Title
How Can Non-Government Organizational Perspectives Inform Community Based Participatory Research in Malawi, Central Africa?

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How Can Non-Government Organizational Perspectives Inform Community Based Participatory Research in Malawi, Central Africa?

by

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ABSTRACT

Background. Community-based participatory research (CBPR) is an egalitarian approach to research that is gaining popularity due to its success in achieving long-term sustainable improvements in community health, yet little CBPR is currently underway in Malawi, Central Africa. Malawians suffer from poverty, food insecurity, HIV and AIDS and have a reported life expectancy of 48 years of age. Although non-governmental organizations (NGOs) have pivotal roles in their work with donors and local communities in addressing these issues, little CBPR literature reflects NGO perspectives.

Theoretical Framework. Ecosocial theory underpins the study with its dual emphasis on social justice and scientific methods. Health disparities are examined in light of social, environmental and economic constructs as well as from a biological basis.

Purpose. The purpose of this research was to explore perspectives of NGO staff in order to understand barriers and facilitators in their work with communities. The study addressed three primary questions: 1) How do NGOs build trust and relationships with community members and agencies?; 2) What are the perspectives of NGO staff regarding their interactions or experiences with donors?; 3) How do Malawi women effect change in their communities?

Methods. Using a qualitative, public ethnographic method, 26 semi-structured interviews were conducted in the US and Malawi of staff, volunteers, board members and partners of NGOs and community-based organizations (CBOs). Interviews were audio-taped, transcribed and the data input into Atlas.ti, and analyzed.

Findings. Three themes emerged: 1) how NGOs gain community trust; 2) donor power; and 3) how socially disempowered Malawi women effect change in their communities.

Study participants consistently advised a bottom-up approach when working with communities and stated that donors and NGOs need to respect cultural norms, listen to community members' priorities, engage communities in activities or research and recognize that communities possess important knowledge. Participants cautioned that while it is easy to slip back into top-down roles, the time and patience required to work from a bottom-up approach does produce long-term sustainable results. Although most participants were unfamiliar with CBPR, their recommendations concur with CBPR principles.

Conclusion: Community-based participatory research is an appropriate approach to working with Malawian communities.

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CHAPTER ONE:

AIMS, STUDY PURPOSE AND CONTEXTUAL SETTING

Introduction

> The keynote of our health work today is the cause and prevention of disease. This at once implies a consideration of social problems because of their close interdependent relation to disease (Tucker, 1916, p. 299).

Community Health Inequities

Community health both nationally and internationally reflects vast inequities that require more than additional resources to redress the imbalance. Power structures, beliefs and values create multiple barriers that help perpetuate disparities in community health (Farmer, 2005). The destructive legacy of research abuses impedes altruistic efforts to improve the health of marginalized communities. Moreover, conventional scientific research reflects power differentials regarding epistemological hierarchies in which community and experiential knowledge is subordinate to evidence-based practice.

Research is highly valued in our society as evidenced by the inundation of studies in the media on disease prevention and treatment. It can be argued that science functions as the U.S. state religion wherein heretics and unbelievers are shunned (MacIntyre, 2001). Science and research studies permeate our culture. Knowledge generation is indeed invaluable for progress. Nevertheless, questioning underlying assumptions that underpin the values and beliefs that support research practices of knowledge generation is necessary to promote equitable distribution of resources.

This chapter will begin with the author's context, a brief overview of community-based participatory research (CBPR), address the study purpose, aims and the entrée and

methodological steps of the study. Following this is a description of the study context in the US and Malawi. An overview of each of the subsequent chapters is provided in this introductory chapter.

Author's Context

Although the use of the first person was discouraged in scholarly writing for many years, more recently qualitative researchers have been called to identify themselves, their biases and individual contexts in an effort to help situate authors and their findings (Denzin, 2005; Horsburgh, 2003). Denzin (2005) says that the role of researchers involves personal responsibility, caring, and "sharing of emotionality" (p. 953). Hiding behind scientific method and disembodied language privileges researchers as "the experts" and can objectify participants. In response to this call for personal accountability through use of the first person, I will begin with a brief description of my context.

I am a white, middle-class woman with a degree in theology from Westminster College in England and experience as a residential social worker in a children's home in Oxfordshire. I worked in banks, helped run a business and later became a nurse. For five years I was a hemodialysis nurse, from which I gained a greater appreciation for the place of prevention in healthcare. I have over 8 years of experience in community health with a large non-profit organization in the Midwest where I worked as community health nurse manager and later as director of community health and youth. I have also worked with staff and community members in public health, churches, non-profit agencies, libraries, senior centers, schools and elsewhere to provide health screening, family

caregiver education, influenza vaccinations, disaster preparedness and response. I have experience in academic administration and I teach community health nursing.

My work with a non-profit organization involved collaboration with a number of local and national non-profit organizations, several colleges and universities. As a result of this experience I gained an understanding of the tension between providing services to those in need and addressing donor/foundation requirements for funding. In addition, I learned about the challenges and benefits of administration, working with volunteers, program development and expansion and working with the media. As a community health nurse, my hope is that this study will help in some way to mitigate power inequities associated with HIV and AIDS issues in Malawi.

Community-Based Participatory Research

Community-based participatory research (CBPR) is a collaborative approach to research that champions equality of voices among partners from academia, non-governmental organizations (NGOs), public health, faith-based organizations (FBOs) and community members. Community-based participatory research has produced positive sustainable results in the improvement of community health (O'Fallon & Dearry, 2002; Israel, Eng, Schulz & Parker, 2005). The use of CBPR can address power differentials and challenge systems and beliefs that perpetuate health inequities and disparities, especially in marginalized populations (Leung, Yen & Minkler, 2004). Community health nurses act as advocates, educators, clinicians and collaborators and can join with others in challenging power structures, beliefs and inequitable practices in marginalized communities to promote and sustain community health.

Community-based participatory research differs from community-based research in that CBPR works *with* a community as opposed to working *in* a community. In CBPR, the community is an equal partner beside academic researchers. Although much can be learned about relationships between academic-community partnerships, there is a subtle, but significant difference when the starting point is based on equal recognition, respect and power among all partners in every aspect of the research process, from determining the research questions to dissemination of results. Community-based research is conducted *in* communities and academic researchers retain control in directing research questions, interventions, evaluation and subsequent dissemination of results, whereas in CBPR, community members share equal power in all stages of the research process (Israel, Eng et al, 2005).

Non-governmental organizations are often chosen as partners in addressing national and international health because of their ability to provide culturally sensitive and appropriate programs and services to communities (Kelly, Somlai, Benotsch, Amirkhanian, Fernandez, Stevenson et al., 2006). Yet, despite an emphasis on equality of voices in CBPR, NGO discourses are often silent in CBPR literature.

Community-based participatory research is increasing in the research world (O'Fallon & Dearry, 2002; Israel, Eng et al., 2005) and although NGOs have a critical role in international settings (Kelly et al., 2006), there is little literature reflecting NGO perspectives. As CBPR is an approach to research that equitably involves both academic and community partners with a growing body of sustainable results (Minkler, Vasquez, Warner, Steussy & Facente, 2006) CBPR is an appropriate approach in resource-poor countries as it is both respectful and builds capacity (Israel, Eng et al., 2005). Partnership

approaches to research and program implementation are not only cost-effective, they demonstrate sustainable results. Understanding NGO perspectives can help strengthen relationships between NGOs, communities and the donors that provide financial assistance in the developing world.

Malawi, Central Africa was chosen as the country in the developing world for the focus of this study. Gaining perspectives of Malawi staff and partners of NGOs and CBOs will increase understanding regarding the role of CBPR as an approach to research and conducting NGO activities in Malawi.

Study Purpose

The purpose of my research was to explore perspectives of NGOs in order to understand barriers and facilitators in their work with communities. NGOs work in two different worlds: the donor world and the communities that they serve. The data from my study was obtained through interviews with NGO staff (US and Malawi), Malawians who work with the NGO to mitigate HIV and AIDS and NGO contacts (individuals who were potential study participants based on their experience working with Malawian communities). See Table 1.1 for study terms and definitions.

The long-term goal of this study is to learn how community health in Malawi can be strengthened or improved. Community-based participatory research is a non-linear approach to research and community health that advocates recognition of multiple perspectives and possibilities to address community health. A greater understanding of NGO perspectives can assist those who are interested in both maximizing resources and promoting social justice in Malawi.

Aims

The study aims to address three primary questions:

1. How do NGOs build trust and relationships with community members and agencies?
    a. What are the characteristics of the relationships between NGOs and communities?
    b. How is trust sustained?
2. What are the perspectives of NGO staff regarding their interactions or experiences with donors?
    a. What do NGO staff recommend regarding their donors?
    b. How do research and service fit with NGO and community partner goals?
3. How do Malawi women effect change in their communities?
    a. What are the gender and power dynamics in Malawian communities?
    b. How can NGOs support Malawi women?

Aims 1, 2 and 3 are explored in chapters 5, 6 and 7 respectively.

Entrée and Methodological Steps

This study evolved in part from the questions raised through analyzing transcriptions from a federally-funded study entitled *Malawi Christians and Muslims: HIV Prevention and AIDS Care* (R01 HD 050147; Rankin PI) and also from my pilot study comprised of interviews and observations of US NGO staff and volunteers (NGO1). In this study, NGOs and CBOs are differentiated by numbers to maintain their anonymity. NGO1 is a US-based NGO that works primarily in Malawi to mitigate

effects of HIV and AIDS. Staff and Board Members from NGO1 graciously allowed me to conduct a pilot study to learn more.

Through analysis of verbatim transcriptions of audio-recorded interviews, it became clear that NGO1 followed the principles of CBPR but stopped short of conducting research. I wondered why CBPR was not conducted in Malawi as it seemed to be a logical fit. Moreover, there was clear resistance to conducting research despite the NGO1's high percentage of PhD-prepared staff and Board Members. For NGO1 staff, the severity of the situation in Malawi necessitated that resources be allocated to service rather than research. Nevertheless, I wondered if conducting research could strengthen arguments for additional resources in Malawi. Aware of the deleterious effects of colonialism, it seemed prudent to ask what Malawian NGO staff and their colleagues thought. Again, NGO1 provided me with introductions –to Malawian staff, partners who work with the NGO in Malawi and other contacts as potential study participants. (See Table 1.2 for a full description of NGOs in the study).

Study Context

This study concerns NGO staff who work to mitigate suffering related to HIV and AIDS in Malawi. They accomplish this by following cultural norms, providing women with education and economic opportunities, working with partners and interfaith organizations, assisting orphans, and supporting public health infrastructures to achieve sustainable improvements in community health.

US Context

NGO1 has an office in California where initial study interviews and observations were conducted. The US setting had modern amenities and access to participants' chosen

locations for interviews in homes, offices and university settings was via highways and paved roads. Participants were easily accessible via telephone or email and all US participants provided written consent for participation in the study that was approved by the Committee on Human Research in San Francisco, California.

The focus of NGO1's work was on the ground in Malawi. There is a nine hour time difference between California and Malawi and emails sent from the US in the evening were often answered the following morning. NGO1 has Malawi staff that help the US staff understand the culture and context of Malawi.

Malawi Context

Malawi is located in Sub-Saharan Central Africa and was rated 162nd out of 177 countries based on its reduced life expectancy, low education levels and poor standard of living (Human Development Report, 2008). Malawi has a population of 13.1 million (Malawi Census, 2008). Life expectancy in 2006 was 48 years of age for Malawians (UNICEF, 2007) whereas life expectancy in the US rose to 78 years in 2007 (Medical News Today, 2007).

Fifty-three percent of Malawians fall below the poverty line and almost 12% of the population were living with HIV and AIDS in 2007 (Global Health Reporting citing UNAIDS, 2008). There is a very high risk for typhoid fever, bacterial and protozoal diarrhea, shistosomiasis, malaria and plague (Index Mundi; 2008). In 2007, it was estimated that 840,000 people were living with HIV and AIDS, 91,000 of them children 15 years of age or younger and that the total number of AIDS-related deaths for both children and adults was 68,000 (Global Health Reporting citing UNAIDS, 2008).

Malawi women are at risk for physical and sexual violence (Mkandawire-Valhmu & Stevens, 2007), and women between 15 and 24 years of age comprised 56.8% of HIV cases in 2004 (UNAIDS, 2004). Malawi women had a literacy rate of 62% in 2004 compared with literacy rate of 79% for males in the same year (Malawi in Figures, 2007). Malawi women with greater education, achieve increased economic gain (Chirwa, 2008), yet educational disparities for females remain the norm in Malawi.

Approximately 96% of Malawians have a religious affiliation (Index Mundi, 2008). As such, religion has a key role in Malawi culture. Christian affiliations account for almost 80% of the population, approximately 13% of the population is Muslim and 3% are affiliated with other religions (Index Mundi).

Malawi citizens are at risk for food insecurity due to climate changes as many of the 85% of the population who live in rural villages rely on subsistence farming (Index Mundi, 2008, Malawi Economic Brief, 2005). Because much of the population resides in rural areas, access to public health is often limited.

Due to increases in healthcare provider salaries, fewer nurses are now leaving Malawi in to work abroad (Vujicic, 2008). Nevertheless, the nurse/patient ratio of one nurse to 54 patients in Lilongwe, Malawi compared with the California standard of one nurse to 5 patients accentuates the gross disparities between Malawi and the US (BBC News, 2006; California Progress Report, 2008). Despite the bleak Malawi statistics, Malawians continue to work with NGOs and others to address the ravages of HIV and AIDS as well as other community health issues. Nurses play a critical role in healthcare, both by providing direct individual care and by working on the systems level to promote community health.

Although Malawi gained independence in 1964 and there has been a continued interest in human rights, Englund (2006) argues that during the 1990s "the great expectations in Malawi were not matched by improvements in the conditions of life among the majority" (p. 5). Despite advances on many levels, over 50% of Malawians live below the poverty line (CBS News, 2007) and Malawi has one of the worst maternal morbidity and mortality rates in the world (The Health Foundation, 2007).

There is controversy over the role of NGOs as promoters of human rights as Englund (2006) and Shivji (2007) argue that many (but not all) NGOs serve the interests of the elite in Malawi rather than the poor majority. Both Englund and Shivji advocate a bottom-up approach that addresses the practical needs of Malawi on the ground rather than paying lip service to empty rhetoric regarding democracy and freedom. NGOs in Malawi must register with the government (Englund) and Pfeiffer, Johnson, Fort, Shakow, Hagopian, Gloyd et al. (2008) argue that NGOs operating independently of the Malawi government erode the public health infrastructure.

Description of Malawi Setting.

Statistics and reports provide important information about Malawi, yet the numbers cannot capture the resourcefulness and dignity of the Malawi people. While I do not wish to romanticize the poverty of Malawians, a strength-based approach necessitates that statistics be placed in context of this ethnographic study. A short description based on observations while in Malawi thus follows.

During observations of rural villages in Mulanje (southern Malawi) and Zomba (south central Malawi), my access to villages from Blantyre began with a journey on a two-lane paved road that merged into long dirt roads and across rough bridges that are

impassable during rainy seasons due to erosion and lack of side supports. Women and children washed laundry against the rocks beneath bridges. Men, women and children walked along the road balancing goods for market on their heads or shoulders. Some walkers wore shoes, many wore flip flops and some were barefoot. Small brick or mud structures were covered with rough thatched roofs or corrugated sheet metal. Windows were small, dark and few in number. Rough shanty road stands were usually vacant with the occasional row of sugar cane lined up on the ground for sale. As women worked, some of the men and boys stood and stared with their arms folded across their chests while children ran free, smiling and waving as vehicles made their way down the bumpy roads. Churches and mosques were frequent sights along the rough and dusty roads. Large banana plants and green fields of tea offset the red dirt in the Mulanje district that is flanked by the Mozambique mountain range.

In the Zomba region several men carried wide loads of charcoal balanced precariously across the back of bicycles. The rhythm of the day was dictated by the sun as electricity was not readily available in rural areas. Despite rampant poverty, the Malawians had a sense of dignity and peacefulness that transcended their physical hardships.

Study participants were well-acquainted with western researchers and wanted to tell their stories. A frequent request was to see the study results. Many voiced complaints that much research takes place in Malawi, but Malawians rarely are able to read the results or appreciate any benefit from the research in which they participated. The findings of this study will be available for all participants through NGO1.

Overview of Chapters

The first four chapters address the background of the study, a review of CBPR literature, the study's theoretical framework and the qualitative methodology of the study. Chapters 5, 6 and 7 are data-based chapters that address the main themes of the study. A synthesis of the study is found in Chapter 8.

Chapter 1.

This chapter serves as an introduction to the dissertation. The author's context and background of the study are discussed in Chapter 1.

Chapter 2

Chapter 2 addresses current CBPR literature and some of the challenges and gaps in CBPR literature. CBPR is dynamic, process-based and the activities of CBPR continue long after initial study aims have been met. The dynamic nature of CBPR is one of the challenges for CBPR in the research world which focuses on outcome-based measurements and static determinants of success. Additionally, in CBPR, health is viewed from the community's perspective which is often at odds with epistemological values of conventional research. For example, in one CBPR study in South Africa scientific knowledge derived from research on cervical cancer and associated risks was the focus for the funders and this conflicted with community member's concerns about issues of violence, teen pregnancy and apartheid (Mosavel, Simon, van Stade, & Buchbinder, s2005). The community's knowledge of what was happening on the ground resulted in different priorities than the funders whose priorities stemmed from knowledge about cervical cancer risks in South Africa.

Community-based participatory research literature is often confusing as CBPR is an approach to research rather than a research method. Quantitative, qualitative and mixed-methods are used in different CBPR studies. In an author-conducted review of CBPR studies, some studies emphasized the CBPR process and others stressed study outcomes. In response, I developed a tool to evaluate the CBPR process employed by the research partners, a separate tool to report the particular study design and interventions chosen by the partners with its associated results/findings and practical outcomes achieved by the study and a third tool for reporting the methods of dissemination of the CBPR findings/results to the wider community.

Chapter 3

Ecosocial theory is a term coined by Nancy Krieger (1994). A discussion of how ecosocial theory can serve as a framework for CBPR is the topic of Chapter 3. Ecosocial theory is grounded in epidemiology and social justice. Because of its strong basis in science combined with a call to examine assumptions about disease and health that might have social, economic, environmental or political rather than genetic causes, ecosocial theory promotes a bottom-up approach to social justice while using scientific arguments and language reflected in the dominant class.

Ecosocial theory can provide a flexible framework for CBPR that incorporates both the dynamic nature of processes and a theoretical basis for challenging existing epistemological and power structures. Ecosocial theory is influenced by ecological theory and epidemiology. Social, political, environmental and economic factors are considered as determinants of physical health for individuals and communities and many

genetic explanations for health disparities are challenged in ecosocial theory. Both CBPR and ecosocial theory embrace the complexities found in community processes.

Ecosocial theory fits well with community health nursing because it acknowledges the complexities of social, environmental, economical and political contributors to health disparities within a scientific framework. Ecosocial theory can provide a framework for the dual roles of advocate and nurse scientist. The constructs of ecosocial theory are examined in Chapter 3.

Chapter 4

Chapter 4 demonstrates how public ethnography complements principles of CBPR and fits with the aims and purposes of the study. Public ethnography draws on multiple disciplines and addresses diverse issues from an interdisciplinary approach in order to stimulate dialogue and promote social justice (Bailey, 2008; Tedlock, 2005). The study participant's interviews are both rich and insightful; nevertheless, based on 26 interviews I cannot presume to present a full ethnographic description of NGOs in Malawi. I can, however, provide a snapshot view of NGO and community-based organization (CBO) staff perspectives in order to promote dialogue and impetus to reduce health disparities in Malawi.

In the beginning of several interviews I had the sense that I was being given the party line and that some participants were a little weary of repeating information for curious westerners associated with donors of NGOs. As questions turned to what the participants saw as most important for Malawi and their own experiences, the party line was replaced with passionate discourses about Malawi struggles and how to address these.

Public ethnography is a method whereby social justice issues are brought to the forefront for the purpose of dialogue and stimulating change. Community health nurses function as advocates and public ethnography is a method whereby health disparities can be exposed and addressed. A life expectancy of 48 years in Malawi when compared with 78 years in the US (UNICEF, 2007; Medical News Today, 2007) is unacceptable. My hope is that this study portrays a clear message that the Malawi study participants want to participate fully in programs and research that is implemented in Malawi.

Chapter 5

I was curious how a US-based NGO gained the trust of Malawi communities. This topic is explored in Chapter 5. Trust is a necessary component in any relationship and is critical for sustainable relationships between NGOs and communities. Participants discuss practical approaches to develop trust between NGO staff and community members in addition to identifying three main barriers to trust: economic, religion and gender.

The way in which an NGO approaches communities affects community trust. If an NGO works from a top-down rather than a bottom-up approach, community members might cooperate; however, participants stated that top-down approaches do not generate trust. Respecting a community's culture and listening to and engaging community members were identified as necessary components in gaining a community's trust. One-on-one relationships between an NGO staff member and a community member provide the basis of trust. As the number and strength of positive relationships increase, trust is attributed to both the NGO and the community as a whole.

Chapter 6

I wondered how NGOs worked with partners as literature on CBPR emphasized the time commitment required to develop partnerships (Hughes Halbert, Weather & Delmoor, 2006). Study participants answered questions about partners, but did not present these relationships as a burden or barrier. Issues of donor expectations and power differentials generated more passionate responses than partnerships issues. Chapter 6 addresses donor issues. Participants stressed that a bottom-up approach is needed in Malawi. Donors were challenged by one study participant to "look at what is beneath the numbers" or to understand what the impact of a program or activity is on the ground in Malawi. In other words, donors are challenged to ask how people in Malawi evaluate their programs and activities rather than focus on numbers of individuals served or outcome-based measurements alone.

Chapter 7

I heard throughout early study interviews that women were the key to mitigating HIV and AIDS in Malawi, yet Malawi women were said to be socially disempowered. This ironic juxtaposition merited further exploration and is addressed in Chapter 7.

Culture was identified as the chief reason for women's social disempowerment, meaning that Malawi women lacked economic power, lacked a voice in their homes and communities and had an increased risk for HIV and AIDS as well as physical and sexual violence (Rankin, Lindgren, Rankin & Ng'Oma, 2005). Poverty increases a woman's risk for HIV and AIDS and conversely, economic gains strengthen a woman's role in her family and community.

A study conducted in South Africa (Kim, Watts, Hargreaves, Ndhlovu, Phetla & Morrison et al., 2007) found that providing training and micro loan assistance decreased a woman's risk for domestic violence by more than fifty percent. In Kim and colleagues' study, women were provided with training on micro finance, HIV transmission, gender norms, sexuality and domestic violence. Further studies are needed to determine if Malawi women's risk for domestic violence would be reduced if they were offered similar economic opportunities and training.

Chapter 8

Chapter 8 concludes with a discussion, implications for further research and how this study can contribute to nursing knowledge.

Community health is complex and defies linear approaches. Study data emphasize the importance of relationships across disciplines and roles. Poor relationships between NGOs and communities can be deleterious to community health. NGO and community relationships are generally established between an individual from each of the two sectors and the strength and number of these relationships can provide a safety net for the community.

Table 1.1: Definition of Terms

Community	A group of individuals that interact socially with each other and share a common geographical space in Malawi.
Donors	Individuals and/or large organizations that provide financial aid to assist Malawians.
FBO	Faith-based organization. Anglican, Baptist, Catholic, Living Waters and Muslim faiths are represented in the sample organizations.
Malawi Women	Adult Malawi women, 85% live in rural villages.
Malawi Men	Adult Malawi men, 85% live in rural villages.
NGOs	Non-governmental organizations.
NGO1	An organization working in both the US and Malawi to mitigate the affects of HIV and AIDS in Malawi, Central Africa.
NGO1 Contacts	Individuals referred to researchers by either NGO1 or its partners (sometimes referred to as a "snowballing" recruitment technique).
NGO1 Malawi Staff	Malawian NGO1 staff based in Malawi.
NGO1 Partners	Individuals and organizations that work with NGO1 to mitigate HIV and AIDS and related issues in Malawi.
NGO1 US Board Members	American individuals who are current Board Members for NGO1.
NGO1 US Staff	American staff based in the US.
NGO1 US Volunteers	Volunteers of NGO1 who support activities to mitigate the effects of HIV and AIDS in Malawi through financial and/or time contributions in the US and/or Malawi.
Participants	Individuals who consented to be interviewed and participate in the study "Community-based Participatory Research: An Analysis of Non Governmental Perspectives".
Sustainability	Participants defined sustainability in terms of community member involvement and frequently stated that the community must be behind any program or research project in order to have long-term results.
Trust	Believing that a person or organization will support words with actions. Trust increases through the sharing of common goals and an ongoing commitment between individuals and organizations.

Table 1.2: Identifiers and Descriptions of Organizations

Identifier	Description
NGO1	An organization based in the US with operational headquarters in Malawi that works to mitigate the affects of HIV and AIDS in Malawi, Central Africa.
NGO2	A protestant organization in Malawi that aids communities in food security, development projects, HIV and AIDS and also provides disaster relief.
NGO3	An organization that works with youth who are living "on the street" to reintegrate the boys and girls to their homes of origin. Social workers address problems that led to youth leaving their homes and work with the youth, families, schools and legal authorities to reconcile differences in order to strengthen families and communities and decrease subsequent occurrences.
NGO4	A Malawi branch of a larger international organization working in several countries that addresses food security and works to provide sustainable systems to end hunger through bottom-up approaches. It also addresses issues around HIV and AIDS and empowering women.
NGO5	An international organization partnering with local organizations working to promote human rights among the poor. It works to address poverty, responds to natural emergencies and political conflict with a goal to assist poor people to obtain necessary resources and maintain human dignity and autonomy.
NGO6	An organization whose purpose is to strengthen families, support women (primarily mothers) regarding family issues, and teach Christian values.
NGO7	This organization includes a school that provides assistance and education for orphans and also provides training for women to generate income through income generating activities (IGAs) such as sewing projects.
NGO8	A faith-based organization (FBO) that helps primarily Muslims with social concerns.
CBO1	This is a FBO that provides care for orphans. Staff are provided with training in child development. Orphans are provided nutritious meals in day centers.
CBO2	This "CBO" is a married couple that provides housing and care for approximately 16 orphans. The children are provided with food, shelter, education and participate fully in family and community activities. The family receives donations from outside sources to provide this care.
CBO3	An organization wherein women learn to help themselves. Widows and other women are taught how to market items that they can grow themselves, or how to sell sewing projects to generate income.

CHAPTER TWO:

UNTANGLING PROCESS AND RESULTS IN COMMUNITY-BASED PARTICIPATORY RESEARCH:

A PROPOSED FRAMEWORK FOR ORGANIZING CBPR STUDIES

Introduction

Community-based participatory research (CBPR) is gaining in popularity (Stevenson, 2007) due to successes in positive, sustainable community health outcomes (Edgren, Parker, Israel, Lewis, Salinas et al., 2005). A review of CBPR literature, however, revealed confusion as authors struggle to describe both the CBPR processes as well as the outcomes of their research. A good process, namely one that follows CBPR guidelines, does not necessarily produce good health outcomes and conversely, good outcomes might not reflect a good process. This chapter provides a brief overview of CBPR and a proposal for organizing CBPR studies to more clearly delineate CBPR processes, research methodology with related community health outcomes and dissemination of results. This chapter will conclude with an analysis of some of the challenges facing CBPR.

Overview of CBPR

CBPR has its roots in participatory action research (PAR) that was influenced by Kurt Lewin in the 1940s (Holloway & Wheeler, 2002). Health is considered from an ecological perspective, both process and outcome are valued and the community is viewed as a unit with strengths as opposed to needs (Malone, Yerger, McGruder & Froelicher, 2006). Often used in education and the social sciences, the focus of CBPR is not to increase knowledge alone; rather, research is addressed in conjunction with

behavior change (Holloway & Wheeler). Developing nations often used participatory research to bring about change in response to social injustices and the strength-based approach is particularly applicable to healthcare (Minkler, Vasquez, Warner, Steussey & Facente, 2006).

Sustainable Results

CBPR has been promoted by the National Institute of Environmental Health Sciences (NIEHS) as an effective methodology to advance understanding of diseases in relationship to environmental factors (O'Fallon & Dearry, 2002). The NIEHS demonstrated its value of CBPR by requiring Centers for Children's Environmental Health and Disease Prevention Research to include a CBPR project in order to receive funding (Israel, Parker, Rowe, Salvatore, Minkler, Lopez et al., 2005). The Centers for Disease Control, the Office of Minority Health and private foundations have issued CBPR requests for proposals (Wallerstein & Duran, 2006). CBPR is well suited to address community health issues in marginalized and underserved populations (Leung, Yen & Minkler, 2004).

Historical Background

According to Wallerstein (2002), Lewin coined the term "action research" which was primarily used by organizational business researchers for problem solving. In the 1970s, radical critiques from social scientists challenged traditional research regarding its distance from social problems (Wallerstein). Rooted in feminism, post-structuralism and post-colonialism, PAR was used to address social inequities regarding social structures, discourses and norms (Wallerstein).

CBPR Definition

The public health definition proposed by Israel, Parker et al., (2005) for CBPR was generally supported throughout all of the reviewed articles (See Appendix A).

> CBPR in public health is a partnership approach to research that equitably involves, for example, community members, organizational representatives, and researchers in all aspects of the research process, in which all partners contribute expertise and share decision making and responsibilities (Israel, Parker et al., p. 1464).

The purpose of CBPR is to promote the health and quality of life for community members through a process which involves equal partnership, power, respect of partner expertise, equal voices in development of plans, and agreement on implementation methods, evaluation and dissemination of results (Israel, Eng, Schulz & Parker, 2005; O'Fallon & Dearry, 2002; Minkler, Vasquez et al., (2006). The reviewed CBPR studies reflect similar values, express partnership language, shared power, respect and methods of dissemination in discussions and conclusions.

Community Definitions

One of the keys to CBPR is an agreed definition of community by stakeholders (Viswanathan, Ammerman, Eng, Gartlehner, Lohr & Griffith et al, 2004). Communities can be understood as groups that function beyond geographical boundaries. For example, due to the Internet, many individuals are able to form communities based on common interests, characteristics and activities that are not restricted to geographical locations. Walter (2006) defines community as "multidimensional" to describe the way in which the various dimensions that characterize community-such as people and organizations,

consciousness, actions, and context – are integrally related with one another, forming the whole that is the community" (p. 68).

Minkler and Wallerstein (2006) include two theoretical frameworks for understanding community. An ecological framework includes geographical, physical, population and heterogeneity characteristics as well as technological and social organizational structures. The second framework is that of a social systems perspective which includes economic, political and social subsystems that affect communities from within and without (Minkler & Wallerstein). Another definition of community is understood as a shared interest, be it political, cultural, social or other interest among a group of individuals that do not necessarily share geographical proximity with each other (Green as citied in Viswanathan et al., 2004). Perhaps the most important definition of the community is that which a particular community uses to define itself.

CBPR Principles

The purpose of CBPR is to promote the health and quality of life for community members through a process which involves equal partnership, power, respect of partner expertise, equal voices in development of research related plans, and agreement on implementation methods, evaluation and dissemination of results (Israel, Eng, Schulz & Parker, 2006; O'Fallon & Dearry, 2002; Minkler, Vasquez et al, 2006). Israel, Schulz, Parker, Becker, Allen and Guzman (2003) identified nine guiding principles for CBPR. First, the community's identity is recognized, whether based on sharing common concerns, its a geographical boundary or defined by social interactions. Second, CBPR takes a strength-based approach as opposed to a pathology approach and builds on community assets. Third, throughout all phases of CBPR, equal partnerships are fostered

and power is shared. From identification of research questions, decisions in methodological approaches and implementation, through evaluation and dissemination of results, all partners have an equal voice. Social inequalities are addressed throughout the process.

Fourth, CBPR focuses on capacity building and an equal exchange of knowledge, skills and expertise. Researchers learn from community members as well as share their area of expertise. Fifth, CBPR balances knowledge generation that contributes to scientific knowledge with practical interventions and policies that address community concerns. Sixth, CBPR has an ecological and public health approach that recognizes that health has multiple determinants. Anthropomorphism has given way to recognition of the import of not-human elements such as the environment.

The seventh principle is that CBPR promotes systems development throughout all stages of the research, including dissemination and strategies to address policy changes. Eighth, dissemination of results not only includes community partners, but also the wider community and beyond. This is expressed in co-authorship of articles and shared presentations at conferences and meetings. Finally, CBPR has a long-term commitment to communities and focuses on sustainable results. Trust is a key element identified in this final principle as relationships are critical in promoting and maintaining positive health changes in communities.

Literature Review Methods

CINAHL, PubMed, Cochrane Library and PsychINFO databases were used to search English language published studies using the following major search terms: CBPR, community partnerships, community-based, participatory, research, NGO,

international and Africa. Manual searching of citations from published articles and Internet links to CBPR was also performed. The review of literature for this chapter was limited to community health studies. Although no limitations of dates were imposed in the search, the studies reviewed were primarily published between 2002 and 2008.

A review of the literature yielded few international health related CBPR studies. A limitation of the review is that only studies published in English were reviewed and that international CBPR publications might not be available through CINAHL, PubMed, PsychInfo and Cochrane Library databases.

Many of the reviewed CBPR studies incorporated several aspects of community health and different populations with interesting combinations of environmental, health and population studies. Vasquez, Lanza, Hennessey-Lavery, Facente, Halpin & Minkler. (2007) discuss a CBPR partnership that addressed food security in Bayview Hunters Point that involved youth, policy changes, environmental justice issues and small business owners. Linnan, Ferguson, Wasilewski, Lee, Yang and Solomon et al. (2005) conducted a study on health promotion, including diet, exercise and cancer screening in an innovative partnership with cosmetologists who primarily served African American women in North Carolina. Krieger, Allen, Cheadle, Schier, Senturia and Sullivan (2002) addressed asthma, domestic violence and community research in their study in Seattle, Washington. Levy, Brugge, Peters, Clougherty and Sadler (2006) addressed pediatric asthma from both medical and environmental perspectives.

Several of the reviewed CBPR studies focused on marginalized or underserved populations with successful outcomes (Andrews, Bentley, Crawford, Pretlow, & Tingen, 2007; Caldwell, Wright, Zimmerman, Walsemann, Williams & Isichei, 2004; Campbell,

Sefl, Wasco & Ahrens, 2004; Carlson, Neal, Magwood, Jenkins, King & Hossler, 2006; Marcus, Walker, Swint, Smith, Brown, Busen et al., 2004; Details can be found in Appendix A.

Untangling Process, Method and Results in CBPR Studies

As many of the reviewed journal articles were focused primarily on the CBPR process, actual research results or findings were often unclear. It was difficult to evaluate the CBPR process (how partners worked together to determine research questions, interventions, evaluations, adapt to changes during the study and how results were disseminated) and the research methodology (study design, implementation and results/findings) as discussions of both process and method were sometimes intertwined. Research results/findings and the subsequent community health outcomes often were neglected in favor of extensive discussions about CBPR processes and clarity suffered as authors struggled to articulate the CBPR process they employed, study designs and outcomes. Finally, few studies provided comprehensive information regarding dissemination of results. As the purpose of CBPR is to benefit communities, discussion of how study results are disseminated is a central issue that merits space in publications.

A good CBPR process doesn't necessarily yield good research results. Similarly, one can have a poor CBPR process and good, or not so good, study outcomes. Critics might be concerned that CBPR does not typically follow the gold standard method of randomized controlled trials (RCTs); however communities have resisted RCT methods due to ethical concerns about denying or delaying benefits for a control group. Cook (2007) argues that an emphasis on a biomedical model is not necessarily the best approach for community health research. The pursuit of knowledge is not the primary

goal of CBPR. Partners in CBPR must determine appropriate actions to address practical issues in the community and Cook maintains that this is a scientific pursuit (equal to the pursuit of knowledge) and requires different evaluation criteria than used in traditional research.

Suggested Organizational Framework for CBPR Studies

Separating CBPR Process from Research Methods

I propose that one solution to untangling CBPR literature is to separate CBPR process from research methodology (methodology being focused on results/community health outcomes) and to provide a comprehensive overview of dissemination methods found in the CBPR literature. This information can be organized in three separate tables: Table 2.1: CBPR Process Evaluation; Table 2.2: Research Design, Results/Findings and Community Health Outcomes; and Table 2.3: Dissemination of CBPR Results.

Process Evaluation

Partners can evaluate the CBPR process according to CBPR guidelines (See Table 2.1, CBPR Process Evaluation). Some guidelines might only require a check box, while others require comments or discussion. For example, research questions either were or were not determined by both researchers and community partners. Determining whether the CBPR process was satisfactory might require comments or discussion as there could be disagreement in this area. Evaluating some CBPR processes might require partner input, such as how well the partners worked together, how satisfied partners were with the process, evaluation, dissemination of results and so on. Table 2.1 can be expanded to include evaluation tools and other methods as appropriate. The goal of this chapter is to suggest tools for organizing CBPR studies that clearly addresses processes and outcomes.

Research Methods and Results/Community Health Outcomes

The goal of CBPR is to improve community outcomes through an egalitarian process between researchers and community partners. As such, CBPR partners determine the best research design and interventions to address their research questions. The research methodology should be evaluated according to standards for the particular methods employed, i.e., case studies, randomized clinical trials (RCTs), focus groups, mixed methods etc.

Community health outcomes achieved through CBPR should be clearly identified and include practical results that are measureable as well as more intangible community benefits. It is important to identify benefits from CBPR that might not be easily quantifiable, e.g., 'due to CBPR, community members have taken the initiative to create independent research projects as they now have the necessary tools.' Table 2.2 provides a tool for reporting research design, results/findings and community health outcomes.

