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Hearing the Voices of HIV Positive Women in Kenya: Secondary Analysis of Interview Data Using Dialogic/Performance Analysis

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HEARING THE VOICES OF HIV POSITIVE WOMEN IN KENYA:
SECONDARY ANALYSIS OF INTERVIEW DATA USING
DIALOGIC/PERFORMANCE ANALYSIS

By

Lenore L. Boris, JD, MS

A Dissertation Submitted in

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May 2015

ABSTRACT
HEARING THE VOICES OF HIV POSITIVE WOMEN IN KENYA:
SECONDARY ANALYSIS OF INTERVIEW DATA USING
DIALOGIC/PERFORMANCE ANALYSIS

by

Lenore Boris

The University of Wisconsin-Milwaukee, 2015
Under the Supervision of Professor Patricia Stevens

The purpose of the study is to demonstrate the use of the dialogic/performance methodology in health research by conducting a secondary analysis of interview data collected from women in Kenya who are HIV positive. Dialogic/performance analysis is a dynamic, interpretive narrative analytical technique. Qualitative research literature inadequately provides specific methodological guidance especially when reusing a data set. Further, the use of the dialogic/ performance method is very limited in health research. These factors point to the significance of this work in explaining dialogic/performance analysis thereby potentially expanding its use by both novice and experienced qualitative researchers. Guidance for conducting a qualitative health research study using dialogic/performance analysis is provided through a critical review of selected studies and an explanation of how this method was applied to the interviews of these women. Skeptics of qualitative secondary analysis question whether methodological challenges can be overcome sufficiently to produce research studies that are trustworthy, sound and meaningful. A secondary intent of this research is to illustrate how methodological issues/concerns related to conducting a qualitative secondary analysis are addressed in the context of using dialogic/performance analysis of narrative data. A discussion of challenges such as context, researcher presence, suitability of data

set and other concerns are addressed through a discussion of how these concerns were resolved in this analysis of the interviews. Finally, the actual findings from conducting this analysis are presented. The analysis shifts the perspective from an exploration of what the researcher wants to know to giving opportunity to hear the voices of these HIV positive women as they tell their stories of the impact of an HIV-positive diagnosis on their identity and lives.

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This study reflects the many voices of the people who shaped my thinking and influenced the work presented here. Most prominent are the voices of the women in Kenya who agreed to share their stories. I serve as a proxy to tell their stories to a wider audience; an audience they probably otherwise could not access. There are the voices of my dissertation committee, Drs. Timothy J. Ehlinger, Penninah Kako, Lucy Mkandawire-Valhmu, and Bev Zabler who provided feedback and guidance to this effort. In particular, the wisdom and insights of Dr. Patricia E. Stevens, my major professor, is evident as she gently guided me in a direction that culminated in this research. I thank them all for their participation and guidance in this journey.

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Chapter 1

Introduction

Qualitative data analysis has been described as “particularly mysterious” (Bradley, Curry and Devers). Speaking more specifically about methods used in secondary analysis, L. Bishop states that “though secondary analysis of qualitative data is becoming more prevalent, relatively few methodological studies exist that provide reflection on the actual, not idealized, process”. This is echoed by other researchers who note the growing interest in secondary analysis of qualitative data but note the scarcity of information about the process of performing secondary analysis as publications emphasize outcomes rather than method (Long-Sutehall, Sque and Addington-Hall).

The techniques available for qualitative data analyses are numerous but “most researchers are unaware of the numerous accessible choices of qualitative analyses” (Leech and Onwuegbuzie). Leech and Onwuegbuzie assert “textbooks that describe qualitative data analysis techniques tend to focus on one data analysis technique or, at best, only a few techniques” and they urge researchers to broaden their understanding and use of qualitative techniques.

This paper seeks to fill the void of studies of the actual process of doing qualitative research, especially secondary analysis, by demonstrating a narrative analysis technique that is infrequently used in nursing. The dialogic/performance narrative

analysis method will be explored in a secondary analysis of data from a study of HIV positive women in Kenya. A dialogic/performance analysis offers a method for optimizing the use of collected data, in particular that data which seems to be extraneous or insignificant in light of the research question, compilation of findings or emerging theory. More importantly, an exploration of the actual process of applying this form of analysis, particularly in the context of a secondary analysis, can provide guidance for qualitative researchers who want to expand the data analysis methods they use.

Problem

There is a lack of studies demonstrating the actual process of using a specific methodological technique in conducting qualitative research. In particular, there is a paucity of research in nursing using the dialogic/performance method of narrative analysis and no research that describes how an investigator would actually employ this method in conducting health research especially in the context of a secondary analysis of interview data. This lack of examples of the actual implementation of the dialogic/performance analytical method in the context of a secondary analysis potentially dissuades use of this method in nursing research.

Commentators speak in general to this problem. Qualitative secondary analysis has been spoken of as an “invisible enterprise for which there is a notable silence amongst the qualitative research community” (Gladstone, et.al.). Miles and Huberman lament the fact there continues, since first noting this issue in 1984, to be a paucity of studies examining the actual process of doing qualitative research. They assert textbooks address hypothetical cases or fragments of empirical work or provide lists of tools for interpreting data within methods sections of the text. Additionally, research studies are

vague about the actual process employed with an analytical technique. “This inattention to the process of doing qualitative research is not a trivial issue. It leads to reports that strain the credulity of the research community; leaves graduate students at a loss when they undertake empirical, mostly non quantitative work in the field; blurs the distinctions between robust and fanciful methodologies, fogging the real import of the findings” (Miles and Huberman).

The problem is framed in the literature as a general statement of the lack of methodological guidance in the use of qualitative analysis techniques especially when conducting secondary analysis. Gladstone et al (2007) assert, “There is little guidance focused on the process of conducting qualitative secondary analysis.” This study narrows the general problem of lack of methodological guidance in qualitative research to a focus on the lack of guidance in describing and assessing the use of the dialogic/performance method of narrative analysis in the course of a secondary analysis.

Significance

A position (such as that taken in this endeavor) that explores the methodological details of a specific qualitative analytical approach in the context of a secondary analysis and generally advocates for expanded use of qualitative research methods especially in the context of a secondary analysis is significant for a number of intertwining reasons. The explanation of the significance of this work includes matters of a practical nature in executing qualitative research as well as enhancements to the quality of qualitative research and the building of health related knowledge.

Although the dialogic/performance method of analysis is used to illustrate how this qualitative analytical tool can be used in secondary analysis in a nursing qualitative

research project, the significance of this work is broader than any specific qualitative analytical method. The significance of this work directly relates to expanding the availability of qualitative analytical tools, in this case, as it applies to studies involving the reuse of interview data of people with a chronic illness. As such, the significance of this work is described in terms of conducting secondary analysis i.e. why the use of secondary analysis can and should be expanded; indeed would potentially expand, if researchers had a bigger toolbox of qualitative analytical tools including the dialogic/performance analytical method.

Cost and challenges of doing qualitative secondary analysis research

The benefits of secondary research are often purported to be related to practical considerations of cost effectiveness, efficiency, convenience and time and/or money savings (Castle, 2003; Windle, 2010). For faculty researchers, the competing demands of teaching and research (including the search for external funding) may lead to a decision to use existing data rather than embarking on new data collection (Irwin and Winterton, 2011). The availability of a larger number of participants in an existing database may be preferable to collecting primary data from a smaller sample (Windle, 2010). The difficulties of reaching elusive populations because of geography or the rarity of the phenomena of interest is another benefit of secondary analysis (Long-Sutehall, Sque and Addington-Hall, 2010). A reexamination of data from a different research perspective can generate new findings (Savage, 2005; Bornat, 2010). Further intrusions of a hard to reach population or on a sensitive topic can be avoided in a secondary analysis (Gladstone et al, 2007). Secondary analysis can provide rich descriptive information (Bornat, 2005; Bishop, 2007).

Doubtless other advantages may drive an interest in conducting a secondary analysis. For example, limitations in conducting the primary study can prompt a secondary analysis. So too may factors either unknown at the time of the original research or external to the research dictate the desirability of a secondary analysis. “Often the possible value of a data set for secondary analysis may not be known until after the primary study has been completed and the researchers identify additional phenomena in the data set that are not represented in the study findings” (Hinds, Vogel and Clarke-Steffen, 1997, p. 414). The use of data collected for a primary study to teach students research techniques is recognized and represents another type of external driver in the use of secondary analysis (Windle, 2010).

While these examples and common sense would suggest that the ability to reuse data provides cost savings and time efficiencies, the efficiencies of reusing data should not be overestimated (Bishop, 2007). More significantly, practical considerations of efficiencies should not dictate the choice of methods (Irwin and Winterton, 2011). Nevertheless, secondary analysis can offer some significant advantages to conducting a primary study.

Missing Important Information

“Researchers often collect more data than they are able to address” (McArt and McDougal, 1985, p. 55). While this comment is dated, it remains relevant today and, arguably, with the advent of new technologies for data collection and analysis, the amount of data collected but not addressed has increased. Further, every investigator, whether undertaking quantitative or qualitative research, has encountered the situation of obtaining data the significance of which is suspect or unknown. This excess of data

creates at least two problems that can contribute to missing important information that can expand understanding of a phenomenon.

The first problem is the disconnect between the data collect and analyzed but which does not ultimately find its way into the final study results. As described by Long-Sutehall, Sque & Addington-Hall (2010) “most studies using interviews as a method of data collection generate narratives that are extensive in relation to the discourse taking place. It is therefore reasonable to expect that there will be a certain amount of data that, whilst being analyzed, will not contribute to the final outcome of the research.” (p. 342)

The second problem is related but slightly different. This problem involves the omission of interesting and/or important data because it does not relate to the study purpose or findings. “However, as part of the data management and analytical processes, qualitative researchers selectively sample and analyze the resulting data. Often, interesting and potentially important data are not considered in the final analysis because they do not directly address the purpose of the study or contribute to the emerging pattern, description, or theory.” (Hinds, Vogel and Clarke-Steffen, 1997, p 411)

Secondary analysis is acknowledged as a way to investigate new or additional research questions using an existing data base (Heaton, 2008). New findings can be generated by examining the data through a new research context or from a different point of view (Irwin and Winterton, 2011). The use of an analytical method different from that used in the original research, in this case a dialogic/performance method, can assist in examining the data with a fresh perspective rather than simply verifying the prior findings by utilizing the same analytical technique and retracing the work of the original investigator.

Understanding Facilitates Work with Other Researchers

Examining data from across disciplinary perspectives can aid in the understanding of a phenomena that is of interest to investigators of various academic backgrounds. “Greater understanding of the processes of qualitative data analysis can be helpful for health services researchers as they use these methods themselves or collaborate with qualitative researchers in a range of disciplines” (Bradley, Curry and Devers, 2007, p. 1758). The dialogic/performance analytical method is not unknown in nursing but is found in greater use in the social sciences. Therefore, nurse researchers who develop a facility in the use of this method and with secondary analysis in general, are better positioned to participate in cross disciplinary research.

Medical Research Needs Diversity that Comes with Using Different Approaches

Malterud (2001, p. 483) noted that “qualitative research is still regarded with skepticism by the medical community, accused of its subjective nature and the absence of facts.” Arguably, some nurse researchers share this view. Persons providing health care, however, encounter issues related to the psychosocial, spiritual, familial and other social science considerations that impact a patient’s health. Chapple (1998) encourages physicians to consider research using qualitative methods pointing out that this type of research can contribute to improved patient centered care – an objective even more significant in light of current health care reforms. Bradley, Curry and Devers (2007) broadly describe practical approaches in the application of qualitative data techniques that they believe are most appropriate for conducting health services research. Unfortunately, they focus extensively on coding methodology to the exclusion of other qualitative analytical methods.

Speaking specifically to doctors but also with clear implications for nursing, Malterud (2001, p. 487) reminds us that “no research method will ever be able to describe people’s lives, minds, and realities completely though, and medical doctors should be reminded that scientific knowledge is not always the most important or relevant type of information when dealing with people.” Increasingly, nursing and medicine are acknowledging the value of research that combines quantitative and qualitative methods. Secondary analysis adds even further to the knowledge base that develops using different approaches in an examination of health related phenomena.

Improve Quality

“By using multiple types of data analysis and, thus, triangulating the results of a qualitative study...the results will be more trustworthy and, as a result, more meaningful.” (Leech and Onwuegbuzie, 2008, p.602) Thus, the more analytical tools the qualitative researcher has in their repertoire; the possibility of more trustworthy and/or more meaningful findings is improved. Expanding ones understanding and use of both secondary analysis and dialogic/performance analysis facilitates the development of alternate methods of data analysis that can therefore help improve the quality of qualitative research.

Purpose

The purpose of this paper is to demonstrate the use of the dialogic/performance methodology in a secondary analysis of interview data. Secondly, the intent is to show how this technique can augment findings derived from the same data set using another qualitative analytical technique.

Research Objectives

This study has as its aim the following objectives:

1. Illustrate the actual methodology used in conducting a dialogic/performance analysis of interview data.
2. Explore the strengths and limitations of the dialogic/performance method of narrative analysis within the context of a secondary analysis.
3. Demonstrate the viability of a secondary analysis using a dialogic/performance method to optimize the use of interview data and shift the perspective of the research from that of the researcher to that of the research participant.

Any interview data could have been used to meet the objectives of this study. The ready availability and willingness of the principal investigator to share access to transcripts of interviews with HIV positive women from Kenya led to the use of interviews on this particular topic. In the course of working with the transcripts to demonstrate the dialogic/performance method of analysis in a secondary analysis, insights into the experience of HIV positive women in Kenya is inevitable. These findings are presented in Chapter 4. There is no intent to compare these insights to the original study using this data or necessarily to other studies that explore the HIV experience of African women. That can be left for another project. The focus of this effort is on demonstrating the use of dialogic/performance analysis in a secondary analysis of interview data.

Assumptions/Definitions

This study is premised on one basic assumption i.e. that secondary analysis is a valid method of conducting qualitative research. While some of the challenges of conducting secondary analysis using the dialogic/performance method on interviews with HIV

affected Kenyan woman will be explored, the intent in this writing is not to dissect, refute or support the overall merits of conducting secondary analysis. The overall merits of secondary analysis are accepted while highlighting the strengths and limitations of using a specific narrative analytical technique in a secondary analysis of interview data.

A simple, basic definition of secondary analysis is used. Secondary analysis is defined as the use of existing data collected for a prior study to answer research questions (Heaton 1998; Doolan and Froelicher, 2009).

The terms ‘original study’ and ‘primary analysis’ are used to reference the study for which the data was initially collected. The investigator who conducted the study for which the data was originally collected (i.e. the original study or primary analysis) is herein referred to as the original researcher or investigator or primary analyst.

The definition of dialogic/performance analysis used in this work is “a broad and varied interpretive approach to oral narrative” (Riessman, 2008, p. 105). Riessman explains that this approach uses elements of thematic and structural analysis but adds other elements. Some authors use or discuss dramaturgical analysis (Hays and Weinert, 2005) and others advocate for dialogic narrative analysis (Frank, 2005). These methods share some of the same underlying theoretical basis but do not appear to be as broad or interpretive as the dialogic/ performance analytical approach which combines elements of both.

Methods

A qualitative study involving a secondary analysis of interview data examined the experiences of HIV-infected women in Kenya was conducted using a narrative analysis technique termed dialogic/performance analysis. An explanation of the development of

the dialogic/performance approach to studying human behavior is provided. Additionally, a condensed discussion of the concerns involved in secondary analysis helps frame the issues involved in demonstrating the strength and weaknesses of conducting a secondary analysis of interview data using dialogic/performance analysis.

Sample

The sample for the secondary analysis was provided by the principal investigator of the original study. The secondary analyst did not obtain information about the sampling methodology in the original study. Data from forty-seven participants supplied to the secondary analyst was used in the secondary study rather than focusing on a sub-sample of the larger group. No effort is made to impose additional selection criteria or address a subgroup of the original study participants. The characteristics that link the study participants for the purposes of the secondary analysis are the fact they are all women, HIV-infected and living in Kenya. These commonalities are sufficient to explore the research questions. Other known demographic characteristics add information about the context of the women telling their story and are considered in the identification and analysis of the women's words in shifting the perspective to the picture of themselves and what is important to them.

A brief summary of the characteristics of Kenya is provided here to help situate the women's words about their lives. Kenya is an east African country that borders the Indian Ocean and is surrounded by Ethiopia and Somalia to the north, South Sudan and Uganda to the west and Tanzania to the south. The climate varies from tropical along the coast to arid in the interior. Less than 10% of the land is arable although the Kenyan

highlands form one of the most successful agricultural regions in Africa. Recurring drought or, in the rainy season, flooding are problematic.

Kenya achieved independence from the British in 1963. A political system with three branches consisting of executive, legislative and judicial functions was established. The political history is marred with violence and fraud especially during the 1990's and again in 2007 when more than 1500 people died as a result of violence that broke out after charges of vote rigging. Kenyans overwhelmingly voted in favor of a new constitution in 2010 which introduced more checks and balances of executive power. The current President was elected by popular vote in 2013.

Kenyans belong to numerous ethnic groups including Kikuyu, Luhya, Luo, Kalenjin and Kamba with only 1% of the population comprised of non-African peoples. The official languages are English and Kiswahili although there are numerous indigenous languages. Christianity is the religion of 82% of the population with Protestants outnumbering Catholics 2:1. Eleven percent of them are Muslims. More than 87% of the population is literate. School life expectancy is 11 years for both males and females. The population has a median age of 19.1 years with almost 94% of the population under the age of 55.

Life expectancy at birth is estimated at 63.52 years. The risk of infectious disease is high. Primary risks include bacterial and protozoal diarrhea, hepatitis A, typhoid fever, malaria, dengue fever, Rift Valley fever, schistosomiasis and rabies. The country is ranked fourth in the number of people living with HIV. Just over 6% of the people, more than 1.6 million are living with HIV resulting in more than 57,000 deaths in a year. The

high level of mortality due to AIDS impacts health statistics such as higher death rates, lower population growth, lower life expectancy and changes in the distribution of population by age and sex.

The shift to urbanization is occurring at an estimated rate of more than 4% a year yet only 24% of the population is found in urban areas concentrated in two cities Nairobi and Mobassa. The labor force works primarily in agriculture (75%) with the remainder in industry and services. The economy has suffered from corruption and reliance upon several primary goods whose prices have been low. The low investment in infrastructure has further undermined Kenya's position as the largest East African economy. The lack of fixed telephone lines dramatically increased mobile phone use with a 65% teledensity. Ninety three percent of roads are unpaved. Recent terrorism events compromise the important tourism industry. The unemployment rate is high at 40% and an estimated 43.4% of the population lives below the poverty line. The per capita GDP is about \$1,800 in contrast to the United States \$52,800. The Kenya schilling is valued at 92.1195 to the US dollar (2015).

Data Collection/Procedures

The principle investigator in the original study provided translated interview transcripts to the secondary research investigator. Fifty-four women participated in the original research. The women were interviewed 1-3 times for a total of 123 interview transcripts although not all transcripts were available to the secondary researcher. Some of the transcripts contained very brief field notes. In addition to the transcripts, the secondary investigator was provided an Excel sheet delineating the women's age, marital status,

number of children, number of years since diagnosis, monthly income, education (years of schooling) and site (urban or rural).

Ethical Considerations

Institutional Review Board approval was sought. The data provided by the investigator in the original research was de-identified. A determination was made that the use of previously de-identified data is a secondary analysis did not require IRB approval. The complementary character of the primary and secondary research questions and the preservation of the intent of the original study provide further support that ethical issues were adequately addressed.

Data was shared electronically between the primary investigator and secondary investigator and stored on a dedicated USB drive accessible only to the secondary investigator.

Dialogic/Performance Analysis

The works of two major intellectuals of the 20th century, Mikhail Bakhtin and Erving Goffman, figure prominently in the development of the dialogic/performance method of narrative analysis. The dialogic understanding from Bakhtin and the performative concepts of Goffman's work are merged into one analytical technique in dialogic/performance analysis. Bakhtin's influence is less overt than that of Goffman but is fundamental to an understanding of how language shapes the development of narratives. An adherence to the dramaturgical metaphor, while useful, nevertheless involves the artificial application of a frame work borrowed from the theater as Goffman noted (1959). A more expansive interpretation of Goffman's work on identity and social interaction using a dramaturgical metaphor combined with Bakhtin's ideas on language is

evident in Riessman's discussion of dialogic/performance analysis in her book *Narrative Methods for the Human Science*.

Riessman, a sociologist, introduces "what I am calling dialogic/performance analysis" (p.105) perhaps the first delineation of this narrative analysis method of qualitative research. Riessman (2008) offers the most comprehensive explanation of dialogic/performance analysis. Dialogic/performance analysis is defined as "not equivalent to thematic and structural {narrative analysis}, but rather a broad and varied interpretive approach to oral narrative that makes selective use of elements of the other two methods and adds other dimensions" (p. 105). Structural and thematic narrative analysis explore "what" is spoken and "how"; dialogic/performance analysis explores the "who", "when" and "why". Dialogic/performance analysis examines to whom a person is talking and for what purpose are they engaged in conversation (Riessman, 2008).

Riessman (2008) uses three exemplars, her own work and the work of two other researchers, to demonstrate the use of the dialogic/performance approach. It is not clear if, at the time of their original research, any of the authors were knowingly or intentionally using a dialogic/performance analytic method. However, Riessman (2008) uses the exemplars because they "share a general thematic interest – the construction and performance of identities" (p.137). Riessman's own work involved the identity of a man disabled by illness and no longer able to work. She also highlights the work of psychologist Lyn Brown (1998) who examined the schooling experiences of white preadolescent girls from two culturally different rural communities. The last exemplar is the work of Karen Gallas (1994), a teacher/researcher who explores "sharing time" in a socioeconomically and racially diverse classroom.

The exemplars are examined in terms of the definition of narrative used, unit of analysis or focus, attention to contexts, and how the data is represented. Wide variations exist. The definition of narrative is not defined, narrow or expansive. The focus is on an individual or a group. The attention to context is little or extensive focus on local context and limited to considerable attention to the societal context. As Reissman (2008) concludes, “Variability is the rule, for future investigators will not find a similar toolkit of research practices, but instead a range of perspectives adapted for different aims” (p.138).

But to understand the methodology of dialogic/performance analysis it is necessary to understand the commonalities that led Reissman to select these studies as exemplars of this technique. Reissman (2008) points to two major principles of the dialogic/performance method. The researchers do examine language and narrative style albeit for different purposes. In doing so, the voice of the investigator and the subjectivity they bring from their own experiences are heard. Reissman (2008) summarizes the principle “investigators carry their identities with them like tortoise shells into the research setting, reflexively interrogating their influences on the production and interpretation of narrative data” (p.139).

The second principle acknowledges that the context in of the interview is a significant component of the analysis of data. “Meaning in the dialogic approach does not reside in a speaker’s narrative, but in the dialogue between speaker and listener(s), investigator and transcript, and text and reader” (Reissman, 2008, p. 139). The broader context of society, history, politics, education and the like provide a background for understanding the meaning embodied in the interview and, in Reissman’s (2008) opinion, “Is a great strength of the dialogic approach” (p.139).

To fully understand dialogic/performance analysis it is necessary to explore the theoretical underpinnings. These include briefly exploring the symbolic interaction perspective as a precursor to understanding the performative and identity work of Goffman and a cursory examination of some of the key concepts of Bakhtin. Additionally a few examples of how the work of both these men is used in health research is provided.

Symbolic Interaction Perspective

The origins of the dialogic/performance analytic method can be partially traced to the work of Erving Goffman, a sociologist. His work was conducted during a period in sociology heavily influenced by the emergence of a perspective termed symbolic interactionism. To fully appreciate the origins and development of the dialogic/performance analytical method a few words should be said about symbolic interactionism.

