerment of individuals or groups of individuals, separate and without relation to the broader contexts of change reflected in earlier definitions. In social psychology, scholars tend to

separate individual, group, or community empowerment. When focusing on individual psychological empowerment, definitions were mostly conceptual in nature, and included constructions of empowerment in terms of self-efficacy, self-determination, and competence (Spreitzer, 1995).

The development literature has also seen a change in definitions of empowerment over time. During the 1990s and 2000s, the concept of women's empowerment was a central focus in development. Generally accepted definitions of empowerment during this time included implicit and overt references to concepts such as control, choice, and decisions. For example, in 2005, empowerment was defined as “a process of increasing capacity of individuals or groups to make choices and to transform those choices into desired actions and outcomes” (Alsop & Heinsohn, 2005). However, new definitions appear to reflect shifts toward older definitions rooted in broader political change. A recent definition of empowerment released by the United Nations states:

“Empowerment . . . is an iterative process with key components including an enabling environment that encourages popular participation in decision-making that affects the achievement of goals like poverty eradication, social integration and decent work for all as well as sustainable development” (2013).

In nursing, definitions of empowerment reflect conceptualizations that include patients and the role of the nurse and relate to health behavior change. For example, “empowerment is a social process of recognizing, promoting and enhancing people's abilities to meet their own needs, solve their own problems and mobilize the necessary resources in order to feel in control of their own lives”, including their own health (Gibson, 1991).

Conceptual, Methodological, and Theoretical Challenges

The unique definitions across disciplines help to illuminate some of the conceptual, methodological and theoretical challenges to studying empowerment in relation to health. These

challenges can be lumped into three categories that are conceptual, methodological, and theoretical in nature: Who needs empowerment? How is empowerment measured? What does empowerment do?

Who needs empowerment?

Conceptual disagreements across and within disciplines continue to exist regarding whether disempowerment is an antecedent to empowerment. Does one have to be disempowered to experience empowerment? This definition can be problematic when used in the context of international development where empowerment efforts often target women living in low-income countries. Conceptualizing empowerment where disempowerment is an antecedent in this context misrepresents women living in low-income countries and assumes all women in these contexts are inherently disempowered and without power or capacity (Mohanty, 1988). Definitions that generalize to large groups of people, particularly women, without attention to context are often the center of critiques by Third World feminist scholars, such as Chandra Mohanty. Beyond rhetoric that constructs women as disempowered, requiring one to be disempowered to experience empowerment has the potential to exclude individuals and communities that could benefit from empowerment interventions. For example, if disempowerment is defined in terms of poverty, policies and interventions for empowering persons would in turn target those who are poor. However, this would not address populations who feel disempowered as a result of factors other than poverty.

Naila Kabeer, a feminist scholar who focused on gender, poverty, policy and economics, has attempted to ameliorate some of the issues created by assuming disempowerment as an antecedent of empowerment. She defines empowerment as, “the process by which those who have been denied the ability to make strategic life choice acquire such an ability (1999, p. 437).

To Kabeer, someone who has lived their entire life having the ability to make choices about their own life would not be *empowered*. Rather, one would first have to be disempowered and then gain the ability to make choices to be *empowered*. Here, choices are strategic life choices, such as where to live, whether to have children, and freedom to work and associate outside the home. This definition is useful as it makes sure those who are most in need are targeted in empowerment interventions; however, it uses a predefined framework of disempowerment, which may not necessarily be appropriate. While some women, for instance, may feel disempowered by gender roles or religious ideologies that are perceived as restrictive, other women may feel empowered by the same roles (Bustamante-Gavino, Rattani, & Khan, 2011).

How to measure empowerment?

Measuring empowerment is difficult as it is a process and can only be measured by its outcomes. There is little consensus about what these outcomes should be. Across disciplines, conceptualizations of empowerment often include a component that centers on decision-making and making choices regarding one's life. However, the types of decisions empowerment refers to are often ambiguous and poorly defined. In the development literature, the decisions focused upon are those made within the home regarding how monies are spent, the ability to leave the home when desired, and decisions about whether or not to have children. Some have contended these definitions are inaccurate for application across populations as not all women desire to have complete power over all decision-making in the home (Zimmerman, 2000). Additionally, there is a value-laden aspect implied in some empowerment definitions and operationalization. When empowerment is measured by whether or not women make their own decisions, there appears to be a standard by which women, across geographic borders and across racial/ethnic

and class identities, are being compared. There is thus little room for women to define empowerment by their own standards.

Nursing science can play a role in advancing definitions of empowerment toward conceptualizations that are more appropriate across populations. In her 1991 concept analysis of empowerment, Gibson emphasized the need for nurses to acknowledge patients' capacity to make decisions about their health, and to respect what those decisions might be, regardless of content. Meaning, patients may be considered as having experienced empowerment if they have increased their ability to make decisions about their health or healthcare, regardless of whether healthcare providers agree with those decisions. Taking this same idea and applying it to other contexts in which empowerment is used, may allow more contextually appropriate measures of empowerment.

When measuring empowerment, it is important to separate individual empowerment from that of family, community, government, or broader areas of empowerment. In the development literature, empowerment is often conflated with goals for social justice, reform, and equality. However, having equal representation of women in government, or having land laws that are equal for both men and women does not capture the entirety of empowerment. These measures are significant, as they relate to structural realities that impact women's lives; however, they do not measure whether women's personal power has increased or whether women have greater control over their lives. Thus, these measures fail to provide specific data related to individuals and contexts that would be useful for designing empowerment interventions. Without specific measures for empowerment, appropriate interventions for supporting women cannot be designed, and empowerment cannot be better understood. Individual empowerment must be

conceptualized and operationalized by context. As empowerment is an individualized process, it must be understood through the realities and perspectives of individuals.

What does empowerment do?

Empowerment is indeed a complex, dynamic concept, and thus difficult to conceptualize and operationalize. In turn, it is difficult to determine causative associations and to utilize in theory and praxis. It is unclear if empowerment should be used as an intervention, a means to an end, or an outcome. It is also still unclear what exactly empowerment *does* and what impact it has. To explain, I will use empowerment in relation to health, in the context of intimate partner violence (IPV) and HIV among women. Women experience IPV, which increase their risk for sexual abuse, rape, and subsequent HIV risk, through controlling behaviors that inhibit negotiation for safe sex (Andersson, Cockcroft, & Shea, 2008). The empowerment of women has been suggested as a means to decrease IPV and HIV risk among women (Kim et al., 2007). Much of the literature exploring the relationship between women's empowerment and IPV has focused on economic and financial empowerment, women's capacity to earn money and to control how money is spent.

Although some authors have found financial empowerment as being a possible protective factor against IPV (Kim et al., 2007), others have found that women's monetary access may threaten men and lead to increased IPV against women (Balasubramanian, 2013). Several studies have also demonstrated a limited interaction between economic empowerment, IPV, and HIV infection, suggesting the need to explore additional factors, which could be thought of as dimensions of empowerment, such as education and social support (Dalal, 2011). The Intervention with Microfinance for AIDS and Gender Equity (IMAGE), conducted in South Africa, was designed to offer economic interventions, in conjunction with methods to reduce IPV

and HIV. After two years, researchers found that these interventions positively affected women's empowerment, IPV and HIV risk behaviors, such as condom use and communication about HIV with partners (Kim et al., 2007; Pronyk et al., 2008). Another study conducted in Côte d'Ivoire integrated an economic empowerment savings program with gender dialogue groups offered to women and male partners and found significant reductions in economic abuse among women (Gupta et al., 2013). These studies demonstrate possibilities for successively impacting IPV and HIV risk behaviors through empowerment interventions. However, there is limited evidence to support causative relationships between empowerment, IPV and HIV risk, and it is unclear whether these interventions could be successfully replicated across populations without harm.

Across the literature, empowerment is discussed as necessary to improving health and wellness among individuals and groups; however, models of empowerment have been under tested and its mechanisms of action are poorly understood. Few theories of empowerment have been presented in the literature. Most discussions surrounding empowerment do not go beyond conceptual frameworks. For example, decision-making power, communication skills, personal strength, self-efficacy, mobilization, education and financial stability are all concepts often considered in relation to empowerment, though it is unclear whether these are facilitators or outcomes of empowerment. Factors that impact empowerment, such as gender norms, structural and institutional inequalities, are often discussed as barriers that negatively impact women's lives; however, these have also not been tested as barriers, moderators, or mediators. Empowerment itself has been used in research as an intervention (Swendeman et al., 2009), tested as a moderator (Rahman et al., 2012), and used as measurement of developmental success (United Nations, 2008). In order for empowerment to become a more useful tool for nurses and healthcare providers, a formal theory of empowerment is needed. The purpose of this study is to

develop a substantive theory of empowerment in the lives of women living with HIV in rural Malawi.

