COMMUNITY ENGAGEMENT IN GLOBAL HEALTH RESEARCH: CASE STUDIES FROM THE DEVELOPING WORLD—THE ZOMBA DISTRICT, MALAWI CASE STUDY

by

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THESIS SUBMITTED IN PARTIAL FULFILLMENT OF
THE REQUIREMENTS FOR THE DEGREE OF

MASTER OF SCIENCE

POPULATION AND PUBLIC HEALTH, GLOBAL HEALTH

In the
Faculty of Health Sciences

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SIMON FRASER UNIVERSITY

Summer 2008

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ABSTRACT

Community engagement influences the success of research. Investigators conducting international research necessitate an understanding of effective practices in community engagement. This case study examines the practice of community engagement in Zomba District, Malawi as part of a larger multiple case studies design with the objective of elucidating global practices of community engagement.

Poverty and disease are widespread in Malawi. Dignitas International, an academic NGO, implemented a community home-based care model for HIV/AIDS services including an Information, Education, and Communication (IEC) community engagement component in Zomba in 2004. This research is based on the analysis of 26 interviews with key informants affiliated with the Dignitas IEC program. The success of the IEC program is influenced by a perception of community ownership and assurance the program can be sustained. Maintenance of the IEC program is dependent on financial, technical, and motivational support for those carrying out IEC activities.

Keywords: community engagement; Information, Education, and Communication (IEC)

Subject Terms: bioethics; community-based health care—rural

DEDICATION

In memory of Pax Chingawale and to the people I met in Zomba.

ACKNOWLEDGEMENTS

Thank you to the 26 interview participants for your time and contribution.

I am grateful for the feedback and assistance from my supervisory committee. Thank you to my senior supervisor Ed Mills for providing the motivation and inspiration to write this thesis. Your commitment to Dignitas and the people in Zomba is obvious. I appreciate your everlasting support and encouragement as well as your academic and professional advice. Kitty Corbett, my supervisor, your expertise in qualitative research and community-based research has been very helpful throughout this process. Thank you for encouraging me to strive for academic excellence, for advocating a theoretical framework, and for your thoughtful edits. Thank you to Malcolm Steinberg, my external supervisor, for your insightful suggestions. Finally, thank you to the chair of my examining committee, Michel Joffres, for your time this summer.

My gratitude to James Lavery and Sunita Bandewar for their ongoing feedback, support, and encouragement in following my intellectual pursuits is immeasurable. Working with you has been a wonderful learning opportunity. Thank you to the ESC global CE case studies team (Anant, Emmanuel, Lara, and Paulina) for assistance in establishing the methodology and for the helpful comments throughout all stages of this project. I am indebted to and am grateful for the support from the McLaughlin Rotman Centre for Global Health who ensured this research could take place.

This research would not have been possible without the assistance of Dignitas collaborators in both the Toronto and Malawi offices. I am especially grateful for the assistance of Sumeet Sodhi, my preceptor, Veronica Van Dam and Sandy Thompson for their care and support in Malawi, and Barry Burciul for coordinating my field visits and helping with analysis.

This thesis is shaped in large part by the wisdom I gained from FHS faculty, staff, and students at Simon Fraser University. Thank you especially to Jennifer Van Rassel, Lynn Kumpula, and Margaret Hilson for your assistance before, during, and after I was in the field.

Thank you to the services of T.C. Transcription and to Georgina Pangani my translator, transcriptionist, and friend in Zomba.

I would also like to thank the following sponsors whose assistance enabled this research:

- Bill & Melinda Gates Foundation
- McLaughlin-Rotman Centre for Global Health
- Simon Fraser University Dean of Graduate Studies Office for the Simon Fraser University Graduate International Scholarship.

Lastly, thank you to my friends and family for your unwavering support.

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LIST OF ACRONYMS

AM	Area Mobiliser
CBO	Community-based organization
CE	Community engagement
CHBC	Community home-based care
CM	Community Motivator
ESC	Ethical, social, and cultural
HBC	Home-based care
IEC	Information, education, and communication
IGA	Income-generating activity
MWK	Malawi kwacha
NGO	Non-governmental organization
PMTCT	Prevention of mother-to-child transmission

GLOSSARY

Term	Definition
Community	A group of people with diverse characteristics who are linked by social ties, share common perspectives, and engage in joint action in geographical locations or settings (MacQueen et al., 2001).
Community engagement	Working together with people united by geographic location, common interest, or shared background to tackle issues affecting the health and well-being of those people (CDC, 1997).
Community home-based care	Community home-based care involves any kind of care given to sick people in their local environment by their families and community members and supported by trained volunteers and skilled health professionals to meet physical, spiritual, material, and psychological needs (WHO, 1993).
Information, Education, and Communication	"Information, Education, and Communication" (IEC) is a term that refers to strategies, approaches, and methods that empower individuals, families, groups, organisations, and communities to actively achieve, protect, and sustain their own health (UNFPA, 1999). Implicit in IEC is the process of learning that fosters decision making, behaviour modification, and social action (UNFPA, 1999).

PREFACE

My thesis started as a practicum project for my Master's degree. I had the opportunity to travel to Zomba District, Malawi to investigate people's perspectives on community engagement as part of a larger multiple-case studies research project on the topic of community engagement in the developing world. I knew from the outset that my case study would be completed by the global community engagement case studies research team as a grant deliverable, but after returning to Vancouver I could do nothing except reflect on the rich data that I collected and the experiences that people shared with me so openly and willingly. It was at this point that I committed to writing a thesis based on my research and completing the Zomba case study myself.

This case study was sponsored by the Bill & Melinda Gates Foundation through the McLaughlin Rotman Centre for Global Health. Advantages of this scenario include the funding available for the project, the fast pace at which data collection and analysis proceeded, and the diversity of experience among the research team members. The perception some people developed because the project was sponsored by the Bill & Melinda Gates Foundation constituted one of the study's challenges.

CHAPTER 1: INTRODUCTION

Community engagement in research is considered an ethical issue researchers must address when conducting a study or introducing a health intervention in order for the effects of the study to be sustained or for the intervention to be adopted and accepted (Berndtson et al., 2007; Singer et al., 2007). Underlying this idea involves an understanding of the meaning of "community" and who is included in the community. How to engage communities effectively is not well known. In light of increasing international research endeavours, including those that require the introduction of new technologies into communities in the developing world, it is increasingly important to have an understanding of effective practices in community engagement. Science has the potential to proceed in advance of careful consideration of ethical, economic, environmental, political, legal, and social issues. Scientists sometimes fail to consider the full range of implications of introducing new technology. For example, poor community engagement resulted in the premature halting of tenofovir trials in Cambodia (Singh & Mills, 2005). One reaction to this episode was the claim that

> [I]t might be prudent to devote as much effort to addressing the complex community challenges of successful trial implementation as we dedicate to the formidable biomedical challenges of developing new forms of HIV chemoprophylaxis (Newman, 2006, p. 302).

Indeed millions of dollars are spent on product development, clinical research, and building of facilities, but processes of engaging communities are left principally to trial and error (Newman, 2006).

There is growing recognition of the importance of ethical, social, and cultural (ESC) issues in research. Recently, a model of key factors that should be considered for the successful development, introduction, and adoption of new health technologies for developing countries was published based on perspectives from developing world key informants. In addition to consideration of political, scientific, and financial issues, these developing world experts suggested consideration of ESC issues including a focus on community engagement (Singer et al., 2007).

Today, global health organizations are including an ESC component in their research initiatives. The Bill & Melinda Gates Foundation is one such example. In 2003 the Foundation implemented the Grand Challenges in Global Health (GCGH) project to address health challenges predominantly affecting people in developing world countries (Bill & Melinda Gates Foundation, 2008). Funding totals approximately $436 million from the Bill & Melinda Gates Foundation, National Institutes of Health, Wellcome Trust, and Canadian Institutes of Health Research. The GCGH initiative specifically funds biotechnological solutions according to seven goals, 14 grand challenges, and 44 research projects (Appendix A). Based in Toronto, Canada, the Ethical, Social, and Cultural Program for the GCGH initiative is the 45th project receiving funding to fulfil two main objectives: 1) provide an advisory service to GCGH investigators

around ESC issues; and, 2) conduct exploratory research around ESC issues in developing world contexts to ensure GCGH technologies are introduced ethically.

In fulfillment of the second objective and due to a previously identified gap in the literature around community engagement (CE) in research contexts and in poor settings, the ESC program is currently conducting a global case studies research project to identify key determinants of success of CE. Twelve cases are being conducted in different research and geographical contexts, all with local collaborators. The case studies research team is composed of seven members with diverse backgrounds. Each member has the role of lead investigator for at least one case study in a developing world research context. The team is comprised of two people from India, one from Ghana, one from Nigeria, one from Lebanon, and two people from Canada.

The case study described in this thesis is based on a partnership between the ESC Program and Dignitas International. It examines community engagement as part of a decentralised health care delivery initiative in Malawi, in the context of Dignitas building capacity to deliver comprehensive community-based HIV care in the region. As the lead investigator for the project, I conducted 26 face-to-face interviews around the topic of IEC and attended eight IEC activities in Zomba District, Malawi. This case study examined community engagement as part of a decentralised health care delivery initiative in a poor nation. This thesis culminates my research and will also contribute to the cross-case comparison for the global case studies project on effective practices in community engagement, described above.

Global Community Engagement Case Studies

Goal and Objectives

The goal of the ESC global CE case studies is to identify key determinants of success of CE through in-depth case studies in various global health research and implementation contexts. Specifically, its objectives are to: 1) identify and describe CE practices associated with a number of research projects related to the development, introduction, and/or adoption of health technologies in the developing world; 2) provide a detailed comparison of the individual case studies; and, 3) identify/develop good practices from the perspectives of multiple stakeholders based on the data.

Zomba District, Malawi Community Engagement Case Study

Goal and Objectives

The goal for the Zomba research study was to conduct a case study that meets the goal of the global CE case studies described above. Specific objectives were developed in collaboration with Dignitas International. They were to: 1) explore the development and implementation of the IEC component of Dignitas International's community home-based care (CHBC) model; 2) provide a programmatic appraisal of the implementation of the IEC program for Dignitas International; 3) help construct a theoretical framework for effective CE to be applied to other Dignitas International projects; and, 4) contribute to the identification of "good practices" in cross-comparisons of the twelve case studies on CE initiatives in the developing world. Completion of the fourth objective is

beyond the scope of this thesis and will be fulfilled by the ESC global CE case studies research team.

Research Questions

To address the research goal and objectives explained above, this case study posed the following four research questions:

1. What were the community engagement activities undertaken by Dignitas in its IEC program and why did Dignitas choose those specific activities?
2. How did various stakeholders perceive the effectiveness of the community engagement effort?
3. What factors (internal and external) contributed to the success/failure of the community engagement effort from the various perspectives? How did these factors influence success/lack of success?
4. What critical lessons were learned during the course of the community engagement effort?

Theoretical Perspective

The research was grounded in theory on community engagement and health behaviour. A *theory* can be defined as "a set of interrelated concepts, definitions, and propositions that presents a *systematic* view of events or situations by specifying relations among variables in order to *explain* and *predict* the events or situations" (Glanz, Lewis, & Rimer, 1997, p. 21). Theories are

relevant to public health practitioners at different stages of program planning, implementation, and evaluation. Program planners, for example, rely on theories to answer why, what, and how questions: *why* are certain people maintaining cultural beliefs with no scientific basis; *what* exactly needs to be known to develop an appropriate intervention; *how* should program strategies be organized to have an impact? Hence, behaviour is explained by theories and models which in turn are meant to result in behaviour change. Research has been described as the bridge between theory and practice, and ultimately the test of applied theory. This case study research project tested several theoretical propositions against the practical community engagement work of Dignitas International using qualitative research methods. My research approach was exploratory and while I did not adopt a community-based research framework, I attempted to answer the research questions by situating the problem in terms of community perspectives and community research theories.

Thesis Outline

The Literature Review and Background chapter of my thesis explores the concept of "community", the theoretical literature around communities, and models of community organization. The concept of community-based research is described with two examples from the literature. I introduce the concept of community engagement, how the concept relates to global health research, and various models of community engagement. Background information on Zomba District, Malawi including social, political, and health issues and an overview of Information, Education, and Communication programs in the country will be

provided. I introduce Dignitas International and describe their CHBC project in Zomba. In the Methods section I explain the case study strategy of inquiry and its research components. I outline my research questions and theoretical propositions. I also provide details of my sampling method and demographic information of the interview participants. The Results chapter addresses the objective to explore the development and implementation of the IEC component of Dignitas International's CHBC model from the emic perspective (i.e., insiders' definitions and understandings) of the interview participants. In addition, I present the recurrent research themes that appear central to the thesis topic based on analysis of the face-to-face interviews according to the case study research questions. I apply an evaluative tone in the Discussion chapter and critically reflect on the concepts I introduced in the Results section from an etic perspective (i.e., outsiders' definitions and understandings). In the Conclusion and Recommendations chapter, I list future areas for research, revisit the theoretical propositions, and provide recommendations for Dignitas International to apply to future IEC programs. Appendices contain a listing of the GCGH projects, interview questionnaires, a listing of IEC activities scheduled and attended, and a summary of HOPE kit activities.

CHAPTER 2: LITERATURE REVIEW AND BACKGROUND

Defining Communities

Understanding "community engagement" begins with the concept of community. Communities are generally considered in geographical terms, although they can also be non-geographical, centered around shared beliefs or characteristics including ethnicity, sexuality, or social class (Minkler & Wallerstein, 1997). Definitions of community include: 1) functional spatial units fulfilling sustenance needs; 2) units of patterned social interaction; 3) symbolic units of collective identity; and, 4) units of people assembling to act politically and make changes (Minkler & Wallerstein, 1997). Kathleen MacQueen and colleagues (2001) recognized the variety of definitions for community and the lack of an accepted definition that can result in contradictory assumptions about communities and difficulty evaluating community public health initiatives. They asked 118 people with varying backgrounds living in the US including African Americans, gay men, injection drug users, and HIV vaccine researchers what the word "community" meant to them with the aim of establishing an evidence-based definition of community. The common definition that resulted was "a group of people with diverse characteristics who are linked by social ties, share common perspectives, and engage in joint action in geographical locations or settings" (MacQueen et al., 2001, p. 1929). There might be some objections to applying this definition of community in other countries besides the US where it was

developed, but the importance of using a definition that reflects community members' understandings remains necessary. Establishing a common definition has consequences for public health researchers; differentiating who belongs and who does not belong to the community is important when attempts are being made to be broadly inclusive of all community members.

Minkler and Wallerstein (1997) explain that communities can be understood by two sets of theories, characterized as an ecological systems perspective and a social systems perspective. In the first case, the focus is on population characteristics including size, density, and heterogeneity; physical environment; social structures; and technological factors, meaning the ecological systems perspective is most relevant in the examination of independent geographical communities. The social systems perspective is mainly concerned with formal economic, political, and other various "subsystems" operating within a specific community both within community systems and how they relate to other "extracommunity" systems (Minkler & Wallerstein, 1997). Saul Alinsky's ideology that communities represent social processes and problems of a society is an example of the social systems perspective. A researcher's or practitioner's perspective on community will dictate how this person believes a community should be organized.

Various models of community organization exist. One well-recognized typology is Rothman's classification into three models of practice: locality development, social planning, and social action (Rothman & Tropman, 1987). Locality development emphasizes community identity, social planning

emphasizes problem-solving, and social action emphasizes both. There are some limitations to this model. The first category, locality development, might restrict organization within geographical boundaries. Upon revisiting his model, Rothman (1996) himself noted that there is often considerable overlap between the model's three components and that each component possesses its own dilemmas. For instance, a great number of community locality development projects receive financial and other forms of support from external organizations. Also, the model is dependent on experts and may not always be concerned with building the problem-solving capacity of the community (Minkler & Wallerstein, 1997). A recent example exemplifying community organization that does not strictly follow Rothman's model is the mobilization of Mercedes-Benz owners from the Chongqing car club in China who filled their vehicles with medical supplies and food aid to deliver to survivors of the Sichuan earthquake (York, 2008). This group of people drove some 500 km to assist casualties that were not necessarily from the same locality.

Community-based Research

Understanding communities and models for community organization enables other concepts to be explored including community-based participatory research (CBPR) and community engagement. There are six fundamental principles of CBPR summarized in Table 1. Minkler and Wallerstein (2003) also emphasize that CBPR principles should include a focus on issues of gender, race, class, and culture as these relate to the research venture.

Table 1 Key principles of CBPR.

1. CBPR is participatory.
2. CBPR is cooperative, engaging both community members and researchers in a mutual contribution process.
3. CBPR is a co-learning experience.
4. CBPR involves systems development and local community capacity building.
5. CBPR is an empowerment process enabling participants to increase control over their lives.
6. CBPR attempts to achieve balance between research and action.

Based on Minkler and Wallerstein, 2003.

There are two trajectories explaining the historical roots of CBPR often referred to as the Northern tradition and the Southern tradition, respectively. Both trajectories are a response to the academic and political crises in the 1960s that sowed fertile ground for new theories and strategies of inquiry that would promote new political and economic democracies (Wallerstein & Duran, 2003). There was a paradigm shift in research toward "participatory research" whereby a plethora of terms and strategies arose varying with the field of study:

> *rapid assessment procedures, rapid rural appraisal,* and *participatory rural appraisal*; *classroom action research, critical action research,* and *practitioner research*; *action learning, action science, action inquiry,* and *industrial action research*; *cooperative, mutual, or reflective practitioner inquiry* ; *constructivist* or *fourth-generation inquiry*; *emancipatory inquiry* ; *popular epidemiology*; *collaborative action research, participatory research, emancipatory* or *liberatory research* and *dialectical inquiry*; *action research* and *participatory action research*; *community-based participatory research* (Wallerstein & Duran, 2003, pp. 27-28).

Community-based participatory research, like the other forms of participatory research, has three goals: research, education, and action (Wallerstein & Duran, 2003). Moreover, it is a collaborative endeavour where the community gains capacity to assess the environment and make health behaviour decisions and

the researchers advance in their pursuit of knowledge by learning from the community.

According to the Northern tradition, the emergence of these participatory forms of research, including CBPR, can be traced to the coining of the term *action research* by Kurt Lewin in the 1940s which involved a rejection of positivism and an espousal of constructivist thought. According to a constructivist theory, the meanings of participants acting in an intersubjective world cannot be separated in an objective fashion (Wallerstein & Duran, 2003). Essentially, this was a problem-solving utilitarian response to the current situation, and the tradition led to the development of consensus models.

