

THE UTILITY OF MOBILE PHONES FOR HEALTH AMONG WOMEN LIVING
WITH HIV IN URBAN MALAWI

by

Linda Dietrich

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ABSTRACT

THE UTILITY OF MOBILE PHONES FOR HEALTH AMONG WOMEN LIVING WITH HIV IN URBAN MALAWI

by
Linda Dietrich

The University of Wisconsin-Milwaukee, 2016
Under the Supervision of Professor Lucy Mkandawire-Vallhmu, RN, PhD

The use of mobile phones are becoming ubiquitous with growing interest by healthcare providers to utilize mobile phone technology for various health-related applications, called mHealth. This is especially true in low-income countries such as those in sub-Saharan Africa. When implementing mHealth applications, it is important to understand the dynamic social, cultural and environmental factors where mHealth will be implemented to ensure that interventions developed are effective. A qualitative study to explore the sociotechnical factors experienced by women participating in an HIV support group in urban Malawi was conducted to enhance our understanding of women's experience with mobile phone use and its implications on their health. Ten individual interviews and one focus group interview were completed with women, using narrative methods and a sociotechnical view to inform data analysis. Narrative structural and thematic analysis were used to analyze the individual interview data, and thematic analysis was used to analyze the focus group interview data. This study offers valuable insights into the sociotechnical factors impacting mobile phone use and its implications on health within this urban context. Findings are discussed under four main areas: 1. Health-related activities and tasks; 2. Social related activities and tasks; 3. Income generation activities and tasks; and 4. Technical challenges. Implications for policy discussed include the scaling up of programs incorporating mobile phones in sub-Saharan Africa as part of the HIV prevention and treatment

plan and partnering with NGO's and churches to leverage funding and existing community based resources. Implications for future research include an opportunity for further theory development around community health frameworks that are sensitive to the African world view of person and community in addition to further exploring the utility of mobile phone technology in enhancing health outcomes for people living with HIV.

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DEDICATION

This work is dedicated to the women in the HIV support group in Blantyre, Malawi who participated in my study. I admire their ability to care for themselves and each other and their willingness to share their stories of their experiences of using their mobile phones.

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CHAPTER 1

INTRODUCTION AND BACKGROUND

The purpose of this qualitative study using a sociotechnical framework with in-depth interviews and a focus group interview was to explore the experience of mobile phone use from the perspective of 10 women who are members of a support group for women infected with the human immunodeficiency virus (HIV) in Malawi in sub-Saharan Africa. Of special interest was how the mobile phones provided benefits to them in their daily health related activities as well as any barriers they encountered in using the phones in their day to day lives.

Statement of the Problem

Mobile phones are becoming ubiquitous, increasingly becoming part of our everyday lives, as well as being utilized in resource limited settings such as sub-Saharan Africa (Aker, Mbiti, Issac, 2010; Castells, Fernandez-Ardevol, Qiu, & Sey, 2009; Ling & Donner 2013). Mobile phones can be utilized to assist with health related activities such as medication adherence, and many studies have been done in sub-Saharan Africa using mobiles to look at their effectiveness in such endeavors (Donner & Mechael, 2013). However, many of these studies have not involved the users nor utilized the user's perspective to identify what their needs are and the impact of using the mobile in their day to day lives. Nor have there been any studies that have specifically focused on women infected with HIV who are using mobiles as members of a support group to identify their experiences with the mobiles from their perspective (Catalani, Philbrick, Fraser, Mechael, & Israelski, 2013). Understanding women's needs and how they use the phones in their day to day lives and daily activities as members of a support group may provide valuable insights into how applications for mobiles to support communities like this can

be developed in the future, or what kinds of support need to be in place to assist them in being able to adopt mobile phone applications for health.

Background, Context, and Significance of the Problem

The number of people who have access to wireless mobile phone networks globally has increased significantly in the last decade. In 2005, 67% of the world's population had access to a wireless mobile phone network. In 2015 that number jumped to 97 %. In 2005, there were just over 700 million mobile phone subscribers globally. In 2015, there are now 7 billion mobile phone subscribers. At least 78% of the 7 billion wireless subscribers live in low and middle-income countries (ITU, 2014, 2015).

In Africa, there are 629 million mobile phone subscribers. In sub-Saharan Africa, mobile cellular penetration stands at over 50% compared to 1% of fixed telephone penetration (ITU ICT Indicators Database, 2014). For most people in sub-Saharan Africa, their first phone will be a mobile phone. Mobile phones provide new opportunities to meet health needs in resource-limited settings. The spread of mobile phone networks in low-income countries is outstripping the establishment of paved roads, electrical power lines, the Internet, potable water delivery, and sewage disposal. In the past, poor, rural, and remote communities were underserved and lacked access to land line telephones. Nowadays, access to a simple inexpensive mobile phone can connect people living in these settings to important information, social support networks, emergency assistance, and income generating opportunities. A mobile phone can also extend and strengthen the healthcare ecosystem through various strategies. The utilization of mobile phones for these purposes has come to be known by the term *mHealth*. mHealth refers to the use of mobile technology to support health programs. The World Health Organization has defined mHealth as, “medical and public health practice supported by mobile devices, such as mobile phones, patient

monitoring devices, personal digital assistants (PDA's), and other wireless devices" (WHO, 2011p, 6). mHealth also involves the use of the technology that is part of the handset in mobile phones such a short messaging service (SMS) as well as what is known as general packet radio service (GPRS) and blue tooth transmitting technology. Other devices used can be basic cell phones, smart phones, or tablets. These devices can be attached to a network full time, intermittently, or not at all. It is believed that using mobiles for health can transform healthcare in low resource settings (Akter, Ray, 2010). In addition to mHealth, owning a mobile phone empowers by providing benefits such as gains in economic opportunities, increased communication, and power in decision making (Melhem & Tandon, 2009).

mHealth Activities in the Context of Sub-Saharan Africa

Common mHealth initiatives seen in sub-Saharan Africa include strategies directed towards client behavior change and communication, sensors and point of care diagnostics, registries and vital events tracking, data collection and reporting, electronic health records, electronic decision support, provider to provider communication, provider work planning and scheduling, provider training and education, connecting remote health workers to trained healthcare providers, human resource management, supply chain management, and financial transactions and incentives (Labrique, Vasudevan, Kochi, Fabricant, & Mehl, 2013; WHO,2011). From increasing adherence to medications for diseases such as HIV or Tuberculosis (TB), or assisting healthcare workers, mHealth studies are increasing in sub-Saharan Africa. According to Mechael, Batavia, Kaonga, Searle, Kwan, Fu & Ossman, (2010), mHealth activities in sub-Saharan Africa fall into one of the following themes in the literature:

- 1) treatment compliance;
- 2) data collection and surveillance;

- 3) health information systems and support tools for healthcare workers;
- 4) health promotion and disease prevention; and
- 5) emergency medical response systems.(p.10).

Limitations in Current Research Approaches to mHealth Studies

From 2010 to 2015 the number of mHealth studies in sub-Saharan Africa has markedly increased as well as the systematic reviews of the published studies that have taken place over the previous 15 years (Aranda-Jan, Mohutsiwa-Dibe, & Loukanova, 2014; Betjeman, 2013; Brinkel, Krämer, Krumkamp, May, & Fobil, 2014; Chib, van Velthoven, & Car, 2014; Gurman, Rubin & Roess, 2012; Martínez-Pérez, de la Torre-Díez, & López-Coronado, 2013).

Recommendations from these systematic reviews include the need to move from the focusing predominately on pilot and feasibility studies and moving to larger, more sustainable trials. There is also a need for consistency in methods and reporting of mHealth studies (Brinkel et al., 2014; Chib et al, 2014; Gurman et al., 2012) and more cross disciplinary collaboration between public health, social sciences, and technology development experts (Chib et al., 2014). Others have noted a lack of application of theoretical frameworks, both from the perspective of theories of health behavioral changes as well as information and communication technology adoption (ICT) adoption, user-centered design, and community based participatory design (Catalani, Philbrick, Fraser, Mechael, & Israelski, 2013; Chib et al., 2014; Donner & Mechael, 2013). It has long been established within the healthcare information communication technology literature that user-centered and iterative design lead to better and more successful system implementations (Dabbs, Myers, McCurry, Dunbar-Jacob, Hawkins, Begey, & Dew, 2009; Ghazali, 2014). Yet, there have been few studies that have incorporated the foundations of a

sociotechnical approach to healthcare ICT inquiry in mHealth studies in sub-Saharan Africa. Limited studies have assessed the sociotechnical aspects and included the users early in the design or dynamically throughout the lifecycle, which is a hallmark of the sociotechnical approach. One is left with the notion after a review of the many studies of what Heeks (2002) has discussed as *design imposing* software projects versus software design projects supporting future state local improvisations, designed dynamically throughout the project lifecycle.

Malawi Context

This study was conducted in Malawi, a low resource, densely populated (18.5 million) Sub-Saharan African country (CIA, 2016). Blantyre is a major city located in southern Malawi with a population of 808,000 (CIA, 2016).

The HIV epidemic continues to pose problems for Malawi. The prevalence rate is 11 % for adults aged 15 to 49. In the southern region of Malawi where Blantyre is located the prevalence rate is 14.5% for 15-49 year old adults. There are gender disparities that characterize the epidemic. HIV prevalence is higher among 15-49 year old women at 13 % compared to men at 8 % (National Statistical Office [NSO] and ICF Macro, 2011). Women aged 35-39 are three times more likely to be infected than men of the same age with a prevalence rate of 24%. HIV is more prevalent in urban areas where 22% of women age 15-49 are infected with HIV as opposed to 10.5% in rural areas (NSO & ICF Macro, 2011). Malawi is one of the poorest countries in the world with 71 % of the population living in extreme poverty (World Bank, 2016).

The gender gaps in educational attainment and political empowerment continue to be some of the highest globally (Hausmann, Tyson, & Zahidi, 2012). This creates a difficult situation as women have difficulty meeting their basic needs such as food, shelter, and clothing (Barnes, Keogh, Nemarundwe, & Nyikahadzoi, 2002). Having to cope with the chronic illness of HIV also

places women in a greater-than-average risk of developing health problems in this community (de Chesnay, 2011).

Purpose

The purpose of this study was to describe how mobile phones were used by HIV infected women in everyday life during the time that they were members of a support group for women in urban Malawi.

Research Question

What are the sociotechnical factors associated with mobile phone use and how are they experienced by a group of HIV infected women who are part of a support group that meets regularly for income generation and support?

Aims

The specific aims of this study were to describe:

1. Experiences of using the mobile phones in their day-to-day lives.
2. How the mobile phones helped women with their income generation and healthcare activities.
3. Identify challenges with utilizing the mobile phones in their day-to-day lives.
4. Identify the sociotechnical factors and meanings of mobile phone use as derived from the perspectives of the HIV infected women.

Research Approach

This qualitative study utilized a sociotechnical systems theoretical framework and incorporated narrative interviews and thematic focus group data to identify how the women used the mobile phones in their day-to-day lives, what they identified as barriers and facilitators to

their use, and activities within the support group. From an ontological perspective it is important to capture the stories of the women in their own voices. Therefore, the women's stories as found in ten individual interviews done in August 2012, and the thematic data from the focus group conducted with the women in August 2012 are the primary unit of analysis in this study.

Assumptions

This study was based on the following assumptions:

- 1) The women's health related activities constituted a type of work that they accurately reported through their personal perceptions, experiences, and behaviors.
- 2) The women's health related activities occurred within a context (sociotechnical system) that comprises interacting components of tasks, technology, environment, and community factors (Valdez, Holden, Novak, & Veinot, 2014).
- 3) These factors act as constraints, facilitators, or both with respect to health related activities.
- 4) The translated interviews were accurate and maintained the participants intended meaning.

Significance of the Study

This study is significant in several regards. It provides practical knowledge regarding how women with HIV in sub-Saharan Africa use mobile phones in their day-to-day lives. It extends the understanding of how mobiles operate as an adjunct in a support group for women with HIV in Malawi in sub-Saharan Africa. Although the use of mobile phones as an adjunct in support groups for women has been studied in other settings (Mas & Morawczynski, 2009; Alam, Yusuf, & Coghill, 2010), this study was unique in that it used a qualitative narrative methodology and sociotechnical lens to obtain the women's reports of their experiences with the mobile phones.

This provided rich user-centric narratives and thematic descriptions of how they interacted with mobile phones as facilitators or barriers in their daily activities, and, revealed interrelationships with mobile phone technologies and user social practices that can be leveraged in future mHealth projects.

Researcher Perspective

As a teacher who has taught systems analysis and design, and an informatics nurse who has been responsible for working with users to help identify their current workflow activities and needs in order to assist in designing software that would meet their requirements, I have seen many problems with implementing software. Whether the software is on mobile phones or computers in clinics or hospitals, when users such as clinician's voices are not heard properly early on in the project lifecycle, and the sociotechnical aspects are not suitably addressed, these systems are not usually adopted and there is measurable failure. On my first trip to Malawi during a community health class, I participated in a project where we were going to create an application on mobile phones for women. We held some focus groups in different villages and I was struck by the variability in the women's current use of the phones. On two different occasions, I was also able to spend time in the HIV clinic in Blantyre where I observed the workflow and software they used in their daily workflow and how this enabled them to work with the population of HIV patients and dispensed and monitored ART medications. After these experiences I felt that there was really a need to understand from the users, or the women's point of view how they were using their phones in their day-to-day lives and what they experienced as barriers in simply using a mobile phone before any further work was done with developing or implementing applications to support them with their health activities.

Definition of Terminology

eHealth

‘Electronic health is the cost-effective and secure use of information and communication technologies (ICTs) for health and health-related fields’. (WHO, 2016)

AIDS

“(Acquired Immune Deficiency Syndrome) AIDS is the most severe phase of HIV infection. People with AIDS have such badly damaged immune systems that they get an increasing number of severe illnesses, called opportunistic illnesses. Without treatment, people with AIDS typically survive about 3 years. Common symptoms of AIDS include chills, fever, sweats, swollen lymph glands, weakness, and weight loss. People are diagnosed with AIDS when their CD4 cell count drops below 200 cells/mm or if they develop certain opportunistic illnesses. People with AIDS can have a high viral load and be very infectious”. (CDC, 2016)

Articulated Work

“All tasks involved in assembling, scheduling, monitoring and coordinating all of the steps necessary to complete a production task (patient trajectory). This means carrying through a course of action despite local contingencies, unanticipated glitches, incommensurable opinions and beliefs or inadequate knowledge of local circumstances. Every real world system is an open system...No formal description of a system (or plan for its work) can thus be complete...every real world system thus requires articulation to deal with the unanticipated contingencies that

arise. Articulation resolves these inconsistencies by packaging a compromise that ‘gets the job done’ that is, that closes the system locally and temporally so that the work can go on” (Gerson, & Star 1986). p. 266)

ART

‘(Antiretroviral therapy) or ART is the use of HIV medicines to treat HIV infection. People on ART take a combination of HIV medicines from at least two different HIV drug classes every day. Because HIV medicines in different drug classes block HIV at different stages of the HIV life cycle, ART is very effective at preventing HIV from multiplying. ART also reduces the risk of HIV drug resistance. ART, sometimes called ARV (Antiretroviral Drugs) can’t cure HIV, but HIV medicines help people with HIV live longer, healthier lives. ART also reduces the risk of sexual transmission of HIV’ (NIH, 2015).

HIV

‘(Human immunodeficiency virus) gradually destroys the immune system by attacking and killing CD4 cells. CD4 cells are a type of white blood cell that play a major role in protecting the body from infection. HIV uses the machinery of the CD4 cells to multiply (make copies of itself) and spread throughout the body. This process, which includes seven steps or stages, is called the HIV life cycle. HIV medicines protect the immune system by blocking HIV at different stages of the HIV life cycle’ (NIH, 2015).

ICT4D

“Information and Communication Technology for Development is defined as Individual or groups of communication technologies, whose adoption or impact supports ongoing and/or future development aims and objectives” (Heffernan, Lin, & Thomson, 2016, p.905).

mHealth

‘**Mobile Health** is a component of eHealth, and involves the provision of health services and information via mobile technologies such as mobile phones, tablet computers and Personal Digital Assistants (PDAs)’. (WHO, 2016)

CHAPTER 2

REVIEW OF THE LITERATURE

This chapter provides a background for the study and is organized into four main sections. In the first section, I have provided a brief review of sociotechnical systems theory, in order to familiarize the reader with those concepts and discuss sociotechnical factors related to mHealth in sub-Saharan Africa including environmental, technical, social, and financial factors. In the second section, studies incorporating mobile phones in sub-Saharan Africa of relevance to this study are discussed including those incorporating mobile phones to promote adherence to antiretroviral (ART) medications such as short message service (SMS) reminders for medication and clinic appointments. In the third section, I provide further context regarding women living with HIV in sub-Saharan Africa including a discussion of issues related to food security and HIV stigma. In the final section, I have provided an overview of Malawi and the impact of the HIV epidemic on the country.

The growing penetration of mobile phones in sub-Saharan Africa suggests that it is fulfilling a human need within a social context. Likewise, the explosion of interest in using mobile phones to support health initiatives suggests a need for further knowledge development regarding the interrelationship of this new technology and its social environment. Because sociotechnical approaches to the study of information technology focus on this relationship, I have identified it as a beneficial approach for this inquiry.

Sociotechnical Systems Theory

The study of sociotechnical systems includes the system that is created by the interaction of people and technology in organizations. Emphasis is on both the human, social, and technological features in concert as they contribute to the behavior of a system (Bostrom &

Heinen, 1977; Cherns, 1987; Coiera, 2015). Although this definition speaks of people and technology interacting within an organizational setting, the sociotechnical perspective has also been applied to the study of people interacting with mobile phones in day-to-day life in Sweden (Berg, Mörtberg, & Jansson, 2005) and applied to mHealth success factors (Keikhosrokiani, Zakaria, Mustaffa, & Venkat, 2014)

A sociotechnical approach to healthcare information communication technology (ICT) studies embraces several key foundations (Berg, 1999; Clegg, 2000; Berg, Aarts & van der Lei, 2003). First, the context where healthcare and patient work occurs is a heterogeneous network and cannot be circumscribed or deconstructed. Care practices arise out of the unique social and political context of this network as a whole versus the technical and the social being separated (Berg et al., 2003; Kling & Schachi, 1982). Second, the nature of healthcare work is that it is characterized by distributed and contingent decision making, with much articulation work that occurs to keep things going in a complex environment. For example, tasks that a ward clerk in a hospital might do may be invisible in a typical ICT evaluation study, which may not emphasize the cooperative nature of work. Whereas a sociotechnical lens would evaluate how the healthcare IT under study unfolds within the web that incorporates all members in the sociotechnical system including the ward secretary as well as the hardware and the social and political relationships (Brown, Shaw, & Mador, 2008; Harrison, Koppel, & Bar-Lev, 2007; Goorman & Berg, 2000). The sociotechnical viewpoint also places importance on gaining insight into the work practices in which an IT application is going to be used prior to implementing it. The idea is to gain knowledge as to the contingent decision making and articulated work that occurs to “keep things going” and get tasks done in the patterns of everyday life. This ideally occurs before one ever begins to develop a system. Additionally, it is important to know what and who makes up the specific sociotechnical

network prior to implementation and evaluation strategies being developed. Third and finally, it is user-centric with users being involved in all stages of an iterative system development lifecycle (Berg, 1999). From a technical viewpoint, the typical systems development lifecycle may have a linear quality moving through the stages of design, build, test, train, and move to production. From a sociotechnical approach, these phases blur and become more iterative as users are involved in each. The sociotechnical implementation process is a change process that has an emergent and dynamic quality versus an enforced and controlled pathway.

Sociotechnical Factors Related to mHealth in Sub-Saharan Africa

In this section, I discuss some of the sociotechnical factors that need to be considered in working with mobile phones for health in sub-Saharan Africa. These factors include environmental, technical, social, and financial. Environmental factors include infrastructure such as electricity and roads. Technical includes phone charging processes, how a particular mHealth application might connect with the rest of the eHealth ecosystem such as a clinic or an electronic health record, what types of handsets are used and the software on the handset, and the Subscriber Identity Module (SIM) Card switching to manage mobile network coverage. Social aspects may include gendered dimensions of mobile phone usage. Literacy and language considerations need to be addressed, as well as ethical issues related to privacy and confidentiality (Wall, Vallières, McAuliffe, Lewis, & Hederman, 2015). Finally, financial impacts may include cost for purchasing a handset, airtime, and the use of beeping or flashing to lower telecommunication expenses.

Profile of Sub-Saharan Africa

For purposes of this review, sub-Saharan African countries have been defined according to the classification utilized by the World Bank in 2015 (The World Bank, 2016). For the 2015 fiscal year, low-income economies are defined as those with a Gross National Income (GNI) per capita

of \$1,045 or less in 2013, calculated using the *World Bank Atlas* method; middle-income economies are those with a GNI per capita of more than \$1,045 but less than \$12,746; high-income economies are those with a GNI per capita of \$12,746 or more. Lower-middle-income and upper-middle-income economies are separated at a GNI per capita of \$4,125. According to this classification of the World Bank, there are 47 countries in sub-Saharan Africa which the World Bank has also labeled “developing only” (The World Bank, 2016). The World Bank reports geographic classifications and data for geographic regions for low-income and middle-income economies only. Low-income and middle-income economies are frequently referred to as “developing economies” and in the peer reviewed and popular literature they are frequently referred to as developing countries. According to the World Bank, the use of the term is convenient; and is not intended to imply that all economies in the group are experiencing similar development or that other economies have reached a preferred and/ or final stage of development. Income classification does not necessarily reflect development status (The World Bank, 2016).

The countries of sub-Saharan Africa vary geographically and demographically. There are 15 that are landlocked, 26 that are coastal, and 2 (Cape Verde and Madagascar) that are islands. The average population density is 70 people per square kilometer. This is highly variable with some countries being very densely populated (Malawi, Ghana, Rwanda, Nigeria, Uganda, and Cape Verde) and others considered sparse (Chad, Niger, Namibia, Cameroon, Sudan, and Zambia) (World Bank, 2016).