Design

Postcolonial Feminisms and Empowerment

Postcolonial feminisms arose out of critiques of feminisms that often-depicted women in low-income nations as victims of patriarchal societies and culture, who are in a state of development, lacking knowledge or capacity (Mohanty, 1988). Through their work in Kenya and Malawi, Mkandawire-Valhmu, Kako, Kibicho and Stevens (2013) challenge these notions and demonstrate women living with HIV in low-income countries are not victims, but rather are women who have the capacity to overcome obstacles and promote change. It is necessary to acknowledge the political, economic, and social environments which oppress women, but that is not to say that women are always victims of this oppression. By putting women's perspectives at the forefront, the social, economic, and political contexts in which they live are not ignored; and the risk of inaccurately portraying women and woman's experiences is reduced.

Decontextualizing women's empowerment can have negative consequences. In 2010, Anyidoho, and Manuh reviewed how women's empowerment was framed by several organizations working toward women's rights in Ghana. These organizations focused on economic empowerment and education while ignoring the political and social environments in which the women lived, thus assuming financially wealthy women were not disempowered, and that women who were educated would automatically be equipped to enter the political arena and become empowered (Anyidoho & Manuh, 2010). Microfinance or economic empowerment programs in other countries led to women being less empowered and at risk for violence, as the women did not maintain control of their earnings, or gave loans to their husbands, which were

then not repaid (Balasubramanian, 2013; Goetz & Gupta, 1996). In countries where gender inequalities are deeply rooted in social and institutional structures, MacIntyre and colleagues (2013) state, “It would be naïve to assume that women should simply stand up, speak for themselves, and confront situations that challenge their power” (p. 112).

Conceptualization of Empowerment

In part one of this two-part article, a conceptualization of empowerment, grounded in the experiences of women living with HIV in rural Malawi was developed. To summarize, women were asked to describe what power, strength, and empowerment meant to them, as well as their experiences with these concepts. Women described the importance of receiving encouragement and support from others through normalizing the experiencing of living with HIV, emphasizing that the diagnosis does not mean they are dying. This encouragement gave them courage to overcome discrimination and stigma they faced and inspired them to work hard toward developing their households. Women sought to stand on their own and be able to depend on themselves to meet their needs. This conceptualization provided a lens through which to analyze data further and construct a theory of empowerment.

Method

This study was conducted using a qualitative approach and a constructivist grounded theory methodology as described by Charmaz (2014). Through theoretical sampling, $n=25$ women were recruited. All women were clients of the K2 TASO non-governmental organization (NGO) located in the Kasungu district of Malawi. Inclusion criteria included 1. Over the age of 18. 2. Diagnosed with HIV/AIDS. 3. Clients of K2 TASO. Following the tenets of theoretical sampling, it was intended that women would be further purposefully selected for inclusion in the study in order to gain a variety of insights as represented by differences in demographic data and

experiences. Due to time restraints, this was not possible and all women who expressed interest in the study were recruited; fortunately, this sample was robust and theoretical saturation was met. Theoretical sampling was applied to recruit participants who had experiences doing business or receiving microloans, livestock, or other resources through projects or programs. The study protocol was approved by the Institutional Review Board of the University of Wisconsin-Milwaukee and the Malawi National Health Services Research Committee.

Results

Demographics

Participants ranged in age from 23 to 61, with the mean age of 42. Time since HIV diagnosis ranged from less than a year to 15 years, with the average being 6.7 years. Each woman reported being married at least once, with 21 of the women having had one or two marriages, three women having been married three times, and one having been married six times. When discussing marriages, women were asked if, when married, they were living in their home village or the home village of their husbands. This was done in an effort to track matrilineal or patrilineal households. In Malawi, women coming from matrilineal cultural backgrounds will often have husbands move to their home villages, where women's relatives live as well; alternatively, patrilineal cultures will have women move into their husband's home villages where his relatives are living. In this study, 14 women had moved into their husband's village, while five had husbands move into their villages. Four women reported that together, her husband and she moved to a new area, two reported differences across marriages, and for six women, it was unclear or unable to be determined if she followed a matrilineal or patrilineal tradition.

All but two women reported having some source of income through farming, piece work, or business. While measuring economic security is difficult, women were asked to estimate the amount of money they made or spent on a daily, weekly or yearly basis, to the best of their ability. More than half of the participants reported making or using less than MK1000 (\$1.33) daily. Between the 25 women, one had no living children, 11 women had one to three, 12 women had four to six living children, and one woman had nine; 14 women reported having had at least one deceased child. In their households, there was an average of 4.4 people, including themselves. Ten women had less than three years of formal education, fourteen had four to eight, and two women had ten years of schooling. Nineteen women reported their ethnicity as Chewa, with the remaining being Sena, Mangianja, Tumbuka, Nkhotakota, and Ngoni; all women stated they were Christian.

Findings

In describing their experiences of empowerment, three major categories emerged, *Protecting Health, Giving and Receiving Encouragement*, and *Working for Household Development*. Each of these categories are relational to each other, as women receive encouragement, they have increased courage, strength, and guidance that assists them in protecting their health and working for household development. Additionally, through acting to protect their health and work for household development women gain insight and strategies that relate to giving encouragement to others. This overarching process, encompassing these three categories was entitled “*Putting your life in the front*”, following this quote by participant 1004 who, when explaining what power meant to her stated, “When we are given power, it affects us in the way that it is like, you have put your life in the front, [people] encourage us to be doing things that make our life to be going on very well” (162-163)”.

Protecting health. Women found a variety of ways to protect and care for their health. For women living with HIV, this process began with being tested and learning their status. Many of the women sought testing after feeling sick and had some inclination they may have HIV.

Volunteering for testing. Participant 1113 explains that she was feeling unhealthy and getting sick frequently, which prompted her to come for testing:

At first, I was having a lot of thoughts about what will happen if I go for the blood test. . . Then I sat down and said, ah ah, I think I should go to the hospital for the blood test so that I should know what exactly is bothering me, [rather] than going to the hospital every time. At least now I should see the way forward, this made me ready for my results. . . And then I voluntarily came for the blood test because my heart was willing to do that.

Participant 1115 also voluntarily went for testing after being sick and not getting better when taking medications, but when she first went, she did not go through with testing. With some encouragement from her husband, she returned for testing the next day:

So lucky enough I heard on radio, they were announcing that if you are sick and getting treatment, but things are not changing it is better to go for blood test (284-285) . . . Then I thought about it, I was like the way they were saying on the radio, I am taking the medication, but nothing is changing, then I told my husband that I need to go to the hospital. . . He gave me transport money to go for the test, the first time I went there, I entered the hospital with fear. Then I asked myself, should I go for the blood test, then I found myself on my home, I didn't do it. My husband asked me, I thought you went to the hospital today, then I said yes, but I did not go for the blood test, I ran from the doorstep. Then he told me to go again. Next day early in the morning, I went back to the hospital and I was prepared for anything (288-293).

Receiving testing during antenatal care. Women also learned of their status was through mandatory testing during antenatal care. In Malawi, women do not have the option to refuse HIV testing if they are receiving antenatal care. If they want to refuse testing, their only option would be to decline antenatal care, or give birth outside of the formal healthcare sector. However, fines and penalties exist to dissuade women from doing so. Unlike the women who volunteered for testing, some women felt ill prior to being diagnosed while pregnant, while others did not.

1111: I went to the hospital with the pregnancy of this baby for testing. . . My life was healthy only that I started to feel cold when I was carrying the pregnancy of this baby.

1120: Before being tested, I was living a good life because I wasn't suspicious about anything. But after getting pregnant and being tested, I was found positive and I had worries for a few days, but after I started coming to the [support] group, all the worries were gone, and I have a good life (366-369).

After being diagnosed, women describe coming to accept their diagnosis. As one woman, who learned of her status during antenatal care, put it:

1123: I was strengthened from [the] hospital, it was a moment when I was pregnant, I visited [the] hospital, when I got tested for HIV and AIDS and found positive. I was counselled to say being HIV positive is not the end of all or end of life, but you need to start a new life (278-280).