Dissemination of Results

All participants are to have a voice, yet published results are usually in research journals that may or may not benefit research participants. Although some of the reviewed articles discuss dissemination in formats other than peer-reviewed journal articles such as Photovoice (a method that uses photos and stories to depict community issues) (Castleden et al., 2007; Rhodes, Hergenrather, Wilkin & Jolly, 2008), most discussions addressed healthcare providers. In defense of research authors, the omission of alternative forms of dissemination of results might be due to targeting specific audiences and journal space restrictions. Additionally, there is no common format for

reporting CBPR and as such, different issues are stressed depending on author, journal, or even perhaps, funding concerns.

Dissemination of some of the findings resulted in policy changes (Vasquez, Minkler & Shepard, 2006). For example, there were strong findings that CBPR influenced policy changes that caused a New York bus fleet to convert to clean diesel fuel use and the installation by the Environmental Protection Agency (EPA) to install "permanent air monitors in Harlem and other 'hot spots'" (Vasquez et al., 2006, p. 101).

Involvement of dramatic presentations, media designs and composition of music were part of the study methods to educate African American adolescents about HIV and AIDS and illicit drug usage (Marcus, Walker, Swint, Smith, Brown & Busen et al., 2004). Perhaps such methods could also be used to disseminate results. Showcasing the creative talents of the adolescents in a community forum would be an effective way to disseminate results to the community and participants.

Dissemination processes were difficult to determine from many of the reviewed articles. Some authors addressed methods of dissemination, while others were less clear. As one of the goals of CBPR is to strengthen communities, despite the space limitations for peer-reviewed articles, it is important to address ways in which results were disseminated. A table for dissemination methods, such as peer-reviewed articles, dramatic presentations, newspaper articles, policy changes etc. can be found in Table 2.3.

Critical Analysis of CBPR

Community Partnership Research

Many research community partnerships in the reviewed studies (Appendix A) had successful outcomes (Swartz, Callahan, Butz, Rand, Kanchanaraksa, Diette et al., 2003;

Teufel-Shone et al., 2006, Savage, XU, Lee, Rose, Kappesser & Anthony, 2006, Levy, Brugge, Peters, Clougherty & Saddler, 2006, Caldwell, Wright, Zimmerman, Walsemann, Williams & Isichei, 2004; Ammerman, Washington, Jackson, Weather, Campbell, Davis et al., 2002). Internationally, more community-based research than CBPR was found. As power differentials continue to be a challenge in the developing world, moving toward CBPR partnerships rather than community-based partnerships would help redress power inequities. Nevertheless, community-based research endeavors substantiate the importance of community relationships and issues of trust. Equal sharing of power as found in CBPR would be a significant step in building trust internationally.

Pilot studies can be very beneficial in learning which aspects of a study are helpful and identifying potential problem areas early in the CBPR process. Utilizing CBPR processes to increase awareness regarding cancer in an American Indian population in Arizona (Coe, Wilson, Eisenberg, Attakai & Lobell, 2006), a pilot study was utilized that helped create a "research-receptive environment and promoted potentially sustainable research capacity in the community" (p. 1980). Coe and colleagues' study promoted improved collaboration among agencies, improved patient care, and an increase in awareness regarding cancer and new partnerships.

Relationships with Communities

Despite participatory and process emphases in CBPR, tensions with traditional research practices remain. Research typically has a beginning, middle and end: research questions and designs are developed, data are collected and analyzed and then results are summarized and submitted for publication. Should funding be available, additional studies might be undertaken. In CBPR, however, capacity building is emphasized so that

the community can continue successful processes or projects. Ideally, communities will continue to develop their own research questions and methods to address these. In reality, funding and human resources are limited and communities might lack necessary resources for further studies.

Additional challenges to the researchers engaged in CBPR are power differentials of education, wealth and privilege and these can be especially conspicuous in international research (Mosavel, Simon, van Stade & Buchbinder, 2005). One way to address some of the inequities is by supporting communities through the provision of training and consulting for community members and organizations. The Photovoice project (photos and stories that depict community issues) in Western Canada (Castleden et al., 2007) was successful in that trained community members continued to take photos after data collection was completed as participants found a meaningful medium whereby their voices could be heard in the community. The PRAISE! Project (Corbie-Smith, Ammerman, Katz, George, Blumenthal, Washington et al., 2003; Ammerman, Corbie-Smith, St. George, Washington, Weathers, Jackson-Christian, 2003)) was also successful in sustaining long-term relationships with communities, due in part, to an emphasis on the importance of relationship building early in the project. As a result of a CBPR study to increase awareness about cancer in American Indians in Arizona, new American Indian researchers emerged (Coe et al., 2006). One consideration of equipping community members with research skills is that one of the benefits of CBPR is shared knowledge. The goal is not to proselytize community members to join academic research ranks. However, community members who are interested in research should be

encouraged to continue to question research methods, epistemological values and power dynamics in light of their unique community knowledge.

Once the data collection period has ended and participants agree on evaluation and dissemination, the researcher's work appears to be done. This is the time that other researchers would 'leave the field', pack up and go home. In CBPR the purpose of a long-term research process is not merely to obtain good data; rather, it is built on a collaborative process of trust and relationships that are meant to extend beyond the confines of a research project.

Some proponents argue that the role of researchers is to equip community members with tools and skills in order that they can function independently. Empowerment, community building and capacity building are terms that help gain funding; however, the notion that researchers are no longer needed after a CBPR project has reached its primary goals is something that the community should determine. If the community is satisfied and wants to function independently this is good. If, instead, the community wants a continued partnership with researchers, this also should be honored. Community members might not have the time or the inclination to become researchers and this should not be an expected result of the CBPR process. If, however, continued research is desired by a community, utilizing experienced researcher's knowledge would strengthen research endeavors.

As the guiding principles of CBPR suggest, equal partnerships should result in decisions that benefit all parties. As funding is often an issue, CBPR processes could be focused on ways to create sustainable partnerships. CBPR processes are time consuming

and once relationships have been established, it seems reasonable that maintaining the partnerships at some level is a worthy goal.

Guidelines on Processes in CBPR

Collaboration, equal partnership, respect and trust are principles that are valued in CBPR. The literature reports that building relationships is a timely endeavor and very important, yet guidelines on process are not emphasized. Despite the numerous references to the importance of community partnerships and relationships (Andrews, Bentley, Crawford, Pretlow & Tingren, 2007, Hughes Halbert, Weather & Delmoor, 2006; Minkler, 2006), there is not a formulaic approach for success. Relationships are personal and built on trust which is established over time. Trust takes time to grow and is easily broken (O'Neil, 2002).

As CBPR is an approach rather than a method, the emphasis is on process rather than a prescriptive edict. This has both benefits and drawbacks in that there is openness to a variety of creative methods to develop CBPR partnerships, determine research questions and the research trajectory; however, the lack of clear direction and multiple options can be overwhelming. In the business world and even in NGOs, the drive toward producing deliverables deemphasizes the value of processes and relationship building.

Participatory Evaluation

Processes can be difficult to evaluate and require evaluation methods that are flexible and respond to changes over time. Additionally as CBPR is a collaborative endeavor, participatory evaluation methods are required. Springett and Wallerstein (2008), state that participatory evaluation is an attempt to include all stakeholders with the goal of effecting meaningful and positive change. The roots of participatory

evaluation lie in participatory action research; it is usually practiced among disadvantaged groups and it reflects a Freirian approach to learning and capacity building (Springett & Wallerstein).

Unlike conventional evaluation, in participatory evaluation the authority of external evaluators is replaced with shared power based on principles of action research (Springett & Wallerstein, 2008). The power dynamics of participatory evaluation change and the researched rather than the researcher holds the power. One of the strengths of participatory evaluation is that there is flexibility in the process that allows evolution of the evaluation process as new information becomes available. A drawback is that the evaluation methods cannot be clearly defined ahead of time and this can cause conflicts with funding entities. Participatory evaluation is in keeping with the guiding principles of equality throughout the research process in CBPR.

Causality and Credit

An ongoing tension expressed in CBPR studies concerns the concept of causality, namely, whether outcomes are the direct result of CBPR interventions and how to claim credit for successes when multiple and complex variables influence communities. At the root of these concerns are questions about how CBPR fits into a scientific framework. Community-based participatory research has been shown to have positive outcomes and this has resulted in an increase in calls for CBPR in public health research (Edgren et al., 2005). It is difficult to trace a single intervention to a community outcome as communities are by nature influenced by multiple factors.

Community-based participatory research is a dynamic process that does not stop once research objectives have been achieved. One of the principles of CBPR is to build

upon community strengths in order that communities develop the tools and capacity to identify and address their concerns. Fostering community self-determination is an iterative process that is complicated by many factors, including the interplay of economic, social, political, racial, cultural and gender perspectives. Relationship building, likewise, is complex. Community-based participatory research can promote practices that create a safety net of relationships to support the community.

Receiving individual credit for accomplishments is a Western notion that might not be appropriate in international or community-focused settings. Certain measures that track individual contributions might not be valued internationally in the same way as in Western circles. Similarly, Western requirements for record keeping might not be as appropriate internationally where the focus is on shared results rather than drawing strong correlations between particular programs and achievements. A balance between good research methods and practical application is thus required.

Tensions between Research and Service

Community-based participatory research is meant to be driven by the beneficiaries of the research; however, in reality, funding is often the driving force. Power inequities continue despite lofty goals. Authors in a study about disability issues noted the "irony" regarding a principle of PAR that requires that the research need must stem from the community, and argued that research often would not be conducted with strict adherence to this principle (Minkler, Fadem, Perry, Blum, Moore & Rogers, 2002, p. 22). Community-based participatory research faces similar challenges; however, the overall goals can still be achieved if community partners are approached with humility and there is an equal sharing in subsequent research processes.

Mosavel and colleagues (2005) found that while cervical health for South African females was the focus of their CBPR, participants identified several other concerns that were not addressed by the study, including poverty, crime, violence, gangs, sexual risks and pregnancy. Mosavel and colleagues stated that they addressed the issues through capacity building, but did not elaborate how they accomplished this, as many community concerns were very different from the study aims and purposes.

Research can be a costly endeavor and when funding is bountiful, much can be accomplished. International research is often conducted in areas of extreme poverty and given the choice between spending money on research or direct service, the latter is often chosen in order to alleviate suffering. In the U.S., funding for marginalized populations can be scarce as well.

Funding and CBPR

A Meta analysis of CBPR studies conducted by Viswanathan et al., (2004) suggested that experts in CBPR participate in funding decisions for CBPR applications. This might seem self-evident; however, as CBPR varies greatly from conventional research and the Meta analysis was conducted in 2004, both knowledge about CBPR and the availability of expert volunteers was most likely limited.

Inherent in research funding is a power dynamic. At stake are not only financial issues, but the epistemological values that underpin what "counts as research." Principles of CBPR are inclusive and all participants are to weigh in on defining the problem, yet research funding often drives the research focus (Mosavel et al., 2005; Cook, 2009). Community-based participatory research as a collaborative process must continue to challenge power inequities and processes that are at odds with collaborative and

participatory research practices. Funding represents a primary source of power that has many layers of ideology interwoven in funding priorities. Challenging the basis of these sources of power can be a part of CBPR efforts when there is a conflict between community-identified needs and sanctioned funding for research.

Barriers and Facilitators

One of the key facilitating factors in CBPR is based on the quality of relationships among partners and the reviewed studies (Appendix A) generally agreed that prioritizing relationships at the beginning of a CBPR study led to success. Several CBPR studies have been conducted that build on the CBPR partnership established in North Carolina to address HIV and AIDS issues in the Latino population (Rhodes, Hergenrather et al., 2006, Rhodes, Yee & Hergenrather, 2006; Knipper et al, 2007; Rhodes, Hergenrather, Remnitz, Arceo, Montano & Alegria-Ortega, 2007; Rhodes, et al, 2008).

Another key facilitating factor in CBPR is an acknowledgment of conflict and development of an agreed method to achieve resolution. Due to the multiple roles that CBPR partners hold and the intersectionality of race, class and culture, there is no single approach to resolution of conflict. Nonetheless, prioritizing relationship building alongside conflict resolution is essential for the sustainability and success of the partnership.

Barriers to CBPR include time necessary to establish and maintain partnerships, funding and the complexity of working with multiple partners. When there is an emphasis on outcomes alone, it is difficult to gain support to build relationships and take time to reach consensus. Even when individuals understand the value of CBPR, whether members of academic institutions or NGOs, they require organizational support in order

to engage in CBPR activities. With pressure to produce results in the academic, business and non-profit sector, the lengthier processes that are involved in CBPR can be a barrier.

Perhaps the best argument in favor of CBPR is the ability to achieve sustainable results. As such, funding is increasing, yet there remains a tension between conventional research methodology and CBPR approaches. True to CBPR principles, resolution of this tension is a process.

After Findings and Funding

There is disagreement as to whether academic partners should remain in the community or whether the community should have the tools to proceed without additional funding or academic support (Viswanathan et al., 2004). Achieving community independence is a worthy goal. A drawback is that communities might lose the emphasis of wider dissemination and publication of its results without the presence of academic partners. Valuable accomplishments might occasionally receive a snapshot research review, but the ongoing development of the community processes might be lost.

Processes are complex concepts that are not easily identified or understood, yet are invaluable in CBPR. As much of conventional research focuses on outcomes, process has taken a subordinate position. Understandably, results are required for ongoing funding and energy to support research efforts. Yet, an exclusive focus on outcomes delimits recognition of activities that are a direct result of relationships that were established during a CBPR or other partnership process. Because activities that arise from partnership research endeavors are not measured as direct outcomes, the full import of their value to communities might not be recognized.

A benefit of maintaining research partners beyond the timeframe of research funding or original purposes of the partnership is that researchers have a different perspective. Processes that are critical to community health can be enhanced through research inquiry and exploration. It is not that community members cannot learn to have a research perspective (Coe et al, 2006), but that strength-based approaches capitalize on the unique contributions of individuals and communities collectively. Researchers and community members alike have skills that can be shared and new skills can be acquired. Each community must determine its own goals and what will work best. Maintaining sustained academic community partnerships provides opportunities to share resources that can benefit both "town and gown." Relationships are identified as key factors in successful partnerships. There is no single prescriptive approach to developing good relationships among community members and research partners. Trust is absent of guarantees by definition, as trust is not needed in the presence of a full guarantee (O'Neil, 2002).

What "Counts" as CBPR?

Community-based participatory research partnerships are often concerned with maintaining rigor; however, control and intervention groups can create ethical dilemmas in community settings. Designing studies with delayed intervention groups, rather than control groups has been one approach to address ethical concerns. As arguments for policy changes are usually not as strong if there are results from an intervention and a modified intervention group, there can be pressure to provide the dramatic differences that can be seen when comparing control and intervention groups. Given that such designs can be unethical, perhaps education is needed regarding appropriate measures

and a rescaling of values regarding the goals to achieve change in community health studies. A research result that might be good in a laboratory setting should not set the standard for community health.

Conclusion

Community-based participatory research partnerships not only produce sustainable results but can strengthen communities with positive benefits beyond original research goals. Tensions between conventional research and service must be addressed in order to increase the use of CBPR internationally. Although many of the reviewed studies have remarkable outcomes, there is still much work to be done to ensure that partnerships are equal and that power is shared. As CBPR occurs within dynamic communities that are constantly changing, navigating and determining effective process strategies is critical.

Establishing trust and collaborative relationships was emphasized throughout the reviewed studies and more research is necessary to understand the wide variety of ways this goal can be achieved. Development of new measures for evaluation will help validate the dynamic approaches that are necessary in non-linear approaches to address complex community health disparities. Ongoing conversations about conventional research and CBPR are needed to help develop processes that are rigorous, effective and flexible enough to have practical application.

Utilization of standardized tools for reporting CBPR would provide much-needed clarity regarding 1) CBPR processes; 2) the chosen research design, related results/findings and community health outcomes; and 3) dissemination of results. The

proposed tools (Tables 2.1, 2.2 and 2.3) can be modified as appropriate; however, these three components are critical in evaluation of the success of a particular CBPR endeavor.

Table 2.1: CBPR Process Evaluation

CBPR Guideline	Yes	No	Comments
Research question(s) were determined by both community and university partners			
Interventions were determined by both community and university partners			
Partners had equal power in the CBPR process			
Evaluation methods were determined by both community and university partners (comment if evaluation methods changed during the research)			
Dissemination of results were determined by both community and university partners			
The overall CBPR process was beneficial for each of the partners			
The overall CBPR process was beneficial for the community			
Capacity building occurred (describe)			
CBPR Partnership will continue beyond the current study			
Did other CBPR studies stimulate this research?			

Table 2.2: Research Design, Results/Findings and Community Health Outcomes

Study Design	Sample Description	Sample Size (N)	Setting/ Location	Findings/ Outcomes (Health, environment, behavior change etc.)	Percentage or Measurement of change	Strengths	Weaknesses

Table 2.3: Dissemination of CBPR Results

		Yes	No	Audience/Publication/ Jurisdiction	Comments
Community	Photovoice (Photos and stories that depict community issues)				
	Dramatic Presentation				
	Artistic Representation				
	Town Hall Meetings				
	Other Meetings				
	Other Methods				
Media	Newspaper Article				
	Magazine Article				
	Television Coverage				
	Radio Coverage				
	Internet Coverage				
	Other				
Government or Policy Making Bodies	Reports to Agencies (Local)				
	Reports to Agencies (National)				
	Constituent visits				
	Policy Changes				
	Other				
Academic Community	Peer-reviewed article(s)				
	Letter to Editor				
	Reflection Paper				
	Book/book Chapter				
	Conference Presentation				
	Other				

CHAPTER THREE:

ECOSOCIAL THEORY AS A FRAMEWORK FOR COMMUNITY-BASED PARTICIPATORY RESEARCH (CBPR)

Introduction

> Ultimately, it is theory which inspires our questions, which enables us to envision a far healthier world than the one in which we live, and which gives us the insight, responsibility, and accountability to translate this vision to a reality. Who shall create this theory? The task is ours (Krieger, 2001, p. 674).

Communities consist of complex social interconnections with multiple influences both internally and externally from individuals, social structures and the environment. Communities are dynamic in nature: they evolve, adapt and their emerging characteristics defy simplistic definitions. Working with communities internationally becomes more complex due to differing historical, economic, governmental and cultural challenges.

This chapter will address how ecosocial theory provides a flexible framework for community-based participatory research (CBPR) and concomitant efforts to address social inequities in community health. I will begin with a rationale for using CBPR, briefly discuss international health and colonialism and outline ecosocial theory. I will then address how ecosocial theory can support CBPR, provide an assessment of ecosocial theory and conclude with a discussion on how ecosocial theory and CBPR can challenge inequitable approaches to health.

Internationally, the challenges of improving community health are compounded and increasingly more complex due to pluralism reflected by diverse participants. As

such, a theoretical framework can create an environment for logical and creative inquiry that promotes ethical action to redress community health inequities.

Why CBPR?

Community-based participatory research is a collaborative approach to research that is based on a commitment to equal participation between researchers and community members to address community challenges. Navarro, Voetsch, Liburd, Giles and Collins (2007) recommend CBPR as an effective approach to address public health issues because of its ecological approaches to health, an emphasis on community participation, collaborative knowledge development and propensity for sustainable change. Multiple determinants of health, both human and non-human, are considered in CBPR.

Whereas traditional research begins with hypotheses and assumptions that are then tested, in CBPR the research process begins when communities identify problems or issues and the ways in which they can address these most appropriately (Minkler 2006; Wallerstein, 2006). Processes are monitored rather than tightly controlled, implementation and evaluation methods may emerge in response to data and community partner feedback and the direction of the research might be altered in response to new knowledge. The dynamic nature of CBPR makes it well-suited to address health promotion and concerns in the changing environment of communities. Nevertheless, traditional research methodology requires strict regulation that is not always feasible in community settings and as such, community research necessitates a methodology based on a philosophy and theory that supports dynamic processes.

Emphasis on Collaboration and Process

Whether one holds that knowledge is power or power is knowledge, the two are inextricably connected (Cheek, 2000). CBPR methods address power and epistemological issues by encouraging both shared power and collaborative knowledge development throughout the research process. Both power and knowledge are dynamic in nature. Although some hold that a fact is static and fixed, due to the contextual nature of facts and ever-shifting contexts, one can argue that knowledge evolves and is influenced by multiple variables. CBPR not only allows for evolution of power and knowledge, this process is encouraged.

Non-profit and non-governmental organizations (NGOs) are often chosen by researchers as partners because of their strong community connections, flexibility and generally decreased bureaucratic processes (Kelly, Somlai, Benotsch, Amirkhanian, Fernandez, Stevenson, et al., 2006). In addition, NGOs are able to effectively address sensitive issues in marginalized populations. The service focus of NGOs often results in culturally sensitive approaches to HIV prevention and care programs that are not generally found in government-generated strategies (Kelly et al., 2006). Community-based participatory research is an approach that encourages diverse partnerships to achieve its goals and the role of NGOs in addressing international health concerns is increasing (Gellert, 1996; Stevenson, 2007).

Sustainable Results

CBPR is an approach to research that the National Institutes of Environmental Health Science (NIEHS) has promoted at the community level due to its success in increasing understanding of health and disease related to environmental factors (O'Fallon

& Dearry, 2002, Wallerstein, nd). Additionally, the NIEHS has required Centers for Children's Environmental Health and Disease Prevention Research to include CBPR projects (Israel, Parker, Rowe, Salvatore, Minkler & Lopez et al., 2005).

A retrospective analysis of a CBPR partnership in Indiana that had been established for ten years was evaluated using a non-probability sampling of 1,000 households in a study to determine the sustainable effects of the original activities (Minkler, Vasquez, Warner, Steussey & Facente, 2006). The retrospective evaluation demonstrated positive results. The community had multiple health issues, including a "smoking rate of twice the national average" (Minkler et al, p. 293). Policy changes were made, a playground and walking trails were developed, the community took greater responsibility for its health and a greater cohesiveness in the community was achieved (Minkler et al.). Linnan and colleagues (Linnan, Ferguson., Wasilewski, Lee, Yang, Solomon et al., 2005) reported that 12 months following a CBPR study in which cosmetologists were trained to provide their clients with health information, post tests showed sustainable results of client health behavior changes.

Addressing International Health and Colonialism

> Can it be morally acceptable, let alone politically stable, to have a world in which there is a 20-fold difference in infant mortality and a 21-year gap in life expectancy between the 51 high-income countries and the 66 poorest countries? (Bloom, 2005, p. 2).

The Harvard School of Public Health International Symposium (Krieger, 2005) addressed social inequities from the standpoint of policy, research, and data. As understanding of social determinants of health becomes increasingly more mainstream,

efforts to address the ravages of poverty and deaths from preventable diseases have approached the challenge from societal as well as medical causes. Nevertheless, although aims are broad, funding is low (Drexler, 2005).

There are multiple factors that contribute toward health disparities in developing countries. Health systems in sub-Saharan Africa are fragile and Malawi is among the poorest of African nations (Palmer, 2006). Brain drain, or international migration of health care workers (Global Health Report, 2008) has been addressed by donors and the Malawi government (IRIN, 2007). While 80-100 nurses per year were seeking work abroad since 2000 (Palmer, 2006), in 2006, this decreased to 30 due to collaborative efforts and changes in health care worker salaries (IRIN).

Working conditions, low wages, family health needs and more contribute to brain drain. Non-governmental organizations are in part to blame for recruiting staff from the public sector and operating independently of public health systems rather than corroborating with them (Palmer, 2006; Pfeiffer, Johnson, Fort, Shakow, Hagopian, Gloyd, et al., 2008). Internal governmental priorities, political agendas and corruption can undermine equitable health systems. Nevertheless, the internal failings of a country to provide equitable health care do not justify colonialism a remedy.

Governmental approaches to reduce health disparities are to be lauded; however, imperious mandates and 'expert' knowledge can be far removed from the realities of poverty as experienced by individuals and communities under poverty's domination. Historically, colonialism has often used research to perpetuate power differentials maintained by the dominant class through reducing groups of people to simple definitions and thus objectifying them (Smith, 2005). Challenges to objectifying research were

voiced through political activism during the 1970s (Smith). Smith maintains that for many indigenous peoples research was "regarded as a tool only of colonization and not as a potential tool for self-determination and development" (p. 87).

International activities to address health disparities should begin with those who are affected. Cultural, religious, economic and sociopolitical considerations play a part in health and to approach health disparities from a medical model of disease alone will not be effective. CBPR encourages an inclusive approach to addressing health disparities. Mosavel, Simon, van Stade and Buchbinder (2005) addressed issues of cervical health in South Africa, not by pushing their own research agenda per funding guidelines, but through listening carefully to members of the community – including janitors, school secretaries, parents, teens and community experts. Mosavel and colleagues were successful in achieving their goals, but cautioned others engaging in CBPR internationally to let the people lead, not the research agenda.

Addressing health is complex and working internationally increases the complexity due to diverse cultures, experiences and values. A theoretical framework that underpins the work of CBPR in addressing health disparities needs to be flexible enough to account for diversity, pluralism and creative inquiry that result in effective, ethical action. Ecosocial theory with its roots in epidemiology and social justice can provide a workable framework for CBPR.

Ecosocial Theory

> …although the biologic may set the basis for the existence of humans and hence our social life, it is this social life that sets the path along which the biologic may flourish – or wilt. As such, it emphasizes why epidemiologists must look first and

> foremost to the link between social divisions and disease to understand etiology and to improve the public's health, and in doing so exposes the incomplete and biased slant of epidemiologic theories reliant upon a biomedical and individualistic world-view (Krieger, 1994, p. 899).

Overview of Ecosocial Theory

Epidemiology is the study of public health disease risks and determinants using quantitative data and methods in clinical research (Johns Hopkins Bloomberg School of Public Health). 'Ecosocial' theory is a theoretical approach introduced by Nancy Krieger (1994) that reflects the evolutionary characteristics of biological life and the impact of social issues such as racism and poverty on disease and health (Krieger, 2001). Nancy Krieger is a social epidemiologist who draws on ecological theory and has challenged traditional scientific approaches in epidemiology that provide biological explanations for diseases without duly acknowledging how social structures contribute to health disparities (e.g. racism, poverty, gender disparities, violence, economic privilege etc.) (Harvard School of Public Health, 2009). Structures that limit power in social, cultural and political settings impact individuals and communities on a daily basis. Krieger's approach advocates for individuals who experience social disempowerment due to oppressive structural arrangements that inhibit their access to health and well-being.

Krieger is clear that her goal is not to produce a totalizing explanation, but a set of useful and testable principles that can guide specific action and inquiry (Krieger, 2001). "Ecology, after all, is a science devoted to study of evolving interactions between living organisms and inanimate matter and energy over time and space" (pp. 671-672).

Assumptions regarding the high incidence of hypertension among African Americans have long been associated with genetic predispositions and a closer examination of the social determinants suggests a very different perspective. Krieger (2001) argues that living in neighborhoods with limited availability of healthy food, economic constraints that encourage cheaper high-fat, high-salt foods, a greater likelihood of being born preterm (which impacts renal function), exposure to toxic substances such as lead, living in stressful environments, inadequate health care, and targeted marketing of alcohol and cigarettes to African Americans contribute to hypertension. Krieger maintains that the ecosocial perspective deconstructs the genetic myth regarding African American hypertension.

Due to the complexities of social, economic, psychological and biological interplay in the realm of health, theorizing must respond in such a way as to integrate individual, societal and environmental factors. Alcohol addiction, for example, is more than a physical dependency upon a substance. Environmental, social, economic and psychological factors can all contribute to an individual's alcohol addiction and removing alcohol alone will not address the complexities of the addiction and produce health. Another approach is thus needed.

Krieger bases ecosocial theory on five basic ecological concerns (Krieger, 2001). The first point is that of scale and the ability to measure "spatiotemporal phenomenon" in quantifiable terms; the second point concerns levels of organization, "theorized and inferred, in relation to specified nested hierarchies, from individual to population to ecosystem"; the third consideration addresses dynamic states that reflect "inputs and outputs" such as in the body's thermoregulation; fourth, mathematical modeling is used

to illuminate processes of interactions between groups (and thus make inferences to larger populations); and the fifth and final point is an understanding of shared commonalities and unique attributes of the processes of populations (p. 672).

Ecosocial Constructs

There are four basic constructs in Krieger's ecosocial theory, namely "embodiment", "pathways of embodiment", "cumulative interplay between exposure, susceptibility, and resistance", and finally, "accountability and agency" (Krieger, 2001, p. 672). Embodiment refers to the ways in which biological and social material is incorporated into our physical beings. Krieger (2001) argues that knowledge of history, society and individual actions are necessary to understand human biology. Historical and societal pressures of racism, violence, community support, affirmation and more are reflected in our bodies just as our dental health reveals exposure to disease, dietary intake and personal care habits. Embodiment is a human discourse that reflects the interplay of history, social and individual influences that are manifested in the physical body. Simply put, our bodies tell the stories of our lives. Against atomism, we are more than our genetic makeup and an understanding of health without knowledge of historical, societal and individual interactions is limited at best.

Pathways of embodiment concern power dynamics and structures that influence reproduction, consumption and production as well as individually shaped biological constraints and possibilities (Krieger, 2001). Evolutionary trajectories are influenced by both societal power and biological structures in the course of human development (Krieger). As applied to international health, colonialism, access to food and clean

drinking water, and individual disease immunity are examples of pathways of embodiment.

The third construct of 'cumulative interplay between exposure, susceptibility and resistance' accounts for the influences on multiple levels of interaction between individuals, neighborhoods, communities, regional entities, as well as national and global domains (Krieger, 2001). Time and space are considered in this construct as well as cumulative effects which are conveyed in pathways of embodiment, or the particular societal power arrangements (Krieger).

The fourth ecosocial construct of accountability and agency concerns how knowledge about embodiment is transmitted via institutions, both government and private, to individuals and communities (Krieger, 2001). Theories, scientific values and causal explanations are addressed in this construct and Krieger calls for epidemiological explanations of the "benefits and limitations of …particular scale and level of analysis" to explain health inequalities (p. 672). A scientific explanation to explain health disparities is not sufficient: full disclosure of the biases and limitations is required. Just as qualitative researchers are called to disclose biases and limitations, Krieger is requiring the same of epidemiologists. Science claims are no longer privileged with unquestioned validation.

Ecosocial Theory and CBPR

Ecosocial theory and the constructs therein stem from the "guiding question of 'who and what drives current and changing patterns of social inequalities in health'" (Krieger, 2001, p. 672). In CBPR knowledge that belongs to communities as well as knowledge that stems from the scientific research community is valued. Anderko,

Lundeen and Bartz (2006) call for an integration of research that addresses both individual and community needs, stating, “There is a critical need for high-quality translational research to support evidence-based practice in primary care settings without losing sight of the individual character and needs of the community” (p. 107).

Structurally-Related Determinants of Health

Epistemological power differentials are addressed in CBPR through an understanding of equal voices. This is not to reduce knowledge to the lowest common denominator; on the contrary, the approach is strength-based and acknowledges information and approaches that might be dismissed when assessing value through a narrow research lens. Allowing increased diversity and recognition of the multiple determinants of health can stimulate creative responses to improve community health.

Diversity in approaches does not mean that processes will be without challenges. Recognizing community resistance to research might entail addressing the dark legacy of unethical research trials in marginalized populations. Krieger (2000) argues that discrimination is a social construct of dominance and power for the privileged that is reinforced and justified by ideologies through individuals and institutions.

Ecosocial theory rejects categorical genetic explanations to understand determinants of health and illness (Krieger, 2000) and requires that explanations of population health move beyond micro, macro or meso levels and embrace integrated approaches (Krieger, 2001). The participatory approach of CBPR necessitates an integrated approach to understanding health. Innate genetic differences are “often invoked, but rarely tested” (Krieger, 2000, p. 46, citing Cooper & David, 1986). While the purposes of CBPR are generally not to produce epidemiological research,

epidemiologists can join with communities in CBPR to help substantiate community calls for action to rectify health disparities.

Issues of Rigor in CBPR

As CBPR utilizes multiple approaches, crosses many disciplines, including, but not limited to medical, social, psychological and educational, there is no one clear method to ensure rigor. As CBPB is an active process, definitions of rigor evolve alongside of the research and research and rigor inform each other. This is fitting with the interactive concepts in ecosocial theory. A drawback to the active nature of rigor in CBPR is that there is often disagreement regarding what constitutes rigor.

Quantitative and qualitative approaches can function as mutually exclusive lenses that block perception of the different perspectives. CBPR principles encourage open dialogue to address differences and move forward into action. Inconsistent evaluation methods weaken the credibility of CBPR. Because CBPR is not a method of research, but an approach, it can encompass many definitions of rigor. Standards for rigor in CBPR should be appropriate for the research design. For example, rigor for a CBPR study with a randomized controlled trial design should be assessed differently from rigor in CBPR with a case study design. Ongoing research regarding rigor and methods of evaluation in CBPR is needed to improve its effectiveness and application to wider settings.

Ecosocial theory can help expand the concept of research in academia and can help community-based participatory research partners develop logical processes from problem conception to dissemination of results. Where there is health and inequality, communities are often concerned with structurally-related determinants of ill health.

CBPR emphasizes the importance of relationship building and provides a forum for community members to articulate their concerns about social structures that impede health.

Ecosocial theory provides a scientific basis to explore and challenge sociopolitical and cultural structures that promote health disparities. Both ecosocial theory and CBPR emphasize social justice. The effectiveness of CBPR is enhanced with a strong theoretical basis for its activities.

Assessment of Ecosocial Theory

As ethics are of paramount importance in CBPR due to the diverse nature of communities and especially when conducting research internationally, assessment of ecosocial theory will be considered from the perspective of ethical theory criteria as outlined by Beauchamp and Childress (2001). Satisfaction of some, but not necessarily all of the eight conditions is advised as the ethical conditions are drawn from political, scientific and legal theory and not every aspect of a theory is applicable (Beauchamp & Childress).

The first condition for ethical theory is that of clarity (Beauchamp & Childress, 2001). Ecosocial theory is clear in that it requires consideration of multiple, complex and interrelating factors for health. The criterion is also met in the dependence of ecosocial theory upon five ecological concerns. Krieger's (2001) four ecosocial constructs build upon each other; however, as concepts such as 'embodiment' and 'pathways of embodiment' are not necessarily shared across disciplines, questions regarding clarity could arise.

The second condition of coherence (Beauchamp & Childress, 2001) is met in that ecosocial theory begins with embodiment and subsequent constructs build logically upon the former. Krieger begins with embodiment, discusses the social structures as pathways of embodiment, and then discusses the "cumulative interplay between exposure, susceptibility and resistance" within social structures. The final construct calls for accountability of knowledge claims that provide explanations about how disease or health occurs in individuals and communities. In this way, the fourth construct thus synthesizes concepts of embodiment, the contribution of biological and social structures and the role of power structures in our understanding of health and wellness.

The third criterion is that of completeness and comprehensiveness of moral judgments (Beauchamp & Childress, 2001). Krieger's ecosocial theory challenges epidemiologists and others to examine their assumptions regarding health and illness that often blame the victim, rely on simplistic genetic explanations and calls for explorations of social and power differentials that impact health. As in Krieger's discussion where she dismisses genetic explanations for hypertension in African American populations, Krieger carefully identifies several social explanations that impact biological functions and dispels simplistic race-based explanations (2001). Although Krieger's work is based in the United States, her challenge to address social structures and power dynamics is appropriate in addressing community health internationally.

The fourth criterion is that of simplicity (Beauchamp & Childress, 2001). Although some of the concepts of ecosocial theory might not be readily understood, the basic tenets of the theory are simple: health in individuals is a product of interplays between biological, social, power dynamics and knowledge generation and promotion.

There are many overlapping and interrelated factors in health and Krieger's arguments are clear and concise as she built a case for viewing health from multiple perspectives.

The fifth criterion is explanatory power concerning the moral life (Beauchamp & Childress, 2001). Krieger very clearly develops her arguments from a scientific perspective and incorporates social arguments to support her work. There is a clear call to action to address health disparities that have been dismissed because of genetically-based arguments. Although Krieger addresses power dynamics, her theory could be strengthened by drawing on other disciplines to support the adverse effects of power differentials on marginalized populations.

The sixth criterion is justificatory power (Beauchamp & Childress, 2001) that challenges current belief systems and allows for criticism. Krieger's ecosocial theory certainly challenges existing beliefs about health and wellness; however, there is no call to challenge her own theory.

The seventh criterion is output power and pertains to the ability to produce judgments that are not found in the original constructs of the theory (Beauchamp & Childress, 2001). Krieger's ecosocial theory invites exploration, examination and creativity in addressing health disparities. Furthermore, Krieger calls for the interrelation of multiple dimensions in order to understand health and illness and does not claim to have completed the task within her theory constructs.

The eighth and final criterion is that of practicability (Beauchamp & Childress, 2001). If the standards are too high, the theory would have little usefulness. Krieger's standards are indeed high and she calls for interdisciplinary efforts that might be costly and time consuming. A simple experiment is much more manageable than a complex

multi-disciplinary approach. Nevertheless, as CBPR begins with notions of equal partnerships and requirements for knowledge exploration and development, ecosocial theory provides a solid framework in which CBPR activities can flourish. Simple approaches might be cheaper and faster; however, as marginalized populations have suffered due to sweeping assumptions regarding the causes of their illnesses, greater time commitments and funding is required to rectify these inequities.