Environmental Factors

Infrastructure: Electrical power. According to the World Bank, sub-Saharan Africa’s largest infrastructure deficit is in the power sector. This has impacts for mobile phone use in relation to charging of mobiles as well as the possibility of connecting mobile phone software to

other parts of an e-health ecosystem such as an electronic health record. The 47 countries in sub-Saharan Africa only generate a combined amount of power consumption measured at 124-kilowatt hours per capita per year. This statistic is one tenth of what is utilized elsewhere in middle and high-income countries. It is not enough to power a 100 watt light bulb for one person for three hours per day (World Bank, 2013). Frequent power outages can also put a drain on equipment and challenge the ability to utilize any type of advanced applications that might require wireless or Internet using mobile broadband as part of their ecosystem. In relation to mobile phone projects, this impacts charging. A ready electrical source cannot be assumed in this setting consistently. Charging a mobile phone frequently incurs an expense on the part of the user. Many times people will pay a small fee to use a centralized charging station created off of a lead acid battery, or pay at a station where there is a shared electrical source available. Solar chargers are becoming available but are inconsistent in their dependability (Wall, Vallières, McAuliffe, Lewis, & Hederman, 2015).

Infrastructure: Roads. Fewer than 40 percent of rural Africans live within two kilometers of an all-season road. This turns out to be the lowest level of rural accessibility in sub-Saharan low and middle income countries. Paved roads are less dense than in other lower income countries in other parts of the world (World Bank 2013). Road density is an indicator of how well connected parts of the country are. The impact of this situation on the use of mobiles and mHealth is both positive and negative. On one hand, for some it is believed to present a positive opportunity to reach those who are not connected by roads in rural areas through the use of mobile technology. However, it may not have the positive outcome expected if the telecommunication provider is not able to reach into the rural area to put up a cellular tower due to lack of accessibility (World Bank, 2013).

Technical Factors

Phone charging processes and software. Due to the issues regarding electrical power shortages and limited availability, it is important to understand what the process of phone charging for mobile phone users in developing mHealth projects in sub-Saharan Africa. There are many creative ways that users accomplish this task. For example, they may own several batteries and switch out batteries with someone who may be going in to town to a battery charging station. From a software perspective, it may be more realistic to run software that can be turned off and not use power and then be turned on again at a later time, rather than software that needs to run all the time. For example, software that runs on mobile phones that are able to be connected later to an electronic health record and uploaded at a clinic versus trying to send things from the field.

Subscriber Identity Module (SIM) cards. Many times mobile networks do not reach all areas and users will typically carry around SIM cards from several carriers and switch them out in their phones in order to reach the appropriate carrier. Or, they know where to locate a signal geographically near their dwelling. Therefore, solutions for users need to take into consideration how these impact design and adoption. Involving users early on in the process would be important to understand these elements and identify how they impact the success of a mHealth project.

Social Factors

Gender. Although there has been rapid growth in mobile phone subscriptions in low and middle-income countries in sub-Saharan Africa, women are 14% less likely than men to own a mobile phone, and over 300 million are women in sub-Saharan Africa (GSMA, 2015). Social norms influence women's access and use of mobile phones, and may contribute to women

experiencing barriers to mobile phone ownership. For example, a study in Kenya found that women felt harassed going in to local mobile operator shops to purchase mobiles that were staffed by males (GSMA, 2015). Security and harassment may be a concern to mobile phone ownership and usage for women. For example, a study in Zambia found that mobile phones aggravated existing gender inequities (Jennings & Gagliardi, 2013). Given these different findings questions remain about how local usage patterns differ based on gender differences.

Language and literacy. In parts of sub-Saharan Africa there are multiple languages spoken. For example, a recent mHealth feasibility study describes the challenge in Cameroon where there are currently 286 ethno-linguistic groups identified (Bigna, Noubiap, Plottel, Kouanfack, & Koulla-Shiro, 2014). This can make the use of SMS or text messaging applications a challenge to design for certain populations. There may be variable or limited literacy rates in the user community of interest (Chan & Kaufman, 2010). This may require use of other strategies for system design such as voice or pictures (Brewer, Demmer, Du, Ho, Kam, & Nedeveschi, Fall, 2005).

Financial Factors

Handsets. The cost of purchasing a handset may be prohibitive for some people in sub-Saharan Africa who live in extreme poverty. mHealth projects may need to take into consideration the cost of furnishing handsets for participants. Simple handsets that do not include smart phone features for accessing the Internet may be best since these would use less battery and require less charging. It is common for people to share phones, therefore if the mHealth project will not be providing phones the design would need to take this into consideration. In Malawi, where this study took place, the least expensive handset cost approximately 5995.00 Malawi Kwacha or \$13.63 US Dollars in 2015. That figure has gone down from 2012 when the

lowest cost mobile handset cost approximately 7,995.00 Malawi Kwacha or \$18.00 US Dollars. This is still a considerable amount if you are making \$1.25 US or less per day and the cost of a handset competes with rent, food, healthcare, and education expenses.

Air time. The cost of purchasing airtime may also be prohibitive for some people in sub-Saharan Africa living in extreme poverty. mHealth projects would need to take into consideration the cost of furnishing air time and how this impacts people's behavior on mHealth projects. Usually this is purchased at a local vendor in tickets in a pay as you go fashion and airtime is added to the phone. For example, in Malawi, there are two telecommunications providers, Airtel and TNM. Although Airtel seemed to have a weaker signal locally in the southern region where this study takes place they sold airtime in units of 25 Malawi Kwacha (about 15 cents USD) while the smallest increment for TNM was 50 Kwacha. Sometimes people will have 25 Kwacha on hand but may not have 50 in their pocket when they want to buy airtime. They will then consider walking or bicycling several kilometers to reach the Airtel mobile signal and put the Airtel SIM card in their phone.

Beeping or flashing. In order to conserve airtime a practice is commonly used called "beeping" or "missed calling" between mobile phone users in sub-Saharan Africa, although it can be known by many different names. This is how it works: One person calls a mobile telephone number and then hangs up before the other mobile's owner picks up the call. If the caller's name and number have been entered into the receiver's mobile address book, then the receiver will see the sender's name on the call log as a missed call. If not, the receiver will see only the number of the mobile placing the call. In whichever case, the missed call is usually intentional; the "beeper" has sent a signal to the receiver without saying a word or sending a text. An added bonus is that "beeping" is free (Donner, 2007). Beeping has become a pattern of daily

use of mobiles. Identifying if there are local ways that beeping patterns are enacted or how they could be incorporated into mHealth applications may be beneficial.

Ethical Implications

There may be privacy considerations to think about in regards to how mobiles are used in day-to-day life in sub-Saharan Africa versus how they are used in the West. Since phones may be shared, one might need to first seek permission from someone else before using a phone if it is shared among a group of people (Wall, Vallières, McAuliffe, Lewis, & Hederman, 2015). Additionally, if it will be used to deliver lab results or interventions that have to do with conditions such as HIV that may carry stigma there may need to be additional considerations if providing sensitive information.

Studies Incorporating Mobile Phones for Healthcare in sub-Saharan Africa

Over the past five years, the number of mHealth studies in sub-Saharan Africa has markedly increased as well as the systematic reviews of the published studies that have taken place over the previous 15 years (Aranda-Jan, Mohutsiwa-Dibe, & Loukanova, 2014; Betjeman, 2013; Brinkel, Krämer, Krumkamp, May, & Fobil, 2014; Chib, van Velthoven & Car, 2014; Gurman, Rubin, & Roess, 2012 and Martínez-Pérez, de la Torre-Díez, & López-Coronado, 2013). Recommendations from these systematic reviews include the need for more consistency in methods and reporting of mHealth studies (Brinkel et al., 2014; Chib et al., 2014; Gurman et al., 2012) as well as more cross disciplinary collaboration between public health, social sciences, and technology development (Chib et al., 2014). Others have noted a lack of application of theoretical frameworks, both from the perspective of theories of health behavioral changes as well as IT adoption, user centered design, and community based participatory design (Catalani, Philbrick, Fraser, Mechael, & Israelski, 2013; Chib et al., 2014; Donner & Mechael, 2013).

There have been few studies that have incorporated the foundations of a sociotechnical approach to healthcare IT inquiry in mHealth studies in sub-Saharan Africa. Few studies have assessed the sociotechnical aspects and included the users early in the design and dynamically throughout the lifecycle. One is left with the notion after a review of the many studies of what Heeks (2002) has discussed as design imposing software projects versus software design projects supporting future state local improvisations designed dynamically throughout the project lifecycle. Yet, studies have shown positive benefits and there are many projects and programs underway that use different mobile phone intervention strategies and mobile phone handset features (Klasnja & Pratt, 2012).

mHealth is being used in sub-Saharan for many purposes. These include: 1) Utilization by healthcare workers for different tasks such as data collection, direct communication, education, scheduling appointments, and communicating with patients (Zurovac, Sudoi, Akhwale, Ndiritu, Hamer, Rowe, & Snow, 2011; Chang, Kagaayi, Nakigozi, Packer, Serwadda, Quinn, & Reynolds, 2008); 2) Education and Health Promotion (Danis, Ellis, Kellogg, van Beijma, Hoefman, Daniels, & Loggers, 2010; Mitchell, Bull, Kiwanuka & Ybarra, 2011); 3) Surveillance of Adverse Drug Events (Adedeji, Sanusi, Tella, Akinsanya, Ojo, Akinwunmi, & Ogundahunsi, 2011); 4) Alerts and Reminders (Crankshaw, Corless, Giddy, Nicholas, Eichbaum, & Butler, 2010; Lester, Ritvo, Mills, Kariri, Karanja, Chung, & Plummer, 2010; Kunutsor, Walley, Katabira, Muchuro, Balidawa, Namagala, & Ikoona, 2010; Pop-Eleches, 2010); and 5) HIV Treatment and Prevention (Catalani et al., 2013). Of the studies just noted, four of them were in Uganda and three of the studies were in Kenya. Most of the Uganda studies were rural, with the Kenyan studies both rural and urban. The predominant Kenyan population was people living with HIV AIDS (PLWHA) with mHealth technologies such as SMS being used for

reminders for antiretroviral treatment adherence. In Uganda, there was one study where SMS technology was utilized for appointment and medication adherence reminders for PLWHA in the rural setting. This study in Uganda was directed at Healthcare workers as the user for sharing of direct communication regarding care management of patients with HIV (Chang et al, 2008). The study found that peer health workers with mobile phones delivering HIV treatment services was an improvement as rated by the users. A similar study was conducted again in 2011 in Uganda on a larger sample of peer community health workers delivering services to PLWHA, findings showed high satisfaction on the part of both patients and community health workers. Some of the problems they experienced included variability in patient phone access, privacy concerns, and phone maintenance issues (Chang et al, 2011). The other two studies in Uganda were focused on education and health promotion for HIV and done in collaboration with the mobile phone providers where SMS messaging was provided as an educational intervention for large numbers of mobile phone subscribers. Many of these studies are focused on acceptability and feasibility of an intervention and most do not articulate the use of theoretical frameworks. Additionally, with the exception of Chang et al, 2008, 2011, there is not an emphasis on participatory approaches involving users in the project. Also, given that HIV infects more women than men (Parker, 2002) few studies explicitly focus on women.

Using Mobile Phones to Promote Adherence to Antiretroviral Therapy (ART) Drugs

SMS Reminders to People Living With HIV/AIDS (PLWHA). Adherence to antiretroviral therapy (ART) is an important part of survival for individuals with HIV. Adherence to ART medications is relevant to the population that participated in my study, so it is discussed here. Strict adherence to antiretroviral therapy (ART) creates prolonged HIV suppression, decreasing the risk of resistance to the ART drugs, improved health and survival,

and decreases the risk of transmitting the disease (DHHS, 2015). When someone has HIV, they lose virologic control as a consequence of non-adherence to ART. This leads to drug resistance which leads to decreased future treatment options. If someone is already on ART and they are able to maintain consistent levels of adherence then they have resultant viral suppression, CD4+ T-lymphocyte (CD4) count recovery, and improved clinical outcomes. (DHHS, 2015) However, if someone has poor adherence to ART and/or experience periodic lapses over their lifelong course of treatment they may not have the same outcomes. Adherence to ART in sub-Saharan Africa can be influenced by a number of factors. These factors include clinical condition, community based support, acceptance of HIV diagnosis, HIV related stigma, and the mechanisms through which stigma can operate such as fear of disclosure (Kako, Stevens, & Karani, 2011; Merten, Kenter, McKenzie, Musheke, Ntalasha, & Martin-Hilber, 2010; Nachege, Adetokunboh, Uthman, Knowlton, Altice, Schechter, & Mills, 2016; Sweeney & Venable, 2016).

In sub-Saharan Africa, poverty and the challenges related to intermittent shortages in ART medication supplies and having to travel long distances to obtain ART medications at a clinic can be a challenge. These are also not mutually exclusive factors in that poverty can create food insecurity which can create difficulty with taking ART medications on an empty stomach and which may set up a situation where tolerance to the medications side effects such as nausea are not managed as well, thus impacting adherence. For example, sometimes a choice may come down to paying for food or the cost of bus fare to the clinic (Haberer, Cook, Walker, Ngambi, Ferrier, Mulenga, & Bangsberg, 2011). Although the ART medications may be subsidized by government programs people still have to go to the clinic to obtain the medication. Several studies have been done in sub-Saharan Africa including: Cameroon (Mbuagbaw, Bonono-

Momnougui, & Thabane, 2012); and South Africa, (Crankshaw et al., 2010). In Kenya, (Lester et al., 2010 and Pop-Eleches, Thirumurthy, Habyarimana, Zivin, Goldstein, de Walque, & Bangsberg, 2011) that were Randomized Controlled Trials (RCTs) of mobile phone interventions using reminders directed towards antiretroviral therapy adherence (ART). These were large RCT's investigated the use of low-cost cell phone text messaging (mHealth) interventions on HIV treatment adherence in Kenya (Lester et al., 2010; Pop-Eleches et al., 2011).

These studies, completed in Kenya in both rural and urban outpatient clinic settings showed that strategic low-cost cell phone text messaging interventions were associated with higher rates of adherence to antiretroviral treatment medications. In the Lester et al. (2010) study the intervention was short SMS messages sent from a clinic site nurse every Monday morning using a bulk SMS messaging program and the patient had to respond within 48 hours. If they did not respond or if they said they had a problem then the nurse called the patient during clinic hours. Adherence was measured at 6 and 12 months follow-up by asking participants how many pills they missed in the last 30 days; those classified as adherent reported taking more than 95% of the provided pills at both follow-up visits. Adherence to ART was reported in 168 of the 273 SMS patients compared to 132 of 265 non-SMS patients. Viral suppression laboratory results were improved in the SMS group compared to the control group. Both of the outcome measures were statistically significant ($p=0.06$ and $p=.04$) The Pop-Eleches et al. (2011) study used four intervention groups with one way messaging 1) Daily Short SMS reminders close to frequency of medication usage. 2) Daily Long SMS Reminders close to time of medication usage were meant to provide additional support. 3) Weekly Short SMS Reminders or 4) Weekly Long SMS Reminders. Adherence was measured using a medication event monitoring system that electronically captured the number of times that the cap to one of their ARV medications was

opened per 24-hour period. The same NOKIA© phones were provided to all participants. Assistance was provided to participants in the intervention and control groups to address electricity and financial limitations. In order to cover fee based charging stations for phones, participants were given 80 Kenya shillings at each monthly visit, and 50 Kenya shillings of phone credits were added to their subscriber identity module (SIM) for their phones every 2 months. Participants were required to show their phone at each visit and if they lost their phones, they were not replaced. Results showed that 53% of those who received weekly SMS had 90% adherence versus the control group which had 40% adherence; this was statistically significant ($p=0.03$). These studies are often cited as showing the effectiveness of using mobiles for health. At least 65% or more of the participants were female and lived on less than \$1.00 - \$5.00 US per day with 28% or more living on less than US \$1.00 per day in both the control and SMS group. The clinic nurses reported a higher number of calls from the participants in the control group – although this was not reported empirically. Interviews were not completed of the participants to determine their perceptions of the impact of the mobile messages.

In sub-Saharan Africa, it is estimated that 22.5 million adults and children are infected with HIV (USAID, 2010). Antiretroviral Therapy (ART) has been instrumental in decreasing the mortality rate and usually measured by clinic visits for medication refills. These next studies investigate the feasibility of using reminders prior to initiating them with a population regarding clinic appointments sent through SMS messages or voice to ARV clinic attendee's mobile phones. These feasibility studies were conducted with a sample of HIV infected participants in the African countries of Uganda (Kunutsor et al., 2010) and South Africa (Crankshaw et al., 2010).

SMS Reminders to PLWHA for Clinic Appointments. In rural Uganda, the Kunutsor et al. (2010) study was completed which evaluated whether SMS or voice messages were feasible for clinical appointment reminders in two rural service areas. One hundred eighty-eight of the participants were female and 88 were male. This study looked at mobile phone use patterns such as sharing, preference for voice or SMS, and willingness to be contacted as part of the study contact (Kunutsor et al., 2010). Although these dimensions are reported and results showed a positive impact on appointment adherence it is not clear how some of these patterns related to each other. For example what the impact of sharing, educational level or gender had on results. Results did show that more females than males turned off their phones during the day.

A feasibility study was completed in an ART Clinic at the McCord Hospital, KwaZulu-Natal, in Durban, South Africa to identify if mobile phones could be used for medication refills appointment reminders (Crankshaw et al., 2010). This was a peri-urban and urban population which charged a monthly user fee of "ZAR140 (approximately \$20 USD)" (Crankshaw et al., 2010, p.730). In this study, the investigators also wanted to determine if adherence messages would be acceptable to participants and identify if there were any differences in phone use by gender. The sample size was 300. Initially a structured interview tool was used by a trained research assistant who was not part of the clinic during visits to recruit the sample of 300 and to obtain consent to receive messages or calls on their mobile phone (Crankshaw et al., 2010). Participants who owned a cell phone totaled 242 and 95% utilized prepaid airtime service. In this study they found that women were more likely to switch off their mobiles during the day and not take calls in some social circumstances. Also, it was more probable that females would share their phones and leave it in an accessible location where others could access it. (Crankshaw et al., 2010). Of the 242 participants, most chose to have contact by both voice and texting. Results revealed some

interesting findings such as 40% of participants reporting theft of one or more previously owned phones; 67% of the sample was female; 23% turned their phones off during the day; 28% reported sharing of their phone; 79% already used the alarm function on their phone for medication reminding. This was a feasibility study pre intervention. These studies involved the users early in the project and partially addressed some of the sociotechnical considerations. However, in this study the investigators came to the participants with a preconceived design and the users were asked to react and respond to that design. This is different than a participatory or co-created project that one might consider when using sociotechnical principles.

Women Living with HIV/AIDS in Sub-Saharan Africa

Food Security

HIV/AIDS can impact food security through negative effects such as difficulty working and income loss. People living with HIV/AIDS (PLWHA) in Sub-Saharan Africa have been linked to food insecurity (Bukusuba, Kikafunda, & Whitehead, 2007; 2010). In Malawi many households participate in agricultural activities such as small holder farming in order to maintain their food supply. When an adult head of household is unable to purchase or produce needed food, then the whole household suffers. Coping mechanisms such as eating less and skipping meals sets up a situation whereby nutrition progressively worsens (Bukusuba, Kikafunda, & Whitehead, 2007). There is evidence that links poverty, food insecurity, and gender inequalities to poor health outcomes for women living with HIV/AIDS in Sub Saharan Africa (Hausmann, Tyson, & Zahidi, 2012). Structural interventions that address these factors are needed at the local level. Interventions such as a focus on social support and microfinance via a support group shows promise in addressing these social determinants of health and health inequities in this population (Pronyk, Hargreaves, Kim, Morison, Phetla, Watts, & Porter, 2006; Weinhardt,

Galvão, Stevens, Masanjala, Bryant, & Ng'ombe, 2009). The use of mobile phones as an adjunct in these types of programs has been studied in other settings (Mas & Morawczynski, 2009; Alam, Yusuf, & Coghill, 2010). Poverty, food security, gender inequality, and the dynamics of the support group membership may influence the sociotechnical factors and the women's relationship with the mobile phones which are the main focus of this study and act as context for this case. Therefore, they are considered important and are discussed here.

HIV Stigma

People living with HIV (PLWH) are subject to discrimination, prejudice, and emotional and social stigmatization that can potentially have a negative impact on their health. This is an important consideration for my population of interest, therefore, I am including it in this review. The People living with HIV Stigma Index has now become a measure for monitoring and evaluation by UNAIDS. For women living with HIV in Malawi this Stigma can become isolating especially if she has married in to a patrilineal family. Many times a woman first learns that she has HIV when she goes in for her antenatal visit. With the stigma associated with HIV, she may be shunned by her husband, her husband's family, and/or her own family. Left alone and sometimes left alone with children she has to fend for herself and her children. In a society that is very community oriented this can be very stressful and make it very difficult to cope with HIV infection.