Symbolic interactionism is a major branch in the field of sociology. Research based on this perspective has made major contributions in the areas of social coordination theory, sociology of emotions, social constructivism, and self and identity theory to name a few (Fine, 1993). A precise description is difficult to pinpoint because of the various strands of theoretical and empirical work but scholars ground the theory in the core principles articulated by Herbert Blumer, as early proponent of symbolic interactionism. The three core principles are:

- "Humans act toward things on the basis of the meanings they ascribe to those things."
- "The meaning of such things is derived from, or arises out of, the social interaction that one has with others and the society."

- "These meanings are handled in, and modified through, an interpretative process used by the person in dealing with the things he/she encounters." (Blumer, 1969, p. 2)

Symbolic interactionism is a framework for studying people's interactions with each other and in the broader context of society by an examination of the meaning of symbols i.e. something that creates meaning. There are five central ideas generally recognized in symbolic interactionism:

1. People are social beings constantly in search of social interaction. Social interaction, the activities between individuals that shape who we are and shape our society, is the focus of symbolic interactionism. Interactions are mediated through the use of symbols.
2. People are thinking beings. Our interactions are not simply the result of conditioning or the influence of others. People engage in an ongoing dialogue with themselves even as they interact with others because we constantly are engaged in thought.
3. People define their environment as a consequence of social interaction and ongoing thought rather than directly sensing the situation they are in.
4. Human action is the result of current thinking, current interactions in our present situation. The past may influence actions because people think about the past and apply the past to the definition of the present situation but action still takes place as a result of what is occurring in the present.
5. People are actively involved in what they do in relation to their environment. In symbolic interactionism, passive interaction with the environment as signified by

words such as conditioning, responding, controlling, imprisoned or formed are not used. (Charon, 2009)

Symbolic interactionism developed in the early 1900. Goffman supposedly disavowed any affiliation with symbolic interactionism (Scheff, 2005). Scholars examining Goffman's body of scholarly work have firmly asserted Goffman's place as a symbolic interactionist (Barnhart, 1994; Snow, 2001; Scheff, 2005). Given the contemporaneous development of symbolic interactionism and Goffman's work and Goffman's prominent role within the profession of sociology, Goffman was undoubtedly influenced by the ideas and debates surrounding the development of symbolic interactionism.

Dramaturgical Metaphor

“All the world's a stage,

And all the men and women merely players:

They have their exits and their entrances;

And one man in his time plays many parts”

As You Like It by William Shakespeare

The performance aspect of dialogic/performance analytical method is a prominent feature in the work of Erving Goffman. Goffman is considered one of the most influential sociologists of the twentieth century contributing to social theory through his work in symbolic interaction utilizing a dramaturgical metaphor. Goffman conducted fieldwork for his doctoral studies in the Shetland Isles off the coast of Scotland examining the daily interactions of island residents and their place within the social context of the island. Goffman examined the everyday mundane social details of people's social interactions.

The work became the basis for his seminal book *The Presentation of Self in Everyday Life* (Goffman, 1959).

In this book, Goffman (1959) conducted a microsociological analysis to explore the details of individual identity, group relations and the transfer and meaning of information within an environment (Barnhart, 1994). Goffman (1959) believed individuals are involved in the exchange of information about themselves. One person seeks to acquire information about the other person and to convey or control information about themselves that is made known to the other person. We seek information about the person's social status, character, experience, etc. just as they are desirous of developing an understanding of us. As Goffman (1959) explained in the introduction to *The Presentation of Self in Everyday Life*, information may be sought as an end in itself but more often "there are usually quite practical reasons for acquiring it" (p.1). The value of the information exchange "helps to define the situation, enabling others to know in advance what he will expect of them and what they may expect of him. Informed in these ways, the others will know how best to act in order to call forth a desired response from him" (Goffman, 1959, p. 1).

Goffman (1959) asserts that individuals wish to control the impression others have of them (p.3). Their objective in controlling others impressions may be to ensure a harmonious relationship, impress others, defraud others, confuse, insult or provide any other impression that may serve their purpose. Thus "regardless of the particular objective which the individual has in mind and of his motive for having this objective, it will be in his interests to control the conduct of others, especially their responsive treatment of him" (p.3).

In *The Presentation of Self in Everyday Life*, Goffman (1959) elaborates on the various aspects of his theory using a dramaturgical metaphor borrowed from performance theater. He analyzes the social interactions of individuals describing the interaction as a performance defined as “all the activity of a given participant on a given occasion which serves to influence in any way any of the other participants” (p. 15). An individual is a performer who attempts to foster observer’s impression of them. A performer can fully believe their act is the real reality or, at the other end of the continuum, know it is all for show. Goffman’s (1959) extensive discussion of the performances of individuals covers such topics as belief in playing ones part, presentation of a front, idealization of the performance (the impression the performer wants others to have), dramatic realization (highlighting specific facts that might otherwise remain obscure), reality and contrivance, misrepresentation and maintenance of expressive control.

The focus on the individual performer is, however, in Goffman’s (1959) opinion, a limited view of the social interaction and can “obscure important differences in the function of the performance for the interaction as a whole” (p.77). Performers are part of a troupe of actors just as a receptionist is the face of the business or a quarterback is part of the offensive team of a larger team in a football game. Goffman (1959) explores the implications of individual’s membership in the team, control of the overall team performance, sustaining the teams impression message, control of the setting and other facets of teams that influence social interaction. In the dramaturgical metaphor, the audience can be viewed as a team. Teams interact with other teams. A baseball team plays against another baseball team in front of an audience. In a hospital, nursing is one

team, physicians on another team, allied health professionals on another team and all are members of the health care team.

The overall function of the team Goffman (1959) goes on to explain is “to sustain the definition of the overall situation that its performance fosters” (p.141). This involves controlling information and requires performers to be able to keep secrets. This is demonstrated in health care, the whole health care team working to provide service to a patient yet only designated persons (usually physicians) are allowed to share certain information (e.g. diagnosis and prognosis) with a patient. A portion of Goffman’s work in *The Presentation of Self in Everyday Life* (Goffman, 1959) is devoted to exploring discrepant roles – performers who in some manner are unable to keep the team’s secrets from another team. This might be an informer, a go-between or some other kind of exchange of information that disrupts a team’s attempt to control the impression they have created. An example in health care is a nurse who informs or confirms a patient’s query about their diagnosis prior to the doctor speaking to them.

Goffman (1959) also explores communication out of character. Members of a team tend to maintain the impression of the team created by their collective actions and adhere to their role within the team. However, out of sight of the audience or other teams, a team may comment on the other team in a derogatory manner inconsistent with the face-to-face interactions. An example is a nurse commenting to a patient about the ongoing difficulties of contacting and receiving a timely response from a specific physician. Team collusion e.g. whispering between team members may disrupt the impression created of the individual member and potentially disrupt the cultivated team persona.

Goffman (1959) offers a treatment of regions defined as “any place that is bounded to some degree by barriers to perception” (p. 106) that is similar to the discussion of teams. In qualitative research, Goffman’s region can probably be thought of as context. Goffman talks about the backstage and front stage, the attempts to control who sees backstage and the performers manner when situated back or front stage. The impact of region helps shape understanding of social interaction just as the back stage and front stage activities shape a theatrical performance. In nursing, the nurse’s station may be thought of as the backstage – a place for candid conversation between health care team members usually outside the hearing of patients. In contrast, the patient’s room, the place where health care team members perform their role could be envisioned as the front stage.

In the conclusion to his book, Goffman (1959) states “this report is chiefly concerned with social establishments as relatively closed systems” (p. 239). Goffman (1959) explains “within the walls of a social establishment we find a team of performers who cooperate to present to an audience a given definition of the situation” (p.238). His focus was not on the individual but was “concerned with the structure of social encounters (Goffman, 1959, p. 254). A hospital or a physician’s office can be understood as a relatively closed health care system. The dramatologic metaphor was a mechanism for describing in familiar and easily understood terms complex social interactions. But, as Goffman (1959) admitted, his attempt “to press a mere analogy so far was in part a rhetoric and a maneuver” (p.254). The theatre, he acknowledged is “a relatively contrived illusion and an admitted one; unlike ordinary life, nothing real or actual can happen to performed characters” (Goffman, 1959, p. 254).

Use of the Dramaturgical Metaphor in Health Research

Goffman's work in *The Presentation of Self in Everyday Life* (Goffman, 1959) articulated his thoughts on social behavior and the presentation of self to others using a dramaturgical metaphor. This approach has been described as "an unusual, anecdotal methodology" (Barnhart, 1994). However, Goffman seemingly was not explaining or advocating for a qualitative analytical methodology. The dramaturgical metaphor was used to explain rather than analyze the data he had collected. The morphology of the dramaturgical metaphor to an analytical technique is unclear.

Goffman's influence in health care research is evidenced by use of the dramaturgical metaphor. Some examples are provided. Haas and Shaffir (1982) applied a dramaturgical analysis to the professional socialization of medical students in an innovative medical school. In dissecting the students experiences they used language of the theatre auditioning (for admission to medical school); taking on the role including wearing the appropriate costume and utilizing props; stage fright confronted as one is immersed in medical education; dress rehearsal as students move into clinical work; and, memorizing lines as they prepare for the licensing exam. This analysis led to the conclusion that "professionalization can be fruitfully analyzed as a progression in which the neophyte is forced to give an even more convincing and correct performance in a role that has a specific honorific status" (Haas and Shaffir, 1982, p. 200).

A study by John (1996) applied the dramaturgical metaphor and impression management principles to health care service encounters. The actors/audience, setting and performance were delineated and dissected. Armed with this dramaturgical view, John (1996) suggests "that the physician adopt some impression management guidelines" (p.

67) with the goal of improving the service encounters. John (1996) believes the dramaturgical view facilitated understanding of the health encounter but noted that each encounter is directed by the medical condition and as a result the physician's performance and the patient's reaction will be different with each performance.

A dramaturgical analysis was used in a study that examined nursing shift reports (Hayes and Weinert, 2006). Like the other two examples, the investigators adhered to a dramaturgical metaphor designating the shift report as a performance and identifying the various actors and their roles in that performance. They found that nursing in shift reports play roles that are influenced by their personality, expectations and the role patterning of the group. The dramaturgical approach used in the study was noted to be a theoretical framework that allowed generalization of this case study (Hayes and Weinert, 2006).

Dialogic Approach

The second theoretical underpinning of the dialogic/performance analytical method is reflective of the work of Mikhail Bakhtin, a Russian literary philosopher and scholar. Bakhtin's work covered diverse subjects and influenced a range of disciplines including history, literature, sociology, psychology, and anthropology. Much of Bakhtin's work was done in the early twentieth century. The complexity of his ideas and the use of his native language Russian in writing combined with world wars and the upheavals in his native country delayed the spread of his work to the United States until the 1980's after his death. Further, his works, much in fragments or rough drafts, is described as "frustratingly vague in their terminology...and encumbered with multiple and ambiguous levels of meaning" (Gardiner, 1992, p. 1). The influence of Bakhtin's work on

development of the dialogic/performance analytical method will be brief and certainly fail to do justice to the breadth and depth of his ideas and life work.

Several concepts introduced by Bakhtin influence an understanding of the dialogic/ performance method. Bakhtin developed a schematic for understanding the human psyche that consists of three components. Emerson (2006) explained these components. The three components are described as “I-for-myself”, “I- for-the-other” and “other-for-me” and serve as a means of understanding the development of our identity. I-for-myself represents our understanding of ourselves and is thought to be an unreliable source of our identity. Our identity, Bakhtin asserts, is developed in the I-for-the-other relationship. In this relationship our identity is developed as a conglomeration of the ways in which others view us. The other-for-me is defined as someone incorporating another person’s perceptions of them into their personal understanding of themselves (their identity).

Thus, in Bakhtin’s schema, the development of our individual identity occurs not in isolation but through our interactions with others (Emerson, 2006). The entities that relate to each other, shaping and reshaping each other may be a mother and child, God and human, self and other, clinician and patient and so on (Gardiner, 1996). In an interview setting, this idea is reflected in the notion of co-construction of narrative. The interviewer exerts an influence on what is said or not said, what topics are addressed, what points need explanation and so on (Salmon & Reissman, 2008). The narrative develops in the social interaction between the interviewer and the interviewee and from that exchange can the meaning be ascertained.

Implicit in the “I-thou” schema is the idea of the unfinalized self. The iterative interactions between self and others impact the voice with which we speak and modify our self identity. The voice a person speaks with, according to Bahtkin (1984), is comprised of the voices of many others and is spoken in anticipation and response to other voices in an ongoing cycle of interactions with others. These interactions modify and mold our identity. Bakhtin (1984), as a literary critic, examined the characters in Dostoevsky’s writings and noted the characters “all acutely sense their own inner unfinalizability, their capacity to outgrow, as it were, from within and to render untrue any externalizing and finalizing definition of them” (p.59). Frank (2005) summarizes Bakhtin’s idea of unfinalizability by declaring, “The core ethical demand of the Dostoevsky-Bakhtin I-Thou relationship is that neither party ever finalizes the other” (p.966).

Bakhtin was a literary scholar who explored several concepts related to the use of language. Central to the work by Bakhtin language and literature is the concept of dialogism - a reference to the way languages interact. Bakhtin’s uses of the term dialogism are ambiguous and, therefore, open to various interpretations of his work on this subject (Vice, 1997). Vice (1997) offers one definition of dialogism – “a ceaselessly shifting power relations between words, their sensitivity to each other, and the relativizing force of their historically motivated clashes and temporary resolutions” (p. 5). Vice (1997) identifies two ways in which Bakhtin uses the term dialogism. Bakhtin uses the term to point to specific instances of language but also to reference the fundamental defining qualities of language (Vice, 1997).

In common parlance, dialogue is understood to describe a give and take of verbal utterances between two people. The idea of dialogism is closely tied to Bakhtin's idea of that as long as a person is alive he is not yet finalized. Monologue and dialogue represents the two ends of a continuum of people's interactions. Dialogue "begins with the recognition of the other's unfinalizability" (Frank, 2005, p.967). To have meaningful dialogue there must be an exchange of not just positions but ideas or positions (Hirschkop, 1998). Frank (2005) summarizes (as he understands the concept) the essence of Bakhtin's dialogism stating "Dialogue depends on the perpetual openness to the other's capacity to become someone other than whoever she or he already is. Moreover, in a dialogic relation, any person takes responsibility for the other's becoming, as well as recognize that the other's voice has entered one's own" (p. 967). Hirschkop (1998) adds his understanding of Bakhtin's concept of dialogism as the idea that each utterance is "double voiced" or, put another way, "a single utterance may contain two, in principle, separate meanings" (p. 185).

One concept developed by Bakhtin is heteroglossia, defined as differentiated speech, which can be thought of in two ways (Vice, 1997). One form is a social language within a single national language e.g. Ebonics within American English or the social language of doctors in contrast to nurse's aides. The second form is different national languages with the same culture e.g. Spanish and English are both used in the United States. These coexisting yet different forms of language are recognized as highlighting social inequalities. Tension develops between the speakers with the speaker of the more prestigious language attempting to exert control and the other speaker resisting that control (Vice, 1997).

Polyphonic is a term Bakhtin used to describe another aspect of language that is a component of dialogism. The term polyphonic means “many voiced”. Riessman (2008) asserts narratives are polyphonic and suggests this means “the author (speaker) does not have the only word, that is, the authority over meaning is dispersed and embedded” (p.107). Polyphonic narratives “explicitly contain a variety of different and often contradictory goals, values, temporal assumptions and attitudes” (Ezzy, 2000, p. 13) yet the speakers “embrace many of the contradictions and tensions in their accounts rather than suppressing them” (Ezzy, 2000, p. 13).

Riessman (2008) distilled the influence of Bakhtin’s work in the development of the dialogic/performance method of analysis. Riessman (2008) highlighted the primacy of the “I-thou” relationship in all utterances. Words are saturated with meaning derived from previous utterances of many people. This polyphonic or multi-voiced aspect of language underlies the idea no one person is the authority on the meaning of an utterance. Rather, the form of the dialogue and the meaning of an utterance are found in the interactions between people and reflect the social and historical context, impreciseness of the speaker, tension between the speakers and other aspects of the dialogic environment (Riessman, 2008).

Use of Dialogic Analysis in Health Research

Like Goffman, Bakhtin’s body of work did not outline a specific analytical method. Based on Bakhtin’s concepts, a dialogic narrative analysis method has been advanced. Frank (2012) has outlined “five commitments” to conducting dialogic narrative analysis on the premise that “to practice dialogic narrative analysis is to sustain a tension between dialogue and analysis” (p. 34). Frank (2012) asserts these commitments are the

foundation for dialogic narrative analysis. These commitments will be outlined followed by two examples of health research utilizing the dialogic narrative analysis method.

The first commitment to the conduct of dialogic narrative analysis acknowledges Bakhtin's concepts of polyphony and heteroglossia. The commitment is to recognize that any one voice is actually comprised of multiple voices. Dialogue is two or more people speaking but, consistent with Bakhtin's ideas, dialogue is also a reflection of the past historical context and use of language in the current utterance. Frank (2012) explains the significance as he points out that someone using dialogic narrative analysis understands co-construction of a narrative differently than other qualitative researchers. In Frank's (2012) words "dialogic narrative analysis's interest is in hearing how multiple voices find expression within any single voice. A storyteller tells a story that is his or her own, but no story is ever entirely anyone's own. Stories are composed from fragments of previous stories, artfully rearranged but never original" (p. 35).

The second commitment is to remain suspicious of monologue (Frank, 2012). Monologue is the opposite of dialogue. Frank (2012) explains that most social research is monological i.e. the methodological approach envisions the study participant(s) as a person who is limited and well defined. The person is as they present themselves. From a dialogic narrative analysis approach, the researcher hears multiple voices from each study participant and hears numerous storytellers. Part of the work in the analysis is to bring the different voices into contact with each other for it is in that intersection of voices dialogue is created and meaning is found.

Frank (2012) asserts that the third commitment extends Bakhtin's concept of dialogue. Stories belong to the person telling the story but also are external to the story

teller in that the story is a composite of stories told by other people, parts of which find their way into the story being told by the storyteller. “We humans are able to express ourselves only because so many stories already exist for us to adapt, and these stories shape whatever sense we have of ourselves” (Frank, 2012, p. 36).

The idea of people as unfinished underscores the fourth commitment. “As long as a person is alive he lives by the fact that he is not yet finalized, that he has not yet uttered his ultimate word” (Bakhtin, 1984, p. 59). The unfinished person draws on stories other people tell and, using these stories, engages in a process of revising their self understanding which then appears in the story they tell. There is no end to this ongoing, repetitive retelling. Frank (2012) identifies the tension created by this lack of finality in personal self definition but the need for research reports to draw conclusions and end. This tension leads to the fifth commitment for an investigator who uses dialogic narrative analysis.

The fifth commitment in dialogic narrative analysis is to not summarize findings. Summarizing findings suggests an end to dialogue and a conclusion that stands separate from the dialogue. Investigators committed to the use of a dialogic narrative analysis method approach analysis with the aim of “increasing people’s possibilities for hearing themselves and others. It seeks to expand people’s sense of responsibility in how they might respond to what is heard...it seeks to show what is at stake in a story as a form of response” (Frank, 2012, p. 37).

Smith (2013) used dialogic narrative analysis to examine the health narratives of people who sustained spinal cord injuries engaging in leisure time physical activity and as a result became disabled. The seventeen male study participants were interviewed

twice, approximately three months apart for 2-6 hours. During the first interview, the men were invited to tell stories about their own lives. In the second interview, Smith (2012) was able to probe more deeply, ask follow up questions and invite reflections based on the knowledge he gained examining the first interview transcripts

Smith (2013) explained the manner in which dialogic narrative analysis was used to explore the data. The study participant stories were examined “not as mere products of telling. The story itself is interpreted and what stories do is analyzed. The analyst’s attention focuses on how a story is put together, and what kind of story is being told (as per a structural analysis)” (Smith, 2013, p. 111). The steps of doing a dialogic narrative analysis include the analyst’s immersion in the data by reading and rereading transcripts and field notes, focus on the stories and translate those stories into images that position the analyst to see (Smith, 2013). The next step of dialogic narrative analysis is to review the conceptual annotations the analyst made as they read the transcripts and field notes. Other memos that commented on theoretical or procedural aspects of the research provide insights into observational and interview data and the interaction between the forms of data (Smith 2013). As the analyst writes their thoughts, a form of analysis, their writing is shaped by dialogic questions. Dialogic questions might address resources available to the study participants which influence their storytelling or connection questions that link the study participant to other people (Smith, 2013).

Smith (2013) concluded a new form of narrative about health which is titled “emergent narrative” is evident in the stories of these disabled men. Smith (2013) suggests this new form of narrative differs from other illness narratives that focus on mortality. The benefit of naming illness narratives is that narratives are “useful for

disabled people to reflect on what story they have been telling – what enabled that story and how that story works on, in and for them, affecting their life – what story they want to tell, and even more important, what story they were not telling (Smith, 2013, p. 117).

The second example of the use of dialogic analysis in health research is a study by Madill and Sullivan (2010) that explores student experiences in medical training. Eleven British medical students (three male and eight female) were interviewed twice. Interview length varied but averaged about 45 minutes. The first interview was to gather information related to their motivation to study medicine, their medical training experiences and their decision to concurrently study psychology. The second interview explored the participant's evaluation of their study of psychology, insights into connections between medicine and psychology and their career plans.

The process of analysis began with identification of “key moments” that is, a bounded narrative that is recognizable as a complete story of an experience (Madill and Sullivan, 2010, p.2196). To qualify as a key moment the story had to be told with palpable emotional involvement of the student and/or emotionally impact the researchers (listeners). The investigators next examined the transcripts containing the key moments. From this examination a table was developed with the following information: “participant; extract; genre(s); emotional register (of learning/truth); space-time elaboration; context” (Madill and Sullivan, 2010, p. 2097). This table was examined for patterns that would form the basis for a more detailed and targeted analysis.

The approach used to analyze the interview data is a form of “Bakhtinian-inspired dialogic analysis” (Madill and Sullivan, 2010, p. 2196) as it is being developed by one of the study author (Sullivan, 2012). Concepts from Bakhtin's work that

permeated the analysis include dialogism, emotional connection to truth, genre and chronotype. Dialogism emphasizes the exchange between speakers in the collective search for truth (Madill and Sullivan, 2010). Bakhtin differentiated between theoretical or abstract truths and the kind of truth significant in dialogism - embodied and lived truths (pravda). The pravda found in the speakers' own experiences and values is infused with the speaker's emotion (Madill and Sullivan, 2010). Bakhtin's concept of genre is that a genre is a "distinct conceptualization of historical time, social space, individual character and moral action" (Morson and Emerson, 1990, p. 301). Madill and Sullivan (2010) view genre as a method of structuring text and facilitating arrangements of space and time, what Bakhtin called chronotype.

The conclusions in Madill and Sullivan's (2010) research on medical students are framed around the Bakhtin concepts. The professional genre is characterized by pedagogical neutrality and distance. The ways in which the professional genre can defuse emotionally laden medical training is illustrated. The role of medical consultants in an affect-laden pedagogy is examined (Madill and Sullivan, 2010). Madill and Sullivan (2010) conclude "learning to use the professional genre is part of enculturation as a medical expert and can be helpful in providing a framework restoring coherence and composure through engaging with, and reformulating, difficult experiences" (p.2202).

Secondary Analysis

The theoretical underpinnings of dialogic/performance narrative analysis are complex and subject to wide ranging interpretation. Implementation of a dialogic/performance analysis requires particular attention to ensuring soundness and transparency in methodology. Not only must the researcher attend to aspects of a sound qualitative study

but in the instant case, in particular, challenges to conducting a secondary analysis must be discussed to lend credibility to the research.