Ecosocial theory has rich ideas with intuitive appeal. The concepts are clear and coherent. Krieger is clear in her presuppositions regarding both the philosophy of science and the nature of social interaction. There is consistency within Krieger's presuppositions that can be validated through CBPR. Furthermore, CBPR presents many meaningful examples of the theories in action. There is not only a potential to inform policy, Krieger's work is a call to action. Krieger says little about the weaknesses of ecosocial theory, but states that it is not meant to explain everything "and therefore nothing" (Krieger, 2001, p. 671). Krieger deconstructs current biologically based theories and general assumptions that are "evidence based." Pluralism is embraced by ecosocial theory. Much of Krieger's writing about ecosocial theory addresses epidemiologists. As ecosocial theory fits well with the principles of CBPR (See Table 3.1), it might be helpful to link ecosocial theory more strongly with other health disciplines.

Conclusion

With its roots in participatory action research (PAR), the emphasis of CBPR is often to challenge power differentials that underlie health and social disparities. As such, activities of CBPR often challenge dominant structures. If dominant power is so

embedded in societies that oppressive epistemological values are not widely recognized, one of the first tasks of CBPR partners is that of educating communities. Ecosocial theory provides a framework for activities that challenge inequitable social and healthcare policies and practices. For example, ecosocial theory challenges dominant epistemological values that hold individuals responsible for their diseases by exposing environmental contributors and factors that affect not only individual, but community health.

Krieger (2001) emphasizes the need for addressing health from multiple perspectives and challenges the *status quo*, but does not provide much guidance for dealing with the process of conflicting ideas. CBPR principles promote conflict resolution and ecosocial theory provides a framework to deconstruct unquestioned assumptions regarding health and disease in individuals, families and populations.

In ecosocial theory, relationships impact health and multiple approaches are encouraged to address health; however, the focus is on the health outcome and not the process. CBPR focuses on processes. Health is an ever evolving entity that requires ongoing engagement. Ecosocial theory presents a call to action and provides a rich framework for the activities of CBPR. The vast disparities of health in the developing world, and even within the U.S., require social action. CBPR has shown sustainable results and can function as a vehicle for social justice.

CBPR can also be a means to challenge epistemological assumptions that participants bring to the table. Much of CBPR remains framed in Western notions of scientific epistemology and understanding of a particular type of inquiry that ‘counts’ as research. Ecosocial theory can provide a framework for creative and probing inquiry on

multiple levels in CBPR that can ultimately improve health at community, family and individual levels.

Table 3.1: Nine Guiding Principles of Community-based Participatory Research (CBPR) (Israel, Schulz, Parker, Becker, Allen and Guzman, 2003)

	Principle
1.	The identity of a community is recognized.
2.	CBPR takes a strength-based approach rather than focusing on a community's deficits.
3.	All partners have an equal voice in all processes involved in research, from determination of the research questions to dissemination of research results.
4.	CBPR focuses on capacity building and an equal exchange of knowledge, skills and expertise.
5.	Knowledge generation for scientific contribution is balanced with practical interventions and policies based on community concerns.
6.	CBPR takes an ecological and public health approach in that multiple determinants of health are recognized.
7.	Systems development is promoted for all stages of research with a focus on strategies for policy changes.
8.	Dissemination of the research is not only for the academic community, but also for the wider community and community members feature as co-authors and co-presenters at conferences and so on.
9.	CBPR involves a long-term commitment based on relationships of trust between partners to produce sustainable health changes in communities.

CHAPTER FOUR:

PUBLIC ETHNOGRAPHY AND COMMUNITY-BASED PARTICIPATORY RESEARCH (CBPR): AN IDEOLOGICAL MATCH

Introduction

> For many public ethnographers, the pretense of value neutrality is not a feature of their work. Public ethnographers care about what they study; they want others to care and engage in public debate about repressive and unfair conditions; they want to work toward the amelioration of unjust practices (Bailey, 2008, p, 276).

The purpose of this chapter is to demonstrate how public ethnography methodologically aligns with my research aim of understanding the processes of non-governmental organizations (NGOs) in their work with Malawian communities to mitigate issues surrounding HIV and AIDS. Community-based participatory research (CBPR) principles provide a philosophical framework for understanding issues of building trust between NGOs and communities, donor/NGO interactions and the role of disempowered Malawi women in the HIV and AIDS crisis. Both public ethnography and CBPR have social justice concerns at their core.

My research focus is NGOs, their culture and processes in working with communities. I will address key issues in working with communities internationally, drawing from principles of CBPR. Although "NGO1", the primary NGO in this study, does not claim to "do" CBPR, NGO1's mission and work aligns closely with CBPR principles and my ultimate goal is to provide greater understanding of the processes, constraints and facilitators NGOs face in order to help inform those who wish to engage NGOs in CBPR to address community health issues. At this point NGO1 is not

interested in "doing research" and understanding NGO1's resistance to engaging in CBPR might be a valuable perspective that is not usually addressed.

There are gaps in the literature regarding NGOs and their work with communities and yet CBPR processes are often implemented via NGOs and community partnerships. Various entities utilize NGOs as critical resources in order to connect with communities to promote community health (Kelly, Somlai, Benotsch, Amirkhanian, Fernandez, Stevenson et al., 2006). Understanding the perspectives of NGOs regarding their processes in establishing positive relationships with the communities that they serve is a critical component in the CBPR process that is not highlighted in current literature. Hughes-Halbert, Weathers and Delmoor (2006) state that the most challenging step in CBPR is establishing a relationship with a community agency, but it is the "most critical" part of the process. (p. 99). The role of NGOs in addressing international health concerns is increasing (Gellert, 1996; Stevenson, 2007).

In this chapter I will discuss qualitative and ethnographic research approaches, key issues in international work and outline my research process using public ethnographic methodology. I will conclude with a discussion about the beneficiaries of research.

Qualitative Research and Ethnographic Approaches

The roots of qualitative research revolve around a search by social scientists for objective analysis and understanding of social processes (Denzin & Lincoln, 2005). Political, religious and ideological values influenced ethnographies from pre-17th century narratives from the age of exploration through colonial ethnographies and then community, immigrant and ethnic studies until the present. Around the mid-1980s,

postmodern and poststructural perspectives challenged notions of separate and objective observers in ethnographies, contending that the researcher's role is interwoven throughout the process (Denzin & Lincoln).

Ethnography and Postmodern Influence

Grounded in anthropology and sociology (O'Byrne, 2007), ethnographic methods have been utilized in numerous ways to describe cultures and communities, often different from the researcher's own (Anderson, 2004). No longer are ethnographers to view a culture as "other" (Campbell, 1998; Emerson, 2001; Fine, 1994), or objectify them and this mandate is in stark contrast to colonial approaches to ethnography. Ethnographers are warned against falling into the role of researcher as the subject and viewing participants as the objects of their study. Melrose (2001) recommends that a researcher conducts research *with*, rather than *on* individuals in order to reduce objectification of participants.

The desire to understand another's perspective is juxtaposed against the constraints and limitations of the researcher's experience. Much debate has ensued regarding the merit of remaining distant from the participants in order to avoid untoward influence by the researcher (Emerson, 2001; Fine, 1993; Hammersley & Atkinson, 1995). It is as if the researcher fears that the participants are like specimens who can be tainted by exposure to the researcher and the resulting ethnography will be less than pure. At the same time, the participants' own understanding of culture might also be disparaged as they are unable to achieve objectivity.

Distorted ethnographies have led to ethical discussions (Fine, 1993, 1994) and questions regarding rigor, validity and ethics in qualitative research abound (Charmaz,

2004; Cho & Trent, 2006; Melrose, 2001). In an effort to address the dilemma of a biased ethnography either intentionally or unintentionally, on the part of the researcher or the participant, various guidelines have been proposed to address the concerns. At the root of these is epistemology: what "counts" as knowledge?

Ethnography's contribution is that claims can be modified as new information becomes available (Cho & Trent, 2006). Rather than providing a static, verifiable account, ethnographies represent a snapshot or a reflection that can be incorporated into a wider realm of understanding. Emerson (2001) states that "ethnography, then, does not seek to represent social 'things in themselves'—if indeed there are such things—but things as they are grasped and shaped through the meaning-conferring response of members" (p. 28).

Biased accounts are considered less than acceptable for the scholarly community; yet it might be a more worthy goal to present several accounts of the same culture, from both insiders and outsiders who state their biases, rather than attempting to produce an account devoid of personal influences. To capture a static, factual representation of the culture of NGOs would be less than meaningful because cultures are dynamic, living organisms that are in constant states of flux. Although a definitive portrayal of this study would be neat and tidy, the "soul" of the NGO culture would be lost.

Given that the purpose of this study was to provide a reflection that might be useful for the participants, Emerson's (2001) concept of ethnography as a snapshot fits well with this study's aims. Another purpose of this study is to stimulate discussion and change to promote health and social justice. The stories, interpretations and analysis today can be reexamined as new knowledge and perspectives arise and so in this regard,

my study functions as a public ethnography.

Interpretive strategies

Public Ethnography.

Public ethnography involves championing social justice causes and researchers incorporate their own perspectives in narratives to promote public action (Tedlock, 2005; Bailey, 2008). Tedlock argues that through passionate accounts that address health, human rights issues, poverty, racism, environmental issues and more, researchers are able to engage the public emotionally and intellectually and thereby inspire action. Tedlock maintains that public ethnography is "both a theory and a practice" in that it blends the "reflection, interpretation and analysis" of field work into a "revolutionary theory" (p. 473).

Non-governmental organizations play critical roles in promoting social justice and international health; addressing poverty, disease, racism and more (Gellert, 1996; Kelly et al., 2006). However, organizations such as NGO1 operate between two very different worlds, that of the U.S. donor base and Malawian communities where issues such as outcome-based measurement are addressed in order to obtain life sustaining resources rather than an interest in scientific method.

On the one hand, NGO1 speaks to the Western world in individualistic terms: "We saved 15,000 lives", "*our* nursing scholarship supports the health infrastructure of Malawi", "through our work testing for HIV has increased from 500 per year in the villages to 200-500 per month" and so on. Statistical accomplishments are touted to convince donors of the reliability and success of the organization. In Malawi, NGO1's voice is very different: "Unless the community is behind it, it won't happen" has a very

different tone as do the claims that "women do all the work" and "I don't even know why they (Malawians) tolerate us (Americans)". In Malawi, NGO1 focuses on service without the bravado of Western "conquest and conquer" motifs.

Combining Interpretive Strategies

Several interpretive strategies are needed to illuminate data analysis of the culture and processes of NGOs in communities. Institutional ethnography is both a trustworthy method and can promote change (Campbell, 1998). Emerson's (2001) snapshot portrayal, aspects of critical ethnography, and Tedlock's (2005) public ethnography which promotes public action through interpretive analysis and passionate narrative, are all appropriate strategies for a study of NGOs and underpinned this study.

Institutional ethnography utilizes interviews, observation and documents as entrée into places where people work (Campbell, 1998). As such, individuals' experiences are examined in a social setting and questions regarding how situations came to be are examined.

The snapshot portrayal provides recognition of my limitations, including the researcher's perspectives, how well the researcher engages participants and the constraints of the particular time periods reflected in the interviews and observations. The goal is to promote greater understanding of NGOs to ultimately improve partnerships that will promote community health.

Critical ethnography, like action research is concerned with research that is emancipatory (Hammersley & Atkinson, 1995). Promotion of "ideals of freedom, equality and justice" is the goal of critical ethnographic research (Hammersley & Atkinson, p. 16). Because my purpose is not merely to provide a descriptive account of

the NGO culture and processes, critical ethnography with its impetus toward action will play an interpretive role in my analysis. My hope is that through my analysis, NGO1 and its donors will continue to explore their different roles and reexamine research possibilities. In this way, I am using a "soft" critical ethnographic approach.

Public ethnography is the primary interpretive method for my study as it draws from both field work and critical ethnography. Public ethnography is persuasive in the way in which it engages the public as it appeals to intellect and emotions. Public ethnography differs from critical ethnography in that it is less confrontational; the focus is on engagement toward action rather than blaming individuals or social structures for social or health inequities.

Public Ethnography and CBPR Principles

The purpose of CBPR is to promote the health and quality of life for community members through a process which involves equal partnership, power, respect of partner expertise, equal voices in development of research-related plans, and agreement on implementation methods, evaluation and dissemination of results (Israel, Eng, Schulz & Parker, 2005; O'Fallon & Dearry, 2002; Minkler, Vasquez, Warner, Steussey & Facente, 2006). CBPR principles include a strength-based approach to communities (rather than a problem-focused approach), equal partnership in research activities, capacity building, "a balance between research and action", recognition of multiple health and disease determinants and their relevance at the local level, development of systems through processes, dissemination of findings to all partners and finally, a long-term commitment to the community (Israel, Schulz, Parker, Becker, Allen & Guzman, 2003, p. 56).

Both public ethnography and CBPR principles are rooted in social justice issues.

The principles of CBPR are based on an egalitarian approach to research, from determining the questions or issues of importance to how these should be addressed, evaluated and subsequent results disseminated. CBPR is a process and like public ethnography, it can be revisited, reinterpreted and reexamined. Unlike a controlled experiment, the variables, tools of measurement and methods for evaluation are not predetermined in CBPR. In contrast to a contained ethnography, a public ethnography is malleable. Both public ethnographies and CBPR are conducive to the dynamic processes found in communities.

Key Issues in International Work

An understanding of the multiple factors that can affect ethnographic research is especially important in studying an NGO based in the U.S. with a mission to provide services in Malawi. Awareness of historical and cultural contexts is vital to the process of establishing trust in Malawi. As one participant stated, Malawians have been "over researched". Rather than provide an ethnographic study of Malawians, the focus of this study was to understand the culture of an NGO in an international context and contribute to the discourse aimed at reducing inequities between donors and NGOs and between men and women in Malawi.

Essentialism

Essentialism, "giving primacy to some aspects of …identity while ignoring others that intersect with and re-form that primary identity" (Dill, McLaughlin & Nieves, 2007, p. 635), is a danger that is difficult to avoid in an ethnography due to limitations of author lenses. Inherent in my Western perspective are many assumptions regarding race, class, age and gender that I may or may not consider as I approach the culture of an NGO

working between the U.S. and Malawi. bell hooks was concerned with justice that supersedes any essentialism of gender, class or race. "When intellectual work emerges from a concern with radical social and political change, when that work is directed to the needs of the people, it brings us into greater solidarity and community" (bell hooks as quoted by Valdivia, 2002, p. 429).

Having identified some of the constraints NGO1 has in establishing trust with a donor base in the U.S. and "on the ground" in Malawi, I became aware of gender and economic power differentials. Intersectionality is a term used to describe the complex relationships between race, class, gender, sexuality and age that requires more than unidimensional explanations (Dill et al, 2007). An awareness of the issues essentialism and intersectionality enabled me to explore questions and positions that I otherwise would not have considered. I asked participants why it was said that women are socially disempowered in Malawi, yet are the key to reducing HIV and AIDS and what participants thought about this (See Appendix B: Interview Guide).

Epistemological Values and the Legacy of Colonialism

Knowledge is not neutral. Epistemological values are embedded in research methodologies, interpretations and dissemination of findings. Historically, colonialism has used research to perpetuate power differentials maintained by the dominant class through reducing groups of people to simple definitions and thus objectifying them (Smith, 2005). Challenges to objectifying research were voiced during political activism during the 1970s (Smith). Smith maintains that for many indigenous peoples research was "regarded as a tool only of colonization and not as a potential tool for self-determination and development" (p. 87). Churchill views research as a tool for liberation

through "*resistance, political integrity, and privileging* indigenous voices" (Churchill, cited in Smith p. 89).

Shivji (2007) castigates colonialism, stating, "The pre-colonial and colonial legacy of Africa is a continuing saga of domination, exploitation and humiliation of the continent by European and American imperial powers" (p.3). Shivji argues that many NGOs function as extensions of governmental power dynamics that mimic colonialism and that the silent discourse of NGOs support globalization. Shivji does not implicate all NGOs, however, as he allows that some NGOs are altruistic and act to support Africans in self-determination.

Smith (2005) argues that even when ethical requirements are put into place to protect research participants, this constitutes an act of power that originates from the dominant class and is imposed upon a marginalized group. The dominant class holds the power to determine what is ethical and how research ought to be conducted. Publication of research is usually in the language of the dominant class. Smith cautions that a total revolt against the academy would only perpetuate marginalization and despite the resulting discord, challenging knowledge process and production would force changes that can ultimately benefit currently marginalized groups. Although the challenges left in the wake of colonialism are complex and difficult to navigate, Smith recommends that rather than abandoning research efforts, researchers should emphasize building relationships with participants in culturally sensitive ways. Bishop (2005) advocates that researchers and participants collaboratively co-construct research stories to provide a discourse. Respect for epistemologies other than those that fit within the dominant paradigm is necessary to redress power imbalances created by knowledge production.

Methods

Design

The study employed a qualitative, descriptive design that used face-to-face interviews and participant observations to collect data about NGO perspectives on developing community trust, donor/partner issues and gender roles. Additionally, the study addressed the work of an NGO, funded by US sources and working in Malawi villages through a Malawian administration and staff. The first phase of the study was conducted in the US and included interviews with US-based staff and volunteers, observations of a staff meeting, public events and informal discussions with staff and donors of the NGO. Based on the findings in the US, the study aims and purposes were adapted to address questions concerning building trust with communities in Malawi, the role of Malawi women in mitigating HIV and AIDS, issues with NGO partners and donors and finally, what Malawian participants saw as the greatest need in Malawi.

US Setting

US interviews took place in California at locations chosen by participants, typically in an office or home and one interview was held in a university conference room. African art was present in many of the participant's homes and offices. All interviews were conducted in English and were audio-taped and later transcribed verbatim. Interview settings in the US had plumbing, adequate light, heating and cooling systems, large windows, efficient internet service that was used to access data on one occasion, and were in general, comfortable. In one office conference room, there was a large oval table surrounded by comfortable chairs and bookshelves lined the walls. Outside the offices and homes was an abundance of trees, shrubbery and flowers. Access

to interviews was via paved roads. All participants interviewed in the US with the exception of a visiting Malawian, had personal computers and were easily accessible via telephone or email. US participants were given study information and signed consent forms prior to participation in the study.

Observations in the US included an NGO1 staff meeting, informal discussions with staff and volunteers and a fund raising event. A fund raising event took place in a wealthy community on the lawn next to a large home and guests were offered valet parking, served gourmet *hors d'oeuvres* and drinks. Guests were told stories about Malawian plights of orphans, poverty, and the ravages of AIDS. Guests bid on various "auction items" such as money for bicycle ambulances, tuition for orphan education, support for HIV and AIDS education and care for a village and more. I wondered even as I participated in the event about the irony of being treated lavishly in order to support those who were hungry. Although the event successfully raised over US$300,000 for Malawi, I wonder whether raising this much money would have been possible without a lavish event. NGO1 staff wanted to show appreciation for their donors and work hard to ensure that donor dollars are used effectively. Further exploration of donor expectations might be warranted.

Malawi Setting

Interviews in Malawi took place in central and southern Malawi, primarily in participants' offices, a local guesthouse and outdoors in rural village settings. Some of the offices/locations were full of natural light and some of the offices were dark. Internet access in the offices was generally very slow and sometimes inaccessible. I walked to some of the interviews from a gated compound along paved roads on dirt walking paths.

The streets were generally full of people walking to and from work, carrying goods to market and many mothers and young girls carried babies on their backs. Some people were gathered round open fires while others sold sugarcane to passersby. As I walked, I was greeted with curiosity, some laughter and occasionally a child would practice his English with me.

Malawi participants, like US participants were hospitable. On several occasions, male Malawi participants did not arrive on the agreed day for an interview. Sometimes they called ahead of time and sometimes they did not. It often took a second attempt for the interview to occur. It was as if they were testing to see if I was committed to talking with them and hearing their stories. Although polite, at the beginning of several interviews it seemed that I was given the "party line" and not until much later in the interview did I sense that the party line had been replaced by passionate discussion about Malawi and Malawians. Female Malawian participants were cautious at first, but seemed to be less suspicious than male Malawians. Perhaps because of my gender, rapport was established in general, earlier in the interviews with Malawi women than with Malawi men.

One interview was held outdoors after a long day of distributing supplies for orphans in a rural village setting. The beautiful Mulanje Mountains could be seen in the distance. The sky was a brilliant blue, and although the dirt roads were rather dusty, the air was fresh and free of smog. We sat on a rough bench in relative privacy while women in matching chitenges (bright fabric tied in sarong-fashion around their waists) chatted after a long day of work. The setting was peaceful and there was a sense of accomplishment and satisfaction as the supplies were gratefully received.

After leaving the setting we drove along a dirt road and women who worked for NGO1 sat in the back of the truck singing as they got a lift back to their villages. One young girl proudly waved to us as she wore her new clothes: a bright party dress from China complete with matching hat. She waved her school book excitedly, shoeless, dancing around in the dirt outside her home. Gardens, clothes lines and wandering chickens were seen en route. Low brick buildings with corrugated steel roofs and small windows lined the road. Churches and mosques were frequent sights. The dirt was red, from iron I was told, and it contrasted sharply with bright green tea plantations. Piles of bricks were littered around kilns. There was a sense of peace despite the struggles of poverty, lack of electricity, plumbing and health care services.

Sample

Participant observations and interviews were conducted with NGO1 staff, volunteers and partners in the US and Malawi (See Table 4.1 for a description of participants). Partners include individuals (staff or volunteers of other NGOs or CBOs) who work with NGO1 in conceptual planning and/or activities on the ground in Malawi related to mitigating HIV and AIDS related issues. Additionally, using snowballing techniques, NGO1 provided introductions to potential participants who are referred to as "NGO1 contacts" in the study (See Table 4.2 for a description of terms). Twenty-six interviews were conducted, six in the US and 20 in Malawi. The sample represented eight NGOs and three community-based organizations (CBOs) and a description of these organizations is found in Table 4.3.

Participants ranged in age from 27 to 78, with a mean age of 48 years. Half of the sample was male and half was female. Sixty-five percent of the sample had worked with

an NGO for 5 years or more and overall, the sample reflected high levels of education in both the US and Malawi.

Approval to conduct the study both in the US and Malawi was obtained from the Committee on Human Research at the University of California at San Francisco and a letter of support was written by the country director of the NGO1 in Malawi. US study participants signed a consent form and participants in Malawi verbally consented and were given a study information sheet as is the custom in Malawi. All participants received information on the study as well as contact information for the Primary Investigator (PI) and Co-PI. Efforts were taken ensure confidentiality of the participants.

Participants over the age of 18 who spoke English, were either staff, partners or contacts obtained through NGO1 comprised inclusion criteria. Rationale for language inclusion criteria was based on the limitation of researchers who were not fluent in Chichewa. Adults were chosen based the target audience for the study and the requirement that NGO1 participants had a minimum of six months with the organization (or were recommended by NGO1 senior staff) was set to provide an experienced response to interview questions. Participants had the option to withdraw from the study at any time.

Applying Methods to Research Purpose, Aims and Questions

Researcher's Perspective

Charmaz's (2006) position that the author's voice need not be silent "replete with assumed neutrality" and that we need not write as "disembodied technicians" is apt (p. 174). To reduce the findings of qualitative research to objectified, disembodied findings is to deny the life, energy and passion of the participants' narratives and work.

My background and presuppositions shaped the purpose, aims and questions of the study. My purpose was to enter into a dialogue with NGO1 staff and volunteers in order to gain increased understanding of the process and challenges NGO1 has in promoting health internationally. Throughout the research process, my questions regarding NGO1's involvement with research activities were at times dismissed, addressed briefly, or redirected toward discussions about service. My interest in research was not a primary concern for NGO1. Nevertheless, as I reflected back to NGO1 how closely it aligns with principles of community-based participatory research, and that NGO1 is in fact doing some research and could be doing more, a dialogue was initiated for further exploration.

As principles of CBPR include sharing of equal voices, I attempted to practice this in my methodological approach to addressing the purpose, aims and research questions. By remaining open to new information that might redirect the study, I was able to learn about the most pressing concerns of NGO1, its partners and contacts rather than superimposing my presuppositions on the organization and producing an account of my expectations without taking account NGO1's perspectives. At the same time, I attempted to maintain a focus on increasing an understanding of the processes, challenges and successes found in NGO1's work and without being distracted by interesting tangents that were not relevant to the overall purpose of the study.

Data Collection

Interviews

Denzin and Lincoln (2005) argue that the interview is not a "neutral tool"; rather it is a "negotiated text – a site where power, gender, race and class intersect" (p. 643,

642). Interviewers have power as they choose the questions while participants have power to answer the questions they choose to answer. There is an artful dance in the exchange of seeking and giving of information. When the interview process is semi-structured and allows for twists and turns in the conversation, possibilities are opened up for new or greater understanding.

Several times I abandoned my interview guide in order to hear the stories of the participants. In this way participants' passion for their work flowed freely and the focus was on the work of the NGO rather than the formal interview process for a research study. As Hammersley and Atkinson (1995) argue, neither an approach whereby the interviewer controls the questions nor an approach whereby the interviewee can direct the conversation removes bias.

As the purpose of my approach was to obtain understanding rather than control for variables in a pursuit of the "truth" about NGOs, I chose the middle ground of semi-structured interviews that allowed for a blending of biases. It could be argued that biases remain regardless of this approach, and if so, they are to be embraced rather than eliminated for they become part of the data and require further analysis.

I am not an objective observer making comments on the activities of NGO1 and its partners in a manner whereby neither the participant is, nor am I affected by the interaction. I do not apologize for "altering" the participant's perspectives by my questions. On the contrary, my hope is that through our dialogue we will both gain new insight and understanding. Throughout data collection, analysis and articulating the findings, I questioned what I brought to the data in terms of my own biases, perspectives and assumptions. I was open to new lenses through which to view NGO1 and its work.

When participants were dismissive of my questions about their partnerships with a university research project, I learned to listen to their stories and what was important to them.

The interview guide created a framework for inquiry (See Appendix B). As the approach was not prescriptive, I questioned the appropriateness of my questions in light of the data I received and found that resistance to some questions opened up new lines of inquiry. (e.g. Do you think that it would be worthwhile to conduct a study to support your program (or activity) goals? If yes, what kind of study would be helpful to the community?). Reflection, analysis and modification of questions occurred throughout the process.

Visual Materials

Visual materials included both written and pictorial materials. I reviewed an unpublished evaluation of a micro loan project in Malawi that was written by a masters program graduate student from the international studies program of a major US university, peer-reviewed articles published by NGO1 staff, trip reports from NGO1's president and CEO, newsletters, fund raising letters, as well as documents and photographs on NGO1's web site.

The evaluation of NGO1's micro loan project corroborated with information I obtained during verbal interviews. While the report was primarily positive, it included a critique with recommendations to promote greater success for Malawian participants. Perspectives expressed in interviews concurred with the perspectives found in peer-reviewed articles written by NGO1 staff members (Rankin, Brennan, Schell, Laviwa, & Rankin, 2005; Rankin, Brennan, Schell, & Rankin, 2005).

Clarke (2005) says that we ignore visual materials “at our analytic peril” (p. 205). Clarke discusses the need for qualitative researchers to analyze visual discourses as well as verbal discourses. A visual discourse is no more transparent and obvious than a verbal discourse and analysis can yield rich insight.

Qualitative research typically favors interviews over documents and physical objects (Sandelowski, 2003). Greater trust is placed in the authenticity of a verbal interview than physical objects. Nevertheless, physical objects and documents can provide a different perspective than an interview and should not be discounted. One might argue that information on the Internet is not physical; however, it is accessed via physical objects and Sandelowski argues that the material aspect of technological information is not to be denied.

NGO1 photographs on the web site, the stories that participants chose to tell and the pain and successes reflected in web site documents together provided a greater understanding than I would have gained from verbal interviews alone. Photographs and stories depicted the plight of Malawians with suggestions for practical support from would-be donors. Sandelowski’s (2003) point that the material and physical objects, as well as more ‘virtual’ objects as found in technology should not be denigrated in favor of the verbal interview is worthy of note; physical objects are not devoid of meaning and should not be excluded in qualitative data. Rose (2001) argues that Western society is a visual society and the lines between what we see and know have become blurred and we sometimes confuse the two. Analyzing both visual and verbal data in qualitative research can help clarify blurred assumptions based on seeing and knowing.

While in Malawi I photographed places and individuals after obtaining verbal consent. I referred to the photographs during analysis and the visual images and the participant voices on audio tapes reminded me of their passion that might have been obscured by written words of the interview transcripts alone.

Observation

Angrosino (2005) maintains that the three primary methods of observation in qualitative research include observing participants in a relationship of rapport, reactive observation in which participants are aware of being observed, but the level of relationship with the researcher is minimal, and unobtrusive observation in which the observed are not aware of being studied. Angrosino further states that there are three procedural methods employed to obtain increased specificity: "descriptive observation", "focused observation" and "selective observation" (p. 732). There is a shift in ethnography that embraces the participants' roles in collaboration with researchers so that the voice of the participant can be heard (Angrosino).

Observations in the US and especially in Malawi helped me understand the context and day to day challenges in Malawi (See Table 4.4 for a description of observations in Malawi). For example, I noticed that although spoken words about empowering women were sincere, cultural practices that undermined full sharing of power between men and women were deeply ingrained.

Data Analysis

Coding

The interviews were audio-recorded and transcribed verbatim. I began coding, or labeling the data section by section rather than line by line as I would have done if I were

using a grounded theory method. I examined the interviews from different angles and considered the context. From the data emerged *in vivo codes* (Cresswell, 2007), such as "on the ground" and "empowering women" which I explored in subsequent interviews and conversations.

Using both a paper and pencil method and Atlas.ti data software I coded sections of interviews in an iterative process. I returned to the interviews and coded again after periods of reflection, analysis and input from colleagues and research participants. Some of the early codes that emerged include trust, empowerment, working in two different worlds, epistemological divides, community, Malawian-led, accountability and poverty.

"On the ground" referred to the work in the villages where approximately 85% of the population lives. In addition, "on the ground" had practical connotations embedded in the concept that were connected with NGO1's commitment to service. Women were identified as doing "all the work". Malawi women are in an ironic juxtaposition between being socially disempowered and holding the keys to reshaping their communities. This theme is explored in Chapter 7.

Analytic Memos and Process Memos

Throughout the study I wrote analytic and process memos (n=74). I reexamined the aims and research questions in light of data obtained in interviews. Clark (2005) argues that analytic analysis does not fracture the data; rather that greater clarity and understanding can be obtained through careful analysis. Process memos were utilized to track both practical and conceptual developments throughout the study.

Themes and Findings

From the codes emerged themes and I grouped appropriate codes under three main themes (in networks in Atlas.ti): 1) Establishing trust; 2) Donor issues; and 3) Socially disempowered women as the key to mitigating HIV and AIDS.

I wrote outlines with subthemes and returned to the data for contextual quotations. Analysis continued during the process of writing manuscripts and I both listened to audio recordings of the interviews and reread the transcripts.

One of the major themes that emerged from the data is how NGO1 established trust in Malawi and its humble, yet responsible process in providing services in an international setting with a culture very different from that of the U.S. A second major theme was the role of donors and decisions regarding program implementation or research in Malawi communities. A third theme that generated much discussion was the role of women, who have low social power yet are seen as the primary force addressing HIV and AIDS in Malawi.

Establishing trust.

Confucius (as cited by O'Neil, 2002) is credited for the notion that "without trust we cannot stand". Trust is an integral part of the fabric of society and is necessary because regardless of the length of a guarantee, all guarantees are partial and limited (O'Neil). Trust was established by NGO1 in part because of their acts of practical service without judgment. As an interfaith organization, NGO1 does not have a theological agenda. As NGO1 worked with villages and communities in providing home-based care and prevention messages, trust was established through consistently fulfilling promises, attitudes of humility and caring. As O'Neil states, trust is "hard

earned and easily dissipated. It is valuable social capital and not to be squandered" (2002, p. 2).

Based on the data, a definition of trust was needed that reflected the participants' stories and advice. Trust was defined, thus, as believing that a person or organization will support words with actions. Trust increases through the sharing of common goals and an ongoing commitment between individuals and organizations. Implicit in trust is a relationship between an NGO and community members. The process of an individual from the community and an NGO staff member working together creates a relationship that is reflected in each of their group affiliations and if positive, the community and the NGO reap the benefits. As the number of positive paired relationships increases, a web of support is created. Conversely, a negative relationship affects the larger organization and the community.

In order to gain understanding of the data and emerging themes, I compiled a retrospective analysis of NGO1's work to establish trust and promote community building in Malawi. I examined NGO1's use of the term "empowerment" and compared it to use in the literature (Minkler & Wallerstein 2006; Minkler, 2006). I compared NGO1's activities and approaches to CBPR guidelines and other approaches to community health promotion (Minkler, 2006; Minkler & Wallerstein, 2006).

Donor issues.

Based on a review of literature in which relationships between academic partners and NGOs was identified as a challenging area, I asked participants about this as many NGOs worked with academic partners. My questions were answered; however, I found that although there were occasional challenges, these were not of much concern for

participants' work with NGOs. The larger issue was the struggle between donor objectives and community-identified needs. NGO staff expressed their struggles of trying to work within donor directives and meet the needs of the community. For example, an NGO3 staff member spoke of his need for social workers and that donor priorities of the number of youth served trumped the depth of work that social workers were able to do. Rather than serve a few very well, there was pressure to increase the numbers served irrespective of the sustainability of the work. Donor ego and community needs were at odds with NGO staff caught in the middle.

Rather than pursuing my original question of relationships between NGOs and academic partners, issues of donor power were explored with participants and in analysis. Mosavel, Simon, van Stade, and Buchbinder (2005) outlined the issues faced in their CBPR study in South Africa between funder priorities of cervical cancer research and community priorities of violence, pregnancy, unemployment and apartheid issues. The researchers worked to serve both masters and many of the NGO staff in my study seemed to be placed in similar roles. Ongoing support for the NGO necessitated pleasing donors while gaining community trust necessitated responding to community priorities.

Socially disempowered women as the key to mitigating HIV and AIDS

I first learned that women were seen as the key to mitigating HIV and AIDS in Malawi in the first (US) phase of the study. I found it ironic that socially disempowered women in Malawi were viewed as the ones "who could turn this thing [HIV and AIDS] around" (NGO1, US Staff, male). When I asked participants about this in Malawi, the response was unanimous: Malawi women are socially disempowered *and* they are the ones who can change the tide of HIV and AIDS in Malawi. I was told by Malawians:

"It's our culture" –women are valued less than men. Yet because women are expected to work, care for the children, orphans and community members, women can influence and shape the views about gender roles as well as HIV and AIDS. When women gained economic power they also gained power within their homes and communities.

I observed Malawi women working persuasively and tenaciously despite gender biases in homes, work and church settings. The women were not daunted by male dominance and directives; rather they worked respectfully and by example to support those suffering from HIV and AIDS and to persuade men in power to view things differently. Women followed a hierarchical protocol in work settings, yet spoke freely of their ideas and concerns.

Rigor

Issues of rigor in qualitative research have long been contested. At one extreme, qualitative researchers attempt to utilize methods of rigor as found in quantitative research, such as validity, generalizability and controlling for variables. Underpinning this attempt at rigor is the belief that objectivity can be obtained in quantitative research (Horsburgh, 2003), and if qualitative researchers follow the same procedures, they, too, can be assured of producing scientific research, if not objective findings.

Others argue that methods for quantitative research are not appropriate, nor are they helpful in qualitative research (Lincoln & Guba, 1985; Guba & Lincoln, 2005). Influences of relativism and post-structuralism have cast doubts upon qualitative researchers' ability to produce objective accounts due to pluralistic perspectives and interpretations. Smith and Hodkinson (2005) state that there is no "'God's eye' point of view" or objective reality.

Nevertheless, although Lather (1993) disparages approaches to validity, Guba and Lincoln (2005) maintain that methodological rigor and community consent as part of a reasoned argument remain useful endeavors. The latter refers to being "*interpretively* rigorous" and pushing the boundaries of social science (p. 205).

Lather (1993) takes a position of questioning and challenging the dominant scientific paradigm while others struggle to work within it, much in the way that Kuhn (1962) speaks about the business of science. Kuhn (1962) argued that focus is necessary to do the work of science and constant questioning of epistemological starting points would be both inefficient and unproductive. Challenging unquestioned assumptions initially occurs at the margins before paradigms are overturned (Kuhn). Both positions are useful in increasing understanding. As a new researcher, my position is at the margins where I question assumptions about what counts as research even as I learn to apply accepted methodologies.

Bailey (2008) contends that rigor in public ethnography is achieved if it generally meets the following conditions:

> (1) its primary means of collecting data is in depth field research, (2) it is motivated by a desire to reduce social injustice, (3) it critiques the structures and social processes that promote inequality, (4) it includes active participation of the scholar in the fight against repressive conditions, and (5) its desired audience extends beyond academic circles to include some facet of the public at large (p. 266).

My intentions in this study have included Bailey's conditions. I hope to meet her final condition by sharing my written work with NGO1 which will in turn share it with both

US and Malawi study participants.

The Beneficiaries of Research

Ultimately, a rigorous process of qualitative inquiry should serve to benefit research participants. To fail to do this can cause objectification of the participants. That is not to say that all rigorous qualitative inquiry will be successful in benefiting participants as there are multiple interpretations and contexts that might have conflicting ramifications. A focus on dialogue, self-reflection, shared power, respect and a continued quest for knowledge and understanding will help lead to research that is beneficial for individuals and communities.

Unlike a randomized controlled trial, qualitative inquiry does not have a fixed end point. Qualitative research is unwieldy and complex, subject to change, revision, reinterpretation and objections. Rather than a linear activity, qualitative inquiry is a process of engagement with a goal of increasing understanding and thereby benefiting individuals and communities, and raises the issue of reciprocity.

Weems (2006) argues that reciprocity is a genre of discourse that is subject to interpretation and contestation. Weems applauds the goal to ensure that participants' voices are heard in ethnographic discourses, but questions not only whether reciprocity in all contexts is possible, but whether it is desirable. Reciprocity can be used to address epistemological and power imbalances and is reflective of emancipatory agendas (Weems citing Lather, 1986).