Starting a new life: Accepting diagnosis. When discussing their experiences of being diagnosed, some women stated that they simply accepted, seemingly doing so in the moment that they were found to be HIV positive:

1113: I just accepted, I wasn't even having any worries and it was because I accepted the situation (222).

1009: I just accepted it, I suffered, but I accepted it has come, and there is nothing that can change it (218-219).

1126: I just took heart and accepted that what's done is done (46).

1122: The time I was told that I was positive, I just accepted, that it was the will of God, I did not want this situation therefore I should just receive treatment for me to have a healthy life, so they gave me the treatment (116-118).

Acceptance was facilitated by encouragement, social support, and counselling through family, friends, spouses, and healthcare providers. Education about HIV and treatment was also helpful, as women understood not only that HIV can be terminal if not treated, but that proper use of medication can prolong life, and is not a death sentence.

Participant 1123 stated: When I got tested at first, I accepted it because they asked me if I was ready to know my results, and I said no problem. When they told me that I am positive, that's when the counselling came to say there are other people who tested

positive but are still alive. Others spend 15 years, even 25 years, so don't be afraid or be stressed (294-297).

Participant 1117 shared the misconceptions she was told, but knew they were incorrect: [T]here were others who wanted to mess with my mind, saying they would pray for me and this disease will go away. I said no, this is a lie. The way I look at it is, that this virus doesn't go with prayers. It is better that I start taking medication (134-137).

For some women, acceptance took time. This was the case for women who had misconceptions about ART, about HIV in general, or who did understand, but found themselves wanting to die.

Participant 1115 explained that after feeling ill and going for testing, she was found to be HIV positive and started taking the medication at that time because she did not want to die. However, after she started to feel better, she did not follow up with counselling or continue taking the medication. When asked why she did not continue her medication she elaborated:

I think by then it was not well known by people, so they [wondered] maybe how it works, they didn't have much information (351-352) . . . In my mind, like I said before, that I was thinking that, ah, if I will start taking the medication, it means that I am going to die fast. Maybe if I am not going to start the medication, in the future, maybe they will bring a new drug, which when you take, the virus is going to die right away. So, if I am taking the old drug, it means when the new drug starts, the virus in my body will not die. . . So, I thought they will call us, those who were not yet on medication, and put us on the new drug, which will kill the virus (358-362).

A year after being diagnosed, Participant 1115 saw others who were taking the medication looking healthy, while she was looking unhealthy. She decided she was wasting her time and that she should start taking the medication. For this participant, even though she declined to take the medication when she was first diagnosed, her rationale was based around the hope and thought that if she waited, a better treatment option would be available. She felt if she took the medication that was currently offered, it would keep her from being able to take advantage of improved treatment in the future.

Participant 1006 discussed how she was diagnosed while pregnant. She felt very stressed and did not take the medication she received. When asked why she had not taken the medications in the beginning, she replied simply, “I was just ready to die” (129). However, this changed over time:

I refused to take them, then it was when some people came to encourage me. So up to now, different people encourage me and give me support, and this has helped me to now the importance of taking the medication to survive, and now I don't have worries like before. (111-114)

For this woman, she did not have any inclination that she might be sick until she received her diagnosis while pregnant. Unlike other women who felt ill prior to diagnosis, she was not prepared for the possibility that she might have HIV. At the time of being diagnosed, she was depressed, thought of dying, and refused to take the medication. However, she received encouragement about the diagnosis, and then, she began feeling sick. It was at this point she was prepared to begin the HIV mediation.

Women who voluntarily went for testing did so because they felt it was best for them to know what was wrong and to seek treatment. While this was not necessarily the case for women who learned of their diagnosis during antenatal care, women came to accept their diagnosis and took medication in order to care for their health and prolong their lives. Additional ways women demonstrated their desire and ability to protect their health was through their relationships with men.

Leaving husband. Several women left their husbands because they felt their health was being impacted by their relationships.

Participant 1122 explained that she was tested and began receiving medication with her husband, but he declined to go to support groups:

That was the root cause of our conflict, for our marriage to end, he refused to join the groups (246-247) . . . I told him let's join groups and encourage each other with friends, we should not have stress, but he kept denying, so that's what happened, the marriage just ended there (256-258) . . . I saw the way he was behaving after we had started taking medication, he was going astray, sleeping with other women, so I saw that this man, he is going to give me more infection, so we separated, and he went packing (280-282).

Another woman, participant 1006 left her husband because he was refusing to be tested for HIV. She explains how counselling at the clinic helped her understand why this was important:

Whenever I visited the hospital, they were telling us it is bad if one person is taking the medication while the other is person is not taking the medicine (199-200) . . . The doctors told me that if you will be the only person taking the medication, I will not make any change. And because of that I made a decision, and I called my relatives. I explained to them and my relatives took me with them (209-201) . . . That is why I moved out so that I can be taking my medicine and be happy with my relatives, closer to them, and in that way I am going to have a healthy day to day life (188-190).

While some women left their husbands to protect their health, others chose their partners in order to do so.

Choosing partners. Participant 1118 shared that when she met her second husband, she asked if he was willing to care for both her and her children from a previous marriage. When he agreed, they began dating. She learned that he was also HIV positive:

I am very happy since we are both on treatment. If he was not on treatment, I could have denied. Other men used to come to tell me, I am not on medication, but I love you. I was explaining to them that I am on treatment, so it's better I go for someone who is also on treatment, so that we are taking the medicine together. (292-295)

While Participant 1126 did not choose her husband based on his status, she discusses her feelings about when they both tested positive:

I just accepted it. Even if I decided to leave, how will that decision be of any benefit to me when I am already done with. I had not known then how I was, but it was obvious that his infection is as good as mine, the virus can't pass me by. (69-71)

In this way, 1126 explains that it would not be beneficial for her to leave the marriage now that both her husband and she tested positive. Another participant 1116, related a similar situation where her husband and she tested positive. Together, they help care for their health. She describes how they take their medication together and how they go to get medications from the clinic:

[My husband] just said, ah ah, here we have accepted. So, you should not get sad, no. I will be exchanging with you when it is time to go and get the medicine. And I will be giving them to you to drink, and you are also to be going. I shouldn't lie, he goes, and when I am sick, he runs to the hospital and collects my drugs for me. (230-232)

Through their relationships with men, women found ways to protect their health and well-being. When women felt their relationships were threatening their health, they left their marriages. These decisions were bolstered by encouragement and support from others, as well as understanding of healthy behaviors, such as treatment adherence and only having one sexual partner. Other women developed relationships with new partners or stayed with existing partners based on their health behaviors. Women welcomed support from partners who were also taking HIV positive and taking their medications.

Working for household development. In describing what empowerment means to them, women repeatedly brought up the importance of improving the state of their households, for their children and for themselves. In do so, women demonstrated how they actively participated in working hard to advance their lives through strategizing and saving money. They also discussed barriers to meeting their needs, as well as how they handled these challenges. Several women had received microloans, livestock, or fertilizer as part of the empowerment programs.

Strategizing. Participant 1122 had received a pig through an empowerment project. She explains,

I received one pig, it bred, then I returned it. Because when I take one pig and it breeds, then I borrow it to a friend, then we share piglets. If there are six, I take three piglets, bright them [to the support group]. When I bring them here, they also give to our other friends to help them (456-459) . . . If I would face problems, if my child needs soap, I would take the pig and sell it (486-487).

However, her pigs fell ill and began dying as a disease spread between them. She decided to move separate two of them in order to keep them from also getting sick.

1122: The rest died last year, and for the two to survive, after the others had died, I moved them from the stable and I put them elsewhere and now they conceived (500-502) . . . So, I decided this is my means of survival...so if they all die, where will my support come from? (517-518).

Other women told stories of how they planned and made decisions about building businesses based on their observations and discussions with others.

Participant 1123, after receiving a microloan, needed to decide what type of business she wanted to start. She explains how she came to her decision to start selling tomatoes, but changed her mind when she realized this was not the most profitable business:

I chose tomato because I knew that every day people need to use tomato when cooking their food... When I saw that with the distance from where I was ordering tomatoes and with the capital at hand, it was not balancing. I was losing. So, I changed and started buying and selling beans, but with the second loan (91-94).

Women strategized how to keep their livestock alive, even when they did not have the resources to treat the animals. They also learned through observing the businesses of others that both failed and succeeded. They decided what businesses to pursue based on these observations, or decided not to pursue certain businesses if, for example, too many people were doing the same business, such as selling tomatoes. Women also planned their work around harvest season. As one woman explains, it is difficult to do business during the rainy season, as they need to frequently be in the fields tending to their crops. However, at the time of this interview, it was harvest season and this was a good time for doing business:

1115: As of now the fields are okay, and you can go to the field in the morning to harvest and in the afternoon, you can arrange your things and go for business (194-195).