The Southern tradition originated three decades later based on Marxist social theory from Latin America, Asia, and Africa as a response to crises of underdevelopment and a shift away from the belief that knowledge was based in the classroom. This tradition broadened the belief that popular and existential knowledge was born out of experience (Wallerstein & Duran, 2003). For example, Freire (1970) in *Pedagogy of the Oppressed* explains that communities are subjects of their own experiences and are not objects of inquiry. Applying this ideology in research is considered "emancipatory research".

Theories of knowledge and theories of power underlie the different traditions of CBPR. Before examining the theories, four core concepts of CBPR need to be defined (Wallerstein & Duran, 2003): 1) "participation" refers to how researchers and communities are involved in the research; 2) "knowledge" refers to the kinds and uses of knowledge resulting from the research; 3) "power" refers

to the associated power dynamics inherent in research; and, 4) “praxis” refers to the practical social application of the research in the community. The generation of new knowledge is the aim of any research endeavour. CBPR raises various knowledge concerns including “defined by whom, about whom, and for what purpose” (Wallerstein & Duran, 2003, p. 35). Knowledge should be recognized as power, but there are other power dynamics at play in CBPR that need clarification in order to understand relationships between researchers and communities (Wallerstein & Duran, 2003).

Understanding the knowledge and power theories of postcolonial, poststructuralist, and feminist varieties can enhance the appreciation of CBPR. A feminist perspective in CBPR attempts to “theorize gender” and recognizes gender as central in power relations (Wallerstein & Duran, 2003). CBPR under a poststructuralist framework will question how language, discourse, and narratives construct our intersubjective world and influence how we view social structures such as health and medicine (Wallerstein & Duran, 2003). Postcolonialism extends this thought to how race became a dominant factor in European colonization. Through this framework, the postcolonial researcher attempts to give a voice to less dominant points of view.

There is a growing number of CBPR efforts carried out in poor countries. The literature highlights a vast number of examples of CBPR. Two will be discussed here. Researchers from the US and South Africa carried out interviews, focus groups, and field visits to engage in cervical cancer prevention research in Cape Town, South Africa. Cervical cancer is the most common

cancer in Black women in South Africa (Mosavela et al., 2005). A major challenge to engaging communities in international health research arises when the community does not recognize the prominence of the health issue maintained by the researchers. CBPR can help build a mutual working agenda between communities and researchers. By systematically interviewing stakeholders, becoming acquainted with communities, and recruiting focus group participants, various perspectives helped to refocus the research goals and objectives around "cervical health". The authors discussed challenges of the CBPR approach including effective community engagement strategies. They asserted that effective community engagement means more than involving "visible, well-known, and research savvy stakeholders," and should provide an opportunity for a diversity of representation among community members (Mosavela et al., 2005). The authors also identified the importance of building relationships between researchers, especially international researchers, and communities as a vital part of engaging communities (Mosavela et al., 2005).

Health Unlimited is also undertaking CBPR in the developing world. Cambodia is one of South East Asia's poorest countries; the country's poorest health indicators are found in the province of Ratanakiri (Riddell, 2006). Maternal health indicators in the province suggest that 14% of women give birth under supervision of a skilled attendant, only 20% of women receive antenatal care, and the maternal mortality rate is over 437 per 100,000 live births (Riddell, 2006). The *Action Research to Advocacy Initiative* by Health Unlimited aimed to address poor maternal health by engaging communities to define health policy and

practice. The initiative combined qualitative research with social action, or in other words was an action research project. The research team conducted focus group discussions and interviews with community members to identify and explore barriers or facilitators to accessing health services. Following the research, community members were invited to attend workshops, where policy makers were also in attendance, aimed towards addressing access barriers and ultimately improving health. The initiative emphasized the importance of empowering women who, like in many other countries, are the primary caregivers in Cambodia. Health Unlimited advocacy projects are ongoing in Cambodia and have since expanded into Peru and Rwanda (Health Unlimited, 2007).

Community Engagement

Definitions of community engagement vary depending on the source. Various organisations study community engagement including the U.S. Centers for Disease Control and Prevention, Tamarack Institute, Wellcome Trust, University of Central Lancashire Centre for Ethnicity and Health, Canadian Institutes for Health Research, and HIV Prevention Trials Network (CDC, 1997; Tamarack Institute, 2008; Wellcome Trust, 2008; UCLAN, 2007; CIHR, 2007; HPTN, n.d.). Table 2 depicts selected definitions of community engagement. Note that none of these definitions specifies *research.* Implicit in all the definitions is an identification of the "community" itself, however broadly it might be defined. "Community involvement" and "community participation" are concepts encompassed by the meaning of community engagement. Community engagement is distinct from public engagement, which I define as a process that

provides people with trustworthy information on key policy issues, elicits their input, and integrates it into decision-making and social action (Cohen et al., 2008).

Table 2 Selected definitions of community engagement.

Source	Definition of community engagement
US Centers for Disease Control and Prevention	A process of working collaboratively with and for groups of people affiliated by geographical proximity, special interest, or similar situations to address issues affecting the well-being of those people (CDC, 1997).
Tamarack Institute	A method to improve communities by identifying and addressing local ideas, concerns, and opportunities (Tamarack Institute, 2008).
University of Central Lancashire Centre for Ethnicity and Health	The simultaneous and multifaceted engagement of supported and adequately resourced communities and relevant agencies around an issue or set of issues, in order to raise awareness, assess and articulate need, and achieve sustained and equitable provision of appropriate services (Winters & Patel, 2003).

Adapted from Tindana et al., 2007, by permission.

Key criteria for engaging communities were identified by the Tamarack Institute (2008) based on research of numerous community engagement initiatives in Canada and the US and one initiative in Egypt. The Institute suggests that community engagement consists of a diverse group of people participating, being engaged, and attempting to solve complicated problems; the engagement results in a vision, measurable results, movement and/or change; intersectoral approach with a focus on collaboration and inclusion; community-based; and balance between community engagement activities and creating action (Tamarack Institute, 2008). The CBPR knowledge and power theories of postcolonial, poststructuralist, and feminist varieties, explained above, can also be applied to community engagement.

The Tamarack Institute webpage (2008) depicts several models for community engagement from various sources, but all are from the developed world context and none are from a research context. Two models, however, are relevant for community engagement in any context because they explain the engagement continuum and key principles of community engagement.

Community Engagement Models

The process of community engagement may be considered like a spectrum or continuum of lower (almost superficial) levels to higher (most legitimate) levels of engagement. The International Association for Public Participation (IAP2) developed one such continuum ranging from lowest level of engagement to highest level of engagement, through informing, consulting, involving, collaborating, and empowering (Table 3). Informing others is simply about filling knowledge deficits, but can hardly be classified as engagement. Consulting is not an engaging process, but simply means feedback is requested; there is no emphasis on establishing criteria around how information received through consultation will be used. Involving and collaborating with others is closer to engagement, where in the former case the community's concerns will be taken into account when making decisions and in the latter case there is a commitment to working together. Empowerment, where the community is fully engaged, is the level of engagement that any agency committed to community engagement will strive for.

Table 3 IAP2 public participation spectrum.

INFORM	CONSULT	INVOLVE	COLLABORATE	EMPOWER
Public Participation Goal:	**Public Participation Goal:**	**Public Participation Goal:**	**Public Participation Goal:**	**Public Participation Goal:**
To provide the public with balanced and objective information to assist them in understanding the problem, alternatives, opportunities and/or solutions.	To obtain public feedback on analysis, alternatives and/or decisions.	To work directly with the public throughout the process to ensure that public concerns and aspirations are consistently understood and considered.	To partner with the public in each aspect of the decision including the development of alternatives and the identification of the preferred solution.	To place final decision-making in the hands of the public.
Promise to the Public:	**Promise to the Public:**	**Promise to the Public:**	**Promise to the Public:**	**Promise to the Public:**
We will keep You informed.	We will keep you informed, listen to and acknowledge concerns and aspirations, and provide feedback on how public input influenced the decision.	We will work with you to ensure that your concerns and aspirations are directly reflected in the alternatives developed and provide feedback on how public input influenced the decision.	We will look to you for direct advice and innovation in formulating solutions and incorporate your advice and recommendations into the decisions to the maximum extent possible.	We will implement what you decide.
Example Techniques to Consider:	**Example Techniques to Consider:**	**Example Techniques to Consider:**	**Example Techniques to Consider:**	**Example Techniques to Consider:**
• Fact sheets • Web sites • Open houses	• Public comment • Focus groups • Surveys • Public meetings	• Workshops • Deliberate polling	• Citizen Advisory Committees • Consensus-building • Participatory decision-making	• Citizen juries • Ballots • Delegated decisions

Source © IAP2 by permission. All rights reserved.

Planning, commitment, and inclusiveness have been cited as key principles of effective community engagement. Planning involves setting objectives and requires considerable time commitment. Evaluation is incorporated into this principle meaning community engagement involves reflexivity and is an iterative process. The second principle, commitment, should

be strived for, but is difficult to measure. Enabling individuals and communities to identify their own “issues for action” means they are ultimately engaged. Inclusiveness is more than simply ensuring communities can attend engagement activities through careful planning, but is about providing the community maximum opportunities for participation (Tamarack Institute, 2008).

A critical concept in community engagement is *who* represents the community being engaged. For instance, do people passively self-select to be involved in engagement activities or are they actively recruited by an external agent such as a local leader? How important are the numbers of people being engaged? *Which* people in the community are being “engaged”? It is easy to criticize many so-called community engagement projects because they are only empowering 10 or so people, although they claim they are engaging the community. Indeed it is important to be aware of what is *not* considered community engagement in research. Simply providing and supplying information or actively ensuring acceptance of an intervention is not community engagement. Rather, it is about ensuring ethical research that is responsive to a community’s needs, is participatory, and results in fair benefits (Participants in the 2001 Conference, 2003).

Developing World Context

Poor countries continue to struggle with a high burden of infectious diseases that contributes to high morbidity and mortality. Globally, about 40 million people are infected with HIV, 95% of them living in developing countries (Global Fund, 2008). AIDS resulted in 2.3 million deaths in sub-Saharan Africa in

2003 (Global Fund, 2008). Every year around two million people die of tuberculosis worldwide (Global Fund, 2008). Malaria is responsible for causing 300 to 500 million clinical cases a year in addition to causing one million deaths worldwide—over 90% of malaria deaths are in Africa (Global Fund, 2008). Besides infectious diseases, poor countries are also experiencing an increase in chronic non-communicable diseases, which are expected to become the main cause of death by 2015 (Zarocostas, 2007).

One potential explanation for unmanageable health problems, or at least an argument why the situation is not improving, is the lack of human resources to deliver health care in these poor countries (Bedelu, Ford, Hilderbrand, & Reuter, 2007; Médecins Sans Frontières, 2007). One arguable explanation for the shortage is the crime that rich countries are committing by poaching trained professionals, including health professionals, from poor countries. This "brain drain" problem has been well-studied elsewhere (Mills et al., 2008; Buchan, 2005). In light of a shortage of professionally trained health care providers, there is a need for trained community members in HIV/AIDS care (Bedelu et al., 2007; Médecins Sans Frontières, 2007). Not only are poor countries faced with high rates of infectious diseases and rising rates of chronic non-communicable diseases, but climate change is also predicted to disproportionately adversely affect poor countries (Campbell-Lendrum & Corvalan, 2007). Funding agencies often decide what global health problems to address according to measurable indicators and outcomes. HIV/AIDS receives considerable funding, for instance, because factors such as number of patients accessing services, like

antiretrovirals (ARVs), HIV screening, and prevention of mother-to-child transmission (PMTCT), are measurable. Community engagement is relevant to effective service delivery and scaling up services because it promotes awareness and fosters a sense of community ownership.

Zomba District, Malawi: Political, Social, and Epidemiological Context

Malawi, often referred to as the "warm heart of Africa", is a small, poor, landlocked country in sub-Saharan Africa facing several of the hardships experienced by other developing countries. Malawi has been independent since July 6th, 1964 and has had a multiparty democracy since 1994 (CIA, 2008). The official language is Chichewa. More than three-quarters (76%) of Malawians live on less than US$2/day and almost half (42%) live on less than US$1/day (Conroy, 2006). While there is increasing urbanization, around 85% of Malawians live in rural areas (Conroy, 2006). Malawi is a rural economy where agriculture accounts for one-third (33%) of the nation's GDP (Conroy, 2006). Any fluctuations in climate or changes that remove workers' attention from the land have the potential to result in devastating consequences. For example, when a family member falls ill not only are minimal family resources used to buy medication and to treat the patient, but less time is spent attending to the land and food supplies diminish.

There are an estimated 900,000 adults living with HIV/AIDS in Malawi and 170,000 people are in need of treatment (Conroy, 2006). There are only 156 physicians employed in the public health sector (Ministry of Health) and the Christian Health Association of Malawi to serve a population of 12 million people

(Conroy, 2006). Clearly, the shortage of trained health professionals needs to be addressed. An additional strategy to improve the situation involves the introduction and adoption of technologies in general and health technologies in particular. The ethical introduction and adoption of these technologies will be dependent on several factors, including community engagement.

Zomba District is the fifth largest district in Malawi. Located in the south of the country, Zomba is renowned for the Zomba Plateau. It is the former capital of Malawi, replaced by Lilongwe in 1975. Its current population is roughly 676,000 with 100,000 people living in the urban town centre. Zomba is home to Chancellor College, the main campus of the University of Malawi. The Zomba Central Hospital and District Health Office are both severely understaffed, lacking in resources, and overburdened with sick patients. The rural population is widely dispersed and faced with transportation obstacles making professional health care almost inaccessible. Zomba has Malawi's fifth highest prevalence of HIV (17.8%, Chipeta, Schouten, & Aberle-Grasse, 2005).

HIV/AIDS and IEC in Malawi

IEC has been applied in Malawi in various contexts such as condom use (Meekers, Van Rossem, Silva, & Koleros, 2007), family planning (Paz Soldan, 2004), and HIV/AIDS awareness (Mwangalawa, 1995). The focus of this research is IEC and HIV/AIDS. The initial organized national government response to HIV in Malawi included an IEC component in addition to medical

interventions (Conroy, 2006).[1] In 1999, the country's National Strategic Framework for AIDS Prevention and Care also included an IEC component (Conroy, 2006). It is important to realize that without addressing upstream factors responsible for HIV/AIDS such as income and gender inequality, IEC alone is unlikely to promote sustained behaviour change. It will hopefully be possible, however, to address some of these factors through IEC. Many HIV/AIDS messages are disseminated through IEC techniques including radio, TV, newspapers, billboards, and posters (Conroy, 2006). Unfortunately these messages are generally inaccessible in remote rural areas where poverty is widespread and literacy levels are low. Dignitas International made IEC a component of its CHBC model.

Dignitas International

Dignitas International is an academic NGO that started a five-year program in Zomba District, Malawi in 2004 with the overall goal to increase access to prevention, treatment, care, and support for people infected with and affected by HIV/AIDS, and to develop tools and guidelines for a sustainable healthcare delivery approach that can be disseminated quickly and cost-effectively (Dignitas International, 2008). Its headquarters are located in Toronto, Canada. In collaboration with the District Health Office, Ministry of Health, the Christian Health Association in Malawi, and other organizations, Dignitas International developed a CHBC model to scale-up the response to HIV/AIDS in

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[1] The first case of AIDS in Malawi was diagnosed in 1985 (Conroy, 2006). The Malawian government, however, was slow to recognize AIDS and it was not until 1987 that a committee of Ministry of Health members designed an AIDS Control Plan (Conroy, 2006).

Zomba. This site was chosen in collaboration with Malawi's Ministry of Health (Dignitas International, 2008).

Preliminary results of Dignitas International's CHBC initiative

According to the Dignitas International website (2008), as of May 2008, positive results in Zomba include:

- 6,000 children and adults started on life-saving antiretroviral medications;
- Over 250 new patients gain access to antiretroviral medications each month;
- 3,500 people continue to be tested for HIV each month at 31 HIV Testing & Counselling (HTC) sites;
- Almost 35,000 pregnant women have accessed PMTCT services to help prevent transmission of HIV to their newborns;
- Almost 2,000 pregnant women continue to access PMTCT services each month at 22 PMTCT sites;
- Hundreds of trained home-based care workers continue to provide essential care to the most ill patients in their homes;
- 18 community-based organizations in Zomba District are supported; and
- Thousands of attendees continue to be directly reached through HIV/AIDS IEC activities every month.

Dignitas International Interactions with the Community

The positive results described above are important to consider in the context of interactions between the community and Dignitas International. In August 2006, prior to the Dignitas-ESC partnership, the IEC program conducted an evaluation of its staff who engaged communities, the Area Mobilisers (AMs), following one year of their employment. The evaluation revealed that 100% of the AMs were committed to doing their work and were all well connected to the communities. Dignitas' celebrated results described above would not have been achieved without the AM's contributions. The AMs helped to strengthen Dignitas International's interactions with other community-level organizations and institutions.[2]

This AM evaluation helped Dignitas identify some obstacles to interacting with communities. They included inadequate IEC materials, resistance from religious groups, lack of voluntary counselling and testing (VCT) sites, poor conduct of partner organizations, objections to paid volunteers, and poor linkages with Village Development Committees. A shift in community engagement models from training AMs to training Community Motivators (CMs) was made to overcome these obstacles. This new CM model was designed to facilitate sustainability, ownership, participation, and transformation.

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[2] Dignitas has worked with the following CBOs in Zomba: Hope for Life, YONECO, Interaide, Sadzi Youth Group, MACOBO, Malosa Youth Group, CADECOM, NICE, Tikondane Support Group, Tilimbike Support Group, Self-Help, Faith Trust, VDC, WVI, Mwambo Youth Group, MACRO, BLM, Village to Village, Hunger Project, Matiya Transmitting Youth Club, and Chikwanga Youth Club.

Rationale for Zomba CE Case Study

Dignitas International's participation in the CE case study emerged from an internal review of the IEC component of the Dignitas CHBC model. The results of this internal review led Dignitas to conclude that IEC activities were not achieving optimal results, primarily because of a lack of community ownership over the program. Thus Dignitas restructured the program, employing a new model of representation and a new process of community engagement emphasizing participatory methodologies. Through the adoption of intervention research methods, Dignitas is actively engaged in monitoring and evaluation of the new IEC program, with a view to implementing it in future projects (Dignitas International, 2008). For Dignitas, the Ethical, Social and Cultural community engagement case studies project represents an opportunity to engage with a higher-level analysis of community engagement and apply lessons learned to continuous quality improvement for the program in Malawi and future project sites.