The primary goal in reciprocity is to return the participant to center stage. However, as noble as this goal might be, in practice, power imbalances might be perpetuated through representation of researchers' complex agendas and participant's

positions as straight-forward. It is arrogant to assume that the researcher has a complex context with competing interests and meanings and the participant's context is simple and transparent (Weems, 2006).

As with every step of qualitative research, contexts, biases and perspectives are complex, for both researchers and participants. Weems (2006) argues that reciprocity should be a process of inquiry rather than a discursive construct. When viewed as a process, reciprocity fits well with the goals of CBPR and its emphasis on equal partnerships and shared power. Plummer (1999) states that in public ethnography there may "be real opportunities for the clarification of the moral and political life of a society through the generation of a public ethnography that is critically self-aware" (p. 648).

My hope is that NGO1, its partners and contacts will benefit from my reflections on their processes and ultimately benefit the Malawians whom they serve. Written work will be available to all participants through NGO1. My findings are subject to interpretation and will hopefully stimulate productive dialogues that will contribute to improved practices and promote community health and social justice.

Conclusion

Although there are vast social inequities between the U.S. and Malawi, the purpose of this study was to stimulate awareness and change in a persuasive rather than a confrontational manner. NGO1 has engaged the people of Malawi and offered its services in addressing the ravages of HIV and AIDS in Malawi. My hope is that changes will occur on three levels: 1) There will be an increased awareness that bottom-up strategies are imperative for sustainable health changes and that though difficult to maintain, persistence is necessary; 2) Donors will understand the need to respond to

community-driven priorities rather than donor directives and donors will encourage NGO staff to listen to community members, value community knowledge and work together to accomplish mutual goals; and 3) Malawi women will be supported in obtaining micro loans, income generating activities (IGAs), education and training in order to alleviate poverty and thereby decrease gender violence and disparities. NGO1 has functioned as an example of how to gain community trust and work with women. Ongoing donor education is needed in order to work as partners to mitigate the effects of HIV and AIDS in Malawi.

In my research, I sought to illuminate the processes whereby an NGO establishes trust with communities and give voice to a group that is not often heard in CBPR literature. Whether or not an NGO engages in CBPR *per se*, understanding the processes whereby NGOs interact with the communities will hopefully illuminate ways to improve partnership relationships.

Simple dictums on how to achieve health are not effective and do not take into account the multiplicity of cultural, social, economic, historical, biological and emotional perspectives that overlap and contradict each other in communities. Achieving community health is a messy process and linear methodologies are limited at best because they ignore the dynamic nature and variation in both individuals and communities. A public ethnographic approach to NGO perspectives is an ideological match for CBPR as it brings issues to the forefront in order to promote egalitarian processes to produce sustainable community health changes.

Table 4.1: *Description of Participant Demographics Related to Overall Study*

Country of Origin	**Malawi**	**U.S.**	**Other***	**TOTAL**
	16	8	2	**26**
Location of Interview				
US	1	5	0	**6**
Malawi	15	3	2	**20**
Organizational Association				
NGO/CBO Staff	13	3	1	**17**
NGO Board of Trustees	0	2	0	**2**
NGO/CBO Volunteer	3	3	1	**7**
Number of years with organization				
.5 – 2 yrs	3	4	1	**8**
3-5 yrs	3	1	0	**4**
6-10 yrs:	4	3	0	**7**
Over 10 years	6	0	1	**7**
Age Range (M = 48 years)	27-65	28-78	**	**27-78**
Race/Ethnicity				
Black	16	1	0	**17**
White	0	7	1	**8**
Asian	0	0	1	**1**
Education				
Certificate/Diploma/ Associates	Female: 4 Male: 0	0	1	**5** **0**
Bachelor's Degree	Female: 0 Male: 4	0	Female: 1 Male: 0	**1** **4**
Master's Degree	Female: 2 Male: 4	Female: 2 Male: 0	0	**4** **4**
PhD/Doctorate	Female: 0 Male: 2	Female: 2 Male: 1	0	**2** **3**
M.D.	0	Female: 0 Male: 2	0	**0** **2**
J.D.	0	Female:1 Male: 0	0	**1** **0**
Gender				
Female	6	5	2	**13**
Male	10	3	0	**13**

NGO (non-governmental organization)
CBO (community-based organization)
*One participant from Britain; one from Philippines, both living in Malawi
**Within 27-78 years, specific range not listed due to small number in category

Table 4.2: Definition of Terms Related to Overall Study

CBOs	Community-based organizations –these organizations are typically small and localized, serving a single community or village.
Community	A group of individuals that interact socially with each other and share a common geographical space in Malawi.
Contacts	Refers to individuals who are not staff of other NGOs or CBOs, but were introduced to researchers by NGO1 staff or partners due to their knowledge or interests related to the study (sometimes referred to as a "snowballing" recruitment technique).
Donors	NGOs that provide financial aid to assist Malawians; also, individuals that provide financial aid either directly or through NGOs.
FBO	Faith-based organization. Anglican, Baptist, Catholic, Living Waters and Muslim faiths are represented in the sample organizations.
IGA	Income generating activity.
Malawi Men	Adult Malawi women, 85% live in rural villages.
Malawi Women	Adult Malawi men, 85% live in rural villages.
NGOs	Non-governmental organizations.
NGO1 (See Table 4.3 for other NGOs and CBOs)	An organization based in the US with operational headquarters in Malawi that works to mitigate the affects of HIV and AIDS in Malawi, Central Africa.
NGO1 Malawi Staff	Malawian NGO1 staff based in Malawi.
NGO1 Partners	Individuals (staff and volunteers) and organizations (NGOs and CBOs) that work with NGO1 to mitigate HIV and AIDS and related issues in Malawi.
NGO1 US Board Members	American individuals who are current Board Members for NGO1.
NGO1 US Staff	American staff based in the US.
NGO1 US Volunteers	Volunteers of NGO1 who support activities to mitigate the effects of HIV and AIDS in Malawi through financial and/or time contributions in the US and/or Malawi
Participants	Individuals who consented to be interviewed and participate in the study "Community-based Participatory Research: An Analysis of Non governmental Perspectives".
Sustainability	Participants defined sustainability in terms of community member involvement and frequently stated that the community must be behind any program or research project in order to have long-term results.
Trust	Believing that a person or organization will support words with actions. Trust increases through the sharing of common goals and an ongoing commitment between individuals and organizations. Implicit in trust is a relationship between an NGO and community members. Relationships between one NGO staff and one community member can positively or negatively affect both the NGO and the community on a larger level.

Table 4.3: Identifiers and Descriptions of Organizations Related to Overall Study

Identifier	*Description*	*Country Affiliation*
NGO1	An organization based in the US with operational headquarters in Malawi that works to mitigate the affects of HIV and AIDS in Malawi, Central Africa.	US-based, primarily works in Malawi
NGO2	A protestant organization in Malawi that aids communities in food security, development projects, HIV and AIDS and also provides disaster relief.	Malawi
NGO3	An organization that works with youth who are living "on the street" to reintegrate the boys and girls to their homes of origin. Social workers address problems that led to youth leaving their homes and work with the youth, families, schools and legal authorities to reconcile differences in order to strengthen families and communities and decrease subsequent occurrences of the youth living on the streets.	Malawi
NGO4	A Malawian branch of a larger international organization working in several countries that addresses food security and works to provide sustainable systems to end hunger through bottom-up approaches. It also addresses issues around HIV and AIDS and empowering women.	International, Malawi
NGO5	An international organization partnering with local organizations working to promote human rights among the poor. It works to address poverty, responds to natural emergencies and political conflict with a goal to assist poor people to obtain necessary resources and maintain human dignity and autonomy.	International, Malawi
NGO6	An organization whose purpose is to strengthen families, support women (primarily mothers) regarding family issues and teach Christian values.	Malawi
NGO7	This organization includes a school that provides education for orphans and also provides training for women to generate income through income generating activities (IGAs) such as sewing projects and provides assistance to orphans.	Malawi
NGO8	A faith-based organization (FBO) that helps primarily Muslims with social concerns.	International, Malawi
CBO1	This is a faith-based organization that provides care for orphans. Staff are provided with training in child development. Orphans are provided nutritious meals in day centers.	Malawi
CBO2	This is a family-based CBO that provides housing and care for approximately 16 orphans . The children are provided with food, shelter, education and participate fully in family and community activities. The family receives donations from outside sources to provide this care.	Malawi
CBO3	An organization wherein women to learn to help themselves. Widows and other women are taught how to market items that they can grow themselves, or how to sell sewing projects to generate income.	Malawi

Table 4.4: Observations in Malawi

1.	NGO1 Village Launch in Mulanje (20 villages represented with over 40 chiefs, representatives from police and the media).
2.	Dinner with NGO1 staff member.
3.	Distribution of supplies for orphans in Mulanje (300 orphans served).
4.	Visited a CBO outside of Zomba for people living with AIDS (dramatic presentation, orphan preschool, gardens, knitting & sewing income generating activities (IGAs).
5.	School outside of Zomba with 3 students supported by NGO1 – 3 girls who spend 14 hours per day traveling to school and attending classes. Due to travel and home constraints (cleaning, chores), students are not able to study as they need. One girl wants to be a pilot, another a nurse and the third girl wants to be a radio announcer.
6.	Church service in Blantyre – singing, dancing, welcoming of Americans.
7.	Church service in Chileka.
8.	Spent time having coffee in the home of a church member who visited Philadelphia's sister church and discussed her struggles with the deaths of her family members.
9.	Visited Chileka market with a NGO1 staff member who explained some of the customs.
10.	NGO1/NGO2 offices – observed on several occasions and spent most of one day there – during interviews for drivers, meeting with coordinators, arrival of ambulances, loading of supplies for orphans etc.
11.	Toured a government-sponsored factory that employs individuals with disabilities.
12.	Private hospital in Chileka, spoke with the physician, nurse and lab technician on duty.
13.	Visit to home of NGO1 staff member.
14.	Stayed at a church-based center staffed by Malawians. Several Malawians gathered most days to work on a US funded research project. Observed Malawi-US interactions and had discussions with interviewers, university faculty, staff and more.

CHAPTER FIVE:

COMMUNITY BUILDING AND ORGANIZING: HOW TRUST WAS GAINED BY A US NGO IN MALAWI, CENTRAL AFRICA

The purpose of this qualitative study was to obtain perspectives of individuals working for and with Non-government organizations (NGO)s in Malawi regarding how a US-based NGO gained community trust in Malawi. Twenty-six semi-structured interviews were conducted in the US and Malawi over a 12 month period. Participants identified three areas that can function either as barriers or facilitators to trust within Malawian communities: 1) gender; 2) the social context; and 3) religion. Additionally, there are three barriers to gaining community trust that can be addressed internally by an NGO: 1) NGO arrogance/assumptions about communities; 2) not obtaining community support for NGO activities; and 3) conducting research or activities that benefit outsiders rather than Malawians. Providing practical support in the form of tangible goods such as soap and clothing for orphans helped reduce community suspicion. Conclusion: When trust is present, an NGO can help communities address health issues with sustainable results.

> Trust is "hard earned and easily dissipated. It is valuable social capital and not to be squandered" (O'Neil, 2002, p. 2).

In an increasingly challenging healthcare environment, maximizing resources in an ethical and culturally sensitive manner has been approached in many different ways. Researchers are becoming progressively more responsive to diversity and pluralism in the community; yet, there is often a gap between research and the individuals who would benefit from it. There has been a shift from an individual focus to consideration of the wider social context in addressing chronic diseases (Navarro, Voetsch, Liburd, Giles, & Collins, 2007). The social determinants of health (environmental, social, economic and cultural factors) create complexities in addressing community health that defy simple linear, top-down solutions. Linear methods of intervention, implementation and evaluation processes are often inadequate in addressing the complexities of multi-dimensional communities.

Research that involves community participation is essential to develop and sustain effective community partnerships. Participatory approaches, while more difficult to evaluate are better able to address the totality of a community's needs (Coombe, 2006). Community-based participatory research (CBPR) is a type of bottom-up approach that is used to actively involve communities in research (Minkler, 2006; Wallerstein, 2006). Within this approach, establishing rapport and gaining trust with communities as well as promoting empowerment are essential to the community capacity building process. According to Minkler, the role of health professionals is to help create conditions whereby communities can develop processes to address their own health concerns. The healthcare professional assumes the role of facilitator rather than expert and the emphasis is on process rather than outcomes alone. The strategy is to "build on and reinforce authentic participation that ensures autonomous decision-making, promotes a sense of community and bonding" and empowers the community as a whole (Wallerstein, 2006, p. 5).

Using the principles of CBPR as a bottom-up approach, the purpose of this chapter is to describe the process of how trust was gained by a Western NGO (NGO1) in partnership with Malawian communities to mitigate the effects of the human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS). The aim was to describe and understand their interactions to achieve mutual goals. NGO1is an interfaith alliance organization that has been actively engaged in Malawi, Central Africa since 2000 with the mission to mitigate the effects of HIV and AIDS. NGO1 places the community at the forefront of its activities and this is reflected in its organizational chart (See Figure 1).

The background and significance for the study will be followed by a description of study methods, findings, limitations and discussion. The conclusion emphasizes the importance of one-on-one relationships between NGO staff and community members as a foundation for trust.

Background and Significance

In 2005, almost one million Malawians (14.1% of the total population) were living with HIV and AIDS. Of these, 91,000 children had AIDS and approximately 550,000 children under the age of 17 had lost one or both parents to AIDS (Global Health Reporting, 2005). In 2005, 78,000 Malawians died of AIDS which is approximately equal to the entire city population of Luxembourg (Global Health Reporting, 2005; European Urban Knowledge Network, 2005).

The average Malawian earns $160 annually (Malawi Economic Brief, 2005). USAID (2005) reports that "over 55 percent of the population lives on less than a dollar a day and UNICEF (2007) reported a life expectancy of 48 years for Malawians in 2006. There is only one physician for every 117,647 people in Malawi (Malawi Economic Brief, 2005 quoting USAID, 2002) and during "critical hours" the nurse/patient ratio can range from one nurse to 60-80 patients (BBC News, 2006). To place in context, in California, the nurse/patient ratio for general medicine is 1:5 (California Progress Report, 2008). Malawi has one of the worst maternal morbidity rates in the world (The Health Foundation, 2007). Approximately 85% of Malawians live in rural villages (Index Mundi, 2008; Malawi Economic Brief, 2005) and as such many rely on subsistence farming that is at risk due to small land plots and climate changes (Malawi Economic Brief, 2005).

Methods

Design

The study employed a qualitative, descriptive design that used face-to-face interviews and participant observations to collect data about how trust was gained between a Western NGO and the Malawian community around the need to mitigate the effects of HIV and AIDS.

Setting and Sample

Participant observations and interviews were conducted with NGO1 staff, volunteers and partners in the US and Malawi. A description of participants' characteristics is presented in Table 5.1. Data were collected over a period of 12 months; half of the sample was male and half was female. A total of 26 semi-structured interviews were conducted (20 in Malawi and 6 in the US) and 65% of the participants were staff of NGOs or CBOs.

Interviews Conducted in the US

Six interviews were conducted in the US with five Americans and one Malawian who was in the US for work-related business. All participants interviewed in the US were associated with NGO1 and they were between the ages of 39 and 78 years. Interviews took place in comfortable offices and homes that were easily accessible by paved roads and no sign of poverty was present in any of the US interview locations.

Interviews Conducted in Malawi

A majority (77%) of the interviews were conducted in Malawi. Malawian participants ranged in age from 27 to 65, with a mean age of 46 years. Malawians

comprised 62% of the participants. The twenty interviews that were conducted in Malawi included three Americans, all of whom were volunteering in some capacity and one was conducting research. One participant of British heritage also volunteered in Malawi and had lived in Africa for a number of years. One Filipino participant worked and lived in Malawi for many years.

Interviews averaged an hour in length and were conducted in locations chosen by participants that included NGO offices, religious facilities, homes and rural village settings. Although some interview locations had all the amenities of the US interview locations, some interviews took place in rural areas that were accessed via rough dirt roads. In the rural areas there was no electricity, no plumbing and many of the individuals in the area had torn or tattered clothing. Some were shoeless while other individuals suffered from food insecurity and had very limited access to health care. The children (many of whom were orphans) often laughed and were interested in the foreign interviewer.

Participant observations in Malawi included an event where over 40 chiefs, several government officials and people from 20 villages gathered together to launch a partnership between NGO1 and the villages in rural Malawi to address HIV and AIDS education, home-based care and orphan assistance. This was the first event for NGO1 that demonstrated community and government support on such a large scale.

Other observations included a village gathering for the distribution of supplies for orphans in the rural Mulanje District; a site visit to a community-based organization (CBO) for people living with AIDS in rural Zomba; and visits to churches, schools, hospital/medical facilities, Malawi homes, and the NGO1 offices in Malawi. Several

informal conversations were held in Malawi with support staff and academics at a guest house, at churches, with NGO staff, with individuals seeking employment at NGO1, with interviewers working on a US-based research project, in a school and with individuals working with a CBO to assist people living with AIDS. These participant observations lasted on average about three hours.

Data Analysis

Verbatim transcripts (n = 26) were derived from audiotapes of the semi-structured, one-on-one interviews. In addition, handwritten notes from participant observations, field notes and memos (n =74) were used for analyses. The transcripts were imported into and coded electronically with Atlas.ti, a data software management program (http://www.atlasti.com/). Codes were categorized into conceptual themes using an iterative process. The conceptual themes were discussed with participants in order to obtain clarification and understanding of interview data and to ensure as much as possible that study results concur with interviewees' perspectives. Participants identified three major barriers to establishing NGO trust at the community level: gender, social context, and religion as well as the barriers of suspicion and lack of community participation (See Table 5.2).

Findings

The Process of Building Community Trust to Minimize the Effects of HIV and AIDS in Malawian Communities

The underlying theme that emerged repeatedly from the data was trust. Trust is the necessary foundation for community building and sustainable health promotion. Trust is defined as believing that a person or organization will support words with

actions. Trust increases through the sharing of common goals and an ongoing commitment between individuals and organizations. Participants emphasized that the community must be "behind" any program or project if it is to succeed. One NGO1 staff member explained:

> If you go out there, be with the people – know what they want, do it the way they like doing it, you are very likely to be trusted. But the only problem that I find, which is a very big problem, is the top-bottom approach When [NGOs use] the top-bottom approach… people are going to exaggerate their problems and you won't know which is their real problem because they have the idea that NGOs are here to [provide hand-outs for] us, so you have to be very careful…to really know what issues are on the ground because once people are not involved, they don't trust you, they might pretend to trust you because they want to benefit from you, but they don't trust you…(NGO1 Malawi Staff, male).

Trust could not be assumed by the US NGO staff, due in part to historical influences of colonialism in Malawi, which has led to Malawians' skepticism of "outsiders." Community trust is achieved in part through respect for cultural norms such as approaching male leaders first even if the focus of an NGO activity is to empower women. Despite the abuses of colonialism (Englund, 2006), results showed that rural communities in Malawi are willing to trust NGOs if NGOs invite the community to be part of the process as one participant explained:

> You really have to build that bridge if you don't build the bridge…especially if they see white people, they say wow! This is the help we are looking for. And the chiefs…if we would go there and call for a meeting to say we have 42 m

> kwacha [US$300,000 to] help the needy and we say "let's call the chiefs" – [and have] a big function [there] and if you call for the chief to give a speech, he is going to tell you all the problems they have: oh we don't have water, we don't have that, we don't have a school…we have so many orphans, so many problems. But if the process started with them sharing in small groups and [they prioritize their concerns and how they should address them,] then you are likely to get more results and trust from the people because they are part of the process and also because they are part and parcel of what is being built on the ground. So they will trust you because if they don't trust you they don't trust themselves! (NGO1 Malawi Staff, male).

Participants identified facilitators and barriers to establishing trust while working with rural Malawian communities. Issues of gender, the social context and religion are three areas that NGOs need to address in Malawian communities. Additionally, participants identified barriers to trust that can be addressed internally by NGOs. A discussion of each of these topics follows.

Overcoming Gender Barriers to Building Community Trust

Participants explained that Malawi is a male-dominated culture, and thus, it was necessary to have a male in leadership who could work with male chiefs and leaders in the community. However, the majority of NGO1 staff and leaders were women. The quote below is a representative exemplar of participants' views about the need to seek approval from male community leaders in order for NGO1 to establish trust with the community about planning a community project.

> You need a man to talk with the chiefs; because if the chiefs don't go along with the proposed intervention, it will never happen. They [NGO staff] asked… the chiefs to nominate 10 women in each of the villages from whom the women coordinators chose five… So when the [women] were chosen, they were put on stipend and we then undertook several weeks of training (NGO1 US Staff, male).

Women are seen as the key to reducing the incidence and effects of HIV and AIDS in Malawi, despite their low social status, risk for physical and sexual violence and lack of economic independence (Rankin, Lindgren, Rankin & Ng'Oma, 2005). When asked how NGO1 approached community building in Malawi, the response was "Through the women, the women *are* the community… we're not changing the status of women, we're changing communities" (NGO1 US Trustee, male). The role of women in Malawi was identified by participants as a one of the strongest resources of Malawi.

> Everything is focused for us on the villages and another specific focus is the women. Almost everything we do has to do with "empowering women" and I realize how condescending and trite that sounds, especially coming from a white male, but the women are the people who can turn this thing around (NGO1 US Staff, male).

Malawi women have little social power, yet they have a prevailing influence on ameliorating suffering from HIV and AIDS. NGO1 trained women coordinators and provided supported by giving them the authority to make decisions as well as the responsibility for program implementation. The coordinators organized health talks in the villages, worked with individuals to answer questions, encouraged testing and helped link individuals with resources. Independent of the US NGO1 staff, the Malawi NGO1

caregivers made a map of each village identifying where all the dwellings were and conducted follow-up visits. An evaluation of the program found that 65% of community members reported that the first time they heard about HIV was from the women, despite numerous NGO-initiated and public health campaigns.

Overcoming Social Context Barriers to Building Community Trust

Health is inextricably bound to social conditions. These social conditions can be a barrier to building community trust during the program planning process. Challenges in the Malawi social context include poverty, food insecurity, lack of educational opportunities, disempowerment of women, and stigma surrounding HIV and AIDS. Poverty is a major social challenge in Malawi. One woman said:

> Every disease as you know is contextually, socially situated. You *cannot* deal with HIV and AIDS without dealing with the social issues that cause it, which is chiefly poverty – it's dealing with the poverty issues, helping people become economically empowered, so that they're not as subject to the conditions that create this (NGO1 US Staff, female).

The central problem of poverty was inextricably linked to HIV and AIDS by a Malawi staff counterpart who said that the biggest problem in her rural community is poverty and that some women will have sexual relationships just to get food to feed their families which places them at risk for HIV and AIDS (NGO1 Malawi staff, female).

A leader in an organization that works with relief and development in Malawi (NGO2) said that the first code or standard in working with the community is to "Do no harm to the community". The second is to:

> Start with what the community knows best. The community has resources. The people can work to change things *on their own*. They don't need outsiders. People have been taught not to trust themselves, but to defer to the experts. They become suspicious if someone who has had training or taken classes and comes into the community and asks them what they know. The expectation is for those who have training to provide the answers and the community doesn't value its own knowledge (NGO2 Malawi Staff, male).

The community's own knowledge has been undermined by outside experts. This Malawi leader observed that many NGOs begin by developing trust, but the danger is that they slip into top-down roles. He cautioned that developing trust takes time and that it is costly if NGOs don't plan well. He further cautioned that communities themselves are suspicious and think that experts are spying on them as they have been 'brainwashed into thinking that others know better'

> We are from the village, what else can we know? But they (communities) know a lot of things, therefore [it takes] patience. They don't believe [in] themselves and they don't know all these books have [been] written by their knowledge…they don't know that they have written books (NGO2 Malawi Staff, male).

Trust is achieved through participation with and in the community. NGO1 addressed the social context through inviting community members to participate in planning and by providing much-needed material supplies. Communication and clear messages to the whole community regarding NGO1's work form the basis of their work as this Malawi NGO1 leader explains:

> We build trust in the communities the way we perform our activities. Like in Mulanje we are doing HIV prevention and care and women empowerment. We usually call people to come for village meetings. The way they participate in the meeting really shows that they are interested and they know that the project is a benefit to them. When we give the kids some items, and before we give the items to the kids we address the community caregivers [and say] that the items should be used for community orphans and we even tell them the reason why we are giving the items to the orphans – because we want to see all the orphans going to school. Because if they don't have clothes, blankets and other items, the orphans cannot go to school. So we are taking the responsibility of the guardians in the communities so that they may become self reliant after completing their education. We have our community caregivers in the villages who supervise if the orphans are really using their items and they write a report to the coordinators and [the] coordinator writes a monthly report to my office (NGO1 Malawi Staff, female).

Observations of Malawi staff overseeing the distribution of supplies for orphans in a community-wide event, visiting schools and orphans supported by NGO1 and visiting CBOs funded by NGO1 provided clear evidence that relationships of trust have been established through practical provision of goods and services to ameliorate the ravages of HIV and AIDS within Malawian communities. The key characteristic of NGO1 staff that was identified by participants in both the US and Malawi was passion for the community. Community members were clear regarding their role, the role of NGO1 and community and recipient gratitude was evident and repeated many times over.

Overcoming Religious Barriers to Building Community Trust

Religion plays a key role in Malawi. While statistics reveal that 79.9% of Malawians are Christians, 12.8% are Muslims, 3% are affiliated with other religions and 4.3% have no religious affiliation (Index Mundi, 2008); what is not evident is how pervasive religion is in day to day Malawian culture. One participant stated that "everyone" in Malawi belongs to a church or a mosque. Religion cannot be fully separated from the social context. Stigma surrounding HIV and AIDS is both a social and a religious barrier that needed to be addressed by NGO1 in order to effectively accomplish its goals to reduce HIV and AIDS related suffering. NGO1 gained trust by recognizing the importance of religion in Malawi and working with Malawians regardless of their religious affiliation.

NGO1 worked with religious leaders to provide education about HIV and AIDS to help reduce stigma as this staff member explains:

> Yes, because it wasn't easy and when we were coming in the different areas…We had to call a group of boys, a group of girls; we could call them on different days and even the religious leader so that those religious leaders, when preaching in their churches or mosques, they have to deliver the messages about stigma, about HIVAIDS and sharing responsibilities in their homes. So we had to call these different communities and train them [and] as a result the message about stigma, HIVAIDS and responsibility sharing in the families [was well-received] (NGO1 Malawi Staff, female).

Participants explained that trust was earned in part because NGO1 works with both Christian and Muslim groups and requires no particular religious affiliation or

beliefs. NGO1 supports activities whereby Christian and Muslims work together. One participant expressed:

> The one thing that I do love about this organization is one: we don't proselytize, so we are not promoting one religion over the other, thus being inter-faith; and two: we really try to listen, at least in the beginning the intent is for the people to tell us what they need, as opposed to us going there and saying "you should be doing this, and you should be doing that". So personally I couldn't because we already had that colonial imperialistic approach and it doesn't work, so that is why I have been very comfortable [working with NGO1] (NGO1 US Board of Trustees, female).

Barriers to Trust That Can Be Addressed Internally By An NGO

Three main barriers to trust that can be addressed internally by an NGO were identified by participants: 1) NGO arrogance and assumptions; 2) Not obtaining community support for NGO activities; and 3) NGO activities and or research that benefits outsiders rather than the community. NGO arrogance and assumptions refer to a power differential whereby the NGO perceives itself as the expert and dismisses, denigrates or ignores community knowledge and expertise.

> So many social workers have failed … because of their education …,they think that they can dominate the people by telling them what to do. They can do what you are telling them to do, but [the community] will not *own* that…I'll give you a good example. I visited in Zimbabwe at that time and in the villages, people didn't have toilets. So, the government decided to, establish communal toilets in the villages. The people were not taught, they were ordered, and so these toilets

> were built. After some time when social workers visited the toilets (public latrines), they found the toilets to be very clean. And [the social workers] asked them, "These toilets are very clean – how do you clean them?" The (villagers) said, "Well, you know we clean them all the time [but] we don't use them." [The social workers said, "You don't use them??" They said, "Yes, we don't use them because these are your toilets, so when you come, you want to see them clean and they are clean. We clean them and that's it. We are not using them." (laughing) I actually saw those toilets myself. Until [the social workers] went in and educated the people, assisted the people and worked *with* them together is when the villagers accepted those toilets and they started using them. It's as simple as that (NGO1 Malawi staff, male).

The arrogant approach inherent with multiple assumptions leads to the second barrier of not obtaining community support or "buy-in". Based on the belief that the NGO knows best, the community is approached as an object to be manipulated in order to achieve goals set by the NGO, ostensibly for the betterment of the community. The programs initiated under this approach may or may not achieve NGO intended goals; however, community trust is not obtained.

A Malawi NGO1 leader explained his approach to building community trust without arrogance and has used this approach to teach other staff members:

> First thing for me, is when you go into the community, you have to lower yourself to be at the level of that community. You are not going with a pocket; you know a bag of money. You are not going with [the] rich knowledge of all your experiences and education and so forth and so on. No! You go in. You

> empathize with the people. You become one of them. For you to be accepted and in that way they should start revealing their secrets to you, it is not an easy fit. Most of the field workers do not achieve that because we want to tell the people what to do. But most of the people in the community, in the villages, have experiences, very rich experiences. And they gain that experience through problems that they have been going through (NGO1 Malawi Staff, male).

Another participant stated, "[Malawians] know their culture, they know what works, they know what they want to do, and they are very resourceful and have great ideas, but just don't have any money" (US NGO1 Board of Trustees, female).

NGO1's activities are clearly community focused and not merely for the benefit of outsiders. NGO1 Malawi staff discussed the strong community affirmation of NGO1 at an event of the authors and one man commented about the unprecedented reception at the multi-village event to launch a partnership that we attended saying,

> So, yes, the reception in Mulanje – it is not fake, it is real. Our approach and how we consult the people, how we work together with them, how we start with the needs assessment… We work with the people… right? So when it comes to things like what you saw, there is an obvious indicator that yes, the program in the first place has been received, but the workers who are there have also been received. (NGO1 Malawi Staff, male).

Limitations

This study primarily reflects perspectives of one particular NGO working in Malawi and is therefore not representative of all NGOs in Malawi. Although the majority of Malawian participants remain connected with extended families in rural

villages, they are educationally and economically advantaged compared to most Malawians; therefore, the findings may not be generalizable to all Malawians who work with NGOs.

Discussion

The main lesson that NGO1 learned by working with the Malawians was that building community trust is a process during which facilitating factors must be enhanced and barriers must be overcome within a socio-cultural context in order to minimize the effects of HIV and AIDS on a community level. This was a salient and recurring theme.

Repeated throughout the data was the concept of "lowering yourself when you come to the community" (Malawi NGO staff). Approaching the community with respect for its socio-cultural values was demonstrated by NGO1 when it approached the chiefs in the village before attempting to move forward. Additionally, NGO1 worked within the government structure by obtaining District Health Commissioner approval before approaching the chiefs. Respect for social hierarchy and protocol helped establish trust with both government leaders and chiefs.

Social Context, Gender and Religion

The social context of poverty, gender disparities and religious beliefs are potential barriers to establishing trust between NGOs and communities. One participant said that higher level development objectives could not be met until poverty was addressed. He spoke about how moved he was by a woman he visited who fainted three times one day because she had had nothing to eat. Women are less well-regarded than men in Malawi and NGOs that want to be supportive of women must not further jeopardize their safety.

Religious attitudes toward people with HIV and AIDS can be stigmatizing (Rankin, Brennan, Schell, Laviwa & Rankin, 2005).

Although social context, gender and religious issues in Malawi can be barriers, paying attention to these three areas through respect and cultural sensitivity can enhance trust between NGOs and communities. NGO1 experienced positive reception from many villages due to its attentiveness to the social context, gender and religious issues. Additionally, NGO1 followed protocol to support government programs, thus acknowledging the importance of the infrastructure of Malawi.

Pfeiffer, Johnson, Fort, Shakow, Hagopian, and Gloyd et al. (2008) criticize the practice of many NGOs for not supporting public health and government activities in poor countries. In contrast, NGO1 expressed the importance of working to support local government and public health efforts and begins each local project only after obtaining District Health Commission input. Additionally, NGO1 has a nurse training program (see Table 5.2) that pays all fees and provides a stipend to nursing students and in exchange requires a three- or four-year commitment upon graduation for the nurses to work in government-operated Malawi hospitals or clinics in order to help support the infrastructure of Malawi. Through these efforts NGO1 demonstrated value for the social context of Malawi and helped decrease suspicion of “outsiders”.

Positive experiences and receiving practical support from NGO1 such as food, clothing, orphan education and nurse training, helped establish community trust of NGO1. Additionally, support for NGO1 work by trusted leaders such as village chiefs and religious leaders lent credence to NGO1 activities. Participants warned that it is easy for NGOs to slip into top-down roles with communities and NGO1 addresses this

challenge by continuing to solicit input from Malawi staff and community members to direct its work. Perhaps the strongest facilitator for community trust is evidenced by community involvement and participation in NGO1 activities.

Conclusion

The strongest verification of trust is found in the community. Program success is often measured by external, predetermined outcomes. When trust is earned, an NGO can help communities address issues utilizing collaborative, effective and sustainable methodology, recognizing that the process is dynamic and fluid. Trust between a community and an NGO fosters an ongoing relationship that transcends organizational purposes and goals. Passion to serve Malawians was identified as the main characteristic of both Malawi and US NGO1 staff and community responsiveness toward NGO1 was articulated in both interviews and observations in Malawi.

Although seemingly simple, a relationship is necessary for trust. This chapter has discussed trust relationships between NGOs and communities using one NGO as an example. These relationships are composed of one-on-one connections. Both positive and negative interactions affect trust at the larger levels of community and NGOs. As the number of positive relationships between individuals from the community and NGOs increase, a ‘web of trust’ is developed. Facilitators and barriers have been identified in order to help pave the way for trust; however, it is the ongoing commitment between the NGO and Malawian communities that sustains past successes and continues to produce creative and effective ways to address the community’s health.