Saving resources. Women demonstrated their abilities to strategize when discussing how they saved money or resources.

Participant 1118 received a microloan and started selling a baked good, mandazi. She began by a smaller bag of flour, and then keeping MK500 profits aside. Eventually, she saved more money and was able to buy some goods for her home.

I started by frying mandazi. I was buying 1Kg [bag of flour] and kept MK500 aside. When I saved more money, I started buy a [larger] bag and I was getting MK12,000 out of it. The capital was increasing, and I started thinking what I need, then I need chairs in my house, I should buy, but my also need clothes. And my business was also progressing (448-451).

Participant 1007 saved a bag of soya beans, so that she would have them to plant as seeds the following year:

I grew soya bean for the first time, and I harvested one bag, the second time two bags, and the other time 10 bags. After that I harvested 11 bags, so every year I keep one bag of soya bean as seeds (156-157) . . . I thought that I should not struggle to find seeds and it's better to save. Some we can use for porridge and the other, we go and plant in our farm and that is how I do it, I don't want to suffer in my life (186-187).

Participant 1120 describes how she would give advice to another woman who was seeking to do business. In doing so, she demonstrates her knowledge of strategizes to help a business grow, as well as saving money to meet her needs:

My advice is, whether they have a loan or not, they can do any business as long as they chose one they know will profit them. Even doing the charcoal business, you can purchase a MK1000 bag and make MK3000 out of it. Of the MK3000, take out the capital and use MK500 or K700 and then put back the rest into the business. If you have a little money, do not choose to live a life your friends are living, just use a little and one day, you will be like them (238-243).

Losing resources. Women were put in difficult situations in which they lost money or resources they had earned or been given through programs. For example, at times husbands stole or used resources, or resources that women had were used to meet basic needs, rather than going toward household development.

Participant 1125 and her husband had been doing well in business and had built a house. Then, her husband decided with the extra money, he could take a second wife:

My husband saw that the money was too much, that I cannot use the money by myself. He married another wife; she came and just used the money. Then I went home and started doing my own things. Then when his money was all finished, that's when he came back (349-352).

Participant 1116 experienced her husband taking both money and resources from her. On the day we met, she admitted her children were ill, but she was unable to bring them to a near-by clinic because they did not have clothes to be in public. When discussing her husband's behavior, she said:

He goes to the field to harvest the sweet potatoes and he is going to hide the sweet potatoes in the bush. He comes home with the hoe only and when I ask him, he says, ahh, don't ask me. Then I discover later and by then he is already gone, and he doesn't come with money. If I ask him, he starts to shout at me (299-301).

Another time, she describes what might happen when she going to make flour for meals:

Maybe we want to go to the maize mill to make flour, then he comes and says, ah ah, I should borrow, I will give you back later. And it happens that we are going to sleep without eating just because we didn't go to make flour (314-315).

Participant 1116 went on to explain that now, she will hide money from her husband. This is a technique similar to one participant 1112 describes. For her, she followed a patrilineal tradition and moved to her husband's home village with her children from a previous marriage. However, her husband has not cared for these children, stating that he will not buy food for the

house as he does not have children there. She explains how she would do piece work for money and then use it for her children:

Sometimes I buy food, like in that basin, and take it to the maize mill and from the maize mill I call my children to come and eat and by then [my husband] is not around, he comes back at night. We eat and after my children clean the plates and are seated quietly, he asks why [is there no food] and [I say] ah, there is no flour (147-149).

For this woman, she has strategized ways to feed her children without her husband taking her funds or using them only for him. She shares that her husband repeatedly tells her to leave and go back to her home village, but she is unable to save enough money for transportation. In this way, her life is also impacted by living by patrilineal traditions. If the husband had moved into her village, it would be the husband being told to leave the village.

Participant 1114 had a similar experience where she had been doing business, but her husband repeatedly came and took the money to use for himself. After two failed attempts at doing business where her husband took her profits, she explains:

[T]hat made me to get tired, I am not longer going to do this business again, I should not bother myself (110-111) . . . If I have hid the money, that was the time I had an opportunity to use it to buy other things, but if I keep it in an open space, it means it's gone, but I help my kids through hiding my money (150-151).

These women found ways to overcome barriers that kept them from meeting the needs of their children and themselves. For them, these barriers include their husbands taking their money or food. This was not a universal experience however, and some women discussed how they worked with their husbands to meet the needs of their homes. One woman, participant 1120 tells how she works together with her husband, and what she sees as potential consequences of not doing so:

Everyone does a business and it's important to tell each other because if you hide it, it's when it brings in misunderstandings. So, when everyone is doing their business, they say well I've sold this amount and you all plan together and things go well (276-283).

While women demonstrated their capacity to handle challenges and work hard to develop their households, they were still faced with barriers. Women brought up living with food insecurity, not having clothes or soap, or cooking oil for the home, as well as not having funds to send their children to school. Relationships with men were at time protective, if these relationships provided some economic security, but this was not always the case. Programs and projects that assisted women with access to resources were at times unsustainable due to the intersecting vulnerabilities that women faced. For example, when women's livestock would fall ill, and they were unable to treat or save any of the animals. In some cases, women's businesses failed after paying back the loan because the profits gained were immediately used for food or other household needs.

Giving and receiving encouragement. In part one of this article, findings were presented that demonstrated how women received encouragement, which included receiving advice and instructions, normalizing of their experiences, and encouragement to work hard to develop their home, to overcome stigma, and to reduce worries and stress. When discussing this encouragement, women highlighted that it was not just that they received support or inspiring words, but that they put it into actions. These themes are reflected in the findings above. Encouragement facilitated women coming to be tested for HIV, to accept their diagnosis and begin treatment. It also played a role in relationships women chose with men. Men who were supportive of women being tested and receiving HIV treatment assisted women in caring for their health. When women were inspired to work hard developing their homes, their actions are demonstrated in how they strategized gaining and using resources.

Giving encouragement: “Being a light for others”. Not discussed at length in the first part of this article is how women described giving encouragement to others. While women told many stories of receiving encouragement through counselling or from their relatives, there were also stories about the reciprocal nature of encouragement between women and others living with HIV, as well as those in the community who have not been tested.

Participant 1007 describes how she accepted her status and how she approaches those who have not:

I feel very good since I accepted it, I received it. So, for those that didn’t accept it, I give them encouragement, that they should not have worries, they should live just like the way I do. I am like a light or other people who are also affected. I am like a role model and I stand for those people.

In discussing her own experiences living with HIV, she helps to normalize the experience for others:

When I am going to the hospital to get my medicine, I am open everywhere I go to talk about my status to people, without hiding anything. I am on drugs, “*You are on drugs?*” Yes, I am on drugs. “*No that can’t be true.*” It is very true. . . Since I made the choice to accept, I thought I could be wiser for everyone to know my status and I don’t have worries even if someone is talking about it, I talk about it everywhere that I am on drugs. I talk about it everyone, even at church in a group of people.

Participant 1116 explains how she encourages others to be tested and to come to the support groups:

As of now I am also the one who encourages my fellow women that they should not be dull, they need to go get tested and if not, you are going to die. As of now, I have been coming with a lot of people to this [support] group. Let’s go, let’s go! If you deny you are going to die, look at us. We work hard, we go to the farm and are there the whole time (101-104).

When asked what advice she might give someone who was recently diagnosed, Participant 1117 stated:

I have advice in my own capacity. I am supposed to tell that I was found positive in [year] and by then I had lost substantive weight. I was emaciated and I wasn't as I look now. So much that [health officer] thought they would lose me at any time. So, I never expected to get to where I am now. So, I am in that positive where I give others the advice that so long as you take your medication daily, your life will be prolonged (311-315).

Women actively participated in supporting others in their communities through normalizing the experience of being tested, taking medication, and living positively with HIV. By sharing what they had been through and what they had learned, women were empowered through receiving encouragement while also empowering others through the same encouragement from which they had benefited.