Summary

The health care system in Malawi is inadequate and incapable of providing health services. There are only 156 physicians to serve a population of 12 million people (Conroy, 2006). Dignitas International recognized the need to explore an alternative decentralised health care model. The government of Malawi was also interested in exploring a decentralised health care model and suggested that Dignitas implement its program in Zomba District. Dignitas International implemented a clinical HIV/AIDS community home-based care program including

an Information, Education, and Communication community engagement component in Zomba in 2004. Dignitas International and local communities identified IEC as an integral part of the health system to raise awareness of available services and to help ensure they are utilised. Originally, paid Area Mobilisers (AM) conducted IEC activities in communities. Due to concerns with sustainability and ownership, this program was terminated after one year and replaced by the volunteer Community Motivator (CM) model. It was necessary for Dignitas International to understand what worked and what did not work with the AM program and to assess the CM model as it was currently operating in communities. For the Ethical, Social and Cultural Program, this collaboration provided an opportunity to explore strategies used to engage communities in a developing world context.

CHAPTER 3: METHODS

This thesis research adopted the case study strategy of inquiry to explore effective practices of community engagement in Zomba District, Malawi.

Type of Study

The case study method approach is a qualitative inquiry strategy that offers a method of learning about a complex instance through extensive description and contextual analysis (Yin, 2003). Another scheme to characterize qualitative studies includes case studies as one of five approaches along with narrative, phenomenology, ethnography, and grounded theory strategies (Creswell, 2003). Robert Stake, a pioneer in case studies research, views case studies as borrowing from a variety of these qualitative strategies. Stake (1995) defends the necessity of focusing on "issues" related to the case and not generating hypotheses in advance of the research since they might take the focus away from the context. Research questions should therefore be posed as "issue questions". In this thesis study, the case study methodology is the most appropriate because the focus, or unit of analysis, is a program and the purpose is exploratory.

Stake (1995) distinguishes instrumental versus intrinsic case studies. In the former instance, the researcher believes the case under analysis will give clarity to the research questions and minimize confusion around the topic in

general. In intrinsic case studies, the case to study is assigned. The distinction between instrumental versus intrinsic case studies is important because it establishes what becomes dominant: the case or the issues. The case is dominant over issues in intrinsic case studies while the issues are dominant over the case in instrumental case studies, meaning instrumental case studies are more abstract. This research study on community engagement is an instrumental case study.

According to Robert K. Yin (2003)—another key thinker in case studies research—there are five components to case study research design: 1) study questions; 2) propositions; 3) unit of analysis; 4) linking data to propositions; and 5) criteria for interpreting the findings. Below I provide a description of these components and demonstrate how I have addressed each of them.

i. Study Questions

Research questions typically ask who, what, where, how, and why (Yin, 2003). The form of research question can dictate the most appropriate strategy of inquiry. Case studies are best suited to answer the “how” and “why” questions; “what” questions are exploratory in nature. The project addressed the following questions, which were developed based on the case study goal and objectives:

1. What were the community engagement activities undertaken by Dignitas in its IEC program and why did Dignitas choose those specific activities?

2. How did various stakeholders perceive the effectiveness of the community engagement effort?
3. What factors (internal and external) contributed to the success/failure of the community engagement effort from the various perspectives? How did these factors influence success/lack of success?
4. What critical lessons were learned during the course of the community engagement effort?

ii. Propositions

Hypotheses guide and direct the scientific method of inquiry while propositions can help maintain the focus in qualitative case studies. The object of formulating *a priori* propositions is not to take the attention away from the context. In the words of Yin (2003, p. 22), "each proposition directs attention to something that should be examined within the scope of study." In conjunction with the CE research team, the following theoretical propositions were developed based on previous experience and the literature about community engagement. They were meant to direct attention to determinants that may impact the success of community engagement and give direction to the study, allowing more nuanced questions to be posed. Table 4 lists the factors that increase the chance of success in community engagement (Singer et al., 2007; Tindana et al., 2007; Minkler & Wallerstein, 2003; Glanz, Rimer, & Lewis, 1997; HPTN, n.d.; Mosavela, et al., 2005; MacQueen et al., 2001; Riddell, 2006; Winters & Patel, 2003):

Table 4 Theoretical propositions: factors that enhance the possibility of success in community engagement.

a.	Early initiation of community engagement activities
b.	Community role in developing the research/intervention
c.	Clear purpose/goals in terms of research activities (both scientific and social/health goals) and community engagement process
d.	Knowledge of the community, its diversity, and its changing needs
e.	Understanding of community perceptions and attitudes
f.	Adequate opportunities to express and respect dissenting opinions
g.	Establishment of relationships, commitment, and trust with formal and informal authorities in communities
h.	Provision of information in accessible, culturally/linguistically appropriate, community-approved format and effective dissemination of that information in accessible formats
i.	Building on existing strong community groups/structures/mechanisms
j.	Permission/authorization from community
k.	Identification, mobilization, and development of relevant community assets and capacity
l.	Maximum opportunities for stewardship/ownership/control by the community
m.	Establishment of, review, and evaluation of engagement strategies
n.	Increased involvement of marginalized groups such as women or indigenous groups or even the poor and uneducated in the community engagement process
o.	The existence of local research ethics boards
p.	The existence of local committees/councils/bodies/gatekeepers who represent community views
q.	Integration of community perceptions and values into research/intervention activities
r.	Supportive government and economic policy
s.	Adequate funding for healthcare
t.	High relevance to local health needs and consumer benefit
u.	Length/scope of commitment.

iii. Unit of Analysis

The unit of analysis describes the actual "case" under investigation. This case study will examine the perspective of individuals with a legitimate interest in the Dignitas IEC activities.

The fourth and fifth components of case study research, linking data to propositions and criteria for interpreting the findings, are closely tied to the analysis stage of the project and are less developed than the other components (Yin, 2003)

iv. Linking Data to Propositions

The case study analysis mapped the theoretical propositions to empirical data. The global case studies research team interrogated the transcripts and emergent analysis using the propositions and other considerations from logic and experience to ensure there were no missing important points and that the interpretations of the data were reasonable and conceptually sound.

The "Network View" component of ATLAS-ti version 5.2 qualitative data software was used to construct and depict codes, referred to as "nodes" in the network, in a conceptual network view. Meaningful relationships can be drawn between two or more nodes. I constructed my network views using the constant comparative method. After analyzing each interview, data were distilled in a network view.

v. Criteria for Interpreting the Findings

To determine if and how closely the data match the propositions, criteria for interpreting findings must be established. The findings were interpreted based on the following criteria:

a) The degree of consistency with starting propositions; and,

b) The extent to which critical perspectives on the effectiveness of community engagement activities from multiple stakeholders were obtained.

Based on the key research questions listed above and the related case study components, an interview topic guide was prepared (Appendix B).

Ethics Approval

Ethics approval was obtained from the University of Toronto for the global CE case studies and from Simon Fraser University for my work on the Zomba District, Malawi case study. Local ethics approval was obtained from the National Health Sciences Research Committee in Malawi.

Place of Study

Data collection for the case study took place in Zomba District, Malawi where Dignitas International is implementing its CHBC model. One interview was conducted by telephone. The case study analysis and write-up occurred in Vancouver, Canada with weekly conference calls among CE global case study team members. A face-to-face meeting with all CE global case study team

members and Dignitas International representatives in attendance took place from April 2-4th, 2008 in Toronto, Canada.

Data Collection

Data was collected in three phases based on two separate trips to Zomba and one telephone interview. The first visit was a ten-day trip (17 May 2007 – 27 May 2007) to get acquainted with Dignitas staff, the CHBC project in general and the IEC project in particular. Data consisted of observations and field notes from one IEC community activity. The second phase was a six week trip to Zomba (12 July 2007 – 24 August 2007) when data was collected from 25 face-to-face interviews and field notes and video from seven IEC community activities. The third and final phase of data collection consisted of a telephone interview with a Dignitas staff (May, 2008) to clarify issues needing elaboration. Data were collected from four separate sources:

i. **Documentation**: Historical documents that might provide information regarding the design and impact of community engagement initiatives, such as IEC activity reports, project evaluations, meeting minutes, written reports, Dignitas International webpage content, and other relevant articles;

ii. **Interviews**: Twenty-six audio-recorded individual interviews approximately one hour in length (with a range of thirty-three minutes to one hour and fifteen minutes) in semi-structured open-ended formats. The language preferences of the study participants were accommodated. Six interviews

were conducted in Chichewa with the assistance of a local translator and the remaining 20 were in English. Interviews with Dignitas staff and the former Area Mobilisers occurred at the Dignitas office in Zomba. The other interviews occurred in the homes of participants, at a school, or in a CBO office. One interview was conducted over the telephone. All participants, except Dignitas staff, were given a bag of rice as a token of appreciation. With consent, all individual interviews were digitally audio-recorded and transcribed. I verified all of the transcripts before proceeding to analysis. Selected interviews were video recorded;

iii. **Direct observation**: Video-recorded observation of meetings, community engagement activities, and research-related activities (dissemination of preliminary findings in Zomba). I attended eight IEC activities in total. Appendix C lists the IEC activities that I scheduled and attended; and,

iv. **Participant observation and field notes**: Residing at the case study site and participating in local activities.

Sampling Method

Purposive sampling was used to identify 16 interview participants in consultation with Dignitas International. I used sequential referral sampling combined with quota sampling to identify an additional 10 community member participants. The five Community Motivators each identified two community members from their area; an attempt was made to achieve a gender and perspective balance among participants.

Sample Size

In July and August of 2007, I conducted face-to-face interviews with 25 participants. Twenty-six participants were invited for an interview; however, one interview was cancelled due to a conflicting IEC activity that I attended. A 26th participant was interviewed in May, 2008. Participants were purposively selected based on some relationship to and/or role in the general Dignitas International CHBC initiative and IEC model in particular. Table 5 depicts demographic information of interview participants. Fifteen (15) males and eleven (11) females were interviewed. Interview participants had diverse backgrounds: Dignitas staff (9; 8 present and 1 former Dignitas staff; 1 from Toronto, 8 from Zomba. Of the 8 Zomba staff, 1 was a Canadian expatriate and 7 were locals), Dignitas community program implementers (8; 5 Community Motivators, 2 former Area Mobilisers, and 1 HBC volunteer), CBO members (4), local leader (1), Health Surveillance Assistant (1), and community members (10). Affiliation with the Dignitas International IEC program among interview participants varied from IEC program developers (5), IEC program implementers (7), IEC recipients (10), and Dignitas staff that had a peripheral affiliation to the IEC program (4). All participants were co-operative and happy to share their personal stories. Some were sceptical about the benefits of the research and requested material gifts.

Table 5 Characteristics of interview participants.

Interview participant gender	
Males	15
Females	11
Interview participant background*	
Dignitas Staff	8

Former Dignitas Staff	1
Dignitas CMs	5
Former Dignitas AMs	4
Dignitas HBC Volunteer	1
CBO Members	4
Local Leader	1
Health Surveillance Assistant	1
Community Members	10
Participant affiliation with Dignitas International IEC Program	
IEC Program Developers (Dignitas Staff)	5
IEC Community Implementers	7
IEC Recipients (Community Members)	10
Peripheral affiliation as Dignitas staff	4

*Total exceeds 26 because participant's background could fit into more than one category.

Data Analysis

Interview transcripts were analyzed and coded using ATLAS-ti qualitative data software. Codes were established based on the case study objectives and formed the basis of the headings in the Results section. In addition to linking data to propositions and establishing criteria for interpreting the findings, as discussed above, the analysis process consisted of triangulation—employing more than one method for interpretation—and member checking.

Analysis occurred in two phases. First the lead investigator analyzed each transcript. A lead reviewer from the research team was assigned to the case study and concurrently analysed the transcripts. Research team members also had the option to make analytical comments on the raw transcripts. A preliminary Results section was written based on this first round of analysis. This provided a vehicle to progressively conceptualize and explore relationships among concepts

and insights within the data in a way that could be readily examined by the research team. In the second stage the lead investigator coordinated analysis of the transcripts among the global CE case studies team members who compared the findings from the interview with the content of the Results section. This investigator triangulation took advantage of the use of multiple analysts to assess accuracy in coding. The research team participated in weekly telephone conference calls to critically and constructively discuss analysis based on transcripts that were distributed electronically to all team members. Other forms of triangulation included theory triangulation (various investigators with different theoretical perspectives analyzed the data) and methodological triangulation (data is taken from interviews, documents, and videos). Member checking (or respondent validation) was possible for two interview participants that had the opportunity to validate their responses by reviewing the interview transcript. We were limited to one data collection visit to Malawi and so we emphasized progressive evolution of the analysis narrative, rather than a more purely iterative relationship between analysis and data collection, which we would have used in the absence of real-world constraints.

Confidentiality

No titles or other identifiers are used to distinguish interview participants and participants cannot be linked to specific quotations. All participants signed an informed consent sheet and had the option of signing a clause that stated they did not wish their names to be linked to specific quotations. No participants exercised this option. Participants also had the option of signing a clause that

stated they did not wish to be listed among the study participants and wished to take part in this study privately. Again, no participants exercised this option. Confidentiality is ensured, however, at the request of Dignitas International.

Researcher's Interpretive Lens

The interpretive lens that I apply to this case study is shaped by my own personal background that I believe I should articulate at the outset. I am a 25-year old, Jewish, female Canadian citizen that was born and raised in Ottawa, Ontario. I attended public school and was enrolled in French immersion from kindergarten to grade 8. I went to a high school for the performing arts where I studied trumpet. Before beginning the Master of Science program in Global Health at Simon Fraser University, I obtained a Bachelor of Science degree from the University of Toronto where I pursued genetics and biotechnology. Prior to conducting this research, I had previously travelled to various cities in Canada, the US, England, France, and Israel. This was my first time being exposed to extreme poverty and disease.

Future Steps

Following completion of the individual global case studies on community engagement, cross-comparisons will be made to identify any common themes and/or patterns across the cases. Preliminary multiple-case study analysis will consist of extracting all relevant data/information, putting information into different arrays, making a matrix of categories and distributing evidence accordingly, tabulating frequency of observed events, putting information in chronological

order, and editing video footage (video recordings will be treated as all other data and will be analysed using ATLAS-ti software) to produce a film on community engagement.

Limitations

There are limitations to any research methodology, including the case study method. Some critics claim case study methods are subjective and make controversial contributions to science (Stake, 1995). Other criticisms are that case study research complicates issues, its results contribute very slightly to the advancement of social practice, it is ethically risky, and it is expensive and time consuming. However, proponents would argue case studies provide unique means of understanding a social phenomenon. Indeed adopting qualitative research methods is a way of intensely studying and interpreting our surroundings and all researchers use qualitative methods, only some do not choose to report them.

One limitation to this research concerns the sample and sampling method. Sequential referral sampling can produce bias, namely nepotism in participant identification. For example, when asked to recommend a community member to interview, one CM recommended his own father. It is important to ask the relationship between participants when using this sampling method.

Another potential limitation to this study concerns the potential opportunity costs for the Dignitas International hosts in Zomba. Rather than directing full attention toward their CHBC model, staff made provisions for the researcher

including drivers to remote rural areas, supervision of certain activities, and office space allocation. In other words, resources were being diverted away from caring for others. An effort was made to minimally disrupt effective programming. Moreover, Dignitas International itself as an organization values intervention research methods to monitor and evaluate its programs. Thus, as described above, the research was mutually beneficial for both Dignitas International and the ESC Program sponsoring the research.

CHAPTER 4: RESULTS

The Results chapter fulfils the first research objective to explore the development and implementation of the Dignitas International IEC program by organizing the data according to the case study research questions. In this manner the emic perspective of the interview participants is highlighted. As cultural insiders, the community members have first-hand knowledge of IEC activities and community engagement strategies used in their villages.

1. Community Engagement Activities and Rationale for the Activities

IEC is one of seven components comprising Dignitas International's CHBC program. There are two IEC Officers who oversee the introduction of the IEC program to specific communities—sensitization meetings with local leaders, selection of Community Motivator, and training of Community Motivator. The goal of the IEC program is community engagement, although there are aspects of community engagement in the other Dignitas CHBC program components. The other components are antiretrovirals (ARVs), home-based care (HBC), prevention of mother-to-child transmission (PMTCT), HIV testing and counselling (HTC), orphans and vulnerable children, and operational research. "*It's found that IEC is needed in all these programs.*" Opinions differ on whether the IEC program should be introduced prior to or following the introduction of the other Dignitas services. On the one hand, some interview participants think that IEC should

precede the introduction of HIV/AIDS services to communities in Zomba. IEC can prepare the community by communication, raising awareness, and disseminating knowledge about Dignitas services so they can be readily accepted when they are introduced. In reality, Dignitas clinical services are established and made available in an area before IEC is introduced,

> *"I think the best program is for HBC [home-based care] to go first to the community. Conduct some assessments then report to IEC according to the findings of the assessment. Then IEC will create a program of activities according to the assessment done by the HBC [home-based care] team. Yes."*

A key person who received training by Dignitas is responsible for implementing the IEC component in communities. Formerly, an Area Mobiliser was hired as the key IEC person. Currently a Community Motivator volunteer holds the task of introducing IEC. The AM and CM models are depicted in Table 6, below. Whereas Dignitas International hired Area Mobilisers to work in various areas within Zomba, the communities chose Community Motivators to work voluntarily in their own communities. Before the community was responsible for selecting a Community Motivator, Dignitas informed local leaders of the IEC program. Area Mobilisers underwent a week of training; Community Motivators had two weeks training. Both Area Mobilisers and Community Motivators conducted IEC activities with their communities.

Table 6 (a) Area Mobiliser model and (b) Community Motivator model.

a) Area Mobiliser (AM) model	b) Community Motivator (CM) model
• Dignitas hired 20 AMs and appointed them to work in specific areas • AM had one week training • AM conducted introductions with local leaders • AM conducted introductions with local community organizations—NGOs, FBOs, CBOs, youth organizations, and support groups • AM disseminated information to the community: community sensitization meetings, school meetings, assembly strategies o IEC materials • AM worked through the health centre • AM built and sustained partnerships • AM program was evaluated by Dignitas International • AM received monthly salary	• Dignitas sensitizes local leaders in specific communities on how to select a Community Motivator • Community establishes a CM support committee (10-12 community members) • CM is selected by his/her own community • CM has two weeks training • CM conducts introductions with local leaders • CM conducts introductions with local community organizations—NGOs, FBOs, CBOs, youth organizations, and support groups • CM disseminates information to the community: community sensitization meetings, school meetings, assembly strategies o IEC materials • CM builds and sustains partnerships • CM works as a volunteer • CM is involved in income-generating activities (IGAs)

Area Mobiliser Model

Dignitas International originally hired 20 Area Mobilisers (AMs) to plan and conduct IEC activities in 20 different areas in Zomba (Figure 1); however, the AMs did not always work in their home communities. Dignitas International hired the AMs on a one-year contract and paid them a monthly salary. Said a Dignitas staff, "*they were making twice as much as a HSA [Health Surveillance Assistant] in the community so that was causing a lot of resentment.*" Following their week of training by Dignitas, AMs made introductions with village leaders and

community organizations. They proceeded to make introductions with community organizations and held community engagement IEC activities such as theatre with IEC messages. Towards the end of their contract, Dignitas staff formally evaluated the AMs, but Dignitas did not inform the AMs of its findings.