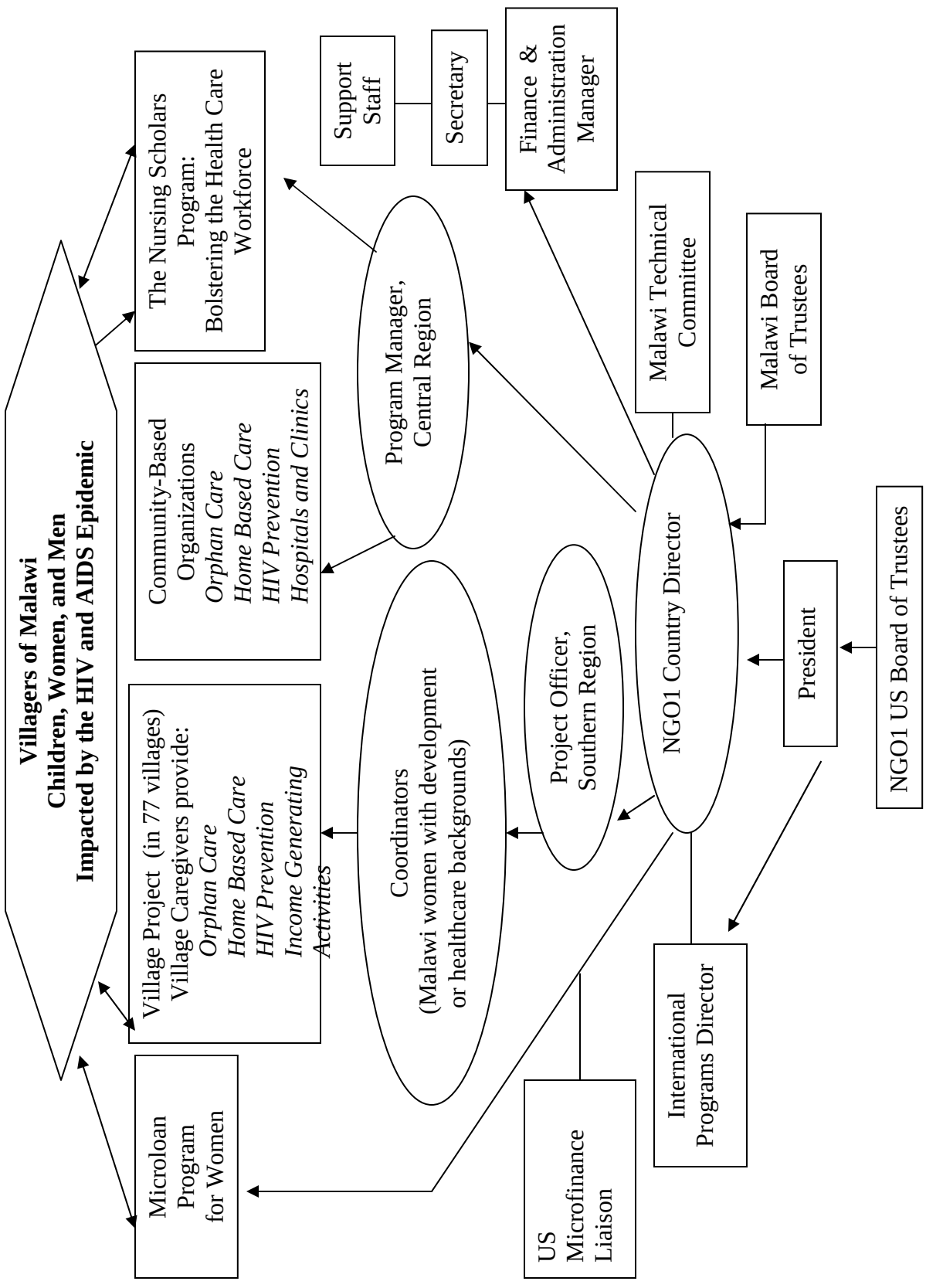


Figure 1: NGO1 Organizational Chart

Table 5.1: *Description of Participant Demographics Related to Findings on Trust*

Country of Origin	**Malawi**	**U.S.**	**Britain**	**Philippines**	**TOTAL**
	16	8	1	1	**26**
Location of Interview					
US	1	5	0	0	**6**
Malawi	15	3	1	1	**20**
Organizational Association					
NGO/CBO Staff	13	3	0	1	**17**
NGO Board of Trustees	0	2	0	0	**2**
NGO/CBO Volunteer	3	3	1	0	**7**
Number of years with organization					
.5 – 2 yrs	3	4	*	*	**7**
3-5 yrs	3	1	*	*	**4**
6-10 yrs:	4	3	*	*	**7**
11-20 yrs	4	0	*	*	**4**
21-25 yrs	2	0	*	*	**2**
Age Range (M = 48 years)++	27-65	28-78	*	*	**27-78**
Race/Ethnicity					
Black	16	1	0	0	**17**
White	0	7	1	0	**8**
Asian	0	0	0	1	**1**
Education					
Certificate/Diploma/ Associates	4	0	1	0	**5**
Bachelor's Degree	4	0	0	1	**5**
Master's Degree	6	2	0	0	**8**
PhD/Doctorate	2	3	0	0	**5**
M.D.	0	2	0	0	**2**
J.D.	0	1	0	0	**1**
Gender					
Female	6	5	1	1	**13**
Male	10	3	0	0	**13**
Marital Status					
Single	4	1	0	1	**6**
Married	9	7	1	0	**17**
Widow/Widower	2	0	0	0	**2**
No Answer	1	0	0	0	**1**

NGO (non-governmental organization)
CBO (community-based organization)
*Not listed due to small number in category and to protect confidentiality
++ Two participants did not report their exact age, but fell within the listed ranges

Table 5.2: *NGO1 Activities to Build Community Trust*

Barriers to Building Community Trust	**Facilitators to Building Community Trust**
Gender	1. NGO1 sent a man meet to meet with village chiefs to listen to village concerns and discuss NGO1 activities that could help address these and thereby acknowledged the community protocol of male leaders speaking with male leaders. 2. Village chiefs and leaders selected 10 respected women from each village and NGO1 coordinators chose 5 of these women to be trained as community caregivers and provided them with a stipend. 3. NGO1 staff met with men, women, boys and girls both separately and together to encourage free discussion about their concerns regarding HIV and AIDS.
Social Context	1. NGO1 followed protocol by obtaining guidance from the District Health Commissioner before approaching village chiefs in order to avoid duplication of services and follow cultural and government protocol. 2. NGO1 listened and asked what the community wanted. 3. NGO1 staff showed humility by sitting with the community literally on their level: on the ground if that was where people were sitting. NGO1 staff ate meals with the community and thereby demonstrated trust and respect for the community as an equal rather than coming in as an outside expert.
Religion	1. NGO1 is an interfaith organization and as such provides assistance irrespective of religious beliefs. 2. NGO1 encouraged Christian and Muslim groups to work together to address issues surrounding HIV and AIDS in their communities.
Suspicion of NGO Motives	NGO1 provided practical assistance of: 1. blankets, soap and clothing for orphans 2. assistance with orphan education 3. training and stipends for nursing students to address the abysmal nursing shortage and help bolster Malawi's infrastructure
Lack of Community "Buy-In" or Participation	1. NGO1 conducted needs assessments and asked chiefs and community members about their priorities. 2. NGO1 employed community members and thereby tangibly recognized their contribution (not merely asking for volunteers). 3. As NGO1 community caregivers are members of local villages, concerns and issues are addressed by members of the community and then brought to the attention of NGO1 leaders, using a bottom-up approach.

CHAPTER SIX

DONORS: BENEFACTORS OR BULLIES?

NGO PERSPECTIVES IN MALAWI, CENTRAL AFRICA

There are power differentials between donors and recipient organizations that can undermine results at the community level. This chapter explores perspectives of staff, partners and contacts of a particular non-governmental organization (NGO1) who work in and with Malawians in Central Africa. The data for this qualitative study is derived from 26 semi-structured interviews that were audio-recorded, transcribed verbatim and analyzed using Atlas.ti, a data software system, to organize themes. Interviews were conducted in the US (n=6) and Malawi (n=20). Non-governmental organizations' (NGOs) and community-based organizations' (CBOs) perspectives about providing community services within the constraints of donor directives in a country beset with poverty, disease and a worsening mortality rate across the population provide a framework for three themes identified in the data: 1) Donor accountability and recognition; 2) What to fund?; and 3) Sustainability. Participant perspectives echo principles of community-based participatory research (CBPR), an egalitarian, bottom-up approach in which community knowledge is valued alongside scientific knowledge. Participants were in agreement that unless the community supported a program, project or research, it was not sustainable. Maintaining bottom-up approaches requires resisting donor dictums, the NGO's internal pressure to be more efficient and external pressures from communities that rely on experts. Donors who support communities in achieving their own objectives act as benefactors rather than bullies.

Introduction

There is no limit to what can be accomplished if it doesn't matter who gets the credit

(P. W. Emerson, 1803-1882).

Today's donors are savvy and require increasingly greater accountability from organizations that receive their support (Feuerherd, 2006). On the surface, this approach is positive as it helps reduce losses due to corruption or inefficiency. It is prudent to require accountability for donated funds. Nevertheless, there are power differentials between donors and recipient organizations that can undermine results at the community level.

This chapter explores perspectives of staff, partners and contacts of a particular non-governmental organization (NGO1) who work in and with a central African country, Malawi, to address the ravages of HIV and AIDS, poverty and other health concerns. Subsequent to overviews of the study's theoretical framework, HIV and AIDS in Malawi, community-based participatory research (CBPR), literature review and data collection methods and analysis will be a description of NGO1. The study findings follow. Non-governmental organizations' (NGOs) and community-based organizations' (CBOs) perspectives about providing community services within the constraints of donor directives in a country beset with poverty, disease and a worsening mortality rate across the population (USAID, 2004) provide a framework for three themes identified in the data: 1) Donors; 2) What to fund?; and 3) Sustainability, depicted in Figure 2. The final section will address how Malawian solutions can be supported by following principles of CBPR (see Figure 3).

Theoretical Framework

The theoretical framework used in this study is ecosocial theory as outlined by Krieger (2001). Ecosocial theory is based on four constructs: 1) embodiment, which refers to the ways in which the social world is assimilated into our physical bodies (e.g. eating sugarcane to help stave off hunger panes will be "embodied" in ones teeth); 2) "pathways of embodiment" refers to social power patterns (e.g. lack of access to nutritious foods and healthcare impact maternal and child mortality and morbidity); 3) "cumulative interplay between exposure, susceptibility and resistance" refers to multiple settings of home, work, school, community, and political domains that affect our physical living spaces (e.g. reduced social and economic opportunities for women in Malawi place

women at greater risk for poverty and domestic violence) and 4) "accountability and agency" refers to scientific knowledge production about embodiment (e.g. the explanations given for inequalities related to health and disease such as attributing increased mortality and morbidity among the Malawian poor to individual choices) (p. 672).

Ecosocial theory provides a framework that addresses multiple factors related to physical, social and ecological levels that affect health and wellness. Power dynamics concerning knowledge production are deconstructed in an effort to understand social as well as physical determinants of health. Donors have power over NGOs that can affect Malawians at the community level in positive or negative ways. From an ecosocial perspective, donor actions impact NGOs and ultimately the health of the communities NGOs serve.

HIV and AIDS in Malawi

The Human Development Report (2008) ranked Malawi 162ndth out of 177 countries measured by life expectancy, adult literacy/school enrollment and purchasing power. In 2007 11.9% of the population between 15 and 49 years of age were living with HIV and AIDS. Of these, 91,000 children had HIV or AIDS and 68,000 Malawians died of AIDS which is over twice the population of Monaco (Global Health Reporting citing UNAIDS, 2008; Infoplease, 2007-2008). Life expectancy for Malawians was 48 years in 2006 whereas life expectancy in the U.S. rose to 78 years in 2007 (UNICEF, 2007; Medical News Today, 2007).

Community-Based Participatory Research

Community-based Participatory Research (CBPR) involves a partnership approach to research that is increasing due to its success in achieving sustainable, positive results for community health (O'Fallon & Dearry, 2002; Israel, Eng, Schulz & Parker, 2005; Wallerstein & Duran, 2006). Partnership approaches have been found to decrease costs and partnerships are one of the funding requirements often found in requests for proposals (RFPs). The term "CBPR" refers to research conducted *with* the community and thus differs from the broader term "community-based research" which refers primarily to the research setting and describes research that is done *in* the community. Partnerships in community-based approaches to research are usually time-limited studies whereas CBPR principles stress a long-term commitment to communities that help produce sustainable outcomes (Gibson, Yeudall, Drost, Mtitimuni & Cullinam, 1998; Holz & Gibson, 2004). If CBPR processes show greater promises of success in communities, (Minkler, Vasquez, Warner, Steussy & Facente, 2006) why does a top-down approach to development and community health programs remain the norm in Malawi? Do donors function as benefactors or bullies in Malawian communities?

Literature Review

A review of the literature in PubMed, Cinahl, Cochrane Library and PsychINFO databases revealed no true CBPR studies in Malawi. However, the CBPR approach has been tried elsewhere in Africa. A CBPR study in South Africa (Mosavel, Simon, van Stade & Buchbinder, 2005; Simon, Mosavel, van Stade, 2007) identified tensions researchers faced when trying to meet community needs that were different from the priorities of those who funded the project and this study is applicable to the topic of

donors and communities. Funders were interested in cervical cancer and community members had more immediate needs concerning poverty, unemployment, violence and apartheid issues (2006). Lund and Taylor (2008) conducted a CBPR study on sun protection for children with oculocutaneous albinism in a boarding school in rural South Africa. Little was said about the CBPR process in Lund and Taylor's study; whereas Mosavel and colleagues discussed the CBPR process at length. Whether conducted in the US or Africa, the voice of NGOs was rarely present CBPR studies.

Data Collection, Methods and Analysis

The aim of the study was to describe and understand NGO perceptions about their work and the role of donors. This study employed a qualitative, descriptive design that used face-to-face interviews and participant observations to collect data concerning NGO perceptions about donors and working in rural Malawian communities to mitigate the effects of HIV and AIDS. Participant observations and interviews were conducted with the primary focal group of the research, NGO1, including staff, volunteers and contacts working in other Malawian NGOs identified through a "snowball" recruitment technique (See Table 6.1). NGOs and CBOs are described as NGO1-NGO8 and CBO1-CBO3 with a description of each organization in Table 6.2. Participant observations were conducted at selected sites of the NGOs. In addition, data were extracted from NGO1's documents. Data were collected over a period of 12 months. A total of 26 semi-structured interviews were conducted: 20 in Malawi and 6 in the US, with a majority (65 %) of the interviewees being staff. Interviews averaged an hour in length and were conducted in locations chosen by participants that included NGO offices, religious facilities, homes and Malawian rural village settings.

Interviews were transcribed from audio tapes and coded using hand written notes and Atlas.ti, a data software management program (Atlas.ti.com). Codes were categorized into conceptual themes using an iterative process that included analysis of field notes and memos. Findings and results were discussed with participants and peers working in Malawi in order to obtain clarification, understanding of interview data and to ensure as much as possible that the authors' conclusions concur with participant perspectives.

Non-Governmental Organization (NGO1)

NGO1 provided introductions to their partners and contacts in order to assist with this study. NGO1 is a US-based interfaith alliance that was founded in 2000 in response to the devastation of HIV and AIDS in Africa, particularly in Malawi. NGO1 has 8 staff members in the US (some part-time). In Malawi, four senior staff members oversee several programs, each with a dedicated staff :1) the women's empowerment village program operates with ten staff coordinators and 133 village level caregivers (the caregivers receive a modest stipend for their work, but are not formally staff members of NGO1); 2) the microloan program with a staff of six serves over 700 women; 3) two mobile clinics with a total staff of 8; and 4) other general support and administrative staff totaling about six. NGO1's mission is to partner with religious organizations in resource-poor countries for community-based HIV prevention and care. It assists communities in developing locally initiated HIV and AIDS interventions that are specific to community needs. These interventions include health education, sexual behavior modification, HIV counseling and testing, social and economic empowerment of women, care for AIDS

orphans, home-based care of ill persons, nutrition, and reversal of stigmatization of people with AIDS, medications, treatments and referrals.

A demographic description of participants is represented in Table 6.3. A majority (77%) of the interviews were conducted in Malawi. Participants ranged in age from 27 to 78, with a mean age of 48 years. Half of the sample was male and half was female. Sixty-five percent of the sample had worked for an NGO for 5 years or more and 73% of the US and Malawi participants reported a bachelor's degree or higher educational level. Organizational characteristics of the NGOs represented in the data are presented in Table 6.2.

Study Findings

Data from study interviews fell into three broad areas: donors, funding priorities and sustainability. Within each of these areas several themes emerged, represented in the boxes shown on Figure 2 which represents the study findings schematically. At the center of the figure are Malawians, situated within social, cultural and economic issues, and the intended target of the donors.

Donors

When study participants discussed "donors" they were referring primarily to international, western-based NGOs that provide funds for their work but at times it was clear that they also meant individuals (people who provide philanthropic contributions to the NGO providing the funds) with whom they had contact. Interview data showed that participants are concerned with accountability to donors and understand the importance of establishing credibility.

Accountability.

Communication and accountability engendered credibility for NGO1 as this participant explains:

> I think on building trust [with] community partners, I can say when we are giving funds to the CBOs or coordinators we encourage them to show us original receipts of whatever they have purchased to use in the CBOs and we always encourage them to have monthly meetings. And we advise them to be transparent. Everyone in the group must know what it is happening. We went to [CBO3]. Everyone in the group knew that we're giving them about half a million Malawi Kwacha (approximately US$3,500) to be used in purchasing the items used in the group. So this is what CBOs are encouraged to follow and do (NGO1 Malawi Staff, female).

This participant described problems that are caused by other organizations that are not accountable and referred to them as "Briefcase" CBOs or NGOs, meaning sham organizations that serve individual rather than community needs and as such present challenges for donors. Donors understandably want to be assured that their money is utilized for intended purposes. NGO1 has a meticulous process for ensuring accountability once funds are dispersed and has streamlined the process for funding requests in an effort to expedite the process of funds reaching the community. Assistance is given to CBOs by NGO1 via a one-page funding request. Malawi NGO1 staff examine organizations to determine credibility and then follow up with site visits to evaluate expenditures and program effectiveness. The participant above explained that maintaining transparency helps ensure credibility both at community and donor levels.

Recognition or "who gets the credit".

Data from interviews and observations revealed two different voices of NGO1. In the US, the voice rang with almost macho bravado, "We saved 16,000 lives; through our work HIV testing has increased by over 400 %; "we've trained over 80 nurses" (NGO1 US Staff, male) and so forth. Yet, the same staff members when speaking of the Malawians and their work had awe, humility and respect: "I don't know why they tolerate us there…; Malawians are very resourceful…our Malawian staff could work elsewhere; everything we do is dependent on the women in Malawi (NGO1 US Staff, male and female)." The bravado voice was used to raise funds while the respectful, humble voice was the one used while doing the work in Malawi. The difference has more to do with expectations of donors who support NGO1 than any inconsistency within the modus operandi of individual NGO1 staff members. One participant spoke about the needs of Malawians and fund raising saying,

> … and again I know how trite it sounds, you're just getting the best, the most generous and alert and caring people [Malawians] that you can find and you bring them all together, you go through a process where people define, they define what needs they have, what they think might be done as an effective way to respond to those and so forth. From that perspective, all we are from the US is the Robin Hood [who] takes the money from the rich and sends it over there to the poor. Robin Hood is my religious hero (NGO1 US Staff, male).

Donor philosophy: Top-down or bottom-up funding approaches?.

Participants reported that international NGOs often take a top-down approach to providing services in Malawian communities, meaning activities or projects are

predetermined and then implemented at the community level. Nevertheless, according to one participant who worked with several NGOs, many NGOs are conducting needs assessments prior to beginning a program:

> So yes…what I can say in general is that in Malawi there has been a lot of work…about the necessity of bottom-up approaches. In terms of reaching out to the community for their real needs, NGOs are really making an effort in my opinion to do that, they have extension workers who go into the villages and do much consultation even before they start a program (NGO5 Malawi Staff, male).

NGO1's philosophy is a bottom-up approach, meaning that the community must be supportive of any activities prior to implementation. Much effort is taken to ensure community "buy-in" and NGO1's success has been, in part, that its staff is closely connected with the community:

> We start from the community, do the needs assessment and then make a decision later, which is very different from some places where I've worked before where we sit in a Board Room, make a decision based on what we know and then go to the field and start doing things…. So to me it's very refreshing because most of the projects are targeted on what is really felt on the ground. You know, that's why the community coordinators are right in the field. They don't have to drive and visit it. They live there, they know the process, the systems – you make better decisions that way. It's a really refreshing environment, that sort of involvement – being a staff member and also a *Malawian* and looking as these things happen to other Malawians, it's quite refreshing…(NGO1 Malawi Staff, male).

Difficulty in maintaining bottom-up approach.

Although bottom-up approaches are favored because they help ensure long-term successes, in practice, it often seems more efficient to take a top-down approach in decision making and implementation because discussion and consensus building consume a great deal of time. Moreover, community members may view the NGO as the expert and expect a top-down approach because of an assumed epistemological hierarchy:

> One of the things that I have observed over time is, I think, there is a strong desire to develop trust amongst ourselves, there is always a point when [we] would want all of us to move towards that desire but later on slip off to what we call top-down approaches. So that's the caution that I would [advise] because there is a temptation to slip off. Participatory approaches take time and much as people say they are costly, if you don't plan well, you will end up doing what you did not want to do. And the other caution is communities themselves like here in Malawi, we have communities that have believed so much in professionals –everything is known by you [the professional] and [wonder] why you are asking them questions. They are probably brainwashed that experts from agriculture, experts from forestry or from academics know better. So therefore…they will always say you have come so tell us all that you have brought for us from the headquarters or from the cities (NGO2 Malawi Staff, male).

Bottom-up approaches in Malawi are difficult to maintain both within the NGO implementing the program because of a desire to be efficient and at the community level where the program is being implemented because of expectations that experts and

professionals will make the decisions. Despite these challenges, the participant above said that it takes time and patience and encourages NGOs to take and maintain a bottom-up approach.

What to Fund?

Staff or Stuff

One of the challenges mentioned by participants is a donor preference to fund material goods rather than human resources. When asked if it would be helpful to conduct a study to demonstrate the effectiveness of social workers assisting to reestablish "street children" with their families and communities, the response was:

> 200%!! Many donors are much more interested in numbers – "We have taken 2000 children off the streets." They don't understand what makes things work. The basis of success is that relationship. How things are working at home, what makes the child stay in school. Numbers speak much more to the donors than real change. Many organizations don't move on with their purpose because they're driven to satisfy their donors. That becomes "Let's just focus on numbers. Ten pounds, ten dollars – what will this achieve? You need people to be the ones to [bring about change]. Some people have been disappointed with me – they send a container of clothes. If I give the children clothes, what does that do to the recipient? They begin to look at me as the supplier of their clothes [rather than learning how to be self-sufficient]. We'll set targets for the children and give them goals to achieve. They work hard in school and we won't just give them [the clothes]. They must see the value and not look at themselves as just useless – as passive receivers (NGO3 Malawi Staff, male).

This participant addresses both donor expectations and the effect of creating dependency. There is a power differential when the grand benefactor provides poor children with clothing that is mitigated if the children in some way "earn" the clothes through their school work.

If human resources and staff contributions are not valued by donors, the work and community results are compromised:

> We need to have a defined level of growth – If I need 20 social workers to do my job, I should not do this with 10 social workers. They'll be rushing around and not achieving the goals. The numbers will be there, but beneath the numbers, people are still struggling, it takes longer and the social worker will spend less time with the children – they'll be spread too thin and the children and families will not have what they need – they might not stay in school…(NGO3 Malawi Staff, male).

Furthermore, results can be misleading if one only concentrates on the numbers of individuals served. If a social worker is not allowed the time necessary to ensure that a "street child" can be reintegrated into his or her family by working with the family, school, legal system, and/or community members, this child is likely to return to the streets. The child who returns to the street might be subsequently "counted" again as social workers reattempt to integrate the child back into the community, and though the numbers will look better, the actual results will cost more on multiple levels.

Donor or Community Priorities

Study participants (from NGO1-NGO8; CBO1-CBO3 as found in Table 6.2) identified several ways to address the challenges of poverty and disease in Malawi. A

comprehensive discussion of participant priorities cannot be addressed here; however, they include addressing poverty through food security, education, water sanitation, nutrition/agriculture training, using wind/solar power and providing treadle pumps rather than diesel pumps for irrigation canals used in farming.

Several participants outlined activities that would benefit from a research study with extensive evaluation to determine the effectiveness of the programs that they either were currently implementing or would like to implement. Malawian participants were clear, however, that although they would like the assistance of research experts, they would like to have control over each stage of a research study, including evaluation. One participant stated clearly that she wanted Malawians to be trained to conduct evaluation rather than have an outsider judge the effectiveness of particular programs. Participant views were in keeping with principles of CBPR.

Sustainability

Sustainability Defined

Participants defined sustainability in terms of community member involvement and frequently stated that the community must be behind any program or research project in order to have long-term results. Moreover, the most valued donor-provided resources were those that addressed immediate needs such as hunger that were provided in conjunction with resources that built individual or community capacity, such as education or income generating activities (IGAs).

> We'll give the donors the numbers. But we go beyond the numbers. What are the real issues that bring about the numbers? The two have to balance. You can choose to have a welfare or human rights organization. If you have a welfare

> organization alone, it makes people useless – they don't know their strength. A rights-based organization on its own is also useless – it doesn't meet their basic needs. The best is a blend of the two. Don't tell me if I'm hungry that I just need education. Feed me and help me find that which beats my hunger. (NGO3 Malawi Staff, male).

Partnerships

When asked about partnerships between NGOs that were required by donors, this participant explained:

> When we talk about partnerships among the international NGOs, ahh…these partnerships are in name only rather than bound on the ground… if you are looking at the work of the NGOs on the ground, you will only see one NGO implementing although you know they have a memorandum of understanding and a cooperation of agreement, you know with another NGO, they will say this NGO is our partner in the field, but if you go in the district, you find that [the partnership is in name only] …In the villages where [one particular NGO] is operating, it is very rare to find another NGO working in those villages; normally those villages would belong to one NGO. So the cooperation that they talk about is very hard to see, maybe they talk about areas of similar interest maybe, or that maybe another NGO is operating in the remaining villages…, but its very rare that, for example in the same number of villages that one NGO is providing this program in this project and another NGO is providing a different program in the same villages… (NGO5, Malawi Staff, male).

If a partnership is required for funding, then NGOs will often comply; however, this does not assure that the partnership is effective. The participant above refers to the villages as "belonging" to the NGO and participants referred to "NGO1" villages.

Average Life Cycle of an NGO Project in a Community

According to one Malawian participant, the average life cycle of an NGO project in a community or village is typically three years and is sometimes extended, yet there is a need to ensure that the community is able to sustain programs after the NGO has left. He said, "If you have invested in a community, not just investing in human capacity but also investing in infrastructure… then you leave that society with something when the project has ended" (NGO5 Malawi Staff, male).

Supporting the infrastructure as well as ensuring that communities have access to necessary resources for continued programs or projects is essential to sustainability.

> Right now what we tend to see is that it's assumed that because people have been taught, they will be able to carry out activities even if what they have been taught relied upon using [outside] resources, now you remove the resources and you expect the people to still carry out the activities regardless…so I think that cannot lead to sustainability and unfortunately that's really what's been happening in most cases (NGO2 Malawi Staff, male).

Dependency

Inadvertently creating dependence on resources such as diesel or external funding was cited as a barrier to sustainable community projects in Malawi. Moreover, there is little measurement of the actual impact on a community when NGOs go in and out of communities.

> The general point I am trying to make is that those activities, those projects that involve locally available materials will definitely continue because the materials to continue with are available, but projects that will need capital injections…will be problematic (NGO5 Malawi Staff, male)

The same study participant cautioned against applying western standards of development in Malawi as it must follow the necessary stages to ensure success. For example, to encourage a farmer to use a pickup truck to transport his vegetables to the city market creates dependency on diesel fuel, decreases the farmer's profits and can create further difficulties due to the irregular supply of diesel. Although utilization of oxcarts is less acceptable to western minds, one participant argued that more profits would be retained by the farmer who used an oxcart rather than a pickup truck.

Donors need to be informed about socioeconomic and cultural constraints within Malawian communities according to one participant. Although this participant advocated for bottom-up approaches, he cautioned that many Malawians are suffering from extreme poverty and need to have food security issues addressed before pursuing development goals.

Trust

Trust is defined as believing that a person or organization will support words with actions. Trust increases through the sharing of common goals and an ongoing commitment between individuals and organizations. One participant explained that trust was gained through community participation and because NGO1 provided practical supplies such as blankets and clothing for orphans:

> I can say that when we started our project in this area we had a meeting with chiefs and we introduced a [NGO1] committee and the caregivers [to the community], so what we are doing in the community is what makes the people trust us (NGO1 Malawi Staff, female).

Discussion

Donors and Accountability

NGOs must register with the Malawi government (Englund, 2006) and US NGOs must be registered with the federal government as charitable organizations in order to be exempt from paying federal income tax (Internal Revenue Service, 2008). Record keeping, evaluation and accountability are important. Additionally, donors want to know whether funds are being used wisely, effectively and whether the evidence supports programs, projects and so forth. The cost of record keeping and "policing" is important for donor/NGO accountability and credibility but should be considered in the context of serving recipient communities.

Conscientious donors expect NGOs to be accountable for funds, focus on a particular mission and provide recognition for donations. Donors want to see the results of their contributions and as such expect details previously not required of NGOs (Feuerherd, 2006). Donor expectations for accountability are understandable given that more than $200 billion was contributed by individual Americans to nonprofit groups in 2005 and corporations and foundations contributed $41 billion (Feuerherd, 2006). All of this is reasonable, but donors should consider that accounting and recognition also requires time and money, leaving less for the intended recipients of donations.

A preoccupation with accounting can be costly to implement and can divert funding from the intended recipients. Too little attention to accountability can damage the credibility of the NGO. Maintaining accountability while streamlining delivery of funds or services to the community is a challenge, but one that must be met in order to maintain credibility both with recipient communities and in the donor world.

Rethinking Donor Recognition

Donors might ask whether requiring a linear relationship between their funds and program results does so at the expense of the communities they serve. It takes time and money to draw the lines between funding and actual results. If partnerships with different donors are involved, the process is complicated in terms of crediting one partner over the other for results that were achieved via a joint effort. Focusing on community results rather than the role NGOs and donors play shifts the emphasis back to the recipients of the funding.

If the donor's goal is improved well-being in a community as defined for example, by a decrease in the number of new HIV and AIDS cases, improved mortality rates, food security, decreasing the overall percentage of population living below the poverty line etc., is it important for any one agency or organization to get credit? Western donors often require a linear explanation between their donated dollars and the outcomes achieved by an NGO.

Bottom-up vs. Top-down Approaches

Communication between community members, NGOs and donors is essential in order to be effective. A top-down approach inhibits communication and undermines the work of NGOs "on the ground". If NGO staff are inhibited by bureaucratic processes,

effectiveness at the community level is compromised. Donors must be informed regarding community perspectives if they wish to support bottom-up approaches and NGO staff need to be accountable to both the community and the donors in their communication of challenges, successes and priorities.

NGOs and donors must work to support community infrastructures, but as Englund (2006) cautions, they must also avoid the trap of perpetuating the very issues they seek to ameliorate. For example, imposing western standards of development in Malawi such as a restricted donation for diesel powered water pumps places communities in a dependent role.

What to Fund

Power dynamics between donors and NGOs often determine what is funded at the community level. Donors are desperately needed to reduce poverty (Kjellstrom & Mercado, 2008). Donors wield much financial power and their funding priorities have enormous power in local communities.

Funding human resources.

Numbers can be misleading. Participants stressed that donors need to understand what is "beneath" the numbers in terms of sustainable behavior change. A successful, sustainable program might serve fewer individuals than a numbers-driven program. Donors might be asked whether their goal is to make bravado claims or to help at-risk communities achieve sustainable changes. The two approaches are not mutually exclusive, but do merit reflection.

A reluctance to fund staff can be based on the premise that such expenditures are not sustainable. Medecins Sans Frontieres reports that "Western and European aid

programmes do not help pay nurses' salaries because the effort was considered 'unsustainable'," and HIV and AIDS prevention and care suffered as a result (IRIN, 2007). However, the UK provided 100 million pounds to reduce "brain drain" by increasing salaries for physicians and nurses in Malawi that has shown promising results (Vujicic, 2008). Vujicic argues that "the more people you have on the ground, the more services you can deliver" (p. 321).

CBPR Principles

Community-based participatory research is not a method, but a research approach that is used to address health disparities and inequities through collaborative processes (Wallerstein, 2002). Although not all of the study participants were involved in research, many emphasized principles found in CBPR that might assist donors. Community-based participatory research principles start with an egalitarian approach to research that can be applied to program implementation and evaluation in Malawi.

Rather than privileging scientific over community knowledge, community members and researchers, or "outsiders" share power equally in determining the issues, what should be addressed, how this should happen and how to evaluate it (Israel et al., 2005; O'Fallon & Dearry, 2002). The entire approach is process-based and as such relies heavily on partnerships, establishing relationships of trust and a commitment to the communities served (Simon, et al, 2007). The final stage is determining how results will be disseminated as shown in Figure 3. Community-based participatory research principles support a shift in power dynamics from donor-directed to community-directed initiatives.

Community-based participatory research principles can be used to address Krieger's ecosocial concerns about the power of the elite that perpetuate health inequities (2000). Community-based participatory research with its egalitarian approaches can be used to challenge unjust power structures that lead to health disparities.

Sustainability

Supporting government and infrastructures is critical in sustaining long-term community health changes (Pfeiffer, Johnson, Fort, Shakow, Hagopian, Gloyd et al., 2008; Nishtar, 2004). NGOs are admonished to support government and pubic health efforts rather than further their own causes at the expense of the infrastructure of the very communities they serve (Pfeiffer et al., 2008). The short-term nature of NGO projects discussed by study participants is also addressed by Pfeiffer, et al. who attribute this to donor pressure to produce outcomes quickly (1-2 years) that undermines long-term more sustainable approaches.

Partnerships

Although many organizations require partnerships because they show greater sustainability (Nishtar, 2004; Rosenberg, Hartwig & Merson, 2008), individual organizations often want credit for their contributions and undermine the very partnerships that they ostensibly require. Some of the most successful improvements occur because of multi-level or multi-system approaches (Nishtar). There are issues of competition and 'who gets the credit?' related to partnerships and funding.

Language

Language is a subtle but powerful medium that can support or undermine bottom-up approaches. It is interesting to note that a participant described one village as

belonging to NGO5, a large, international, western-based NGO. Although this suggests ownership of the NGO, in Malawi the meaning might be related to NGO responsibility for the village. NGO1 refers to "NGO1 villages" as this nomenclature serves to raise confidence with donors and thereby raises funds. The naming of "NGO1 Villages" does not seem congruent with the humble and respectful voice US NGO1 staff use to describe Malawians. Language is important and the message in the West, at least, perpetuates the notion of the NGO's power over the community. Perhaps NGOs and donors can work together to explore language that will help raise funds without perpetuating notions of donor dominance. There are different interpretations of the practice of naming villages after NGOs and this topic deserves further scrutiny.

NGOs and donors are in a position to ensure bottom-up approaches despite the perceived power of governments (Englund, 2006). Donors and NGOs leverage enormous power and as such can dominate communities or support them.

Conclusion

Participants were in agreement that unless the community supported a program, project or research, it was not sustainable. Although accountability and recognition are important for credibility, associated costs should be considered in order to ensure maximum service delivery to the community. Donors should be wary of numbers. A lower number served might be reflective of more effective and sustainable changes in communities.

A top-down philosophy undermines community strengths whereas a bottom-up approach not only reflects recognition and value of community knowledge, bottom-up approaches are more sustainable. Maintaining bottom-up approaches requires resisting

donor dictums, the NGO's internal pressure to be more efficient and external pressures from the communities that rely on experts. Despite these challenges, participants' advice included taking time to establish trust and build relationships, ensure that communities support projects or studies and to consider the value of human contributions versus tangible supplies. Consensus on the ground is critical to long-term sustainability.

Because poverty in Malawi is so extreme, food security issues should be addressed first and foremost. Higher level goals for community health, economic growth and socio-cultural changes must come from the community; however, community members require basic sustenance before these goals can be fully achieved. Donors who support communities in achieving their own objectives act as benefactors rather than bullies.

Figure 2: Schematic Representation of Study Findings Related to Donors

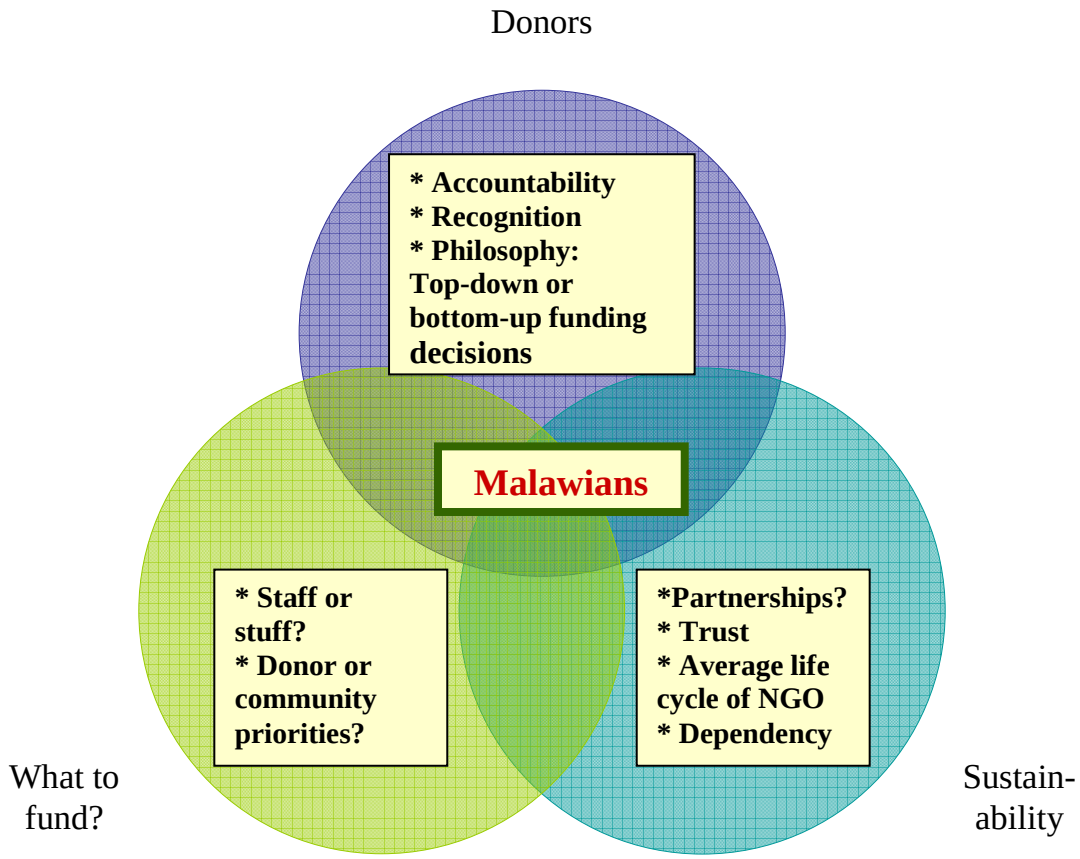


Figure 3: Malawi-Directed Research using CBPR Principles

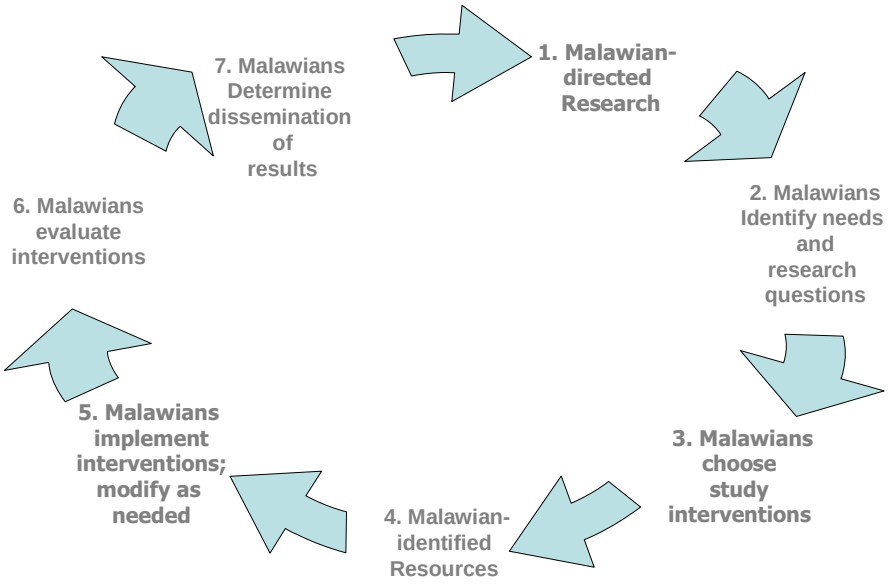


Table 6.1: Definition of Terms Related to Findings on Donors

Community	A group of individuals that interact socially with each other and share a common geographical space in Malawi.
CBO	Community-based organizations are local organizations (smaller in scale than NGOs) that provide programs or services to benefit communities.
Donors	Individuals and organizations (located almost exclusively in the US and Europe) that donate funds to NGOs.
FBO	Faith-based organization. Anglican, Baptist, Catholic, Living Waters and Muslim organizations are represented in the sample.
IGA	Income generating activity.
NGOs	Non-governmental organizations.
NGO1 (see Table 6.2 for description of other organizations)	An organization whose donor base is in the US and works to mitigate the affects of HIV and AIDS in Malawi, Central Africa. NGO1 has offices in the US where the staff are mostly dedicated to fundraising efforts. Program staff are based almost exclusively in Malawi.
NGO1 Contacts	People who were identified to the study investigator as potential subjects by either NGO1 or its partners (This method of recruitment is referred to as a "snowballing" technique).
NGO1 Malawi Staff	Malawian nationals who serve in Malawi as staff for NGO1.
NGO1 Partners	Individuals and organizations (both community-based organizations and other Malawi NGOs) that work with NGO1 to mitigate HIV and AIDS and related issues in Malawi.
NGO1 US Board of Trustees	American nationals who are current Board of Trustees Members for NGO1.
NGO1 US Staff	American nationals who serve in the US as NGO1 staff.
NGO1 US Volunteers	Volunteer American nationals of NGO1 who support activities to mitigate the effects of HIV and AIDS in Malawi through financial and/or time contributions in the US and/or Malawi.
Participants	General term to include all individuals who consented to be interviewed and participate in the study "Community-based Participatory Research: An Analysis of Non-Governmental Organization Perspectives".
Sustainability	Participants defined sustainability in terms of community member involvement and frequently stated that the community must be behind any program or research project in order to have long-term results.
Trust	Believing that a person or organization will support words with actions. Trust increases through the sharing of common goals and an ongoing commitment between individuals and organizations

Table 6.2: Identifiers and Descriptions of Organizations Related to Findings on Donors

Identifier	*Description*
NGO1	An organization working in both the US and Malawi to mitigate the affects of HIV and AIDS in Malawi, Central Africa.
NGO2	A protestant organization in Malawi that aids communities in food security, development projects, HIV and AIDS and also provides disaster relief.
NGO3	An NGO that works to with youth who are living "on the street" to reintegrate the boys and girls to their homes of origin. Social workers address problems that led to youth leaving their homes and work with the youth, families, schools and legal authorities to reconcile differences in order to strengthen families and communities and decrease subsequent occurrences of the youth living on the streets.
NGO4	A Malawian branch of a larger organization that addresses food security and works to provide sustainable systems to end hunger through bottom-up approaches. It also addresses issues around HIV and AIDS and empowering women.
NGO5	An International organization partnering with local organizations working to promote human rights among the poor. It works to address poverty, responds to natural emergencies and political conflict with a goal to assist poor people to obtain necessary resources and maintain human dignity and autonomy.
NGO6	Purpose is to strengthen families, support women (primarily mothers) regarding family issues and teach Christian values.
NGO7	This organization includes assistance for a school that provides education for orphans. It also provides training for women to earn money through income generating activities (IGAs) such as sewing projects.
NGO8	A faith-based organization that helps primarily Muslims with social concerns.
CBO1	This is a faith-based organization that provides care for orphans. Staff are provided with training in child development. Orphans are provided nutritious meals in day centers.
CBO2	Approximately 16 orphans are housed with one family and are provided with food, shelter, education and participate fully in family and community activities.
CBO3	An organization wherein women to learn to help themselves. Widows and other women are taught how to market items that they can grow themselves, or how to sell sewing projects to generate income.