Discussion

In this study, a theory of empowerment among women living with HIV in rural Malawi was constructed through the analysis of individual in-depth interviews with 25 women. Empowerment here is conceptualized as the receiving of encouragement and support from others and from themselves, gaining material assistance and working hard to develop their homes. This conceptualization is informed by a postcolonial feminist lens. Women demonstrated how empowerment in action worked in their lives, represented by the social process of *Putting Your Life in the Front*. Three major categories within this process include: *Protecting Health*, *Working for Household Development*, and *Giving and Receiving Encouragement*.

Contesting representations of women in the global South as victims of oppression without capacity (Mohanty, 1988), women in this study demonstrated how they dealt with their diagnosis, protected their health, and strategized to make the most of the limited resources they had at their disposal. After experiencing illness, women actively sought to be tested, understanding that it was best to know their status and to receive treatment if they were HIV infected. These actions were supported through campaigns to inform community members of the

signs and symptoms of HIV infection, such as being frequently ill and not feeling better, even after receiving treatment for ailments. Campaigns such as these, as well as an overarching move toward the normalization of living with HIV may help to promote uptake of testing (Jaganath, Mulenga, Hoffman, Hamilton, & Boneh, 2013; Sano et al., 2016). Through the stories of women in this study, encouragement and normalization not only supported women to care for their own health, but women also went forward to do the same, encouraging others to see that through testing and taking medication, one can live with HIV and still prosper. These findings mirror those from other studies in which women living with HIV sought to become role models within their communities (Bhengu, 2010; Souza, 2010). Thus, empowering women through encouragement is beneficial to not only individuals but to entire communities.

While women disclosing their status and openly encouraging others to seek treatment may be beneficial, it is also important to situate these findings within the societal context in Malawi. Men in Malawi continue to lag behind women in testing and uptake of treatment (MDHS, 2017), which can put women at risk if their husbands are engaging in risky sexual behaviors (Mkandawire-Valhmu et al., 2013). Women in this study left husbands and relationships in order to protect their own health and developed new relationships or remained with husbands who also had HIV but were supportive of treatment. For healthcare providers supporting women living with HIV, these contextual factors should be taken into consideration. For instance, there needs to be deliberative efforts and interventions to encourage men to come for HIV testing, counselling, and treatment. It may not be practical to expect women to leave their husbands, even if men are having relations outside of the marriage or refusing testing taking into account that women often experience deeper levels of poverty while also being solely responsible for their children if they leave their husbands (Mkandawire-Valhmu et al., 2013).

Through strategies for using and saving resources, women in this study actively worked to develop their households. Supporting women in learning and developing these skills holds promise, such as through Village Savings and Loans Associations (Hendricks & Chidiac, 2011). Still, a number of barriers presented challenges that hindered women's efforts. At times, men would steal money or food, leaving women and children without. In these instances, women found ways to hide money or food in order to meet their basic needs and the needs of their children. However, in other instances, men and women worked together to make and save money. This highlights the importance that one intervention may not fit every woman; programs that insist couples are given assistance and work together may not necessarily be beneficial while for some families and households, they may.

Limitations

Women in this study were clients of a health clinic affiliated with a local Non-Governmental agency in the Kasungu District of Malawi. In addition to providing healthcare, K2 TASO is funded by international donors and is able to provide clients with funding for transportation and food that is not offered to clients at other health clinics. Clinicians at K2 TASO partner with additional international NGOs that provide aid through various development projects such as microfinancing or livestock breeding. Clients of K2 TASO, including the women in this study, were likely to have opportunities to participate in these projects than what would be expected for the majority of Malawians living in rural areas. While there are a number of development agencies in the country, it is not clear how widespread development activities are and the extent to which Malawians in the most remote parts of the country benefit from development initiatives. Thus, women in this study were provided additional benefits and opportunities for material assistance and our findings should be understood within this reality.

Additionally, during one interview it was apparent that the participant may have believed she was being interviewed to join a project in which she would receive microloans to start a business. While we tried to reinforce that we were solely asking questions about their experiences, it is possible my own positionality influenced participants if they believed there may be something for them to gain based on their responses. Regardless, our findings indicate that development projects are beneficial to the empowerment of women living with HIV and that supporting the work of development agencies in countries like Malawi is a worthwhile endeavor.

Recommendations for Future Research

This study contributes to the current literature by introducing a substantive theory of empowerment among women living with HIV in rural Malawi. While this study alone does not answer all questions as to who needs empowerment, how to measure empowerment, or what empowerment does, our findings provide direction for future research. Women in the current study described empowerment as a continuous process rather than a singular end point. Assuming women are either disempowered or empowered is thus flawed. Continuing to study empowerment through the perspectives of women living with HIV in the global South can provide insight into how women who experience intersecting vulnerabilities based on their gendered realities, poverty and their HIV status, may be supported. Measuring empowerment may be possible through focusing on the noumena of empowerment, such as decreased worry, stress, and fear, uptake of testing and treatment adherence, and using encouragement in action through protecting one's health, working to develop one's home, and providing support to others.

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CHAPTER VI: DISCUSSION AND SYNTHESIS

This qualitative study utilized grounded theory methodology to construct a framework of empowerment among women living with HIV in the Kasungu District of Malawi. This framework was used to guide the development of a substantive theory of empowerment. Consistent with a postcolonial feminist perspective, findings highlight the capacity and agency of the participants, while providing social and political context. Empowerment, as defined by women in this study focused on receiving strength through normalizing living with HIV; women were empowered through their own hard work developing their homes, and through utilizing material assistance. In constructing a theory of empowerment guided by this framework, women's actions and experiences through the process of empowerment are explained. This theory, *Putting Your Life in the Front*, shows how women *Protect Health, Work for Household Development*, and *Give and Receive Encouragement* through their actions and decisions. In this chapter, the three manuscripts generated from this dissertation will be discussed, emphasizing how these works challenged development discourse of women's empowerment and contribute to the literature, as well as implications of the study findings for policy, practice, and future research. Finally, limitations of the study will be covered.

Synthesis of Findings

Across the three manuscripts generated from this dissertation, universalizing and essentialist views of women and cultures in the Global South were challenged. The first was published in *Advances in Nursing Science* in 2016 entitled: *Raising Questions About Capitalist Globalization and Universalizing Views on Women: A Transnational Feminist Critique of the World Development Report: Gender Equity and Development* and is included in Chapter III of this dissertation. This article contributed to current literature a critical analysis of a report by the

World Bank on gender equity and development. Using a transnational feminist perspective, the uncontested capitalist and globalization motivations, and the universalizing and essentialist language, of the World Bank was challenged. Through this published manuscript, an example of how the work of organizations with global power and influence, such as the World Bank, can be critically analyzed using a feminist perspective was disseminated. In this paper, the importance of centering women who experience the greatest challenges to their health and wellbeing, in our research and seeking to promote global justice, while avoiding essentializing narratives, particularly in development discourse, was emphasized. This includes the women located in the Global South, as well as ethnic minority women in the Global North who do not necessarily benefit from global capitalism and have been historically, and continue to be, harmed by it.

As demonstrated in the first manuscript, organizations such as the World Bank may use frameworks of empowerment that are universalizing or homogenizing, assuming all women have similar experiences and will have a similar progression toward gender justice. Through this lens, women in the Global North are used as examples of how to reach gender equality, at the detriment of recognizing the unique experiences and contextual factors of the lives of women in the Global South. Essentialist views of gender and culture have also been used in development discourse and have been a focus of critique by feminist scholars (Kabeer, 2005; Jagger, 2005; Mohanty, 1988). Essentializing narratives of gender creates dichotomies between women and men as those who are oppressed victims and those who are perpetrators of oppression; while cultural othering, or cultural essentialism, assumes all people within a particular culture hold the same traditions and beliefs. Through the second and third manuscripts produced from this study, these perspectives were actively challenged by centering the voices of women who are

underrepresented in the literature, and sharing their stories and narratives that demonstrate the heterogeneity among women of the Global South, as well as women living with HIV in Malawi.

In the second manuscript, a conceptual framework of empowerment was constructed through the narratives of women living with HIV in the Kasungu District of Malawi, Africa. The purpose of this manuscript was to explore how this sample of women define and describe empowerment, and in doing so, develop a framework to guide the construction of a theory of empowerment and avoid applying a decontextualized definition of empowerment. Women living with HIV defined empowerment in terms of receiving encouragement through advice, and the wherewithal to have courage and to persevere, as well as to work hard to develop their homes for their children and themselves. Programs that aided women through microloans or material resources were important sources of support for women, but what women did with this assistance was emphasized. Women described how empowerment positively impacted their mental health by reducing their worries, stress, and fear.