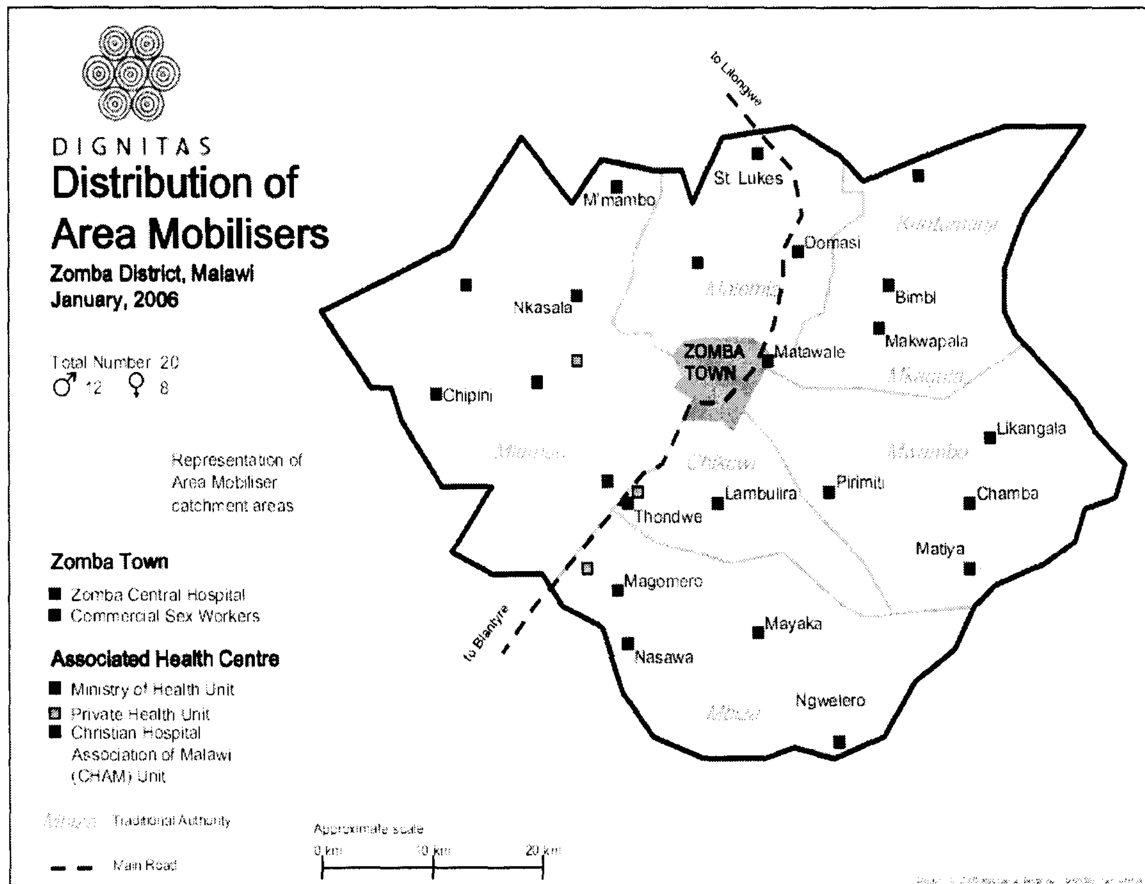

Figure 1 Distribution of Area Mobilisers, January, 2006.

Area Mobiliser Termination

Because of concerns about lack of ownership and sustainability, Dignitas phased-out the AM program at the end of the AM's one year contract and replaced it with the CM program. The "*communities also had to consent*" to the termination of the AM program and they were, according to a Dignitas staff person, "*informed*" during this process. Moreover, the new CM model was not

simply "imposed" on the communities, but Dignitas "*sort of went step by step with the communities,*" to develop a "*problem tree*" where it became obvious the communities needed a Community Motivator program. The Dignitas staff person described this process as challenging and that it took "*longer than I anticipated.*" The AM program was phased out between August and September, 2006. Communities initiated the CM selection process in November, 2006. The CM training did not occur until February, 2007.

Community Motivator Model

The CM program was initially implemented in five areas in Zomba (Figure 2). Dignitas IEC staff had the goal of scaling-up the CM program to 20 areas by December 2007. The Dignitas IEC staff introduced the CM program to local leaders in each of the five areas. Local leaders then engaged the community to select a 10- to 12-member CM support committee. This committee helped coordinate the CM selection process. The CM represents his/her own community and is selected by fellow community members.

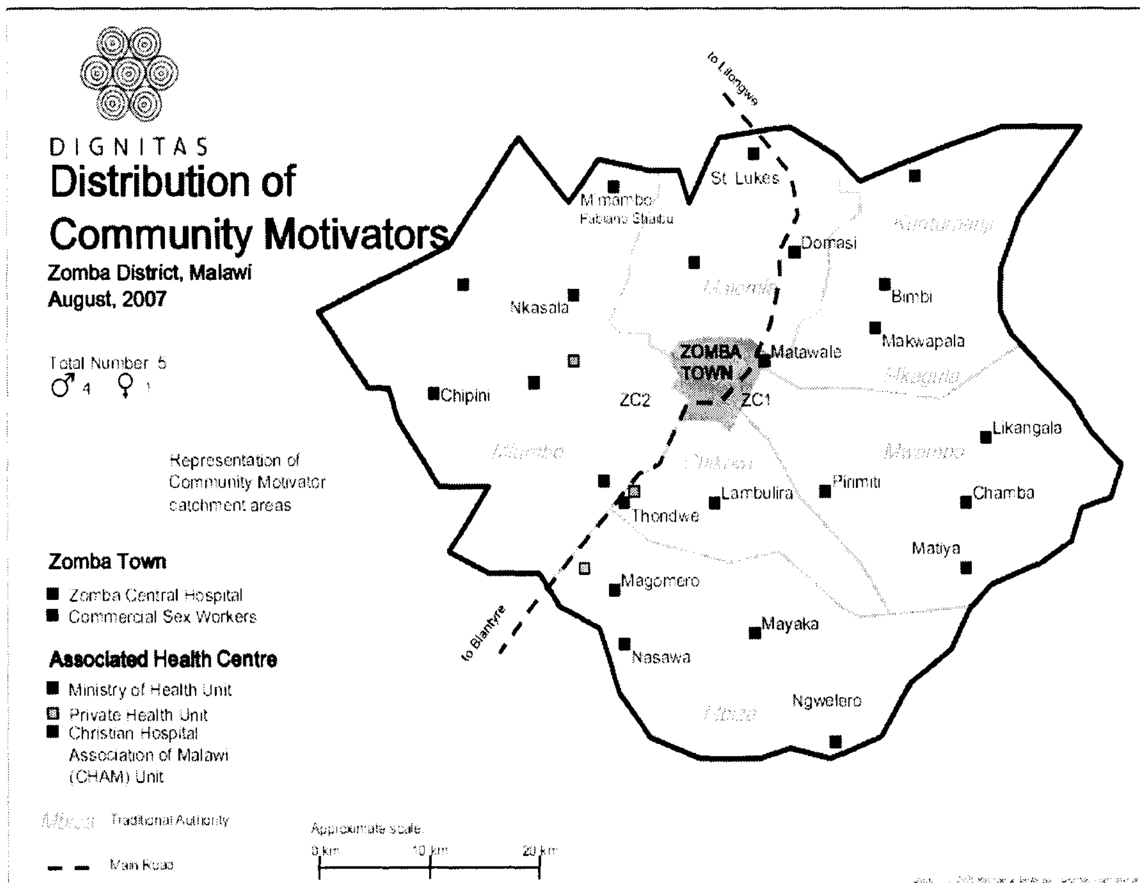

Figure 2 Distribution of Community Motivators, August, 2007.

One CM described his role as follows:

> *"conduct community meetings, conducting awareness campaigns in the area of HIV/AIDS, STIs, and community development as well. I also provide counselling in all areas of Dignitas programs. In addition to that I always report to Dignitas International and also to the TAs, Traditional Authorities, of my areas as well as the committee. In addition to that I also provide technical support to the CBO in my catchment area. That's my role."*

A few interview participants explained that IEC acts like a "*bridge*" between Dignitas and communities via the Community Motivators that are community-based but who report to Dignitas. This linkage between Dignitas and communities also represents a linkage between the outside world and communities since Community Motivators receive information from Dignitas that would not necessarily be available to communities otherwise.

Qualities/Characteristics of Community Motivators

Distinct qualities or characteristics are necessary to engage communities. In other words, being a Community Motivator is not a job for everyone. Personality is probably an important aspect of what makes community engagement, and IEC, successful. Dignitas staff, former AMs, and CMs listed "*friendly*", "*trustworthy*", "*polite*", "*open*", "*hardworking*", and "*charming*" to describe what kinds of qualities are assets for IEC positions. Another quality mentioned was the ability *"to speak English to easily communicate with people from different nations."* Because the CM *"elaborates things and explains clearly"* he helps to promote understanding by the community and clarifies community misconceptions.

Another quality or characteristic of CMs that appears in the data is the sense of responsibility they feel towards their community. Underpinning this characteristic is the insider/outsider concept: people working in their own communities feel a sense of responsibility to their communities, which data suggest is likely related to sustainability of the project, since when Dignitas leaves the site the CM will remain and can continue working.

Because the CMs work as volunteers, not only is the sense of responsibility necessary, so is passion and commitment towards the community. Experience likely shapes personality and inclines people to work with diverse communities. The interview participants had diverse work backgrounds before and after working with Dignitas.

It is the IEC activities themselves that define the community engagement aspects of the model; however, before explaining the IEC activities a brief overview of community participants' perceptions of "community" is necessary.

Definitions of Community

Zomba District is composed of several rural communities. The participants' understanding of their community is thus important to the project's implementation and function. How Dignitas defines community is also important since they are involved in supporting IEC community engagement activities. Six community member interview participants were asked to define, in their own words, the term "community". They were also asked how they thought Dignitas defined "community" and whether there were any differences in the two definitions. Two participants gave a definition based on geographical terms, three participants gave a definition based on ideological terms, and one participant gave a definition that had both a geographical and an ideological underpinning. Within the categories "geographical" and "ideological", definitions were essentially identical ranging from "*it's an area*" to "*a place where people live*" according to geographical terms, and ranging from "*[It] is a group of people that stay together and work together for the development of the area*" to "*[people] staying together and helping each other and building something solid that can help other people*" according to ideological terms. None of the participants could identify a difference between their own

definition of community and Dignitas' definition. This aligned and realistic understanding can enable a positive working relationship between Dignitas and communities and overall effectiveness of the IEC program.

IEC Activities

The CM holds a variety of community engagement IEC activities including sensitization meetings (for example to reduce stigma and discrimination and on the dangers of HIV/AIDS); meetings with youth, disabled, local leaders, and people living with HIV/AIDS (PLWHA) to disseminate HIV/AIDS information ("*IEC messages*"); sporting activities; school visits (Dignitas sends letters to District Education Managers to obtain permission to introduce the IEC program in schools); condom demonstrations; promotion of safe sex and of Dignitas services; drama (plays/theatre); poetry; traditional dances; youth festivals, and HOPE kit (a toolbox of HIV activities). The CM "communicates" HIV information (such as the benefits of an HIV test) and messages around positive living (such as remaining hopeful in light of HIV/AIDS).

CMs hold weekly or bi-weekly IEC activities, but the frequency of meetings is left to the CM's discretion. Certain "*assembly strategies*" such as sporting activities, drama, poetry, dances, and HOPE kit are effective at engaging large groups of people. Even meetings can be an assembly strategy whereby people congregate, mutual learning is promoted, support is offered, and information is disseminated. One such assembly strategy involves dissemination of IEC information following religious services (of any kind) when many people are congregated.

IEC activities are generally held within the community itself, although occasionally they are held in the privacy of the CM's home. The latter is a flexible option provided by some CMs and is not a condition demanded by Dignitas. There are a variety of ways that community members are notified that IEC activities and meetings will be taking place that depend on the community. In some cases, the CM him-/herself notifies community members by going door-to-door. Other times, the CM notifies the community through the local leader who calls his/her community to assemble. Letters are sometimes delivered to notify people of events. A Dignitas staff mentioned that media is used to advertise Dignitas activities and the organization itself within Zomba, however the interview participant also noted the use of media has not been fully optimized. IEC activities are essentially about "keeping people busy," whether they are surrounded by their peers at football games or are being educated by trained role models.

The attendance at IEC activities, which interview participants said varies depending on the organizer (more people attend activities organized by their own CM than activities organized by Dignitas) also varies with the type of activity being organized; Dignitas IEC activities are generally sensitization meetings, whereas CM IEC activities are generally theatre, dances, plays, sporting activities, and HOPE kit.

IEC Meetings

"Meetings" are an integral IEC activity, both in terms of program design and implementation. One interview participant described his role as a CM is to:

"*conduct community meetings.*" Meetings are organized by Dignitas to introduce new initiatives to communities, such as the CM program itself, and by the CM to disseminate IEC information. Attendance at meetings varies from small groups of local leaders to large assemblies of community members. Often, Dignitas organizes meetings with specific groups such as local leaders, youth groups, or the disabled. Meeting format varies between "one-way" or "two-way communication". In the former instance, Dignitas staff or the CM him-/herself presents information to an organized group of people. In the latter instance, the people in attendance present issues for discussion themselves. In both cases, the agenda is set by the person who organizes the meeting, but the flexibility of the agenda will depend on whether one-way or two-way communication is used. Community member interview participants emphasized the importance of being informed of meeting time and place in advance of meetings. They also explained that it is unprofessional and unacceptable for meetings to start late since people are often gathered in advance. The CM does not work alone in his/her community but IEC activities are supported by a Community Motivator committee.

IEC Community Motivator Committee

The IEC committee is not just involved in CM selection but actually provides operational support and participates in activities. As one community member described, this support ensures the CM will not work in isolation and helps overcome the challenge of working in a large area. The committee provides supervision of activities which could potentially be linked to monitoring and

evaluation. One CM committee member explained that he can provide guidance to the CM by monitoring his behaviour:

> "*Despite that maybe sometimes he's childish, he can be very childish. But we are here as a committee and can advise him that, 'This is not the way.' Now he's coming along.*"

Another community member explained the current CM model is an improvement over the AM model because of support from the CM committee: "*this time it works better. It is working better because [...] they are supporting each other.*"

Dignitas International Support for IEC

The CMs work voluntarily although they receive the following forms of support from Dignitas: motivational, training, technical (presence and support at community IEC activities; assistance planning, implementing, and funding IGAs; and, working with local CBOs), resources (such as a bike, posters, and pamphlets), and HIV/AIDS services (including antiretrovirals, PMTCT, HBC, VCT, orphans and vulnerable children, and operational research). Said a Dignitas staff,

> "*We've actually jumped the fence and started to support the groups so that they can become more self-reliant and self-sustainable. I think that's very unique. I mean everyone talks about it, but it's a big gamble, a big risk you know to release resources and money basically to put right into the hands of the community.*"

Basic supplies provided by Dignitas to the CM include,

> "*Bicycle they have given him also an umbrella, the raincoat, gum boots and also bags that can help him to carry some other goods to the meetings.*"

Training

Training is an integral form of support provided by Dignitas to the CMs and is the principal way the latter receives HIV/AIDS information. Community Motivators receive two weeks of training before they begin their IEC activities in their communities.

IEC Materials

Dignitas has limited IEC materials such as posters, pamphlets, and leaflets that it distributes through the CM. A Dignitas staff described that IEC messages are designed by Dignitas (not the communities) and that they are based on work by previous organizations that have used IEC in Zomba or Malawi.

HOPE kit

Another IEC material used by the CMs and which was commonly mentioned in the interviews is the HOPE kit, which contains a variety of HIV/AIDS activities (Appendix D). Interviewees explained large groups of people are enticed to participate in IEC activities when they are aware the CM will be bringing the HOPE kit. When using the HOPE kit, the CM fosters an environment where people can openly present issues rather than preparing issues to discuss in advance. In this way, the HOPE kit also helps to clarify misunderstandings. One community member explained, for example,

> *"using the HOPE kit it has helped to bring the community leaders and religious guys together and discuss the issues."*

Income-generating Activities

Dignitas recognizes the need to provide the unpaid volunteer CMs with support and encourages communities to design IGAs. Dignitas provides grants to communities to start-up IGAs; the community itself is responsible for supporting the IGA. The CM, the CM support committee, and community member volunteers are the ones managing the business. Examples of IGAs include selling clothes and bike maintenance shops.

Community Support for IEC

As mentioned above, the CM committee composed of community members is a central form of community support in the CM model. In addition, the community accepts the CM program (by attending activities and assisting the CM) and provides support (both time and monetary). When the CM program was initially introduced, some communities resisted it. Communities resisted for various reasons, some did not think it was fair to take away someone's salary, others did not understand the need to terminate a program that was working well in the community. In these cases it was necessary for Dignitas to "*convince*" these communities to adopt the program,

> "*But as we convinced them that it was really important for them to be in the forefront to learn the phase of the program. That changed their mindset. They started supporting the program.*"

Dignitas "*convinced*" the communities by holding sensitization meetings with local leaders and community members.

The word convinced, however, does not necessarily mean imposing values and beliefs onto the community. As mentioned by a former Dignitas staff

person, Dignitas held active dialogues to introduce the CM program and the community was engaged to develop the CM program. Eventually, as a Dignitas staff described, the community was supporting the CM program by contributing monthly financial donations. Community members also assist in the operation of local IGAs.

A CM emphasized the community is trying to support the IEC program with little assistance and dependence on Dignitas:

> "*The community on their own they are trying as much as possible to make sure they are on the ground and they are supporting. Though with few resources, because the community has few resources.*"

Local Leaders

An initial community assessment led Dignitas to appreciate that it is crucial to engage local leaders before introducing a program to specific communities in Zomba. Dignitas staff contacted local leaders, including faith leaders, to gain access to the community when it implemented the CM program. On how someone becomes a local leader, a CM explained,

> "*Here according to our culture, it comes through blood [...] Just go today and say, 'I am going to go and be a chief.' It can't happen (laughter). Yeah, yeah, yeah.*"

Another Community Motivator described the local leaders as "*gatekeepers*" to the community. In other words, entry into a community is only possible if local leaders are properly engaged. The process of IEC in Zomba begins with meetings with local leaders and is followed by meetings and activities with the community itself.