Malawi Country Overview

This study was conducted in Malawi, a low resource, densely populated (18.5 million) Sub-Saharan African country (CIA, 2016). Malawi is a landlocked country on the continent of Africa. It is located in eastern Africa and is bordered by Lake Malawi for much of its eastern border with Mozambique as well as its northern border with Tanzania. It is also bordered via land to the north

with Tanzania east south and southwest with Mozambique and to the west and northwest with Zambia east by Lake Malawi with Mozambique and to the eastern shore with Tanzania and Zambia. Historically, Malawi was known as Nyasaland from 1891 to 1964 when it was under British rule. In July of 1964, Malawi gained Republic status (CIA, 2016). The country is mostly agrarian with 80% living in rural areas. The percentage of those of age 15 who can read and write is 81% for males and 68% for females. Currently Malawi is one of the poorest countries in the world with 71% of the population living in extreme poverty (World Bank, 2016). Blantyre is the city where the women's group is located in southern Malawi with a population of 808, 000. (CIA, 2016)

The HIV Epidemic in Malawi

The HIV/AIDS epidemic continues to pose problems for Malawi. The prevalence rate is 11% for adults aged 15 to 49. In the southern region of Malawi where Blantyre is located the prevalence rate is 14.5% for 15-49 year old adults (National Statistical Office [NSO] and ICF Macro, 2011). There are gender disparities that characterize the epidemic. HIV prevalence is higher among 15-49 year old women at 13 % compared to men at 8% (National Statistical Office [NSO] and ICF Macro, 2011). Women aged 35-39 are three times more likely to be infected than men of the same age with a prevalence rate of 24%. HIV is more prevalent in urban areas where 22% of women age 15-49 are infected with HIV as opposed to 10.5% in rural areas (NSO and ICF Macro, 2011). The gender gaps in educational attainment and political empowerment continue to be some of the highest globally (Hausmann, Tyson, & Zahidi, 2012). This creates a difficult situation for women and their children living in extreme poverty who have difficulty getting basic daily needs met such as food, shelter, school fees, and transportation (Barnes, Keogh, Nemarundwe, & Nyikahadzoi, 2002). In addition, having to cope with the chronic

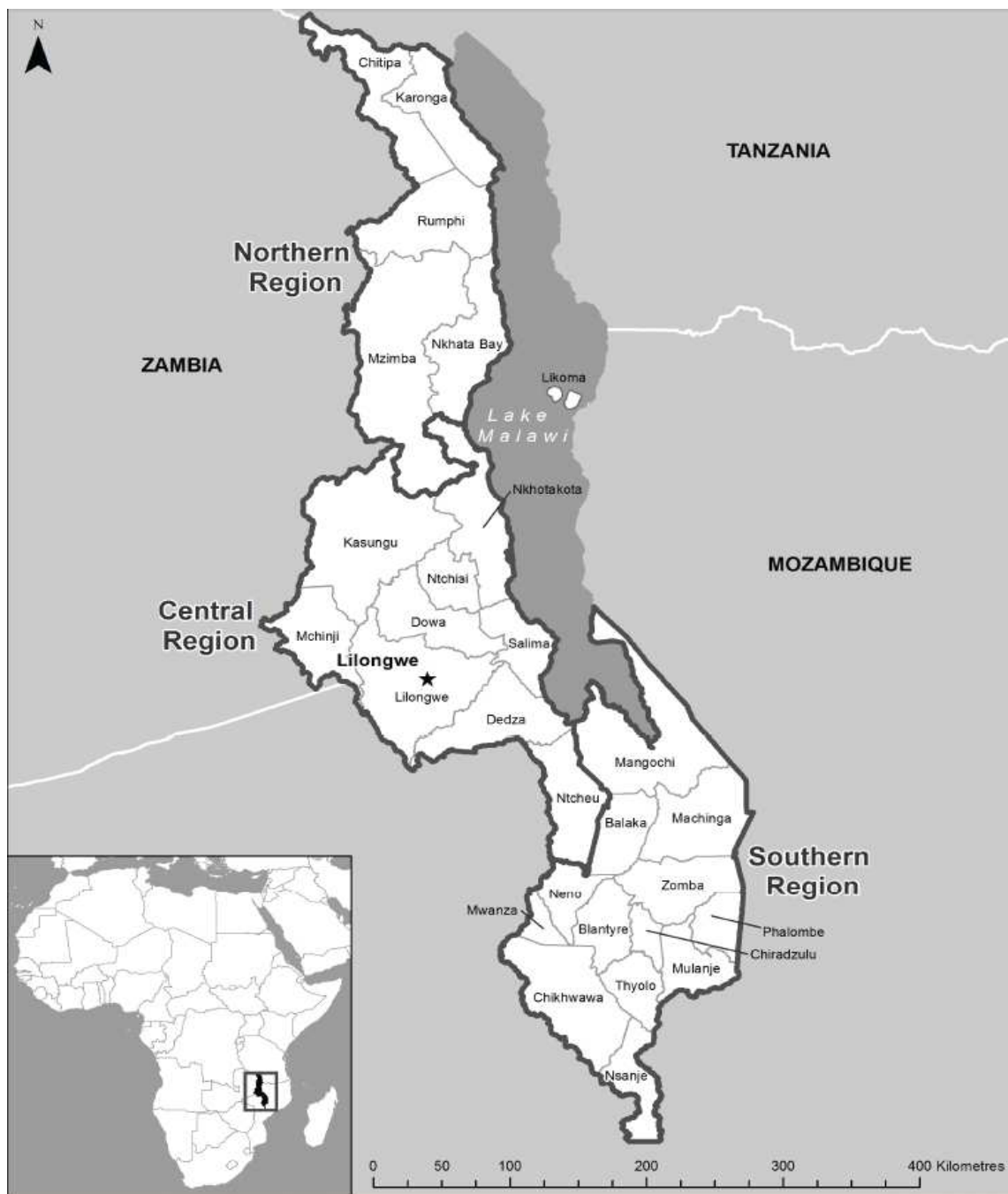
illness of HIV may place women at greater-than-average risk of developing health problems (de Chesnay, 2011). The study was completed in Blantyre which is the second largest city in Malawi located in the Southern region (Figure 1).

Figure 1

Malawi

National Statistical Office (NSO) and ICF Macro. 2011. Malawi Demographic and Health Survey 2010.

Zomba, Malawi, & Calverton, Maryland, USA: NSO and ICF Macro.



Discussion

ART Adherence is important for people living with HIV in sub-Saharan Africa. However, it is also important to understand what the daily patterns of use of mobile phones may be for women and how mobiles may be used for more than just medication adherence. This kind of information is valuable to know prior to designing any mHealth applications such as those that might be used for ART adherence. There may be other needs that women with HIV have in this population. Asking women to tell their stories about their interaction with mobile phones in the context of using them for health support may reveal knowledge that has been unknown until now because most mHealth studies have not asked; either because the approach has been focused on a biomedical approach to the disease of interest or because mHealth in its early stages is just beginning to identify the importance of looking at the sociotechnical aspects impacting mHealth in the sub-Saharan African context.

Although the mHealth studies discussed in this chapter showed positive outcomes on adherence to ART therapy, these studies did not investigate the use of mobile phones as experienced by the user. The sociotechnical lens tells us that there is an interrelation between the social and the technical. Considerations such as culture, economics, infrastructure, and gender are distinct forces that impact the user context in sub-Saharan Africa. Exploring this through the user's viewpoint can enrich our understanding of what the requirements are for successful mHealth implementations or reveal new information that we may not have considered before to incorporate into design to increase sustainability of mHealth applications. For example, understanding how phones are used more communally could possibly lead to different types of interventions in using mobile phones that are more congruent with how they are actually used. Further, rarely did studies focus on how gender or community was a factor in mobile phone

adoption or how mobile phones were adopted or used by women in a community setting and how that might impact their health. Studies using information communication technology for development (ICT4D) have shown positive impacts using mobiles for socioeconomic empowerment of women in resource-limited settings (Gill, Brooks, McDougall, Patel, & Kes, 2010; GSMA, 2015). However, there are no healthcare related studies that specifically focus on this area (Pronyk, Hargreaves, Kim, Morison, Phetla, Watts, & Porter, 2006 is the exception). Although phones may be used for mHealth they can be used for more. A sociotechnical approach using narrative inquiry allows for a broader investigation.

Finally, there is a dearth of studies from the perspective of nursing science regarding the use of mobiles in low resource settings. Because nursing science seeks to understand humans and health in the context of their environment this viewpoint is especially relevant and needed at a time that knowledge is being developed in the use of mobile phones for health.

CHAPTER 3

METHODS

Introduction and Overview

In this chapter, I will explain the methodology used in this qualitative study. Semi-structured interviews and a focus group were used to gather data. The analysis of data was completed to explore the experience of mobile phone usage from the perspective of the women in the support group in Malawi. This chapter is organized into three main sections. Section one contains a summary of the study design, sample selection, and data collection procedures. Section two provides a description of the data analysis using narrative methodology in combination with thematic analysis. Finally, means used to assure trustworthiness and protection of participants is discussed.

Theoretical Perspective

Sociotechnical Framework

A sociotechnical theoretical framework was used to frame the inquiry for this study. The foundational aspects of the sociotechnical approach to information communication technology inquiry include the interrelationship between technology and its social environment, addressing problems from the users perspective, a focus on the work and the contingent nature of the work, and the iterative nature of design and implementation as a dynamic change process (Berg et al., 2003; Brown et al., 2008). User centered and iterative design requires an understanding of the setting where work occurs. For example, in the case of those implementing computerized provider order entry (CPOE) systems in electronic health records in healthcare systems, they need to understand who their users are, what their needs are, and their typical work processes (Collins, Currie, Patel, Bakken, & Cimino, 2007; Wears & Berg, 2005). Accordingly, in the case

of mHealth users in sub-Saharan Africa, those helping to develop mHealth applications need to understand who their users are, what their needs are and their typical health related activities or daily work processes. In order to improve mHealth application design it is critical that we understand typical user health related activities associated with mobile phones and how they typically use the technology in their daily practices. Although many of these sociotechnical studies have been done in healthcare organizations in regards to healthcare workers, there is increasing interest in building applications that address people in the community and the technologies that integrate with their daily lives (Valdez, Holden, Novak, & Veinot, 2014, 2015).

To capture these user experiences I completed a qualitative study of 10 HIV infected members of a support group in Blantyre, Malawi in sub-Saharan Africa using narrative analysis for interview data and thematic analysis for one focus group in August of 2012. Narrative is one of the primary ways of organizing and communicating for sense making in world and the interpretive process is central to shaping and understanding a story and is at the heart of human knowing (Bruner, 1991). Narrative centers on people and the intentions for their actions, their goals, and personal experience. The properties of character, setting, action, and response are essential to narrative. These contextual facets and their emotional consequences are so significant that literature achieves its power by being contextually sensitive where science achieves its power or significance by being contextually independent (Bruner, 1990). Therefore, the narrative method is well suited to inquiry using a sociotechnical theoretical lens because of the need to understand the women's interactions and experiences with the mobile phones in context.

Purpose

The purpose of this study was to describe how mobile phones were used by HIV infected women in everyday life during the time that they were members of a support group for women in urban Malawi.

Research Question

What are the sociotechnical factors associated with mobile phone use and how are they experienced by a group of HIV infected women who are part of a support group that meets regularly for income generation and support?

Aims

The specific aims of this study were as follows:

1. To describe the experiences of using mobile phones in women's day-to-day lives.
2. To describe how mobile phones helped women with income generation and healthcare activities.
3. To identify challenges with utilizing the mobile phones in women's day-to-day lives.
4. To identify the sociotechnical factors and meanings of mobile phone use as derived from the perspectives of HIV infected women.

Design of Study

Both narrative and thematic analysis were used to analyze data derived from in-depth interviews and focus group data. Interviews are frequently used to elicit narrative experiences (Ryan, Coughlan, & Cronin, 2009). The method of narrative analysis used with the interview data combines Labov's (1972, 1997) structural method, and Riessman's (1993, 2008) analytic and interpretive guidelines to analyze the data that met narrative criteria from participant interviews. In this study, narrative criteria were met when there existed a discrete story of

personal experience which was characterized by a temporal ordering of events that had a recognizable beginning, middle, and end organized around a plot that had a point or moral (Polkinghorne, 1988, 1995; Riessman, 1993). To elicit narrative accounts, participants were encouraged to talk about one or two example situations in response to a question. Many of their responses met the narrative criteria but others provided data that answered the research questions using responses that did not take narrative form. Thematic analysis using approaches employed by Coffey and Atkinson (1996) and Reissman (2008) were used for those responses that were the results of the focus group interview or did not meet narrative criteria from the interviews. Analytic techniques are described in the data analysis section of this chapter.

Rationale for Qualitative Research

My focus will be on telling the story of the women and their socially embedded practices of using mobile phones, the interactions of mobile phone use with their sociotechnical network of daily life stories of experiences using the mobile phones in their situated context. Unlike the positivist approach to research where the underlying assumption is that the researcher can objectively distance themselves from the phenomena under study, with interpretive approaches human interaction is a primary data source. The researcher is constantly engaged in human interactions and relationships. These human interactions and relationships are impacted by the researcher's language, social class, gender, and ethnicity. The notion of the researcher engaging in value free inquiry is over (Denzin & Lincoln, 2008). In addition, the philosophical orientation of the researcher impacts their "analytic bracketing" throughout the research process (Gubrium & Holstein, 1997). Analytic bracketing is an orientation of the researcher focusing on the "what's and how's of interpretive practice" where on the one hand you need to assemble a complete and contextually accurate description of the phenomena and on the other hand produce a discursive

dialog between the researcher and self and researcher and the phenomena (Holstein & Gubrium, 2005). Therefore, in order to capture the situated meanings of the experiences the women have with their mobile phones in their own voices, I chose to utilize a qualitative approach with narrative methods. My interpretations and understandings of the situation are an intentional part of the discourse and are seen in understandings which are documented throughout the project in data such as field notes and reflexive journaling.

Assumptions

This study was based on the following assumptions:

- 1) The women's health related activities constituted a type of work that they accurately reported through their personal perceptions, experiences, and behaviors.
- 2) The women's health related activities occurred within a context (sociotechnical system) that comprises interacting components of tasks, technology, environment, and community factors (Valdez et al., 2014)
- 3) These factors act as constraints, facilitators, or both with respect to health related activities.
- 4) The translated interviews were accurate and maintained the participants intended meaning.

Methods

Research Site

The interviews were completed in Blantyre City in Malawi (Figure 2) Blantyre City is located 282 km southeast of Lilongwe City which is the capital of Malawi, and has a population of 808, 000 (CIA, 2016). Blantyre City was founded in 1876. It was a Church of Scotland mission station named after David Livingstone's Scottish birthplace. In 1895, it became

Malawi's first municipality. Blantyre is the capital of the Blantyre District and the Southern Region and is considered the commercial capital of Malawi (MCI, 2011). The interviews and focus group took place at Soche Baptist Church where the support group meetings took place. Soche Baptist Church is located within the Soche East administrative district of Blantyre city in a hilly area, reachable by main paved roads and then local dirt roads.

Research Sample

This study built upon an existing relationship already in place with the women's support group at the Soche Baptist church in Blantyre, Malawi. The sampling strategy involved a purposive, convenience sample of 10 women in the support group who were already participants in an existing support group study that was being conducted by faculty members of the College of Nursing at the University of Wisconsin-Milwaukee. In July of 2011, at baseline there were 20 members of the Soche women's HIV support group. Each was provided a low-cost mobile phone and a monthly stipend of \$1.00 U.S. for airtime. A baseline support group study survey was completed in July 2011.

Recruitment Procedures

Prior to my arrival in Malawi, contact was made with the group coordinator to arrange meetings with the women from the support group. The group coordinator notified the women of the research opportunity and arranged dates for the interviews and the focus group.

Inclusion Criteria

Women were included in this study who were members of the support group at baseline in July of 2011 and were provided with a mobile phone and had completed the baseline survey as part of the support group study and who completed the support group study follow up survey in August of 2012. A basic mobile phone worth approximately \$18.00 U.S. was provided to each

woman at baseline in July of 2011. The women were compensated \$1.00 U.S. per month for mobile phone time and charging assistance dispensed by the support group coordinator.

Exclusion Criteria

Members who left the group, members who passed away, and new support group members who were not members at baseline in July of 2011, were not provided a mobile phone, had not completed a baseline survey or the follow up survey in August of 2012 were excluded from this study.

Data Collection

Interviews

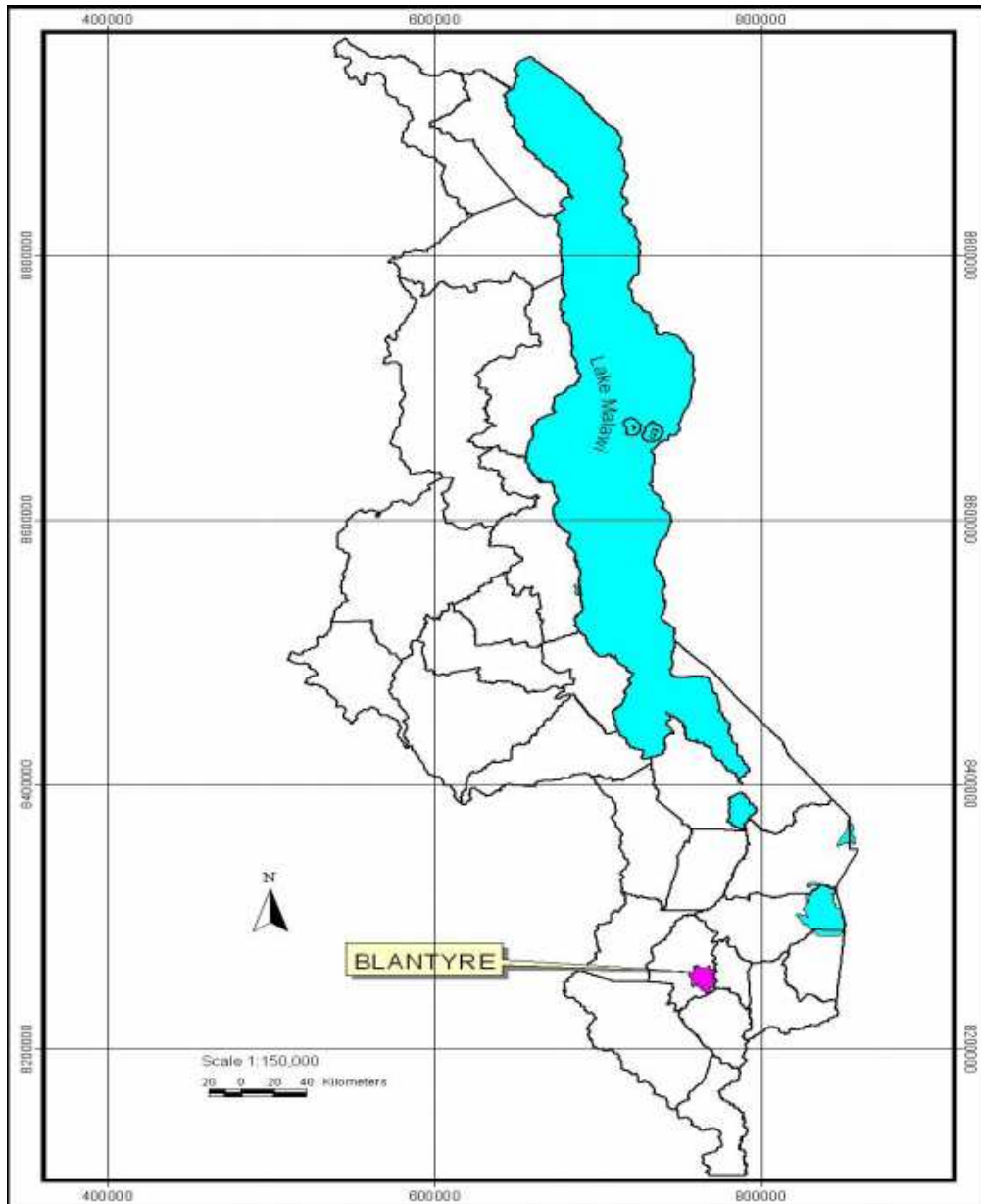
An interview guide (Appendix A) was utilized to interview 10 women who were members of the HIV support group at Soche Baptist Church in Blantyre, Malawi to elicit experiences using their mobile phones regarding perceived benefits to their health when they were ill and income generation activities. Additionally, they were encouraged to provide examples in order to share narrative experiences. Probes were used when women reported technical difficulties with their phones to identify what some of the factors might be. These were done one-on-one in a comfortable private location on the church grounds away from the rest of the group. The interviews were completed with the assistance of our Malawian Research Assistant who spoke Chichewa, the local Malawi language. Each interview took approximately 1 to 1.5 hours to complete. All of the interviews were conducted by myself in English and then interpreted by our Malawian team member translator in Chichewa. Any responses or questions were interpreted back to me so that I could probe if further clarification was needed on the meaning of the question. As a show of respect, I wore a *chitenje*, common female daily attire in rural Malawi which was a large piece of fabric worn over your pants which looks like a below-

knee length wrap around skirt. During these interviews, I was able to take field notes and to get to know the women more directly. Many times the women had small children that stayed for the duration of our time together. Tea and bread were provided by the Program Coordinator during these sessions which made for a more relaxed milieu. The interviews were digitally recorded, transcribed, and translated to English.

Focus Group

One focus group interview was completed with all 10 participants using a one-page guide exploring how the women were using the mobile phones (Appendix B). The interview was conducted by myself in English with concurrent translation and assistance from our Malawian research assistant who spoke Chichewa. The focus group session was digitally recorded, transcribed, and translated to English. The focus group was conducted in Chichewa by native speakers. Occasionally some of the women would answer in mixed English and Chichewa but predominately it was Chichewa. Their answers would be interpreted back to me in real time by our Malawian research assistant and then I would ask a question again or probe in English and she would interpret back to the women in Chichewa. This was the rhythm we established during the focus group session. The focus group guide was open-ended which encouraged them to discuss their experiences with using the mobile phones in their day-to-day lives. You did not refer to Figure 3.1 in the text. Any figures or tables should be referred in the text.

Figure 2 Blantyre City



Notes: Source: Costly Chanza, Blantyre City Administration (2010) Mercer, Tim, Millennium Cities Initiative

Procedures

Phone Provided to Participants

In July 2011 the women in the support group were provided with a ZTE-G S51 Model phone that is offered through one of the two cellular providers in Malawi. This handset cost \$18.00 USD or 2600 Malawian Kwacha each. The women were also provided with \$1.00 each USD per month or 150 Malawian Kwacha for charging their phones up with airtime each month. This was provided monthly through the program coordinator. The decision was made to go with the least expensive handset to identify how usable this model would be and to enhance sustainability.

Individual Interview and Focus Group Procedures

Informed consent was obtained prior to conducting the individual and focus group interviews with the assistance of our Malawian research assistant, whom the women felt comfortable with and had already developed a rapport with, reading the informed consent document that was written in Chichewa that was provided to each woman. At this time, I discussed the purpose of the individual interview and focus group questions and reassured them that they did not have to answer any questions they did not feel comfortable with in English. This was then translated in Chichewa, and discussed with each woman, and each woman was encouraged to ask any questions at this time if they did not understand something. They were also told that they did not need to answer any questions that they did not feel comfortable answering. The informed consent document, which was printed in their native language, Chichewa, was then read through to them in their native language Chichewa, by our Malawian research assistant. Next, the informed consent was then obtained in writing after answering any questions. If the woman was not able to write her name, she was asked to make an X. The

consent was witnessed and signed by the women being interviewed, myself, and our Malawian research assistant. The woman being interviewed was provided a copy.

The purpose of the in-depth interview is exploration of a topic in detail (Schensul, Schensul, & LeCompte, 1999). These interviews were exploratory, open-ended using a semi-structured interview guide designed to provide a space that would evoke women's stories about the use of mobile phones in their everyday lives. An open ended and open listening method allowed the participants to tell the stories at their own pace. They were not interrupted as the flow was important to capture for narrative analysis. Emerging concepts were probed through questions posed at the end of the narrative flow or the end of the interview (Richards & Morse, 2012). The interviews were audio-recorded using a digital recording device. During the interview process, genuine interest and respect was shown to each woman. I collected data regarding participant's non-verbal behaviors, gestures, and emotional tone during these sessions. The interviews and the focus group sessions were held at the Soche Baptist Church where the support group met for meetings and to work on their income generation activities like rug making. The interviews were held in a private room next to the main church meeting area. The focus group was held in the main church meeting area. The focus group session was digitally recorded. This session lasted one hour and thirty-seven minutes. Field notes were taken at the end of the session capturing any significant impressions, group interaction, and emotional tone.