Women discussed their desires for economic stability and being able to depend on themselves to meet their needs, drawing some parallels to the goals of economic empowerment often discussed in the development literature. This finding is important as it informs the development of focused interventions that seek to support women's current goals and desires, as well as highlighting the potential fallacy of applying a universalizing view of women globally. For women in this study, how they sought to achieve their goals of economic stability, as well as barriers to achievements, were explicated in the third manuscript, chapter VI.

Through their narratives, women demonstrated their capacities and agency to work toward meeting their needs. For women living with HIV, a dimension of empowerment, protecting health, emerged. Actively participating in the caring for their health was essential and

was bolstered by empowerment through encouragement received from family, friends, clinicians, and support groups. These findings are consistent with other studies conducted with people living with HIV. Among women living with HIV in Kenya and Malawi, women shared how they were encouraged by friends and within support groups to overcome their worries and persevere (Mkandawire-Valhmu, Kako, Kibicho, & Stevens, 2013). Although conducted with adolescents living with HIV in Uganda, self-reports of treatment adherence were associated with social support from family and caregivers (Damulira et al., 2019).

In this study, an environment in which testing and receiving treatment for HIV was normalized aided women in receiving voluntary testing when they were feeling ill and initiating treatment. For some women, their relationships involved men creating barriers to their health, while for other women, men were supportive of HIV treatment. However, the socioeconomic position of women played a role in these decisions. In Malawi, there is evidence to suggest that marriage is a source of economic stability for women with limited alternatives to meeting their basic needs and the needs of their children (Mkandawire-Valhmu et al., 2013). Economic dependence may thus lead to women remaining in unhealthy relationships. Additionally, contradictory to cultural essentialism, women in Malawi may follow either matrilineal or patrilineal traditions, or neither. Future research needs to explore how matrilineal and patrilineal traditions facilitate or challenge women's ease of leaving a marriage when the marriage has implications for their health and wellbeing. Additional research is also needed to explore the relationship between normalizing HIV treatment, disclosure of status, and medication adherence, as one study conducted with women living with HIV in rural India suggests that internalized stigma, and hiding one's diagnosis, may negatively impact medication adherence (Ekstrand et al., 2019).

Finally, the third manuscript contributes to the literature by providing examples of how women living with HIV actively participate in working toward developing their homes through strategizing and saving money to build businesses, farm, and breed livestock. Women discussed in detail how they learned from others, observing the types of businesses people conducted, what worked and what did not work. They were aware of the amount of money they were able to use for the purchase of goods at wholesale and how much profit they would be able to make, accounting for transport and other costs. When speaking of profit, women discussed the specific amounts of money they would budget for needs in the house, money they would set aside for saving, as well as money set aside for repaying loans they may have taken. When women dealt with situations that challenged their ability to care for their children or themselves, they found innovative ways to overcome. For instance, when their husbands, for some women, stole food or resources, women hid their money, or would serve dinner to their children and themselves before men returned home. However, not all men created barriers to women's health and wellbeing, as in some narratives, women shared how they worked together with their partners to build businesses and to develop their households.

These findings demonstrate the ways in which universalizing, and essentialist views can be damaging when seeking to empower women globally. By assuming all women across the world are similar, that all women and men are similar, or that all people within a given population are similar, nuances within the experiences of individuals are missed. These nuances are important to understanding the specific desires and goals of people, as well as their capacity and agency. In the case of this study, we highlighted the unique experiences, facilitators, barriers, and desired outcomes of the process of empowerment among women living with HIV in the Kasungu District of Malawi while challenging problematic narratives of development discourse.

Implications for Policy and Research

While implications for policy, research, and practice have been discussed in the three manuscripts, the importance of recognizing support groups on a national level was not mentioned. In Malawi, mandates exist for HIV counselling when one is receiving testing for HIV and when someone receives a positive test. Through the current study, the efficacy of this counselling is supported as women discussed the importance of the encouragement they received during this time. However, this counselling is mandated at the start of treatment initiation and does not ensure ongoing support or education. For women in the current study, the importance of continuous encouragement was repeatedly mentioned. This was especially true in relation to the encouragement women said they received from support group participation. Within support groups, women received education and support in taking their medications, they were strengthened to have courage and persevere in the face of discrimination or life setbacks, and their experiences of living with HIV were normalized. Through these experiences, some women also felt heartened to go out and support others by encouraging people to be tested and to take medication, at times even accompanying them to clinics for testing. However, in this study, all women were clients of K2 TASO, a health clinic that is supported by an international NGO. This funding covered the cost of the support groups.

Many women living with HIV in Malawi may not have any access to a support group. Even for women in this study, as reported by some participants and corroborated by clinic staff, some support groups charged a fee for members to join, in order to pay for food during meetings, or to support small gardens to grow food. Even when an NGO is funding support groups, some women were unable to afford the extra cost of memberships and were thus excluded from the benefits of support groups. It is recommended that seeking to fund support groups through

government monies, in the same way HIV counselling is mandated, would be beneficial to people living with HIV. Additional research specifically regarding the outcomes of support groups in relation to women's empowerment may help to bolster the case for funding of support groups. Studies have shown the potential for support groups for people living with HIV in minimizing morbidity and mortality, improving quality of life, and enhancing treatment retention (Bateganya, Amanyaiwe, Roxo, & Dong, 2015). Additionally, on a national level, many indicators of health and health knowledge are measured through the Malawi Demographic and Health Survey (2017), but support groups are not mentioned in these surveys. Measuring support group participation would provide a basis for tracking a substantial source of knowledge and encouragement for people living with HIV. In the case of women living with HIV, these measures could be useful in tracking progress toward gender equity.

Limitations

Limitations to this study include the language used in translating empowerment into Chichewa. As described in chapter I and chapter V, decisions were made by the first author to construct empowerment using three different translations of empowerment from English to Chichewa, the common language spoken in Malawi. In doing so, the author had influence over how empowerment was described by participants. To minimize the bias created by the translation of empowerment, decisions were made based on generally accepted paradigms of empowerment in the literature, which support both an external and internal form of empowerment.

An unintended limitation was recognized during data collection. It is possible that my role as a nurse associated with K2 TASO may have impacted the narratives shared by the participants. When discussing projects or programs related to development, some women may

have felt they would receive additional assistance from the clinic, or me, depending on how they represented themselves. This had not occurred to my research assistant or myself until we were nearing the end of data collection and one woman, when asked what type of business she might like to do, responded, “We get to pick?”. This comment led my assistant and I to believe this participant thought we were interviewing her to be a part of a program.

My personal perspective and positionality were also discussed in chapter I and chapter V, as well as the methods of reducing the influence of bias through reflexivity. In order to help mitigate my own perspective on influencing data analysis and construction of results, a confirmability audit of the findings was conducted. At this time, due to the COVID-19 pandemic and limited resources, this audit has not yet been completed. It will be completed before findings are submitted for publication by two PhD prepared Malawian women who have not yet been associated with this study.

Conclusion

The purpose of this dissertation was to explore empowerment among women living with HIV in Malawi. Through individual in-depth interviews and the use of grounded theory methodology, women’s definitions and experiences of empowerment were analyzed and a theory of empowerment constructed. A postcolonial feminist perspective provided a critical lens through which to analyze the data, as well as challenge depictions of women in the Global South. Findings from this dissertation demonstrate the unique ways women living with HIV experience empowerment and provide guidance to scholars developing and measuring interventions for support the health and wellness of women.

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APPENDIX A: INFORMED CONSENT

Informed Consent: English



Informed Consent for Research Participation

IRB #: 19.A.143

IRB Approval Date: 22-02-2019



MINISTRY OF HEALTH NATIONAL HEALTH SCIENCES RESEARCH COMMITTEE

Study title: Empowerment among women living with HIV in Malawi, Africa

For questions about the research:

- **Student Principal Investigator:** Victoria Scheer, BSN, RN; +1 920 217 8442; VLSCHEER@UWM.EDU
- **Principal Investigator:** Lucy Mkandawire-Valhmu, + 265 993 739 216

For questions about your rights as a research participant:

- **Institutional Review Board:** +1 414 229 3173, irbinfo@uwm.edu
- **National Health Sciences Research Committee:** +265 1 726 422/418, modhoccentre@gmail.com

Introduction: Hello, my name is Victoria Scheer, I am a nurse and a student from the College of Nursing in Milwaukee, Wisconsin in the United States. I'm inviting you to participate in a research study. Participation is completely voluntary. If you agree to participate now, you can always change your mind later. There are no negative consequences, whatever you decide.