After Dignitas introduces the CM program to local leaders the community is encouraged to select a CM support committee and the CM himself or herself. The following statement by a community leader implies that there is some basis for selecting community members, such as the extent of their involvement in community development, and selections are not made randomly,

> "*a list of people that work hard towards the development of the village, it is these people we choose if there are any important issues that need sorting out.*"

Meeting with chiefs is not just a Dignitas strategy; a CBO member explained his organization also engages local leaders. One reason why it is so important to engage local leaders, explained a CM, is because they meet on their own to discuss programs in their areas. If they do not feel like they have been involved or they do not understand the program properly, they might oppose the program: "*These local leaders they meet on their own when you are not there.*"

A community member explained there are certain opinion leaders in the community who might not have the same status as local leaders, but who do have a great influence in their village: "*Yeah these [opinion leaders] are influential leaders in the community. They don't have any position in the community but very influential.*"

Partners/Collaboration

Another aspect of the IEC model is partnering and collaboration. As many CMs explained, "*[I] can't work in isolation.*" Dignitas International is essentially involved in three-way collaboration with local CBOs/FBOs/NGOs, government organizations, and communities. Dignitas solicits other organizations to partner

with and responds to requests for support from local organizations. Local health workers and CBOs also support the CM program by providing the CMs with information. Dignitas helped build linkages with the government and other agencies:

> *"And these CBOs are getting drugs from Dignitas and Dignitas is working in relationship with Ministry of Health. And here in Zomba it's the District Health Office that we are working with."*

One interview participant, a community member and health surveillance assistant (HSA), explained that partnering with the local CM provides the CM access to a large group of assembled people, for example an under-five clinic:

> *"When we are going to a clinic, even yesterday, we were there at the door. We were together with [our CM] and she gave them the information that people required."*

The HSA can also access groups of people assembled for IEC activities and disseminate messages:

> *"Sometimes we do work together [...] she do tell us on such a time I am going into your community somewhere I am having a meeting with the CBOs or with the chiefs."*

AMs worked mainly through the health centres, whereas CMs go into the field and interact with community members.

Intended Beneficiaries

Designing programs specifically for the community means people should no longer be identified as "target groups" but as "intended beneficiaries" (Cernea, 1991). There are three groups of people in particular who can be classified as intended beneficiaries of the Dignitas IEC program: women, youth, and other vulnerable groups.

Women

Dignitas IEC events appear to benefit women, since they are often held in conjunction with under-five clinics and women are the traditional caregivers in Zomba. Community members described women as "*empathetic.*" Some community members explained women are more interested in IEC activities while men are at work and youth are in school when meetings are scheduled so cannot attend. One community member clarified that not all youth are in school. This interview participant also explained that Dignitas IEC events involve local leaders whereas CM IEC events engage youth.

Youth

Data suggest that youth ought to be the main audience for IEC messages because they are unable to receive sexual health information from their parents:

> "*Parents are unable to talk to their children about maybe HIV/AIDS. There are other issues that are very sensitive. So due to feel of embarrassment, they don't feel they should talk to their children.*"

A Dignitas staff agrees with the need to involve youth. Not only are youth future leaders of Malawi, but they are the ones at risk of HIV infection and who have been left orphaned by AIDS. Moreover, the life expectancy at birth in Malawi is 42 years (WHO, 2005), meaning even HIV-negative people need hope and reassurance that life can still be meaningful: "*Because sometimes the people they miss out because they feel that they are dying anyway so they don't care.*"

Vulnerable Groups

Interview participants commonly said elderly and disabled populations are unable to attend IEC events. Other vulnerable groups, besides youth and women

mentioned above, that ought to benefit from IEC but who might not be benefitting from IEC activities include orphans, albinos, and commercial sex workers. Whereas government initiatives often exclude or are insufficient to target people living in rural areas, a community member explained this is a positive aspect of the Dignitas IEC program that specifically targets rural villages.

A community member explained that when Dignitas organizes IEC meetings, not many people attend (*"about 20 if not 15 people"*) versus other interview participants including former AMs that explained when CMs hold activities there are anywhere from 50 to hundreds of people in attendance. This might be linked both to the concept of community individuality/uniqueness (some communities are more engaged than others) and to the insider/outsider concept (CMs, who are community "insiders" have greater success at mobilising community members than Dignitas "outsiders").

2. Perceptions of Effectiveness of IEC

Data suggest community members and local leaders valued the AMs and that they felt engaged by them since they continually asked AMs to hold activities in their areas, attended events in high numbers, and asked questions following programs. Another metric of success for the AM program was that community members increasingly accessed clinical HIV/AIDS Dignitas services such as voluntary counselling and testing. Also, there was a community outcry when the AM program was terminated.

The AM model was not, in the opinion of both Dignitas staff and community members, community-owned or sustainable. According to a Dignitas employee,

> "*[I]t was a good program only that there wasn't all that program ownership from the communities. As well it wasn't sustainable because each and every month we were paying them close to MWK10,000*" (approximately CDN$75.00).

According to Dignitas staff, the CM program is successful. This can be explained in part by the articulation of objectives and expectations at the outset,

> "*We laid out clear expectation of what we expected of them and also we were very clear about what they could expect from us.*"

Area Mobiliser Model versus the Community Motivator Model

Community Member Perspectives

Two community members remarked they saw no difference between the AM and CM models—one of these community members is from a community where the CM was also the former AM. Other community perceptions differ. Indeed one interview participant was happy with the change, although it was difficult, and explained the transition was motivated by the community itself:

> "*Then during that meeting when we are trying to change their [Area Mobiliser] approach we said okay, 'We need to choose somebody independent. We need to choose somebody who is not involved in so many programs. Somebody from the community so that can just work effectively so that all the resources and information can be shared equally.'*"

Another community member thought the AM program was effective because the person received a salary that enabled him/her to devote time to the job, unlike the CM who must juggle competing priorities. The CM program, however, is better at involving others because Dignitas engaged the chiefs to

explain the CM program to them, unlike the AM program that was implemented without engaging local leaders first. To ensure sustainability of the CM program, however, this interview participant emphasized the need for the CM to receive some form of payment.

Half the community members interviewed (5 out of 10) were not familiar with the former Area Mobiliser program.

Dignitas Staff Perspectives

Unlike the AM model that was active in 20 areas within Zomba, at the time of data collection for this case study the CM model was only being implemented in five areas. One reason for scaling-down to fewer areas is related to the supply and demand concept of IEC. Dignitas staff believed that IEC needed to be scaled down to fewer areas to ensure it was operating in areas where Dignitas HIV clinical services were already available. This assists the success of the HBC program, for example, because the CM acts as a link between the community and the HBC team.

Another perspective is from a Dignitas staff member who explained the CM model is an improvement over the AM model because CMs come from the same community where they work.

Dignitas International Support for IEC

One CM explained that support from Dignitas while it is there, can be slow to arrive and that current support is inadequate for all needs:

"Dignitas has provided some other support to Community Motivators, but the problem was this support has taken very long time, yeah, to be conducted [...] So there should be more support."

Another CM agreed:

"they gave [me] a loan that [I] can help himself to do business but [I have] to pay it back slowly slowly. [...] They gave [me] MWK30,000 (approximately CDN$220) *but the way [I] live and the way [I] do [my] job [I feel] that it wasn't enough. But yeah that's what they gave."*

Another CM seemed confident that Dignitas provided enough support:

"now that we have good mobility, yeah we have that bike, that bike was given by Dignitas, the committee has a bike and the committee was given an IGA, I was supported by an IGA-so it means the problem of support its been relieved. Now with good mobility, everything I think will be ok. Sure."

Acknowledging Dignitas' support of local CBOs, a community member said,

"For me it's just to thank, to thank Dignitas for what they are doing for the community, IEC also for helping even us as a CBO. They are doing a good job, yeah, so just for them to continue to involve people in the community for any activity."

Training

Most CMs (3 out of 5, but 3 out of 3 who were directly asked) said two weeks training was insufficient because of the extent of information Dignitas provides to them and considering the initial lack of HIV/AIDS knowledge. CMs suggested refresher training throughout the course of their tenure. Another suggestion was to extend training to the CM support committees. Dignitas helps increase the capacity of CBOs by extending training to members of local organizations:

"Even Dignitas trains the CBOs on how they can take information and deliver it to the community so that the community can cope with it properly."

IEC Materials

Participants stated the IEC materials are "*very helpful,*" explaining why "*people scramble for them.*" As a result there is a shortage of materials. The IEC materials might not be helpful to everyone, however, because the messages are in English. Not only are people with low levels of literacy unable to understand the messages, they are inaccessible to people with no knowledge of English. A Dignitas staff described that IEC messages are designed by Dignitas (not the communities) and that they are based on work by previous organizations that have used IEC in Zomba or Malawi.

Income-generating Activities

While the necessity of IGAs is clear, there is some concern over the funding available to start-up a business,

> "*as much as I appreciate that Dignitas International has come up with an initiative that gives us MWK30,000* (approximately CDN$220) *as a Community Motivator to run a business, 30,000 here in Malawi is not enough for one to run a business.*"

By not paying its CMs, Dignitas is effectively transferring ownership of the IEC program, and arguably of the Dignitas HIV/AIDS services to the community. IGAs, in particular, serve the function of supporting the CM and transfer the responsibility of the program to the community itself,

> "*That's why we put in the IGA part. So that the communities should know that it's their role. And the chiefs, the local leaders are supposed to be the managers of those committees and the Community Motivator selected them so that this program should not stop even if Dignitas is not there. So they take a leading role than Dignitas.*"

There are burdens associated with this responsibility best stated by CMs themselves who question whether the IGA will yield sufficient profit,

> "*as well I was received MWK21,000* (approximately CDN$150) *to start a small business so that the profit can support myself. If that money is going to be lost, I think it could be difficult for me to support myself.*"

Local Leaders

Villages in Zomba are governed by local leaders. Engaging chiefs can be considered an important factor influencing the success or lack of success of the IEC program. When asked, "*How do you think that Dignitas IEC programs have been so successful?*" one community member responded,

> "*It's because they involve the, the chiefs. Yeah because the, the chiefs they do try to tell the people. They do have their own meetings so during those meetings the chief is able to tell to the people.*"

Partners/Collaboration

The idea of partnering or collaborating with the government was described as a strategy: "*[Dignitas did not want to] run away from the government.*" A Dignitas staff lamented it can be difficult to partner with the District Health Office (DHO), which has its own IEC program because the DHO does not appear to have clear objectives. Dignitas, on the other hand, is determined to systematically implement IEC. Another Dignitas staff said partnering with the DHO helps increase the scope of IEC. The DHO IEC program, with its greater capacity, can cover the entire District of Zomba.

Ownership

The IEC program fosters community ownership by encouraging communities to take a leadership role and select their own Community Motivator. Underpinning this strategy is the insider/outsider concept that suggests insiders (Community Motivators represent communities to which they belong) are better positioned to promote programs in their own areas because of a unique knowledge of their local customs.

According to a former AM, ownership means that communities are running their own activities in the absence of the AM:

> *"Even if I'm at home they were continuing working in their areas and they were even telling me, 'We have got activity at such and such a place, will maybe visit her' So I had some information from them."*

A CM reiterated that community members await IEC programs from the CM and even request them at specific times:

> *"And some people, some chiefs they used to come even to my home and tell me that 'We have got a community meeting, so we need you to tell our people the information which is supposed to be given."*

Another aspect of ownership, according to a Community Motivator, means supporting the IEC program. Also related to ownership is the community's perception of Dignitas and of the CM him-/herself,

> *"Because now they don't look at those people as Dignitas [...] it's our own people supported by Dignitas."*

A community member explained the IEC CM program is community-owned because the community itself raises issues to be addressed at IEC

activities and the Dignitas staff themselves do not present issues for discussion. In the words of a CM,

> "*Dignitas have trained us these things that the community has to decide what sort of things they wanted instead of Dignitas to make for the community what things they can bring.*"

This was reiterated by a Dignitas staff, who explained,

> "*The selection [of IEC activities] itself is the communities are the ones because we don't want Dignitas to be in the forefront of selecting the activities.*"

The relevance of an intervention underpins the concept of ownership. Specifically, interventions meeting the local health care needs are more likely to be adopted:

> "*[I] can see the change because of the people that come here, especially the pregnant women that the Community Motivator speaks to. They used to go to Zamba. [...] Before the women used to go to Zamba and Zamba is like where the women used to deliver children. They used to be helped by other women not a hospital, it's not a hospital. But because of the Community Motivator they are told to come to the hospital to get tested and they are told that if they are positive there is a way that the child can go negative given nevarapine, that it helps. So [I] see that the program is working.*"

Sustainability

The AMs received a monthly salary whereas the CMs work voluntarily. Communities recognized the work of former AMs and arguably the work of the CMs as "*serving the communities*" and believed they ought to be paid in return for their services. When asked, "*But who is going to pay these people?*" discussions revealed that community members themselves were responsible for community initiatives, while outsiders like Dignitas are still expected to provide support:

"[The communities a]re supposed to be front-liners in giving support to whatever, whoever is going to take place, to take over from the Area Mobilisers."

In some communities, there was resistance to the idea of the community itself and not Dignitas supporting the IEC program. A Dignitas staff explained that IEC staff organized meetings with local leaders to convince them of their responsibility to support the IEC program:

"There were some chiefs or local leaders who were resisting, that 'you know we are poor, we even fail to help ourselves and how can we help somebody when we even fail to feed our families so how can we help somebody else?' So it was like resisting the idea. So we came in again in one area [...]. We had this meeting three times for them to accept the idea. To understand mainly, not to accept, but to understand. And now they understand what is their role. What they need is just support."

Thus, for the time being CMs are working voluntarily. According to one CM who was a former AM,

"No, I can work with them because I'm here. This is my area. What I want is to assist my fellow friends and my fellow fathers and mothers here [...] I'm living here, I was born here in that particular village [...] I allowed them to work as a volunteer. That's why I'm here."

In other words, some CMs feel a sense of responsibility to their communities. Some time after the implementation of the CM program, however, CMs had concerns about sustainability and whether they would be able to support themselves especially in light of competing priorities such as supporting oneself and one's family:

"So maybe uh those people who are assisting me they can fail to assist me. So for that particular, for that particular problem maybe I can find something to do. Maybe I can leave this community, then I can go and find a job for that so that I can have money to support myself."

One CM explained that if he received a salary he would not have to spend considerable time planning and mobilising resources but instead would be able to devote that extra time to his community. Receiving a salary would also increase efficiency of the CM program as the CMs could visit more areas in the field:

> "*So within a short period I would have covered every area of [*my catchment area*]. For the period of maybe two or three years, you could be talking of having reached every area maybe three times or four times. Whereby now we are talking of one year can go, we cannot finish all the areas in [*my catchment area*].*"

A community member discussed the tendency of some organizations to provide allowances to people who attend their events. He cautioned that Dignitas should not provide allowances unless it is committed to always making them available, otherwise people will stop attending IEC activities:

> "*I should say the tradition of giving allowances when they have got a meeting is good but on the other hand it is bad because when the resources will not be there then nobody will attend the meetings because no allowances, no drinks will be provided.*"

Another community member implied the method to ensure sustainability is by involving local leaders and community members at the early stages of program implementation:

> "*Since at the beginning if you involve the community and the local leaders they know what is going on. Then they follow the procedures so it's not different for them to continue it, yeah.*"

Metrics of Success

Many interview participants acknowledged that measuring the impact or success of the IEC program is difficult since what is being measured can be confounded by various factors (such as the presence of other organizations

doing IEC) and that some outcomes related to sexual behaviour are simply non-verifiable (such as condom usage dependent on self-reporting).

Quantifiable metrics of success include the number of people attending IEC activities and meetings, number of high school dropouts, and the number of people accessing Dignitas services:

> *"You can really see that there's a positive attitude toward the programs. Yeah. But then I would say all in all there's an increase in number of patients towards each program who are ready to access the services."*

Non-quantifiable metrics of success include the ability to pose questions, discussions amongst community members, and behaviour change:

> *"Sometimes if [men] fail to attend another meeting when they hear that at such a date they will [Dignitas] go to another village so they make sure to go there."*

There was an "*outcry*" when the AM program was terminated which might be considered a metric of success of the IEC AM program. Another metric of success is the community's acquired knowledge and the capability of answering questions posed to them by the CM.

Behaviour Change

Behaviour change is considered an important metric of success, although it may be impossible to verify as discussed above with respect to condom usage. It is about "*actively*" taking the information that is being disseminated by the CMs. Dignitas staff and community members explained that as a result of IEC activities in their communities, people are accessing Dignitas services such as ARVs, HTC, and PMTCT. Another observation by a community member is that

community groups such as men who previously did not attend IEC activities, started to attend after being engaged. Based on discussion with one interview participant, behaviour change can be promoted by establishing role models in communities:

> "*People were already aware that there is HIV around but they need somebody to guide them.*"

There is evidence from the data that faith leaders are changing their behaviour in response to IEC:

> "*He admitted that, 'No we were wrong. We were wrong and I think I am going to change because I was one of the people who were telling people that I have prayed and Jesus has healed you, stop using the ARVs.' With that information I have seen that there is some improvement. People are using the information.*"

Unintended Consequences

Two interview participants implicitly raised the issue of unintended consequences potentially associated with the IEC program if it reduces "*fear*" among community members surrounding HIV/AIDS:

> "*Before when they had HIV and AIDS they used to be worried and everything, but through the message that has been brought by the IEC program through the [...] Community Motivator the people they know that they can get medication and stuff.*"

> "*The other things that he does are encouraging people to go for testing and those that are HIV positive he reassures them so that they do not live in fear, so they have a long life, so they can work on their own, have businesses, etc., so that they can upgrade their lives.*"

3. Factors Influencing the Success or Lack of Success of the IEC Initiative

The Dignitas IEC initiative occurs in the context of intricate social, economic, political, and cultural "internal" and "external" factors. I explained to

interview participants that “internal factors” are any forces acting within the community itself or the Dignitas International organization itself that influence the success or lack of success of the IEC initiative. “External factors” are any forces acting outside the community itself or the Dignitas International organization itself that influence the success or lack of success of the IEC initiative. Many interview participants had difficulty responding due to a poor understanding of the distinction between internal and external and due to lack of clarity around the meaning of “forces” or “factors”.

Internal Factors

Internal factors influencing the success or lack of success of IEC activities include any factors dealing with the community structure or Dignitas structure such as local context, local culture, community individuality/uniqueness, internal and external Dignitas relationships, and monitoring and evaluation.

Local Context

The local governance structure consisting of local leaders influences the acceptance and implementation of IEC. Community leaders act as gatekeepers to the community influencing attendance at IEC meetings and activities. Before Dignitas started to implement its programs, it spent time learning about social structures in place. Local governance in Zomba is overseen by the centrally elected government in Malawi: the job description of the District Commissioner (a centrally appointed position) includes overseeing the administration of local governments. Figure 3 depicts this affiliation. An established system, however,

does not mean a functioning and effective system. In other words, data did not show there was any involvement of the District Commissioner in IEC activities despite his presumed role according to the model.