Reflexive Journaling

Reflexive journaling assists the researcher in locating himself or herself as the researcher in the data generation and interpretation process (Mason, 2002). Reflexive journaling was completed throughout the one year evaluation process. Reflexivity or reflexive thought is a term describing the critical thinking used to examine the dynamic interaction between "self and the data occurring during analysis" (Burns & Grove, 2009, p. 545). Reflexivity is part of discursive practice which acknowledges the co-creation of knowledge between participant and researcher. This approach to research "fosters integrative thinking, appreciation of the relativity of truth, awareness of theory as ideology, and willingness to make values explicit" (Hall & Stevens, 1991 p. 21). Reflexivity occurs when using questioning internal dialogue, the researcher makes inferences, personal observations, hunches, and emotional reactions and writes these in field notes (Pelto & Pelto, 1978). Although I made attempts at describing behaviors, for example, when I sat down with one of the women to do an interview I thought that she was sad. This led me to dialoging with myself about my interpretations of sad and why I would label her that way. As a novice researcher, I engaged in analytic dialogue by identifying meanings in my interpretations through asking questions such as: *How is this environment impacting me? How is her interaction with her environment and technology not like me? How is our interaction with the environment impacting our relationship? How can I possibly understand what it is like to go through each day in this environment? How is that interaction affecting the course of the research?* During this study reflexivity was thus accomplished through dialogue with self and maintaining a questioning practice.

Data Management

Data management involves the “systematic, coherent process of data collection, storage and retrieval” (Huberman & Miles, 1994, p. 428). Ongoing procedures included keeping all data in a secure location. All written and digital information were kept in the strictest confidence and were inaccessible to anyone but members of the research team. Identifying information was removed from transcribed data and audio-recordings. Transcripts only used numerical identifiers. Transcripts were entered into NVivo, a software program for qualitative data analysis, used only numerical identifiers, and were kept only on my personal computer and were password protected.

Cross-Language Translation

Cross cultural research has its challenges and one of them is assuring that cross-language translation of materials is trustworthy. Trustworthiness was established at different times throughout the study as follows: (1) Prior to data collection, I reviewed the interview guide and the focus group guide with our Malawian research assistant and one of the UWM faculty members who was from Malawi via email, to assure that they were free of any colloquialisms (Santos, Black, & Sandelowski, 2015); (2) During data collection, the individual and focus group interviews were concurrently interpreted (Wallin & Ahlstrom, 2006). During an interview or focus group, I asked a question in English; our Malawian research assistant would then interpret and ask it in Chichewa. Then, the women would answer, usually in Chichewa, although sometimes they would answer in English. Next, our research assistant would interpret the answer from Chichewa to English to me. This is the rhythm that we established. All of these were then digitally audiotaped; (3) At the end of each day during data collection, our Malawian research assistant and I were able to hold a debriefing session where we would briefly go over

each interview or the focus group and summarize any significant interpretations or unresolved questions. Our Malawian research assistant was an experienced qualitative research assistant and had assisted with many other studies. She interacted with the support group previously and readily established rapport with the women. She served as interpreter for all interviews and the focus group; and (4) To enhance credibility, translators proficient in the Chichewa language and culture living in Malawi were utilized, and all transcripts were checked against taped interviews for equivalence and consistency to assure the translation was reliable. In addition, I was able to engage in discussions and questioning via phone with any of the translators if there were questions about the translated documents.

Ethical Considerations

Human Subjects Approval

The study was approved by University of Wisconsin Milwaukee Institutional Review Board (IRB) and Malawi Ministry of Health.

1. University of Wisconsin-Milwaukee Institutional Review Board approval received June 21, 2012, #11.389. Expiration Date July 22, 2013. (Appendix C: Copy of Informed Consent).
2. Letter of Exemption Malawi Ministry of Health, National Health Services Research Committee approval received January 18, 2013 (Appendix D: Copy of Letter)

Informed Consent

All appropriate procedures for obtaining and documenting informed consent were followed and are described in the procedures section of this document.

Risks to Human Subjects

Risks to the women were considered minimal for this study. The interview data did not probe into sensitive aspects such as abuse or illegal conduct. Safeguards for confidentiality included the consent process and adherence to the ethics of confidentiality. The women were assured that their participation was voluntary and that they did not have to participate if they chose not to and could stop the interview at any time without fear of retribution or loss of the compensation gift.

Compensation to Research Participants

A modest compensation gift was provided to each women in gratitude for their time and effort when the support group members all met together worth approximately \$5.00 each USD. This was provided to the women in a group setting (cooking oil, sugar, rice, and bowl) during a separate meeting from the interviews and focus groups sessions to thank them for their time. The group coordinator provided tea and snacks for the group participants and the research team during the interviews and focus group.

Protections against Risk

Procedures to protect participants against risks included maintaining confidentiality of the data: All data including digital recordings, transcriptions, and field notes were stored in password-protected files. Numbers were used for participant files and pseudonyms for data analysis and reporting and storage. I also created password protected back up files stored in a physically separate location. Hard copies of transcripts were scanned into password protected files, with the original forms kept in a locked file cabinet that only this researcher has access to.

Intended Use of Results

This study will be used for my dissertation study for my PhD. Findings will be shared with the project coordinator and the Malawi Ministry of Health.

Data Analysis

Data analysis occurred in three main phases: (1) Demographics, (2) Narrative analysis was completed for the ten interviews; and (3) Thematic analysis was completed for the one focus group interview and the non-narrative data from the interviews. The step-by-step process for analysis of these data is described in this section.

Demographics

Demographic data were collected at baseline in 2011 on the sample that were members of the support group. This was updated to reflect the sample in August 2012 and is reported in the results section under demographics.

Narrative Analysis

The primary narrative analytical data for this study were the ten-recorded in-depth interviews with support group members. Narrative analysis has to do with what is commonly considered storytelling. When someone is speaking they connect events in a sequence with consequences for later action and meaning they want the listener to acquire from the story (Reissman, 2008). Narrative and story are frequently used interchangeably. The use of story in this case study refers to any content relating to a time when a participant is discussing an interaction event with the mobile phone or mobile phone artifacts and processes. These

narratives will serve as a way of understanding the meaning of using mobile phones in their daily lives both from a daily perspective but also any cogent episodes that are related.

Narrative is one way that human beings express their personal experience and make sense of that experience (Bamberg, 1997). These personal experiences are expressed in what is commonly called stories. Narrative research focusing on personal stories can be considered both product and method. Stories are the aspects that surface in an interview when a participant describes a situation. In stories, a common element is the contingency. (Riessman, 2008). Contingency means there is some action or “and then.” To put it simply, there is frequently a beginning, middle, and end (Creswell, 2007). Uncovering this structure of events in a personal narrative takes many forms. An overall framework for narrative study that I incorporated into my analysis was based on the model developed by Labov and Waletzky (1967; Labov, 1972; Labov, 1997; Labov, 2010). It is based on the definition of a narrative as being a “specific linguistic technique to report past events” (Labov, 1997, p. 395). This framework is helpful in uncovering the event structure of a storied narrative. Originally I had intended to use the data from the interviews to obtain the women’s narrative accounts of their experiences with mobiles. It became evident, however, that the interview questions engendered some responses that were non-narrative. That is, they did not meet the criteria for a temporal ordering of events or a story. However, I determined that these non-narrative data contributed to interpreting the women’s experiences with the phones. Therefore, these data were added to the thematic coding along with the focus group data.

Narrative Event Analysis

There are many elements that can be examined in narrative analysis event structure. For purposes of this study, the following structural elements were utilized: abstract (AB), orientation

(O), complicating action (CA), evaluation (EV), resolution (RE), and coda (CO) (Labov, 1997; Labov, 2010). Abstract summarizes the point of the narrative, for example, "this is the story about a woman who had her phone stolen the first week"; and it may or may not always be present. Orientation provides information regarding the time and place of the event, the identity of the participant, and their initial behavior (Labov, 1997; Labov, 2010). It answers the questions, "who, when, where, and what were they doing?" (Labov, 2010, p. 3). The complicating action in the narrative considers the temporal organization, sequencing, turning point or crisis, and answers the question "And what happened (then)?" (Labov, 1997, p. 5). Evaluation provides the narrators interpretation and judgments of events. Resolution is how the conflict or crisis in the story or plot is resolved. A coda is a final clause which returns the narrative to the present time and may or may not be provided by the speaker. Table 1, which was adapted with permission from a similar table created by Robichaux (2003) provides a synopsis of the events used for analysis in this study with some descriptive quotes as examples.

Table 1 Narrative Events				
Narrative events	Code	Definitions	Descriptive quotes	Elective
Abstract	AB	Summarizes the point of the narrative	“Sometimes on the side of the business because we do other businesses, you would tell each other that a profitable business is found in this place”	Yes
Orientation	O	Provides information regarding the time and place of the event, the identity of the participant and their initial behavior	“When I got ill my phone helped me because I managed to call Tadala.”	No
Complicating Action	CA	Considers the temporal organization, sequencing, turning point or crisis and answers the question “And what happened (then)?”	“when one is sick, they would get money and go to the member to cheer her up and give her some money and buy some necessities”	No
Evaluation	EV	Narrators Interpretation and judgements of events	“It is very difficult to hear someone when calling, the sound is bad”	No
Resolution	RE	How the conflict or crisis in the story or plot is resolved	“If one goes sickly just like it happened to me, they take the money and give the patient to use it at her house”	No
Coda	CO	A final clause which returns the narrative to the present time	“so now it becomes easy to go to the hospital”	Yes

Note: *Source:* Robichaux, 2003, p. 98, adapted with permission

Data were coded using a multiphase process. Labov’s (1997, 2010) framework provided a structure for me to identify which content met criteria for narratives. For example, not all

narratives needed to contain a coda or an abstract but they did need to have the other narrative events listed in Table 1 of an orientation, complicating action, evaluation, and resolution to be considered narrative material. I have shown this by including a column entitled elective. If something is elective = *Yes* that means it does not need to be present to meet the criteria of the story but it is nice to have, whereas if something is elective = *No* that means that it needs to be present to meet the criteria for a story or narrative to be present. This served as one of the first steps in the analysis process to help me bracket the narratives found in each transcript.

First, while in Malawi, I listened to the digital recordings of the interviews at the end of the day during data collection and read my field notes. At this time, I was able to debrief with our Malawian research assistant and write down any additional notes from these interactions. Next, upon returning to the United States I read through the transcripts, field notes, and research notes several times to familiarize myself with the content. I completed generalized coding for gross content that met the structural criteria for narratives by writing in the margins and identifying the stories in the data and indicating their boundaries in each interview transcript. Originally I had bracketed stories co-created utilizing myself, our interpreter, and the narrator. However, on further consultation with my major professor, an analytical decision was made to only include the narratives created from the women's voices only in keeping with the methodological and epistemological focus of the study.

Once I identified the narratives for each participant, I used NVivo software to bracket them. Each women's transcript was entered into NVivo with only a number as an identifier. Then, I marked each story for their structural elements as described in Table 1. At this point, I identified the number of stories as 41. These became my units of analysis. For each of these stories, I carefully read the narrators recounting of interactional events, their evaluation of those

events, any specific content that would answer the aims of this study, such as environmental conditions or any mention of problems or benefits with mobile phones, their interpretations and responses. Then, I wrote any notes regarding this in the margins of the transcripts for further coding. Next, for each story, I constructed an “adequate paraphrase” (Stevens, 1992) which contained the main story plot and context so I could utilize this as the unit of analysis to make the analysis more manageable. My next step was to gather the transcripts of each story with its adequate paraphrase and identify thematic connections between the women’s stories. These data were analyzed and coded through an iterative process of moving back and forth between parts of the text and the whole text in several sequences. In each of these sequences, I read the narrative sections to identify any evaluative statements or salient qualities of the narrative such as words or phrases being repeated. I also compared across narrative accounts to identify any similar or dissimilar elements looking for narrative components across accounts. Then, I demarcated the narrative using broad thematic codes. This cycle was completed three times as I read through the coded material and updated codes throughout the coding exercise as new codes were developed and others were merged or dropped as needed. Finally, I coded the narratives for each mobile phone story in relation to the themes that emerged and the specific aims of the study and identified the narratives that would be exemplars to be reported in findings.

Focus Group Analysis

First, while in Malawi I listened to the digital recording of the focus group at the end of the day we completed it and reviewed my field notes. I debriefed with our Malawian research assistant and wrote down any additional notes and upon return to the United States, I read through the transcripts, field notes, and research notes again to familiarize myself with the content.

The focus groups (non-storied data) were analyzed using thematic analysis and constant comparative coding as described by Ritchie and Lewis (2009), and Coffey and Atkinson (1996). First, the transcripts were reviewed and initial themes and concepts were written in the margins. Next, I labeled and tagged data by concept using NVivo software. Then, I constructed an index of the concepts and themes from the data. Using post it notes and a wall chart, I sorted and re-sorted concepts and categories to identify themes and subthemes grouping them by levels of generality. Then, I numbered and indexed the categories and subcategories. The research questions guiding the study provided organizing categories. Consequently, each participant's responses were reviewed multiple times for words, phrases, or statements that had common properties or elements and appeared to be instances or examples of the following: (1) beneficial experiences of using mobiles, (2) problematic experiences with using the mobile phones, and (3) subcategories under the broad themes derived from (1) and (2). In the next cycle of analysis, I identified which theme or concept was being referred to in the labeled or tagged data in NVivo. This involved reading each sentence, phrase, or paragraph and deciding to which part of the categories and subcategories it applied and marking that in NVivo until all categories and subcategories were exhausted for the non-narrative data. This was entered into an Excel spreadsheet to summarize the final content of the tagged data and thematic matrices of six main themes and eight sub themes. The thematic matrix was used to decide what exemplars to use for reporting. Themes one through five included benefits of having a mobile. Theme six included the technical challenges women reported in regards to caring for their phones. Themes number one, five, and six included subthemes which are reported in the results section. Each theme is discussed and exemplars presented that capture the women's experiences in their own words.

Ensuring Scientific Adequacy

Trustworthiness

Guba (1981) discusses four criteria that should be taken into account to assure trustworthiness. These include credibility, transferability, dependability, and confirmability. To assure that a qualitative research study is well constructed and descriptive of the phenomena the study is set out to measure then these criteria for trustworthiness need to be constructively evaluated.

Confirmability

Confirmability refers to the degree to which the study results can be confirmed or substantiated by others. To enhance confirmability, I have incorporated audit trails and documented all procedures for checking and rechecking data throughout the study. Riessman (1993) suggests that the investigator can make it possible for others to determine the trustworthiness of narrative analysis by: (a) describing how the interpretations were produced, (b) making what was done visible, (c) specifying how successive transformations of the data were accomplished, and (d) making primary data available to other researchers. These recommendations were incorporated in the present study. Confirmability also assures that the focus group and interview data accounts adequately reflect what the women are trying to say are not biased by the researcher in such a way that they do not adequately portray their stories (Marshall & Rossman, 1999). As a white English-speaking woman from the United States doing research with women in sub-Saharan Africa, this was accomplished throughout the study by ongoing conversations with my major professor, reflexive journaling, and maintaining cultural sensitivity.

Credibility

Credibility concerns the extent to which a study truly represents the stories and interpretations of the participants. During the study this was accomplished through triangulation of materials such as audio recordings, transcriptions, field notes, and reflexive journaling.

Coherence is another check on rigor that can establish credibility. Coherence speaks to how well research conclusions are consistent with and supported by the raw data, and that methodological evidence that analytic discourse has been accomplished (Hall & Stevens, 1991). For this study, checks were employed as described by Hall and Stevens (1999) throughout the research process as part of questioning through analytic bracketing as part of reflexive journaling.

Dependability

Dependability is a criterion that focuses on how repeatable a study might be. (Guba 1981). It relates to the consistency of the findings. Different than quantitative methods where you would have criteria such as interrater reliability, qualitative methods are designed to the research situation. Therefore, dependability is enhanced through using rich descriptions of methods of data gathering, analysis, and interpretation. This enables the reader to identify how repeatable or how distinctive the study may be (Kielhofner, 1982). To achieve dependability, I performed ongoing checks of methods and procedures used in data collection and data analysis. I provided examples of my data analysis process. Examples include pre-interview processes, interview questions and procedures, focus group questions and procedures, narrative analysis steps and examples, thematic coding steps and examples, and evolutionary plot and theme development for narratives. This serves as my audit trail (Bloomberg & Volpe, 2008) to add transparency to my study and increase dependability.

Transferability

Transferability describes the degree to which findings fit into contexts external to the current study situation determined by degree of similarity or goodness of fit between the two contexts. Lincoln and Guba (1985) conceptualize transferability as being the responsibility of the person wanting to transfer findings to another situation or population than that of the original study. If the original researcher presents sufficient descriptive data to allow for comparison, he or she has made it possible for research audiences to apply findings to similarly-situated populations. Transferability was enhanced with rich descriptions of data from the participants. These rich descriptions have also been called complexity. Complexity has to do with the degree to which research reflects the complexity of reality (Hall & Stevens, 1991). This is similar to dependability in that the researcher does not aim for identifying the average but really capturing the variability of the phenomena (Hall & Stevens, 1991). In this study, this was accomplished by ensuring that the situation was captured and described in the women's narratives regarding their experiences with the phones and the various contextual influences that impacted them in their day-to-day lives.

Summary

In this chapter, I have provided an overview of the theoretical commitments for this study, its design, and the methods I employed. I also discussed the setting and context of the study, described my sample, ethical considerations, and how I have ensured scientific rigor. Next, I will review the findings in Chapter 4.

CHAPTER 4

RESULTS

This chapter discusses the findings of this study about the experiences the women had with using their mobile phones emphasizing how the mobiles helped them in their daily lives as well as when they were ill and the challenges they encountered. The data are from ten women who were members of a support group for HIV infected women in Blantyre, Malawi in sub-Saharan Africa. It includes data from ten interviews and one focus group collected in August of 2012. The narrative data from the interviews were analyzed using structural and thematic narrative analysis and the non-narrative data were analyzed using thematic analysis and are reported as part of the focus group data. The focus group was analyzed using thematic analysis. While some of the narratives were complex, the non-narrative content relating to challenges with technology is less so. In an effort to effectively portray the findings, results are organized as follows: (1) demographic results; (2) a description of interview and focus group narrative and non-narrative responses; (3) interview results, narrative exemplars; and (4) focus group results, non-narrative thematic analysis with illustrative quotes.

Demographic Results

The mean age of the women (N=10) was 42 years with ages ranging from 27-64 years, and a Self-reported literacy rate of 75%. Mean years since HIV diagnosis was six years, with three of the women married, one separated, and six6 widowed. (Table 2).

Table 2

<i>Demographic Profile N = 10</i>		
<i>Literacy</i>		
Rate of self-reported literacy	75%	
<i>Age, Years since HIV Diagnosis</i>		
Mean age	42 yrs.	
Range	27 - 64 yrs.	
Mean years since HIV diagnosis	6 yrs.	
Range years since HIV diagnosis	1 - 13 yrs.	
<i>Marital status</i>		
Married	3	30%
Separated	1	10%
Widowed	6	60%
Divorced	0	

Interview Results Narrative Themes and Exemplars

The narratives of the women regarding their experiences with using mobile phones revealed eight main story types with twelve sub-themes listed in Table 3 below.

Table 3

<p>Narrative Themes and Subthemes</p> <p>Narrative Theme 1: Stories About How the Phones Helped Them When They or Someone Else in the Group Was Sick</p> <p><i>Sub-theme 1: Calling someone in the group when you are sick and they come to visit you at home</i></p> <p><i>Sub-theme 2: Communicating with each other by phone in order to visit a sick group member in the hospital</i></p> <p><i>Sub-theme 3: Calling someone in the group when you are sick and you are able to get to the hospital</i></p>
<p>Narrative Theme 2: Stories About Calling Practices within the Support Group;</p> <p><i>Sub-theme 1: Calling processes around calling the group coordinator first</i></p> <p><i>Sub-theme 2: Calling processes around calling a senior group member first</i></p> <p><i>Sub-theme 3: Calling practices when the group coordinator initiates a call to group</i></p>
<p>Narrative Theme 3: Temporal Aspects of Mobiles</p> <p><i>Sub-theme 1: “In no time,” “fast”</i></p> <p><i>Sub-theme 2: Saves time and walking</i></p>
<p>Narrative Theme 4: Stories About How the Mobile Phones Assisted with Clinic and Medication Reminders</p> <p><i>Sub-theme 1: ART medication reminders</i></p> <p><i>Sub-theme 2: ART clinic appointment reminders</i></p>
<p>Narrative Theme 5: Experiences of Mobile Phones Helping when There is a Funeral</p>
<p>Narrative Theme 6: Experiences of Mobile Phones Helping with Income Generation</p>
<p>Narrative Theme 7: Stories About Being Able to Communicate with Relatives</p>
<p>Narrative Theme 8: Stories About Technical Problems with Mobile Phones</p> <p><i>Sub-theme 1: Charging</i></p> <p><i>Sub-theme 2: Headpiece failure</i></p>

The mobile phones helped the women with their health by serving as a way to communicate and connect with group members and relatives when they were sick, or reminders

for clinic appointments and taking medication. Mobiles helped with income generation by helping them communicate ahead of time with potential buyers for goods which saved them unnecessary transportation costs. The mobiles were not without their problems including problems with the durability of headsets and charging. All of the quotes used in the exemplars use pseudonyms to protect the confidentiality of the women.

Narrative Theme 1: Stories about how the phones helped them when they or someone else in the group was sick

The most frequently identified orientation to a narrative the women used was: “When” I” or a group member is sick.” This was usually evaluated beneficially with a plot about how the phone call had helped them in some way. A dominant plot in these habitual stories started with an orientation of “When I was sick,” or “When a group member is sick,” ending with a resolution most often of someone coming to visit or being able to go visit the person who is sick, whether at home or in the hospital or by providing assistance in going to the hospital.

Sub-theme 1: Calling someone in the group when you are sick and they come to visit you at home. In these narratives, the women would call someone with their mobile phone, usually just one person in the group. This one person would then call another and then they would come and visit the sick group member at home. In this narrative, Harietta, after being asked during the interview about how the phone helped her when she was sick, provides a story about how she makes a call and reports that she is sick to a support group member and the resolution is that she gets a visit. Her evaluation is that it helps her a lot.

“The mobiles made getting in touch with other members for support easy and quicker. The mobile phone helped me a lot because I only call and say I am sick and my friends they came to visit me.”

Harietta

Ellen orients us to a story about when there is sickness in the group and they call each other, and this is resolved with everyone going together to gather and visit at the sick person's house.