Secondary analysis was long considered an appropriate methodology within the context of conducting deductive, quantitative research (Heaton, 1998; Fielding, 2004; Gladstone, Volpe and Boydell, 2007). The interest in using secondary analysis of qualitative data and the increasing legitimacy of secondary analysis has accelerated (Fielding, 2004). Some authors believe this is the result of investigators narratives that often include issues related to the primary research but are never fully explored (Long-Sutehall, Sque, and Addington-Hall, 2010). Others point to the policies of research groups that require applicants to demonstrate a need for collecting new qualitative data and expect researchers to archive and make the data available for future studies as accelerants of secondary research (Irwin and Winterton, 2011). The underutilization of qualitative research data is viewed as a primary reason for conducting secondary analysis (Fielding and Fielding, 2000) and possibly a reason for a presumably increasing interest in secondary analysis.

Whatever the reason for the expanding use of secondary analysis in qualitative research, the expansion is not without debate. The suggestion has been made that qualitative data is being archived with greater frequency but data on actual use of the archived datasets for secondary analysis is lacking casting doubt on whether there is truly an expansion of the use of secondary analysis (Parry and Mauthner, 2005). Whether secondary analysis is on the rise or not, there is significant opportunity for further expansion (Irwin, Bornat, and Winterton, 2012).

The debate about the validity of qualitative secondary analysis covers all aspects of this method. The advantages and disadvantages of secondary analysis in qualitative research are assessed (Windle, 2010). Debates about context and researcher presence abound (Bishop, 2006; Irwin and Winterton, 2011). Ethical, legal, data management and security issues are highlighted (Doolan and Froelicher, 2009). Even the very definition of secondary analysis and the blur between what is categorized as primary versus secondary analysis is contested (Heaton, 2008; Windle 2010).

The intent here is not to revisit the merits of secondary analysis in the aggregate. Nevertheless, attention to specific concerns in conducting this secondary analysis of interview data must be addressed to demonstrate the challenges and how they were overcome when implementing a research study designed to explore the merits of the dialogic/performance analytical method.

“Researchers doing secondary analysis need not only understand research concepts related to designing a new study, but additionally must be aware of challenges specific to conducting research using an existing data set” (Doolan and Froelicher, 2009, p. 203). It is these “challenges” that will be addressed. Ultimately, the secondary analysis is constrained by the study design and methods used in the original study (Doolan and Froelicher, 2009) thus overcoming the limitations imposed by the original study is essential for a legitimate secondary analysis. The specific issues and challenges to conducting this secondary analysis of interview data using a dialogic/performance method include conceptualization of the study, selection of a research question, ensuring suitability of the data set, addressing context, relationship to the original researcher, and ethical considerations. Although discussed separately, these challenges are intertwined in

the research process. The extent to which the challenges are overcome lend credence to the notion the dialogic/performance method of doing secondary analysis is a viable options for researchers who wish to expand their toolbox of analytical techniques.

Conceptualization of the Study

The literature on research methods assumes research questions are determined first followed by the selection of the method and design of the study including sampling, data collection and analytical technique (Shadish, Cook and Campbell, 2002; Doolan and Froelicher, 2009). In the instant case, the application of the dialogic/performance analysis method was the outcome of a class assignment to apply a narrative analysis technique to interviews of HIV positive woman. The interviews and a one paragraph description of the original study for which the interviews were collected were supplied by the instructor. The assignment was to undertake a narrative analysis with the goals of the original study as a guide. Given the data set and assignment, a research question was developed to facilitate a secondary analysis with the narrative analysis technique, dialogic/performance analysis, selected to fulfill the assignment.

The central question is - How successful was this study in overcoming this disruption in the usual development of a research study in achieving a sound study and credible findings? This question cannot be answered in isolation but is dependent on overcoming the challenges of doing a secondary analysis.

Research Question

A basic definition of a research question is that “research questions are the specific queries researchers want to answer in addressing the research problem” (Polit and Beck, 2008, p. 81). The research problem is a specific “enigmatic, perplexing, or troubling

condition” (Polit and Beck, 2008, p. 81) within a broad topic area the investigator is interested in exploring. Basic research methods texts and experienced researchers advise novice researchers of the sequence of developing a research – identify an area of interest and potential problems, perform a literature review, pose research questions, develop the methodology and so on (Polit and Beck, 2008; Doolan and Froelicher, 2009). The use of an existing data set alters this sequence and creates a different set of methodological considerations the first of which is developing the research question.

Secondary analysis can be used to reexamine data to answer the original research question using different techniques or to validate the results of the original research (McArt and McDougal, 1985; Doolan and Froelicher, 2009). But, secondary analysis can also be used to explore new research questions (Irwin and Winterton, 2011). A limitation of secondary analysis is that the original research potentially had a different research question (Doolan and Froelicher, 2009). The selection of the research methods, sample, analysis and other aspects of the research were selected to appropriately address the original research question and therefore, may not be suitable for a secondary analysis built on a different research question. Doolan and Froelicher (2009) suggest that if an investigator “anticipates doing secondary analysis, it is important to define the preliminary research question prior to identifying a data set” (p.205). Meaningful answers to a research question are dependent on appropriateness of the existing data set to explore the research question posed in the secondary analysis.

In this study, the researcher was given the data and asked to analyze the data selecting a method from within the category of narrative analysis. Development of the research question followed the selection of data. The challenge than is to demonstrate that

the research question used in the secondary analysis was appropriate for the existing data set.

Suitability of Data Set

An extant data set can be used for a variety of purposes including answering new research questions not envisioned in the original study but the appropriateness of using an existing data set must be carefully evaluated (Heaton, 2008). The suitability of a data set for secondary analysis begins early in the conceptualization of the study with selection of a research question. “For secondary analysis to be appropriate, the principal investigator must have an important research question and a data set that is adequate to address the question” (Doolan and Froelicher, 2009, p. 205). The original study was planned for a specific question with the research methods, measures, and analytical technique selected to create a cohesive study. Thus, the use of a data set for a different purpose will require justification that the data set is suitable or, alternatively, it may be necessary to refine the intended research question (Doolan and Froelicher, 2009).

The justification for use of a data set must wrestle with some practical matters. In some instances changes over time may limit the research questions that could be addressed with the data. This is evident when data is collected prior to an intervention (Doolan and Froelicher, 2009) but could conceivably happen where the natural progression of time (e.g. people aging) render the data inappropriate for a particular research question.

The data fit, i.e. whether data collected for one purpose can be used for another purpose, is a function of the nature of the data. In qualitative research, data is often very rich offering a depth and breadth of coverage of topics suitable for a number of research

questions (Heaton, 2008). Examination of the form of the data (interviews, diaries, surveys, etc.), the variables, the method of initial data collection including type of sampling will all factor in to an assessment of the data's fit with the research question (Heaton, 2008; Doolan and Froelicher, 2009).

The quality of a data set also enters into a consideration of the suitability of the data set for a secondary analysis. The researcher proposing a secondary analysis finds they are constrained by the study design and measures chosen in the original study (Doolan and Froelicher, 2009). This includes the decisions made about sampling, adequacy of the data, quantity of data collected, issues related to the management of missing data or excessive loss to follow-up are handled, recording of data, storage of data, transcription of data and availability of code books or other resources to explain the initial data collection (Doolan and Froelicher, 2009). Any of the issues, if not carefully evaluated can adversely impact the use of the data set in a secondary analysis.

Hinds, Vogel and Clarke-Steffen (1997) proposed an assessment tool for evaluating the suitability of a data set for secondary analysis. The tool addresses access to both study documents and the original research team; credentials of the original research team, completeness of the data set, ability to assess quality of the interviewing, fit of the data to the proposed secondary research question and quality and completeness of the data set (Hinds, Vogel and Clarke-Steffen, 1997, Appendix A). The criteria outlined in the assessment tool are echoed by later authors (Heaton, 2008; Doolan and Froelicher, 2009).

Potentially a researcher will have to negotiate with the original researcher for use of a data set (Hinds, Vogel and Clarke-Steffen, 1997). The original researcher may want

to evaluate whether the proposed research question is important and adds to an understanding of the phenomena. Additionally practical matters such as transcription or translation of interviews, sharing a whole or partial data set, inclusion of field notes or other material in what is provided for the secondary analysis, input of the original researcher into the secondary analysis design, authorship or other factors may have to be negotiated (Clarke and Cossette, 2000).

The issues surrounding the suitability of the data set containing the interviews of HIV positive women in Kenya for a secondary analysis using the dialogic/performance method of analysis will have to be answered sufficiently to demonstrate that the data set:

- Is suitable to answer the research question
- Is of sufficient depth and quality to be appropriate for the selected analytical method
- Is not precluded or adversely impacted by obstacles set forth by the original researcher

Context

Irwin and Winterton (2011) note that “it is the contextual dynamics of data production that is the particular strength of qualitative research” (p.6). The significance of context is closely linked to the concept of the co-construction – the widely held view within qualitative research that the interviewer participates in the production of qualitative data in an interview setting (van den Berg, 2005). Context in secondary analysis is often thought of as “an issue of proximate knowledge of participants and of their immediate circumstances” (Bornat and Winterton, 2012, p. 78). Some authors suggest that this view of context is limited and does not fully elucidate the role of context in generation of data

or analysis of data in qualitative research (van den Berg, 2005, Irwin and Winterton, 2011)

Potential use of qualitative data for secondary analysis is thought to increase dramatically when extensive context from the original research is available (Fielding 2004, Heaton, 2004, Bishop 2006). Exactly what is meant by context, however, is unclear. Bishop (2006) notes “specific definitions of context are rare, with van den Berg (2005) one notable exception (p. 8). As a preface to a discussion about context and the different kinds of context, van den Berg (2005) states “the general phrase ‘bring in the context’ is in fact very ambiguous. It means different things in different strands of qualitative research and there are different conceptions of which context is relevant and how this context should be used on behalf of the interpretations of interview discourse” (section 4).

The inaccessibility of the original context or the secondary researcher’s distance from that contextual data has led some researchers to conclude this is a primary limitation of qualitative secondary analysis (Mauther, Parry and Backett-Milburn, 1998). The contextual information is considered so important by qualitative researchers that one author was led to propose “minimum guidelines on contextual information required on behalf of secondary analysis of qualitative interviews (van den Berg, 2005, section 5). These guidelines listing information that should be available to the secondary researcher include:

- Information about the interaction between interviewer and interviewee including audiotapes or detailed transcriptions of interviews
- Whole transcripts, not just parts

- Information about the background characteristics (age, gender, race, social class, etc) of the interviewer and interviewee
- Information about the place, time and setting of the interview
- Information about how the interviewee is selected
- Information about relevant others that are known to the interviewee

Even with this minimum information Van den Berg (2005) opines that just this information “may be insufficient for some research goals ...it is unavoidable that secondary analysis permits only a limited range of possibilities for research” (section 5).

An aspect of context that arises in secondary analysis relates to epistemological issues. To what extent is it possible and is it necessary for a second researcher to understand the context that was integral to the original research to produce meaningful, valid findings to new questions posed in a second study reusing data? (Irwin and Winterton, 2011). Even when the second study is undertaken by one of the original researchers, some authors suggest the researcher will experience a sense of distance from the context which delimits the possibility of valid findings in the secondary study (Hammersley, 1997, Mauther, Parry and Backett-Milburn, 1998).

From this brief overview of the position of context within secondary analysis several conclusions can be drawn. First, context is acknowledged to be important although precisely what context and how it is important is unclear. Second, some minimum knowledge of the context from the original research is desirable. Third, the understanding of context must be reframed in discussion of secondary research as considerations of context impact analytical and methodological issues differently in secondary research versus original research. The challenge in the current research is to

demonstrate that the issues of context in using a dialogic/ performance analysis of interview data adequately address the concerns and therefore, issues of context do not detract from the production of meaningful, valid findings.

Relationship to Original Researcher

Parry and Mauthner (2005) report that re-use of data is predominately undertaken by the original researcher or someone on the original research team rather than someone not connected to the initial research. The involvement of the original research team is believed to influence the decision to undertake secondary analysis and offers some benefits (Heaton, 1998). Access to the original data set including field notes and tapes; consultation with the original research to assess quality, contextualize the data or cross check secondary analysis results; and negotiating agreements to use data are offered as benefits of involvement of the original researchers in the secondary analysis (Heaton, 2005). The benefits of contact with the original researcher led many authors to “recommend performing a secondary analysis of an existing dataset only when there is access to the primary investigator and the original research study (Windle, 2010).

The questions related to the relationship of this investigator to the original researcher are: to what extent did the investigator have contact with the original researcher and how did the amount of contact impact the study?

Data Analysis

The difference between conjecture and a scientific approach to data is “a thorough, well prepared, and well documented analysis” (Malterud, 2001, p. 486). Malterud (2001) goes on to acknowledge that the process of systematic analysis varies from research study to research study and is dependent on the research question, type of data, analytical

approach and other factors. Statements such as the material was read by several authors or a qualitative analytical computer program was used to analyze the data fail to explain the analytical process sufficiently (Malterud, 2001). Malterud (2001) warns that “the more intuitively the analysis procedure is accomplished, the harder it is to account for what has been done” (p. 487).

Leech and Onwuegbuzie (2008) offer a compendium of techniques for conducting qualitative data analysis. Interestingly, secondary analysis is listed as a separate technique for conducting qualitative research with no reference to the methodology of utilizing this technique. Secondary analysis is described as “analyzing non-naturalistic data or artifacts that were derived from previous studies” (Leech and Onwuegbuzie, 2008, p. 601). The description is silent as to how that analysis is to be conducted.

Heaton (2008) offers an overview of secondary analysis of qualitative data and comments that “when I first began my research on secondary analysis of qualitative data, the first thing I realized was that there was no clear, accepted, definition of the methodology. In the existing literature, secondary analysis of both quantitative and qualitative data was defined in various ways” (p.34). Heaton (2008) articulates the two primary purposes of secondary research as investigation of new or additional research questions and verifying prior research findings. Irwin and Winterton (2011) offer a more expansive list that includes assessing credibility for generalizing findings and providing methodological insights. Heaton (2008) also discusses modes of secondary analysis i.e. distinctions in how the data for secondary analysis is obtained. Secondary analysis is contrasted with primary analysis (Windle, 2010) and discussed in terms of control over the collection of data, knowledge of context, and differing ethical considerations. These

authors do not, however, offer a compendium of analytical methods that can be used in secondary analysis.

Explicit discussion stating any method used for primary analysis can be used for secondary analysis was not found. However, the taxonomy of Leech and Onwuegbuzie (2008) is inconsistent with the dichotomy of primary versus secondary analysis with overlapping methodologies. Researchers have used a variety of qualitative research methods to conduct secondary analysis such as an interpretive, interactionist framework (Gladestone, Volpe and Boydell, 2007), comparative thematic approach (Long-Sutehall, Sque and Addington-Hall, 2010) and thematic coding using computer software (Bishop, 2007) However, Irwin and Winterton (2011) warn “diverse qualitative research strategies will render the resulting data more or less amenable to secondary analysis (p. 9).

Ethnographic research is cited as an example of a strategy that is too closely aligned with the research for secondary analysis to be feasible. In contrast, semi-structured interviews are viewed as more discreet and therefore, amenable to secondary analysis (Irwin and Winterton, 2011).

One limitation of secondary analysis is purported to be “the inability to follow strictly the guidelines of the chosen data analysis method” (Szabo and Strang, 1997, p. 68). This is attributed to the lack of control over conceptualization of the study, data collection decisions, depth of contextual information or problems and/or biases in the original study that cannot be overcome in the secondary analysis. “The original researchers’ presence, and aspects of proximate context, permeates the data in ways that are not always evident for subsequent users of data (Irwin and Winton, 2011, p.7).

Overcoming these limitations may preclude specific analytical approaches in the

secondary analysis or even render a secondary analysis unfeasible (Szabo and Strang, 1997). In conducting their own research Long-Sutehall, Sque and Addington-Hall (2010) assert “ not only is it recommended that the research questions for the secondary analysis be sufficiently close to those of the primary research, but that the data collection and analytical techniques in the primary dataset are similar to those applied in the secondary analysis” (p.337).

The challenges of data analysis utilizing a dialogic/performance method in a reuse of data are to demonstrate the analytical method is:

1. consistent with the overall design (conceptualization, use of existent dataset, context) of the secondary analysis
2. not hampered by any deficiencies of the original research
3. reported with sufficient detail and transparency to allow for a critical review of the analysis

Ethical Considerations

Informed consent when conducting research on data that is being reused presents some additional ethical considerations to the standards for obtaining informed consent in original research. The standards for informed consent include a full and meaningful disclosure to study participants about the purpose of the research, measures to maintain confidentiality and potential uses of the data; participants freely given consent to voluntary involvement in the study; and, an awareness of the right to withdraw at any time (Corti, Day and Backhouse, 2000). Presumed consent for secondary analysis cannot be assumed (Heaton, 1998) or be considered implied by vague language in the consent form (Long-Sutehall, Sque, Addington-Hall, 2010). Primary researchers do not

necessarily anticipate that the data they are collecting will be used in a secondary analysis. Therefore, they may not have informed research participants of the possibility of sharing data with others or reusing the data for purposes beyond those for which it was originally collected (Heaton, 2008). The lack of informed consent and the opportunity for obtaining it or lack thereof may prove to be an insurmountable barrier to conducting secondary research.

The issue of anonymisation using data collected by someone else can create two problems. If the data has been anonymized by the primary researcher the second researcher potentially is left with data so stripped of detail as to render it unacceptably distorted (Corti, Day and Backhouse, 2000). The researcher conducting a secondary analysis is relying on the appropriate removal of identifying details with no ability to assess if indeed this has occurred.

Conversely, if the second researcher receives unredacted data the issues of confidentiality and informed consent assume greater significance.

For the proposed secondary analysis using the dialogic/performance method how the issues of informed consent and maintaining the confidentiality and anonymity of the study participants will need to be addressed in a satisfactory manner.

Introduction to Manuscripts

The next four chapters are intended to be stand alone articles suitable for publication. As such the reader may find some repetition of verbiage or concepts necessitated by the need to ensure the chapters can be understood without reference to other sections of these

writings. The final chapter offers a synthesis that is not intended for publication. What follows is a brief review of the objective of each of the chapters.

Chapter Two is a critical review of literature that focuses on research studies that have utilized the dialogic/performance analysis method. The chapter investigates research studies from a variety of disciplines to glean an understanding of how this method, which has been described as “broadly interpretative” (Riessman, 2008), of narrative analysis is actually executed. This guidance can be helpful to a novice researcher or an experienced research who seeks to expand their qualitative techniques toolbox.

Chapter Three explains the implementation of the dialogic/performance analysis method in a secondary analysis of data. The principal investigator of the original study *HIV Transmission Risk, Access to Treatment, and Self-Management of Illness over Time: An In-Depth Longitudinal Study of HIV-Infected Women in Kenya* (Kako, Stevens and Galvao) supplied transcripts from interviews with HIV-infected women in Kenya for the secondary analysis. The methodology of the application of a dialogic/performance analytical technique to this data is discussed while addressing the challenges of conducting a secondary analysis. The focus is on dispelling concerns about conducting qualitative secondary analysis by re-conceptualizing issues that seemingly undermine the soundness, reliability and quality of such research. The analysis of the interviews of HIV positive women in Kenya in a secondary analysis using dialogic/performance analysis is used to illustrate how the challenges to conducting qualitative secondary analysis can be overcome.

The focus of Chapter Four is on the methodology of dialogic/performance analysis as applied to the interviews of HIV positive women in Kenya.

Dialogic/performance analysis is a flexible method that can be implemented in several ways provided the researcher stays true to the philosophical concepts underlying the method and includes an examination of the themes - what was said; structure – how the story was told; and dialogic/performance – who a person is talking to, for what purpose and in what context.

Chapter Five summarizes the findings derived from a dialogic/performance analysis of the transcripts of HIV-infected women in Kenya. The voices of these women are heard in the stories constructed from the woman's own words as they digress from answering the interview questions in the original study. While the women supply information related to the primary study's aims exploring their gender-based experience as an HIV- infected person in an African country, they also give insights into their priorities and concerns post HIV diagnosis and how the diagnosis has reshaped their lives. The findings from this secondary analysis offer, from the viewpoint of the study participants, an enhanced understanding of the significance of an HIV diagnosis within the context of the daily lives of these women.

The sixth and final chapter synthesizes the outcomes of this research. The major points from each chapter are summarized. Included is a description of implications for nursing practice, potential policy implications and directions for future research.

References

- Bakhtin, M. (1984). *Problems of Dostoevsky's Poetics* (C. Emerson, Trans.). University of Minnesota Press: Minneapolis, MN.
- Bishop, L. (2007). A reflexive account of reusing qualitative data: beyond primary/secondary dualism. *Social research online*, 12(3)2.
doi:10.5153/sro.1553
- Blumer, H. (1969). *Symbolic Interactionism: Perspectives and Method*. Englewood Cliffs, NJ: Prentice Hall.
- Bornat, J. (2003). A second take: revisiting interviews with a different purpose. *Oral History*, 31(1), 47–53.
- Bradley, E. H., Curry, L. a, & Devers, K. J. (2007). Qualitative data analysis for health services research: developing taxonomy, themes, and theory. *Health services research*, 42(4), 1758–72. doi:10.1111/j.1475-6773.2006.00684.x
- Castle, J.E. (2003). Maximizing research opportunities: secondary data analysis. *Journal of Neuroscience Nursing*, 35, 287-290.
- Chapple, A and Rogers, A. (1998). Explicit guidelines for qualitative research: a step in the right direction, a defense of the 'soft' option or a form of sociological imperialism. *Family Practice*, 15(6), 556-561.

- Charon, J. M. (2009). *Symbolic Interactionism An Introduction, An Interpretation, An Integration*. Upper Saddle River, NJ: Prentice-Hall.
- Clarke, S.P. & Cossette, S. (2000) Secondary analysis: theoretical, methodological, and practical considerations. *Canadian Journal of Nursing Research*, 32(3), 109-129.
- Corti, L., Day, A. & Backhouse, G. (2000). Confidentiality and informed consent: issues for consideration in the preservation of and provision of access to qualitative data archives. *Forum Qualitative Sozialforschung/ Forum: Qualitative Social Research*, 1(3), Art. 7, <http://nbn-resolving.de/urn:nbn:de:0114-fqs000372>
- Doolan, D. M., & Froelicher, E. S. (2009). Using an existing data set to answer new research questions: a methodological review. *Research and Theory for Nursing Practice*, 23(3), 203–215. doi:10.1891/1541-6577.23.3.203
- Emerson, C. and Morson, G. (2006). "Mikhail Bakhtin." *The Johns Hopkins Guide to Literary Theory and Criticism* (Eds. Michael Groden, Martin Kreiswirth and Imre Szeman). Baltimore, MD: The Johns Hopkins University Press..
- Ezzy, D. (2000). Illness narratives: time, hope and HIV. *Social Science & Medicine*, 50(5), 605–17. doi:10.1016/S0277-9536(99)00306-8
- Fielding, N.G. & Fielding, J.L. (2000) Resistance and adaptation to criminal identity: using secondary analysis to evaluate classic studies of crime and deviance. *Sociology*, 34(4), 671-689.