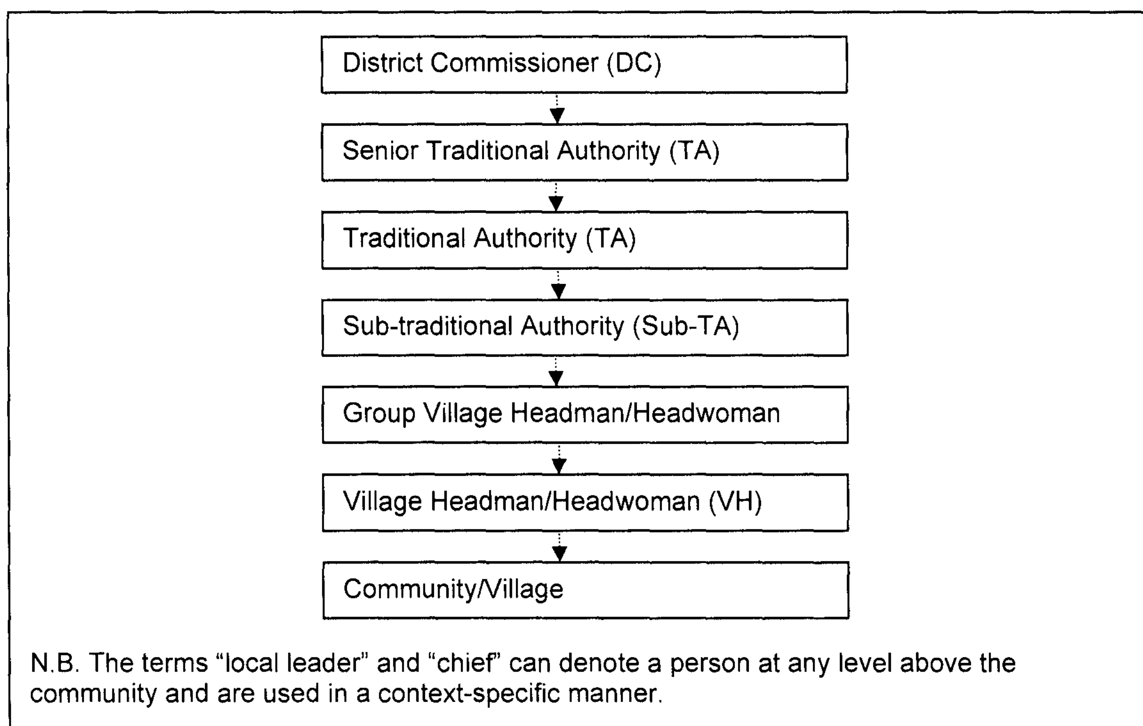

Figure 3 The centrally elected government (DC) oversees the local government in Zomba District, Malawi.

Local Culture

Ultimately, IEC aims to change behaviour that might contribute to the spread of HIV/AIDS. There are a number of cultural practices that can exacerbate HIV-transmission.

> "*If somebody is married and a husband dies, people don't know why that person died. Then our culture says a young brother should marry that widow. It's culturally accepted. Or, even if you have got your own wife, but a brother's wife you can even take her as a second wife. To actually continue supporting the children. That is acceptable. There are other also acceptable say if somebody is barren, maybe husband is barren [...] they take somebody outside and sleep with your wife so that she's impregnated. That is also accepted. And there are other traditional beliefs that when youngsters, the children go for traditional initiations, when they*

come back from their traditional ceremonies, they should sleep with an adult. But by encouraging those kinds of practices, HIV transmission is still going on. So we have got to break some of those traditional taboos."

"Like sometimes you would find that people are you know circulating rumours or maybe you know they believe that if you are HIV-positive you know then you have to sleep with a girl a virgin then you know your status changes. If you are positive then you become negative. Such kind of myths you know and misconceptions."

Working through the cultural practices that might spread HIV/AIDS could involve engagement with local leaders. Traditional healers also have practices that might spread HIV such as using one surgical blade for circumcision or cutting tattoos or sucking the blood of a person that was bitten by a snake. Faith leaders sometimes pray for people and tell them they can stop taking their ARVs.

Community Individuality/Uniqueness

While transferability of the IEC program to other areas in Malawi or outside the country was identified as an important theme in the interviews, community individuality/uniqueness—a seemingly contradictory concept since it implies non-transferability—was another theme identified in interviews. Different communities have different needs, continually explained by participants, and even the success of an IGA, for example, will depend on unique qualities of a community:

"People have decided to do the income generating activities in different ways according to their communities. There are some communities that they do businesses; there are some that they don't. So it totally depends to the need of the community."

The unique characteristics of different communities within Zomba is also manifest in the different ways they responded to the termination of the Area Mobiliser program, to the introduction of the Community Motivator program, and

to the selection of the CM himself or herself. In one IEC site, for example, the Village Headmen selected five candidates. Dignitas representatives and local community leaders interviewed these people and chose the most qualified candidate as the CM. In another IEC site, however, local leaders selected the previous AM to be the CM for this site without conducting interviews with other community members.

The different people that attend IEC activities is another aspect of individuality. Some respondents stated youth commonly do not attend, but other respondents said youth attend in high numbers.

Internal and External Dignitas Relationships

Dignitas International builds relationships with other Dignitas staff, community members, and partners. A Dignitas staff member said the success of IEC is due to internal support from Dignitas supervisors. A CM said he is grateful for supervision he receives from Dignitas staff. Finally, a CBO member explained she was motivated to work with Dignitas based on the relationship Dignitas built with her organization:

> "*What made [me] want to work with Dignitas was the promise they gave [us] that [we] must join forces and help people because Dignitas saw that [we] didn't have other things like medicines. Dignitas told [us], 'Let's work together the way you're helping them continue,' and then they [Dignitas] provide other things-medicines.*"

Monitoring and Evaluation

Numerous interviewees underscored the importance of monitoring and evaluation to influence the success or lack of success of IEC. CMs and former

AMs emphasized the importance of disseminating the findings of the evaluation and to follow-up on the findings. Dignitas International conducted a formal evaluation of the AM program; however, it did not inform the AMs or IEC staff of the findings. One former AM insisted this would have been valuable information because the AMs often continued to work with communities, albeit in a different capacity. Similarly, CMs expressed the desire to receive feedback so they can know what is working well in their communities and what aspects of their work need improvement.

A local leader herself indicated she is in an ideal position to evaluate the CM and monitor his activities since she attends events herself and takes note of the proceedings. A CM conducted her own monitoring and evaluation activities in her area. She asked community members, "*Do you know this?*" When asked the same question on a second occasion, community members had sufficient knowledge to answer:

> "*So when I go there another time I talked to them. Maybe last time I came here I was asking this information, this information, and this information. Now I have come to tell this information is supposed to be like this and that and that. And you go after maybe a month and ask them, they can answer what maybe we was talking last time.*"

External factors

External factors influencing the success or lack of success of IEC involve the presence of co-existing (local) organizations, local government policies, and the socio-economic climate.

Co-existing (Local) Organizations

Local CBOs/FBOs/NGOs might influence some of the outcome measures for IEC because they provide similar HIV/AIDS messages. This increases a community member's likelihood of receiving information and in turn altering their behaviour. At times, unfortunately, participants explained other organizations give conflicting, inaccurate information.

A community member explained that when Dignitas partners with other organizations the demand for IEC is increased beyond the capacity of the program itself.

Various organizations working in Zomba might have greater funding than Dignitas meaning they are capable of providing allowances or other incentives to community member participants. This can influence the success of the Dignitas IEC model.

Government Policies

While a Dignitas staff described Zomba as politically stable, there are government initiatives that influence health. One interview participant mentioned attendance at IEC and youth group meetings has recently increased and explained this might be the result of education policies:

> *"Yes, um before 1994, we had no free primary education in this country. And since we entered a multi-party system of government, they introduced free primary education. Since then I saw a number of people going to school."*

Parents, pastors, and other members in influential positions such as local leaders and CMs are also in a position to encourage youth to stay in school.

Other policies in Malawi around property rights, marriage certificates, birth/death certificates and adoption might also influence IEC.

Socio-economic Climate

Poverty, unemployment, and illness are widespread in Zomba. Interview participants said that whether it has been a good harvest year or not, might influence the success or lack of success of the IEC program.

4. Lessons Learned

Working with communities is not for everyone: "*some of us we are not born to talk to the entire community.*" Also, it takes time to gain acceptance from the community. This is facilitated if you are considered an "insider":

> "*it's a bit difficult working in the community. [For the community] to accept you, you have to treat yourself as the same community to be working with the community.*"

Community Motivators themselves explained they acquired many skills that will continue to assist them in their capacity as CMs and will certainly be assets in any future community work or employment in general, such as public speaking skills, HIV/AIDS knowledge, and interpersonal skills. A person working in community engagement must be able to cope with criticism:

> "*If people are sensitizing for the right cause they should be able to allow such criticism and apply it to the program so that the program should run smoothly.*"

A former AM even shared a personal insight about taking his own advice and going for VCT. A Dignitas staff learned that community engagement is a slow and challenging process:

> *"Ok with community engagement it's a long very long slow process. But it's worthwhile thinking about. It's costly. Not financially but just time wise and getting things moving it's a slow-moving monster. And to make sure that you continue to go back and renew this connection. That's a good lesson eh?"*

A Dignitas staff explained it is important not to take the community's knowledge for granted and to continue to engage communities.

Transferability

Another lesson learned in IEC is about the ability to transfer the program from place to place. Just as a Dignitas staff explained the IEC CM program cannot be transferred to other areas in Zomba before it is perfected in the five initial sites, a community member emphasized that before transferring the IEC CM program outside Zomba or Malawi, it needs to be perfected in Zomba. Both these comments imply improvements are needed to the IEC program in Zomba and there is a considerable time commitment needed to ensure sustainability and replicability/transferability.

From the perspective of a Dignitas staff, transferring the IEC CM program to other areas in Zomba will be assisted due to the careful documentation process used to introduce and implement the program in the original five areas. Transferability of the CM program to other areas (within Zomba, outside Zomba but within Malawi, or outside Malawi) hinges on encouraging exchange visits so CMs and committee members can promote the model. In turn Dignitas will

become better known. Community ownership underpins this concept because it implies,

> "*we are coming up with our own very good way of achieving whatever we are looking at.*"

A community member explained transferability depends on local needs/priorities and is related to the concept of community individuality/uniqueness. Specifically,

> "*If the people in those areas are interested about the information different organizations have to bring, like they are [interested] here. It would depend on their need to learn how things are through organisations that are offering to educate them.*"

Not only will a community's needs influence transferability, but culture will also dictate whether the IEC program can work outside Zomba. A Dignitas staff explained the context in which the program is introduced influences whether it will be adopted and that the program cannot work everywhere.

One community member provided concrete suggestions to enable replication of the IEC CM program. Firstly, it will be beneficial to mobilize pre-existing organizations such as youth clubs and CBOs. Secondly, community leaders must be mobilized. Finally, a community member stated that if messages are accurate then they can be useful anywhere.

IEC Challenges

Working as a CM requires considerable time commitment since communities are diverse and, as one interview respondent stated, the "*one size fits all*" approach is ineffective. CMs are not expected to be working as full-time

volunteers; however, CMs implied that fulfilling their job responsibilities successfully makes it difficult to balance with other work.

CMs and community members recognized that the CMs are responsible for a large working area and that it is difficult to access all community members. The CMs thus need a support committee, scale-up, monitoring and evaluation, and assistance from local leaders.

Related to this issue of large working areas is the challenge of mobility and the need to travel far distances. Providing CMs with bicycles can mitigate this challenge. As CMs explained; however, bikes cannot function effectively in all circumstances, for example, in inclement weather or in hilly areas. Also, participants explained bicycle maintenance is still a major problem.

Some interview participants lamented CMs are overworked. There is the recognition by Dignitas that CE takes time and can be a slow process. For example a Dignitas staff described the AM to CM transition as "*a slow process*". It is challenging for CMs to work as volunteers. If they were paid, a community member explained they would have more time to hold meetings and do their job.

Community perceptions and understandings appear to be an important part of community engagement. For example, lack of clarity around the issue of payment results in people having misperceptions about CMs' living situation. A CM stated he works as a volunteer and must possess other resource-mobilising skills to afford rent on a house, for example. Community members who incorrectly believe CMs get paid, think they must be financially stable. The belief by community members that people working for international organizations are

paid is based on the perception of NGOs as an industry. This challenge interferes with the success of IEC. For example, due to inadequate community engagement and lack of benefit sharing in previous clinical research in Zomba, there is widespread suspicion among community members who think going for an HIV test is a strategy to enlist large groups of people to donate blood so it can be used by rich Western researchers to make a profit. In other words, community members fear exploitation by Dignitas. A Dignitas staff explained,

> "*There are some people who are not willing in the community to come to the Dignitas activities. What they feel is these people they have just come to get information from us and them it's getting money, that's the problem.*"

Both former AMs and current CMs identified the shortage of IEC materials as a challenge. Also some community members have low levels of literacy and cannot read or understand English. This challenge is associated with the local context in Zomba, which presents other challenges to IEC including lack of attendance at IEC activities due to poverty and disease.

Another challenge is including all community members in IEC meetings and activities. Interview participants said that some meetings and activities exclude some community members such as men, or simply do not outreach to enough community members. Assembly strategies are listed as an activity that is more inclusive and encourage everyone from the community to attend. The people that do attend are sometimes under a misperception that they will get something in return, such as an allowance. One challenge with assembly strategies is related to its success; many issues are raised when large crowds of

people gather, but due to time constraints there is difficulty addressing all the issues.

CHAPTER 5: DISCUSSION

In the Literature Review and Background chapter I discussed what is known about communities and community-based research and described two examples of community-based participatory research. In the Results chapter I presented findings from the case study of community engagement in Zomba. In this section I critically evaluate selected topics from the results section and address the second research objective to provide a programmatic appraisal of the implementation of the IEC program. In other words this is an etic perspective of the interview responses.

1. Community Engagement Activities and Rationale for the Activities

Area Mobiliser to Community Motivator Termination

The AM program was phased out between August and September, 2006 and the communities initiated the CM selection process in November, 2006. The CM training did not take place until February, 2007. This means there was a six to seven month transition period when communities did not have IEC. Moreover, 15 communities that previously had an AM were left without an IEC program. The implications of the disengagement and re-engagement process and the lessons learned that could assist community engagement programs elsewhere are areas for future research. These are important questions that require monitoring and evaluation.

Qualities/Characteristics of Community Motivators

Often, guidelines for CE are generic and assume a particular set of skills are possessed by people doing the engaging but they are devoid of personality, however, personality is probably an important aspect of what makes CE successful. Personality, not just skills and experience drive community engagement. Personal characteristics of people working with communities will not only promote positive relationships with community members, but will also enable the CMs to build networks with people in local organizations that might assist sustainability of the CM initiative. It seems to follow that it would be an asset for the CM to have pre-existing local contacts in the health field or from other organizations involved in community engagement.

IEC Activities

The HOPE kit activity, with its ability to bring diverse groups together, will be important to highlight and resolve conflicting community perspectives. Concerns about sustainability are reduced assuming the HOPE kit materials can remain in the communities even after Dignitas leaves Zomba.

Only half the community members interviewed (5 out of 10) were aware of the former AM program (see Results) implying Dignitas might benefit from more efficient use of communication channels to advertise the IEC component. Haider (2005) recommends a multimedia strategy using a mixture of one-way and two-way communication. Simply notifying residents of Zomba about IEC can be done by one-way communication such as radio and newspaper advertisements. These are effective approaches because they enable large groups of people to receive

the messages, however, they are dependent on access issues; not everyone has access to a radio or newspaper. Two-way communication, or the inter-personal approach (Haider, 2005) is most effective to motivate people who are aware and have some knowledge of the IEC program, but who need additional motivation to participate.

Community Motivator Training

The data indicate that training is an integral form of support from Dignitas International and enables the CMs to work effectively in communities. A number of questions around training are unanswered by the data: What is the most appropriate duration for training? How and why were two weeks decided? Is refresher training necessary? What compensation do attendees receive during the training period? What is the training curriculum? Also, supporting local CBOs and CM committees through training activities will likely promote sustainability.

Income-generating Activities

IGAs might be an effective way to support communities and ensure sustainability. It is important to note that while the review process of IGAs, including the distribution of start-up grants, is supported and coordinated by Dignitas leading one to think the initiative is not sustainable or fully community owned, the business ideas themselves are coming from the communities. In light of poor capacity and lack of resources, a grant is necessary simply at the outset. In other words, the IGA is still owned by the community and, assuming success of the IGA, will also ensure sustainability. How financial decisions are made, such

as the amount Dignitas grants a group for starting a business, might benefit from more clarity.

When the CM model with IGAs is compared to the previous AM model which was terminated after one year due to lack of economic sustainability, it points to ownership as an important issue and it seems the risks associated with unsuccessful business endeavours are reasonable to take in order to ensure ownership of the program.

Local Leaders

A program in Zomba must be accepted by local leaders for the community to access it since local leaders act as gatekeepers to the community and can influence attendance at IEC meetings and activities. This raises questions about how representative local leaders are and whether they respect the best interests and needs of community members in terms of Dignitas IEC objectives. In other words, local leaders might be adequate political representatives for their own village, but inadequate representatives for their villages in terms of community engagement. While one local leader who was interviewed implied there was a basis to her decision-making, whether leaders in all the villages in Zomba are as meticulous as this local leader is a separate issue. Regardless, due to the importance of local leaders in Zomba culture, the necessity to develop a positive working relationship with them is highly recognized (Conroy, 2006). It is difficult to know whether local leaders should be the beneficiaries of IEC activities when youth represent the majority of the population. In other words, what should take

precedence when trying to engage communities: local culture (which would entail engaging local leaders) or risk factors (which would entail engaging youth)?

Local leaders including faith leaders are in a position to disseminate information to large groups of people. As some interview participants articulated, sometimes they give inaccurate information. Other times they prepare the community to receive the information from Dignitas. Opinion leaders will possibly be another important group to engage with IEC messages since they are in a position to disseminate messages to others. It will be crucial to ensure proper information is disseminated.

Intended Beneficiaries

The community must decide and clearly state the intended beneficiaries of the IEC program. This way relevant groups that are commonly excluded can be targeted. As a Dignitas staff lamented, "*there are probably a lot of different people outside what we call the community that aren't accessing any of these services.*" In light of cultural practices that involve men and gender inequality that restricts a woman's ability to negotiate safe sex, there ought to be increased efforts to involve men and promote their own behaviour change. Deciphering when and where men gather might help to engage this underrepresented group.