Purpose: I want to understand what power and strength mean to women living with HIV.

Procedure: You and I will meet where ever you'd like, and I will ask questions about being given power and strength, your health, how you care for your health, and living with HIV. Our conversation will last about an hour, and will be recorded on an audio recorder, so I can listen again later. The interview will take place at a time and place of your choosing. I may review your health passport and health records from hospitals and clinics where you receive care. I may collect the month and year of visits to health clinics or hospitals, diagnoses, and any treatment or medications you received. I may also observe you in

public, in your home during visits, and during our conversation. The estimated number of participants may change, maybe between 10 and 40.

I will record your responses with this gadget. The recordings will be used for translating into English and comparing your experiences with those of other women. If you do not want to be audio-recorded let me know and I will write down your responses. Participation in this study will not cost you anything. For your time, you will receive a bag of sugar and a bottle of oil.

Benefits: You may enjoy sharing your experiences. We may be better able to understand strength and power, and how we can support women living with HIV.

Risks: Some questions may be very personal or upsetting. You can skip questions you don't want to answer. Because I am working with the clinics, being seen with me might make others think you are HIV positive. We can meet only at the clinic if you'd like. There may be risks we don't know about yet. Throughout the study, we'll tell you if we learn anything that might affect your decision to participate.

Privacy and Confidentiality: During the interviews, your name will not be used, you will be assigned a study ID number. Your responses will be treated as confidential and any use of your name and/or identifying information about anyone else will be removed from the typed copy of our conversation. There will be document that links your study ID and name. The only time your name will be used is to review your medical records; after doing so, the document linking your study ID number and your name will be destroyed, so your information cannot be matched to you. All study results will be reported without identifying information so that no one viewing the results will ever be able to match you with the responses. Direct quotes may be used in publications or presentations. All paper data will be kept with the research team until it is put on a computer. Then the paper copy will be destroyed. Data from this study will be saved on an encrypted password protected computer for 5 years. De-identified data may be used for other future research. Data will be destroyed in 2024. Only Victoria Scheer and certain individuals will have access to your information, including select faculty and students from the university, the transcriptionist, and a few Malawians who are assisting with the research. However, the Institutional Review Board at UW-Milwaukee or appropriate federal agencies like the Office for Human Research Protections, and the Malawi Ministry of Health may review this study's records.

Study Approval: This study has been approved by the University of Wisconsin-Milwaukee Institutional Review Board and the Malawi Ministry of Health National Health Sciences Research Committee.

Verbal Consent

If you have had all your questions answered and would like to participate in this study, please say out loud that you would like to participate. Remember, your participation is completely voluntary, and you're free to withdraw from the study at any time. By consenting to participate in this study, you will also be authorizing me and the research team to review your health passport and health records.

Name of Researcher obtaining consent (print)

Signature of Researcher obtaining consent

Date

Informed Consent: Chichewa



Informed Consent for Research Participation

IRB #: 19.A.143

IRB Approval Date: 22-02-2019



MINISTRY OF HEALTH NATIONAL HEALTH SCIENCES RESEARCH COMMITTEE

Mutu wa kafukufuku: Kulimbikitsidwa kwa amayi amene ali ndi kachiroombo kodzetsa edzi kuMalawi
Mafunso okhudzana ndi kasfukufuku:

- **Dzina la mwana wa sukulu opanga kasfukufuku:** Victoria Scheer, BSN, RN; +1 920 217 8442; VLSCHER@UWM.EDU
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Mafunso okhudzana ndi ufulu wanu ngati olowa nawo m'kafukufuku:

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Malonjerano: Ndikukupemphani kuti mulowe nawo m'kafukufuku. Kulowa nawo m'kafukufuku ndi kufuna kwanu/kusankha kwanu. Ngati mungavomere kulowa nawo, mutha kusintha maganizo popanda vuto. Palibe vuto lina lili lonse pa chisankho chimene mungapange

Mutu wa kafukufuku: Ndikukupemphani kuti mulowe nawo m'kafukufuku. Kulowa nawo m'kafukufuku ndi kufuna kwanu/kusankha kwanu. Ngati mungavomere kulowa nawo, mutha kusintha maganizo popanda vuto. Palibe vuto lina lili lonse pa chisankho chimene mungapange

Zochitika: Inu ndi ine tikomana kwina kuli konse kumene inu mungakhale omasuka kokomana ndipo ndidzakufunsani mafunso okhudzana ndi kupatsidwa mphamvu, ndinso mafunso ena okhudza umoyo wanu, komanso umoyo wanu pokhala ndi kachiroombo kodzetsa matenda a edzi. Kucheza kwathu kudzatenga ola limodzi ndipo ndidzatepa kucheza kwathuku pa kanema iyi. Cholinga chotepa kucheza kwathu ndi kuti ndikabwerera kunyumba, ndikamvetse bwinobwino mayankho amene munandipatsa. Ndidzayan'ganaso makalata anu ndi bukhu lanu lakuchipatala. Ndizalembanso zimene ndikuona pa chikhalidwe chanu mukakhala kubwalo, pa khomo panu komanso mukucheza kwathu. Chiwerengero cha nthu amene angalowe nawo m'kafukufukuyu atha kusintha kukhala pakati pa anthu khumi ndi anthu makumi anayi. Ndidzapemphanso kuti nditolere masiku amene munayendera ku chipatala, matenda amene anakupezani nawo ndinso mankhwala ena ali onse amene munalandira.

Ndidzatepa mayankho ano pa kanema iyi. Mayankho anu ndidzatanthauzira mu chingerezi. Ndidzalingalira mayankho anu ndi mayankho a azimayi ena. Kutepa ndi kofunikira pa kafukufuku ameneyu. Ngati simufuna

kuti ndikutepeni, ndiuzeni ndipo mayankho anu ndidzalemba pa pepala. Simulipira chiri chonse kuti mulowe nawo m’kafukufukuyu. Pokuthokozani, tikupatsani pekete la shuga ndi botolo la mafuta ophikira.

Ubwino: Mutha kusangalatsidwa kucheza ndi azimayi ena amene amaona mabvuto ofanana ndi anu komanso kumva kwa anzanu mabvuto amene iwo amaona. Kucheza nanu kudzatithandiza ife kuti timvetse mmene achipatala tingapitirizire kukuthandizani maka azimayi amene muli ndi kachirombo kodzetsa edzi.

Ziopsyeyo: Mafunso ena atha kukhala okhumudwitsa. Mutha kudumpha mafunso ena ali onse amene simuli omasuka kuyankha. Chifukwa choti ndikugwira ntchito ndi abungwe komanso achipatala, anthu akakuonani mukucheza nane, atha kudziwa zoti muli ndi kachirombo kodzetsa matenda a edzi. Tikhoza kukomana kuchipatala ngati mungasankhe kuti zitero. Pakhoza kukhala ziopsyeyo zina zimene sitingathe kudziwa. Kafukufukuyu ali mkati, ndidzikuuzani ngati pali mabvuto ena amene atha kukupangitsani kuti musankhe kusalowa nawo m’kafukufukuyu

Kusunga chinsinsi: Pa kucheza kwathu, dzina lanu silidzagwiritsidwa ntchito. Tidzakupatsani nambala mmalo mogwiritsa ntchito dzina lanu. Mayankho anu adzasungidwa mwa chinsinsi ndipo dzina lanu kapenanso china chiri chonse chokuzindikiritsani chidzachotsedwa mu zolembedwa. Padzakhala pepala lina limene lidzatithandize kulumikiza nambala yanu ndi dzina lanu. Nthawi imene tidzagwiritse ntchito dzina lanu ndi polandula makalata anu akuchipatala. Tikadzamaliza kalandula ameneyu, tidzan’gamba kalata imene ikulumikiza dzina lanu ndi nambala yanu kuti wina ali yense asathe kulumikiza zimene mwanena ndi inu. Zotsatira za kafukufukuyu zidzaulutsidwa popanda wina ali yense kudziwa mayankho amene inu munapereka. Zimene mwanena tidzatha kugwiritsa ntchito muzolemba kapena zogawana ndi anzathu ena ogwira ntchito za chipatala. Koma dzina lanu silidzaulutsidwa kwina kuli konse. Makalata onse okhudza kafukufukuyu adzasungidwa ndi ochita kafukufuku mpakana tidzayike pa kompyuta. Tikadzatero, makalatawo tidzaotcha. Zotsatira za kafukufukuyu tidzasunga pa kompyuta imene ili ndi nambala ya chinsinsi kokwanira zaka zisanu. Zotsatira za kafukufukuyu zitha kudzagwiritsidwa ntchito m’kafukufuku wina kutsogolo kuno. Zotsatira za kafukufukuyu tidzazifufuta mu chaka cha 2024. Victoria Scheer ndi anthu ena adzatha kuona zotsatira za kafukufukuyu, kuonjezera maziphunzitsi ndi ana a sukulu ena a ku univesite, otanthauzira ndinso aMalawi ena amene akuthandize ndi kafukufukuyu. Komanso ogwira ntchito ku Institutional Review Board imene imayang’anira za ufulu olowa nawo m’kafukufukuyu ku univesite yotchedwa University of Wisconsin-Milwaukee, mabungwe ena ngati bungwe lotchedwa Office for Human Research Protections komanso a unduna wa za umoyo kuno kuMalawi athanso kuona nawo makalata okhudza kafukufuku ameneyu.