“I benefited in the way that we were calling each other when there is sickness, we were calling each other saying that such and such person from our group is sick,...So in that way we all together are going to gather and visit the house.” Ellen

Sub-theme 2: Communicating with each other by phone in order to visit a sick group member in the hospital. Frequently the women told stories about calling each other to let each other know when another group member was sick and that they would be going to the hospital, they would meet up there together to visit the sick person.

Sylvia orients us to an example of when someone has felt sick or passed away, her evaluation is that the mobile phone has made it easy to communicate about going to the hospital to visit a group member who is sick. It is resolved by going to the hospital to visit a patient.

“It was really helping a lot. If somebody from the group has felt sick or passed away it was easy to communicate with friends. The day to go to the hospital for visit, we just call one another to say ‘on such and such day, we should go to the hospital to visit a patient.’”

Sylvia

Sub-theme 3: Calling someone in the group when you are sick and you are able to get to the hospital. Being able to get to the hospital is important when you are sick. It is especially difficult when you have limited funds and limited modes of transportation. Although the support group coordinator had a car none of the other support group members did. Most of

the support group members got from place to place by walking or by taking a bus which can be difficult to do by yourself when you are ill.

Melina talks about a time when she was sick, characterized by her not being able to perform activities of daily living. At the beginning of our conversation, she had described how relatives would not always be counted on to respond in a timely manner but members of the support group could. She establishes this point of view in her narrative that supported the notion that group members came through with assistance either by visiting her or going to the hospital.

“Sometimes there are times when you fail to do some activities by yourself but after I tell the group, they would come to assist me as I already said that relatives are a problem but the group members would come to assist and assist me after I call them, be it going to the hospital.”

Melina

Faye’s evaluation is that using the phone to call some people when she was sick helped her a lot and it was resolved by getting taken to the hospital.

“It helped me in the way that when I was sick I managed to call some people for them to take me to the hospital, so it has helped me a lot.”

Faye

Narrative Theme 2: Stories about Calling Practices within the Support Group

Stories were told about how the women called each other when they were sick. Several stories oriented to the first call frequently being the group coordinator and then ending in a resolution of the coordinator instructing them on what to do such as go to the hospital. This also worked when the coordinator initiated a call from a leadership perspective to bring the group together. Many of the stories used the evaluative phrase with emphasis on “I just call,” or “I just make one call,” or “I only call” emphasizing the simplicity of just being able to call one person

such as the group coordinator, Tadala or senior members Cynthia or Henrietta who held elected positions in the group as chairperson and treasurer, in order to garner resources within the support group.

Sub-theme 1: Calling processes around calling the group coordinator first.

Ellen recounts her story about when she was sick and needed to get to the hospital, she initiated her call with Tadala, the group coordinator. In this case, the story is resolved by her being able to pay for transport to the hospital:

...”What happened was that I called Tadala on the phone, they are supposed to take money from the group’s savings when one of us is sick. It helped me to find transport.”

Ellen

Sub-theme 2: Calling processes around calling a senior group member first.

Ellen provides a story of using her mobile phone to call a senior member first who instructed her to go to the hospital and not just stay home. Her evaluation was that it was very helpful.

“When I got ill my phone helped me because I managed to call Tadala “aah I am sick” and she tells us what to do that, “aah you need to go to the hospital you should not just stay home,” so it was very helpful for me.”

Ellen

Sub-theme 3: Calling practices when the group coordinator initiates a call to the group. Harietta describes a habitual event where the support group coordinator might need to let other members of the support group know something to communicate to the group, and she will initiate a call with one person then there is another complicating action of calling another group member and so on. The resolution is that everyone meets on time.

“When the pastor’s wife (group coordinator) has got something to say and she wants us to come, she just calls one person and that one person will call another person and another person will call a friend and in that way we all meet on time.”

Harietta

Narrative Theme 3: Temporal Aspects of Mobiles

The temporal aspects of phones includes stories where the women use evaluative statements such as “fast” or “in no time” or “right- way” or “at the same time.” In these words, they seem to infer that the value of the mobile phone is in its ability to let them do things in a timely or simultaneous manner. Additionally there are stories about how the use of phones saved them time walking because they could call and communicate through the phone where in the past they may have had to walk to go and talk with someone. This included activities within the context of the support group. For example, if they were not going to be present for a meeting they were supposed to let member know they were going to be absent, otherwise it would be an unexcused absence. This was a group norm they agreed upon since group meeting we used to do income generation work such as rug making.

Sub-theme 1: “In no Time,” “Fast” The term in no time or fast was used by several women in their recurring stories regarding communication when they or others were sick. In

these narratives, the women indicated the importance of the speed or just in time nature of phone communication.

Melina's evaluation is that the phone helped her a lot when she was sick and she uses the phrasing "in no time" with the resolution of seeing how we would help each other.

"This phone helped me a lot with my health, first for example whether am at home and sick, I would communicate with my friends **in no time** and see how we would help each other."

Melina

Melina tells an episodic story about being very sick with malaria and the events that happened after initiating a call to Cynthia, one of the two senior group members and chairman of the group. In this story, she describes her symptoms, and elaborates from a temporal perspective using evaluative phrases such as "at the same time" and "helped at once." The resolution in this case did not just end with her being taken to the hospital, but she was also paid frequent visits by support group members and assisted by a member of the group who provided medication. She has a compelling coda (CO) at the end indicating this was a significant event where she realized the importance of the phone in providing her with access to resources.

"When I was sick, I remember this other time I was seriously sick with malaria, in the past two months, I called Cynthia informing her that I was not feeling fine, she came at the same time and took me to the hospital because I was not able to walk by myself and I was helped at once at the hospital and they used to pay me frequent visits. And also this woman in the group... that practices traditional healing, she also brought more drugs after I called her because I was coughing a lot so she brought medication for me to be taking. And after I did this, it turned out that the cough disappeared and malaria

stabilized. I actually saw that without phone I wouldn't have gotten better because I was not feeling well most of the times so the phone helped me to access treatment after calling my friends.”

Melina

Sub-theme 2: Saves Time and Walking. The women had stories about when using the phones were able to save them from walking. In Malawi, many of the women walked a lot, otherwise they got around by small bus. Since it costs funds to use the bus many times the women would walk instead. So if they could call to let someone know they would not be somewhere instead of having to walk to communicate that saved them a lot of time and effort.

Brenda related the value of having the phone in the support group context because she no longer had to actually walk up to the church herself to walk or find someone to walk up to the church to let the group members know she would not be attending a meeting.

“When I had the cell phone and I am sick, it was easy to communicate with my friends that today am sick and I will not come to the meeting. But before we had the cell phones it was very hard because when you are sick you were supposed to send someone to the group to tell them that you are not coming. So the cell phones were good for us because we were saving time just to call someone and pass the message instead of walking up to here to tell the other members about your situation”

Brenda

Narrative Theme 4: Stories about How the Mobile Phones Assisted with Clinic and Medication Reminders

A common narrative included how the mobile phones assisted the women with both clinic and medication reminders. Going to the clinic is how the women obtained their

antiretroviral medications. Many of the stories regarding clinic reminders and medication reminders are intertwined.

Sub-theme 1: ART medication reminders. In these stories the women discuss how they call and ask each other if they have taken their ART medication. This is further supported in the Focus Group thematic analysis data as well.

Brenda's story orients with "the time we had a mobile phone." She was one of the group members who had problems with her phone and was no longer using it. The use of the word "just" is used to evaluate action and meaning in the phone communication event. The action and meaning inferred is that of simplicity and temporally, "now," as characteristics of using the phone in the context of being sick and clinic and medication reminders.

"The time we had the mobile phone, we benefited a lot because we were able to communicate with our friends when there is something important. For example, when someone is sick, it was easy to know because we **just** call and pass the message. We were also able to remind each other going to go to the clinic and get the medicine when it is time to go. Some they even forget sometimes to take their medicine, so we were calling them maybe on the time that they should not forget. "*Have you taken your medicine?*" no, you have to take them now."

Brenda

Sub-theme 2: ART clinic appointment reminders. Many of the group members provided narratives about calling other support group members to remind them when they had clinic appointments.

Faye's narrative about the benefits of using a mobile includes reminding each other of medication. Reminding each other of medication many times coincided with clinic reminders as they traveled to the Antiretroviral (ART) clinic at the local hospital campus for follow up and to obtain their ART medications. Faye's narrative ended in a coda, bringing us back to the present about this being the first time for her to have a phone.

“...and sometimes we forget the date to go and receive medicine, so we remind each other on that to say that today is the day to go and receive medicine and it was my first time to have a phone.”

Faye

Harietta enters into her narrative as “us.” She seems to articulate a group or shared identity when she talks about how “we” remind each other. It's as if she is telling the groups story not just hers. Notwithstanding, she talks about what would be the usual scenario – and resolution – that you just get ready and go.

“The mobile phones have helped us a lot, we remind each other about visiting the clinic ‘have you gone to the hospital, go to the hospital you told us that you are supposed to go on this day’ so with that when you check on your calendar you see that you really need to go on that date and you just get ready and go....”

Harietta

Narrative Theme 5: Experiences of Mobile Phones Helping when there is a Funeral

Many times the women's stories about phone benefits would orient at both when I or someone is sick and when there is a funeral. This narrative was frequently resolved by mobilization of other support group members to see the person in the hospital or all gather together to attend the funeral.

Ellen's narrative, like others in the support group appears to use a shared identity when conveying her story using "we" and "our." The resolution comes when we all gather together "and visit the house where there is the funeral." Her evaluation is that her life benefited from this.

"My life benefited from that because when there was a funeral we were calling each other and when it was time to go to the hospital. I benefited in the way that we were calling each other when there is sickness, we were calling each other saying that such and such person from our group is sick, aaah no there is a funeral we were calling one another that such person from our group has passed away. So in that way we all together going to gather and visit the house where is the funeral." Ellen

When I asked Yvonne how the mobile phone had helped her she shared that if there was a funeral they called each other with the phone to communicate.

"When I am sick I call my friends and let them know that I am sick and if there was an illness or funeral we were using the phone." Yvonne

Narrative Theme 6: Experiences of Mobile Phones Helping with Income Generation

Another common storyline included accounts of how the phones helped with income generation and how income generation also helped when one was ill. One of the roles of the support group was income generation through the group enterprise. At the time of the interviews, the women had earned money from raising and selling chickens and making mats. This occurred as a complicating action or resolution to a story about when they were ill and a mobile phone call led to the outcome of being visited by other group members who provided funds from the

income generating activities, and sometimes funds would make it possible to get assistance or get to the hospital.

In the following narrative, when a mobile phone call when one is sick initiates a visit from a support group member, that support group member is able to bring material aid due to the income generation activities the group is doing. Melina emphasizes how selling the mats have helped when group members are sick, and they have personally helped her as well because when one is sick you are not able to earn money to get necessities like soap and oil. Her evaluation is that this is very essential.

“These ways especially what has really helped us are the mats we are selling, these mats. So these especially when I was sick I wasn't doing any other business so the group does it that when one is sick, they would get money and go to the member to cheer her up and give her some money and buy some necessities. They did the same with me, they brought me some money, they gave me soap and oil at the time I was sick so I could get help and they do the same with other people, so these help us a lot in our homes because once you are sick, you fail to work for you to earn some money so if people help you in this way I see it as very essential.”

Melina

Sylvia related a similar story about monies being available when someone was sick:

“The time I was sick it helped me because as a group, when we sell our stuff, if one goes sickly just like it happened to me, they take the money and give the patient to use it at her house”

Sylvia

Many women in the group had other businesses where they made money outside of the support group. The plots in these narratives involved the phone acting as a conduit for the

women to inform each other about business opportunities. The mobile phones allowed them to make going to market and finding buyer decisions on the fly because of the flexibility that the mobile phones brought to their situation.

Melina provided an abstract, initiating the narrative of how mobiles helped with income generation. She summarized her point first by giving a statement of general proposition about the typical sequence of events when mobiles assist with other businesses. She then elaborated by discussing specifically how the phone helped in the instance of her fritter business and selling sugar cane. The plot line was an opportunity for the sale of sugarcane at a profitable cost, which was communicated via phone to interested parties for decision making. If the decision was made that this was indeed a good opportunity the result was then *rushing* to the location based on decisions made via phone communication. In these narratives importance was placed on the ability to be able to rush somewhere to take advantage of a good business opportunity. Melina ended in a coda bringing us back to the present moment and establishing her identity as someone who had a business selling sugar cane and baking fritters.

“Sometimes on the side of the business because we do other businesses, you would tell each other that a profitable business is found in this place, so we could inform each and make decisions **to run to there** and find things that would help you.” Melina

“I bake fritters and most of the time to find baking flour is a problem most of the time so for flour to be found it is sometimes difficult. So we sometimes tell each other that you can find flour in such a place so we do find flour there. Initially, I also used to sell sugar canes, so where sugar canes are available, we could **rush to go** and buy the sugar cane to sell at home. These are the businesses that I do, selling sugar canes and baking fritters.”

Melina

Narrative Theme 7: Stories about Being Able to Communicate with Relatives

These stories oriented at a time when the women were sick, and resolved with being able to communicate with someone farther away like a relative or family in a village. The narrator evaluated the mobile phone as being helpful in terms of their health because they could communicate with their relatives. Since 80% of the population of Malawi is rural many of the women may have lived in rural villages prior to being married and moving to Blantyre. Therefore, many of them may be many miles from their home villages and it may be difficult for them to stay in touch with their families.

Teresa orients us to her story by saying “But” with the phone as if she is saying this is life after the phone – now I am able to communicate with family and friends when they are sick. She is positive about being able to communicate with relatives.

“But with the phone I was able to communicate with my family and friends when we have meetings or when our friend is sick. The mobile phone helped me a lot because I was able to communicate with my relatives.” Teresa

Sylvia related how the phone helped her communicate with family and friends in her village. She narrated an incident about when her phone was confiscated and destroyed by the police. She ended her narrative bringing us back to the present with her evaluation of the significance of that event on her ability to continue to communicate as she had been. During the interview her non-verbal conveyed her concern about losing her ability to communicate with others with her mobile phone.

“It helped me in terms of my health because I gave the number to my friends in the village the relations and members of the group. So when I am sick I just make a call and

we want to see others or even my daughter...So the phone it was helping me a lot. For the police to break it as they did, I was so worried a lot. Sylvia

Narrative Theme 8: Stories about Technical Problems with Mobile Phones

Women's narratives regarding problems with the phones included stories about difficulties with charging the phones or the phones not holding a charge, and problems with headpiece failure. Many of the data reported during the interviews regarding technical problems with the phones was non-narrative and is reported in the thematic coding with the focus group data.

Sub-theme 1: Charging. Many of the women had challenges with charging the phones and with the batteries maintaining a charge. Two of the women were able to charge the phone in their homes. The rest of the women either used a neighbor or had to pay to have it charged at a local charging station. One woman had her phone stolen several months after she had the phone given to her after she left it at a charging station.

Brenda provides an example of how her phone was unable to hold a charge and she is unable to use it. She resolved this by borrowing a phone from a friend.

“...and also every time when I have charged the battery you find out after some minutes the battery is empty. So I am not using it now...I am not able to talk with people because the battery is always down.” Yes my friend has lent me a phone and that is the one I am using now.” Brenda

Melina tells a story about technical problems with her phone including, it just going off or not keeping a charge. Her phone lasted ten months since it was provided to her. She had just purchased another phone three months prior to the interview.

“The phone that I received stopped working so I bought another one. I remember the month that it stopped working. It stopped working in the month of May. Sometimes when the phone is in your pocket, you notice that it has switched off by itself and stopped working. It also started to misbehave, sometimes when charging you would find that it writes charger removed and stopped charging, I took it to the repair and they said that the charging system had a problem.”

Melina

Sub-theme 2: Headpiece Failure. Several of the women reported not being able to hear clearly on the phone or that it would just stop working.

Harietta talked about problems with the headpiece and not being able to hear others. She was concerned that many of the phones were now broken but valued having them for communication.

“We want phones because it helps us a lot on communication.” Some of the phones are dead. For the past six months when I switch it on we cannot hear each other” Harietta

Brenda had problems with her earpiece failing.

“I still have my cell phone but it’s not in good condition. It is very difficult to hear someone when calling, the sound is bad.

Brenda

Focus Group Results

Thematic Analysis

Thematic analysis of the women's responses from the focus group interview data yielded six main themes and eight sub themes listed in Table 2.2 below. Each theme will be discussed and exemplars given that capture the women's experiences in their own words.

Table 4

Focus Group Non-Narrative Themes and Sub-Themes
Focus Group Theme 1: Managing Medications Sub-theme 1: Go and Receive Sub-theme 2: Have you taken your medicine? Sub-theme 3: The phone reminds me
Focus Group Theme 2: When you get Sick
Focus Group Theme 3: Funerals
Focus Group Theme 4: When I didn't have this phone
Focus Group Theme 5: Ways of communicating Sub-theme 1: Flashing Sub-theme 2: Calling or Texting
Focus Group Theme 6: Technical Challenges with Mobile Phones Sub-theme 1: Charging Sub-theme 2: Airtime Sub-theme 3: Headset Failures

Theme 1: Managing Medications.

The theme of managing medications was the most frequently identified benefit women talked about in the focus group interview. This theme includes all of the ways that they utilized the mobile phone to assist each other with adherence to ART treatment but also medications they needed for other ailments. The sub themes included 1) *Go and Receive* which includes ways that

women used mobiles as reminders to go to the clinic to receive their ART treatment; 2) *Have you taken your medicine?* is a subtheme that describes the ways the women interacted via mobile to remind one another to take their daily medication; and 3) *The phone reminds me* sub-theme includes ways the women used the phone's time and alarm function to remind themselves to take their medications .

Sub-theme 1: Go and receive your medication. The women discussed their experiences with using the phones to help each other remember to go to the clinic to pick up their antiretroviral medications.

“The phones have benefited us in so many ways, we were communicating with our friends to remind them the days to go and receive the medication....”

Sub-theme 2: Have you taken your medicine? Many of the women mentioned using the phones to call one another and remind each other about taking their medications. This was accomplished in various ways as described by a number of the women in the excerpts below.

“When taking medication, we call each other, I told them that I drink at 6 o'clock, maybe Ellen would call and remind me the time. Then, I would know that she is reminding me of the medication. She calls direct. I am Ellen the time to 6. She does not say much because I told them that I drink 6:00”...

“I raised my hand because the phones have helped. The phones have helped because I am quick to forget. So when I had the phone my child would call me telling me that it's time for me to drink medicine so I would take and drink at the same time so the phones helped us...”

“The phone has really helped me. It is reliable. Because I forget easily so sometimes somebody would call me at night to ask whether I have taken my medicine or not, maybe they will tell me to drink when sleeping so when it’s before bed time they would call me asking if I have taken the medicine. If I say no they will tell me: it’s time to drink the time is up. So the phone is very important. It has helped up a lot.”

Use of the mobile phones also helped with medication adherence as seen in the following situations. For example, in one case one women is traveling to a funeral and the second is traveling somewhere for a visit and forgot her medications but they are both able to call someone and obtain their medication because now they have the phone to do so whereas in the past they did not.

“Maybe sometimes when I have received news that there is a funeral at the village, when I call them they remind me to take my medicine with me.”

“The goodness of the phone is that when I want to drink medicine or I have gone somewhere, you can call the neighbors or the visitor I am close with that they should call the child we should meet at such and such a place (there`s my thing which I use I did not drink), so she should bring to me.”

Sub-theme 3: The Phone Reminds Me. In this sub-theme, the women discussed how they used the phone itself to help them remember to take their medicine on a daily basis and talk about what it was like before they had a mobile phone to help remind them.

“The time to drink medicine, when I did not have a phone, I would just see that its morning and I would say that I will drink at 6:00. I did not know the time. I did not have. So then when I had a phone I could see that the time was 6:00 pm and I am supposed to drink medicine at night. I

would see if the sun is going. I would say it's time to drink medicine so the phone has helped a lot.”

“ ... I like to set the alarm for 6:00. Even when I am travelling I would carry my medicine”

“The phones have helped me a lot ...it has time and date. When I look at the date I know when to go and receive medication. When I look at the time, I know that I drink medicine at 7:00 once a day.”

One participant talked about being in a relationship with the phone describing it as her husband. She kept it with her all the time and counted on it to remind her when to take her medications.

“So when I look at my old phone it doesn't show anything. I depend on the new phone that's my husband”

The phone also allowed group members to not just receive reminders for their ART medications, it also allowed them to contact others in the group who would give them advice over the phone about what medications to take in an illness situation.

“The goodness of the phone, it was helping me. If my legs hurt and we have something that we should talk about, I was suffering how am going to walk. But with the phone you will call and agree with the people they will do for you. *Or there is medicine they will tell you which medicine to drink.* Right there at home so that how we get along.”

Theme 2: When You Get Sick

The theme of when you get sick contains reports of how the mobile phone assisted women when they were sick and how the phones helped them.

“The goodness of the phones I saw is that it is good, because when I am sick, the group knows in very good time.”

“It has benefited us in a way that when our friend gets sick, the one who hears first would phone the rest of us telling us that our friend is sick. So we would run to go and see her, if there is need to go to the hospital, we would go to the hospital in our group.”

“ The phones have benefited us when you are not feeling well in your body and you will not manage to go to support group, you would just use the phone to communicate that you will not manage to go you are feeling like this, like that, or maybe I am going away.”

Theme 3: Funerals

Just as in the narratives, many of the women mentioned that being notified of a funeral through mobile phones was very beneficial.

“The phone has benefited us in so many ways. We were communicating with our friends to remind them the days to go and receive medication and also reminding if you have taken your medication and also when *there is a funeral at the village*, we were using the same phone to hear of the problem.”

“Before the phone, it was difficult to hear from the village. When someone has passed away they would write a letter and you would get it when they had already buried the person. So because of the goodness of the phone I bought my own phone and communication was no longer difficult.”

Theme 4: When I Didn't Have this Phone

Many of the women spoke of how it was for them when they did not have their mobile phone as a way of pointing out its benefits now that they had it. These benefits included knowing when a relative was sick, saving time walking, knowing when someone had passed away, and being able to communicate with relatives.

In the next three accounts of the women discussing what it was like prior to having a mobile phone they provide us with an evaluative orientation to their accounts first by saying that they were living a hard life and they were suffering. Next, they go on to tell us why, including failing to pass a message to their relatives if they were sick, or not being able to hear news about how their child was, or being able to communicate with other members of the group or friends or family.

“When I didn't have this phone I was living a hard life because I was failing to pass a message if I was sick to my relatives. But when I had this phone I was using it to communicate.”

“The time I had no phone, I was suffering. To hear how my child is I was suffering. But when I had a phone from the group, I hear everything. That's the goodness about phones.”