Youth should benefit from IEC activities not only because their own parents and local leaders cannot discuss issues of sexual health with them, but also because the calibre of sexual education in schools in Malawi, let alone in Zomba, is questionable (Conroy, 2006) and not all youth attend school.

Moreover, almost half of the population (46%) in Malawi is under the age of 14 (CIA, 2008). Also, the WHO (2005) reported that young people between the ages of 13-24, especially females, are most at risk of HIV infection. It is especially important to engage children and youth because they are left orphaned due to AIDS in Malawi.

2. Perceptions of Effectiveness of IEC

Before Dignitas started working in Zomba, health care was centrally delivered out of the Zomba Central Hospital (ZCH). It was difficult for many people to access this health centre. The decentralisation of health care enables more people to access HIV/AIDS services. The implementation of the IEC program follows this route of decentralisation:

> "*we're just trying to follow the ARV-decentralisation line. So where the ARVs are being decentralised to the communities we'll follow that with the Community Motivators. As well as home-based care and all the other services.*"

Hence IEC is a necessary and integral component of the Dignitas International CHBC model.

The concept of supply and demand underpins the question about what comes first: IEC or HIV clinical services? It is ineffective to promote HIV clinical services that are unavailable—or to create demand without supply. It might be equally futile to have a supply when there is no demand. In other words, IEC could raise awareness about clinical services that will be available later. The notion that IEC prepares the community to receive Dignitas services implies that

IEC is merely about linking people to services. Surely it means more than creating demand. This depends on one's perspective about what constitutes effective community engagement. Take for example the multifaceted concept of community ownership. For Dignitas, community ownership can serve several purposes: ensuring sustainability of the program, removing/lessening the financial burden on Dignitas, and facilitating the Dignitas mission to create demand for services in the community. For the community, ownership means giving greater meaning to activities, ensuring sustainability, providing a sense of independence, and lessening stigma and discrimination by creating demand for HIV/AIDS services. Engaging in a debate around the ideal implementation time for IEC versus Dignitas clinical services is perhaps less important than ensuring the components of the Dignitas CHBC model are each implemented effectively.

Comparing IEC to the other components in the CHBC model can highlight areas that are working well and areas that need improvement. For example, there is a strong connection between the IEC and home-based care components. Both programs rely on meaningful partnerships with CBOs and depend on trained volunteers to implement activities. Both HBC and IEC volunteers are expected to devote a considerable amount of time to the job, receive support from Dignitas, and engage local leaders. One important difference is the HBC component includes refresher trainings whereas the current IEC component does not. Both programs have dealt with issues of acceptance and resistance (when introducing to the program to a village) and possess unique challenges. A major

challenge for HBC, for example, is being short staffed, whereas IEC faces the challenge of a constant shortage of IEC materials.

One interesting comparison between the HBC and IEC models is the concept of Dignitas "*building bridges*" between the organization itself and communities. In the HBC model, CBOs link Dignitas with the community versus the CMs that link Dignitas with the community in the IEC model. This linkage between Dignitas and communities also represents a linkage between the outside world and communities; Dignitas provides, by way of the CM or CBO representatives, information that is otherwise unavailable to community members. Both HBC and IEC programs foster community ownership by encouraging communities to take a leadership role and select their own volunteers. Underpinning this strategy is the insider/outsider concept that suggests insiders are better positioned to promote programs in their own areas because of a unique knowledge of their local customs. HBC and IEC volunteers are both community-based. Community ownership and the insider/outsider concept are both related to sustainability and can help ensure a program continues to run in the absence of an outside organization.

The Dignitas HBC volunteers are performing the role of community health volunteers, namely delivering health services at the community level. Community health volunteers are *not* paid unlike community health workers (CHW) who receive financial remuneration. CHW is not a new concept. A WHO study group in 1989 defined the term as follows:

> Community health workers should be members of the communities where they work, should be selected by the communities, should be answerable to the communities for their activities, should be supported by the health system but not necessarily a part of its organization, and have shorter training than professional workers (WHO, 2007, p. 3).

Since then, there has been considerable research around the role of CHWs. Berman, Gwatkin, and Burger (1987) evaluated six CHW programs and found they increased health care coverage and equity of health services; however, they delivered services inconsistently. Other research calls for greater evaluation of CHWs (Haines et al., 2007; Swider, 2002), emphasizes the need to pay CHWs (Farmer, 2008; Haines et al., 2007), and warns against overly high expectations of CHWs (Haines et al., 2007; Swider, 2002; Farmer, 2008; Berman et al., 1987). Unlike the Dignitas IEC component that transitioned from paid AMs to volunteer CMs, the Dignitas HBC component will be transitioning from unpaid HBC volunteers to paid HBC workers. The justification for paying HBC workers is they are delivering health services. What will be the implication for IEC CM *volunteers* who are performing an important role in improving and sustaining community health? Dignitas International has stated they would like to pursue this topic of parallels between HBC and IEC in a published manuscript.

Ownership

Referring to cultural practices that might spread HIV/AIDS, one interview participant explained that "*Dignitas cannot handle those matters, but the community itself can handle that,*" underscoring the need for community ownership of the IEC program to engage communities and to fulfil the Dignitas objectives. This also implies that ownership hinges on addressing issues that are

relevant to a community. Paulo Freire (1970) explains how pedagogy can be used to effect change. The concept of "*conscientização*" or "critical consciousness" accelerates the process of social change needed to achieve critical thought (Freire, 1970). This can lead, in a participatory and emancipatory process that is initiated at the grassroots level, to critical actions to change one's conditions.

Sustainability

One of the challenges that needed to be addressed when transitioning from the AM program to the CM program related to sustainability was the issue of payment or salary. Working voluntarily means a CM's competing priorities might divert their efforts and energy away from the CM program and it will not be sustained. Receiving a salary would thus increase efficiency of the CM program as the CMs could visit more areas in the field. Dignitas will not, however, give the CMs a salary. Even if support for the CMs will not come in the form of a salary, communities have poor capacity and thus require other forms of support from Dignitas at least in the short term. How this will affect long-term sustainability can only be determined once Dignitas leaves Zomba.

In terms of CM selection, data suggest a certain motivation is needed to enable the transition from working in a paid position to working as a volunteer. While the current CMs evidently possess this sense of responsibility to their communities, it is unclear whether this will be true in the future. In other words, there needs to be something more dependable than a quality or characteristic of the CM to ensure sustainability of the IEC program.

Metrics of Success

One metric of success of the IEC program is the community acquiring knowledge. Knowing with certainty whether knowledge has been acquired, however, is difficult. Taken to an extreme, organizations might assume knowledge has been attained and leave a community prematurely. Taken to the other extreme, organizations might find themselves,

> "*undermining the capacity of the community. You assume you're the, the master of the game. So that kills a lot of potential, community's potential.*"

Thus it is advisable not to make assumptions and rather engage in monitoring and evaluation.

Every year there is a high number of high school dropouts due to early pregnancy. Engaging youth in school about the consequences of pregnancy will hopefully result in a decrease in unwanted and unplanned pregnancy which can be verified by monitoring the number of high school dropouts each year. It will then be possible to claim the decrease is a consequence of effective community engagement.

Behaviour Change

It is crucial to understand how and why religious leaders in Zomba are changing their behaviour. Based on discussion with one interview participant, one way to promote behaviour change involves leadership and establishing role models in communities. Behaviour change models recognize this "*change agent*" as a person capable of influencing people's adoption of behaviour deemed appropriate by an organization (Haider, 2005). Behaviour change occurs when

people *believe* they can change. Not only is the CM an ideal role model for promoting behaviour change, but so are people occupying influential positions in communities such as local leaders, religious leaders, and other opinion leaders. Knowledge of theoretical health behaviour change models will be an asset for Dignitas.

Unintended Consequences

Reducing fear for a person living with HIV/AIDS is not the same as reducing stigma and discrimination and the way others interact with PLWHA. Dignitas is encouraged to become familiar with the literature around this topic.

3. Factors Influencing the Success or Lack of Success of the IEC Initiative

Internal Factors

Local Context

Local context is closely associated with various government policies (external factor) since this can result in gender and income inequality. For example, there are widespread low levels of education and literacy in Zomba due to education reforms.

Another aspect of local context influencing the success or lack of success of IEC is community member's roles and responsibilities. It is a village member's obligation to attend funerals which can interfere with other community events such as IEC programs. Widespread illness, including HIV and the community

need to care for others also prohibits people from attending IEC activities (Conroy, 2006).

Local Culture

It is important to be aware of local cultural beliefs and traditions that might influence the success of the community engagement initiative because it seems there is disagreement or uncertainty regarding roles and responsibilities for addressing them. This might be impacting effectiveness of community engagement initiatives. Considering the purpose of this study is to elucidate these practices with respect to effective community engagement, suggestions by participants on how to navigate cultural beliefs are important. In other words, exposing cultural beliefs that might increase the spread of HIV/AIDS by disseminating accurate HIV information can result in behaviour change. An understanding of local cultural beliefs is crucial in order to change people's misconceptions and promote behaviour change. Working through the cultural practices that might spread HIV/AIDS could involve engagement with local leaders. It will also be important to involve traditional healers to change behaviour.

Monitoring and Evaluation

The data left an important question unanswered: when is the best time for monitoring and evaluation? Dignitas evaluated the AM model after one year, but there was no baseline measurement for the purpose of comparison. Similarly, there was no baseline evaluation of the CM program. A local leader herself

indicated she is in an ideal position to evaluate the CM and monitor his activities since she attends events and takes note of the proceedings. Dignitas could take advantage of this relationship between local leaders and the community and implement a monitoring and evaluation framework accordingly.

An effective evaluation involves considerable time commitment and resources. In light of poor resources, however, a less formal monitoring and evaluation such as the one implemented by a CM in her own community explained earlier, might be a creative strategy for monitoring purposes.

Since the goal is for the IEC program to be sustainable, an evaluation must also be conducted once Dignitas has left Zomba, which might not be possible for some time since the communities indicate they still require support from Dignitas.

External Factors

Co-existing (Local) Organizations

Many activities implemented by local CBOs/FBOs/NGOs qualify as IEC activities except they are not specifically Dignitas projects. It follows they might influence some of the outcome measures—for example, the national response to HIV/AIDS in Malawi involves an IEC component. This might confound evaluation of the Dignitas IEC program. It will be important to develop criteria to separate the Dignitas initiative from external organizations. This will likely involve rigorous monitoring and evaluation activities.

Government Policies

Many people in Zomba still do not have access to school. Some data suggest the CM might be capable of outreaching to these people. If the CM is meant to be the answer to a lack of education in Zomba, he or she will require much more training and resources.

4. Lessons Learned

IEC Challenges

Both former AMs and current CMs identified the shortage of IEC materials as a challenge. This is unfortunate because IEC materials, like assembly strategies, help bring crowds:

> "*He comes with his materials and shows them to people. This catches their attention and they are eager to learn.*"

Also some community members have low levels of literacy and cannot read or understand English; not only is it important to ensure dissemination of accurate information, but the information must be understandable.

A former AM identified the challenge of mobility, thus, even if the CM program is scaled up to four-times its current size it seems covering the area will still be difficult (since there were originally 20 AMs).

Widespread illness and a community member's responsibility to care for others and attend funerals can prohibit people from attending IEC activities. The IEC program therefore must be accommodating to the needs of a community.

Transferability

Responses to this question must be interpreted with the knowledge that most respondents have likely not travelled far, if at all, from Zomba in the first place. It can be argued, that transferability will likely depend on context and the perceived need for IEC around HIV/AIDS.

Strengths and Limitations

There are several strengths to consider about this case study research. This is the first case study to critically and formally investigate the Dignitas International IEC program since the implementation of the CM model. Lessons learned can be shared with other NGOs implementing IEC or community engagement programs in different contexts around the world. An additional strength to consider is the collaboration between Dignitas International and the ESC CE global case studies research team. Both groups derived benefits from the partnership and it is an example of the possible success based on mutual understanding. Providing a medium for Malawian voices to be expressed, in particular the voices of community members who are generally unheard, is considered another success of this case study. Additional successes will become apparent when it is possible to compare this case study's results with the other CE global case studies. There are also several limitations to this research, which I consider lessons learned.

Interview Bias

There are at least six categories of interview bias ranging from forgetfulness on the part of the respondent to sloppiness on the part of the researcher (Neuman, 2006). Interviewer bias, where the researcher neglects to probe or to probe properly, posed a challenge to this case study. Instead of asking,

> "*You said some people do not understand that you are not receiving a salary; does that mean that they trust you or that they do not trust you, what does it mean*?"

I should not have mentioned "trust"—since predictably the respondent answered in terms of trust—and should have asked,

> "*How does receiving a salary or not receiving a salary influence your relationship with the community*?"

There are several other instances in interviews where I asked leading questions that might have directed the response of interview participants.

Language Barriers

Interview participants were given the option of having the interview in English or in Chichewa with a translator. Accommodating the preferences of respondents when English was requested might have sacrificed some quality since understanding might not have been ideal. As described by one interviewee, "*I believe that if your questions were in Chichewa it would have been much better.*" Although questions were available in Chichewa, respondents perhaps did not possess the foresight necessary to appreciate the benefit of having an interview conducted in their first language.

There were also challenges to conducting interviews in Chichewa with the assistance of a translator. Although I trained the translator, I could never be certain what was being said in a language that I do not speak or understand.

Non-universality of Interviews

Stake (1995) suggests that interviews are the "main road to multiple realities" and highlight various perspectives around a specific case. While there is some truth to this statement, I argue that face-to-face qualitative interviews with one interviewer and one respondent are a Western construction and are not a universal concept. Said one participant,

> "*Because the interview was private, I don't know if I answered your questions or not. I hope I was able to answer the questions to your satisfaction.*"

This quotation attests to the reality that in Malawi, women are not accustomed to speaking for themselves and do not always have confidence in their responses. Perhaps focus group discussions with a group of women might have been a better approach to help sensitize women to Western forms of research.

Interview Analysis

Interview coding occurred retrospectively and areas that needed further exploration could not necessarily be pursued. One interview in May 2008, however, was able to address gaps in the research findings. Ideally, data analysis overlaps data collection in qualitative case studies; however, due to time

constraints, only eight interviews were transcribed and verified in the field and only two of those were actually analyzed in the field.

CHAPTER 6: CONCLUSION AND RECOMMENDATIONS

While a number of conclusions can be drawn from this case study, there are also many areas for future research. Community ownership of the IEC program is essential to ensure sustainability. Enhancing the community's capacity to undertake community engagement activities, for example by supporting IGAs and local community-based organisations, will likely promote sustainability of IEC. The data make clear the importance of engaging local leaders in Zomba to promote IEC activities. Finally, it is clear that "insiders" are best suited to undertake community engagement activities because of their intimate knowledge of the community where they work and live.

Dignitas collaborators and ESC CE team members identified a number of areas for further exploration. Firstly, an investigation of potential partners in Zomba was suggested and an examination of what this collaboration might entail. A deeper understanding of community structures is desired around how communities are organized in terms of structure and partnerships. For example, what other actors such as NGOs/CBOs/FBOs are in the environment? An understanding of which groups have engaged which communities before Dignitas started working in Malawi is needed. How do prior sensitizing experiences influence the adoption of the IEC CM model? The impact of "disengaging" and "re-engaging" during the AM-to-CM transition could benefit from more clarity. Related to this concept is the discord around salary and the "firing" of AMs at the

end of their contract. One reason this was poorly explained is related to a sampling issue: only three former AMs were interviewed. More former AMs should be interviewed to highlight multiple perspectives on this single phenomenon. Finally, better knowledge of pre-existing guidelines in Zomba around community engagement is desired. Investigating the areas for elaboration will contribute to the understanding of effective strategies in community engagement.

Theoretical Propositions Revisited

Fulfilling the third research objective to help Dignitas International to construct a theoretical framework for effective community engagement to be applied to other Dignitas International projects is assisted by returning to the theoretical propositions and explaining, briefly in some instances, how each was observed in practice (Table 7).

Table 7 Theoretical propositions substantiated by field observations.

Theoretical Proposition	Field Observations
a. Early initiation of community engagement activities	Before Dignitas started to implement its programs, it spent time learning about social structures in place. This is how Dignitas learned it was important and crucial to engage local leaders before introducing a program to specific communities.
b. Community role in developing the research/intervention	The community, along with Dignitas staff, developed the CM model.
c. Clear purpose/goals in terms of research activities (both scientific and social/health goals) and community engagement process	Dignitas openly stated objectives of the IEC CM program with communities in Zomba.
d. Knowledge of the community, its diversity, and its changing needs	Before Dignitas started to implement its programs it spent time learning about social structures in place. Dignitas began by contacting local leaders and then engaged with communities. Dignitas recognized the "*one size fits all*" approach does not apply to

	community development. Knowledge of the community's *changing* needs is associated with the transition from the AM to CM program.
e. Understanding of community perceptions and attitudes	Community perceptions and misperceptions are integrated into IEC activities through creative formats including theatre, song, and dance.
f. Adequate opportunities to express and respect dissenting opinions	One interview participant explained that it is difficult to express internal problems due to the close, even familial, relationships among Dignitas staff. No other interview participants discussed whether appropriate channels existed to express opinions.
g. Establishment of relationships, commitment, and trust with formal and informal authorities in communities	Dignitas recognized the importance of relationship-building as a vital strategy to engage communities.
h. Provision of information in accessible, culturally/linguistically appropriate, community-approved format and effective dissemination of that information in accessible formats	IEC materials need to be more accessible for audiences with low levels of literacy.
i. Building on existing strong community groups/structures/mechanisms	Dignitas began by contacting local leaders and CBOs, and then engaged with communities.
j. Permission/authorization from community	Dignitas began by contacting local leaders and CBOs, and then engaged with community.
k. Identification, mobilization, and development of relevant community assets and capacity	Dignitas collaborates with local CBOs and provides training.
l. Maximum opportunities for stewardship/ownership/control by the community	The CM model is based on principles of ownership.
m. Establishment of, review, and evaluation of engagement strategies	There was a formal evaluation of the AM program in 2006 that led to the transition to the CM program. This case study can be considered a review/evaluation of the CM model. Future evaluations are scheduled.
n. Increased involvement of marginalized groups such as women or indigenous groups or even the poor and uneducated in the community engagement process	Women are more engaged than men. Youth need to be involved. Need greater involvement of elderly, disabled, orphans, albinos, and commercial sex workers.
o. The existence of local research ethics boards	Not applicable to the Zomba case study.
p. The existence of local committees/councils/bodies/gatekeepers who represent community views	Community Motivator committee.
q. Integration of community perceptions and values into research/intervention activities	IEC activities are designed by community members.
r. Supportive government and economic policy	Stable government in Malawi. Dignitas works in close collaboration with the District Health Office in Zomba and the proposal for Dignitas

	to initiate the CHBC project in Zomba came from the Ministry of Health itself.
s. Adequate funding for healthcare	No. Dignitas depends on trained community members to voluntarily deliver health services (there are plans to transition from volunteer community health workers to paid community health workers).
t. High relevance to local health needs and consumer benefit	Yes. Almost 1 in 5 people have HIV/AIDS in Zomba (Chipeta et al., 2005).
u. Length/scope of commitment.	Dignitas plans to be in Zomba for at least five years, with the possibility of extension. By hiring and training local Malawians, there is a higher likelihood the project will be sustained after Dignitas departs the field.