Chilolezo chopanga kafukufuku: Kafukufukuyu wavomerezedwa ndi a univesite yotchedwa University of Wisconsin-Milwaukee oyan’ganira za ufulu wa anthu olowa nawo m’kafukufuku komanso a unduna wa za umoyo amenenso amaona za ufulu wa anthu olowa nawo m’kafukufuku.

Kupereka chilolezo cha pakamwa

Ngati mafunso anu onse ayankhidwa ndipo muli omasuka kulowa nawo m’kafukufukuyu, nenani mokweza kuti mukufuna ndithu kulowa nawo. Kumbukani kuti kulowa nawo m’kafukufukuyu ndi kosakakamiza ndipo muli omasuka kusiya pa nthawi yina iri yonse. Povomera kulowa nawo m’kafukufukuyu, mukundipatsanso chilolezo kuti ndione nawo makalata anu akuchipatala.

Dzina la otenga chilolezo (dindani)

Sayinetcha ya otenga chilolezo

Tsiku

APPENDIX B: CURRICULUM VITAE

Victoria Scheer, PhD, RN

EDUCATION

University of Wisconsin-Milwaukee, College of Nursing, Milwaukee, WI Ph.D. in Nursing Areas of emphasis include feminist theory, women's empowerment, women's health, and international nursing. Dissertation: "Women's Empowerment among women living with HIV in the Kasungu District of Malawi"	Aug 2020
University of Wisconsin-Milwaukee, College of Nursing, Milwaukee, WI B.S. in Nursing	2011

AWARDS

Chancellor's Graduate Student Award for Talented Students, <i>UWM College of Nursing</i>	2012 – 2015
Nancy A. Wright Memorial Fellowship for Promising Students, <i>UWM College of Nursing</i>	2012 – 2013

TEACHING EXPERIENCE

University of Wisconsin-Milwaukee, College of Nursing, Milwaukee, WI Teaching Assistant Collaboratively and independently planned and led lectures for Health and Illness I, and Professional Roles II; designed in-class learning activities; assisted in reviewing and revising exams and assignments and graded in-class and weekly course work.	2018-Present
Program Assistant-Community Health Care in Malawi, Africa Aided planning, organizing and supervising student activities, and assisted in guiding student discussions.	2018; 2019
Substitute Clinical Instructor-First Semester Long-term care rotation Coordinated clinical experiences focusing on learning objectives, led student discussions, and provided feedback.	1/1/2017
Teaching Assistant Collaborated on lecture and coursework development for Public Health/Community Nursing, Growth and Development, Leadership; graded assignments, led lectures on community health specialties, death and dying, and NCLEX preparation.	2012-2014

WORK EXPERIENCE

Advocate Aurora Health Care, Milwaukee, WI Registered Nurse Triage and assess patients seeking behavioral and AODA health services.	2020-Present
Medical Staffing Network, Milwaukee, WI Registered Nurse Provide direct patient care to residents in residential and inpatient behavioral health, rehabilitation, and long-term care settings.	2017-Present

Brightstar Care of Milwaukee, Milwaukee, WI

Interim Nursing Manager

Oct 2016 – Jan 2017

Oversaw day to day management of staff RNs, CNAs, PCWs. Reviewed and revised policies and procedures in accordance with federal and state laws, corporate and Joint Commission standards.

Efficacy of a M-Health Self-Management Intervention (R01NR013913-01)

Research Assistant

2014-2015

Collaborated on designing and implementing data collection procedures, developed protocol for remotely downloading and managing a Health Management application to participant smartphones.

Allay Home and Hospice, Brookfield, WI

Registered Nurse Case Manager

2012-2015

Coordinated care with patients, patients' families and caregivers. Reviewed and updated care plans as needed. Provided direct patient care.

RELATED EXPERIENCE

Study Abroad Student Colloquium, UWM College of Nursing, Milwaukee, WI

Presenter

2016

Presented on experiences studying abroad in Malawi, lessons learned.

Global Health Forum, University School of Milwaukee, Milwaukee, WI

Co-Panelist

2014

Served on a panel reviewing, discussing, and sharing feedback related to student presentations on global health topics.

Global Health Graduate Student Colloquium, UWM College of Nursing, Milwaukee, WI

Presenter

2014

Shared literature review methods and findings related to women's empowerment in Malawi, Africa.

College of Nursing Student Colloquium, UWM, Milwaukee, WI

Co-Presenter

2012

Collaborated on disseminating data, analysis, and findings of studies conducted in Malawi, Africa and Kenya, Africa, presentation: "Women and Children Stride toward an AIDS Free Generation in two East African Countries".

Kenya, Africa

Undergraduate Research Assistant

2011

Participated in conducting interviews with women living with HIV as part of the study: "HIV Transmission Risk, Access to Treatment, and Self-Management of Illness over Time: An In-Depth Longitudinal Study of HIV-Infected Women in Kenya".

Malawi, Africa

Study Abroad Participant

2011

Participated in community health education and support while experiencing and learning about public health in Malawi, Africa.

PUBLICATIONS AND PAPERS

- Mkandawire-Valhmu, L., Kendall, N., Dressel, A., Wendland, C., **Scheer, V.L.**, Kako, P. ... Egede, L. (2020). Women's work at end of life: The intersecting gendered vulnerabilities of patients and caregivers in rural Malawi. *Global Public Health*.
<https://doi.org/10.1080/17441692.2020.1730930> 2020
- Mkandawire□Valhmu, L., Weitzel, J., Dressel, A., Neiman, T., Hafez, S., Olukotun, O., Kreuziger, S., **Scheer, V.** ... & Morgan, S. (2019). Enhancing cultural safety among undergraduate nursing students through watching documentaries. *Nursing inquiry*, 26(1), e12270.
<https://doi.org/10.1111/nin.12270> 2019
- Wesp, L.M., **Scheer, V.**, Ruiz, A., Walker, K., Weitzel, J., Shaw, L., Kako, P.M., & Mkandawire-Valhmu, L. (2018). An emancipatory approach to cultural competency: The application of critical race, postcolonial, and intersectionality theories. *Advances in Nursing Science*, 41(4), 316-326. Doi: 10.1097/ANS.0000000000000230 2018
- Ryan, P., Papanek, P., Csuka, M. E., Brown, M. E., Hopkins, S., Lynch, S., **Scheer, V.** ... & Hoffman, R. (2018). Background and method of the striving to be strong study a RCT testing the efficacy of a M-health self-management intervention. *Contemporary clinical trials*, 71, 80-87. 2018
- Olukotun, O., Mkandawire-Vahlmu, L., Kreuziger, S. B., Dressel, A., Wesp, L., Sima, C., **Scheer, V.**, ... & Kako, P. (2018). Preparing culturally safe student nurses: An analysis of undergraduate cultural diversity course reflections. *Journal of Professional Nursing*, 34(4), 245-252. 2017
- Scheer, V. L.**, Stevens, P. E., & Mkandawire-Valhmu, L. (2016). Raising Questions About Capitalist Globalization and Universalizing Views on Women. *Advances in Nursing Science*, 39(2), 96-107. 2016
- Mkandawire-Valhmu, L., **Scheer, V.**, Yerges, A., Olukotun, O., Dressel, A., & Kako, P. (2015). *Advancing the Health of Women and Children in Malawi and Kenya through Global Partnerships for Development: Academic-Community Collaborations*, United Kingdom: Ashgate Publishers. 2015

MEMBERSHIPS

Sigma Theta Tau International Honor Society of Nursing
 Midwest Nursing Research Society