Table 6.3: Description of Participant Demographics Related to Findings on Donors

Country of Origin	**Malawi**	**U.S.**	**Other***	**TOTAL**
	16	8	2	**26**
Location of Interview				
US	1	5	0	**6**
Malawi	15	3	2	**20**
Organizational Association				
NGO/CBO Staff	13	3	1	**17**
NGO Board of Trustees	0	2	0	**2**
NGO/CBO Volunteer	3	3	1	**7**
Number of years with organization				
.5 – 2 yrs	3	4	1	**8**
3-5 yrs	2	1	0	**3**
6-10 yrs:	5	3	0	**8**
Over 10 years	6	0	1	**7**
Age Range (M = 46 years)	27-65	28-78	*	**27-78**
Race/Ethnicity				
Black	16	1	0	**17**
White	0	7	1	**8**
Asian	0	0	1	**1**
Education				
Certificate/Diploma/ Associates	4	0	1	**5**
Bachelor's Degree	4	0	1	**5**
Master's Degree	6	2	0	**8**
PhD/Doctorate	2	3	0	**5**
M.D.	0	2	0	**2**
J.D.	0	1	0	**1**
Gender				
Female	6	5	2	**13**
Male	10	3	0	**13**

NGO (non-governmental organization)
CBO (community-based organization)
* One participant from Britain; one from Philippines, both living in Malawi
**Not listed to protect confidentiality

CHAPTER SEVEN:

SOCIALLY DISEMPOWERED WOMEN AS THE KEY TO ADDRESSING CHANGE IN MALAWI:

HOW DO THEY DO IT?

Malawi women are in the ironic juxtaposition of being socially disempowered while, at the same time, thought to hold the key to shaping an effective community response to the HIV crisis. Based on this juxtaposition, a descriptive, qualitative study was conducted in Malawi and the US where 26 participants from non-governmental organizations (NGOs) and community-based organizations (CBOs) discussed roles of women in Malawi. Interviews were audio-taped, transcribed and analyzed. An improvement in women's economic status was identified as the strongest factor in reducing gender inequities. Through providing stipends for rural Malawi women, one NGO created some unintended changes in gender roles. In conclusion, those with power, resources and the will to assist Malawians can best do so when supporting Malawian-identified priorities.

Introduction

> There is no other force as strong as gender inequality. You cannot continue to marginalize 52% of the world's population and expect to achieve social justice or equity…The weight that is placed on women internationally, what they are subjected to and what they cope with, is almost beyond the capacity of the mind to comprehend: female genital mutilation, international sexual trafficking, honor killings, child brides, sexual violence and rape, economic disenfranchisement, no property rights, no inheritance rights, and very little political representation (Lewis, 2008).

In Malawi, men make most of the decisions, women often have no voice, are seen as servants, and often taught that if their husbands want to have sex with them that they cannot refuse, even if they risk being infected with HIV or are sick with AIDS (Rankin, Lindgren, Rankin & Ng'Oma, 2005). If their husbands die, some Malawi women risk

being dispossessed of all of their belongings (Rankin, Brennan, Schell, Laviwa & Rankin, 2005). If a woman is HIV positive, even if she has contracted the disease from her husband, she could be sent away in shame; if a woman suggests that her husband use a condom, she risks being beaten (Rankin, Brennan et. al., 2005). More recently, dynamics surrounding HIV and AIDS have disrupted traditional power arrangements, gender roles and processes on multiple levels in Malawian society

Repeatedly it has been said that women are the ones who could turn around the HIV and AIDS crisis in Malawi. Malawi women seem to be in the ironic juxtaposition of being socially disempowered while, at the same time, thought to hold the key to shaping an effective community response to the HIV crisis. Based on this juxtaposition, a study was conducted in Malawi where participants from non-governmental organizations (NGOs) and community-based organizations (CBOs) were asked to explain the role of women in Malawi. The transcripts data revealed the honest struggles men and women had with their faith, social mores and culture as HIV and AIDS wrought suffering and death in their communities.

This chapter begins with a presentation of the theoretical framework for the study followed by a brief background of Malawi and a description of the study methods and procedures. Two main themes generated from the data findings will be addressed: 1) gender and power dynamics in Malawi and 2) examples of how an NGO (NGO1) has supported women in rural Malawian communities with some unintended effects on gender roles. The purpose of this chapter is to generate discussion, dialogue and promote effective strategies to support Malawi women's health and well-being. The aim was to describe and understand gender inequities and Malawi women's responses.

Malawians have many innovative approaches to the challenges they face although external aid often comes with predetermined directives that do not include Malawian perspectives or priorities. If women are the key to changing the devastating tide of HIV and AIDS in Malawi, understanding Malawi women's perspectives is of paramount importance.

Theoretical Framework

The theoretical framework underpinning this study is ecosocial theory as outlined by Krieger (2001). Ecosocial theory has four basic constructs: 1) embodiment is a concept that the biological cannot be known apart from one's history and that the "material and social world" are incorporated into the world (e.g. wife beating affects women's health and increases their risk for HIV); 2) pathways of embodiment refer to societal power structures that affect our "patterns of production, consumption and reproduction" as well as individual and evolutionary biological constraints and benefits; (e.g. societal preferences for males in education result in fewer economic opportunities for women that can keep women in poverty and affect their health; 3) "cumulative interplay between exposure, susceptibility and resistance" refers to how our pathways of embodiment are affected in time and space on multiple levels, including individual, regional, political, in our homes, neighborhoods, public settings and more (e.g. when decisions to preference male access to education and employment are found in multiple levels such as in families, schools, businesses and policies, there is a cumulative effect that increases the number of barriers for women to overcome; 4) "accountability and agency" refers to the ways in which knowledge and explanations are generated by institutions such as government, and businesses to "explain social inequalities in health"

(p. 672), e.g., explaining that HIV and AIDS is a moral or individual issue in Africa does not account for the role of poverty in increasing a woman's risk for HIV.

Background and Significance

Health of Malawians

The average Malawian earns $160 annually (Malawi Economic Brief, 2005) and over half the population lives below the poverty line (CBS News, 2007). Life expectancy in Malawi was only 48 years in 2006 (UNICEF, 2007) due to HIV and AIDS, malaria, and malnutrition. Malawi has one of the worst maternal morbidity and mortality rates in the world (The Health Foundation, 2007). Approximately 85% of Malawians live in rural villages (Index Mundi, 2008) and as such many rely on subsistence farming that is at risk due to small land plots and climate changes (Malawi Economic Brief, 2005).

Women in Malawi

Women in Malawi face physical and sexual violence (Rankin et al., 2005; Mkandawire-Valhmu & Stevens, 2007). In 2004 Malawi women comprised 56.8% of HIV-positive adults and 14.4% of women between the ages of 15 and 24 years are HIV positive compared to 6.5% of young men of similar ages (UNAIDS, 2004; UNAIDS referencing Malawi National AIDS Commission, 2003).

Fawole (2008) maintains that Malawi women also face economic violence as when another person exercises "complete control" over a woman's money, resources or activities (p. 168). James (2008) states that pressures on female leaders in Malawi, Uganda and Kenya have gender-based challenges that include sexual harassment, lower salaries, an absence of promotion opportunities and greater family responsibilities. Despite extensive gender inequities, not all studies portrayed Malawi women as

powerless to act. Mkandawire-Valhmu and Stevens (2007) addressed ways in which Malawi women are overcoming domestic violence and Schatz's study (2005) described strategies employed by Malawi women to protect themselves and their families from HIV and AIDS.

Chirwa (2008) reports that education was statistically linked with performance of female-owned but not male-owned businesses in Malawi. Although education is a positive factor for Malawi women, the literacy rate for females in 2004 was 62% compared with 79% for males (Malawi in Figures, 2007).

NGOs in Malawi

Non-governmental organizations are often utilized by donors and international aid organizations to obtain access to communities (Kelly, Somlai, Benotsch, Amirkhanian, Fernandez, Stevenson et al., 2006). NGO1 prioritizes working with Malawi women. Although it is generally agreed that women in Malawi are of low sociocultural and socioeconomic status, HIV and AIDS have contributed to a shift in gender roles (Mkandawire-Valhmu & Stevens, 2007). This study explores NGO and CBO staff perspectives about the role of women in Malawi.

Study Method and Procedure

Study Design

The study employed a qualitative, descriptive design that used face-to-face interviews and participant observations to collect data about how trust was gained between NGOs and the rural Malawian community, the role of partnerships with other organizations, and how socially disempowered women function in Malawi around the need to mitigate the effects of HIV and AIDS.

Participants answered the following open-ended questions about the role of women in Malawi: “Some people say that women are the key to addressing the problem of HIV and AIDS in Malawi, despite being socially disempowered. What do you think of this? How do women work together in the community in Malawi?”

Sample and Setting

Participant interviews lasting approximately 1-2 hours each were conducted at locations of their choice with staff, volunteers and partners in the US and Malawi of NGO1. See Table 7.1 for a description of the participants and see Table 7.2 for a description of NGOs and CBOs represented in the study. Data were collected over a period of 12 months. A total of 26 semi-structured interviews were conducted: 20 in Malawi and 6 in US, with a majority (77%) of the interviewees being staff. One Malawian was interviewed in the US and 3 participants from the US, one from Britain and one from the Philippines were interviewed in Malawi.

Malawian participants.

Malawian participants were adults over age 18, worked either for NGO1 (a US-based NGO that works primarily in Malawi) or a partner NGO or CBO. The majority had family members in rural villages. These participants represent the middle class elite in Malawi; however, many discussed their strong ties to their home villages and expectations from their communities to improve village life because of their privileged education and economic status.

Non-Malawian participants.

Two female participants, one British and one Filipino, lived and worked in Malawi. Eight participants were American and of those, 88% were either staff, volunteers or board members of a US-based NGO (NGO1).

Data Analysis

Verbatim transcripts were derived from audiotapes of the semi-structured, one-on-one interviews. Field notes provided context for the interviews. Conceptual memos were used for analyses. The transcripts were imported into and coded electronically with Atlas.ti, a data software management program. Codes were categorized into conceptual themes using an iterative process. Conceptual themes were discussed with participants in order to obtain clarification and understanding of interview data and to validate the analysis. From the data concerning Malawi women, two conceptual themes were identified 1) gender and power dynamics; and 2) NGO support of Malawi women (see Table 7.3).

Findings: Gender and Power Dynamics

Three factors were identified that shape gender and power dynamics in Malawi: culture, women's caregiving role, and economic power. Culture was identified as the chief reason for women's social disempowerment in Malawi, while women's caregiving activities and increasing economic power were given as explanations as to why women are able to effect change in their communities. Through caregiving activities women influence children and help decrease stigma as they care for those with HIV and AIDS. Economic power increases women's power both in their homes and their communities.

Culture

> One woman discussed gender roles in terms of culture saying,
>
> The problem is, I think, our culture. Normally they say the men are the head of the families; then the women are always like the inferiors. Men look at themselves as the superiors and then the women are the inferiors. So because of the way they have been brought up with our culture, even the women themselves …even [when they are] given some power they would be refraining because of the culture. So what we are doing as church leaders is we always say that though we are women, we should also have a voice because we are the ones facing most of the problems. This is so because, for example if a member of the family is sick, it is a woman who takes care of that person. Even when death occurs in the family the sufferer will be the women so we should also be, you know, bold enough to say this is not good…you know we should be there to speak for ourselves (NGO7, CBO3, Malawi staff, female).

Both male and female study participants agreed that culture plays a major role in limiting the power of women. It would be naïve to assume that women should simply stand up, speak for themselves and confront situations that challenge their power. Culture is not only an external factor affecting women's power; cultural beliefs about the inferiority of women have been internalized by both men and women. A male participant identifies culture as the key reason for women's social disempowerment in Malawi:

> The number one reason is culture - why women are less empowered is that women are treated as kitchen people. Cook me good food! Not as people who can contribute to the wellbeing of the families. If a girl is born, not as much

> attention is given to her - as someone who can contribute, [whereas] a boy child is seen as having a potential to contribute earnings to the family. People's perceptions are beginning to change…A boy was not sent to the kitchen [but to the] farm, or outside the house. The girl was sent to the kitchen. I don't clean, even if I am sitting in dirt. My sister must clean it (NGO3 Malawi Staff, male).

As this quote demonstrates, gender biases are inextricably linked to economic power and begin early in life. Girls have less potential for earning and are therefore devalued over boys. Women are typically homemakers while men typically earn money outside the home.

> …but culturally in Malawi, women do the family jobs; what I am saying is that the man could be someone who goes out to get some money but the actual processes of the structure of the family, it has to be the woman. It's very cultural, women…even if you go to a funeral, you find that close to the body are women; men are all far away, people who do the cooking are women, most of the logistics are organized by women, men will just organize things like transport and what have you, sort of like the short jobs that look more challenging, but all routine jobs are mostly done by women (NGO1 Malawi Staff, male).

The influence of television, the Internet, education and current changes within Malawi are contributing to a shift in culturally acceptable roles for women.

> The man today has been challenged. Women are getting more power and are beginning to talk and are able to say to their husbands that having seen the goodness of this and the badness of that, we should do [thus and so]. What I see is as young boys get exposed to this kind of life, perceptions are changing.

> Children are exposed to TV information, internet, human rights movement - much information in school about HIV and AIDS and their right to choose. Today generations are so different (NGO3 Malawi staff, male).

Another participant explained the role of culture and limited power of some women, including power to prevent HIV infection and access to food in the home:

> [It's] our culture. Because if the husband is HIV positive and the wife is HIV negative, the husband [can refuse] to use a condom. But if a woman is HIV positive and the man is HIV negative, a man can definitely divorce the woman. That's the culture we have lived in. And the other thing is if there is little food at home and you have children in that house, the first person to eat is the husband and the remains should go to the children. It's our culture; we have lived with it (NGO1 Malawi Staff, female).

Culture and decision making.

Participants said that men typically make decisions in Malawi and often make them independently of women. One participant explained that while NGOs often work in a hierarchical manner, the female staff in NGO1 work to reach consensus:

> It's like the Malawian culture traditionally is a business culture where we make the decisions in the board room and we hope that they work [in the community]… So from the onset, [NGO1] said we want to help women, and the staff members of NGO1, I think almost 90% of them are women. And women debate a lot but they reach a consensus… (NGO1 Malawi Staff, male).

One participant spoke of his work with an NGO in rural communities where women asked for female condoms as they were unable to either negotiate with men to use

condoms, or could not trust that the men would use them if they agreed. Additionally, if a Malawian woman was seen with a male condom, she risked stigmatization and being labeled as a prostitute. Carrying a female condom was not associated with stigma. The participant had to negotiate with an organization to supply the community with female condoms and a woman in the community agreed to educate her peers regarding effective use of female condoms. The organization's leaders said that female condoms were appropriate for literate populations and the rural community did not fit this profile. After much negotiation, the participant's NGO was able to obtain and distribute condoms with successful results.

> So we said …if we fail to provide the condoms to the communities that are looking for condoms we will be answerable one day because we didn't fulfill what communities were looking for…[The organization] gave us 3000 female condoms for a trial and now they have given us about 10,000 female condoms almost every month (NGO4 Malawi staff, male).

The participant further said that the impact of this project reached the media and parliament of Malawi and female condoms are now available in some of the larger cities. Author observations included seeing large billboard-type advertisements for female condoms in semi-rural settings. Women banded together to request female condoms, chiefs supported their requests and NGO staff advocated with organizations to make their request possible.

Rural women and power limitations.

Although the women in one community were successful in obtaining female condoms to help protect them from HIV and other sexually transmitted diseases, another

participant spoke of the limited power of many rural women:

> Well…women have…I should say they don't have much power to change the HIV/AIDS infection because it depends on the type of women you are talking about. Because for rural women who are economically poor, the families, even those which are dangerous [threaten physical and or sexual abuse], because they offer them support [food, housing etc], the woman is forced to be part and parcel of that marriage relationship (NGO7 Malawi staff, female).

The women identified by the participants who had less power typically lived in rural communities where cultural gender norms maintained the status quo of the subjugation of women and a woman's power was limited due to extreme poverty, lack of education and economic resources.

Women's Caregiving Role

One frequently identified theme in the data was that women have the power to change the HIV and AIDS crisis because women are the caregivers for children and for those who are sick. Women have influence over children and help shape their values.

One Malawi woman worked for an orphanage with a manager who did not allow the orphans to integrate with the community for fear that they would learn "bad manners". This woman resigned because she did not agree with the owner/manager's philosophy and later welcomed 18 orphans into her home to live with her husband and children. Including the nannies that assist in the woman's home, there are now often as many as 24 people at meals. The woman's husband relays the story of her vision and the outcome saying,

> There were 100 children with nannies taking turns caring for the children…the children were completely detached from the community… it was just about food and bathing and it was like they were in a cage…And [after seeing the positive results from inviting orphans to live in our home and connect with the community] the [owner] now agrees that this is the best way of raising these children; you are not restricting them, they are growing normally and with the idea that they are part of the community, they can go to their friends and come back, we wanted that interaction (CBO2 Malawi staff, male).

This Malawi woman not only influenced the children in her care, but by assisting orphans to be fully integrated in the community, she helped decrease stigma surrounding orphans. One participant spoke about the importance of keeping women involved in orphan care:

> So if you talk about caring for children, women spend most of their time looking after children. So if you talk about caring for orphans, the women have to be in the forefront, because if you marginalize women, the men would stop the project within two months because they cannot sustain it because it's culturally what they are not used to doing (NGO1 Malawi Staff, male).

Economic Power

Malawi women do the majority of the work in their homes, churches and communities, yet typically earn little money. Poverty increases a woman's risk of HIV and AIDS:

> Ah in my community the problem that we have - should I say the biggest is poverty. Especially in our diocese because it is rural…so that is our biggest

> problem and with…HIV and AIDS we have a very big problem. Because of poverty some women indulge in sexual relationships just to get something maybe to feed their families (NGO1 Malawi Staff, female).

Another participant (NGO1 Malawi staff, female) said that through providing income generating activities (IGAs) for women, the sick and orphans were supported and the women themselves had less risk for HIV because they had sufficient food and were less likely to engage in sex for money. Women who contributed financially to their families gained power and a voice by virtue of their earnings. Being able to earn money or a gain in economic power has a direct impact on women's health:

> When women have income, there is more settledness - a chance to think about themselves much more - trying to say "let's make our women see themselves from outside of the box, because they have been kept in the box and told "No! *Man* is the decision maker, the head" (NGO3, Malawi staff, male).

Another woman explained the changing dynamic of gender roles as related to economic power stating that women now have a voice in decision making because

> …the first villages we were in for the first 3 years, in those areas the women were given some [IGAs] and this has assisted the women to promote empowerment because they were able to source money for themselves and able to assist…their families. So, husbands are now happy that they are sharing responsibilities with their wives (NGO1 Malawi staff, female).

Nevertheless, Malawi women remain disadvantaged in micro and small enterprises and Chirwa (2008) states that "there is a need therefore to promote

microfinance institutions that target financing of non-farm economic activities, with a deliberate bias towards providing credit to women entrepreneurs" (p. 361).

Education, role models and economic power.

Participants identified education as a means to greater empowerment for Malawi women and although this is not new information (Englund, 2006; Sachs, 2005), the impact of role models in rural Malawian villages should not be underestimated. At the village launch referred to earlier, women coordinators and community caregivers from NGO1 led the festivities while over 40 chiefs, media representatives, police and the district health commissioner observed. Men, women, girls and boys watched as the coordinators and community caregivers of NGO1 danced in their matching "uniforms" of chitenges (fabric tied in sarong-like fashion around their waists and some had matching head scarves). The uniforms set these women apart as leaders in their community. They were paid for their work, brought knowledge about HIV and AIDS to their villages, provided care for those who were sick and helped dispel stigma surrounding AIDS. Additionally, they were honored by the top leaders in their community.

One participant encourages women to receive theological training so that "when" the Anglican Church allows the ordination of women, they will be ready (NGO6; CBO3 Malawi staff, female). Another participant cited culture as the main reason Malawi women were socially disempowered and lack of education as the second reason:

> The number two problem is that girls haven't been given much chance to go to school. If boys are educated, they can make money for the family. [The parents say] "She'll be okay" [as she will be married, taken care of by another…]. The understanding now coming is to educate girls - when girls become self reliant,

> they will be able to stand in the family and will be able to say if her husband has HIV and AIDS, "Why don't we use condoms?" (NGO5 Malawi staff, male).

Participants spoke of youth programs that provided HIV and AIDS education that helped offset negative gender roles concerning sexuality and about innovative ways that helped girls attend school. In one rural area, work by NGO1 helped increase girls' school attendance by 50%.

Findings: NGO Support of Women

NGO1 was founded in 2000 in response to the devastation of HIV and AIDS in Africa. NGO1 began its work with religious organizations to decrease HIV in Malawi, Sub Saharan Central Africa. Primarily, NGO1 is committed to involving Malawi women in leadership positions and this staff member explains the rationale:

> You see that most of the women in Malawi don't hold big positions… and it's the men who will be in top positions making decisions. This is true in many organizations. The problem is that if you don't involve women in the top, the problem I see is that you are unlikely to get good results because you don't feel what they feel and know (NGO1 Malawi Staff, male).

Effects on Gender Roles in Malawian Communities

In one of the village programs NGO1 staff experienced an unintended effect on gender roles. After obtaining buy-in from village chiefs, 10 women were nominated by the chiefs in each village and NGO1 coordinators selected 5 of these women to become community caregivers. The community caregivers were given training and a stipend so that they could provide education, home-based care for individuals with HIV and AIDS and oversee orphan support in their communities. Because the community caregivers

were working, they needed assistance with cooking and cleaning in their homes and so began to pay others to do this work.

An unintended result was that some of the husbands of the community caregivers wanted to keep the earnings of their wives in the household, so the husbands began to do household chores, cooking and cleaning. As discussed above, Malawi men typically do not do household chores and women typically do not earn money. By paying women for their work, NGO1 unintentionally effected a change in the gender roles at the family level.

Discussion

Responses to HIV and AIDS by Malawians and international aid are impacting gender roles in Malawian villages. Study data revealed that gender roles are influenced by culture, the way women care for and influence children and economic power in Malawi. As women become more knowledgeable about HIV and AIDS, IGAs and preventing malnutrition, their power increases inasmuch as they can negotiate for safer sex and are regarded more highly in their communities. It is important to note that the concept of knowledge as power implies action; knowledge retained in a vacuum is not powerful. Malawi women are gaining knowledge and participants spoke about how they were using their education to support, or empower other Malawi women.

Both the pressure for men to make decisions in a vacuum and women having no voice are gender-based cultural constraints. While one might comment on the injustice of men's power over women in Malawi, it is important to note that this power dynamic results in negative consequences for both genders: women are not autonomous and men are socially isolated. Nevertheless, gender roles are changing in Malawi and one

participant attributed the HIV and AIDS pandemic as the reason for the changes in cultural attitudes toward women.

For some women, nothing has changed. For others, education, earning even a little money and finding their voices to speak to their husbands, families and communities is resulting in a shift in attitudes. When a woman is paid, she is simultaneously viewed more favorably in the community and she has less risk of engaging in sex so that she can buy food for herself or family. Financial contributions for the family can shift the power balance between husband and wife. The ecosocial construct of pathways of embodiment refers to the ways in which power structures affect health, and study data demonstrated how cultural gender biases and barriers to education and economic independence places Malawi women at risk for HIV and poverty-related health issues.

As Malawi women gain education and economic power they are able to positively influence cultural perceptions about women's roles in their families and communities. NGO1 was effective in supporting Malawi women by respecting cultural norms and by assisting women to gain education and economic power and in doing so, NGO1 helped shift power structures that discriminate against women. Additionally, NGO1 supported women to mitigate HIV and AIDS by providing training and stipends for women in rural villages to work with their neighbors to provide education about HIV and AIDS and oversee the care of orphans.

There is much work yet to be done as many women remain at risk of physical and psychological harm due to abuses of power differentials. Activities that support the infrastructure of the public health system and provide education and economic opportunities for women can help redress socio-cultural inequities. In order to do these

activities, however, dialogues with Malawians and establishing relationships of trust are of paramount importance in order to provide sustainable results that do not perpetuate paternalistic power dynamics.

Conclusion

Malawi women are gaining power through their work and the ways that they care for their children, orphans and individuals suffering from AIDS. As women gain education and economic power they are reshaping attitudes about gender in Malawi. Many Malawian men are also working to improve life for Malawi women. Despite overwhelming poverty and the AIDS pandemic, Malawians maintain hope and continue to work to improve their communities. Those with power, resources and the will to assist Malawians can best do so when supporting Malawian-identified priorities.

Table 7.1. Description of Participant Demographics Related to Findings on Women

	Malawians	Non-Malawians (Participants from the US, UK and Philippines)	TOTAL
Study Participants	16	10	**26**
Role			
Staff	13	4	**17**
Board Member/Trustee	0	2	**2**
Volunteer	1	3	**4**
Academic/Student	2	1	**3**
Age Range (M = 46 years)	27-65	28-78	**27-78**
Race			
Black	16	1	**17**
White	0	8	**8**
Asian	0	1	**1**
Education			
Certificate/ Diploma/Associates			
Female	4	1	**5**
Male	0	0	**0**
Bachelor's Degree			
Female	0	1	**1**
Male	4	0	**4**
Master's Degree			
Female	2	2	**4**
Male	4	0	**4**
PhD/Doctorate			
Female	0	3	**3**
Male	2	3	**5**
Gender			
Female	6	7	**13**
Male	10	3	**13**
Marital Status			
Single	4	2	**6**
Married	9	8	**17**
Widow/Widower	2	0	**2**
No Answer	1	0	**1**

Table 7.2: Identifiers and Descriptions of Organization Related to Findings on Women

Identifier	*Focus in Malawi*	*Country Affiliation*
NGO1	HIV and AIDS and related health concerns primarily in rural areas. Promotes empowerment for women.	US-based, primarily works in Malawi
NGO2	Food security, development projects, HIV and AIDS and also provides disaster relief.	Malawi
NGO3	Youth who are living "on the street", works to reintegrate the boys and girls to their homes of origin. Social workers work with the youth, families, schools and legal authorities to reconcile differences in order to strengthen families and communities.	Malawi
NGO4	Providing sustainable systems to end hunger through bottom-up approaches, HIV and AIDS (and related issues) and empowering women.	International, Malawi
NGO5	Human rights, poverty, responding to natural emergencies and political conflict, assisting poor people to obtain necessary resources and helping them to maintain human dignity and autonomy.	International, Malawi
NGO6	Families, women (primarily mothers) regarding family issues and promotes Christian values.	Malawi
NGO7	Orphan education, training and microloans to provide economic empowerment for women.	Malawi
NGO8	Muslim faith-based organization that assists families with social concerns.	International, Malawi
CBO1	Orphan care with an emphasis on child development and nutrition.	Malawi
CBO2	Family-centered orphan care for approximately 16 orphans	Malawi
CBO3	Women's empowerment. Widows and other women are taught how to generate income from produce or sewing projects.	Malawi

Table 7.3: Malawi Women: GenderRoles, the Way Women Work and How One NGO Supported Malawi women

1. Gender Dynamics are influenced by:
    - Culture
        - Women's roles are traditionally subordinate to men
        - Women are expected to work and serve
    - Caregiving Roles
        - Women influence children and orphans through their care
        - Through care for individuals who are sick and dying, women decrease stigma surrounding HIV and AIDS
    - Economic Factors (poverty v. earning money)
        - Education provides women with more economic opportunities
        - Earning even a little money altered women's power within their families and communities
2. NGO1 assisted women gain power in families and communities because it
    - Followed cultural norms to gain trust of village chiefs and thereby the community
    - Provided education and economic support in the form of training and stipends for community caregivers and future nurses
    - Provided support for orphans (blankets, clothing, soap, school supplies)
    - Provided funds for secondary education for orphans
    - Supported the public health infrastructure of Malawi by working with District Health Commissioners and by requiring that nurses who receive funding for training remain in Malawi 3-4 years and work at specified community clinics

CHAPTER EIGHT:

DISCUSSION

Introduction

In this final chapter, I will begin with the role of community health nurses in working with populations to improve community health. This will be followed by a discussion of community-based participatory research (CBPR), non-governmental organizations (NGOs) and the Malawian context with a critique and proposed solution for reporting CBPR studies. Next will be a discussion of CBPR in Malawi and analysis of the perspectives of US staff from one NGO (NGO1). NGO1 provided entrée to participants who work with other NGOs and community-based organizations (CBOs) in Malawi and US NGO1 staff helped me reframe my questions for Malawian participants. Based on study analysis, I developed a conceptual model (see Figure 4) as a synthesis of the study and following an outline of this model will be a discussion of three main findings in the study with concluding remarks about bottom-up approaches in addressing Malawian community health.

Community Health Nursing Roles

As a community health nurse I value a strength-based approach to communities (Minkler, 2006) rather than a deficit-based approach. My goal was to ask participants from non-governmental organizations and community-based organizations (CBOs) to share their perspectives regarding their work and to determine whether participants might find CBPR useful in improving Malawian community health.

Of the 26 study participants, three were nurses, two Malawians and one American. These nurses were all NGO1 staff, held leadership roles and their nursing

perspectives helped shape the activities of NGO1. Each one of these nurse participants demonstrated advocacy and collaboration in their day-to-day work. These nurses valued research and the application of scientific knowledge to better Malawi communities but also recognized that community members have knowledge and resources. Non-governmental organizations are often the connection between communities and donors and the three nurses functioned on a smaller scale in a similar way to NGOs. The nurses provided a public health perspective for their NGO colleagues and donors and worked collaboratively with diverse groups to advocate for Malawi communities.

Community health nurses focus on populations rather than individual clients (Clark 2008). Clark identifies several roles of the community health nurse: advocate, caregiver, educator, counselor, role model, case manager, coordinator, collaborator, liaison, case finder, leader, change agent, coalition builder, policy advocate, social marketer and researcher. Each of these roles fits well with the principles and activities of community-based participatory research (CBPR). (See Table 3.1 in Chapter 3 for an outline of CBPR principles).

CBPR, NGOs and the Malawi Context

Community-based participatory research is an egalitarian approach to research that involves all partners in each aspect of the research process from determining relevant research questions to dissemination of results at the completion of a study. Principles of CBPR (Table 3.1) guide CBPR processes and Hughes Halbert, Weathers and Delmoor (2006) state that while relationships are the most challenging aspect of CBPR, they are the most important. Respect between CBPR partners will ultimately be demonstrated by their interactions with community members.

Community-based participatory research is a bottom-up approach to research that requires a foundation of good partner relationships. These relationships take time and obtaining consensus among diverse members can be challenging and even frustrating. A linear research process is simpler than CBPR; however, study participants emphasized that long-term results will not occur in Malawi unless there is community buy-in and this necessitates relationship building.

Only two true CBPR studies in Africa were found in a review of current literature (Mosavel, Simon, van Stade & Buchbinder, 2005; Lund & Taylor, 2008). Mosavel and colleagues' study was titled "Community-based participatory research (CBPR) in South Africa: Engaging multiple constituents to shape the research question" and Lund and Taylor's study was "Lack of adequate sun protection for children with oculocutaneous albinism in South Africa". Despite the advantages of CBPR, little CBPR activity is currently underway in Malawi, sub-Saharan Central Africa. No CBPR studies in Malawi were found in a review of literature. However, some Malawi participants in this study stated that they were aware of CBPR studies that were being conducted in Blantyre, Malawi.

Community-based participatory research is not to be confused with community-based research which refers to research that is conducted *in* communities. Community-based participatory research is done *with* communities and is based on a relationship of partners who determine the salient research questions and methods necessary to achieve mutual goals for communities. In CBPR, attributes that each partner brings to the process are valued. Through the process of working together partners learn from each other and community members gain knowledge and tools necessary for effective research that

produces sustainable results. Community-based participatory research is a process and the purpose is not to achieve specific outcomes or results alone, rather the process itself is valued as contributing toward the betterment of the partners and the communities they serve.

Despite the emphasis in CBPR upon equal voices, little was heard from NGO staff perspectives in a review of literature. Non-governmental organizations are often the critical connection between donors and communities and as such I wondered why the NGO voice was lacking in international CBPR studies and the non-profit voice was lacking in US CBPR studies. The larger question, however, is why are there so few CBPR studies in the developing world?

Critique of CBPR Literature: 3 Issues

Reporting of CBPR studies in journals is inconsistent and there are three main issues: 1) CBPR processes are often intermingled with research results/findings making it difficult to evaluate the overall process of a CBPR based on CBPR principles; 2) Research outcomes and results/findings are often obscured in long discussions about processes and partnerships in CBPR journal articles, making it difficult to evaluate the practical success or application of the study; and 3) few CBPR journal articles articulate how research results/findings were disseminated to the wider community despite the emphasis in CBPR on sharing knowledge generated by CBPR to the wider community in order to demonstrate community relevance such as changes in policies.

Some studies stress the CBPR processes while others focus on the research design and outcomes. This causes confusion for readers as there is not a clear method to evaluate the success of the CBPR process utilized by partners in a study, nor is there a

clear way to evaluate the particular research design and methodology employed by CBPR partners. Moreover, the primary purpose of CBPR is to serve the community, not academic partners. Dissemination of research results is reported in peer-reviewed journals using academic language and journal articles do not consistently report other methods of dissemination of CBPR findings that might be more appropriate for communities, such as town hall meetings, policy changes, dramatic presentations, newspaper, radio or television coverage, public art displays and so forth.

My proposed solution to address the inconsistencies in CBPR studies is to use three tools that I developed: 1) a tool to evaluate CBPR processes; 2) a tool to evaluate research methodology and results or findings; and 3) a tool for reporting dissemination of research results/findings to the wider community (See Chapter 2 Tables 2.1, 2.2, & 2.3). The tools can be adapted as needed by the partners. Clearly demarcating the process of a CBPR partnership from the chosen research design and interventions is vital. A good partnership might not produce good research and conversely, good research might not reflect good partnerships that are sustainable after studies are completed. Reporting how results were disseminated to the wider community in CBPR journal articles has been sketchy at best.