The propositions were developed to help maintain the focus in the research, to direct attention to determinants that may impact the success of community engagement, and give direction to the study allowing more nuanced questions to be posed. They were clearly not all relevant nor were they all equally relevant in the Zomba District case study. Cross-case comparison will likely reveal that different propositions take precedence in different research contexts. The fact that collected data do support most propositions indicates that these are components that increase the chance of success in community engagement and that they are excellent starting points to consider when engaging in international community-based research. One missing proposition is the need for ongoing support for those people undertaking community engagement activities.

Recommendations to Dignitas International

Based on the data collected, a theoretical framework for effective community engagement that can be applied to other Dignitas International projects will be composed of four components: 1) community capacity-building; 2) monitoring and evaluation; 3) ownership; and, 4) sustainability.

Recommendations to Dignitas International that I propose will improve the

current IEC CM program can also be categorized according to these components.

Community capacity-building: Train local CBOs/FBOs/NGOs who will remain in the area and who could take on the role of providing support, encouragement, and supervision and ultimately ensure the long-term sustainability of the IEC program. Provide ongoing refresher training to CMs. Extend IEC training to the CM committee. Organize opportunities for the CM and committee to travel to other areas to see how IEC functions in different contexts. Provide training around business management in rural markets.

Monitoring and evaluation: Evaluate the CMs, disseminate findings, and follow-up on results. Three main findings and the recommendations to address them are firstly to scale-up the IEC program to enable coverage of a greater number of areas and increase the number of CMs working in certain large areas. Secondly, ensure IEC materials are available in local languages and are appropriate for the average level of literacy in the community. Consider making pictorial messages available. Finally, clarify intended beneficiaries of the IEC program and appropriately design programs for these groups. Emphasize including men and youth.

Ownership: Involve communities to select the CM and support committee, to design IEC messages, and to develop and implement IEC activities.

Sustainability: Ensure adequate support for the CM and address the fact that CMs are overworked. Foster linkages between HBC volunteers and IEC

volunteers. Partnerships not only promote sustainability, but also help strengthen capacity.

Adopting these recommendations will help Dignitas to improve its IEC component of the CHBC model. Additionally, the framework can be applied to ensure community engagement efforts are optimized in Zomba and other Dignitas projects.

Community engagement has emerged as a key component of international health research endeavours. Knowing how to engage communities requires an understanding of the concept of communities and the theories around community mobilisation. Interest in communities and community organization led to community-based research including community-based participatory research with the goals of research, education, and action. A number of theories underlie the concept of CBPR including knowledge and power theories of postcolonial, poststructuralist, and feminist varieties (Wallerstein & Duran, 2003). The concept of community engagement in research can be considered a spin-off of CBPR whereby researchers work collaboratively with groups of people on issues affecting the well-being of those people (CDC, 1997). As part of a cross-case comparison research project with the goal of identifying key determinants of success of community engagement, this case study project in Zomba District, Malawi critically evaluated the IEC component of Dignitas International's community home-based care model. Diverse findings include the need to ensure support for people implementing IEC activities, the need for community ownership, and the importance of fostering a sustainable

initiative. IEC activities should be engaging for the community and designed creatively to attract large groups of people. IEC messages being delivered need to be locally relevant and accessible to the audience. Importantly, community engagement is a slow process and time is needed in advance of program development to learn about the community itself. The "*one size fits all*" approach does not work in community engagement. The findings from this case study will contribute to the elucidation of global practices of community engagement in the developing world and ultimately will assist the acceptance and adoption of ethical health technologies capable of decreasing the global burden of disease.

APPENDICES

Appendix A: Grand Challenges in Global Health Research Projects

Bill & Melinda Gates Foundation, 2008.

GOAL 1: IMPROVE VACCINES

- **Grand Challenge #1:** Create Effective Single-Dose Vaccines

1. A live recombinant attenuated salmonella anti-pneumococcal vaccine for neonates
2. Linking innate and specific immunity to develop single dose vaccines for neonates

- **Grand Challenge #2:** Prepare Vaccines that Do Not Require Refrigeration

3. Bacterial spores as vaccine delivery systems
4. Optimization of vaccine stability through high throughput formulation
5. Thermostable vaccines with improved stability at non-refrigerated temperatures

- **Grand Challenge #3:** Develop Needle-Free Delivery Systems for Vaccines

6. Development of a targeted mucosal vaccine delivery technology
7. Nanoemulsions as adjuvants for nasal spray vaccines
8. Needle-free delivery of stable, respirable powder vaccine
9. Needle-free vaccination via nanoparticle aerosols
10. Surface modified nanostructures as delivery vehicles for transmucosal vaccination

GOAL 2: CREATE NEW VACCINES

- **Grand Challenge #4:** Devise Reliable Testing Systems for New Vaccines

  11. A humanized mouse model to evaluate live attenuated vaccine candidates
  12. Development of novel mouse models for HIV and HCV infection
  13. Novel mouse models for testing HIV and HCV vaccines

- **Grand Challenge #5:** Solve How to Design Antigens for Effective, Protective Immunity

  14. Enhancing the immunogenicity and efficacy of vectored vaccines
  15. Improved vaccine efficacy via dendritic cells and flavivirus vectors
  16. Novel antigen design and delivery for mucosal protection against HIV-1 infection
  17. Protective genetically attenuated *P. falciparum* sporozoite vaccine

- **Grand Challenge #6:** Learn Which Immunological Responses Provide Immunity

  18. Biomarkers of protective immunity against TB in the context of HIV/AIDS in Africa
  19. Comprehensive studies of mechanisms of HIV resistance in highly exposed uninfected women
  20. Immunity to prevent pneumococcal transmission: correlates of protection and herd immunity
  21. Learning from the Human Genome how protective immunity against malaria works
  22. Molecular analysis and modeling of HIV-1 transmission, containment, and escape
  23. Protective immunity against severe malaria in young children

GOAL 3: CONTROL INSECT VECTORS

- **Grand Challenge #7:** Develop a Genetic Strategy to Control Disease-Transmitting Insects

24. Developing coupled transgenic ribozyme and insecticide resistance approaches to establishing dengue virus refractoriness in natural populations of *Aedes aegypti* mosquitoes

25. Genetic strategies for control of dengue virus transmission

26. Homing endonuclease genes: new tools for mosquito population engineering and control

27. Modifying mosquito population age structure to eliminate dengue transmission

► **Grand Challenge #8:** Develop a Chemical Strategy to Control Insects

28. Disruption of malaria transmission by chemical manipulation of anopheline olfactory responses

29. Molecular approaches to alter olfactory driven behaviours of insect disease vectors

30. Molecular design of selective anticholinesterases for mosquito control

GOAL 4: IMPROVE NUTRITION

► **Grand Challenge #9:** Create a Nutrient-Rich Staple Plant

31. Engineering rice for high beta carotene, vitamin E, and enhanced Fe and Zn bioavailability

32. Improving cassava for nutrition, health, and sustainable development

33. Nutritionally enhanced sorghum for the arid and semi-arid tropical areas of Africa

34. Optimization of bioavailable nutrients in transgenic bananas

GOAL 5: LIMIT DRUG RESISTANCE

► **Grand Challenge #10:** Discover Drugs and Delivery Systems that Limit Drug Resistance

35. Natural products inhibit intracellular microorganisms via cellular mechanisms

36. Novel therapeutics that boost innate immunity to treat infectious diseases

GOAL 6: CURE INFECTION

- **Grand Challenge #11:** Create Therapies that Can Cure Latent Infections

    37. Drugs for treatment of latent TB infection

- **Grand Challenge #12:** Create Immunological Methods that Can Cure Chronic Infections

    38. Engineering immunity against HIV and other dangerous pathogens
    39. Immunological strategies for curing chronic Hepatitis virus infections
    40. Novel therapeutic vaccines for acute and persistent Papillomavirus infections
    41. Preclinical and clinical evaluation of a post-exposure TB vaccine

GOAL 7: MEASURE HEALTH STATUS

- **Grand Challenge #13:** Develop Technologies to Assess Population Health

    42. Population health metrics research consortium project

- **Grand Challenge #14:** Develop Diagnostic Tools for Multiple Conditions at Point of Care

    43. A point of care diagnostic system for the developing world
    44. Integrated rapid test platforms appropriate for the developing world

Appendix B: Interview Guides

Interview Guide for Non-community Members

Introduction

- Thank the key informant for participating and briefly describe objectives of project.
- Review Study Information Sheet and provide copy of Consent Form for signature.
- Outline the interview format.

Demographics

- "Could you briefly outline your involvement in the community engagement initiatives for your project or community?"
- "Have you had other experience with community engagement that might be relevant to this discussion?"

Stakeholder Perceptions

- "What was your role in the project?"
- "Who designed the community engagement initiative?"
- "What spurred the project's formation?"
- "How would you describe the framework or model of the project?"
- "Could you outline the major components?"
- "How were these components selected and designed?"
- "How long did it take to implement the project?"
- "How was the project received by the community?"

- "How many people attend the IEC events/activities?"
- "How were community perceptions measured?"
- "What was the impact/outcome?"
- "Would you participate again? Why or why not?"

<u>Determinants of Effectiveness</u>

- "How would you rate the success of the community engagement initiative? What factors influenced its success?"
- "What was the single most significant determinant of effectiveness?"
- "If you did not consider the community engagement initiative effective, what was the single most significant reason for its lack of success?"
- "How was effectiveness impacted by internal forces?"
- "How was effectiveness impacted by external forces?"

<u>Lessons Learned</u>

- "Was a formal evaluation conducted? If so, what were the findings of the evaluation?"
- "Who conducted the evaluation and what was the evaluation process?"
- "What lessons have you learned from your experience with this community engagement initiative?"
- "Do you plan to implement other community engagement initiatives? If so, how are they different from the project we discussed?"
- "How can the experience here be transferred to other community engagement projects?"
- "Which components of the project, if any, do you think may be unique to your

community?"

Closing

- "Is there anything else about community engagement that you would like to discuss?"
- "Do you have any questions about our research project or, more generally, about the Grand Challenges in Global Health initiative?"
- Thank participant.

Interview Guide for Community Members

Introduction

- Thank the key informant for participating and briefly describe objectives of project.
- Review Study Information Sheet and provide a copy of Consent Form for signature.
- Outline the interview format.

Demographics

- "Could you please tell me how you've been involved in Dignitas community events?"
- "What other experience do you have attending community events?"

Stakeholder Perceptions

- "What kinds of Dignitas IEC events are held in your community?"
- "How does Dignitas give out its IEC messages?"
- "How often are IEC events held in you community?"
- "How do you find out IEC events will be taking place?"
- "How many people attend the IEC events/activities?"
- "Who attends IEC events? Are different groups of people represented equally?"
- "Who does not attend IEC events? What can be done to include them?"
- "How do you define community? How does Dignitas define community? What are the differences between the definitions?"

Determinants of Effectiveness

- "Is the IEC program working in your community? Why or why not?"
- "What makes the IEC program successful?"
- "How is the success of the IEC program impacted by internal forces?"
- "How is the success of the IEC program impacted by external forces? (Things that are outside the control of Dignitas?)"
- "What is the impact of the IEC program?"

Dignitas Area Mobiliser to Community Motivator Transition

- "Are you aware of the Area Mobiliser program that Dignitas used before it started the Community Motivator program?"
    - "If yes, what are the differences between the two programs?"
    - "Which program was better at involving community members? Why?"

Lessons Learned

- "Can the IEC program be replicated outside your community, outside of Zomba, or even outside of Malawi? How?"
- "What is different about the Dignitas IEC program compared to other community engagement programs in Zomba?"

Closing

- "Is there anything else about community engagement that you would like to discuss?"
- "Do you have any questions about our research project or, more generally, about the Grand Challenges in Global Health initiative?"
- Thank participant.

Appendix C: IEC Activities

I attended eight IEC activities in three of the five Community Motivator areas in Zomba (Table 8).

Table 8 IEC activities scheduled and attended by case study investigator.

Date of Activity	Type of IEC activity	Type of data
24-May-07	Committee meeting	Observational notes
16-Jul-07	HTC sensitization meeting	Video
26-Jul-07	CM grant donation	Video
8-Aug-07	IEC sensitization meeting with commercial sex workers	Video
15-Aug-07	Community event: boys initiation ceremony	Video
17-Aug-07	Community IEC event	N/a: activity cancelled due to funeral
20-Aug-07	Community event: <5-clinic and IEC	Video
21-Aug-07	Community event	Video
22-Aug-07	Community event	N/a: activity cancelled due to funeral
22-Aug-07	IEC scale-up sensitization meeting	Video

Appendix D: Summary of HOPE Kit Activities

Activity	Why do this activity (Objectives)	What happens, in short (Summary)	Time needed
Section 1: Understanding HIV and AIDS			
1A **Wildfire**	• So that participants appreciate how HIV (and other STIs) can spread in a community ▪ *To show that HIV is a serious issue which needs addressing and has personal risk implications.*	This quick participatory exercise simulates how HIV can spread in a community, using an unusual hand greeting to represent having unprotected sex. It introduces discussion about HIV transmission and personal risk.	10—15 minutes
1B **Who is living with HIV?**	• To address assumptions and stereotypes about who is / is not living with HIV. • To clarify that physical appearance is a very poor indicator of HIV status. • To improve understanding of issues for people living with HIV, and what it means to live positively and openly with HIV. • To encourage participants to get tested in order to know their HIV status.	Participants select, from a range of photographic images of people (a diverse ethnic / gender / age mix), who they think is or is not living with HIV. The reasons for their choices are discussed before the facilitator describes their case history and confirms that in fact they are all living openly with HIV.	15-20 minutes
1C **What happens in the body of someone living with HIV or AIDS?**	▪ To clarify the difference between HIV and AIDS ▪ To explain in a memorable way what happens to a person's body and immune system once they are infected with HIV and how this can progress to AIDS. ▪ To clarify how someone living with HIV can feel and appear very healthy for many years. ▪ To explain simply what ARVs do.	This activity uses a short drama sketch to demonstrate and explain in a memorable way about HIV, AIDS, opportunistic infections, and what anti-retroviral drugs do. It involves members of your audience as characters called "White Blood Cell", "HIV", "Infection" and "Anti-retroviral".	15-30 minutes
1D **How HIV can and cannot be spread**	▪ To clarify the different ways that HIV can and cannot be spread.	Participants discuss what does and does not put someone at risk of HIV transmission.	10-15 minutes

Section 2: Narrow Bridges			
2A Walking the Bridges	• To clarify the choices available for preventing infection with HIV and other STIs. • To give participants an experience of (metaphorically) using Abstinence, Faithfulness and/or Condoms to prevent HIV infection, stay healthy and reach their goals and dreams in life.	Participants try walking across narrow stick bridges (representing Abstinence/ Faithfulness and Condom use) over water infested with crocodiles, hippos and snakes (representing STIs, HIV and other dangers) to get to an island (the future they want).	15 – 20 minutes
2B Walking the Bridges for People Living with HIV and AIDS	• To emphasize that people living with HIV can still have a good life and achieve what they want and value in life. • To clarify that focusing on what we want in life is often more helpful than focusing on the problems we face. • To identify different ways of helping and supporting PLWHAs.	This activity uses the *Walking the Bridges* activity in a different way, to promote discussion around the issues facing people living with HIV/AIDS. It demonstrates ways in which friends, relatives, colleagues and others in a community can support and care for someone with HIV or AIDS.	10 – 20 minutes
Section 3: Future Islands			
3A Future Islands	To help participants • Think about how they would like their life to be in the future. • Identify steps for reaching their desired future 'island' in ways which keep them safe from HIV infection.	Each participant creates what is for them a compelling 'Future Island' representing how they would like their life to be at some point in the future. They focus on their future island, and link safer sexual practices (i.e. staying on the bridges or boats of abstinence, faithfulness and condom) to arriving on their future islands.	30 – 45 minutes
Section 4: Fleet of Hope			
4A Fleet of Hope with Card Characters	• To help participants explore and openly discuss some HIV related issues facing them and others in their community.	Three boats representing Abstinence, Faithfulness and Condom are available to avoid the flood of HIV (a blue cloth) and other dangers in it. Participants tell stories about different card characters, and put them on one of the boats or in the water.	30 – 45 minutes
Section 5: Practical Issues on the way to your Future Island			
5A	• To help mainly younger,	Using the Forum Theatre	20 - 40

Practical Issues Around Abstinence	unmarried participants develop skills and strategies for being assertive and saying 'No' to sex. • To help young people and their parents initiate discussion about sex and health.	technique (see notes at the start of this section) with scenarios relevant mainly to young, unmarried people, this activity develops strategies and skills for saying 'No' to sex and talking about what you do and do not want in a relationship.	minutes
5B Practical Issues Around Being Faithful	• To help mainly married people and those in long term sexual relationships to address issues they may face.	This activity uses the Forum Theatre technique (see notes at the start of Section 5) with a scenario relevant to those married or in long term relationships.	20 - 40 minutes
5C Practical Issues Around Condoms	• To promote accurate knowledge about condoms and where they can be obtained locally. • To build skills to negotiate condom use in a relationship and convince others of the benefits of using them. • To build skills to use male and/or female condoms properly.	Forum Theatre scenarios can be used to explore issues of both negotiating condom use and to develop the practical skills of using both male and (if available locally) female condoms.	30 – 60 minutes
5D Voluntary Counselling and HIV Testing (VCT)	• To clarify to participants what Voluntary Counselling and HIV Testing involves and where they can get it. • To highlight some of the benefits of Voluntary Counselling and Testing	This activity clarifies what VCT involves and where it is available, and then explores issues for someone considering going for VCT.	20 – 40 minutes
5E Practical Issues for People Living with HIV and AIDS, and their Friends and Families	• To give those who are living with HIV (or think they may be) some ideas to help them stay healthy and live longer. • To build skills and ideas on how to provide practical support and encouragement for people we know who are living with HIV or AIDS.	This section deals with issues around living positively with HIV, including disclosing your status to your family members and others. It also uses Forum Theatre to build skills around responding to a friend or relative who discloses their HIV positive status to you.	30 – 60 minutes

Adapted from Labouchere, Mkandawire, Böse, & Joinet, 2005. Johns Hopkins Bloomberg School of Public Health Center for Communication Programs.

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