“When I did not have a phone I was worried how I will know but when I found the phone I reached the point that whatever was happening here they were telling me and when I get sick, I would call and tell them and people would come and see me...I was talking to the people from the group here and also my relatives when things are not okay with me, I would call them.”

At times women infected with HIV may have decreased functional abilities if they become ill this could relate to a number of reasons. Sometimes due to poverty they may not have enough food to eat which may make it difficult to take their medications on an empty stomach. Additionally, they could have other conditions such as malaria, or depending on how their ART therapy is being managed at the time they could be going into AIDS and just not be able to walk. The underlying value of connectedness emerges in her statement about: “But with the aid of the phone, a lot of things are happening.” So it is not so much just the phone but it is the connectedness the phone brings regardless of not being able to walk.

“I was living a hard life. Because communication with my friends, my family and also here at the group, it was difficult. When I had no phone it was hard to communicate with relatives and also people from the group. It was difficult that I should greet them in any way. *So when there were different problems I would walk with my legs and when you could not walk, it was very difficult. Some nice things would pass us by because of not having a phone. Messages would pass us by.* But with the aid of a phone, a lot of things are happening.”

Theme 5: Ways of Communicating

In this theme the women describe the different ways that they communicated using the mobiles and it includes two sub-themes: flashing and the use of text messaging or calling.

Sub-theme 1: Flashing. Flashing explores the practice of “beeping” or “missed calling” between mobile phone users. This is accomplished by calling a number and hanging up before the mobile’s owner picks up the call. This is done many times to save airtime as the receiver pays for the call. However, in many countries it has become such common practice that it is an everyday way of communicating.

“Sometimes we would flash each other when you don’t have airtime but when you have airtime, you would call your friend direct. Or if the airtime is not enough to call you would write an SMS.”

Clearly it is important to have a relationship with someone before you start flashing them. There is risk involved in flashing otherwise as the narrator below discusses your message may not get conveyed, as they may not understand that you are flashing them because you do not have any airtime left.

“Most of the times when we want to pass on a message to the group ... you try to buy airtime a little bit to call the group. For you to flash it does not work but you have to find airtime to call. When you are calling the group, you have to try to find airtime to call. If you do not have airtime, you might find that the airtime is not enough, you only have K10, and you just write a message. But with our relatives, they just flash us and we flash them also but at the group most of the times we use airtime to pass on the message properly because you might find that you are flashing your friend and that person does not have airtime so the message you wanted to pass across will not be conveyed”

“When I see that I don’t have any airtime in the phone, I am supposed to flash. If am flashing someone and they know am flashing, they don’t call, I flash again and they don’t call, if I have a problem and I need that person to call me I should tell them my problem because I don’t have money to buy airtime so that is the reason I flash.”

Several members said that they did not flash members of the group but they did flash their relatives if they had to and that their relatives flashed them frequently. Again, the

impression was that that you would need to have a closer relationship with someone before you flashed them.

“I don’t flash the people from the group but my relatives are the ones who flash me.”

This group member was part of another HIV Education group in the community. So, the idea that no one flashed her implied that flashing was reserved for more informal type of communication. Or, there was more risk involved with the message going through flashing.

“People don’t flash me because I have a lot of responsibility so they just call me when they want me but I flash my husband I don’t want to..... I can call anyone but when I don’t have airtime, I just call, flash my husband but my friends I buy airtime worth K35 and call them.”

This was an interesting dialogue regarding how two group members are using their mobile phone to communicate yet neither of them has airtime to communicate.

“People flash me. When I don’t have airtime, at the group where the number is coming from I flash back that they should know that I don’t have airtime too”

In this narrative she is saying that if both women are flashing then the assumption is both have no airtime, yet, someone needs help and the resolution is someone borrows money and then they are able to communicate.

“I too when I don’t have units I do flash. I flash the group. If I have a problem be it sickness or what, when I don’t have airtime I flash my friends and when they too don’t have airtime, they flash me back so sometimes we are forced to go and borrow money. I

am flashing her and she is also flashing me so I put the airtime and call her. Then we agree.”

Several of the women told similar narratives, explaining that if a person really has an important message that it cannot be trusted to flashing and if the person has no airtime and does not have any funds then the person must walk to communicate the message. They explained that many of the messages that they have to convey, especially within the group are too important to leave to flashing.

“I have been in that situation where there’s no airtime in the phone so we use our legs walking. And that person who is not replying she also doesn’t have units. We walk. ...I feel very strong we need to meet.”

Sub-theme 2: Calling or Texting. This sub-theme includes the women’s accounts of their preferences for calling or texting using the mobile phone. Many reported the reason they did not like texting was eye problems. A few would do either although the preference was calling versus texting. Some noted it was less expensive airtime to use text messaging. Most of the women reported eye problems, or difficulty visually seeing text messages. The current phone that was provided did have a very small font that was difficult to see in the daylight.

“Calling when you have a lot of airtime you can be calling but sending a message is cheaper. To my side I have eye problems, so for me the best way is just calling.”

“I also have eye problems so a message is difficult to me, but I love calling.”

Most of these women like to call directly to assure that their message gets through, the perception seems to be that to call is to “communicate properly.” Most agree that if you do not have airtime that that is when you would send a message, inferring it is less ideal.

“The main thing to me if I don’t have units, the big thing is just to send message. If I don’t have enough airtime, I would rather send a message. If I have a lot of airtime I can call but if I have less, I can just send a message.”

“I prefer calling because when I call I communicate at the same time so I am assured that my message has been conveyed unlike when I send a message, it can be that the message is not yet delivered.”

Some of their statements describe calling later and checking to see if someone received the text message implying that the texting is less dependable in their perception than the calling for sending a message.

“A message is good, calling is good, both are important. When you have airtime you will call but when you don’t have enough, send a message. When you see its quiet, you will call asking if she has not received the message. Because a message shows in the phone if it has arrived or not. So we call. So if we say calling and sending a message, they are good to me.”

Theme 6: Technical Challenges with Mobile Phones

This theme includes the identified technical challenges women talked about while using the phones in their day-to-day lives. It includes three subthemes of charging, airtime, and headset failures.

Sub-theme 1: Charging. Charging was discussed within the context of where they were able to charge their phones, whether at home or with a neighbor, how long it would take them to charge the phones, charging or battery failures and whether or not they paid for charging. From the women’s reports, it was clear that for most of them, charging the phone was indeed a

challenge. The phones often took a while to charge and this proved difficult if the women had to travel a long distance to access electricity in order to have their phones charged. A number of women had to pay to have their phones charged. Some of the women had electricity in their homes and were able to charge the phones at home. Some had neighbors with electricity who let them charge their phones for free. It generally took three hours to completely charge the phone's battery. The reported battery life was between 1.5 to 3 hours, with most of the women reporting less than 2 hours.

Sub-theme 2: Airtime. Airtime includes the women's reports of how much airtime they required monthly. Although this might be considered more financial per se as this has to do with the cost of paying for time to charge up the phone so you can make calls. In Blantyre, Malawi this accomplished through the process of buying tickets usually at stands. Most of the time a person can buy these in units of in denominations as low as 50 kwacha top up scratch card denominations. In discussing this with the women they felt that \$1.00 to \$2.00 USD per month was a reasonable stipend for them as support group members to utilize for support group activities.

Sub-theme 3: Headset Failures. In this sub-theme, the women reported issues with the headset having various problems. Sometimes the phones would read SIM card error. The women also described the phones as fragile and said they needed to be treated like babies in order to make them last. The women also complained that the phones "blocked" or just turned off.

"Those phones if you do not press the buttons properly, they block."

“I have carried the phone, sim card error, you try to move it to do what, and it will switch off.”

“My thoughts are that we should take care of the phones like a baby, the way we take care of the baby, the phone is also supposed to receive the same care.”

FINDINGS IN RELATION TO THE RESEARCH QUESTIONS

In this chapter, I review the findings from both the interview narrative analysis and the focus group non-narrative analysis and discuss them in relation to the research question and aims for the study. The main research question was: What are the sociotechnical factors associated with mobile phone use and how are they experienced by a group of HIV infected women who are part of a support group that meets regularly for income generation and support?

To review, I applied sociotechnical systems framework to the support group dynamics in order to provide the context for responding to the research questions. In view of sociotechnical systems, the user of the mobile phones, in this case the women in the support group are not situated separately. They are affected by other women around them and by whatever tasks the other women in the support group must also accomplish while using the mobile phones. The utility of the system is thus determined by how well it matches the support group's social structure and workflow. In this study, findings from the interview and focus group data provided insight into some of these structural and workflow related tasks accomplished within the support group. Although these are reported separately, these elements are in fact interrelated, and many of these factors cut across several thematic areas, which is the dynamic nature of sociotechnical systems. For example, in the health related category of using the phone to call the group coordinator (social/structural) when I am sick (health related) the outcome was that a woman received a visit at home (health related) and then she was also joined by two senior group

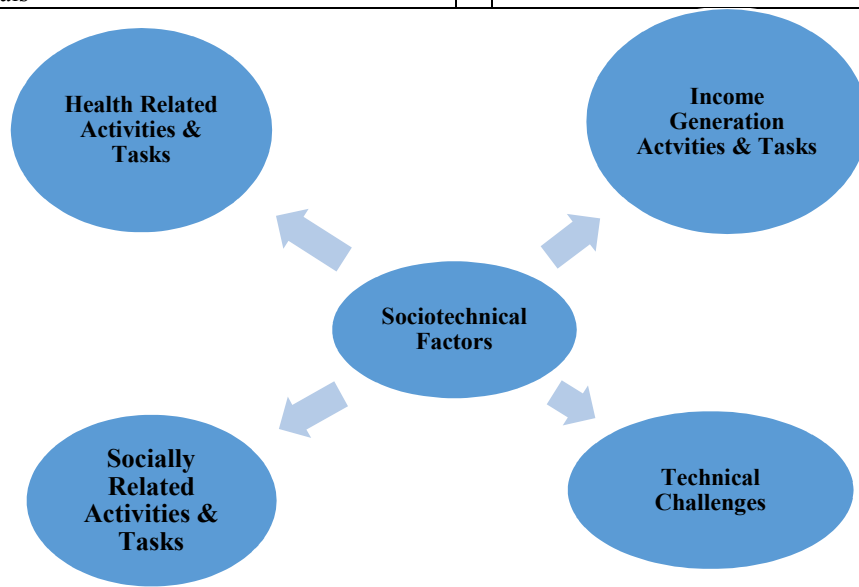
members (social/structural) who brought funds that were earned through the support group income generation activities. The findings in relation to the research questions are divided into four sections graphically portrayed in Figure 5.1 and described below.

- 1) **Health Related Activities** – health related activities included all of those tasks that were accomplished using the mobile phone when someone was sick. These included calling someone when they were sick or another group member was sick. It also includes ART reminders and Clinic reminders. Phone calls that save a group member’s time walking are also considered health related activities because they meet functional status needs by decreasing unnecessary walking or they keep women from having to walk when ill. Calls related to funerals also fell under this category.
- 2) **Socially Related Activities** – socially related activities included all of those tasks that were accomplished using the mobile phones within the social structure of the women’s support group. These included calling practices where the group coordinator or a senior group member was called first, or the group coordinator initiated a call to bring the group together. Calling practices that maintained connectedness of group members, including being able to communicate with relatives and other group members, the practice of flashing and women’s preferences for calling or texting were also included in this category.
- 3) **Mobile Phone Calls and Income Generation** – this included those activities that assisted the women in generating income for their basic livelihoods so that they could purchase food or transportation. The mobile phones allowed women to make going to the market and finding buyer decisions on the fly because of the flexibility that mobile phones brought to the situation.

- 4) **Technically Related Challenges** - most of the challenges the women experienced with the mobiles were in the technical category and included problems with charging, airtime, and headset failures.

Figure 3 Sociotechnical Factors Associated with Mobile Phone Use by Women Who are Members of an HIV Support Group in Blantyre, Malawi

<p>Health Related Activities and Tasks</p> <ul style="list-style-type: none"> • Using the mobile to call when sick <ul style="list-style-type: none"> ○ <i>Calling another group member when sick</i> ○ <i>Accepting a call from another group member when sick</i> • Using the mobile for medication and clinic reminders <ul style="list-style-type: none"> ○ <i>Using the mobile phone to call to remind each other to take daily ART medications</i> ○ <i>Using the mobile phone to remind each other about ART clinic appointments</i> ○ <i>Using the mobile phones date, time and alarm functions as reminders to take daily ART medications on time</i> • Calls using the mobile phone that save time walking • Using the mobile phone to call each other related to funerals 	<p>Income Generation Activities and Tasks</p> <ul style="list-style-type: none"> • A mobile phone call is initiated, and a group member who is ill obtains material aid. • Using the mobile phone to make buy/sell decisions on the fly and inform each other in a timely manner
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<p>Socially Related Activities and Tasks</p> <ul style="list-style-type: none"> • Calling processes within the support group <ul style="list-style-type: none"> ▪ <i>Calling the group coordinator or senior group member first when you are sick</i> ▪ <i>The group coordinator initiates calls out to the whole group</i> ▪ <i>Using the mobile phone to communicate with relatives that are far away</i> ▪ <i>Using the mobile to flash another group member</i> ▪ <i>Calling or texting on the mobile phone</i> 	<p>Technically Related Challenges</p> <ul style="list-style-type: none"> • Charging Phones • Airtime • Headset failure
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Research Aim 1, 2, 3, 4a, 4c: Sociotechnical Factors

Health Related Activities and Tasks

Using the Mobile to Call When Sick

Calling another group member when they were sick. An important need that women had was being able to call another group member when they were sick themselves. Usually, they called the group coordinator or senior group member first. This call would result in either advice being given, a home visit (sometimes with resources provided,) or assistance with going to the hospital.

Accepting a call from another group member when sick. Correspondingly, an important task that the women had was to answer a call about another group member who was sick. Usually this call was initiated from the group coordinator. This call could be about the women being sick at home or in the hospital and would result in going to visit the woman at home (sometimes with resources provided) or in the hospital.

Using the Mobile for Medication and Clinic Reminders

Using the mobile phone to call to remind each other to take daily ART medications. Using the mobile phone to help each other remember to take their ART medication was a significant undertaking mentioned by many of the women, and the most frequent task mentioned during the focus group meeting. Some said other women in the group called them, some reported their children called to remind them. One woman said that she ended up getting awakened at night because she had already fallen asleep but then took her medication after the call. Others provided examples of when they were traveling or going to a funeral and had not thought to bring their medication, but then received a call from another group member, and were

able to have someone obtain their medications for them. Many of the women had communicated with someone regarding what time(s) their ART medications were to be taken on a daily basis and had pre-arranged ahead of time that this person would call them to remind them to take their ART medication.

Using the mobile phone to remind each other about ART clinic appointments.

Another critical undertaking that the women in the support group had was making sure that they attended the ART clinic. This is where they are followed up for their HIV status and CD4 counts. This is also where they obtained their ART medications. The women provided examples of using the mobile phones to call each other and remind each other about their clinic appointments. They talked about checking the calendar and reminding each other that you need to go on this day.

Using the mobile phones date, time and alarm functions. Several of the women reported using the phones date, time, or alarm functions to assist them in taking their daily medications. One woman talked about depending on her new phone that showed the time and date *like her husband* to remind her to take her medications.

Calls Using the Mobile Phone that Save Time Walking

The women discussed several situations where they had to walk when the mobile phone could have been the substitute. For example, one situation would be flashing, where an important message needed to be conveyed but the women may not have had any airtime to call so they ended up walking. Another time a woman provided an example of needing to let the support group know that she would not be attending and needing to let them know in person prior to the phone. Whenever the women discussed walking they frequently used terms like suffering or hardship. Therefore, anything that could save them the effort of having to walk, especially when ill had a positive impact.

Using the Mobile Phone to Call Each Other Related to Funerals

Many of the women used the phone to call each other when there was a funeral. Usually there would be one call and then one group member would call another and so on. Then they would meet up as a group at the woman's home where the funeral was taking place. Many times the women from the support group would be the ones to clean and wrap the body as others would not, due to the stigma related to HIV in the community.

Research Aim 1, 2, 3, and 4a: Sociotechnical Factors

Socially Related Activities and Tasks

Calling Processes within the Support Group

Calling the group coordinator or senior group member first when you are sick.

Within the support group there was a structural calling workflow utilizing the group coordinator and senior group members articulated by several of the women, usually used when someone was calling when sick.

The group coordinator initiates calls out to the whole group. Calling the group coordinator workflow was used in reverse when the group coordinator would initiate a call to the whole group to gather them together for some reason, usually to visit a sick group member in the hospital or it might be to go to a funeral.

Using the mobile phone to communicate with relatives that are far away. The women were able to stay connected to relatives, family, and friends when they were sick or know when their relatives were sick or when someone in their village had a funeral. Whereas before they had the mobile phone many "messages passed them by."

Using the mobile to flash another group member. Flashing is done by calling a number and hanging up before the mobile's owner picks up the call. This is done to save airtime as the receiver pays to make the call back. Flashing serves as messaging system to the receiver of the call to call the person who flashed back. Flashing, a sub-theme of communicating is intertwined with airtime, a sub-theme having to do with technical challenges of mobiles. Although technically speaking airtime is more of a financial issue, this contributes to the social issues that surrounds whether flashing someone is acceptable or not. First, because it puts the burden of paying for the call on the receiver, so you need to have the kind of relationship that would be amenable to that kind of transaction. Second, if both parties have no airtime then your message is not likely to get through.

Calling or texting on the mobile phone. Most of the women preferred to call instead of text. Three of the women reported having eye problems and that they could not see the font for sending a message. Even though it was not ideal, several of the women reported that they did text at times because it was less expensive.

Research Aim 2: Sociotechnical Factors

Income Generation Activities and Tasks

A mobile phone call is initiated, and a group member who is ill obtains material aid

The category of income generation is intertwined with calling when sick because many times a home visit resulted in material aid such as oil, soap, or rice being provided to the women from income generation activities that the group had been involved in.

Using the Mobile Phones to Make Buy/Sell Decisions on the Fly and Inform Each Other in a Timely Manner

The mobile phones allowed the women in the group who had other businesses outside of the support group to make going to market and finding buyer or selling decisions on the fly easier because of the flexibility of the mobile phone. If a decision was made that something was a good opportunity then the result would be for the interested parties to “rush” to a location based on the phone communication. This theme also meshed with saving time and walking because they could make these decisions ahead of time and not waste a trip to the market.

Research Aim 3 & 4b: Sociotechnical Factors

Technically Related Challenges

Challenges with Charging Phones

The challenges that women had with charging their phone batteries included the following: Some women did not have electricity so they had to pay to get their phones charged at a charging station. Phones were unable to hold a charge for very long, on average, only 2 hours. One woman had her phone stolen at a charging station.

Challenges with Airtime

Although airtime may be considered more financial, a decision was made to place it in the technical category as it creates a technical problem when you have no airtime to run the phone. The women reported what they felt was a reasonable stipend from the support group funds for their mobile phones was \$1.00 to \$2.00/month USD. In Blantyre, airtime on their phone is “topped off” by buying tickets. These tickets are then scratched off to reveal a code and that code is then entered into their phone to provide them with more time on their phone. When

speaking with the women they would typically not talk about how much time they had left on their phone in minutes but in kwacha, the local currency.

Challenges with Headset Failures

Several of the women reported that after about 6 months the phones started to fail such that they were unable to hear the person on the other end. Some said they would get a message that said SIM card error, others said that the phone just “blocked.” Usually they said that the earpiece failed. Two of the women said that the phones were so fragile that they needed to take care of these phones “the way we take care of a little baby.”

Summary

The interviews with ten HIV infected women in the support group in Malawi yielded rich findings which were described in this chapter. The narratives from the interview responses, and the themes that emerged from the focus group and their exemplars were discussed. The major findings in relation to the aims of the study were summarized and illustrated in a graphical model (Figure 3). In the next chapter, I summarize my major conclusions, discuss my findings in relations to the extant literature, as well as implications for further research and policy. Additionally, I review the strengths and limitations of this study and implications for policy, future research, and nursing.

CHAPTER 5

DISCUSSION

The use of mobile phones is becoming ubiquitous and there is growing interest by healthcare providers to utilize mobile phone technology for various health related applications, called mHealth. This is especially true in low income countries such as many of those in sub-Saharan Africa. However, when implementing mHealth applications it is important to understand the dynamic social, cultural, and environmental contexts where it will be implemented. The theoretical framework used to inform this study was the sociotechnical view where one looks at the social (people) and the technology (phones) and how they interact. Paying attention to these factors is important because it can help those who implement these programs assure that they are more effective. An exploration of the sociotechnical factors experienced by a group of women who were members of an HIV support group in Blantyre, Malawi was conducted to better understand their experience. The findings of this study as detailed in Chapter 4 provide beneficial understandings regarding the experiences of HIV infected women in Blantyre, Malawi who were members of a support group and how they used their mobile phones to assist each other with various activities. These findings offer valuable insight into the sociotechnical factors of this context. In addition to the findings discussed in the previous chapter, they are also conveyed here as major conclusions. Discussion of findings will be structured around four major conclusion areas: 1. Health related activities and tasks; 2. Social related activities and tasks; 3. Income generation activities and tasks; and 4. Technical challenges. First, I will provide an introduction of the major conclusions, then discuss each topic in more depth in relation to pertinent literature and implications. Then I will talk about the limitations of the study, as well as implications for nursing and policy. Finally, I will discuss future directions for research.

MAJOR CONCLUSIONS

Within the area of using the mobile phones for health related activities and tasks the women were able to use the mobile phones as a communication tool within the structure of the support group in ways that helped them shape their health trajectory to keep them healthy and functional. Reminding each other to take their ART medications and remember their clinic appointments was seen as a collective responsibility and social obligation. If the support group collective and social capital are a pathway to facilitating adherence then perhaps the mobile phones are acting as bonding agents, increasing social capital within the support group. When using the phones date and time functions as reminders, the women treated the phones like social actors, (babies, and husbands). Perhaps this can be explored further and leveraged in adoption of new technology during mHealth implementations. In regards to socially related activities and tasks the women had typical calling practices and workflows in which they called the group coordinator or senior group member first, or the group coordinator would initiate a call out to the whole group. This resulted in a coordinated articulated workflow and contingent decision-making process with different outcomes. This was a practice that “kept things going” in the group. Another valuable social practice was using the phones to communicate with each other and with their relatives. This seemed to help the women deal with the stigma associated with HIV. Flashing was used between the support group members usually because of monetary constraints and had moral implications. It was a common, complex, interactive workflow involving the mobile phones within the social structure of the support group, and the individual contingent actions taken by the women. Voice was the preferred method of communication over texting. The main reason for not texting was due to poor vision. In regards to income generation the mobile phones had a mediating effect on the women's livelihood strategies. Finally, charging,

airtime and headset failure are interrelated mediated sociotechnical factors that need to be investigated and designed when developing mHealth projects in Malawi.