- Fielding, N. (2004). Getting the most from archived qualitative data: epistemological, practical and professional obstacles. *International Journal of Social Research Methodology*, 7(1), 97–104. doi:10.1080/13645570310001640699
- Fine, G. A. and Smith, G. eds. (2000). *Erving Goffman. Vol. 1–4*. Los Angeles, CA: Sage Publications.
- Frank, A. W. (2000). Illness and Autobiographical Work : Dialogue as Narrative Destabilization. *Self*, 23(1), 135–156. doi:10.1023/A:1005411818318
- Frank, A. W. (2005). What is dialogic research, and why should we do it? *Qualitative health research*, 15(7), 964–74. doi:10.1177/1049732305279078
- Gardiner, M. (1992). *The Dialogic of Critique: M. M. Bakhtin and the Theory of Ideology*. New York, NY: Routledge, a division of Routledge, Chapman and Hall, Inc.
- Gardiner, M. (1996). Alterity and ethics: a dialogic perspective. *Theory, Culture and Society*, 13, 121-143.
- Gladstone, B. M., Volpe, T., & Boydell, K. M. (2007). Issues encountered in a qualitative secondary analysis of help-seeking in the prodrome to psychosis. *The Journal of Behavioral Health Services & Research*, 34(4), 431–42. doi:10.1007/s11414-007-9079-x
- Goffman, E. (1959). *The presentation of self in everyday life*. New York: Penguin.

- Haas, J. (1982). Taking on the role of doctor: a dramaturgical analysis of professionalism. *Symbolic Interaction*, 5(2), 187–203.
- Hammersley, M. (2010). Can we re-use qualitative data via secondary analysis? notes on some terminological and substantive issues. *Sociological Research Online*, 15(1). doi:10.5153/sro.2076
- Hays, M. M., & Weinert, C. (2006). A dramaturgical analysis of shift report patterns with cost implications: a case study. *Nursing economic\$, 24(5)*, 253–62, 227.
Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/17131617>
- Heaton, J. (2008). Secondary analysis of qualitative data: an overview, 33(3), 33–45.
- Hinds, P. S., Vogel, R. J., & Clarke-Steffen, L. (1997). The Possibilities and Pitfalls of Doing a Secondary Analysis of a Qualitative Data Set. *Qualitative Health Research*, 7(3), 408–424. doi:10.1177/104973239700700306
- Hirschkop, K. (1998). Is dialogism for real. *The Contexts of Bakhtin: Philosophy, Authorship, Aesthetics* (ed David Shepard). Amsterdam, The Netherlands: Overseas Publishers Association.
- Irwin, S., & Winterton, M. (2011). Debates in Qualitative Secondary Analysis : Critical Reflections A Timescapes Working Paper Debates in Qualitative Secondary Analysis : Critical Reflections A Timescapes Working Paper, 3349(4).

- Irwin, S., Bornat, J., & Winterton, M. (2012). Timescapes secondary analysis: comparison, context and working across data sets. *Qualitative Research*, 12(1), 66–80. doi:10.1177/1468794111426234
- John, J. (1996). A dramaturgical view of the health care service encounter Cultural value-based impression professional behaviour, 30(9), 60–74.
- Kako, Peninnah, PhD, RN, FNP, Patricia Stevens, and Anna Galvao. *HIV Transmission Risk, Access to Treatment, and Self-Management of Illness over Time: An In-Depth Longitudinal Study of HIV-Infected Women in Kenya*. N.p., n.d. Web.
- Leech, N. L., & Onwuegbuzie, A. J. (2008). Qualitative data analysis: A compendium of techniques and a framework for selection for school psychology research and beyond. *School Psychology Quarterly*, 23(4), 587–604. doi:10.1037/1045-3830.23.4.587
- Long-Sutehall, T., Sque, M., Addington-Hall, J. (2010). Secondary analysis of qualitative data: a valuable method for exploring sensitive issues with an elusive population?. *Journal of Research in Nursing*, 16(4), 335-344. Doi: 10.1177/1744987110381553
- Madill, A., & Sullivan, P. (2010). Medical training as adventure-wonder and adventure-ordeal: a dialogic analysis of affect-laden pedagogy. *Social science & medicine* (1982), 71(12), 2195–203. doi:10.1016/j.socscimed.2010.09.048

- Malterud, K. (2001). Qualitative research: standards, challenges, and guidelines. *Lancet*, 358(9280), 483–8. doi:10.1016/S0140-6736(01)05627-6
- McArt, E. W. and McDougal, L. W. (1985), Secondary Data Analysis—A New Approach to Nursing Research. *Journal of Nursing Scholarship*, 17: 54–57.
doi: 10.1111/j.1547-5069.1985.tb01418.x
- Morson, G.S., & Emerson, C. (1990). *Mikhail Bakhtin: Creation of a Prosaics*. Stanford University Press: Stanford, CA.
- Parry, O & Mauthner, N. (2005). Back to Basics Who Reuses Qualitative Data. *Sociology*, 39(2), 337–342. doi:10.1177/0038038505050543
- Polit, D.F., & Beck, C.T. (2008). *Nursing Research: Generating and assessing evidence for nursing practice*. Philadelphia, PA: Wolters Kluwer.
- Riessman, C.K. (2008). *Narrative methods for the human sciences*. Los Angeles, CA: Sage Publications.
- Salmon, P. and Reissman, C. (2008). Looking back on narrative research: an exchange. *Doing Narrative Research* (ed by Molly Andrews, Corinne Squire and Maria Tamboukou) London: Sage
- Savage, M. (2005) Working class identities in the 1960's: revisiting the Affluent Worker Study. *Sociology*, 39(5), 929-948.
- Scheff, T. J. (2005). Looking-Glass Self: Goffman as Symbolic Interactionist. *Symbolic Interaction*, 28(2), 147–166. doi:10.1525/si.2005.28.2.147

- Smith, B. (2013). Disability, sport and men's narratives of health: a qualitative study. *Health Psychology : official journal of the Division of Health Psychology, American Psychological Association*, 32(1), 110–9. doi:10.1037/a0029187
- Snow, D. a. (2001). Extending and Broadening Blumer's Conceptualization of Symbolic Interactionism. *Symbolic Interaction*, 24(3), 367–377.
doi:10.1525/si.2001.24.3.367
- Sullivan, P. (2012). *Qualitative Data Analysis Using a Dialogic Approach*. Sage Publications: London UK.
- Szabo, V, & Strang, V. (1997). Secondary Analysis of Qualitative Data. *Advances in Nursing Science*, 20(2), 66–74.
- Van Den Berg, H.. (2005). Reanalyzing qualitative interviews from different angles : the risk of decontextualization and other problems of sharing qualitative data. *Forum Qualitative Sozialforschung/ Forum:Qualitative Social Research*, 6(1), Art. 30, <http://nbn-resolving.de/urn:nbn:de:0114-fqs0501305>.
- Vice, S. (1997). *Introducing Bakhtin*. Manchester UK: Manchester Press.
- Windle, P. (2010). Secondary data analysis: is it useful and valid? *Journal of PeriAnesthesia Nursing*, 25(5)m 322-324. doi: 10.1016/j.jopan.2010.07.00

CHAPTER 2-MANUSCRIPT 1

CRITICAL REVIEW OF SELECTIVE LITERATURE EXPLORING THE
DIALOGIC/PERFORMANCE METHOD OF NARRATIVE ANALYSISLenore L. Boris¹ and Patricia Stevens²¹ University of Wisconsin Milwaukee, College of Nursing, Milwaukee, WI, USA² University of Wisconsin Milwaukee, College of Nursing, Milwaukee, WI, USA

Qualitative researchers are urged “to extend themselves past the recurrent use of the same type of analysis.” (Leech and Onwuegbuzie, 2008) However, the application of qualitative research methods to the analysis of data is impeded by a relative lack of attention to practical strategies for the analysis of qualitative data. (Bradley, et al., 2007) The purpose of this paper is to provide greater clarity and direction for use of the dialogic/performance method of narrative analysis described by Riessman (2008) in the conduct of a qualitative secondary analysis research study. This will be accomplished by first, providing a broad overview of narrative inquiry in general; second, summarize the theoretical foundations for dialogic/performance analysis; third, reviewing in-depth the three foundational studies Riessman (2008) cites as exemplars for her conception of dialogic/performance analysis; fourth, review three more recent examples that have cited dialogic/performance analysis as the basis for their methods; and fifth, synthesizing the major elements that comprise dialogic/performance analysis in practice. These insights into dialogic/performance analysis can guide novice or experienced researchers who want to expand the analytical tools they have available to do their research.

Background

Dialogic/Performance Analysis Defined

Dialogic/performance analysis has connections to the structural and thematic methods of narrative analysis but is recognized as a distinct form of narrative analysis. Riessman (2008) advanced this method describing dialogic/performance as “not equivalent to thematic and structural but rather a broad and varied interpretive approach to oral narrative that makes selective use of elements of the other two methods and adds other dimensions.” Riessman conceptualizes the thematic element as an examination of what is

said i.e. the story content – the plot, the characters, and the common patterns that emerge. The structural element explores how the story is told; how the narrator organizes and presents the content of the story. Dialogic/ performance analysis adds one more dimension which explores to whom the story is addressed, under what circumstances and for what purpose.

Narrative and Narrative Analysis

A brief discussion of narrative and narrative analysis is warranted to establish a common perspective for the discussion of the narrative analysis method dialogic/performance that follows. A precise definition of narrative evades consensus. An expansive definition of narrative holds that narrative is everywhere and “everything is a narrative or, at the least can be treated like one.” (Czarniawska, 2004) Written text, paintings, movies, news articles, diaries, biographies, records, photographs – in short any form of capturing communication – can be considered as narrative. Identifying sources of narrative, however, is different than defining narrative. As Riessman (2008) asserts “all talk and text is not narrative.”

Riessman laments that narrative “has come to mean anything beyond a few bullet points.” Attempts to define narrative include narrative as “a discourse form in which events and happenings are configured into a temporal unity by means of a plot.”

(Polkinghorne, 1995) Labov and Waletzky (1967, 1997) talk about defining characteristics of narrative that includes a temporal ordering when describing past events. Specific features of narrative, as conceptualized by Labov and Waletzky, are orientation (the time, place and situation); complication i.e. the main body, the action; evaluation (why is the story being told, what is the point?); resolution i.e. what happens; and coda

(the return of the listener to the present moment). Czarniawska remarks, “Narrative is understood as a spoken or written text giving an account of an event/action or series of events/actions, chronologically connected.”

Narrative is understood in different disciplines in different ways complicating efforts to define the term precisely. Narrative is often used synonymously with story (Riessman, 2008). To some scholars, story is a form of narrative with characteristics such as characters and plots that differentiate story from other types of narratives (Coffey and Atkinson, 1996). Stories are ordered sequentially and temporally and include an unexpected action that calls for a reaction (DeFina, 2003). Other scholars (Labov, 1997) view stories as a broader field than narrative because storytellers can relay events in which they were not involved.

Notwithstanding the distinctions between story and narrative or variations in the very definition of narrative, scholars of narrative agree “the everyday use of the narrative form is all pervasive.” (Czarniawska, 2000) The research studies selected for this review do not adhere to a common definition of narrative. An inclusive, expansive definition of narrative seems to offer the most latitude and flexibility when using dialogic/performance analysis.

The significance of narrative lies in recognition that narrative offers a different way of knowing. Bruner (1990) articulates two forms of knowledge – narrative and logico-scientific. Logico-scientific knowledge explains the world by identifying casual connections from which general laws can be developed and tested to confirm or refute the knowledge of the world gained using this approach. Narrative mixes objective and subjective aspects of the way people see the world focusing on the intentions and actions

of people while situating them in time and context. Narrative, from the Latin *narrare*, means “to tell, relate, recount, explain, ‘literally’ to make acquainted with, from *gnarus* ‘knowing.’” (Barusch, 2012) This difference in perspective on how one approaches exploration of the world underscores the real significance of narratives and narrative research.

Narrative analysis is “the systematic study of narrative data.” (Riessman, 2008) But, this simple definition belies the complexities of narrative analysis. Like the multitude of definitions/conceptualizations of narrative, there are many views and methods of narrative analysis. Numerous resources (Holloway and Freshwater, 2007; Holstein and Gubrium, 2012; Riessman, 2008; Ritchie and Lewis, 2009) outline various narrative analytical strategies. Holstein and Gubrium point out that “methods of analysis do not emerge out of this air. They are informed by, and extend out of, particular theoretical sensibilities.” The same theoretical perspective evident in analysis guides the design and methodological choices in the development of an overall research study. To understand and implement dialogic/performance analysis to narrative data it is necessary to examine the underlying theoretical foundation.

Dialogic Performance Analysis Theoretical Foundation

The theoretical underpinning for the dialogic/performance method of narrative analysis is found primarily in the work of Erving Goffman and Mikhail Bakhtin. The contributions of Goffman and Bakhtin to the method are complex and subject to interpretation as they offer a perspective rather than a tool that can be replicated in a research study.

Goffman (1959) was interested in human behavior and people's attempts to influence the impression others have of them. In his seminal work *The Presentation of Self in Everyday Life*, Goffman used a dramaturgical metaphor to explain how individuals act a part to an audience. The dramaturgical metaphor identifies the individual (the performer), the other person or people (the audience), the backstage (the behind the scenes influences in an interaction), the front stage (the interaction) and other components of performance theater (e.g. props or the symbols such as handshakes, turn taking in conversation, etc. used in interactions). Goffman used the dramaturgical metaphor to examine and explain interactions between people i.e. the performances of individuals as a mechanism for understanding the part a person plays, the impression a person wants others to have of them, the control of the amount and type of information revealed to another and other aspects of social interaction.

Bakhtin proposed that the human psyche consists of three components. Emerson (2006) described the three components as "I-for-myself," "I-for-the-other" and "other-for-me." I-for-myself represents our understanding of ourselves. I-for-the-other refers to the conglomeration of ways in which others view us. The other-for-me is defined as someone incorporating another person's perceptions of them into their personal understanding of themselves (their identity). The I-for-the-other component is central to the development of our identity (Emerson, 2006). In Bakhtin's schema, the development of our individual identity is an iterative process shaped through our interactions with others. The interaction with others impacts the voice with which we speak and modifies self identity. Our voice is comprised of the voices of all persons we previously interacted with and is spoken in anticipation of and response to other people in an ongoing cycle of

interaction and change (Bakhtin, 1984). The interaction modifies and shapes our identity. Our identity is an aggregate of the ways in which others view us and, further, implicit in Bakhtin's conceptualization of identity is the idea our identities are never finalized.

Bakhtin rejected the common understanding that dialogue as a verbal give and take between two people and spoke of dialogism. One understanding of the imprecisely defined term dialogism is that meaningful dialogue is dependent on a person's willingness to be reshaped by their verbal interaction with another person (Frank, 2005). Another facet of dialogism is the idea that in the process of our identity being modified as we engage in dialogue our voice comes to incorporate the ideas or positions of the other person (Hirschkop, 1998). Dialogism is intricately connected to Bakhtin's concept of the unfinalized self – the idea identities are always evolving in response to interactions with others (Frank 2005).

Methods

Literature Search

Peterson and Langellier (1997) noted that social scientists took “a ‘narrative turn’ to conceptualize, interpret and critique diverse storytelling phenomena.” The conditions that fed the narrative turn arise from “diverse shifts in Western thought, epistemology, technologies and social practices that began in the 1960s.” (Riessman, 2008) The initial interest in telling the stories logically led to an interest in analyzing the stories. Narrative inquiry flourished but as Chase concluded, “researchers new to this field will find a rich but diffuse tradition, multiple methodologies in various stages of development.” (Denzin & Lincoln eds., 2005) Narrative study is found in every field and social science discipline and is used to study an array of topics suggesting to Riessman (2008) that “methods of

narrative analysis are ripe for a detailed methodological inquiry.” To that end Riessman’s text *Narrative Methods for the Human Sciences* offers an introduction to narrative analysis and presents a typology of narrative analytical methods. This review of selected research studies extends the exploration of narrative techniques by elucidating considerations in conducting a research study and in implementing an analysis using dialogic/performance analysis, one method of narrative analysis defined by Riessman.

Riessman (2008) discussed three research studies as prototypes for dialogic/performance analysis, one of four broad approaches to narrative analysis. Despite the somewhat dated nature of the prototypes, the formative influence of these foundational studies in Riessman’s development of the dialogic/performance method warrants a review of these research efforts. These three studies are compared and contrasted to three more recent research studies that also purport to use dialogic/performance analysis. A search of major data bases including Academic Search Complete, Primo Central and Google Scholar to obtain English language research articles utilizing the dialogic/performance method of narrative analysis was conducted to identify recent examples. Despite the plethora of articles using either dialogic or performance analysis there was a paucity of articles using dialogic/performance analysis. Three social science studies that incorporated some discussion of how the dialogic/performance method was implemented in doing the analysis of data were selected to include in this review.

The articles selected are not a comprehensive list but do provide a basis for examining the methodology of application of dialogic/performance analysis to narrative data. The articles are summarized with a focus on aspects of the research study most

heavily influenced by the theoretical underpinnings of this analytical method. Guidance for novice or experienced researchers in the application of a dialogic/performance analysis to data is offered based on knowledge gleaned from this review.

Results

Foundational Studies Serving as Exemplars for Riessman’s Dialogic/Performance Analysis

Riessman (2008) introduces three foundational studies to illustrate the dialogic/performance method of narrative analysis. The studies examine school experiences of white preadolescent girls from two culturally different rural communities (Brown, 1998), “sharing time” in a socioeconomically and racially diverse classroom (Gallas, 1994), and Riessman’s (2003) own work on self identity of men disabled by illness and no longer able to work.

Brown (1998) explored school girls’ active resistance to “dominant notions of femininity.” Nineteen girls, ages 11-14 years old, in two socio-economically diverse schools were selected as the subjects. The study was structured to include bimonthly focus groups of girls belonging to preexisting groups and periodic individual interviews over a year. The group encounters were videotaped and interviews audio-taped for later analysis.

Brown (1998) does not specifically state use of dialogic/performance analysis, however, the influence of Bakhtin’s work is clear. Brown discusses her own background and the influence it has on her understanding and reporting of the girls’ voices. She recognizes the power ascribed to her as a social scientist and educator means the knowledge produced “will inevitably differ from the meanings ascribed by the girls.”

(Brown, 1998) Consistent with Bakhtin's views, Brown (1998) describes the developmental process the girls experience hearing the voices arising from the social relationships and interactions and incorporating these voices into their own developing identities.

Analysis occurred through the use of "a voice-centered 'Listener's Guide'" (Brown, 1998). The Listener's Guide necessitates at least four readings of the transcribed narrative and is an approach that facilitates "close, in-depth analysis and is designed to accommodate different research questions." (Brown, 1998) The first reading examined the overall narrative and the relationship to the research questions. The second reading listened to the first person voices of each girl. The girls' personal anger and discussion of the people or experiences that provoke their feelings was the focus of the third reading. In the fourth reading, Brown (1998) attended to the girls' expression of conventional thoughts of femininity and attempted to identify the source of the girls' exposure to those thoughts. In a fifth reading, Brown (1998) examined the girls' resistance to the conventional definitions of femininity as expressed through words or gestures.

Brown (1998) created "interpretive summaries" from which she generated her findings. The themes of class identity and anger identified in the readings were explored while attending to how the girls used language. Brown created a matrix that tracked each girl's voice within the group which facilitated examination of the timing and context of each girl's contribution to the group dialogue. In addition to this structural analysis, Brown examines to whom it is the girls are speaking and for what purpose.

Gallas (1994) was interested in classroom practices and how they could be improved to enhance a child's ability to learn. Gallas believed that "narrative accounts

best represent the process of education.” Children tell their personal narrative in an effort to understand, explain and order their world. Gallas concluded children’s narratives “can become a powerful vehicle for thinking and learning.” Gallas realized children’s personal narratives are not limited to the use of words to tell a story but includes children’s dramatic play, drawings, movement, songs and other forms of expression.

Throughout the school year, Gallas, an elementary school teacher, collected children’s narratives—the stories, pictures, audio or video recordings, and artifacts brought for sharing time. The ongoing process of data collection provided material to explore the teaching and learning that occurs in a classroom. Gallas outlines the research model used stating “as a teacher-researcher I do not determine beforehand the categories of information I am looking for, the nature of the data, or the questions to be asked.” As a teacher-researcher, Gallas adopts an attitude of not knowing and loss of control over the meaning given to the routine classroom practices as the beginning of the research process. Gallas believes that “by allowing children fully to uncover their own stories and meanings, by, in fact, abdicating control of a situation and looking at it without an internal censor, new understandings can be gained.” The process of data collection and analysis is “a continuous cycle of reflection and of questioning those reflections...the data, the process, and even the questions are all constantly changing and rearranging themselves in different relationships” (Gallas, 1994) as new understandings of the classroom teaching and learning emerge.

Like Brown (1998), Gallas (1994) does not identify dialogic/performance analysis as the methodology. The influence of Goffman and Bakhtin is evident. Echoes of Goffman’s notions of performance are found in Gallas’ discussion. For example,

discussing the common classroom activity of sharing time, Gallas (1994) reflects on the extent to which children control what information they are willing to share, audience (i.e. the rest of the class) response, props the child might use, teacher's role as director of the activity as if Goffman's metaphor of a theatrical performance had been applied.

References to Bakhtin's work are scattered throughout Gallas' research. Gallas (1994) acknowledges that relaying the children's stories is filtered through her eyes and life experiences and that she has been personally involved in shaping the narrative. She talks about hearing in the children's personal narratives the voices of their parents or other people in their life. Consistent with Bakhtin's concept of the unfinished self, Gallas (1994) discusses how she is changed by the children's narratives and thus modifies her approach to teaching and how the children's identities evolve as revealed in the stories they present through various communication mediums.

Riessman (2008) used her own work as an exemplar of the dialogic/performance method. In a secondary analysis Riessman (2003) constructed two case studies to explore the masculine identity of men disabled by multiple sclerosis. Riessman (2003) identifies two theoretical perspectives, structural and performative, used to conduct the research. The research study's title *Performing Identities in Illness* suggests the heavy influence of the performative perspective which is confirmed in a reading of the study. The work does not specifically address the influence of the dialogic perspective.

Explicative comments throughout the research provide insight into how the performative method guided the investigator. As a starting point, Riessman (2003) states, "a clinical case involves presentation and expression by two social actors: the patient presents symptoms and makes claims about himself, and the clinician in turn presents a

case to others in an expressive portrayal.” Riessman (2003) outlines performative concepts of Goffman in the context of an illness narrative as the foundation for this research. Performative concepts addressed in the study include people staging performances to save face in difficult situations such as chronic illness; investigators participate in the production of the illness narrative; gender, class and historical context matter in the creation and interpretation of illness narrative; and, narrators control the terms of the telling (Riessman, 2003).

Riessman (2003) approached the analysis of the two cases asking questions such as, “Why was the illness narrative developed this way and told in that order? How does he/she strategically make preferred identity claims? What was the response of the listener/audience and how did it influence the development of illness narrative, and interpretation of it?” In analyzing the data, Riessman drew on contemporary understandings of gender, class and historical context to situate the men’s performance of their illness narrative within the social context of their lives. As part of the analysis, Riessman “used the performative view to interrogate the audience (myself) as an active figure in the production of, and reaction to, the illness narrative.”

Riessman (2003) attended to theme, structure and dialogic/performance. The structure of the discussion with each study participant differs greatly. Both men are challenged by the impact of a chronic, disabling illness on their life and identity. Burt tells story after story to construct his preferred identify, whereas Randy engages in a reflective monologue. As an academic, Randy’s talk suggests he views his illness as an opportunity for personal growth, reordering of life priorities and a reconstruction of his identity. In contrast, Burt attempts to hold on to his pre-illness identity as a working man

despite the deterioration of his physical abilities and the breakdown of his social world evident in a divorce and loss of employment. Riessman (2003) discusses how gender and social class shape each man's masculine identity noting that "although neither of the two narrators explicitly acknowledged objective conditions and contradictions—they 'naturalized' them – the lives they represent were saturated with class and global politics."