As communities are the focus of CBPR, how research results/findings, or the knowledge generated by the research is disseminated to the wider community is a critical topic that deserves space in journal articles. I developed a tool to produce the information in table format; however, this could be modified per author preferences. The important point of the three tools is to provide readers with clarity regarding the success

of the CBPR process, the actual outcomes, results or findings of a CBPR study and how this information was disseminated to the wider community.

CBPR and Malawi

Communities possess their own knowledge but can also benefit from knowledge derived from scientific research. However, as power imbalances between researchers and communities can arise, CBPR addresses these challenges through an egalitarian approach to research that involves community members in every aspect of the research process, from identification of research questions to dissemination of results. Community-based participatory research is not a panacea for power imbalances; rather, in CBPR issues of power are to be addressed and process is valued as well as outcomes. CBPR begins with building relationships that contribute to long-term sustainable results (Navarro, Voetsch, Liburd, Giles & Collins, 2007).

Malawi is one of the poorest countries in the world, has suffered from abuses of colonialism (Englund, 2006; Shivji, 2007) and with an average life expectancy of 48 years (UNICEF, 2007) due to AIDS and other diseases, Malawi seems well-suited to activities of CBPR to create sustainable health changes in both urban and rural communities. Nevertheless, as a white, western outsider, my belief that CBPR would be useful in Malawi required substantiation from individuals who work on the ground with communities.

Analysis of NGO1 Perspectives

Non-governmental organizations are often the link between researchers or donors and communities. The first phase of this research study involved an NGO based in the US that primarily works in Malawi to mitigate HIV and AIDS related conditions

(NGO1). My interest was in CBPR, but NGO1 was resistant to research despite an abundance of PhD-prepared staff and members of the Board of Trustees. The crisis situation in Malawi necessitated that funds be readily available to mitigate suffering as efficiently as possible. It was as though the NGO staff and Board of Trustees viewed research as an unjustifiable extravagance.

As I learned how this particular NGO approached Malawian communities, I came to the realization that NGO1 followed all of the principles of CBPR, but stopped short of actual participation in research. I wondered if research studies on the NGO's programs and services would strengthen justification for NGO1's approach to working with Malawian communities that would generate additional funding for its work. Moreover, I wanted to hear NGO1's Malawi staff perspectives as well as perspectives from other Malawian NGO and community-based organization (CBO) staff.

Conceptual Model: Bottom-Up Approaches to Community Health in Malawi

The conceptual model for this study is based on a synthesis of study participant perspectives and current related literature (depicted in Figure 4). When one Malawi nurse participant was asked what she would like to do regarding her work with an NGO in Malawi, although she had never heard of CBPR, her response echoed the principles of CBPR: \ Malawians want to direct research studies in their communities and Malawians rather than outsiders want to evaluate the interventions so that they will have the knowledge about what works best in their communities. This nurse said that Malawians would need to be trained in evaluation methods by outside experts with the goal that Malawians would be able to conduct evaluations using scientific research methodology independently. The views expressed by this Malawi nurse reflect empowerment

strategies that are supported by Israel, Schulz, Parker, Becker, Allen and Guzman (2003), Minkler, (2006), Wallerstein (2006) and Walter (2006).

In working with Malawian communities, NGO1 followed the principles of CBPR by respecting cultural protocols and asking community leaders what was most important to address in their communities. NGO1 did not go in with a "cure", but listened, provided tangible resources to address immediate needs, worked with community members as partners and trained community caregivers in peer education. In this way, NGO1's work is community owned and not just superimposed upon the community for the life cycle of project-specific funding. Malawians are at the top of the model and in the role of directors of CBPR processes.

Ecosocial Theory

Ecosocial theory with its dual emphasis on scientific knowledge and social justice underpins the conceptual model for this study. Ecosocial theory provides a starting point for deconstruction of knowledge based on perpetuating power imbalances and the examination of ways in which social, political and environmental factors shape health and disease in communities. Study participants valued scientific knowledge, but also emphasized that communities have valuable knowledge that needs to be recognized by donors and NGOs that work in Malawi. Moreover, randomized controlled trials (RCTs), behavior change models, and other science-based research interventions cannot be superimposed upon Malawi communities and produce long-term sustainable outcomes unless the people are behind it.

Study participants emphasized that Malawian communities might cooperate with NGOs in projects in order to obtain incentives, but unless there was trust between a

Malawian community and an NGO, the project would not be sustainable. Malawians know what works in their communities and are wary of outsiders who come to conduct research or activities in Malawi without obtaining community collaboration. Donors have much power due to their financial leverage and this can create barriers even for the most well-intentioned donors. Participants warned that donors need to look at "what is beneath the numbers" when using outcome-based measurement criteria to evaluate program success. Ecosocial theory can promote rigorous scientific methods of evaluation to address social, political, economic and environmental constructs that influence community health. Ecosocial theory provides a framework that uses scientific methodology while attending to issues of social justice.

Ecosocial theory has a clear organizational framework that encompasses the dynamic processes and multiplicity of factors affecting health. Unlike the linear nature of (RCTs), community health research necessitates attention to processes and constantly changing variables. Study participants were clear that relationships of trust between NGOs and communities are necessary to achieve long-term sustainable results in Malawi. Gaining community trust is a process that cannot be reduced to a formulaic study intervention. Community-based participatory research is a process that is based on relationships and as such it requires a theoretical framework that allows for evolution and growth. Ecosocial theory provides this flexibility in combination with a basis in rigorous scientific method.

Assumptions regarding race, class, gender, age and their intersectionality are addressed in CBPR and other bottom-up approaches to community health and social justice issues. Study participants emphasized that although Malawi women are socially

disempowered, they can effect change in their communities. When NGOs assist Malawi women to gain economic power (through paying stipends, providing micro loans or education for nurse training), they are also benefiting these women's health. Ecosocial theory provides a framework for examining effects of multiple interventions on community health.

Epistemological claims of dominant social classes are subjected to rigorous examination. Community knowledge is valued in CBPR and can be used as an impetus to change unjust policies and practices that promote health disparities. In ecosocial theory, scientific explanations for health disparities are challenged using scientific methods combined with the lens of social justice perspectives. Ecosocial theory grounded in scientific knowledge and social justice underpins the conceptual model (Figure 4).

Advocates and Organizations

Community health nurses, healthcare providers and other advocates work in various capacities with a variety of organizations, including academic institutions, NGOs, CBOs, charitable foundations, government agencies, religious organizations and more to promote Malawian community health. In order to provide equitable healthcare, continuity of care and sustainable changes, the infrastructure of the Malawi Ministry of Health (public health system) must be supported rather than undermined by independent NGOs or other organizations. All organizations working to improve community health in Malawi can best do so when supporting the public health infrastructures of Malawi, the Ministry of Health, rather than promoting individual organizational agendas. For this

reason, the advocates and organizations working in Malawi are placed under the Malawi Public Health System in the conceptual model.

CBPR Processes

Using CBPR that is directed by Malawian community members, interventions can be implemented, adapted and evaluated to determine the benefits for Malawian communities. Results of CBPR activities are disseminated via public ethnography in the form of peer-reviewed articles, dramatic presentations, community meetings, media reports and more. The entire model is focused on the individuals in Malawian communities.

Understanding what works and what does not can be informed by CBPR processes which provide a framework for exploring effective interventions and evaluation of activities to improve community health. Community-based participatory research is an egalitarian approach to research that is based on relationships between partners that emphasizes the strengths and resources of communities.

Malawi: Children, Women and Men

The focus of the research is the Malawians themselves, children, women and men and their collective communities. The conceptual model depicted in Figure 4 represents a goal for an equitable process of conducting research and implementing projects and programs in Malawi. CBPR principles were supported by study participants who said, “unless the community is behind it [research, project or activity], it won’t last”, “the people have knowledge”, “Malawians are very resourceful…they just don’t have money” and that Malawians should be able to conduct their own program evaluations. In the

CBPR section of the model, Malawians determine salient research questions and participate in each stage of research processes for the benefit of their communities.

Public Ethnography

A complaint that was voiced by participants was that much research is being done in Malawi, but often the community never sees the results or benefits from the knowledge that Malawians help to generate. Public ethnography is a method for dissemination of research results or findings to local and wider communities. Public ethnography differs from traditional ethnographies which attempt to provide a comprehensive description of a culture in that the purpose of public ethnography is to engage the wider community in a dialogue and promote social justice. Public ethnography is depicted as the last step of the conceptual model's bottom-up approach to community health in Malawi.

Study Findings

There were three main themes identified through study analysis: 1) barriers and facilitators to community trust; 2) donor power; and 3) gender roles –how socially disempowered Malawi women are the ones who can affect change in their communities. A discussion of each of these themes follows.

Barriers and Facilitators to Community Trust

> Because if you only reach out to those who are able to make it, then you cannot know why some people still remain underprivileged. So through training and advocacy programs, process of consciousness and awareness raising, especially on issues of the right to a decent living, right to food and food security, the right to development, [NGO2 stresses that] each person, regardless of whether she is a

> woman or man, has [this] right [and this strategy] has helped us to work with the most underprivileged (NGO2 Malawi Staff, male). (See Chapter 4, Table 4.3 for a description of all NGOs in the study).

Trust is defined in this study as believing that a person or organization will support words with actions. Trust increases through the sharing of common goals and an ongoing commitment between individuals and organizations. Action supports trust and as members interact with each other and build relationships this creates a flexible framework for creative responses to community health challenges.

Barriers and facilitators to community trust were identified by participants and included respect for cultural norms, listening to community members and asking them about their priorities and involving community members in any project or research activity if sustainability is a goal. In Malawi, culture, religion and gender roles were identified as potentially challenging areas for western NGOs. NGO1 hired Malawi staff to help navigate cultural, religious and gender protocols and involved local community members in its activities to help foster community involvement.

Study participants identified three barriers to community trust that NGOs can address internally in their organizations: 1) NGO arrogance in not recognizing community knowledge; 2) not involving community members in NGO activities; and 3) not sharing knowledge gained from activities or research with the communities in which the NGO works (i.e., when the NGO's work benefits outsiders rather than Malawian communities).

The discussion on trust between NGOs and Malawian communities in this study has primarily been in broader, organizational terms. It is important to note that the

process of gaining community trust is built on individual dyads between an NGO staff member and a community member. As the number of positive relationships between staff and community members increases, trust is attributed to the organization itself. In other words, positive relationships between one staff/community member dyad reflect positively on the broader organizational level. Conversely, negative dyad relationships reflect poorly on the broader relationship between an NGO and a community.

There is no formulaic method for gaining community trust. Although participants have outlined major facilitators and barriers to trust, ultimately, relationships of trust with community members evolve when NGOs are respectful, do what they say they will do, and involve community members fully in all processes.

Participants echoed the principles of CBPR in their discussions about trust. By respecting cultural norms, NGOs acknowledge the cohesiveness of the community. Listening to the community's priorities, engaging the community in activities and sharing information with the community an NGO help build trust. Doing what is promised substantiates words with actions.

Donor Power

My original questions were concerned with academic partner/NGO issues. Study participants addressed my questions; however, participants for the most part had resolved their challenges with academic partners. Of greater concern to study participants was the issue of donor power. Bottom-up approaches were advocated when discussing both community trust and donor power. NGO staff advocated for community members' priorities and empowerment strategies.

One participant said that donors often want to serve communities, but need more information so that they can be more effective. Communication between NGOs and donors is of vital importance. As Malawi NGO staff often have extended family members living in the rural villages that the NGO serves (James, 2008), they can function as interpreters and community advocates when speaking with donors or their representatives.

Participants cautioned that donors should be wary of numbers as a program's value cannot be defined by the number of participants served alone. One participant said that donors need to understand what is "beneath the numbers" and said that social worker time was needed to work with families and community agencies in reintegrating a child back into his or her home in a sustainable way. Although spending less time on each child would yield a greater number served, the child might return to the street again and possibly even be "recounted" in the numbers served.

Staff from NGO1 had two different voices: when speaking with donors, there was almost a bravado tone as staff described their accomplishments and when staff spoke about Malawians and their work on the ground in Malawi, their tone was quiet and respectful. As donors learn more about what Malawian communities want, perhaps the bravado tone will not be necessary.

Community consensus was identified as critical to long-term sustainability; however, because conditions of poverty are so extreme in Malawi, some participants advised that food security and basic human needs be met before initiating other activities or research. Participants reiterated again and again, that it is important to ask community members about their concerns and priorities and to listen to what they way. When donors

support bottom-up approaches to communities, they function as benefactors rather than bullies.

Gender Roles: How Socially Disempowered Malawi Women Effect Community Change

Participants were in agreement that Malawi women are in general socially disempowered, meaning that they have less economic power, less of a voice in their homes and communities and have fewer educational opportunities than their male counterparts. Participants identified culture, lack of educational and economic opportunities as the main contributors to women's social disempowerment.

Nevertheless, women are affecting changes in gender roles as they care for children, orphans and individuals suffering from HIV and AIDS. Participants stated that as women gain economic power, their risk for HIV and AIDS decreases as they do not engage in sexual activities to obtain money for food, clothing or their basic subsistence needs. Several participants stated that poverty was the greatest risk for a woman contracting HIV.

Supporting women in income generating activities (IGAs) and providing training and education so that women can work in public or private sectors are two ways that help mitigate gender injustice in Malawi. Kim, Watts, Hargreaves, Ndhlovu, Phetla, Morison and colleague's study on "Understanding the impact of microfinance-based intervention on women's empowerment and reduction of intimate partner violence in South Africa" (2007) found that domestic violence was reduced by more than fifty percent when IGAs and training were provided for women in South Africa.

Based on both interview data and observations, women in Malawi generally use consensus building methods to affect change rather than confrontational approaches.

Non governmental organizations that wish to support Malawi women need to observe cultural protocol so that women are not placed at higher risk for physical or emotional violence.

Both male and female participants expressed the need to empower Malawi women. Cultural beliefs are ingrained and despite great intentions, it is easy to slip back into male dominated roles. Just as participants said that it is easy for NGOs or donors to slip back into top-down roles, the same is true with gender power dynamics.

Study Limitations

This study reflects the views of 26 participants and is not representative of all Malawian staff of NGOs and CBOs. Study participants had a high level of education that was not reflective of the general population of Malawi.

Further Research

Although NGO and CBO staff voices are mostly silent in current literature, the voices of Malawians who live in rural villages are rarely heard. Further studies are needed to examine community member and other NGO staff perspectives to determine if these corroborate with this study's findings. Additionally, studies on Malawi-directed initiatives are needed and CBPR is an approach that emphasizes that all partner voices are heard.

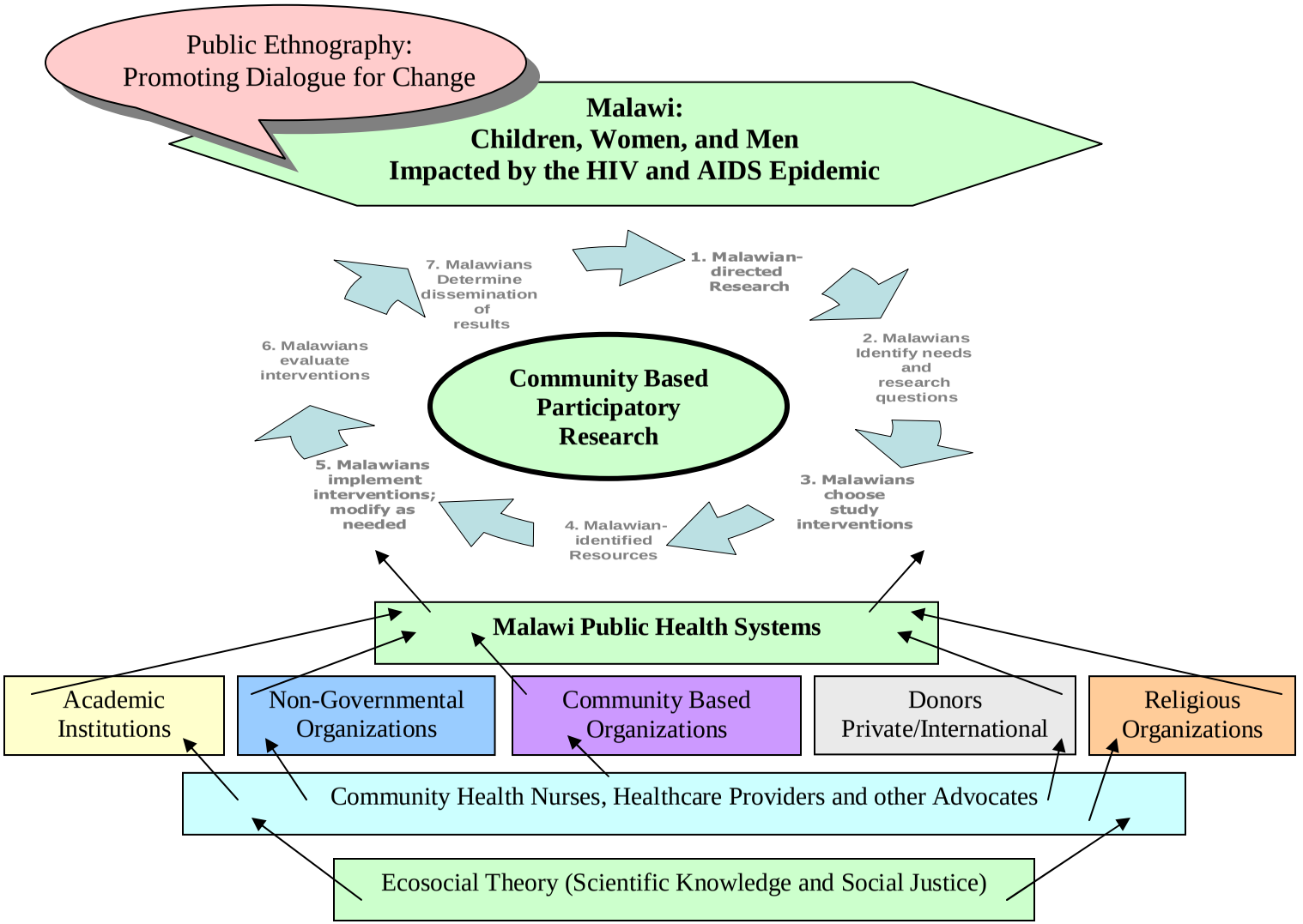
Conclusion

Throughout each of the three themes of trust, donor issues and gender roles, study participants were in agreement regarding the need for a bottom-up approach in Malawi. To gain community trust, NGOs must start with the community and listen to its priorities, recognize community knowledge and involve community members in NGO activities.

Donors need to listen to NGO staff and community member-identified priorities and not use their financial power to dominate NGOs or communities. Malawi women are effecting change, have the ability to help redress the ravages wrought by HIV and AIDS and their voices must be heard. Each of the women in the study had very clear ideas regarding what was needed in Malawi and how to accomplish it. A bottom-up approach was advocated by each study participant.

Principles of CBPR reflect a bottom-up approach that promotes social justice for communities. As a community health nurse, my hope is that the voices of this small group of participants will be heard and that their efforts to promote community health in Malawi will be strengthened through research grounded in both scientific rigor and social justice.

Figure 4: Conceptual Model of a Bottom-Up Approach to Community Health in Malawi



References

Ammerman, A., Corbie-Smith, G., St. George, D. M., Washington, C., Weathers, B., & Jackson-Christian, B. (2003). Research expectations among African American church leaders in the PRAISE! Project: A randomized trial guided by community-based participatory research. *Journal of Public Health, 93*, 1720-1727.

Ammerman, A., Washington, C., Jackson, B., Weather, B., Campbell, M., & Davis, G. (2002). The PRAISE! Project: A church-based nutrition intervention designed for cultural appropriateness, sustainability, and diffusion. *Health Promotion Practice, 3*, 286-301.

Anderko, L., Lundeen, S., & Bartz, C. (2006). The Midwest nursing centers consortium research network: Translating research into practice. *Policy, Politics, & Nursing Practice, 7*(2), 101-109.

Anderson, E. (2004). Urban ethnography. In C. Ragin, J. Nagel, & P. White (Eds.), *Workshop on Scientific Foundations of Qualitative Research*. Sociology Program, NSF.

Andrews, J. O., Bentley, G., Crawford, S., Pretlow, L., & Tingen, M. S. (2007). Using community-based participatory research to develop a culturally sensitive smoking cessation intervention with public housing neighborhoods. *Ethnicity & Disease 17*, 331-337.

Angrosino, M. V. (2005). Recontextualizing observation: Ethnography, pedagogy, and the prospects for a progressive political agenda. In N. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (3rd ed., pp. 729-745). Thousand Oaks, CA: Sage.

Atlas.ti Software for qualitative data analysis, management and model building. http://www.atlasti.com/.

Bailey, C. A. (2008). *Public Ethnography*. In S. N. Hesse-Biber & P. Leavy, (Eds.), *Handbook of emergent methods,* (pp 265-282). New York: Guilford Press.

BBC News (2006). Diary of a journey back. Retrieved online May 25, 2009 from http://news.bbc.co.uk/2/hi/health/4884868.stm

Beauchamp, T. L. & Childress, J. F. (2001, 5). *Principles of biomedical ethics*. Oxford, England: Oxford University Press.

Bishop, R. (2005). Freeing ourselves from neo-colonial domination in research: A Kaupapa Maori Approach to creating knowledge. In N. Denzin & Y. S. Lincoln, *Handbook of qualitative research* (3rd ed., pp 109-138). Thousand Oaks, CA: Sage.

Bloom, B. R. (2005). Foreword in *Health disparities and the body politic: A series of International symposia*, p. 1-3. Boston, Massachusetts: Harvard School of Public Health.

Caldwell, C. H., Wright, J. C., Zimmerman, M. A., Walsemann, K. M., Williams, D., & Isichei, P. A. C. (2004). Enhancing adolescent health behaviors through strengthening non-resident father-son relationships: A model for intervention with African-American families. *Health Education Research, 19*, 644-656.

California Progress Report (2008). *California's nurse-patient ratio and law saving lives, reducing the nursing shortage.* Retrieved January 12, 2009 from http://www.californiaprogressreport.com/2008/01/californias_nur.html

Campbell, M. L. (1998). Institutional ethnography and experience as data. *Qualitative Sociology, 21*(1), 55-73.

Campbell, R., Sefl, T., Wasco, S. M., & Ahrens, C. E. (2004). Doing community research without a community: Creating safe space for rape survivors. *American Journal of Community Psychology, 33*, 253-261.

Carlson, B. A., Neal, D., Magwood, G., Jenkins, C., King, M. G., & Hossler, C. L. (2006). Community-based participatory health information needs assessment to help eliminate diabetes information disparities. *Health Promotion Practice, 7*, 213s-222s.

Castleden, H., Garvin, T., & Huu-ay-aht First Nation. (2008). Modifying Photovoice for community-based participatory Indigenous research. *Social Science & Medicine*, 66, 1393-1405.

CBS News. (2007). Country Fast Facts: Malawi. Retrieved August 18, 2009 from http://www.cbsnews.com/stories/2007/10/10/country_facts/main3352066.shtml and http://www.cbsnews.com/stories/2007/10/10/country_facts/main3352066.shtml

Charity Navigator (2007). Giving USA 2007, the annual report on philanthropy. *AAFRC Trust for Philanthropy.* Retrieved February 2, 2009, from http://www.charitynavigator.org/index.cfm?bay=conten.view&cpid=42

Charmaz, K. (2004). Premises, principles, and practices in qualitative research: Revisiting the foundations. *Qualitative Health Research, 14*, 976-993.

Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. Thousand Oaks, CA: Sage

Cheek, J. (2000). The work of Michel Foucault. In J. Cheek (Ed.), *Postmodern and post structural approaches to nursing research* (pp. 22-32). Thousand Oaks, Ca; Sage.

Chirwa, E. W. (2008). Effects of gender on the performance of micro and small enterprises in Malawi. *Development Southern Africa, 25*, 347-362.

Cho, J. & Trent, A. (2006). Validity in qualitative research revisited. *Qualitative Research, 6,* 319-340.

Clark, A. (2005). *Situational analysis: Grounded Theory after the postmodern turn.* Thousand Oaks, CA: Sage.

Clark, M. J. (2008) *Community health nursing: Advocacy for population health,* 5th ed.: Upper Saddle River, NJ: Pearson Education.

Coe, K., Wilson, C., Eisenberg, M., Attakai, A., & Lobell, M. (2006). Creating the environment for a successful community partnership. *American Cancer Society,* Retrieved November 8, 2006 from http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=pubmed&dopt=Abstract&list_uids=16929483

Cook, W. K. (2007). Integrating research and action: A systematic review of community-based participatory research to address health disparities in environmental and occupational health in the USA. Retrieved February 8, 2009 from Community Campus Partnership for Health. http://depts.washington.edu/ccph/index.html)

Coombe, C. (2006). Participatory evaluation: Building a community while assessing change. In M. Minkler (Ed.) *Community Organizing and Community Building for Health,* 2nd ed. (pp. 368-385). Rutgers: New Jersey.

Corbie-Smith, G., Ammerman, A. S., Katz, M. L., St. George, D. M. M., Blumenthal, C., Washington, C et al. (2003). Trust, benefit, satisfaction and burden: A randomized controlled trial to reduce cancer risk through African-American churches. *Journal of General Internal Medicine, 18,* 531-541.

Cresswell, J. W. (2007). *Qualitative inquiry & research design: Choosing among five approaches,* (2nd ed.). Thousand Oaks, CA: Sage.

Denzin, N. K. (2005). Emancipatory Discourses. In N. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (3rd ed., pp. 933-958). Thousand Oaks, CA: Sage.

Denzin, N. K., & Lincoln, Y. S. (2005). Introduction: The discipline and practice of qualitative research. In N. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (3rd ed., pp. 1-32). Thousand Oaks, CA: Sage.

Dill, B. T., McLaughlin, A. E., & Nieves, A. D. (2007). Future directions of feminist research. Intersectionality. In S. N. Hesse-Biber (Ed.), *Handbook of feminist research: Theory & praxis* (pp. 629-636). Thousand Oaks, CA: Sage.

Drexler, M. (2005). Investigating health disparities: New agendas for National Health Research Institutes in M. Drexler, *Health disparities and the body politic: A series of international symposia,* (pp. 24-40). Boston, MA: Harvard School of Public Health.

Edgren, K. K., Parker, E. A., Israel, B. A., Lewis, T. C., Salinas, M. A., Robins, T. G., et al. (2005). Community involvement in the conduct of a health education intervention and research project: Community action against asthma. *Health Promotion Practice, 6*, 263-269.

Emerson, R. M. (Ed.). (2001). The face of contemporary ethnography. In R. M. Emerson, *Contemporary field research: Perspectives and formulations* (pp. 27-53). Prospect Heights, IL: Waveland Press.

Emerson, R. W. (American Poet, Lecturer and Essayist, 1803-1882). Retrieved February 4, 2009 from http://thinkexist.com/quotation/there-is-no-limit-to-what-can-be-accomplished-if/406865.html

Englund, H. (2006). *Prisoners of freedom: Human rights and the African poor*. Berkeley, CA: University of California Press.

European Urban Knowledge Network. (2005). Retrieved June 12, 2008 from http://www.eukn.org/eukn/themes/Urban_Policy/Luxembourg-Urban-Policy_1337.html

Farmer, P. (2005). *Pathologies of power: Health, human rights, and the new war on the poor*. Berkeley, CA: University of California Press.

Fawole, O. I. (2008). Economic violence to women and girls: Is it receiving the necessary attention? *Trauma, Violence and Abuse. 9*, 167-177.

Feuerherd, J. (2006). Donor savvy in changing charitable marketplace. *National Catholic Reporter*. Retrieved February 7, 2009 from http://findarticles.com/p/articles/mi_m1141/is_19_42/ai_n26693879

Fine, G. A. (1993). Ten lies of ethnography: Moral dilemmas of field research. *Journal of Contemporary Ethnography, 22*, 267-294.

Fine, M. (1994). Working the hyphens: Reinventing self and other in qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.) *Handbook of qualitative research* (pp. 70-82). Thousand Oaks, CA: Sage.

Gellert, G. A. (1996). Non-governmental organizations in international health: past successes, future challenges. *International Journal Health of Planning and Management, 11*(1), 19-31.

Gibson, R. S., Yeudall, F., Drost, N, Mtitimuni, B., & Cullinan, T. (1998). Dietary interventions to prevent zinc deficiency. *The American Journal of Clinical Nutrition, 6a8* (suppl), 484S-487S.

Global Health Reporting. (2005). Retrieved December 5, 2007 from http://www.globalhealthreporting.org/countries/malawi.asp?collID=11&id=1249&malID=1251&tbID=1250&hivIC=1246&malIC=1247&tbIC=1248&map=1253&con=Malawi&p=1

Global Health Report (2008). Documenting the brain drain in Malawi. Retrieved online May 25, 2009 from http://globalhealthreport.blogspot.com/2008/06/documenting-brain-drain-in-malawi.html

Global Health Reporting (2008). UNAIDS 2008 Report on the global AIDS epidemic. Retrieved online April 17, 2009 from http://www.globalhealthreporting.org/countries/malawi.asp?collID=11&id=1249&malID=1251&tbID=1250&hivIC=1246&malIC=1247&tbIC=1248&map=1253&con=Malawi&p=1

Guba, E. G. & Lincoln, Y. S. (2005). Paradigmatic controversies, contradictions and emerging confluences. In N. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (3rd ed., pp. 191-215). Thousand Oaks, CA: Sage.

Hammersley, M., & Atkinson, P. (1995). *Ethnography: Principles in practice* (2nd ed.). London: Rutledge.

Harvard School of Public Health (2009). Nancy Krieger. Retrieved May 6, 2009 from http://www.hsph.harvard.edu/faculty/nancy-krieger/

The Health Foundation (2007). Reducing maternal death rates in Malawi. Retrieved online October 13, 2008 from http://www.health.org.uk/current_work/case_studies/reducing_maternal.html

Hellsten, S. K. (2001). From human wrongs to universal rights: Communication and feminist challenges for the promotion of women's health in the Third World. *Developing World Bioethics. 1(2),* 98-115).

Holloway, I. & Wheeler, S. (2002). *Qualitative research in nursing* (2nd ed.). Oxford, United Kingdom: Blackwell Science Ltd.

Holz, C. & Gibson, R. S. (2005) Participatory nutrition education and adoption of new feeding practices are associated with improved adequacy of complementary diets among rural Malawian children: A pilot study. *European Journal of Clinical Nutrition. 59,* 226-237.

Horsburgh, D. (2003). Evaluation of qualitative research. *Journal of Clinical Nursing, 12,* 307-312.

Hughes Halbert, C. H., Weathers, B., & Delmoor, E. (2006). Developing an academic-community partnership for research in prostate cancer. *Journal of Cancer Education, 21*(2), 99-103.

Human Development Report. (2008). Malawi: The human development Index -going beyond income. Retrieved August 10, 2009 from http://hdrstats.undp.org/en/2008/countries/country_fact_sheets/cty_fs_MWI.html

Index Mundi (2008). Malawi demographics profile. Retrieved August 10, 2009 from http://indexmundi.com/malawi/demographics_profile.html and http://indexmundi.com/malawi/economy_overview.html

Internal Revenue Service. (2008). Retrieved April 18, 2009 from http://www.irs.gov/charities/charitable/article/0,,id=136459,00.html

IRIN. (2007). Malawi: Donors and govt pool funds against brain drain. *UN integrated Regional Information Network, May 28, 2007.* Retrieved March 10, 2009, from http://www.irinnews.org/PrintReport.aspx?ReportId=72414

Israel, A. B., Parker, E. A., Rowe, Z, Salvatore, A., Minkler, M., Lopez, J., et al. (2005). Community-based participatory research: Lessons learned from the Center's for Children's Environmental Health and Disease Research. *Environmental Health Perspectives, 113,* 1463-1471.

Israel, B. A., Eng, E., Schulz, A. J. & Parker, E. A. (2005). Introduction to methods in community-based participatory research for health. In B. A. Israel, E. Eng, A. J. Schulz & E. A. Parker (Eds.), *Methods in community-based participatory research for health.* (pp. 3-26). San Francisco: John Wiley & Sons.

Israel, B. A., Schulz, A. J., Parker, E. A., Becker, A. B., Allen, A. B. & Guzman, J. R. (2003). Critical issues in developing and following community-based participatory research principles. In M. Minkler and N. Wallerstein (Eds.), *Community-based participatory research for health,* (pp. 53-76). San Francisco: Jossey-Bass.

James, R. (2008). Leadership development inside-out in Africa. *Nonprofit Management and Leadership. 18,* 359-375.

Johns Hopkins Bloomberg School of Public Health. Epidemiology. Retrieved May 26, 2009 from http://www.jhsph.edu/dept/EPI/

Kelly, J. A., Somlai, A. M., Benotsch, E. G., Amirkhanian, Y. A., Fernandez, M. I., Stevenson, et al. (2006). Programmes, resources, and needs of HIV-prevention nongovernmental organizations (NGOs) in Africa, Central/Eastern Europe and Central Asia, Latin America and the Caribbean. *AIDS Care, 18(1),* 12-21.

Kim, J. C., Watts, C. H., Hargreaves, J. R., Ndhlovu, L. X., Phetla, G. & Morison, L. A. et al. (2007). Understanding the impact of microfinance-based intervention on women's empowerment and reduction of intimate partner violence in South Africa. *American Journal of Public Health, 97, 1794-1802.*

Kjellstrom, T., & Mercado, S. (2008). Towards action on social determinants for health equity in urban settings. *Environment & Urbanization, 20,* 551-574.

Knipper, E., Rhodes, S. D., Lindstrom, K., Bloom, F. R., Leichliter, S. L., & Montano, J. (2007). Condom use among heterosexual immigrant Latino men in the Southeastern United States. *AIDS Education and Prevention, 19,* 436-447.

Krieger, J, Allen, C., Cheadle, A, Schier, J. K., Senturia, K., & Sullivan, M. (2002). Using community-based participatory research to address social determinants of health: Lessons learned from Seattle Partners for Healthy Communities. *Health Education & Behavior, 29,* 361-382.

Krieger, N. (1994). Epidemiology and the web of causation: Has anyone seen the spider? *Social Science Medicine, 39,* 887-903.

Krieger, N. (2000). Discrimination and health. In Lisa F. Berkman & Ichiro Kawachi (Eds.) *Social Epidemiology.* New York: Oxford University Press.

Krieger, N. (2001). Theories for social epidemiology in the 21st century: An ecosocial perspective. *International Journal of Epidemiology, 30,* 668-677.

Krieger, N. (2005). *Introduction in Health Disparities & the Body Politic: A Series of International Symposia*, p. 5-9. Boston, MA: Harvard School of Public Health.

Kuhn, T. S. (1962). *The Structure of Scientific Revolutions*, (3rd ed.). Chicago: University of Chicago Press.

Lather, P. (1993). Fertile obsession: Validity after poststructuralism. *Sociological Quarterly, 34*, 673-693.

Leung, M. W., Yen. I. H., & Minkler, M. (2004). Community-based participatory research: a promising approach for increasing epidemiology's relevance in the 21st century. *International Journal of Epidemiology,* 33, 499-506.

Levy, J., I., Brugge, D., Peters, J. L., Clougherty, J. E., & Saddler, S. S. (2006). A community-based participatory research study of multifaceted in-home environmental interventions for pediatric asthmatics in public housing. *Social Science & Medicine, 63,* 2191-2203.

Lewis, S. (2008). Building global alliances in a world of health care inequities. *Policy, politics and Nursing Practice, 9*, 307-312.

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry.* Thousand Oaks, CA: Sage.

Linnan, L. A., Ferguson, U. O., Wasilewski, Y., Lee, A. M., Yang, J., Solomon, F., et al. (2005). Using community-based participatory research methods to reach women with health messages: Results from the North Carolina BEAUTY and health pilot project. *Health Promotion Practice, 6*, 164-173.

Lund, P. M. & Taylor, J. S. (2008). Lack of adequate sun protection for children with oculocutaneous albinism in South Africa. *BMC Public Health. 8, 225.* Retrieved May 22, 2009, from http://www.biomedcentral.com/1471-2458/8/225

MacIntyre, R. (2001). Religion as metaphor. In P. Munhall (Ed.). *Nursing research: A qualitative perspective*. (3rd ed., pp. 467-503). Sudbury, MA: Jones & Bartlett.

Malawi Economic Brief. (2005). Retrieved August 10, 2009 from http://www.scotland.gov.uk/Resource/Doc/54357/0012603.pdf

Malawi in Figures. (2007). Retrieved August 18, 2009, from http://www.nso.malawi.net/data_on_line/general/malawi_in_figures/Malawi_in_Figures.pdf

Malone, R., Yerger, V., B., McGruder, C., & Froelicher, E. (2006). It's like Tuskegee in reverse: A case study of ethical tensions in institutional review board review of community-based participatory research. *Health Policy and Ethics, 96,* 1914-1919.

Marcus, M. T., Walker, T., Swint, J. M., Smith, B. P., Brown, C., & Busen et al. (2004). Community-based participatory research to prevent substance abuse and HIV/AIDS in African-American adolescents. *Journal of Interprofessional Care, 18,* 347-359.

Medical News Today. (2007). US life expectancy goes up to 78 years. Retrieved April 20, 2009, from http://www.medicalnewstoday.com/articles/82331.php

Melrose, M. J. (2001). Maximizing the rigor of action research: Why would you want to? How could you? *Field Methods, 13,* 160-180.

Minkler, M. & Wallerstein, N. (2006). Improving health through community organization and community building: A health education perspective. In M. Minkler (Ed.), *Community organizing and community building for health* (2nd ed., pp. 26-50). New Brunswick, NJ: Rutgers University Press.