Sociotechnical Analysis

To review, through a sociotechnical analysis, one seeks to assess the technology, in this case, the mobile phones from the user's perspective, and how the mobile phones can best be incorporated into the women's activities. Further constructed on this sociotechnical viewpoint, these social, technical, health related, and income generation related tasks, activities and issues are complementary and cannot be separated (Keikhosrokiani et al., 2014). Additionally, within this study they occurred within the dynamic collective structure of the support group created by and for the HIV infected women in Blantyre. This collective structure is also complementary to the identified sociotechnical factors and cannot be separated. The women in this study were not isolated individual users of their mobile phones. They were affected by the other women around them and by all the various tasks and activities they described that they needed to complete while using the mobile phone. So, the benefit of this sociotechnical system is determined by how well it fits the support groups collective structure and workflows, not just some of the isolated tasks and functions for which the phone is designed. For example, from a sociotechnical systems analysis perspective the conclusions reveal that the interactions among the women in the support group restricted or shaped the interactions between the women and the mobile phones in the four areas of health related, social, income generation, and technical related. Additionally, some of the women's willingness to adopt or modify their attitudes about using different system capabilities such as texting instead of calling was probably impacted by the attitudes of other women in the group at the social level.

Health Related Activities and Tasks

Calling Each Other When Sick

The women interacted with each other and used the mobile phone within the structure of the support group in ways that helped them shape the trajectory of their health. When they were sick they were able to call on one another for assistance. This is important when you have HIV, as it is a chronic disease and it is critical to keep it from advancing in its trajectory to AIDS. (Deeks, Lewin, & Havlir, 2013). Fatigue is a common symptom in HIV which can be related to side effects of ART medications and altered body chemistry (Doenges, Moorhouse, & Murr, 2014). Within the context of sub-Saharan Africa there could be food security issues, and HIV replicates faster in the presence of malnourishment (Gill, 2010). Therefore, obtaining assistance from someone in a timely manner, whether they come to visit and bring you food or other funds to get to the hospital can mean the difference between compensating and staying functional and healthy or decompensating into a poorly functioning trajectory. In this way the women used the mobile phone as a communication tool within the women's collective. This served as a surveillance system to help monitor and detect when women were sick so a call could be placed to the group to prevent their condition from deteriorating. This was exemplified by women saying several times in their narrative "Before I had the phone, life was hard." The women also described how the phone alleviated their suffering by describing that "before the phone I was suffering". In the context of their health, before the phone in order to communicate with someone in the support group when they were not feeling well, they would need to walk to find someone to send a message, which is difficult when one is fatigued and is of ill health. But the phone allowed them to simply call someone in the support group and save them from walking, keeping them connected to the resources within the group, when they functionally could not do

so for themselves. In this way the mobile phone was used as a sort of self-surveillance instrument in helping the women maintain their functional status.

Using the Mobile for Medication and Clinic Reminders

One of the most frequent findings from both the interviews and focus group data was the reports of how the women interacted with each other, using the mobile phones to remind each other to take their ART medications as well as to go to their clinic appointments. The implementation of ART programs to the public is a challenge in resource limited settings of sub-Saharan Africa (Ferradini, Jeannin, Pinoges, Izopet, Odhiambo, Mankhambo, & Fedida, 2006; Tassie, Baijal, Vitoria, Alisalad, Crowley, & Souteyrand, 2010).

In order to maintain the therapeutic benefit of ART treatment, individuals must continue to take the medication. Making sure that people who have HIV continue to not only take their medication but also refill their prescriptions as part of their visits to the clinic is all part of adherence in this population. If someone does not make their clinic visit, or silently transfers to another clinic, or dies, then they are considered “lost to follow up” depending on how these outcomes are measured (Geng, 2010, 2011). Poor retention is a problem. In a recent AIDS Progress Report completed by the government of Malawi; by the end of September 2014, of the 745,133 patients ever initiated on ART, 521,319 (69%) were retained alive on ART, 71,525 (9%) were known to have died, 158,580 (21%) were lost to follow-up, and 3,418 (<1%) were known to have stopped ART (Malawi National AIDS Commission, 2015, p.38).

Research on adherence suggests that community support improves adherence to ART in resource limited settings in sub-Saharan Africa (Zachariah, Teck, Buhendwa, Fitzerland, Labana, Chinji, & Harries, 2007; Nachega, Skinner, Jennings, Magidson, Altice, Burke, & Theron, 2016). Frequently when the women in the support group described how they would use the phones to

call and remind each other to take their ART medications, they would use the collective “we.” It was clear that they felt responsible to each other and were diligent in articulating their expectations to the other group members through direct phone calls when it was time to take their ART medication. They worked in pairs in this way where one woman would call and *say it is time for you to take your medication* and then hang up. This sense of collective responsibility to managing each other’s ART medications is similar to findings in studies completed in sub-Saharan Africa that found success with adherence to ART was related to meeting social obligations (Merten, Kenter, McKenzie, Musheke, Ntalasha, & Martin-Hilber, 2010; Ware, Wyatt, Geng, Kaaya, Agbaji, Muyindike, & Agaba, 2013). For example, in an ethnographic study done by Ware and colleagues in three different countries in sub-Saharan Africa, they found that patients that were taking ART medications followed their prescribed regimen in order to maintain approval with their helpers (helpers were those that were helping them take their ART medications and remind them of their clinic appointments). Their conclusion was that this represented a form of fulfilling social accountabilities and maintaining social capital (Ware, Idoko, Kaaya, Biraro, Wyatt, Agbaji, & Bangsberg, 2009).

Social capital is a multifaceted concept (Dasgupta, 2000). It includes features of social organization, such as trust, norms, networks, and coordinating actions (Putnam, 1993). “Bonding” social capital encompasses localized relationships between homogenous community members or neighbors, such as that found in the solidarity of the structure of support group members (de Silva & Harpham, 2007). Community based ART support programs for persons with HIV are drawing increasing interest in sub-Saharan Africa. As HIV moves to more of a chronic illness in sub-Saharan Africa, models of antiretroviral treatment rollout that are sustainable need to be considered. If community participation and social capital is a pathway to

facilitating adherence to ART then more studies are needed to understand the relationships between these various formal or informal community models and treatment adherence. In this setting, mobile phones may act as a facilitative “bonding agents” in the collective increasing social capital within the group.

Using the Mobile’s Date, Time and Alarm Functions

It is interesting to note that some of the women used this function while others did not. For anyone using a mobile phone as an adjunct for ART therapy they should assess if the user understands how to use this function. Another interesting finding was that when discussing this function on her phone and how she interacted with it one of the women kept calling it her husband. People will often treat computers, phones, or other technological media like people (Reeves & Nass, 1996), expecting media to obey social rules and treat them like other social actors. When there is a problem with technology, they do not always attribute it to the technology itself (Oren, Salomon, Kreitman, & Don, 1990).

Similarly, women attributed the phones with the characteristics of a baby and talked about treating the phones like you would a baby and caring for them as you would a baby. In this setting, the mobile phone was thus a social actor, sometimes thought of as a husband in the sense of interacting as a helper for reminding someone about their ART medications and at other times, as a baby in the sense that women needed to care for it so that it would not be easily damaged. These social responses to computers, phones, and other media as if they were people is not obvious to people doing it and happens without conscious awareness (Bargh, Chaiken, Govender, & Pratto, 1992). The implications of this for those implementing mHealth would be to understand what the social interaction is with the mobile phones and the community members

and listen to how technology is addressed as social actors. This can be leveraged in adoption of new technology during implementation.

Using Mobile Phones to Save Time Walking

In these narratives the women talked about how using the phones frequently saved them from walking with the point being that walking was difficult for them functionally. They described that before the phones they would have to walk and they would be very tired. With the initiation of ART, HIV has now become more of a chronic disease as long as one stays on their medication. One of the most commonly reported symptoms is fatigue (Mannheimer, Wold, Gardner, Telzak, Hullsiek, Chesney, & Friedland, 2008) and a major task that women have in their day-to-day lives is walking in order to get to where they need to go. By placing a call using their mobile phone rather than walking to deliver communication, this can assist with saving energy, helping women maintain their functional status.

Calling Each Other Related to Funerals

When a group member died women would receive a call regarding where the funeral was to be held and they would all meet there and prepare the body and be present at the funeral. In this way, the phones enabled them to remain connected and bonded in their social relationships and meet their responsibilities to the group. These narratives and responses were not just about funerals but about how they would support group members who had died. Several of the group members who died did so in the hospital and then had a funeral at their home. Some were quite ill prior to going to the hospital. They were not following the group's norms around self-care and taking their ART medications and were not participating in the group activities such as sewing rugs for income generation. From a sociotechnical perspective, the interaction of the women using the phones within the sociocultural dynamics of the support group as it impacted their

health is important. In this case, there were implicit social norms that were set within the support group about “how we will be.” These seemed to be promulgated by the group coordinator and the senior group members, but they were also followed by the other group members who were interviewed by me. Those group members who did not follow those norms had left the group or had not survived. In August of 2012, an expectation of support group membership was participation in making rugs which were sold for income generation. Income was shared equally among group members, who participated in rug making, for food, transportation, or other needs when members were ill. For those who did not want to participate in the income generation activities they would usually leave the group. Several previous members who had declined to participate in rug making had passed away, yet, the support group members still made it a point to attend their funerals. With the increase in funerals it is difficult from a financial perspective to keep up with always providing funeral feasts as is the custom, so any assistance in this area is valuable. The women’s support group made it a priority to attend funerals and to bring food whenever they could and to stay through the burial. The phone calls made by the women assisted them in supporting the women through their death.

It would be remiss to discuss end of life events such as how the women might have participated in funerals of group members without the time period leading up to the funeral. As discussed earlier, HIV is now becoming more of a chronic disease, and with that there needs to be more of a focus on palliative care services available for people as their trajectory moves from becoming very ill to AIDS and moving from home to hospital to clinic and back home again depending on their illness trajectory. mHealth development and the use of palliative care services and support groups has the potential to fill this gap (Allsop Powell & Namisango, 2016;

Beratarrechea, Lee, Willner, Jahangir, Ciapponi, & Rubinstein, 2014; Herce, Elmore, Kalanga, Keck, Wroe, Phiri, & Rigodon, 2014)

Socially Related Activities and Tasks

Calling the Group Coordinator or Senior Group Member First

It was clear that within the social structure of the support group there were members who had more authority. The women's support group had been meeting for at least two years prior to the interviews and focus group and the group coordinator, the pastors wife had been in her role throughout that period of time. The senior group members had been in place for at least one year. The women reported that they called them first. This dynamic has implications for anyone who would be designing a mHealth application for a group of women living with HIV. It would be very important to identify a group coordinator or natural leader that the group members respect and trust. The group coordinator and two senior group members had the women's trust and respect. This does not necessarily mean though that in any particular community that the senior group members would have the trust and respect of the group members. The social dynamic that was observed in this community helped it to operate very efficiently. For example, when one of the women was sick, she would call the pastor's wife (group coordinator) first or one of the senior group members first. In this workflow, the calls were first triaged by a senior group member first who was most knowledgeable. This also saved airtime because the call was going to the right resource (group coordinator/leadership, senior group member) who had control of the resources (support group funds and support group contact information). Next, a visit from the group coordinator, or senior member might be the result (with resources), or a phone tree type communication response might have been initiated to the rest of the group, to have them visit the sick woman at her home. Additionally, it might result in instructions for the woman to go to the

hospital. All of these approaches were more efficient with saving airtime because if a sick woman would just call any member of the group, she might be getting someone less knowledgeable, or who had not taken on the responsibility of acting in a surveillance capacity. The senior group members held positions in the support group where they managed funds as well. This placed them in a position to be able to dispense financial resources if needed to members if they were called first. The group coordinator was the wife of the minister of the church where the women met on a regular basis and where they worked on the rugs they made for sale. It would be important to leverage these existing community establishments like churches to work on mHealth projects.

The Group Coordinator Initiates Calls Out to the Whole Group

When the group coordinator wanted to get in touch with the whole group she would make one call, then in a “phone tree” fashion the group would call the next person then the next person, and so on. This was an efficient way of getting the message out to the whole group. Additionally, this was congruent with the groups preferred mode of communication which was direct calling versus texting. mHealth projects would benefit from this sort of sociotechnical structure as a rapid and cost effective way of communication. The group coordinator acted as a communication conduit that kept the group connected. She was also knowledgeable and articulated group norms and held group members responsible to self-care activities such as taking ART medications, keeping appointments, participating in income generation activities, and attending funerals. She was one of the first to be called when a member was sick. The group coordinator was the pastor’s wife at the local church where the group met for working on their income generation activities. Leveraging these kind of community based relationships would be a sensible approach for working on a community based approach to mHealth projects.

Using the Mobile Phone to Communicate with Relatives that are Far Away

The women reported that using the mobile phones to keep in touch with their relatives was beneficial. Many of the women had family who lived in villages in rural areas that were many miles away from where they currently resided in Blantyre. Yet they maintained contact by talking with them on their mobile phones. The social support they received by being able to keep up on news of their family and the village was important to them and kept them linked to a larger community and family. This is congruent with social capital theory in relation to bonding. As discussed earlier in relation to the dynamic of ART medication adherence, bonding social capital refers to localized relationships between homogenous community members or neighbors (de Silva & Harpham, 2007). However, it has also been described as trusting and cooperative relations between members of a network who are similar in terms of social identity (Kawachi, Kim, Coutts, & Subramanian, 2004). In using the phones to stay in touch with their relatives, the women may have increased their social capital by using the mobile phones as bonding mechanisms. Social capital indicators have been associated with decreased levels of shame, one of the mechanisms of stigma which is associated with a diagnoses of HIV (Sivaram, Zelaya, Srikrishnan, Latkin, Go, Solomon, & Celentano, 2009). When people living with HIV are part of a support group and there is a reciprocal relationship present with other groups in daily life, then measures of stigma were also lower (Sivaram et al., 2009). Obtaining relationships with outside groups or relatives through the use of mobile phones might be explored as an intervention in future mHealth projects.

Using the Mobile Phone to Flash another Group Member

Flashing is a common practice in many sub-Saharan African countries (Etzo & Collender, 2010; James & Versteeg, 2007; Mbarika & Mbarika, 2006; Sinha, 2005). In the sub-Saharan African context, flashing can mean different things such as a request for call back, a pre negotiated message, for example, or when you want me to pick you up (Donner, 2008). The flashing that was reported by the women in the support group were requests to call back. One of the common reasons that the women made these call back beeps to other women in the group was because of monetary constraints and not having enough airtime. From a sociotechnical systems perspective, it is a case in point of the dynamic interaction between social practices and the technological factors of the mobile phone ecosystem. It uses the call log and address book functions on the mobile phone and the way the telecommunication companies' bill in sub-Saharan Africa (prepaid scratch off cards, caller pays). The other finding that was significant in the women's flashing behavior was that there were several social rules with moral implications within the group that were associated with flashing.

A common unwritten rule was that the call back flashing goes to someone with more kwacha. This mediation focuses on who is going to pay for the voice call. Many of the women did flash other women in the group when they had no more airtime. The women's stories described a situation where neither party had enough airtime. The resolution was that they would either need to borrow kwacha to buy airtime, or walk to the person's home themselves, or, send someone to walk to the person's home. In the context of the support group with women infected with HIV where the women called each other when they were sick for various reasons, these communications were important and taken seriously. Another unwritten rule was that you used call back flashing with family all the time but not with women in the group. The assumption was

that call back flashing to someone all the time required a more trusted relationship. Finally, the women did not flash too much. In listening to the women speak about flashing it was clear that the preferred way of communicating was calling because of the type of information that they had to pass along. There was an inferred “This is the way we do it here” group norm about calling versus flashing. In this situation, from a sociotechnical perspective there is a complex interaction of the mobile phones, the social structure of the support group, and individual actions taken by the women.

Flashing and Adaptive Structuration Theory

There are other sociotechnical theoretical lenses that have been applied to this phenomenon of interest in this context that resonate with these findings. Adaptive structuration theory (AST) (DeSanctis & Poole, 1994; Yates & Orlikowski, 1992) was utilized as a framework for looking at flashing or beeping practices of 13 small business owners in Kigali, Rwanda (Donner, 2008). In this model, features of the technology are selected by the user and in so doing this helps to shape how the technology will interact and affect the structure of the group. Simultaneously, there are preexisting group norms that influence what features are used and how they are used. This is another way to see how a sociotechnical system evolves over time by looking at both the technical and group structure. In the Rwanda study (Donner, 2008), results revealed similar rules governing the use of flashing, except in this group one of the rules was “if you are asking for favorable treatment, do not send a callback flash.” This was not the case in the women’s support group as it was understood that if you sent a callback flash that you did not have the funds to do a voice call. The AST may be a helpful theoretical model to apply for future research when looking at mHealth adoption in support groups as it allows the possibility to identify different types of communication practices. For example, sets of scripts or “interaction

templates” for commonly identified mediated communication messages could be created (Orlikowski, 2008).

Calling or Texting on the Mobile Phone

The women reported that they preferred voice calls versus texting for communication as well as reminders for ART and clinic reminders. This is congruent with what Kunutsor et al. (2010) found in their prospective study when they asked participants what they would prefer for ART clinic reminders in Uganda. The majority of the female participants preferred voice calls. In the other randomized controlled trials that used SMS reminder interventions (Lester et al., 2010; Pop-Eleches et al., 2011) whether or not they asked the participants preference for voice or SMS is not reported. These implications are of concern in that if SMS messaging is not a natural or typical part of the everyday usage of the mobiles for a group then it may impact adoption of the intervention and the sustainability of the intervention after the study is over. In the support group the women reported having difficulty seeing text messages. Vision assessment was not reported in the Kenyan studies. When a text message arrives on a phone you can see there is a message even if you cannot read the text, so in a way it acts as an alert function. This has implications for future mHealth studies as it would be important to understand how users prefer to give and receive communication with mobile phones and to understand the reasons why. If vision is a problem and SMS messaging is a more cost effective option, then perhaps vision appropriate applications could be considered if applicable. Or, funds need to be considered in order to assure that users have enough airtime to be able to use the voice calling function. Additionally, further research could be done with some of the women who seem to be comfortable with using text to identify why they have adopted it.

Income Generation Activities and Tasks

A mobile call was initiated and a group member who is sick was provided material aid. The women told stories about calling on the phone and one of the women from the support group would come to their home and bring either money or food or other items. In this case the mobile phones were serving in a linking up function and assisting the women with livelihood strategies. Livelihood has been defined as “a means of living, and the capabilities, assets and activities required for it” (Masanjala, 2007, p.1033). A connection has been identified between poverty and the HIV epidemic in sub-Saharan Africa (Masanjala, 2007). ART medications have made it possible for people to live with HIV for many years. For the HIV infected women in the support group who live in poverty this means that they depend on their ART medication continuing to be provided by the government or other organizations free of cost or subsidized at a price that they can afford. Social relations and livelihood strategies can impact one’s risk and vulnerability in moving from just being infected with HIV to having AIDS and becoming more acutely ill. The income generation activities of the group allowed the women to earn a livelihood. The mobile phones had a mediating effect on their livelihood strategies. For three of the women this was their first phone. Many low-income women cannot afford to own a mobile phone and rely on shared access through family or friends. It is not clear how this may impact one’s livelihood (Abraham, 2009). The ability of women to call and receive material aid may be more of an outcome of the impact of the mobiles on their livelihood strategies. Future studies on mHealth should include investigation of how they used the mobile phone within the support group on the income generation tasks the support group was involved in such as rug making and raising chickens. This was not investigated in this study.

Using the Mobile Phones to Make Buy/Sell Decisions on the Fly and Inform Each Other in a Timely Manner

Several of the women had businesses on their own and used the mobile phones for expansion and enhancement of their existing activities. This is in alignment with existing literature on mobile phone impact on livelihoods in Africa (Jagun, Heeks, & Whalley, 2008; Sife, Kiondo, & Lyimo-Macha 2010; Molony, 2009; Overa, 2006). These studies found that the use of mobile phones helped people make more beneficial use of existing networks and relationships they already had. One way people receive economic benefit is through reduced search costs (Aker & Mbiti, 2010). Just as the women described, they also benefited from reduced search costs; they did not have to physically in person search for a buyer of goods but used their networks by phone to identify buyers and reduced costs.

Technically Related Challenges

Charging Phones

Some of the women reported challenges with charging phones as they did not have electricity at home or did not have a neighbor who let them use their electricity. These women had to pay to have their phones charged. This typically cost 50 kwacha and ranged from 1.5 to 3 hours. This was congruent with other literature on mHealth studies where subsidies were provided to participants for charging. For example, in a Kenyan study examining adherence to ART (Pop-Eleches et al., 2011) they provided \$1.00 USD monthly. A significant amount of the literature now suggest that solar chargers may be a good option where there are no viable power sources (Boyce 2012; Källander, Tibenderana, Akpogheneta, Strachan, Hill, Asbroek, & Meek 2013). However, these can be problematic under cloudy and rainy conditions. These implications need to be taken into account when planning a mHealth project to assure that all members will be able to keep their phones consistently charged.

Airtime

Airtime may be considered an economic challenge that has a technical and social outcome. Airtime has been discussed previously as it has mediated interaction effects in beeping or flashing as an outcome. When the women in the group did not have airtime left they ended up flashing other women in the group if they needed to communicate with them rather than placing a voice call. During the focus group discussion some women provided opinions that flashing was not the way to pass information within the support group. This inferred that flashing was not acceptable and that seemed to place some moral conflict on those who could only use flashing to communicate. In this study, the women were provided a subsidy for airtime equivalent to \$1.00 USD monthly. In the literature based on the Kenyan study mentioned earlier in regards to charging (Pop-Eleches et al., 2011) 50 Kenya Shillings of phone credit was added to participants' phones every 2 months. Having airtime that was set aside for health related communication within the support group would be important in facilitating a mHealth project. Strategies to assure that this would occur would need to be developed. One way could be to have the group coordinator hold a bank of airtime where she could "top-up" phones of members if they flashed her when they had no airtime time based on group set rules. This process is available in Malawi. This would be an important sociotechnical consideration for any mHealth project in sub-Saharan Africa.