Dialogic/Performance Analysis

Three recent articles that specifically identify use of the dialogic/performance analysis are offered to explore how researchers apply this method of narrative analysis to the actual data.

Busanich, et al. (2012) identified dialogic/performance analysis as the analytical approach used to examine data collected to explore the relationship of body, food and exercise in physically active individuals. Nine recreational distance runners were interviewed. Open-ended questions were used to elicit stories about the runners' experiences with food, experiences as runners and thoughts about their bodies.

Data analysis conformed to the thematic components of dialogic/performance analysis as outlined by Riessman (2008). Thematic analysis was used to "identify common and different meanings around the body, food and exercise," thus the focus of this aspect of analysis was on the content of the story (Busanich et al., 2012). Links between emergent themes allowed the researchers to develop further insights into the meaning for participants about body, food and exercise and the relationship between these factors (Busanich et al., 2012).

The structural aspect of the dialogic/performance analysis was not segregated during analysis. The investigators focused on how the study participants' stories represented a performance within a cultural context. The researcher took extensive field notes that "reflect on what discursive and narrative resources runners drew upon to shape their subjectivity and experience and what purposes their stories served." (Busanich et al., 2012) Gendered narratives (e.g. female bodies are flawed) and cultural perceptions (e.g. exercise is a punishment for eating too much) inform the study participants in constructing their personal stories (Busanich et al., 2012). The personal stories revealed the meaning of food, exercise and body for these physically active study participants. The personal stories were a performance of the gendered identity adopted by each participant and shaped by the cultural context influencing beliefs about food, exercise and body. The meaning of the relationship of food, exercise and body found in the personal stories were compared and contrasted to sport and exercise physiology literature relevant to this topic.

The second example of a research study specifically stating use of the dialogic/performance method to analyze data is a study involving South African women who volunteer to provide home-based care to HIV/AIDS persons (Naidu and Sliep, 2012). Three interviews from each woman were solicited, translated and transcribed. With the investigator controlling and directing the first interview, specific questions about the nature of the women's work were asked. In contrast, an unstructured second interview asked the women to talk about their life story. The investigators desire was to create an opportunity for alternate possibilities of identity, aside from their role as caregiver, to emerge as stories. The third semi-structured interview asked women to reflect on their roles as mothers and helpers within the community and how the women

perceived these roles in relation to their work as volunteers. The women were prompted to recall what family members said about their work and personalities (Naidu and Sliep, 2012).

Naidu and Sliep (2012) state analysis of the data was done using dialogic/performance analysis. Referencing Riessman's (2008) concise explanation of this technique as broad, varied and interpretative; Naidu and Sliep outline the essence of the dialogic/performance analysis approach stating, "the analysis requires close reading of the contexts, including the influence of the investigator, the setting and social circumstances on the production and interpretation of the narrative."

Thematic analysis was conducted using NVIVO8 software. The most frequently occurring themes in the text were then examined in structural analysis that focused on the where and when of the specific theme within the interview. Attention was given to the manner in which study participants constructed their narratives including the ordering of ideas and the influence of the interviewer. Also examined were participants' efforts to "convey their ideas and convince, collaborate with, or correct the interviewer." (Naidu and Sliep, 2012)

In the third step of analysis, the influence of Bakhtin is evident as the investigators reviewed the interviews to find "whereby re-accentuating the voices of others provided speakers with a mechanism to establish positions for themselves." (Naidu and Sliep) During this level of analysis, the researchers attended to the structure of the interviews by noting topics repeated, initiated spontaneously or addressed despite what the interviewer was asking. Attention was given to turn taking and management of the

topic in addition to focusing on participant comments that seemingly were intended for an external audience (Naidu and Sliep, 2012).

The third article examined the narratives about well-being of elderly women in Sweden who lived in special accommodation housing (Svensson, Martensson and Muhli, 2012). A specific focus of the research was on how the women created their own identity and meaning based on their life experience but filtered through their current situation living in a residential care facility. Interviews were formatted in a conversational style with open-ended questions that provided participants an opportunity to tell their story to the listener in a co-production of the narrative. Follow-up questions were asked during the interview to solicit more in depth information to enhance understanding of the women's narratives and their perception of well-being (Svensson, Martensson and Muhli, 2012).

Svensson, et al. (2012) started analysis from the premise that narrative analysis reveals how a person's life experience and the context in which life's activities occur shape a person's perception of reality. The analytical approach sought to answer the questions who, when, and why i.e. for what purposes were the narratives constructed with attention "given to how the facts got assembled *that way* in the story." (Svensson, et. al, 2012) The five narratives were viewed as one case for the purpose of identifying themes.

Analysis was a five step process. In the first step, two of the investigators listened to the interviews several times to develop an overall appreciation of the data. Step two consisted of transcription of the interviews followed by numerous readings of the transcripts during which coding was used to identify themes and group text of these themes into topic clusters. The clusters were analyzed examining the "specific content of

what (what is spoken) and how, who, when and why {dialogic/performance} in the narratives.” (Svensson, et. al, 2012) Step three involved a sorting by chronological order of the themes and events discussed in the narratives. The fourth step consists of another reading, this time of the chronological themes in the narrative. This step confirmed that elements contributing to the women’s sense of well being throughout their lives were captured in the researchers work up to that point.

The final step involved consensus of selection of three themes for more in-depth analysis by the three authors. The themes focused on childhood memories, family and work and well-being opportunities at the special accommodation housing as sources of well-being. Textual material from the narratives supported findings. In the interest of providing transparency of their analytical technique the researchers included their analysis in the research article. Presented under the heading of results, the analysis details the interpretive selection of the narrative data and understanding of the narrative construction that is summarized in a discussion instructive of the themes being explored.

Characteristics of Dialogic/Performance Analysis

Riessman (2008) describes some common characteristics of the exemplars she identifies as foundational studies to explain this method of narrative analysis. The three exemplars involve the “construction and performance of identities.” Methodologically the exemplars have common features that include a research relationship between the researcher and interviewee that includes the voice of the researcher in constructing the dialogue and the researcher’s open speculation about the meaning of the interviewee’s words. The written report of each exemplar deviates from the customary research format

to meld methods, findings and discussion into a “purposefully self-conscious and subjective report.” (Riessman, 2008)

Two other commonalities are identified by this literature review can be added to characteristics of dialogic/performance analysis. These two characteristics relate to the willingness to explore any aspect found within the data of the broad topical area of interest and the inclusion of three overlapping, yet distinct aspects of analysis that employ an eclectic choice of analytical tools.

Journey through Unmapped Territory

Researchers using dialogic/performance analysis demonstrate a willingness to exploring any aspect of the topic they are interested in that may arise within the narrative data. The linear research roadmap connecting the gaps in what is known about a phenomenon, the research question, the identification of data specifically addressing the research question and the development of new knowledge is substituted by a road trip through the narrative exploring whatever seems interesting or informative. Gallas (1994) articulates this point thusly, “my stance as a teacher-researcher often begins by situating itself in an attitude of not knowing and loss of control, not in a physical sense, but in the existential sense of losing control of the meaning of habitual practices.” In other words, abandoning what is known to be open to what the data reveals.

Each study clearly identified the phenomena of interest. Svensson et al. (2012) were interested in the well being of elderly women living in special housing accommodations. Busanich’s et al. (2012) interest was the relationship of body, food and exercise in distance runners. The expansiveness of the topic sometimes made a one sentence summary of the topic difficult. Gallas’ (1994) interest in how children

communicate their understanding of the world leaves many unanswered questions about the intent of the research. The purpose of the road trip through the narrative of the topic of interest was typically phrased using broad descriptors such as “explore and describe,” (Riessman, 2003) “understand and describe,” (Svensson et. al, 2012) or “expand understandings.” (Busanich et al., 2012)

What is known from the literature about the topic was not ignored. However, references to research on the same topic were just as likely to be addressed in the findings as to appear in an introductory section describing the background and proposed focus for research. Each study narrowed the field of investigation but still left many potential paths to travel. Riessman’s (2003) plan was to “explore and compare an aspect of each man’s illness narrative: masculinity in the face of disease.” Sexuality, physical health, male roles, income, etc. as aspects of masculinity were all left open to exploration. Naidu and Sliep (2012) proposed to “explore how women at HBCV’s display agency in the context of AIDS care based on their identity as women volunteers.” Within this intent, the research could have gone in many directions such as exploring the influence of age, marital status, education, cultural norms, or other factors on agency. Only one study (Busanich et al., 2012) reported specific yet broad research questions.

The data collection phase displayed the same willingness or openness to a range of possibilities. Data collection was intentionally constructed to allow participants to tell their personal narratives (Naidu and Sliep, 2012). Brown (1998) determined interview topics after lengthy discussion with the girls about what they viewed as important. Sessions began with a topic or question but as Brown (1998) noted, “more often than not the girls veered away from our queries and toward more personally pressing concerns.”

Gallas (1994) outlines the research model used stating, “As a teacher-researcher I do not determine beforehand the categories of information I am looking for, the nature of the data, or the questions to be asked.”

This same openness to follow the narrative wherever it went in a journey of exploration leading to greater understanding is evident in the analysis of data. In the three exemplars offered by Riessman (2008), the researchers continually questioned their understanding of words and events in the narrative, “who precisely is speaking and under what circumstances?” (Brown, 1998) or “how gendered really is Randy’s narrative performance?” (Riessman, 2003) or “should a child be allowed to publically disclose to her classmates the difficulty conversations of her life?” (Gallas, 1994) The result of this openness is a very rich, descriptive and detailed analysis of a myriad of factors that shape the development of and performance of identity. Gallas (1994) captured the essence and benefits of this approach. “The process of inquiry begins with a question or with confusion. The journey I take to answer that question or see into the confusion often leads to places I never intended to go.”

Construction and Performance of Identities

Riessman (2008) explained that the construction and performance of identities means identities are “dynamically constituted in relationships and performed with/for audiences.” Two aspects differentiated the emphasis of identity in the studies utilizing dialogic/performance analysis. One aspect relates to the extent the investigator focused on individual identity versus the identity of a group. The second aspect is a deliberate examination of external factors shaping identity.

Riessman (2003) examined how a debilitating illness shaped the masculine identity of two men. Each man's narrative performance displays a complex and shifting expression of their masculine identity. The character of each man's masculine identity and reconfiguration in response to a debilitating illness was discussed individually then compared and contrasted to each other and to the cultural understanding of masculinity. Riessman (2003) states, "I used the performative view to interrogate the audience (myself) as an interactive figure in the production of, and reaction to, the illness narratives." During the interview, Riessman (2003) noted the dominant view at the time of the interviews was to view gender and sexuality as dichotomous and therefore failed to acknowledge a participant's efforts to describe the dual aspects of his gender.

Gallas (1994) uses specific individuals to illustrate the nature of sharing time. Jiana, a homeless six year old, Gallas (1994) reports, "taught us many things about language, teaching and community." Her story is relayed in depth because it incorporates many of the themes that emerged in Gallas' (1994) exploration of sharing time. The themes were wide ranging from the benefits of sharing time in developing speaking and listening skills for the individual child to the development of community within the classroom and the ramifications of these observations in classroom practices. Jiana's story embodies most of the themes; however, Gallas could just as easily have used several children to illustrate concepts. The focus was not Jiana's individual identity but rather the shared identity and experience of the children in the classroom.

Similarly, Busanich, et al. (2012) used individual responses to illustrate the running narrative of two groups – male and female distance runners. The runners drew on the cultural understanding of food and exercise to create personal stories that "became the

platform through which running and gendered identities were performed.” (Busanich, et al., 2012)

The studies by Svensson, et al (2012) and Naidu and Sliep (2012) emphasized group identities. Svensson et al. (2012) examined identity as one factor that impacted the well being of elderly women in special housing accommodations. Naidu and Sliep (2012) investigated the aspects of identity that motivated women to volunteer as HIV/AIDS caregivers. Brown (1998) states that a deliberate decision to not detail the girls individually was made to protect the girls’ confidentiality. The study compared and contrasted the gender identity of two groups of adolescent girls whose lives’ experiences reflect their social class. Brown (1998) did not present the girls words and action as a performance although from descriptors, the girls respond to external factors and adjust their responses as an actor might in reaction to an audience. The works of Svensson, et al (2012) and Naidu and Sliep (2012) do not discuss their observations or findings in terms of performance.

The second aspect of construction of identity evident in studies utilizing dialogic/performance analysis is the emphasis and examination of external factors that shape study participants identity. The external context forms the basis for understanding the construction and characteristics of the identity revealed in these studies. Busanich, et al. (2012) pointed to the contemporary cultural and gendered discourses that shaped study participants’ views of exercise and food and its impact on their identities as distance runners. The constraints and influence of living in special housing accommodations modified elderly women’s senses of identity. (Svensson, et. al, 2012) Naidu and Sliep (2012) show the influence of volunteer work in shaping women’s sense of identity. A

chronic, disabling illness and the impact of the illness on functioning propelled men to examine their masculine identity. (Riessman, 2003)

Gallas (1994) highlighted the evolving identity of children as they participate in the commonplace classroom activity of sharing time. Brown (1998) also conducted research in the educational setting but was sensitive to the experiences outside of school (e.g. home life) that shaped the girls' identities and expressions of feminism at school. Contemporary norms, living arrangements, work, illness, participation in a classroom activity, and home life are a few examples of external factors shaping identity explored through dialogic/performance analysis.

Relationship between Researcher and Study Participant

Riessman (2003) comments that, "qualitative research in the modernist tradition has minimized and/or ignored the identities of the investigator and their relationship with the subject, assuming that scientific standards and ethics could produce unbiased generalizable findings." This perspective, Riessman notes, has shifted to incorporate investigator subjectivity into the investigation because of the awareness that the researcher's position affects what is seen in the study participant. A characteristic of the dialogic/performance method is to acknowledge at the onset the importance of the interaction of the researcher and study participant in the creation of the narrative and the meanings gleaned from the narrative.

In her own work, Riessman (2003) discusses a specific incident in the interview that illustrates the limitations of her own understanding and comfort level and how her position shaped the original interviews. Randy initiated the topic of sexuality and spoke of his increasing comfort with his feminine side suggesting he may be bi-sexual.

Riessman speaks of her confusion about what these thoughts meant. Embarrassed in response to the idea of sexual ambiguity, Riessman moved the interview on to the next question. From the hindsight of twenty years and changes in cultural understandings, Riessman's secondary analysis reflects on this exchange as a clear example of how the relationship of narrator (the study participant) and audience (the investigator) shaped the direction and telling of the narrative. The approach in the secondary analysis was to acknowledge the researcher/participant relationship and explore several possible interpretations arising from the dynamics between them.

This same level of self reflection and acknowledgement about the interplay between researcher and participant is evident in the work of Gallas (1994). Gallas, discussing her role as a teacher-researcher remarks, "For the purposes of seeing, hearing, and perceiving children's meanings, I seek to expose my limitations as an interpreter of the world, rather than conceal them." The stories Gallas selects for scrutiny are "a personal account of the process of research," and in the retelling of the stories Gallas asserts, "I lose all claims to objectivity." The stories help Gallas to understand the children's world and how they learn as much as it is "to document my journeys into understanding my own history as a learner and they underscore how the legacy of a teacher's schooling lives on in her practice."

The relationship of researcher and study participant in constructing the narrative and its influence on analysis is minimized or absent in the three more recent examples. The study by Naidu and Sliep (2012) is devoid of discussion about the personal engagement of the researcher with the study participants. Busanich, et al. (2012) relies on relevant literature about the social, cultural and historical discourses of the relationship of

gendered perceptions of body, food and exercise. This knowledge is used to compare and contrast the personal narratives of the runners in the study and explore how the runners drew from these discourses to define their identity as distance runners. An unstructured interview format offered rich data, but absent was any discussion of the authors' personal characteristics or interactions with interviewees in shaping the narrative or influencing the analysis.

Svensson et al. (2012) describe the interviews as dialogues which permitted the elderly person to “tell their story as a dynamic co-production between the teller and the listener.” The researcher's background as a nurse specializing in the care of the elderly is noted to provide a pre-understanding of the care context and influence the interpretation of the narratives. One way this influence is seen is the selection of specific extracts from the data that are explored in depth as sources of the women's well being. However, this realization is presented in a dispassionate, impartial manner lacking the connectivity and interplay noticeable in the works of Gallas, Brown and Riessman.

Analyzing Data: Theme, Structure and That Something More

Various approaches to the actual analysis of data are evidenced in these studies.

However, each study acknowledges the essence of dialogic/performance analysis is a three part examination of themes, structure and something more. The third component is sometimes misleadingly named dialogic/performance analysis. (Naidu & Sliep, 2012) Collectively, the three components characterize dialogic/performance analysis as an effort to examine what is said (themes), how it is said (structure) and for whom; in what context the narrative is generated.

Each study examined all three components, yet there was no consistency in selection of analytical tools or approaches. Svensson et al. (2012) identified themes through multiple readings, used coding to place text in topical clusters and chronologically sorted themes prior to examining in depth the influence of a theme on the identity of participants. Naidu and Sliep (2012) used NVIV08 software to identify themes than turned their attention to a structural investigation of where and when themes occurred in the narrative. Analysis for Busanich et al. (20102) began with a search for references to body, food and exercise from which emerged common themes that were then linked to the cultural and social context of attitudes surrounding these topics. Brown (1998) used a researcher developed tool called a Listener's Guide which guides the investigator toward recognizing the various voices in the text. This was followed by the development of interpretive summaries a further tool for analysis.

Reflexivity and iteration summarize the approach to data analysis used by Brown (1998), Gallas (1994) and Riessman (2003). Repetitive journeys through the data incorporated self reflection that questioned the researchers understanding of the data. A continuous process of examining the data, assessing the researcher's role in the creation and interpretation of data, questioning one's understanding and/or assumptions, returning to the data for more information or a different view ultimately leads to an understanding of the phenomena of interest. The process of data collection and analysis is "a continuous cycle of reflection and of questioning those reflections" ...the data, the process, and even the questions are all constantly changing and rearranging themselves in different relationships" (Gallas, 1994) as new understandings emerge.

This characteristic of attending to thematic, structural and that something more is linked to the construction and performance of identity. Naidu and Sliep (2012) assert “dialogic/performance analysis is concerned with how social reality is constructed in interaction and how identity is dialogically created.” Identity is manifest through interplay of relationships that occur in and shift over the destabilizing effects of time and space. (Naidu and Sliep, 2012) This tri-part analytical method explores the dynamic development and transformation of identity through an examination of the thematic and structural elements of the narrative while attending to the context in which the identity forms.

Presentation of Findings

Several factors about the manner in which findings were reported are worth noting. These include the addition of quotes from individual study participants, the interspersing of references to other research findings from the literature, a discussion of the involvement of the researcher in co-creating the narrative and the intermingling within the findings of other aspects of the research study typically segmented into their own section.

Three of the studies (Gallas, 1994; Brown, 1998, Riessman, 2003) shared thoughts about their role in data generation and/or their feelings as they worked with the participants. The discussions were rich with examples of study participants’ words or actions to illustrate conclusions. Brown’s (1998) work is representative of this group. Brown’s findings were presented in the aggregate but also included quotes from specific girls illustrating a particular finding. Woven through the presentation was discussion of other researchers or intellectuals whose thoughts influenced either Brown’s method or

conclusions. The approach to data collection and analysis is incorporated sporadically within the discussion of the research findings.

These same three studies incorporated parts typically segregated from findings such as discussion of method. Absent was delineation between components of a research study but instead an intermingling of research purpose, sampling, analysis, findings, etc into a dynamic and fluid presentation of the research effort. The three newer studies revert to separating some of the components of the research study. Naidu and Sliep (2012) illustrate this point with distinct sections addressing literature review, methods, findings, etc.

Busanich et al. (2012) discussion of findings presented conclusions in terms of the study group as a whole and drew distinctions between male and female participants where the findings differentiated along gender lines. Individual participants were highlighted either by description or quotes to illustrate specific findings. Findings were interspersed with references to other research pertinent to specific observations.

A deliberate decision in the Naidu and Sliep (2012) research was made to report findings as a collection of information gleaned from all the interviews rather than using one interview as an exemplar for the group. Naidu and Sliep commented with this approach “the polyphonic/multi-vocal nature of narrative would be more authentically represented through various voices of the women.” The discussion accentuated findings with references to the work of others on this phenomenon of interest.

Discussion

Commonalities in the application of dialogic/performance analysis to narrative data distinguish research using this method. Distilled to the essential elements, research using

dialogic/performance analysis requires the investigator to relinquish preconceived ideas to be open to whatever meaning or understanding can be derived from a narrative of individual or group identity. The examination of data demands an acknowledgement of the interrelationship of researcher and study participant and its impact on findings. The content of the narrative, how the story is told, and to whom and for what purpose the story is told characterizes the tri-part approach to dissecting the data. The findings reported are rich with the words and behaviors of study subjects. Distinct sections of a research study are often indistinguishable as the discoveries are discussed intermingling purpose, methods, and findings. Yet, as the variations in these studies reveal, the commonalities are dynamic and flexible.

Even as these researchers made different decisions in the design and conduct of the research, evident were efforts to stay faithful to basic concepts central to dramaturgical and dialogic perspectives based on the works of Goffman and Bakhtin. These concepts include Goffman's ideas that we each play a role and control the information we share with others and Bakhtin's ideas of dialogism and unfinished self. As illustrated in the articles reviewed, the ideas of Goffman and Bakhtin that underlie this analytical method allow for flexibility in the research process.

Conclusion

“What is considered a vice in science – openness to competing interpretations – is a virtue in narrative.”(Czarniawska, 2004) Novice or experienced researchers looking for definitive guidance in the use of dialogic/performance analysis method may find the examples used in this review leave more room for discretion than hoped. With a basic understanding of the theoretical foundation underlying this method of analysis and

conformity to the characteristics that define dialogic/performance analysis in mind, researchers need not be timid about applying this method to their research efforts. In Bakhtin's schema, meaning is found in the interaction between a researcher and the creator of the narrative. Our response is individualized and unique. In that interaction we come to understand something of the other and we ourselves are transformed. As health care professionals studying matters related to patients and the care delivered, that transformation has the potential to enhance understanding of patients' conditions, increase empathy and improve the quality of the care we provide.

References

- Bakhtin, M. (1984). *Problems of Dostoevsky's Poetics* (C. Emerson, Trans.). University of Minnesota Press: Minneapolis, MN.
- Barusch, A. (2012). *Refining the narrative turn: when does storytelling become research?*. Gerontology Society of America. November 16, 2012. San Diego, CA.
- Brown, L. M. (1998). *Raising their voices: The politics of girls' anger*. Cambridge, MA: Harvard University Press.
- Bruner, J. (1990). *Acts of meaning*. Cambridge, MA: Harvard University Press.
- Busanich, R., McGannon, K. R., & Schinke, R. J. (2012). Expanding understandings of the body, food and exercise relationship in distance runners: A narrative approach. *Psychology of Sport and Exercise*, 13(5), 582-590.
doi.org/10.1016/j.psychsport.2012.03.005
- Coffey, A. & Atkinson, P. (1996). *Making Sense of Qualitative Data: Complementary Research Strategies*. Thousand Oaks, CA. Sage Publications, Inc.
- Czarniawska, B. (2000). The uses of narrative in organizational research. *GRI Report 2000:5*. Gothenberg, Sweden: Gothenberg Research Institute.
- Czarniawska, B. (2004). *Narratives in Social Science Research*. Thousand Oaks, CA. Sage Publications, Inc.
- DeFina, A. (2003). *Identities in narrative: A study of immigrant discourse*. Amsterdam: John Benjamins.
- Denzin, N. & Lincoln, Y. eds. (2008). *Collecting and Interpreting Qualitative Materials*. Thousand Oaks, CA. Sage Publications, Inc.