Minkler, M. (2006). Introduction to community organizing and community building. In M. Minkler (Ed.), *Community organizing and community building for health,* (2nd ed., pp. 1-21). New Brunswick, NJ: Rutgers University Press.

Minkler, M., Fadem, P. Perry, M., Blum, K., Moore, L., & Rogers, J. (2002). Ethical dilemmas in participatory action research: A case study from the disability community. *Health Education & Behavior, 29*(1), 14-29.

Minkler, M., Vasquez, V.B., Warner, J. R., Steussey, H. & Facente, S. (2006). Sowing the seeds for sustainable change: A community-based participatory research partnership for health promotion in Indiana, USA and its aftermath. *Health Promotion International, 21. 293-300.*

Mkandawire-Valhmu, L & Stevens, P. (2007). Applying a feminist approach to health and human rights research in Malawi: A study of violence in the lives of female domestic workers. *Advances in Nursing Science, 30*, 278-289.

Mosavel, M., Simon, C., van Stade, D. & Buchbinder, M. (2005). Community-based participatory research (CBPR) in South Africa: Engaging multiple constituents to shape the research question. *Social Science & Medicine 61,* 2577-2587.

MW Census Report. (2008). Retrieved March 22, 2009, from http://www.nso.malawi.net/

Navarro, A. M., Voetsch, K. P., Liburd, L. C., Giles, H. W., & Collins, J. L. (2007). Charting the future of community health promotion: Recommendations from the National Expert Panel on Community Health Promotion. *Preventing Chronic Disease, Public Health Research, Practice and Policy, 4*(3), 1-7.

Nishtar, S. (2004). Public – private 'partnerships in health –a global call to action. *Health research policy and systems*. Retrieved February 10, 2009, from http://www.health-policy-systems.com/content/2/1/5

O'Byrne, P. (2007). The advantages and disadvantages of mixing methods: An analysis of combining traditional and autoethnographic approaches. *Qualitative Health Research 17,* 1381-1391.

O'Fallon, L. R. & Dearry, A. (2002). Community-based participatory research as a tool to advance environmental health sciences. *Environmental Health Perspectives, 110*, 155-159.

O'Neil, O. (2002). A question of trust. *BBC Reith Lectures.* Retrieved January 25, 2008, from http://www.sfu.ca/~etiffany/teaching/phil120/overheads_2_16_06.html

Palmer, D. (2006). Tackling Malawi's human resources crisis. *Reproductive Health Matters, 14*(27), 27-39.

Pfeiffer, J., Johnson, W., Fort, M., Shakow, A., Hagopian, A., Gloyd, S. et al. (2008). Strengthening health systems in poor countries: A code of conduct for nongovernmental organizations. *Health Policy and Ethics. 98,* 2134-2140.

Plummer, K. (1999). The "Ethnographic Society" at century's end: Clarifying the role of public ethnography. *Journal of Contemporary Ethnography, 8,* 641-649.

Rankin, S. (2006). Malawi Christians and Muslims: HIV Prevention and Care. National Institutes of Health (R01 HD 050147).

Rankin, S., Lindgren, T., Rankin, W. W., & Ng'Oma. (2005). Donkey work: Women, religion, and HIV and AIDS in Malawi. *Healthcare for Women International, 26*(1), 4-16.

Rankin, W. W., Brennan, S, Schell, E., Laviwa, J., & Rankin, S. (2005). The stigma of being HIV-positive in Africa. *PLOS Medicine. 2,*702-704.

Rankin, W., Brennan, S., Schell, E., Laviwa, J., & Rankin, S. (2005). The stigma of being HIV-positive in Africa: HIV-related stigma is fueling the epidemic, and disempowering women even further. *PLOS Medicine, 2*(8), 1-3.

Rankin, W., Brennan, S., Schell, E., & Rankin, S. (2005). A call for community: Two papers on HIV and AIDS related stigma in Africa. Retrieved September 1, 2007, from http://www.theNGO1.org/pdfs/combined_stigma.pdf

Rhodes, S. D., Eng, E. Hergenrather, K. C., Remnitz, I. M., Arceo, R, Monano, J., et al. (2007). Exploring Latino Men's HIV risk using community-based participatory research. *American Journal of Health Behavior*, *31*, 146-158.

Rhodes, S. D., Hergenrather, K. C., Wilkin, A. M., & Jolly, C. (2008). Visions and voices: Indigent persons living with HIV in the Southern United States use Photovoice to create knowledge, develop partnerships and take action. *Health Promotion Practice, 9*, 159-169.

Rhodes, S. D., Yee, L. J., & Hergenrather, K. C. (2006). A community-based rapid assessment of HIV behavioural risk disparities within a large sample of gay men

in southeastern USA: A comparison of African American, Latino and white men. *AIDS Care, 18,* 1018-1024.

Rhodes, S., D., Hergenrather, K. C., Montano, J., Remnitz, I. M., Arceo, R., & Bloom, F. R. et al. (2006). Using community-based participatory research to develop and intervention to reduce HIV and STD infections among Latino men. *Aids Education and Prevention, 18,* 375-389.

Rose, G. (2001). *Visual methodologies: An introduction to the interpretation of visual methods*. Thousand Oaks, CA: Sage.

Rosenberg, A., Hartwig, K., & Merson, M. (2008). Government-NGO collaboration and sustainability of orphans and vulnerable children projects in southern Africa. *Evaluation and Program Planning, 31,* 51-60.

Sachs, J. D. (2005). *The end of poverty.* New York: Penguin.

Sandelowski, M. (2003). Taking things seriously: Studying the material culture of nursing. In J. Latimer (Ed.), *Advanced qualitative research for nursing* (pp. 185-210). Malden, MA: Blackwell.

Savage, C. L., Xu, Y., Lee, R., Rose, B. L., Kappesser, M., & Anthony, J. S. (2006). A case study in the use of community-based participatory research in public health nursing. *Public Health Nursing, 23,* 472-478.

Schatz, E. (2005). 'Take your mat and go!': Rural Malawian women's strategies in the HIV/AIDS era. *Culture, Health and Sexuality, 7,* 479-492.

Shivji, I. G. (2007). *Silences in NGO discourse: The role and future of NGOs in Africa.* Fahamu: Oxford, UK.

Simon, C., Mosavel, M., van Stade, D. (2007). Ethical challenges in the design and conduct of locally relevant international health research. *Social Science & Medicine 64,* 1960–1969.

Smith, J. K., & Hodkinson, P. (2005). Relativism, criteria and politics. In N. Denzin, & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (3rd ed., pp. 915-932). Thousand Oaks, CA: Sage.

Smith, L. T. (2005). On tricky ground: Researching the native in the age of uncertainty. In N. Denzin & Y. S. Lincoln, *Handbook of qualitative research* (3rd ed., pp. 85-108). Thousand Oaks, CA: Sage.

Springett, J. & Wallerstein, N. (2003). Issues in participatory evaluation. In M. Minkler & N. Wallerstein (Eds.)*, Community-based participatory research for health (*2nd ed., pp. 1-36). San Francisco: Jossey-Bass.

Stevenson, J. (2007). Recent publications regarding community-based participatory research (CBPR). Retrieved February 8, 2009, from http://academicdepartments.musc.edu/nursing/departments/researchoffice/documents/CBPR_annotated_bib.pdf

Swartz, L. J., Callahan, K. A., Butz, A. M., Rand, C. S., Kanchanaraksa, S., Diette, G. B., Krishnan et al. (2003). Methods and issues in conduction a community-based environmental randomized trial. *Environmental Research, 95,* 156-165.

Tedlock, B. (2005). The observation of participation and the emergence of public ethnography. In N. Denzin, & Y. S. Lincoln *Handbook of qualitative research* (3rd ed., pp. 467-481). Thousand Oaks, CA: Sage.

Teufel-Shone, N. I., Siyuja, T., Watahomigie, H. J., & Irwin, S. (2006). Community-based participatory research: Conduction a formative assessment of factors that influence youth wellness in the Hualapai community. *Journal of Public Health, 96*, 1623-1628.

Tucker, K. (1916). Katherine Tucker. In P. Van Betten & M. Moriarty (Eds), *Nursing illuminations: A book of Days*, (2004, p. 299). St. Louis: Mosby.

The Health Foundation. (2007). Retrieved October 13, 2008, from http://www.health.org.uk/current_work/case_studies/reducing_maternal.html

UNAIDS. (2004). Women, girls and HIV/AIDS in Malawi. Retrieved August 10, 2009 from http://womenandaids.unaids.org/documents/factsheetmalawi.pdf

UNICEF (2007). Malawi Statistics. Retrieved online May 25, 2009 from http://www.unicef.org/infobycountry/malawi_statistics.html

USAID. (2006). Mothers group takes HIV/AIDS Pandemic into their own hands. Retrieved August 10, 2009 from http://africastories.usaid.gov/search_details.cfm?storyID=499&countryID=13&sectorID=0&yearID=6

USAID. (2005). Malawi. Retrieved August 10, 2009 from http://www.usaid.gov/locations/sub-saharan_africa/countries/malawi/

Valdivia, A. N. (2002). bell hooks: Ethics from the margins. *Qualitative Inquiry, 8*, 429-447.

van Manen, M. (1990). In *Researching lived experience: Human science for an action sensitive pedagogy*. Ann Arbor, MI: Althouse Press.

Vasquez, V. B., Minkler, M., & Shepard, P. (2006). Promoting environmental health policy through community-based participatory research: A case study from Harlem, New York. *Journal of Urban Health, 83*(1), 101-110.

Vasquez, V.B., Lanza, D., Hennessey-Lavery, S., Facente, S., Halpin, H. A., & Minkler, M. (2007). Addressing food security through public policy action in a community-based participatory research partnership. *Health Promotion Practice, 8,* 342-349.

Viswanathan, M., Ammerman, A., Eng, E. Gartlehner, G., Lohr, K. N., Griffith, D. et al. (2004). *Community-based participatory research: A summary of the evidence Volume II Appendices.* RTI International-University of North Carolina Evidence-Based Practice Center.

Vujicic, M. Addressing global health and health financing disparities: The role of donor agencies. *Policy, Politics, & Nursing Practice, 9*, 313-322.

Wallerstein, N. (2006). *What is the evidence on effectiveness of empowerment to improve health?* Copenhagen, WHO Regional Office for Europe (Health Evidence Network report: Retrieved November, 16, 2007, from http://www.euro.who.int/Docuent /E88086.pdf

Wallerstein, N. B. & Duran, B. (2006). Using community-based participatory research to address health disparities. *Health Promotion Practice, 7*, 312-323.

Wallerstein, N. B. (2002). http://depts.washington.edu/ccph/pdf_files/wallerstein.pdf

Wallerstein, N. B. (nd). Introduction to: Community-based participatory research (CBPR) and participatory evaluation. Retrieved April 5, 2008 from hsc.unm.edu/som/fcm/MPH/**cbpr**%20and%20participatory%20evaluation.ppt

Walter, C. (2006). Community building practice: A conceptual framework. In M. Minkler (Ed.) *Community organizing and community building for health*, (2nd ed., pp. 66-78). New Brunswick: NJ: Rutgers University Press.

Weems, L. (2006). Unsettling politics, locating ethics: Representations of reciprocity in postpositivist inquiry. *Qualitative Inquiry, 12*, 994-1011.

APPENDIX A: COMMUNITY-BASED PARTICIPATORY RESEARCH STUDIES

Investigator Year	**Health Focus**	**Sample**	**Design**	**Theory**	**Major Findings**	**Strengths**	**Weaknesses**	***Relevance for CBPR in Malawi***
Ammerman, A., Corbie-Smith, G., St. George, D. M, Washington, C., Weathers, B, Jackson-Christian, B. (2003). Research expectations among African American church leaders in the PRAISE! Project: A randomized trial guided by CBPR	Nutrition and cancer	N=60 Pastors and community workers from 60 churches in North Carolina from a CBPR inter-vention	Survey evaluation of expectations regarding CBPR with randomized inter-ventions -- Faith-Based Organiza-tion(FBO)	Ecolo-gical	1) 80% survey response from church liaisons 2) Identified primary motivation for participation (cancer prevention, nutrition education, health education concerns 3) Community members and leaders reflected reticence to participate in research 4) 77-80% response from pastors that researchers were doing “pretty well or very well” 5) African Americans cannot be considered as a homogenous group	1) The role of the community partner’s expectations of research is not widely studied, and impacts subsequent use of CBPR in communities 2) CBPR guidelines were applied throughout, e.g., participation in all aspects of research	1) Delayed intervention groups were less responsive in survey participation 2) Lower satisfaction overall with process suggesting that randomized projects might not be as effective in CBPR (Further research is necessary in this area)	1) Study raises questions about appropriate-ness of randomized controlled trials (RCTs) in CBPR 2) Research partner expectations are identified; these are important considera-tions 3) Reiterated the resistance to research by many African Americans

Investigator Year	**Health Focus**	**Sample**	**Design**	**Theory**	**Major Findings**	**Strengths**	**Weak-nesses**	***Relevance for CBPR in Malawi***
Ammerman, A., Washington, C., Jackson, B., Weather, B., Campbell, M., Davis, et al., (2002)	Cancer, nutrition	N= 1300 1300 people from 60 churches in eight North Carolina eight counties.	5 year randomized controlled trial to test nutrition program in African American churches with the University of North Carolina, Chapel Hill using CBPR and partnership with FBOs A church-based nutrition intervention designed for cultural appropriate-ness, sustainability, and diffusion	Social Ecolo-gical, Bandura's social cognitive theory	1) Identified additional need for dissemination of information, ensuring that materials are in "concordance with the organizational mission" (p. 289) 2) Cancer evoked fear and beliefs that individual behaviors are important alongside faith 3) Pastor served as role model for behavior change 4) Differences found between Caucasian and African American focus groups – black groups responded better if pastor supported program; white groups responded better if program helped bring in more members	1) The authors planned for sustain-ability in the interven-tion stage and claimed to be one of the first groups to do such 2) Used 6 focus groups to obtain qualitative data to guide interven-tion 3) Deeply ingrained behaviors were adjusted.	1) Delayed interventio n group was "anxious" to implement a positive inter-vention; adjust-ments were made which might have weakened compariso n. However, overall benefit to com-munity was clear.	1) Identified need for cultural relevance in CBPR 2) Demon-strated sustained, positive behavior change based on interventions 3) Identified importance of role models in community health changes (pastors in African American groups) 4) For whites, relevance of programs for wider community was evidenced by increase in membership

Investigator Year	**Health Focus**	**Sample**	**Design**	**Theory**	**Major Findings**	**Strengths**	**Weak-nesses**	***Relevance for CBPR in Malawi***
Anderko, L., Lundeen, S. & Bartz, C. (2006). The Midwest Nursing Centers Consortium Research Network: Translating research into practice	Primary, public health, health policy	Multi-site, multi-state collaboration for CBPR to "inform practice, education and health policy" in the Midwest (p. 101). All sites are run by nurse practitioners.	Federally funded non physician primary care research network established to deliver health care and reduce disparities through CBPR. Used pre-post inter-vention on knowledge and behavior of health and wellness activities	Ecolog-ical	1) "Extremely positive" evaluations of program (p. 105) 2) 8 out of 19 agencies participated in 8 week wellness project with positive weekly outcomes 3) Primary care settings did not approach care in the same way – both public health and primary care/medical models were used by nurse practitioners 4) Physical activity in pre/post-test increased from 39.9% to 47.5% 5) Nutritional status in pre/post-test improved from 30.5% to 56.8% with $p < .01$	1) Model is successful as it addresses healthcare from a primary preventative, and decentralized perspective rather than from a medical diagnosis in a highly centralized system 2) Study strengthens use for CBPR for vulnerable populations and public policy	With federal funds and RWJ Foundation funding, community consensus was not sought at the beginning per CBPR recommen-dations; however principles must be guided by what is feasible	1) A complex program across communities in different states achieved clinically and statistically significant health outcome in marginalized populations 2) Study based on CBPR pilot study, achieved positive health outcomes – 3) Allowed for different approaches among partners while maintaining rigor

Investigator Year	**Health Focus**	**Sample**	**Design**	**Theory**	**Major Findings**	**Strengths**	**Weak-nesses**	***Relevance for CBPR in Malawi***
Andrews, J. O, Bentley, G., Crawford, S., Pretlow, L., Tingren, M. S., 2007	Smoking cessation	Drawn from 6072 residents in 16 housing develop-ments in Augusta-Richmond Co. GA African American women, low-income, 40% smokers, 63% of all household had at least one smoker	CBPR. Partners included academics, neighborhood residents and community health workers. 2 neighborhoods randomized to treatment conditions Intervention n = 51; control, n =52 Smoking patches, education. Used CBPR to develop a culturally sensitive smoking cessation intervention with public housing neighborhoods	Ecological and Rescinow's use of cultural sensitivity for health promotion, 1999	1) Preliminary data showed that written materials that are culturally sensitive and "meaningful" would help with smoking cessation 2) Ethnical food was preferred as an incentive along with gift cards and door prizes 3) Collectivism was important – the community, children's health 4) 6 month continuous smoking outcomes were 27.5% in intervention group; 5.77% in comparison group	1) Meeting times were chosen according to resident preferences 2) Childcare was provided during meetings 3) Credible partners, Community Health Workers who were former African American smokers assisted with the research 4) Storytelling n=15 and spirituality was integrated	Authors stated that they would describe their process; however, the process described was primarily their activities once the partner-ships were established and initial processes were not delineated.	1) Communitar-ian approach was important in this study which might be more similar to Malawian communities than a typical Western community 2) Storytelling was found to be an important part of behavior change 3) Positive health outcomes were achieved in a marginalized group that has not often participated in research

Investigator Year	**Health Focus**	**Sample**	**Design**	**Theory**	**Major Findings**	**Strengths**	**Weak-nesses**	***Relevance for CBPR in Malawi***
Caldwell, C. H., Wright, J. C., Zimmerman, M. A., Walsemann, K. M., Williams, D. & Isichei, P. A. C. (2004)	Substance abuse, violence, and early sexual initiation prevention	77 African Ameri-can partici-pants	Several agencies, African American participants and the University of Michigan worked through a CBPR approach to develop interventions from focus groups prior to implementation of Fathers and Sons Program 45 contact hours over a 2 month period; 32 hours of intervention sessions; 13 hours of homework/eve nt participation with a "booster session" 4 months after end of project	Ecological, strengths based, theory of reasoned action	1) Focus group, theoretical evidence and empirical findings suggest need to strengthen communication between fathers and sons 2) Father involvement with sons had significant positive outcomes for 3 target areas of concern; some variances will require further research 3) 3 consistent themes – effective communication, enhancing cultural perspectives and "practicing parenting and refusal skills" (p. 650)	1)Fathers and Sons Program was successful and CDC funding will be used for subsequent research 2) The literature review guided the process and theoretical concepts were supported by the outcomes 3) Few studies have focused on the association between violent behavior of youth and father involvement	Tables and diagrams were used to explain findings and frame-work. A table of outcomes would have been helpful, but researchers will follow up with pre-test/post-test and use a quasi-experiment al design to evaluate conceptual model	1) Innovative topic of father-son relationships and association with violence and early sexual initiation had positive results using CBPR approach – suggests that CBPR is adaptable to community needs 2) Supports importance of relationships of community members on social outcomes (father-son and violence) 3) Time constraints were identified as a barrier in CBPR process

Investigator Year	**Health Focus**	**Sample**	**Design**	**Theory**	**Major Findings**	**Strengths**	**Weaknesses**	***Relevance for CBPR in Malawi***
Campbell, R., Sefl, T., Wasco, S. M. & Ahrens, C. E. (2004)	Sexual violence	N= 102 Racially diverse sample of female rape survivors in Chicago	Community-based research design, qualitative and quantitative methods, interviews to ascertain rape survivors' use of agencies	Feminist	1) Methods to identify "hidden population" were successful (p. 253). 2) No significant difference in demographic characteristics were found between sample and general population, further supporting method 3) Local community leaders and business owners saw research as helpful to women and assisted researchers gain entry to gatherings for recruitment 4)Despite the research focus of the study, women found it personally helpful to tell their stories	1) Achieved goal of creating a research sampling plan for rape survivors who had and had not worked with formal agencies, a difficult population to identify 2) Ethical considerations of women were maintained "without sacrificing methodological rigor" (p. 253) 3) Needs of both researchers and women in sample were met	1) Women were interviewed using a qualitative method and then were asked specific questions for quantifiable measures. Quantitative findings were not addressed 2) One of the goals of the study was to compare outcomes for women who did and did not report assaults. The outcomes were not discussed in this article and although readers were referred to, a brief discussion would have been helpful	1) Despite research focus, participants found personal satisfaction in their involvement in the study 2) Quote shows promise for CBPR: "Participating in this study was the most helpful thing I experienced in working through the rape. It wasn't counseling or therapy, I was always clear it was research, but it was research that was caring and healing. I was listened to …Participating in this study made me feel valued as a person…I am so grateful for all that your work has given me" (p. 259)

Investigator Year	**Health Focus**	**Sample**	**Design**	**Theory**	**Major Findings**	**Strengths**	**Weak-nesses**	***Relevance for CBPR in Malawi***
Carlson, B. A., Neal, D., Magwood, G., Jenkins, C., King, M. G., & Hossler, C. L. (2006).	Diabetes	306 African Americans from 5 distinct counties in South Carolina	Panel composed of 9 members using a CBPR approach, conven-ience sample, focus group and newly developed survey tool to obtain needs assessment regarding health information access	Ecolo-gical, empow-erment	1) Significant differences found in age ($p < .001$), education level ($p = .0014$) and diabetes education ($p = .0004$) 2) Source of health information also varied according to age 3) The majority "expressed a need and desire to learn how to access and use the Internet and libraries for health information" (p.219s) 3) Participants > 60 "were almost twice as likely to want to learn to use the Internet" and more than 4 times as likely to want to learn to obtain health information from the Internet 4) Participants with <12 years of education relied on family and friends for health information	1)Sample included high risk for diabetes population including 36% previously diagnosed with diabetes 2) Good use of findings that individ-uals with low education levels and incomes, once thought to be the least likely to use the Internet, were among "the fastest adopters of Internet technology" (219s)	1) The sample was drawn from a rural area and might not be applicable to urban areas 2) As instrument used was new, further research is needed to test validity and reliability	1) CBPR approach with marginalized population (limited education; some older adults) resulted in positive education outcomes 2) Reinforced importance of education in obtaining accurate health information

Investigator Year	**Health Focus**	**Sample**	**Design**	**Theory**	**Major Findings**	**Strengths**	**Weaknesses**	***Relevance for CBPR in Malawi***
Coe, K., Wilson, C., Eisenberg, M., Attakai, A., Lobell, M. (2006).	Cancer	American Indian population in Arizona and University of Arizona and University and Indian Health Services	Using a participatory research approach, developed partnerships and conducted pilot project	Ecological	1) Improved collaboration among agencies 2) improved patient care 3) increase in awareness regarding cancer 4) new partnerships	1) Created a "research-friendly" environment, creating a sustainable model 2) New American Indian researchers	Limitations of five year grant; however, successes achieved speak well to sustainability. Results will be shown in future study; as a pilot limited health outcomes are available.	1) CBPR process improved collaboration, patient care and helped form new partner-ships 2) Created "research friendly" environ-ment in population that was previously suspicious of research activities.

Investigator Year	**Health Focus**	**Sample**	**Design**	**Theory**	**Major Findings**	**Strengths**	**Weak-nesses**	***Relevance for CBPR in Malawi***
Hughes Halbert, C. H., Weathers, B., Delmoor, E. (2006).	Prostate cancer	Academic-community partnership between University of Pennsylvania and members of the Philadelphia chapter of the National Black Leadership Initiative on Cancer for CBPR	CBPR to evaluate developme nt of partnership in order to explore quality of life after prostate cancer diagnosis. Descriptive process utilizing research and theory to both guide and evaluate process.	CBPR/ eco-logical frame-work	1) The most challenging step is establishing a relationship with a community agency, but is the "most critical" (p. 99) 2) It is critical to discuss difficult issues early in the partnership despite the risk of failure for the partnership to progress 3) Community partners stressed that racism and discrimination were factors in quality of life following prostate cancer diagnosis, thus influencing the study design 4) Agencies fear academic needs will "overshadow their needs" (p. 101)	1) Incorporated research that showing that agencies have similar mistrust of research as do many minorities and therefore built trust prior to proceeding 2) Partners were involved in each step of the research, findings were disseminated in both a written report and a flow chart – use of two methods to reflect the voice of participants	1) Partner-ship develop-ment challenges outlined clearly, however: discussion regarding health outcomes was limited 2) Language regarding future implication was based in what CBPR researchers "should" do, which is not as reflective of the collabor-ative process inherent in CBPR	1) Focus on the importance of establishing relationships 2) Addressed agency mistrust of research 3) Identified issues of racism that affected quality of life following prostate cancer diagnosis and used this information to help design study more appropriately 4) Use of two methods to disseminate information that is more reflective of the partnership

Investigator Year	**Health Focus**	**Sample**	**Design**	**Theory**	**Major Findings**	**Strengths**	**Weak-nesses**	***Relevance for CBPR in Malawi***
Krieger, J, Allen, C., Cheadle, A, Schier, J. K., Senturia, K., Sullivan, M. (2002).	Asthma, domestic (also addressed domestic violence, com-munity research)	"Urban, socio-economically marginalized Seattle communities" (p. 361).	RCT design used for Asthma study	Ecological	1) Community members opposed control group for study, advocating for interventions for both groups. A lesser intervention was used in the comparison group resulting in weaker findings. Community members had greater under-standing of value of research in terms of policy; however, might not have changed interventions 2) Community members in domestic violence prevention project informed researchers of method to prevent perpetrators from attending groups	1) Strong participation of community agencies, researchers and community members 2) Followed general CBPR principles and adapted them as needed by the projects – did not let method dominate community needs	More emphasis on outcomes would strengthen the case for using CBPR	1) Community resistance to RCT, ethical issues related to conventional research practices as applied in community settings. 2) Community needs guided projects rather than a rigid adherence to CBPR 3) Researchers listened to community's knowledge about methods to prevent perpetrators from attending groups of at-risk women

Investigator Year	**Health Focus**	**Sample**	**Design**	**Theory**	**Major Findings**	**Strengths**	**Weak-nesses**	***Relevance for CBPR in Malawi***
Levy, J., I., Brugge, D., Peters, J. L., Clougherty, J. E. & Saddler, S. S. (2006).	Pediatric asthma	Single cohort of 50 asthmatic children ages 4-17 drawn from three different public housing facilities in Boston, MA. 70 % were Hispanic; 28% African American	CBPR approach to provide interventions to reduce pest infestation, provide limited case management and collect longitudinal data	Ecolo-gical	1) Respiratory symptoms decreased significantly between beginning and end of study; 95% of children had symptom improvement 2) No significant change noted in severe asthma attacks or hospitalizations 3) Quality of life related to asthma improvement found 4) Cockroach allergens were reduced (58% of children found to be allergic in study) 5) Peak flow meter changed from 25% - 86% use at least once per month)	1) Used statistical analysis to evaluate data 2) Noted that environmental interventions might have caused decreases in respiratory symptoms suggesting that future research focusing on environmental factors in a more controlled study would be beneficial	1) 50 out of 78 children had adequate data resulting in an attrition rate of 36%. 2) No comparison to other children with asthma	1) Study demonstrated significant improvement of health outcomes and increased use of medications as ordered, demonstratin g usefulness of CBPR to improve health issues 2) Addressed health from both a physical and environ-mental perspective

Investigator Year	**Health Focus**	**Sample**	**Design**	**Theory**	**Major Findings**	**Strengths**	**Weak-nesses**	***Relevance for CBPR in Malawi***
Linnan, L. A., Ferguson, U. O., Wasilewski, Y., Lee, A. M., Yang, J., Solomon, F., Katz, M. (2005).	Health promotion (diet, exercise, cancer screening)	2 beauty salons from a convenience sample of 24 in North Carolina. 1 salon served predominantly Whites and the other, predominantly African Americans. 5 cosmetologists partnered with the organization	CBPR pilot project to determine effectiveness of cosmetologist health discussions with clients utilizing qualitative and quantitative methods – interviews and post-test surveys	Ecological	1) Cosmetologists were "very satisfied" with training and confident of their abilities to deliver health promotion messages to their clients (p. 167). 2) African American client correlation with cosmetologist discussions and behavior change readiness was stronger than that of White clients with the same interventions 3) Stronger correlation with frequency of health discussion and behavior change readiness found 4) 12 month follow-up showed similar results	1) CBPR guiding principles were effectively applied, e.g., in working with cosmetology organizations to recruit sample; working with cosmetologists in planning, implementation and evaluation phases 2) Sustainability shown by 12 month post-test, including cancer screening tests, improved physical activity, nutrition, better understanding of health information from provider, asked health provider more questions 3) Good use of both qualitative and quantitative methods to provide a broader understanding of the role cosmetologists have regarding health behavior changes	Pilot study, small sample, limited to particular geographic area	1) Innovative approach was evaluated 2) Sustainable health behavior results were shown up to 12 months after pilot 3) Rigor of research method helps validate CBPR

Investigator Year	**Health Focus**	**Sample**	**Design**	**Theory**	**Major Findings**	**Strengths**	**Weak-nesses**	***Relevance for CBPR in Malawi***
Lund, P. M. & Taylor, J. S. (2008)	Sun protecti on for children with oculocut aneous albinism (OCA) in South Africa	N=90 Children with OCA in a boarding school in South Africa. (40 female and 50 male)	CBPR approach was used to investigate sun protection (hats, sunscreen use). Peer group semi-structured interviews combined with resident nurse input. This study is based on an earlier study in the same school that did not produce effective results.	Not stated.	1) Gender differences in sun avoidance were found as females sought shade while males played soccer during recreational periods. All but one student had at least one hat, and 38% of the sample used sunscreen 2) Only 12% of the sample used government sponsored sunscreen tubes due to access difficulties 3) Hat brim width was insufficient and authors provided several recommendations, some of which involved little cost to help provide children with greater sun protection	1) Study clearly outlines designs, methods, and findings 2) Study supports government decision to sponsor free tubes of skin protection factor (SPF) 15 as research shows only marginal advantages of increased SPF use in children with OCA 3) Authors found that didactic processes did not address issues sufficiently and advocated for a social learning model, providing practical suggestions to meet the need for the particular community that has limited access to Internet	1) Little was said about the CBPR process and success of the partner-ship 2) No mention of how this informa-tion will be disseminat ed to the children, children's parents and others was given in the article	1) Few CBPR studies in Africa are reported in current literature and this CBPR study highlighted benefits of CBPR approaches 2) Research design and consent process were clearly stated 3) Focus was on a population in a rural area with limited access to services and study produced practical solutions through a participatory process that could be emulated in Malawi

Investigator Year	**Health Focus**	**Sample**	**Design**	**Theory**	**Major Findings**	**Strengths**	**Weaknesses**	***Relevance for CBPR in Malawi***
Marcus, M. T., Walker, T., Swint, J. M., Smith, B. P., Brown, C., Busen, N., et al., (2004).	HIV and AIDS	African Ameri-can. Youth	CBPR using "look, think, act" proposed by Stringer. CBPR to prevent substance abuse and HIV and AIDS in African-American adoles-cents	Faith-based, CBPR	HIV and AIDS knowledge about the same between control and comparison groups. Greater compassion for those with HIV, less drug use, greater fear of HIV and AIDS in comparison group.	1) Used drama, media, music grandparents' life histories 2) An esteemed African American playwright, Thomas Meloncon participated 3) Clearly addressed stakeholders in results section 4) Used peer education 5) Faculty gained increased credibility as authorities from community stakeholders	1) Fear of HIV and AIDS was used as a goal and a higher percentage of fear of HIV and AIDS among youth was interpreted as a success of the program. The goal of CBPR is to work toward strengths and build capacity. A much stronger measure, in my view, would be less fear due to increased awareness and assurance of ability to engage in safe behaviors regarding HIV and AIDS; however, it is up to the partners to determine their process 2) "Project results will be reported relative to each stakeholder group" – this is good, however, actual results are needed in CBPR studies to help strengthen the literature	1) FBO and non-profit partnership – demonstrates successful partnership outcomes 2) Greater compassion for individuals with HIV was achieved through partnership. Stigma concerning AIDS has been identified as a problem (Kelly) in Africa and stigma adversely affects health

Investigator Year	**Health Focus**	**Sample**	**Design**	**Theory**	**Major Findings**	**Strengths**	**Weaknesses**	***Relevance for CBPR in Malawi***
Minkler, M. Vasquez, V.B., Warner, J.J., Steussey, H. & Facente, S. (2006).	Respira-tory	N= 1,000 Indiana University School of Nursing, Healthy Com-munities of Henry County (HCHC), and the residents of New Castle, IN	Minkler et al. critically examined the ten year CBPR partnership development, research, policy, activities and sustainability of the IU School of Nursing and the New Castle community. The CBPR was formed to address many health issues including a "smoking rate of twice the national average" (p. 1) A non-probability quota sampling of 1000 households provided health data that the partnership	Based on strengths based approach-es and action as part of the research process" (p. 2).	1) Nearly 50% response rate to survey 2) Community took greater responsibility for their health 3) Non-smoking measure passed 4) Built a play-ground 5) Developed trails project 6) Many achievements occurred informally 7) HCHC helped provide labor for trails project 8) Partnership exemplified sustainable change through CBPR	1) Princi-ples of CBPR were followed 2) Con-cepts of true partner-ship were sustained through-out 3) Wide representa tion of commun-ity entities in the partner-ship	1) 2 groups with the poorest health were under represented 2) Increased responsibilit y of health could be attributed to national emphasis on health 3) Limited discussion regarding changes in smoking, dietary habits and exercise, the original aim 4) It would have been helpful to have current stats on the city's Healthy People ranking	1) Community participation in CBPR has sustainable results 10 years later – including policies regarding smoking, maintaining walking trails and a play ground to encourage physical activity. 2) Use of scientific-based data about the community's health compared to national averages spurred the community into action 3) This study underscores the need to report actual health data to strengthen research regardless of the focus of a particular manuscript

APPENDIX B: INTERVIEW GUIDE

1. Tell me about your organization's purpose. [How well does the NGO purpose fit with the goals of CBPR? Are they complementary? Is the NGO role based primarily on its access to certain communities rather than shared purposes?]

2. What is your experience with the organization? [Explore the culture of the organization.]
    a. Probes – How would you describe your organization?
    b. Tell me about your role with (NGO1/organization.)
    c. What is a typical day like for you?
    d. What is the atmosphere at NGO1 (or other organization) like?

3. What are some of the characteristics of an employee/staff member/volunteer that fit best with your organization? [What is the culture of the organization? Describe the partnerships between NGOs and community organizations.]
    a. Probes: Give me an example of how your organization works to help people in Malawi.
    b. Give me an example of how your organization partners with (CBO1, churches, etc.)

4. Will you describe your relationship with the community groups you work with? [What are the perspectives of NGOs that interact with community organizations/boards?]
    a. Probes: Tell me about your work with community groups/boards.
    b. What is your primary role with these community groups/boards?
    c. What benefits have you found in your partnership with community groups/boards?
    d. What are some of the challenges that you've found in partnering with community groups/boards?

5. What are the time commitments for your organization in partnering with community agencies? [Several studies have mentioned the burden of time on NGOs due to the collaborative emphasis of CBPR. Much time is necessary to build relationships and consensus.]

6. What resources were needed to facilitate the partnership? [How does participation affect NGOs on an operational level? CBPR is a long process which might cause a strain on NGO resources.]
    a. Probes: Staff? Office materials? Financial resources?

7. How does your organization's mission statement fit with the goals of the community-based participatory research project? [Are the mission statements compatible? Does the partnership offer funding that might influence the direction of its work?]

8. What has been helpful to your organization as a result of your partnership? [What factors facilitate mutual goals?]

9. How has your involvement in this project affected your organization? [Identify barriers and facilitators from the NGO perspective.]
    a. Probes – What has worked well?
    b. What has been a challenge?

10. Does your work involve any contact with universities or academic institutions? [What are the perspectives of NGOs that interact with academic institutions?]
    a. Probes – If so, how does your partnership with the university/academic institutions impact your day to day operations?
    b. How has your work load changed (if it has)?
    c. How are your project priorities the same/different than they were a year ago?
    d. What, if any, are some of the benefits in working with universities/academic institutions?
    e. What, if any are some of the challenges?

11. Some people say that women are the key to addressing the problem of HIV and AIDS in Malawi. What do you think of this? How do women work together in the community in Malawi?

12. How do you build trust in the community?
    a. Probe: With community leaders? With community members? Tell me about some of your successes.)
    b. What do you think is the most important action in building trust?
    c. Tell me about a situation when trust was broken and the response to this.

13. Although I can't provide you with funding, if you had the resources, what activity would you like to do in the community?
    a. Probe: What resources would you need to do this? /What resources do you/the community have that would help?
    b. What (if any) skills would you or your co-workers need to accomplish this activity? /What skills do you/the community have related to this?
    c. What barriers would you anticipate? /What would help this activity succeed?

14. What activity or change do you think would help your community the most?
    a. Probe: What is the biggest need in your community right now?
    b. What has worked in the past to address this issue?
    c. What resources do you have in your community to address this issue?

15. What kind of knowledge, information or data would be useful to the community?

16. Do you think that it would be worthwhile to conduct a study to support your

program (or activity) goals? If yes, what kind of study would be helpful to the community?

17. What would cause you to participate in future community-based participatory research or other studies or research projects?
    Probe: What advice would you give to other NGOs considering similar partnerships?

18. What would you like to discuss that I haven't mentioned?
    a. Is there anything that you've shared that makes you uncomfortable?
    b. Is there anything that you'd like me to keep in confidence?

Thank you so much for your time. I appreciate being able to learn more about your perspectives.

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