Headset Failure

It is difficult to determine exactly what the technical failure point is from the women's description. For example, it could be that the phone's batteries have failed and that is what caused the headpiece to fail. Or, the original batteries from the phones could have become "spoiled" from being charged on poor quality chargers which are customarily used. Many times these chargers provide inconsistent levels of voltage which could have ruined the battery and in

turn ruined the headset. It is unclear as to the wear and tear on the headset. For example, it could have been dropped, carried around in a pocket, or left out in the sun, but these questions were not asked in this study. We did purchase the lowest cost Chinese made phone available through the telecommunications vendor. Many of the women were unable to keep this phone workable for the full year as it failed. However, it is recommended that low end phones are more suited to low and middle income country mHealth projects due to their affordability. They are also less likely to be stolen (Sanner, Roland, & Braa, 2012).

Women replaced this phone by sharing with a relative or purchasing a new phone. This is congruent with a study done in South Africa where they found a high rate of mobile phone turnover due to damage (Crankshaw et al., 2010). They also found that women were more likely than men to keep their phones turned off for periods of time during the day (Crankshaw et al., 2010). Another study completed in Kenya found that it was normal for many users to turn their phone off during the day to save battery usage, despite the fact that it made them uncomfortable because they might miss important communications (Wyche & Murphy, 2013). In this study turning their phones off during the day was not a finding. However, it was not investigated in this study and would be something requiring further inquiry in future studies.

Mediating Technical Factors

Charging, airtime, and headset failure are interrelated mediated sociotechnical factors that need to be investigated and designed in developing mHealth projects in sub-Saharan Africa. These factors have been discussed generally in many studies that need to be considered. Yet, few have actually examined how these are already used within a community of existing users, let alone HIV infected women in sub-Saharan Africa. The realities of their sociotechnical context and how they interact with their existing mobile phones is different than assuming how they

might be able to use mobile phones for health. These technical findings revealed that a lack of airtime credit was a considerable barrier to the women, not only because it was a limiting factor for their communication but because it impacts the way that they would usually use the phone. In their day-to-day lives in the support group, women make quick calls, they use flashing, or they call the coordinator first and use a call tree type of process. It is unknown whether women in the support group attempted to keep their phones on all the time or if it would have been more of a normal process to keep them off for periods of time if they were not members of the support group. It is uncertain what impact this may have had on the life of the battery and headset as well as their airtime. The infrastructure has a major impact on how the phones are used. That is, electricity is not always available, neither is it reliable. Even for those who had electricity in their homes, there are frequent outages. During my visits to Malawi outages were usually a nightly occurrence. Therefore, in designing a mHealth project assumptions will need to be made and contingencies decided upon with the community as to how important communications will be dealt with if mobile phone devices experience a down time and how charging and replacements will be handled.

Limitations

The results of this study may be limited by the use of only one data collection point for the interviews and focus group. A longitudinal approach would have allowed for more probing and follow up and may have revealed further knowledge about factors such as the women's mediated actions between the mobile phones and airtime, or more specific information on how they used the phones for medication adherence.

This was a cross-cultural study which merits consideration as a limitation. Although I was able to address issues for cultural relevancy, appropriate methodology and analytical validity

with my Malawian professor, limitations due to time constraints and meanings lost in translation may have reduced my ability to capture relevant meanings or interpretations of the data from the interviews or focus group. While these elements were important considerations in understanding the women's stories, a more in-depth ethnographic study and rigorous cross translation procedure would have exceeded the scope of this study. However, all efforts were made to make cross language translation timing and transcription of the recorded interviews and focus group transparent.

Another limitation is that this was conducted in an urban area and did not include women living in rural Malawi who constitute the majority of the population of women in Malawi. Nevertheless, while this was a not a study that looked at the specific needs of rural women in Malawi in relation to mHealth and HIV, the findings from this study could still be transferable to a rural populace.

Policy Implications

Policies for Promoting Use of Mobile Phones for Women's Health in Sub-Saharan Africa

Disparities exist in mobile phone ownership in low and middle-income countries. Women are 21% less likely to own a mobile phone than a man. This increases to 23% for African women, 24% for the Middle East, and 37% if a woman lives in South Asia (GSMA, 2015). Other issues that impact access are lack of time and infrastructure. For example, many rural women have limited or no access to electricity. This creates challenges in charging phones as discussed earlier. Mobile phones are being used to fight poverty by promoting income generation (Futch, 2009). With a mobile phone women can contact a health care provider and receive important information on how to care for sick family members or call to get the best price at market for chickens or crops. Money can safely be transferred via mobile phones (Hughes & Lonie, 2007; Mascarenhas, 2010; Mas &

Morawczynski, 2009). Giving mobile phones to women can be key to influencing the dynamics of poverty and ill health in resource-limited settings. Poor health in resource limited settings cannot only be addressed from a medical pathophysiologic model, it also needs to be understood as a human response to the dynamics of poverty related to the broader socio-economic and political ecosystem. Mobile phones can influence healthcare in resource-limited settings by improving women's social capital in their community and potentially improving their economic situation.

Stakeholders

In this section, I will discuss the stakeholders who would be impacting policy on promoting the use of Mobiles for health in resource limited settings. Examples of stakeholders in this arena at the local community level would be the women using mobiles and their ART clinic where they are followed for the ART medications. These clinic stakeholders are interested in assuring that the patient is adherent to their medications and appointments. The women are interested in income generation and being able to sustainably manage the income generation activities, provide support to their fellow support group members, and also medication and appointment adherence. The church might be sponsoring the women's support group so their leadership would also be stakeholders and be interested in assuring that any program has continued evaluation and monitoring for effectiveness. The Ministry of health structure and entity applicable to caring for this population would also be a stakeholder to provide any program planning and evaluation. For example, if Community Health Workers might be able to be connected to the support group then perhaps clinic visits and transportation time could be impacted. Other stakeholders include other Government, Academics and NGOs that are working on mHealth projects. Currently there is a Malawi mHealth group that meets at least quarterly in Lilongwe to discuss projects and identify synergies. For example, projects benefit from being

able to negotiate as a large group to the telecommunications provider stakeholders such as Telecom Networks Malawi (TNM). TNM is the second largest mobile operator in Malawi with a subscriber base of 1.6 million and a market share of over 42%. TNM covers 74% of Malawi and over 85% of the population. Current efforts of the mHealth Malawi group are to work with TNM to establish NGO based accounts that allow charge backs to many phones being used for delivery of services usually by community health workers. TNM is interested in making a profit and one way to meet their interests is to work collaboratively on a pricing structure for NGO's that will meet all party's needs. Some of the current NGO's involved include: USAID, Management Sciences for Health, Baobab Health, D-tree International, Medic Mobile, UNC, UNICEF, and Village Reach. Broader stakeholders would include the nursing and global public health community as a consumer of evidence in identifying the programs that may work for promoting health for women living with HIV in resource-limited settings. In addition, the engineering and IT community are stakeholders as a consumer of evidence regarding how women use the technology in their day-to-day lives from a human computer interface perspective. Adult education is another area of interest as literacy issues may be identified in this study with recommendations on how to approach them in this population as well as needs to create specific culturally based content. At the government, Ministry of Health officials and potentially the WHO would be interested in evaluative studies that showed an impact on the social determinants of health. All of these entities would be "mapped" as part of the study of who were members of the ecology of the study setting. The main message for policy makers would be to share what works at a micro-community level and to assure that the women's voices and needs are heard by those that fund programs and evaluate the effectiveness of intervention programs for women with HIV/AIDS. Additionally, those that design and market mobile

handsets and software, and those that are interested in continued inquiry in this area would also constitute stakeholders.

Policy Recommendations

Based on the results of this study the following policy recommendations would be disseminated to stakeholders:

1. As part of HIV/AIDS funding include referrals to support groups and partner with NGO's and churches to leverage funding sources and existing community based resources. Include mobile phones and income generation, peer support as part of intervention and group coordinators or case managers that are trained in education around care of persons with HIV.
2. Conduct interdisciplinary research using a social determinants of health framework; looking at upstream structural determinants inclusively such as livelihoods, social capital, as well as other measures and utilization of peer based longitudinal interventions with mobile phones and income generation (interventions used from #1 above) are utilized to determine effectiveness. See measures used by the IMAGE study (Kim, Ferrari, Watts, Hargreaves, Morison Phetla, & Abramsky, 2009; Pronyk, Hargreaves, Kim, Morison, Phetla, Watts, & Porter, 2006) as well as those looking at multilevel and structural interventions (Weinhardt, Galvão, Stevens, Masanjala, Bryant, & Ng'ombe, 2009; Weinhardt, Galvão, Mwenyekonde, Grande, Stevens, Yan, & Watkins, 2014).

Implications for Nursing

Nursing Informatics

This study has implications for nursing informaticians who practice according to the definition of nursing informatics as defined by the American Nursing Association Definition of Nursing Informatics:

Nursing informatics (NI) is the specialty that integrates nursing science with multiple information and analytical sciences to identify, define, manage, and communicate data, information, knowledge, and wisdom in nursing practice. NI supports nurses, consumers, patients, the interprofessional healthcare team, and other stakeholders in their decision-making in all roles and settings to achieve desired outcomes. This support is accomplished through the use of information structures, information processes, and information technology. (American Nurses Association, pp.1-2, 2015)

Community Informatics

Building upon practice in nursing informatics is the nursing informaticians who practices in a community setting. One of the key learnings I had as I went through my graduate studies in community health nursing was selecting a theoretical model for “community” that we would apply in our practice. Most of the theoretical models of community also contain the concept of person. Community informatics is a relatively new discipline of study having to do with physical communities and the design and implementation of technologies and applications that enhance and promote their objective. Community informatics uses information communication technologies (ICT) to “provide resources and tools that communities and members can use for their local economic, cultural and civic development, community health and environmental

initiatives” (Gurstein, 1999, p.2). Applying a community informatics view to this study has relevance for nursing informatics. Although not explicit, the person in a community informatics approach is a citizen imbued with rights and agency and the informatics nurse would be assisting them in utilizing ICT’s, mobile phone technologies for economic, sociocultural, and health initiatives.

Accordingly, based on the findings of this study, from a community perspective the women worked together synergistically and in mutuality. When they were together they were very supportive of one another. Focus group sessions with women with HIV in this population have been noted to be transformative events in other studies (Mkandawire-Valhmu & Stevens, 2010). Others have noted the collective capacity of these groups (Mkandawire-Valhmu, Kako, Kibicho, & Stevens, 2013). According to Ikuenobe (2006), “traditional African societies were founded on the idea of communalism and sustained as a community of shared beliefs and values that transcended the individual person” (Ikuenobe, 2006 p. 53). Therefore, the informatics nurse, when working with an African community on a community informatics project needs to be aware of their highly communal nature. I found that my ideas of personhood that I was brought up with from the west, where independence and individualism tend to be valued and may consequently bias one’s views of a person and how they relate in a community do not fit in the African context. Rather, in this setting a person is more defined by their belonging and relationships in the community. Listening to the community of women’s voices is essential in designing programs to support women with HIV. Additionally, harnessing the power of the community in promoting health in this population seems to be yet untapped. Nursing informaticians who work in sub-Saharan Africa need to work with interdisciplinary teams, and leverage other members of the information technology ecosystem, as well as existing churches

and NGO's to leverage the community structures in promoting needed social support, combating stigma and honoring the resilience and agency in women living with HIV.

Directions for Future Research

There is a lack of nursing informatics studies in sub-Saharan Africa with women with HIV. Future research should look to several areas. Studies that use a community informatics framework with women living with HIV in support groups and identify how the community mediates health with technology, while addressing the technology infrastructure concerns around airtime and charging. Research partnerships should be developed with faith based organizations and NGO's to develop strategies for funding and intervention and evaluation frameworks that are interdisciplinary, holistic, and longitudinal and can capture the voices and at the same time have an emancipatory effect on women living with HIV. Finally, there is an opportunity for further theory development around community health frameworks that are sensitive to the African world view of person and community.

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APPENDIX A: INDIVIDUAL PARTICIPANT INTERVIEW GUIDE

Take notes on what the translator conveys about each individual's answers to these questions:

What benefit if any have you received from having the mobile phone over the past year?

Can you talk about what benefits you might have received from the mobile phone?

Can you give an example?

How has having the mobile phone helped you in taking care of yourself and your health?

How has the mobile phone helped you when you have been ill?

How has the mobile phone helped you with the income generation activities?

APPENDIX B: FOCUS GROUP GUIDE

Introduction: We want to thank-you for meeting with us individually and taking the time to answer our questions. We have been impressed by how you have helped each other and how your income generating activities have been going. You have told us individually about the use of mobile phones. Today we would like to have a discussion with you as a group about the mobile phones, and lessons you have learned as a group.

Open-ended discussion questions:

For those of you who still have your mobile phones what has been the most helpful about having the mobile phone? What has been the most problematic with the mobile phones? What do you dislike most about the mobile phones?

Many of you no longer have your mobile phones. How might we plan/proceed to reduce the chances of losing your phone? Or of phones not working?

One of the things we are interested in is how you are currently using the mobile phones to communicate with each other. Many of you spoke about flashing each other. Can you give some examples of how you use flashing to communicate with each other? For example do you use this when you want another group member to call you? How important has that been? How have you used the mobile phone capacity/kwacha/time?

Can you talk about what your lives were like before the mobile phones? What if anything has changed since you have the mobile phones?

For those of you that used the text message function on your phone what kind of messages do you send to each other? We are thinking of making some preconfigured templates of common messages for you and would like to know which may be most helpful. If we were to do a class on how to do use phones what would you like to cover? Are there things you would like to know more about in relation to the mobile phones?

Many of you have discussed how the mobile phones have helped you feel more connected and that having the ability to communicate with each other has helped the support group. Can you provide some examples where the mobile phones have been particularly helpful in your life? For example, for helping you stay healthy? What about when you have been ill?

How have the phones helped you to take your daily ART medications?

Is there anything else that anyone feels that we should discuss in relation to this project?

Thank-you for your participation in this discussion

APPENDIX D: MALAWI MINISTRY OF HEALTH APPROVAL FOR RESEARCH

Telephone: + 265 789 400
Facsimile: + 265 789 431

All Communications should be addressed to:
The Secretary for Health



In reply please quote No. MED/4/36c

MINISTRY OF HEALTH
P.O. BOX 30377
LILONGWE 3
MALAWI

January 18, 2013

Linda Dietrich
University of Wisconsin Milwaukee

Dear Mrs. Dietrich,

Subject: Request to Use existing Monitoring and Evaluation HIV Support Group Data for Soche Baptist Church

Thank you for submitting your letter for exemption to the National Health Sciences Research Committee (NHSRC). Your request was evaluated in light of the regulations that govern the protection of human subjects. We have determined that your proposed project employs surveys and use of monitoring and evaluation data that pose no more than minimal risk to participants since the information was obtained in such a way that one's responses will not be linked to one's identity or identifying information. Moreover, accidental disclosure of the participants' responses would not have the potential to harm the person's reputation, employability, financial status, or legal standing. For these reasons, the NHSRC has determined that your proposed study is exempt from further review.

For *any* proposed changes in your utilization of this data, please submit a Request for Modification letter to the NHSRC. Please be aware that changes to the use of this monitoring and evaluation data may prevent the research from qualifying for exempt review and require submission of a new NHSRC application or other materials to this office.

If you have additional questions or require clarification of the contents of this letter, please contact me

For: Chairman, National Health Sciences Research Committee

National Health Sciences Research Committee
Ministry of Health
PO Box 30377
Capital City, Lilongwe 3, Malawi

CURRICULUM VITAE

Linda Dietrich MSN, RN-BC

Education

- **Current**, University of Wisconsin-Milwaukee PhD Nursing (expected graduation Dec 2016)
- **2007**, University of Colorado, Denver, Colorado/Post Masters Certificate in Nursing Informatics
- **1991**, (Aug) University of Portland, Portland, OR, Master of Science Community Health Nursing
- **1991**, (May) University of Portland, Portland, OR, Bachelor of Science, Nursing/ADN to MSN program
- **1979**, Gateway (Mesa) Community College, Phoenix, Arizona, Associate Degree, Nursing

Dissertation Title: The Utility of Mobile Phones for Health Among Women Living With HIV In Urban Malawi

Other: 2012, Biomedical Informatics Fellow National Library of Medicine at the Marine Biological Laboratory, Woods Hole Massachusetts May 27 – June 2, 2012

Professional Experience

- **Mar 2015 – current** Consultant, Independent, Quality and Informatics Portland, OR,
- **Sep 2015 - Jul 2016** Patient Safety Specialist OR Health Sciences University Hosp Portland, OR
- **Mar 2014 - Mar 2015** Senior Clinical Lead. Deloitte Canada, Clinical Systems Transformation Project Vancouver, B.C.
- **Mar 2013 - Mar 2014** Interim Leader, B.E. Smith, Lenexa, Kansas. Director Clinical Transformation, Ascension Health , St. Louis, MO
- **August 2012 - August 2013** University of Colorado College of Nursing Denver, Colorado. On-Line Instructor Graduate level Systems Analysis & Design Course with Dr. Diane Skiba
- **Jul 2010 - Jul 2012** Director, Clinical Applications & Informatics UCH, Colorado Springs, CO
- **Apr 2009 - Jul 2010** SmartNurse Inc., President. Portland, OR, Informatics Consulting
- **Aug 2007 - Oct 2008** Chief Nursing Informatics Officer Palomar Pomerado Health, San Diego, CA
- **May 2005 - Jul 2007** Clinical IT Consulting System selections, ROI, Strategy, Optimization
- **Feb 2003 - May 2005** Healthlink Inc., Houston, Texas, Senior Consultant Advisory Services
- **Nov 1998 - Feb 2003** Cerner Corp, Kansas City, Missouri, Cerner Consulting
- **May 1998 - Nov 1998** One Health Plan of OR/Great West Life, Portland, Director of QM/UM
- **Sept 1997 - May 1998** Alternare Group and Resources Select, Portland, OR, CM, UM, DM
- **Aug 1993 - June 1997** Kaiser Sunnyside Hosp, Portland, OR, Dir Professional Practice & Quality
- **Sep 1991 - Aug 1993** Bess Kaiser Hosp, Portland, OR, CNS Med/ Surg. Periop, Ortho, & Oncology
- **Sep 1989 - Sep 1991** St. Vincent Hosp & Medical Center, Portland, OR Assistant Director of Nrsng
- **Aug 1984 - Sep 1989** Asante Community Hosp, Grants Pass, OR, Director Med/Surg & Pediatrics
- **Apr 1982 - Aug 1984** Coral Reef Hosp, Miami, Florida, Charge Nurse 13 bed ICU/CCU
- **Dec 1979 - Jan 1982** Maricopa County Hosp, Phoenix, AZ, RN, Level 1 Trauma ED, Burn Unit, & Surgical ICU

Publications

Contributing author (2015) American Nurses Association *Nursing Informatics Scope and Standards of Practice: Second Edition*. The American Nurses Association, Silver Spring Maryland.
<http://www.nursesbooks.org/Main-Menu/Standards/Nursing-Informatics-2nd-Ed.aspx>

Dietrich, L. (2006) Transforming Clinical Documentation: Preparing Nursing for Change, Appendix F. page 327-333, in *Introduction to Nursing Informatics*. Hannah, Kathryn J.; Ball, Marion J.; Edwards, Margaret J.A. (Eds.) Edition: 3. Springer

Rothschild, A., Dietrich, L., Ball, M., Wurtz, H., Farish-Hunt, H., Cortes-Comerer, N. (2005) Leveraging Systems Thinking to Design Patient-Centered Clinical Documentation Systems. *International Journal of Medical Informatics*. 74, 395-398

Dietrich, L., Rothschild, A., and M.J. Ball (March 16, 2005) Patient-Centered Clinical Documentation: Problem-Driven electronic health records can help defragment healthcare. *Healthcare Informatics Extra on-line*

Dietrich, L. (1992) The Caring Nursing Environment. pp. 69-87 Gaut, D., (Ed.) *Nursing Practice: The Presence of Caring*. National League for Nursing Publication #15-2465.

Presentations

American Nursing Informatics Association National Conference. Parlez-vous Informatics? Speaking the Language of Informatics to Improve Patient Care. Paris Las Vegas Hotel and Casino • Las Vegas, NV • March 18, 2014. American Nurses Association – Nursing Informatics Scope and Standards Revisions. Linda Dietrich, MSN, RN-BC, PMP, CPHQ; Leigh Ann Chandler Poole, PhD, CRNP, FNP-BC, RN; Troy Seagondollar, MSN-I, RN-BC, CPHIT, CPEHR.

The Use of Cell Phones for Health Support by Women with HIV in Sub-Saharan Africa: A Community Informatics Case Study: Poster Presentation, Linda Dietrich, MSN, RN PhD student University of Wisconsin College of Nursing, Milwaukee, Wisconsin, USA. *Sigma Theta Tau 24th International Nursing Research Congress*, Prague, the Czech Republic. July 22-26, 2013

Using SMS Messaging to Enhance the Capacities of an HIV Support Group in Malawi: Poster Presentation, Linda Dietrich, MSN, RN PhD student & Pat Stevens, RN, PhD University of Wisconsin, Milwaukee, Wisconsin, USA. *NI 2012: 11th International Conference on Nursing Informatics*, Montreal, Canada. June 23-27th, 2012

Strategies to improve adoption of nursing information technology: A nursing informatics and nursing leader Partnership, May 23, 2007, *Informatics Across the Spectrum: American Medical Informatics Association Spring Congress*, Orlando, Florida (poster)

Avoiding The F-Word: IT Project Morbidity, Mortality, and Immortality: *AMIA Symposium Fall 2006*. Co-presenter

Implementation of the Electronic Health Record: Creating an Infrastructure to Support Successful Implementation and Improve Care. November 9, 2006, *Emerging Trends in Healthcare Technology: How Patients Can Benefit*, Tacoma, Washington

Nurses' Attitudes about Computers: A Study. October 15, 2005, *77th Convention and Exhibit, American Health Information Management Association: At the Edge of the Sea on the Brink of the Future*, San Diego, California

Certifications

- National Association for Healthcare Quality: *CPHQ certified*
- American Nurses Credentialing Center: *Certified Informatics Nurse*
- Project Management Institute: *PMP certified*
- HFMA/AONE *Certificate in Healthcare Finance*

Affiliations

- Midwest Nursing Research Society
- Western Institute of Nursing
- National Association Healthcare Quality
- American Nursing Informatics Association
- Oregon Public Health Association, Nursing Special Interest Group
- Healthcare Information Systems Society, Portland, Oregon Chapter
- American Medical Informatics Association - Nursing Informatics Working Group
- Project Management Institute, Portland, Oregon Chapter
- Sigma Theta Tau, Beta Psi; Eta Nu; Omicron Upsilon; Alpha Kappa-at-Large Chapters
- American Nurses Association