- Emerson, C. and Morson, G. (2006). "Mikhail Bakhtin." *The Johns Hopkins Guide to Literary Theory and Criticism* (Eds. Michael Groden, Martin Kreiswirth and Imre Szeman). Baltimore, MD: The Johns Hopkins University Press.
- Frank, A. (2005). What is dialogic research, and why should we do it? *Qualitative Health Research*. 15 (7), 964-974. doi: 10.1177/1049732305279078
- Gallas, K. (1994). *The Languages of Learning: How Children Talk, Write, Dance, Draw, and Sing Their Understanding of the World*. New York, New York: Teachers College Press.
- Goffman, E. (1959). *The presentation of self in everyday life*. New York: Penguin.
- Hirschkop, K. *The Contexts of Bakhtin: Philosophy, Authorship, Aesthetics*. Ed. David Shepherd. Australia: Harwood Academic, 1998. Print.
- Holstein, J. & Gubrium, J. (2012). *Varieties of Narrative Analysis*. Thousand Oaks, California: Sage Publications Inc.
- Holloway, I. & Freshwater, D. (2007). *Narrative Research in Nursing*. Malden, Massachusetts: Blackwell Publishing Ltd.
- Labov, W. & Waletzky, J. (1967). Narrative Analysis. In J. Helm (ed.) *Essays on the Verbal and Visual Arts*. Seattle, Washington: University of Washington Press.
- Labov, W. "Some Further Steps in Narrative Analysis." *The Journal of Narrative and Life History* (1997): n. pag. Web.
- Leech, N. L., and A. J. Onwuegbuzie. "Qualitative Data Analysis: A Compendium of Techniques and a Framework for Selection for School Psychology Research and Beyond." *School Psychology Quarterly* 23.4 (2008): 587-604. Web.

- Naidu, T., & Sliiep, Y. (2012). Understanding the agency of home-based care volunteers: establishing identity and negotiating space in AIDS-home-based care in rural KwaZulu-Natal, South Africa. *African Journal of AIDS Research*, 11(2), 143-152. doi:10.2989/16085906.2012.698082
- Peterson, E. & Langellier (1997). The Politics of Personal Narrative Methodology. *Text and Performance Quarterly*, 17(2), 135-152.
- Polkinghorne, D. (1995). Narrative configuration in qualitative analysis. *Qualitative Studies in Education* (8)1, 5-23.
- Riessman, C. K. (2003). Performing identities in illness narrative: Masculinity and multiple sclerosis. *Qualitative Research*, 3(1), 5-33. doi: 10.1177/146879410300300101
- Riessman, C.K. (2008). *Narrative methods for the human sciences*. Los Angeles, CA: Sage Publications.
- Ritchie, J. & Lewis, J. (2009). *Qualitative Research Practice A Guide for Social Science Students and Researchers*. Thousand Oaks, California: Sage Publications Inc.
- Svensson, A., Mårtensson, L., & Hellström M. U., (2012). Well-being dialogue: Elderly women's subjective sense of well-being from their course of life perspective. *International Journal Of Qualitative Studies On Health And Well-Being*, 7. doi:10.3402/qhw.v7i0.19207

CHAPTER 3-MANUSCRIPT 2

MEETING THE CHALLENGES OF CONDUCTING
A QUALITATIVE SECONDARY ANALYSIS

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Introduction

Secondary analysis can be used for several purposes that include verifying, refining, offering new perspectives, or refuting the findings of the primary study; or in a synthesis of multiple research studies (Leech, 2008). Researchers recognize that interviews as a method of data collection generate a large amount of data that, while interesting, informative or important, may not contribute to the final research outcomes. (Hinds, Vogel and Clarke-Steffen, 1997; Long-Suthehall, Sque & Addington-Hall, 2010)

Secondary analysis offers the opportunity to maximize the use of data that were potentially costly or difficult to obtain while adding to a body of knowledge. Despite a growing interest in qualitative secondary analysis, academics note the scarcity of information about the process of performing secondary analysis (Long-Suthehall, Sque and Addington-Hall, 2010).

Active debates about the merits of achieving sound and credible research results from a qualitative secondary analysis abound. Advantages and disadvantages of qualitative secondary research are dissected (Windle, 2010). The need to understand context and the necessity of researcher presence are passionately addressed (Bishop, 2006; Irwin and Winterton, 2011). Data management including storage and security issues, ethical and legal concerns is discussed (Doolan and Froelicher, 2009). The debates extend to the very definition of secondary analysis and the blurring of differences between primary and secondary analysis (Heaton, 2008; Windle, 2010).

Definitive resolution of debates about the merits of conducting qualitative secondary analysis are beyond the scope of this article but they serve as a backdrop and underscore the significance of adding to the understanding of the process of performing

qualitative secondary analysis. “Researchers doing secondary analysis need not only understand research concepts related to designing a new study, but additionally must be aware of challenges specific to conducting research using an existing data set” (Doolan and Froelicher, 2009, p. 203). The goal of this article is to provide methodological guidance by illustrating how these “challenges” of context, researcher presence and other issues are addressed in a qualitative secondary analysis study using the narrative analytical approach – dialogic/ performance analysis.

Dialogic/ Performance Analysis

The dialogic/performance analysis method combines elements of thematic and structural analysis with features unique to this technique (Riessman, 2008). The thematic element examines what is said (i.e. the plot, the characters and the common patterns that emerge in telling the story). How the story is told is examined in a structural analysis looking at how the narrator organizes and presents the story to persuade the listener to understand the story from the narrator’s perspective. A third element explores to whom the story is addressed, under what circumstances and for what purpose. These three elements form the conceptual foundation of dialogic/performance analysis (Riessman, 2008).

Dialogic/performance analysis is a broadly interpretive technique (Riessman, 2008) with ties to the philosophical work of Erving Goffman and Mikhail Bakhtin. Goffman used a dramaturgical metaphor in an explanation of social interactions (Goffman, 1959). In a simplistic explanation of Goffman’s work, people play a role in interactions with others and attempt to shape people’s impression or understanding of themselves by controlling the kind and amount of information they share (Goffman, 1959). Bakhtin’s contribution with complex ideas of dialogism, polyphonics,

heteroglossia, and unfinished self-defying concise definitions (Emerson, 2006). These concepts are closely linked to Bakhtin's idea that our identity is unfinished and constantly evolving as we interact with one another. Goffman and Bakhtin share the perspective that narrative develops in the social interaction between the interviewer and the interviewee and from that exchange can the meaning be ascertained. The idea that meaning is found at the intersection of people's social interactions helps us to understand the other and concurrently changes us. Dialogic/performance analysis offers an approach to examining data that captures the meaning ascertained by the researcher through their interaction working with the data.

The Research

I conducted a secondary analysis using dialogic/performance analysis applied to interviews originally collected for a study titled *HIV Transmission Risk, Access to Treatment, and Self-Management of Illness over Time: An In-Depth Longitudinal Study of HIV-Infected Women in Kenya* (Kako, Stevens & Galvao). This method offered the opportunity to add to our understanding of the experience of HIV positive women in Kenya by shifting the focus from a researcher-driven perspective to that of the participant's perspective. "To think of an interviewee as a narrator is to make a conceptual shift away from the idea that interviewees have answers to researchers' questions and toward the idea that interviewees are narrators with stories to tell and voices of their own" (Denzin & Lincoln eds., 2008, p. 70). This shift in perspective opened the analysis of data to the possibility that these Kenyan women would provide information about their experience being HIV positive that the researchers may not have even known to ask.

The use of dialogic/performance analysis opened the research to concerns about a number of challenges that could potentially undermine the credibility and soundness of the research. These challenges include conceptualization and coherence of the study design; fit of research question to existing data set; suitability of the data set; context; contact between researchers; data analysis; and informed consent, confidentiality and anonymity. Each of these challenges is discussed to provide insights into how they were conceptualized and addressed in the conduct of my study.

Confronting the Challenges

Conceptualization and Coherence of the Study Design

The challenge related to conceptualization of my research is captured in the question - how successful was this study in overcoming the disruption in the usual development of a research study in achieving a sound study and credible findings? The development of my study followed a path from data set, to selection of a narrative analytical technique, to determination of the research questions, to analysis of the data leading to a discussion of the findings. This path was initially driven by an advanced qualitative research class assignment to analyze the interviews using a narrative analytical technique of our choosing.

This path to development of my study stands in contrast to the more typical approach where the research proceeds linearly through the conceptualization, design/planning, empirical, analytical and dissemination phases (Polit and Beck, 2008). The real test of the usefulness and quality of a research endeavor is not its adherence to a prescribed set of guidelines for the development of the study but rather the soundness of the findings. Hammersley (1997, p. 135) said it thusly “what is crucial for the testing of

knowledge claims is not how those claims were produced but their cogency in light of the evidence.”

The success of the approach used cannot be answered without determining how well the other challenges to conducting this research were met. Selection of a research question that complements the original research question, an analytical technique that accommodated to the data set available, adoption of a view of context consistent with the analytical method used and other factors lend credence to a conclusion that the altered path for developing the research study allowed for a sound study that offers credible findings.

Fit of Research Question to Existing Data Set

“In secondary analysis, the fit between available data and the new research question is clearly the most important issue to resolve” (McArt & McDougal, p. 4, 1985). This idea is echoed “a research question that differs considerably from that of the primary study may be unanswerable in a secondary analysis of a qualitative data set” (Hinds, Vogel and Clarke-Steffen, 1997). Recent debates on the merits of secondary analysis suggest a limitation of a secondary analysis is the misfit between data collected and the secondary research question. Doolan & Froelicher (2009) assert that changes over the time between initial data collection and secondary analysis may limit which research questions are appropriate.

In my secondary analysis, the concerns expressed about potential misfits between the data collected for a different research question and the research questions in the secondary study are resolved by a complementary alignment of the research questions. The secondary analysis builds upon the aims of the original study but rather than focusing

on what the researchers wanted to know, the research questions were developed to examine what the women wanted to tell me. Dialogic/performance analysis provided a fresh look guided by an underlying perspective that the study participant was not simply answering the interviewer's questions but was providing a performance that would reveal their identity and experience as HIV positive women in Kenya.

Gladstone, Volpe and Boydell (2007, p. 435) assert "Another important factor in establishing the quality of the study was that the new research question not only fit with the old data but arose directly from the primary data." In my research, the new research questions arose directly from the data by focusing on the women's presentation of their experience living as HIV positive women. The research questions used to conduct the analysis were broadly written in an effort to reduce my biases and their influence on my reading and allow the women's own words to lead me to an understanding of the impact of their diagnosis on their identity and lives.

Suitability of Data Set

The primary challenge in conducting the secondary analysis using an existing data set is to demonstrate that the existing data set is appropriate for answering the research question. Is the data set suitable to answer the research question (i.e. is the phenomena of interest aligned between the research question and the data set)? Is the data set of sufficient depth and quality to be appropriate for the selected analytical method? Is the use of the data set precluded or adversely impacted by obstacles set forth by the original researcher?

The cost effectiveness, efficiency, convenience and time savings of using an existing data set are often reasons for support of conducting secondary analysis of

qualitative data (Szabo and Strang, 1997; Doolan and Froelicher, 2009; Windle, 2010). An existing data set can contain content of interest to a researcher. If the data set is large or study participants are difficult to recruit, the use of an existing data set may be preferable to collecting a smaller sample of primary data (Windle, 2010). The travel expenses and logistics, the sensitive nature of the research topic, the potential challenges to recruiting study participants and other factors indicate that for this project a secondary analysis using a different analytical method than that used in the original study is a cost effective and prudent effort to maximize the knowledge that can be obtained from the words of the women in the original study.

Generally a presumption exists that the researcher will design a study including recruiting participants and developing data collection processes subsequent to the determination of the research question (Doolan and Froelicher, 2009). Decisions about the sample needed such as sample size, inclusion and exclusion criteria and method of sampling are integral to the overall study design and premised on the research question. The secondary analyst uses a data set that already reflects sampling decisions thus they “must work within the confines of whatever study design and measures were chosen for the parent study” (Doolan and Froelicher, 2009; p. 204). This includes whatever decisions were made related to sampling. The flexibility and openness to explore whatever topics the study participants mention inherent in a dialogic/performance analytical approach negates the presumed limitations of initial sampling decisions. The characteristics of the sample are more descriptive of the context than constraints on methodology or knowledge production.

Clarke and Cossette (2000) speak to the need for a secondary analyst to be familiar with the methods used to recruit the original study participants. Sampling issues that arise in the course of doing a secondary analysis include selection biases, representativeness of the original sample and selection of subgroups from a larger primary dataset. These issues do not seem problematic when conducting a dialogic/performance analysis. Dialogic/performance analysis is built, in part, on the concept that meaning is found at the junction of the interaction between researcher and study participant. For my research, the analysis of data involved individual original study participants. The make-up of the group of women in the original study and the potential that selection criteria created a group that is not representative is not relevant to understanding each woman's individual experience. When claims are made for a group as a whole, issues of the representativeness of the underlying sample become more problematic if the researcher attempts to assert the experience of this group can be generalized to the whole universe of people with x characteristics. The collective experience of this group was examined and discussed but no attempt was made to assert these findings could be generalized to the whole universe of HIV positive women in Kenya.

Dialogic/performance analysis has been applied to a wide variation (2-19 participants) in the sample size recruited (Riessman, 2003; Gallas, 1994). Researchers who choose a very small sample expressed the advantage of being able to attend to the smallest details of the participants' experiences (Riessman, 2003; Lorenz, 2011). Larger samples tracked a natural grouping such as the students in a classroom (Gallas, 1994) or a purposeful attempt to recruit participants who fit the sampling criteria. (Busanich,

McGannon and Schinke, 2012) The only limiting factor to sample size in the use of dialogic/performance analysis appears to be the generally acknowledged time consuming nature of qualitative research. Nor does the literature suggest a requisite number of study participants. For my study, I used all participants from the original study for whom I had complete interview transcripts.

Early discussions of secondary analysis of qualitative data cited the lack of control in generating data as one of the limitations of this mode of inquiry. The availability of the original researcher to the secondary investigator was perceived to be critical to resolve problems such as unclear procedures in data collection, missing or inaccurate data and other concerns (McArt & McDougal, 1985). The lack of control could be perceived in conceptualization, generation or recording of the data set. Further, problems or biases in the original resources may impact the secondary analysis (Szabo & Strang, 1997). To overcome this limitation, proponents of secondary analysis urge communication between the investigators in the original and secondary research. The relationship of the secondary analyst to the original research team is a practical consideration. If the secondary analyst was part of the original research team this would facilitate access to original data, consultation with the original researchers and cross-checking of secondary analysis results (Heaton, 1998). Thorne (1990) urged a reporting of the original research in the secondary analysis including an outline of and the data collections procedures of the original study. A recommendation to assess the quality of the original data with a set of criteria was recommended. This assessment could determine the completeness of the data set, the accuracy of transcription, interpretability of the data and other factors (Hinds, Vogel and Clarke-Steffen, 1997).

I was not part of the original research team nor was an assessment of the quality of the data undertaken. The principal investigators in the original study provided the interview transcripts, field notes and demographic information about the study participants. As part of the analysis, interpretive summaries were created which were reviewed by the principal investigators who offered confirmation that these summaries captured the women's voices. Additionally, the final findings were reviewed by the principal investigators. This approach is consistent with the changing thoughts about primary-secondary researcher communications.

The thoughts about secondary analysis are evolving with debates about the desirability or necessity for the secondary researcher to communicate with the primary researcher or be intimately familiar with the primary research. Hammersley (2009) offers a construct that supports the independent use of the same research material by primary and secondary analysts while finding the outcome of the research to be indistinguishable in terms of validity. A distinction is made between data (i.e. the material collected or generated during the data gathering part of the research process) and evidence. Evidence is defined as the analyzed data which forms the basis for inference and for the descriptive and explanatory conclusions drawn from the data. Hammersley (2009, Point 4.2) writes "From this point of view , it may seem that data cannot exist independently of the research process, whether this is 'primary' or 'secondary' they are formed by the processes in which they are given meaning through being used as a basis for drawing inferences."

Building on this point of view, Irwin and Winterton (2011, p.8) comment "Sociological data will support different theoretical understandings and 'being there' is

not the final arbiter of the adequacy of such understandings.” If the use of pre-existing data is thought of as a new process of re-contextualizing data as posited by Moore (2006), Irwin and Winterton (2011) conclude secondary analysis is “on a more equal footing with primary analysis, as well as reminding users of the continual relevance of the socially shaped nature of data and its interpretation.”

The points of view expressed by Moore (2006), Hammersley (2009) and Irwin and Winterton (2011) are consistent with Goffman’s and Bakhtin stance that meaning is found in the interaction between two persons. New meanings can be derived from data that was collected by someone else without any loss of fidelity. Dialogic/performance analysis is particularly suited to re-using data because it offers an opportunity to explore data that may have been overlooked or was not relevant to the research questions of the primary researcher. Further, using the same data, the method fundamentally emphasizes the interactive nature of creating meaning leading to conclusions or findings by the secondary investigator that may or may not be consistent with or even related to the outcomes derived by the primary researcher.

Context

Arguably no issue is a greater challenge to secondary analysis in qualitative research than that of context. The understanding of context must be reframed in discussion of secondary research as considerations of context impact analytical and methodological issues differently in secondary research versus original research. The position of context within secondary analysis, including dialogic/performance analysis, is acknowledged to be important although precisely what context is relevant and how it is important is unclear. The challenges of context and how they were addressed within the secondary

analysis I conducted using dialogic/performance analysis to examine narratives are reviewed here.

Riessman's (2008, p.105) discussion of dialogic/performance analysis acknowledged the role of context in narrative. Riessman notes that interactively (dialogically) produced narrative requires a "close reading of contexts including the influence of investigator, setting, social circumstances on the production and interpretation of narrative." This close reading is necessary in dialogic/performance analysis to answer the questions to whom is the utterance spoken, when and for what purposes? Answers to these questions supplement the portion of the analysis that examines theme (i.e. what is spoken) and structure (i.e. how it is said). Langellier states (in Lincoln and Denzin, eds., 2003) "from a pragmatic perspective, personal narrative performance is radically contextualized: first, in the voice and body of the narrator; second, and as significantly, in conversation with empirically present listeners; and, third in dialogue with absent or 'ghostly audiences'." (p.444) It is this understanding of context rather than social, historical, political or other context that is the focus of dialogic/performance analysis. Riessman's focus is on understanding how the contextual factors enter into the narrative and how the narrative is coproduced as these complex and intertwining contextual features influence the investigator, the study participant and their interaction.

Complicating the ability to definitively address concerns about context when conducting a secondary analysis is recognition that a generally agreed upon definition of context is lacking. The concept of context seems to mean different things in different strands of qualitative research, each focused on aspects of the context that appear more

relevant to interpretation of the interview data (Van den Berg, 2005). To be sure, context cannot and should not be ignored in secondary analysis but a certain amount of discretion and ambivalence remains even after a researcher accepts a specific conceptualization of context in which to ground their research.

One definition of context reflects the view context represents a close knowledge of study participants and of their immediate circumstances (Bornat and Winterton, 2012). From this viewpoint, “an intense personal involvement in the fieldwork constitutes a necessary prerequisite in order to grasp the relevant context and to interpret interview transcripts” (Van den Berg, 2012). This perspective would virtually render secondary analysis of qualitative data impossible. “Primary researchers have a specific and privileged relationship to the data they generate, through their relationships with research participants and the immediate context of the research. The implication is that this generates forms of reflexivity, and knowledge and insights which are not available to analysts coming to the data as re-users” (Irwin and Winterton, 2011, p. 7).

The counter argument to the position that a valid analysis is only possible through close proximity to the data is that valid analysis is determined by the adequacy of researchers’ systematic attention to the context of knowledge construction in all stages of the research process rather than proximity to the original context (Mason, 2007). Moore (2006) argues that data is not given to a researcher but rather in both secondary and primary research qualitative data is constructed. A secondary analysis of qualitative data is a process of re-contextualizing the data not simply reusing existing data. Hammersley (2009) distinguishes between data and evidence. Hammersley believes data can be given or constructed. Evidence is the analyzed data that gives rise to the descriptive and

explanatory claims presented in the findings. This distinction is useful to support the idea that primary and secondary researchers are positioned differently working with the data, and primary investigators cannot limit or control the knowledge and insights that can be derived from the data by other researchers. Irwin and Winterton (2011, p.8) summarize the argument thusly “Primary analysts have a privileged relationship to the data they have generated, but do not necessarily have a privileged claim on the arguments which can be made from that data.” Data can support different understandings derived through different analytical approaches thus close proximity to the data is not essential to the development of credible findings in a secondary analysis.

Dialogic/performance analysis sidesteps the need for an intense personal involvement in the generation of data. What is at the core of a dialogic/performance analysis is the idea that meaning is found at the intersection of the interaction between the investigator and the study participant personified in the interview transcripts. The interaction of the primary researcher and study participant is rendered irrelevant to the meaning the secondary researcher may find as they interact with the data. Just as two people may respond similarly or differently to a representation a person makes in a graphic (e.g. painting), musical (e.g. song) or literary (e.g. poem) form so it is with a primary and secondary researchers derivation of the meaning to be found as they interact with the study participants. Neither interpretation is “wrong” or “right” but rather represents different understandings of the complexity of any human interaction. An accounting of the decisions and processes used in the study methodology enable other investigators to evaluate the strength, credibility and soundness of findings whatever analytical technique is employed.

The qualitative research paradigm is premised on the notion that production of data is influenced by the broad constellation of historical, biographical, cultural, social, political or other context (Irwin and Winterton, 2011). This influence is seen at multiple points in the research including the landscape in which the research is funded or conducted and the influence these contexts have on the study participant's responses or the investigator's interpretation of data. This more expansive definition of context recognizes context as the social, political and historical setting that shape the study participant and their responses and the co-creation of the data during the interview. This viewpoint supports an assertion that secondary analysis of qualitative data, if it can be conducted at all, is very limited the further the secondary researcher is from the original production of data (Mauthner, Parry, and Backett-Milburn, 1998).

Bakhtin's concepts of polyphony, heteroglossia and dialogism, foundational philosophical components of dialogic/performance analysis, remove the onerous task of identifying relevant factors from the broad constellation of contexts that shape the researcher, study participant and even the study. The voices study participants speak with reflect the historical, cultural and other contexts that shape who they are. Their voices are an amalgamation of the multiple voices encountered in prior interactions and voices that get reflected in the current utterance. Similarly, investigators interact with the data as they are that moment - a composite of the social, historical and other context that has shaped their identity. Specific knowledge of contextual factors and proximity to the production of data are not needed to find meaning in the interaction under review. Consistent with Goffman's ideas, both parties will control the information they supply to the other, filling in details of social, historical or other context as needed to control and

convey the impression of themselves they want the other to develop during the interaction. In a sense, the parties involved in the interaction, the study participant and the investigator, bring the relevant context to the interaction as it is reflected in their words.

Van den Berg (2005, section 4.1) discusses three conceptualizations of context—broad, intermediate and narrow. The extra-discursive template (aka the broad concept) is “conceptualized as socially constructive as well as constituted by structural features of society” which generally leads to an interpretation of text as “the imprint of structural inequalities.” As an example of this approach, Van den Berg cites an assumption that western societies are culturally and structurally racist. Thus, when analyzing interviews that include racial topics, an assumption of an underlying racism may result in the researcher excluding contradictions in the data that are inconsistent with this assumption. A better approach to interpreting data Van den Berg asserts is for the researcher to attempt to discover what context is relevant to interpreting the data. This position ignores the input of the study participant in identifying what is relevant – a position fundamentally incongruent with the tenants of dialogic/performance analysis.

The intra-discursive product is a narrow conceptualization that removes methodological problems with context. This viewpoint posits that the only relevant context is that evidenced by participants in their talk. Van den Berg finds this view too narrow for several reasons. The shared knowledge base or common ground of researcher and participants sometimes negates a need for a participant to demonstrate relevant context. Study participants may selectively use context that emanates from different historical, cultural or other origins potentially distorting the actual relevance of the reference demonstrated in their talk. Third, this viewpoint artificially fractures talk from

other forms of social behavior. This conceptualization of context ignores the input of the other party to the interaction, the investigator. Similar to the extra-discursive template this view represents a position inconsistent with the tenants of dialogic/performance analysis.

Van den Berg advocates for a concept of context that takes a middle ground posing that “the kind and measure of contextualization needed on behalf of the analysis of textual data should be derived from the research design” (Section 4.3). Contextual knowledge needed is dependent on the research goal and the type of data. The advantages of this approach are implicit as this view recognizes that identification of all relevant contexts is unattainable and context is always limited. Parsimony as the principle for selecting relevant context is promoted. Van den Berg proposes minimum guidelines for the contextual information required in a secondary analysis of qualitative interviews with the caveat that these minimums may be insufficient for some research goals. These guidelines are:

- Detailed transcripts or audiotapes
- Complete interview not just parts
- Background characteristics of interviewer and interviewee (at the least the obvious or knowable characteristics such as age, gender, race, social class, etc.)
- Information about the place, time and setting of the interview
- Information about the selection of interviewees and how they were approached to cooperate
- Information about relevant others known to the interviewer or interviewee

This conceptualization of context is both relevant and workable when undertaking secondary analysis using dialogic/performance analysis. This view of context is also consistent with the philosophical foundations of dialogic/performance analysis which suggests any relevant context is brought to the interaction by the persons involved in the interview. The focus is on the moment interviewer and interviewee or in a secondary analysis, interviewee as revealed in the written transcript and investigator as they interact with that representation.

In a secondary analysis, the investigator may lack opportunity to sort through social, cultural, historical or other contextual factors to determine their relevance. In my own research examining the interview transcripts of HIV positive women in Kenya, very little of the broader context in which these women lived was known. In a few instances, the women mentioned broader contextual events e.g. civil conflict in the country or famine as a background to their answers to particular questions. Occasionally the women used a term not known by me that appeared to reference an item or event that was unfamiliar but could basically be understood in the context of the information sharing. For example, many women talked about working in their *samba* which I understood to be a garden plot or talked about participating in merry-go-rounds; a seemingly financial arrangement for the women to share finances and help women with acute financial needs. Could information about the broader context have been attained perhaps through discussion with the primary researcher or readings on the social, political, economic and other aspects of life in Kenya today? Perhaps but this begs the question. The threshold question is - was any of the broader contextual information needed to adequately analyze data using dialogic/performance analysis in a secondary analysis of the interview

transcripts? My experience using this technique with the interviews suggests the answer is no, broader contextual information is not needed.

Available to me as the secondary researcher was some of the information Van den Berg posits as minimum contextual information. Complete transcripts of the interviews and field notes were provided by the original investigator. Additionally, a demographic sheet that detailed each participants age, marital status, number of children, years since diagnosis, monthly income, education level, and site (urban or rural) was provided as well as the number of times the interviewee was interviewed. Basic information about the original researcher available included gender, ethnic background, and university affiliation. Other characteristics of the interviewer were revealed reading the transcripts. The interviewer's offer to conduct interviews in English, Swahili or a local dialect confirmed fluency with native languages that suggested a familiarity with Kenya. A synopsis of the goals of the original research was also given to me.

Specific information about the place, time and setting of the interview was not known as the transcripts were being examined. Information about the interview setting became clear reading the transcripts e.g. the women were interviewed at a health care facility when they were there seeking care or medications. Also unknown was how the women were recruited although the basic facts that they were all women, HIV positive and involved in treatment appeared to be minimum criteria for participation. In some transcripts the women commented about food or money for transportation hinting these items were provide as an incentive to be interviewed.

Nothing was know about relevant others that may be known to either the interviewer or interviewee. Van den Berg (2005) offers that this information about others

who serve as gatekeepers, other interviewees, etc. may be helpful in determining if the interviewer and interviewee had a common knowledge base or had knowledge of the other person. Either could influence the conduct of the interview or the analysis of data. The social interplay that characterized the initial dialog in the interviews leads to a conclusion that the interviewee and original interviewer did not know each other or share common acquaintances.

The intermediate concept of context articulated by Van den Berg (2005) offers a viable perspective for the role of context in a secondary analysis of interviews using dialogic/performance analysis. The minimal contextual information needed according to the guidelines was generally available or could be derived from the interviews themselves. The intermediate concept of context melds well with the philosophical underpinnings of dialogic/performance analysis, the research purpose, and the process of data analysis as demonstrated in this particular research. Limited contextual knowledge did not preclude a secondary analysis of the transcripts of HIV positive women in Kenya using dialogic/performance analysis and the generation of knowledge that adds to an understanding of this population.

Issues of context whether discussing primary or secondary analysis arise. The type of contextual information needed-the relevance of contextual information available, the necessity for certain types of contextual information to address the research question, the compatibility of conceptualization of context with theoretical perspective assumed for the study and other issues weigh on the design and process of conducting qualitative research. Researchers who use data collected for another study are limited to what is available. Irwin and Winterton (2011, p. 16) conclude “examples of qualitative secondary

analysis demonstrate the insights to be gained from acknowledging the legitimacy of multiple interpretations derived sensitively from the same data. Ultimately it is the fit between data and research questions rather than proximity to the original context that will enable sufficiency and validity.”

Contact between Researchers

There are two questions that need to be addressed in regard to contact between the primary and secondary researcher. To what extent did the investigator have contact with the original researcher? How, if at all, did the amount of contact impact the study?

Heaton (1998, p. 4) discussed the relationship of the second researcher and the original research team. She suggested a secondary analysis is best accomplished by a member of the original research team because they would have access to all the original data. If not part of the original research team, the secondary researcher needs access to the original data including all field notes and “ideally they should also be able to consult with the primary researcher(s) in order to access the quality of the original work and to contextualize the material.”

More recently, Windle (2010, p.323) notes “many authors recommend performing a secondary analysis of an existing dataset only when there is access to the primary investigator and the original research study.” The rationale for this position speaks to developing an appreciation for the strengths and limitations of the original study and how these characteristics may inform or impact the secondary analysis. For example, challenges to recruiting study participants may have created a sample that was satisfactory for the original research but could potentially skew research results in a

secondary analysis based on a different research question or using a different methodology.

The value of contact with the primary researcher may be a function of the purpose in conducting a secondary analysis. Investigators who want to reuse data may not recognize or appreciate the manner in which the original researchers influence permeates the data (Bornat, 2005). If the goal of the secondary researcher is an attempt to replicate findings or reveal methodological insights on the techniques used in the primary study conferring with the primary researcher may be a critical step for the secondary analyst.

Reuse of data that involves a different research question or a different methodology may not be sensitive to the influence of the original researcher rendering conversation between the two researchers unnecessary.

Discussions with the primary researcher about the design and conduct of their study, so the thinking goes, could avoid problems in the secondary analysis. The strength of this position is diminished by a variety of factors. Intimacy with the design, processes and analysis in the original study does not necessarily give rise to greater insights into potential flaws or recognition of strengths. Fielding (2000, p. 21) states “primary data analysis is always subject to the problem that researchers will have entered the field and collected their data with particular interests in mind...this is probably more often an implicit or unwitting process, but this actually makes the problem worse, since the primary researcher may sincerely believe that such processes have not been at work and so may be blind to their effects.”

Researchers are not necessarily involved in all aspects of the research. Research assistants, translators and other people may have a hand in the collection of data,

analysis, interpretation, and write up of the research. At each phase the discretion exercised and decisions made ultimately influence the research (Gladstone, Volpe & Boydell, 2007). Secondary researchers who attempt to gather information from the original researcher that might help inform their own study may find the effort yields little, if any, useful guidance. Irwin and Winterton (2011, p.6) remark that, “even the same researchers returning to their own previously produced data will experience some sense of dislocation from that original context.”

In this application of dialogic/performance analysis in a secondary analysis of interviews with HIV positive women from Kenya I was not a part of the original research team. The principal investigators shared interview transcripts. They were aware of and supported the analytical work through a review of interpretive summaries and final results and suggestions for strengthening the presentation of the research. There was recognition that the women “spoke” to each researcher independently and each researcher gleaned from the interaction their own understanding of the lives and identity of these women. “Qualitative strategies based on interview or other data generation external to the researcher means that not being there will be less of an issue” (Irwin and Winterton, 2011, p. 9) and, one might add, a limited role for the original researcher may be less of an issue. This stance is consistent with the ideas advanced by Goffman and Bakhtin.

Distance from the original researcher, distance from the methodological decisions in the original research, even distance from the context of the original may have advantages. “Distance may open up new avenues of enquiry. Indeed, as we have seen, distance achievable by those originally involved, as by secondary analysts coming to the data for the first time, may engender new kinds of insight into the data” (Irwin and

Winterton, 2011, p. 9). Fielding (2000, p. 21) suggests that “secondary analysts may have a legitimate claim to greater plausibility since it is less likely that the analytic interests which are employed will have played a part in the interactional field from which the data were derived.” A secondary research purpose that was not demanding of contact with the original researcher and a philosophical perspective that emphasizes unique interactions eliminated the need for me to maximize contact with the primary researcher with no perceptible impact on the quality of the secondary research.

Data Analysis

The challenges of data analysis utilizing a dialogic/performance method in a reuse of data are to demonstrate the analytical method is:

1. consistent with the overall design (conceptualization, use of existent dataset, context) of the secondary analysis
2. not hampered by any deficiencies of the original research
3. reported with sufficient detail and transparency to allow for a critical review of the analysis

Points 1 and 2 have already been addressed in the discussion of the research question, the suitability of data and elsewhere to conclude that the approach to data analysis was consistent with the overall research design and that any deficiencies in the original data did not hamper the utilization of dialogic/performance analysis in a secondary analysis of interviews with HIV positive women in Kenya. Turning to point 3, unlike the application of a specific statistical test in quantitative data analysis, qualitative data analysis even in the use of commonly used methods such as Grounded Theory Analysis varies in the

details of application to the data as evidenced by the Glaserian and Straussian strands of grounded theory (Polit and Beck, 2008).

A review of extant studies in which dialogic/performance analysis was used revealed some diversity in application. All the studies included an examination of theme, structure and dialogic/performance, but the approach to each component varied considerably. For example, addressing the thematic component, Naidu and Sliep (2012) used NVIV08 software to identify themes whereas Svensson et al. (2012) used coding to place text in topical clusters. Svensson et al. (2012) offered a structural analysis that explored transcripts line by line. In contrast, Riessman (2003) edited the transcripts, focusing on segments of interviews that addressed a topic e.g. the interviewees desire to be a working man. Busanich's et al (2012) focus on context drew on the gendered narratives and cultural discourses surrounding food and exercise, comparing and contrasting the study participants' narratives on the relationship of body, food, and exercise with that found in exercise psychology and sport literature. Brown (1998) noted the demographics and characteristics of the communities the girls in the study came from, but also emphasized the context of each girl's life as revealed in their individual narratives.

The flexibility of dialogic/performance analysis to accommodate various methodological tools offers researchers a great deal of latitude and creativity in the development of their own approach to examining the data. It is incumbent on investigators to offer sufficient detail and transparency in reporting their findings to allow for a critical review of their work. The findings of my own research are reported

elsewhere. The reader of those findings will be the judge of whether the explanation of my data analysis approach is adequate and coherent.

Informed Consent, Confidentiality and Anonymity

The literature on secondary analysis raises concerns about ethical issues related to informed consent, confidentiality and privacy (Corti, Day and Backhouse, 2000; Gladstone, Volpe and Boydell, 2007). How is informed consent handled in a secondary analysis research study? How can the study participants' confidentiality be maintained? Does de-identifying the data distort the data rendering it unusable for a secondary analysis? These are just a few of the kinds of questions that arise when contemplating a secondary analysis. How the issues are addressed is study-specific. In the present research, these issues were easily resolved and did not prohibit utilization of the data set or erode the content of the interviews.

Interviews from the primary study *HIV Transmission Risk, Access to Treatment and Self Management of Illness over Time: An In-Depth Longitudinal Study of HIV positive Women in Kenya* were electronically provided to the secondary researcher by the original study's principal investigators. The study participants' names were changed. No information was provided about where (other than country) or when the interviews were conducted. A demographic sheet provided information age, marital status, number of children, rural or urban, education level and years since diagnosis. No key that correlated the pseudonyms to the participants' actual names and other information that could identify the women was provided. The interviews were stored on a dedicated USB flash drive kept in the control of the secondary researcher. Printed copies of the transcripts were kept in a locked file box.

Ideally all primary researchers would include a specific request regarding the potential for secondary analysis in their consent forms to facilitate future research projects. Informed consent for secondary analysis when the original consent form was silent is problematic. Issues of confidentiality, non-maleficence and fidelity are as relevant for secondary analysis as for any research (Long-Sutthall et. all, 2010). One standard for evaluating the appropriateness of conducting secondary analysis is to determine if a re-use of the data violates the contract between the primary researcher and study participants. Factors to make this determination are to assess the fit between the original and secondary research questions and the potential shift away from the initial intention of research (Heaton, 1998). This professional judgment is supplanted today by rigid requirements to seek approval from an Institutional Review Board.

The Office of Human Research Protections within the United States Department of Health and Human Services is charged with implementing 45 CFR 46 which is a set of regulations covering Institutional Review Boards (IRB) (<http://www.hhs.gov/ohrp/index.html>). These regulations permit an IRB to waive or alter the requirement for informed consent provided that the IRB finds the following four conditions are met:

- The research involves no more than minimal risk to the subjects;
- The waiver or alteration will not adversely affect the rights and welfare of the subjects;
- The research could not practicably be carried out without the waiver or alteration; and

- Whenever appropriate, the subjects will be provided with additional pertinent information after participation.

45 CFR46.116 (d)

In 2011, the DHHS Secretary's Advisory Committee on Human Research Protections made a specific recommendation on compatibility of secondary use with consent. The recommendation facilitates the conduct of secondary research stating (p.4):

“The determination of whether a proposed secondary research use is compatible with the original consent will be context-specific based on a range of considerations. If the original consent form specifically prohibited the proposed research activity, it is presumed the research is not allowed. If the consent does not prohibit the proposed use, IRBs should consider several questions to determine compatibility:

1. What is the nature of the proposed secondary research?
2. Could it be reasonably understood to fall within the scope of research that was described in the original consent form?
3. Does the new research use impose new or significantly greater risks (including privacy risk) not described in the initial consent form?
4. Are there known concerns of the study populations(s) about the proposed new use?”

IRB approval for my study was sought but determined to be unnecessary for a secondary analysis of de-identified data. The study participants did not need to be provided any additional information to conduct the secondary analysis.

Health related research must comply with IRB requirements and federal rules related to research involving human subjects. The Health Insurance Portability and

Accountability Act of 1996 (HIPAA) may impose additional requirements for conducting health related research. HIPAA was not applicable to this research effort but it does apply to secondary research that involves data collected by covered entities – hospitals, health care providers, and health care plans, etc. Covered entities may also include individuals. HIPAA facilitates secondary research as study participants in health related research understand that their consent to participate includes consent for the data to be used for secondary analysis without obtaining further consent (Windle, 2010). This is an accurate, albeit oversimplification, of the application of HIPAA to research efforts. Information for health care researchers who want to conduct research on data collected by covered entities can be obtained at

<http://privacyruleandresearch.nih.gov/healthservicesprivacy.asp>.

Conclusion

This article explored aspects of a secondary analysis that could be especially challenging when attempting to examine data in a secondary analysis using dialogic/performance analysis, and offered an explanation of how these challenges were overcome.

Hammersley (2009, section 2.4) notes “we do not need to assume that the secondary analysis automatically involves problems that primary analysis always avoids. It would be sufficient that there is a tendency for certain sorts of problems to be more likely to arise in reusing existing data than in projects where at least some of the data are specially generated by the researchers to answer their own research questions.”

Hammersley asserts certain types of problems are more likely to arise on one side or the other of the primary-secondary boundary but the problems are not restricted to one side. Conceptual distinctions alert the researcher to tendencies toward certain issues

arising but are not absolute differences. Researchers facing the challenges of conducting a sound research study involving secondary analysis will need to confront the challenges within their own study design. They can do so with the knowledge that methodological problems of qualitative research do not fall neatly into impacting only primary or only secondary research.

References

- Bishop, L. "A Reflexive Account of Reusing Qualitative Data: Beyond Primary/secondary Dualism." N.p., 30 May 2007. Web. <<http://www.socresonline.org.uk/12/3/2.html>>.
- Bornat, J. "A Second Take: Revisiting Interviews with a Different Purpose." *Oral History* 21.1 (2003): 47-53. Web.
- Brown, L. M. *Raising Their Voices: The Politics of Girls' Anger*. Cambridge, MA: Harvard UP, 1998. Print.
- Busanich, R., K.R. McGannon, and R.J. Schinke. "Expanding Understandings of the Body, Food and Exercise Relationship in Distance Runners: A Narrative Approach." *Psychology of Sport and Exercise* 13.5 (2012): 582-90. Web.
- Clarke, S. P., and S. Cossette. "Secondary Analysis: Theoretical, Methodological, and Practical Considerations." *Canadian Journal of Nursing Research* 32.3 (2000): 109-29. Web.
- Corti, L., A. Day, and G. Backhouse. "Confidentiality and Informed Consent: Issues for Consideration in the Preservation of and Provision of Access to Qualitative Data Archives | Corti | Forum Qualitative Sozialforschung /forum: Qualitative Social Research." N.p., 2000. Web. <<http://www.qualitative-research.net/index.php/fqs/article/view/1024>>.
- Denzin, N. K., and Y. S. Lincoln. *Collecting and Interpreting Qualitative Materials*. Thousand Oaks, CA: Sage Publications, 2008. Print.

- Doolan, D. M., and E. S. Froelicher. "Using an Existing Data Set to Answer New Research Questions: A Methodological Review." *Research and Theory for Nursing Practice* 23.3 (2009): 203-15. Web.
- Emerson, C., and G. S. Morson. "Mikhail Bakhtin." *The Johns Hopkins Guide to Literary Theory and Criticism*. Eds. Michael Groden, Martin Kreiswirth and Imre Szeman. Second Edition 2005. The Johns Hopkins University Press, 2006
- Fielding, N. G., and J. L. Fielding. "Resistance and Adaptation to Criminal Identity: Using Secondary Analysis to Evaluate Classic Studies of Crime and Deviance." *Sociology* 2000: 671-89. Web.
- Gallas, K.. *The Languages of Learning: How Children Talk, Write, Dance, Draw, and Sing Their Understanding of the World*. New York: Teachers College, 1994. Print.
- Gladstone, B. M., T. Volpe, and K. M. Boydell. "Issues Encountered in a Qualitative Secondary Analysis of Help-Seeking in the Prodrome to Psychosis." *The Journal of Behavioral Health Services & Research* 34.4 (2007): 431-42. Web.
- Goffman, E.. *The Presentation of Self in Everyday Life*. Garden City, NY: Doubleday, 1959. Print.
- Hammersley, M. "Can We Re-Use Qualitative Data Via Secondary Analysis? Notes on Some Terminological and Substantive Issues." *Sociological Research Online* 15.1 (2010): n. pag. Web.
- Heaton, Janet. "Secondary Analysis of Qualitative Data: An Overview." *Historical Social Research* 33.3 (2008): 33-45. 2008. Web.

- Hinds, P. S., R. J. Vogel, and L. Clarke-Steffen. "The Possibilities and Pitfalls of Doing a Secondary Analysis of a Qualitative Data Set." *Qualitative Health Research* 7.3 (1997): 408-24. Web.
- Irwin, S., Bornat, J., & Winterton, M. (2012). Timescapes secondary analysis: Comparison, context and working across data sets. *Qualitative Research*, 12(1), 66-80. doi:10.1177/1468794111426234
- Irwin, S., and M. Winterton. "Debates in Qualitative Secondary Analysis: Critical Reflections A Timescapes Working Paper." *Timescapes Working Paper* No. 4 (2011): n. pag. Web. <<http://www.timescapes.leeds.ac.uk/assets/files/WP4-March-2011.pdf>>.
- Kako, P., PhD, RN, FNP, P. Stevens, and A. Galvao. *HIV Transmission Risk, Access to Treatment, and Self-Management of Illness over Time: An In-Depth Longitudinal Study of HIV-Infected Women in Kenya*. N.p., n.d. Web.
- Long-Sutehall, T., M. Sque, and J. Addington-Hall. "Secondary Analysis of Qualitative Data: A Valuable Method for Exploring Sensitive Issues with an Elusive Population?" *Journal of Research in Nursing* 16.4 (2011): 335-44. Web.
- Lorenz, L. S. (2011). A way into empathy: A 'case' of photo-elicitation in illness research. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 15(3), 259-275. doi:10.1177/1363459310397976
- Mason, J. "'Re-Using' Qualitative Data: On the Merits of an Investigative Epistemology." *Sociological Research Online* 12.3 (2007): n. pag. Web. <<http://socresonline.org.uk/12/3/3.html>>.

- Mauthner, N. S., O. Parry, and K. Backett-Milburn. "The Data Are Out There, or Are They? Implications for Archiving and Revisiting Qualitative Data." *Sociology* 32.4 (1998): 733-45. Web.
- McArt, E. W., and L. W. McDougal. "Secondary Data Analysis? A New Approach to Nursing Research." *Journal of Nursing Scholarship* 17.2 (1985): 54-57. Web.
- Moore, N. "The Contexts of Data: Broadening Perspectives in the (re)use of Qualitative Data." *Methodological Innovations Online* 1.2 (2006): n. pag. Web.
- Naidu, T., and Y. Sliep. "Understanding the Agency of Home-based Care Volunteers: Establishing Identity and Negotiating Space in AIDS-home-based Care in Rural KwaZulu-Natal, South Africa." *African Journal of AIDS Research* 11.2 (2012): 143-52. Web.
- Polit, D. F., and C. Tatano. Beck. *Nursing Research: Generating and Assessing Evidence for Nursing Practice*. Philadelphia: Wolters Kluwer Health/Lippincott Williams & Wilkins, 2008. Print.
- Riessman, C. K.. *Narrative Methods for the Human Sciences*. Los Angeles: Sage Publications, 2008. Print.
- Svensson, A., L. Mårtensson, and U. Hellström Muhli. "Well-being Dialogue: Elderly Women's Subjective Sense of Well-being from Their Course of Life Perspective." *International Journal of Qualitative Studies on Health and Well-Being*, 7 (2012): n. pag. Web.
- Szabo, V., and V. R. Strang. "Secondary Analysis of Qualitative Data." *Advances in Nursing Science* 20.2 (1997): 66-74. Web.

Thorne, S. (1990) 'Secondary Analysis in Qualitative Research: issues and implications' in Morse, J.M. (Ed.) *Critical Issues in Qualitative Research Methods*. London: Sage.

Van den Berg, H.. "Reanalyzing Qualitative Interviews from Different Angles: The Risk of Decontextualization and Other Problems of Sharing Qualitative Data | Van Den Berg | Forum Qualitative Sozialforschung / Forum: Qualitative Social Research." N.p., 2005. Web. <<http://nbn-resolving.de/urn%3Anbn%3Ade%3A0114-fqs0501305>>.

Windle, P. E. "Secondary Data Analysis: Is It Useful and Valid?" *Journal of PeriAnesthesia Nursing* 25.5 (2010): 322-24. Web.

CHAPTER 4-MANUSCRIPT 3

THE APPLICATION OF DIALOGIC/PERFORMANCE ANALYSIS TO
INTERVIEWS OF HIV POSITIVE WOMEN IN KENYA

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This article examines the methodology of dialogic/performance analysis as it is applied to interviews of HIV positive women in Kenya in a secondary analysis. Details of employing this technique can vary provided the researcher stays true to the philosophical perspective that underpins the method (Boris & Stevens). Bradley, Curry & Devers (2007) claim, “There is no singularly appropriate way to conduct qualitative data analysis, although there is general agreement that analysis is an ongoing, iterative process that begins in the early stages of data collection and continues throughout the study.” (p. 1760) This comment can be refined to assert that there is no singularly appropriate way to utilize dialogic/performance analysis in an examination of interview data.

Dialogic/performance analysis is a dynamic and flexible approach that, in a secondary analysis, facilitated a focus on data that deviated from the initial researcher questions thereby generating a new understanding of the identity and lives of these women post HIV diagnosis. In this article, I focus on the methodology I used in applying dialogic/performance analysis to narrative data. Substantive findings are reported elsewhere. (see Chapter 5; Giving Voice to HIV Positive Women in Kenya-Findings from a Dialogic/Performance Analysis)

Background

I conducted a secondary analysis of interview transcripts of HIV positive women in Kenya using dialogic/performance analysis. The data used came from the study *HIV Transmission Risk, Access to Treatment, and Self-Management of Illness over Time: An In-Depth Longitudinal Study of HIV-Infected Women in Kenya* (Kako, Stevens & Galvao). The Principal Investigator was Dr. Peninnah Kako; Co-Principal Investigator, Dr. Patricia Stevens. The specific aims of the original study were to: 1) explore gender

roles and HIV transmission risks, 2) examine personal and contextual factors that influence women's capacity to access HIV treatment on a consistent basis over time, and 3) describe the daily behaviors women perform over time to manage HIV/AIDS and maximize their health and the health and well-being of their families. Findings from the primary study have been published (Kako, et al 2012). I was drawn into the women's narratives of their lives post-diagnosis and fascinated by the power and potential of utilizing dialogic/performance analysis in a secondary analysis to understand more in-depth the women's experiences.

The intent of my research was two-fold. First, dialogic/performance analysis was used to explore the impact of an HIV positive diagnosis on the identity and lives of women in Kenya. Second, my study was intended to demonstrate the application of dialogic/performance analysis to narrative data as guidance to health care researchers who may want to use this method. The specific aims of the secondary analysis were to:

1. Excavate the larger identity story each participant communicated in her responses to interview questions about HIV transmission risk, access to HIV treatment, and self-management of her HIV illness.
2. Synthesize across the identity stories major themes (what was said), structures (how it was said) and "that something extra" (for whom, in what context, and to what purpose they were generated).
3. Examine dramaturgical elements (Goffman), dialogic elements (Bakhtin), and performance of identity (Riessman) within the interview transcripts to describe the processes by which participants communicated the distinguishing characteristics that defined them as persons.

Discussion of the first aim centers on explaining the approach used to analyze the interviews. The description of aim two illustrates how the major themes were identified but reserves the report of those themes for another article (Boris and Stevens, 2015). The third aim provides researchers with limited knowledge of dialogic/performance analysis illustrations of and insights into the influence of dramaturgical, dialogic, and performance of identity elements in shaping the perspective underlying this approach to analysis.

Dialogic/Performance Analysis

Dialogic/performance analysis was identified as one of four broad approaches to narrative analysis that are not mutually exclusive and can be adapted and combined in a research study (Riessman, 2008). The four approaches to narrative analysis include thematic, structural, dialogic/performance and visual analysis. Dialogic/performance analysis shares philosophical and theoretical histories with performance (dramaturgical) analysis and dialogic analysis but is not a technique that simply melds these two analytical methods. A broadly interpretive method, dialogic/performance analysis seeks to explore the thematic, structural and dialogic/performative aspects of a narrative. The method addresses questions of what was said- the content of the story and how it was said- the presentation of the story. Additionally, this method explores to whom the discourse is directed and the purpose and context of the discourse.

Theoretical Framework

Symbolic interaction theory and literary theory inform dialogic/performance analysis (Riessman, 2008). The performance portion originates in the tradition of Erving Goffman's extended symbolic interaction theory and his use of dramaturgical metaphor in an explanation of social interactions (1959, 1981). The dialogic portion originates in

Mikhail Bakhtin's work on the philosophy of language especially the concepts of dialogism and unfinished self (Emerson et al, 2006).

Performance analysis flows from Goffman's work. Goffman's ideas have evolved over time but the basic premise is that people attempt to show their best face in times of difficulty such as chronic illness. The persons interviewed do not just give information but instead undertake a performance for the audience in which they project a picture of who they are (Goffman, 1974). The narrator controls the amount, type and quantity of information provided to the listener in an effort to convince the listener of their perspective. Thus, an examination of a participant's "performance" may yield additional information beyond the awareness of the investigator (the listener) or captured in prior research. As an analytical technique, some researchers have closely tracked the components of a theatrical performance such as actors, audience, back stage, front stage, props, etc. to analyze interactions (Hays & Weinert, 2006; Monrouxe, Rees & Bradley 2009). Other researchers have loosely acknowledged the influence of Goffman's ideas in their analytical work (Axinn & Pearce, 2006) or adopted portions of the dramaturgical metaphor (Fixsen & Ridge 2012) but did not delineate all the aspects of the performance using a dramaturgical metaphor.

Dialogic analysis is shaped by Mikhail Bakhtin's ideas. In Bakhtin's conceptualization, the development of our individual identity occurs not in isolation but through our interactions with others (Emerson, 2006). Bakhtin's complex ideas of dialogism, polyphonics, heteroglossia, and unfinished self influence the social interaction and thus the development of identity. The term *dialogism* incorporates several ideas among them the thought that for dialogue to be meaningful there must be an exchange of

ideas and positions and an openness of participants to be shaped by the interaction in which they are engaged (Frank, 2005). Dialogism is closely linked to the concept that our identity is in a constant state of change and evolution captured in the phrase - unfinished self. Polyphonic, i.e. many voices, suggests the speaker does not have the only voice but that their words reflect the voices of all persons in their past interactions (Ezzy, 2000). Heteroglossia, defined as differentiated speech, highlights the tension that develops between speakers with the speaker of the more prestigious language attempting to exert control and the other speaker resisting that control (Vice, 1997). People's interactions with one another are influenced by the historical, cultural and social context. This brief summation gives a sense of Bakhtin's influence in dialogic analysis but fails to capture the expansiveness and depth of Bakhtin's work. Dialogic analysis is less scripted than dramaturgical analysis. Researchers can employ innovation and creativity in determining how Bakhtin's concepts shape the methodology of dialogic analysis.

Goffman and Bakhtin share the perspective that narrative develops in the social interaction between the interviewer and the interviewee and from that exchange can the meaning be ascertained. The idea that meaning is found at the intersection of people's social interactions helps us to understand the other and concurrently changes us.

Dialogic/performance analysis offers an approach to examining the data that captures the meaning ascertained by the researcher through their interaction working with the data.

The ideas of these two philosophers are complex and multifaceted. Within studies using dialogic/performance analysis researchers focus on different aspects of their work. For example, a study by Brown (1998) focused heavily on the polyphonic voices of school age girls describing their expectations about gender reflecting the influence of

Bakhtin. In contrast, Svensson et al. (2012) emphasized the “dynamic co-production between the teller and the listener,” (p.3) highlighting the production and presentation of the story along the lines of Goffman’s work. Whatever specific focus on the particulars of Goffman’s and Bakhtin’s work, the ideas of Goffman and Bakhtin are central to an application of a dialogic/performance analysis whether it is used in a primary analysis or secondary analysis of narrative data.

Methods

Sample

The 54 HIV positive Kenyan women who participated in the original research were interviewed 1-3 times for a total of 124 transcripts. Interviews were conducted by the Principal Investigator, a native Kenyan, in English; or in Swahili or Kamba and translated into English by cultural insiders. The principal researcher shared the transcripts with me along with field notes. In addition, I was provided an Excel spreadsheet delineating the women’s ages, marital statuses, number of children, number of years since diagnosis, monthly income, education (years of schooling) and site (urban or rural). A complete set of translated interviews was not available for five participants, and one set of transcripts contained inconsistencies; thus I was able to complete an analysis for forty-eight of the original participants. I examined a total of 109 transcripts covering a total of 899 single spaced pages. Fourteen of the participants had been interviewed once; eight interviewed twice; and twenty-six interviewed three times. The average length of a transcript was 8.1 pages and ranged from 3 to 30 pages. All names used in this report are pseudonyms.

Table 1.1 Summary of Demographic Characteristics N=48

Characteristic	Mean	Median	Range
Age in years	38.29	35.5	25-67
Number of Children	3	3	0-10
Years since Diagnosis	4.1	4	2 months – 17 years
Years of Schooling	8.69	8	0 – 16 years
Monthly Income	3,445 Ksh	3223 Ksh	400-15,000 Ksh
US \$1= 75 Kenyan shillings	\$45.93	\$42.97 (Mode = 1,000 Ksh \$13.33)	\$5.33 - \$200
Site	23 rural	25 urban	
Marital Status	Single -8 Widowed – 13 Divorced - 5 Separated - 2 Cohabiting – 0 Married - 20		

Nature of the Data

The original interview questions were designed to elicit data that would support the aims of the original research as defined by the researcher. The first interviews began with questions about the woman's name; age; tribe; languages spoken; birthplace; marital status; living situation; and number, gender and ages of children. Subsequent interviews began with general questions about the women's health and any changes in their lives since the prior interview. Responses sometimes triggered other questions to fully comprehend the woman's situation. For example, if the woman lived with her mother she was queried about other members of the household. Alternatively, follow-up questions solicited more information. Women who did not use condoms, for example, were asked about the partner's reaction to a suggestion to use condoms.

Examples of questions the primary investigator used include:

- How do you think you got the disease?
- From the time you came to know, how has your reaction been?
- How do people take you?
- How do you think this disease affected your family?
- How do you remember to take your medications?
- Where do you get your strength?
- Do you use condoms?
- Do you attend support groups?
- Do you use traditional healers?
- If you meet somebody who tested HIV positive what would you advise them?
- Have you ever been stigmatized?
- What are you doing everyday to continue living well and healthy?

Analytical Process

The analysis required attention to the three components of dialogic/performance analysis: a) thematic - exploration of content focusing on what was said, b) structural - attention to how the story was told, and c) dialogic/performance – focus on to whom the story was addressed, under what circumstances and for what purpose. For illustrative purposes, I delineate how I examined each of these components, and from them created interpretive summaries that capture the women’s identities and the impact of an HIV positive diagnosis on their lives.

Immersion in the data is considered to be an important first step in qualitative data analysis. This step facilitates an understanding of the data in its entirety (Bradley, Curry & Devers, 2007). Numerous readings of the transcripts occurred. I read the transcripts and re-read the transcripts numerous times until I had a sense of who these women were and what they were trying to say. The first reading gave an overview. The second and third readings involved a closer examination of passages where the participant provided information beyond what was being asked. The content of these passages was deemed a part of what the study participant wanted me to know. Further readings attended to themes in these passages that seemed to be emerging as I reflected upon understanding what the women were telling me about their experiences.

Passages that suggested the theme around which the woman's story was developing were underlined. For instance, early in the interview, "Ruth" complains that her husband "does not send money for the kids to go to school." Her husband told her, "The kids get education depending on how their mother is giving service to the father." She comments about education over and over; "The most important thing is education. If there is no education there is no peace," "Let me tell you the truth that I get one thousand shillings and something and it the ones I use to educate my child," and "The most important thing that can make me be at peace is education." Ruth answers the interviewer's questions, but invariably Ruth returns to the theme of education. She remarks on her health and her limited income. She describes how prioritizing expenditures between her own health care and her children's education is challenging. Her dream of educating her children continues as the focus of her conversation

throughout the interviews until she concludes near the end, “It (HIV) has affected the education of these children so much.”

Diagramming the interviews in an attempt to trace the structure of the women’s stories proved to be difficult. In telling their stories, the women were constrained by the flow and direction of the interview questions and the interviewer’s control over topics and timing. Their stories started and stopped as the interviewer changed topics or did not follow up on something the women said. Their stories did not arise in the sequential and temporal ordering typical of stories, but were interspersed throughout the narrative.

“Joyce’s” story of faith provides an example. Early in the interview Joyce is asked from where she gets her strength. Joyce immediately addresses the role of her religious beliefs in her life, “Before I do anything I pray to my Redeemer.” Over and over, Joyce inserts within answers to questions references to her faith. Asked, “Are there people who approach you and you are married?” In her disjointed response Joyce references her faith, “But I care so much that God can give me long life;” “I talk with my children that Jesus will find some people since when he was being born, he still found people;” and, “I want to be alive when He {Jesus} is coming because I hear He is coming soon.” Throughout the interview Joyce references the defining aspect of her identity and the factor that drives her response to her diagnosis.

Review of the demographic information prior to reading each woman’s interviews provided some context for understanding her situation. The women provided further details that shaped the context during the interviews. Asked where she works, “Eve” explains, “Currently I am not working. After college I got married and I started feeling sick. But now I am doing an internship in a manufacturing industry.” The

dialogic/performance elements of the analytical process also examined passages where the study participants spoke to an external audience. “Sarah” speaks to a wider audience when she tells the interviewer, “Thank the people of Kalali for their work and they should continue testing and giving advice to people to encourage people and try another project to assist our children.”

Creation of Interpretive Summaries

I captured the women’s stories in interpretive summaries. The interpretive summaries used segments of interview data crafted into a coherent expression of each participant’s story punctuated by the woman’s own words. This is similar to Brown’s (1998) development of interpretive summaries in the work she did examining the development of gender identity in adolescent girls. The interpretive summary presents a picture of what each woman wants others to know about whom she is and what is important to her in the context of describing HIV transmission risk, access to treatment, and self-management of illness for the primary study. The interpretive summaries were crafted following numerous readings of the transcripts and were shaped by the content, structure and purpose of the identity stories participants provided. Thematically stories proved consistent across the multiple interviews with each woman; often providing much greater detail about the narrative theme introduced in the first interview.

In the title of each interpretive summary I attempted to capture the essence of the story. Titles such as *Trying to Reconcile the Irreconcilable*, *The Triumphant God*, *The Story of the Wise Woman*, *The Burden of Secrecy*, *The Heart of the Entrepreneur*, and *The Breakdown of Family* illustrate the range of topics the women focused on in telling

their story. The interpretive summary gives voice to the women describing who they are and how their life was shaped by an HIV positive diagnosis.

Addressing the Specific Aims

Specific Aim # 1 Excavate the identity story each participant communicated in her responses to interview questions about HIV transmission risk, access to HIV treatment, and self-management of her HIV illness

Dialogic/performance analysis is characterized by the focus on the development of a study participants' identity. Their identity is presumably impacted by their diagnosis and experience living as an HIV positive woman in Kenya. The original study goals and the resultant interview questions may or may not have provided study participants opportunity to address what they believed were the significant factors in shaping their identity as HIV positive women.

The original investigator commented in the field notes of her interview with "Pam" it "felt like she had more to share but was selective what to share." That was the sense I had reading the interviews. It seemed the women wanted to talk about topics not specifically raised by the interviewer. The women wanted to tell their stories, on their terms but were limited by the questions they were asked. I began to read the interview from a new perspective asking myself over and over-what is this woman trying to tell me? What do they want me to know about whom they are and how this HIV positive diagnosis impacted them?

An attempt to unearth the identity story of each participant began with two questions to guide readings of the transcripts:

1. What story was the woman trying to present within the context of her illness, family and community?
2. What information did the woman provide related to the specific aims of the study; HIV Transmission Risk; Access to Treatment; and Self -Management of Illness over Time; and did that information align with her own story?

The premise was that the dialogic/performance method of analysis allows the researcher to shift the perspective from what the researcher wants to learn to what the women want to tell us about their experience being HIV positive in Kenya. These questions were intended to be broad enough to allow the woman to tell her own story about the experience of being HIV positive in their country while acknowledging the influence of the original research design in the development of the narrative.

Content

What the study participants told the interviewer, i.e. the content of the story, was significant to the development of their identity. The study participants did not blatantly attempt to control the conversation. They politely answered questions posed to them by the original researcher. However, study participants did not necessarily stay on point in responding to questions posed in the original research and at times their answers were so brief as to suggest the study participants failed to see the relevance of the question to their life. They likely responded with greater or lesser detail as dictated by their personality, emotional state, and comfort with the interviewer, or other factors. The words of these women drew me into their lives.

Sometimes a definitive or poignant statement by the women seemed to me to define the woman and highlight what was significant to them. Forty-one year old

“Esther” is *Living in the Shadow of Death* as she reveals in her own words, “Living with fear and worry all the time, it’s like I am just waiting for my day.” “Jasinda’s” story of *Regrets* is suggested in her announcement, “What I had planned in my life is not what happened.” Her husband declined to go for pre-marital testing. Later it became evident he was HIV positive at the time of their marriage. Jasinda and one of her three children acquired the HIV infection. Thus Jasinda concludes, “At that moment I regretted why I got married because if I was to work as a maid, it would have been better for me.”

Other times, as the women responded to questions, they seemed to me to build a picture of who they were. “Betty” retains *A Spirit Undeterred*. Betty’s no-nonsense, practical outlook to life is reflected in her response to her HIV positive diagnosis. Betty reports, “I was not shocked and therefore I was given the medicine, and I started taking right away.” The benefits were evident as she declares, “There is a great change since I don’t get sick like the way I used to get sick.” Asked the hardest thing she has experienced being HIV positive she claims, “There is nothing, and it is better this time that I know because if I had not yet known that I am positive then I would have spread the sickness.” Betty is not fearful of something bad happening because of her diagnosis as evidenced in her declaration “I don’t fear anything.”

Emphasis on a particular aspect of her life also suggested to me the story the woman was attempting to tell. For “Louise” an HIV diagnosis is captured in the title I gave her story *The End of the Life*. In her own words, “Me I saw death has reached...the way we used to take HIV as death.” Louise’s greatest concern is integral to her identity as a mother and surfaces clearly in her answers. She confesses; “I think so much on these other kids {her three younger children}. How they will go on with education in case I die

or the father. I think so much. Nothing else except these kids.” Louise discloses her life’s focus and biggest worry. “I pray that God may help them grow to a stage where they can be independent. It is my great concern how they can live without me.”

Women would address topics that, it seemed to me, revealed their perceptions of themselves. Sixty-seven year old “Rachel’s” story *For Each Their Day to Die* represents an attitude toward her diagnosis that is shaped by her faith. Rachel says of the death of her husband of 48 years, “I don’t think he died because of the sickness but you know each person has got a day to die.” Rachel’s reaction to her husband’s death reflects her deep faith, “I told God that I will not stand on his way, let him go where God prepared for him. I told God to give me courage until the last day since each who is created will once go back home. So when your time to go reaches, you must go home.” Rachel acknowledges the adverse impact advancing age and widowhood has on accessing health care for HIV positive woman as she reports, “The widow and the old are left without anything. Like there are those doctors who say they don’t want to treat the old since they are almost dying and of no use.” Despite her age, Rachel identifies as a vibrant person so death does not need to be hastened unnecessarily but will come when it is one’s time to go home.

Occasionally, the women’s responses to questions were so brief and devoid of emotion it was clear that whoever they were prior to their diagnosis, their identity was lost in their despair and defeat. *Alone and Afraid*, twenty-eight-year-old “Purity” relays her story in brief, concise answers to questions. Her responses are devoid of emotion. Her HIV positive diagnosis came two years earlier. She is dealing with the challenges of being a single parent of a small child while simultaneously experiencing the ill health

resulting from HIV infection and malaria. Alone and without resources, thoughts of how to manage her situation dominate her thinking.

Structure

Structural attention focused on those portions of the interview that suggested the study participant was attempting to tell their own story within the framework of the interview questions. Topics raised spontaneously within the context of answering an interview question, topics tangential to the interview question, topics discussed despite the absence of questions from the interviewer, and questions or comments addressed to an external audience (i.e. not the interviewer) were viewed as the study participants attempt to direct the interview to topics significant to them regarding their experience being an HIV-infected woman in Kenya. The lengths of the study participant's discourse on a topic as well as the repetition of a topic were additional components of the structural analysis. The results of these techniques complemented what I tentatively identified as their stories in the review of content.

“Everlyn” provides an example of spontaneously raising a topic. Everlyn outlines the difficulties of accessing care, “When you go to the outpatient in Logala they do not give you free medicine and you pay like any other patient. The project of Homecare does not pay for us anymore. If one goes there with no money then she will not be treated.” Everlyn is asked by the interviewer to, “Tell me any hard thing you have faced with this disease.” Initially Everlyn responds with, “It is hard to get a job,” then uses this question to discuss her plan to address this problem; “If I can get a business, it can help me a lot to eat well and pay for the medicine without struggling.” Repeatedly Everlyn returns to the idea of having a business by discussing the availability of loans, temptation to use the

loan for other priorities like food and consequences of defaulting on the loan. For Evelyn, owning a business is the key to having sufficient finances to pay the expenses of treatment. In Evelyn's story, *Keeping the Faith*, she concludes her story. "She should keep her trust in God and He will help her." "If we can get someone to sponsor the women to have their own businesses then this can be marvelous and how we pray that one day God will hear our prayers and answer us accordingly."

"Patricia" displays *The Heart of an Entrepreneur* as her narrative contains tangential, long passages describing her businesses. In response to the question "How much money do you think you get a month in your home?" Patricia initiates a discussion of her businesses; a theme she returns to several times during the interviews. Patricia states, "These days the business I not doing very well," so she "tries to get loans." She buys charcoal and sells it at a 300 Ksh profit. Patricia reports she recognizes that, "When I buy rubber shoes (to sell), the more you buy the more profit." She prefers to "be mobile" because when "you rent the shop then the city council licenses...they include a lot of things which consume your money." With money from a loan Patricia took a risk. "I go to Gikomba open air market and I buy T-shirts and I iron them and I go round selling." The list of products she has sold seems endless. Her understanding of business is evident in her risk taking, knowledge of business regulations, timing of market conditions, selection of products and sale location, and turning a profit.

Dialogic/Performance

The dialogic/performance component explored the purpose, the context of the discourse, and to whom the discourse is directed. The women's purposes for sharing information were not necessarily articulated. In some cases, they expressed confusion as to why the

interviewer was interested in what they had to say. Joyce asks the interviewer, “What do you have for us because you have interviewed us for several times,” and “Can we get a donor out of it?” At the end of some interviews, the women asked where they get the food or transportation money they were promised for participating in the interviews. Pam is told by the interviewer, “You are going to get some food right from here... sorghum and beans, three kilograms.”

Some women hoped the interviewer would help with a specific need. “Elizabeth” told the interviewer, “If you can get a group which can help us get help to start up businesses then it can be good.” “Mary” tells the interviewer, “You see how you can help us with food.” To which the interviewer responds, “Mine is to collect the data and file the reports so that those who help may see read them and see how they can help.” Ignoring the interviewer’s response, Mary presses, “Ooh and if you can get school fees for one who has finished form four.” Betty told the interviewer, “I want you to get for us medicine that can heal us completely so as to stop taking the medicine.” Most often the women spoke directly to the interviewer. Occasionally the women wanted the interviewer to be a messenger to elected officials or health care providers. Sarah asked the interviewer to “just to thank the people at Kalali {the health clinic} for their work and they should continue testing and giving advice to people, encourage people and try another project to assist our children.”

Most women spoke primarily to the interviewer. The study participants were sensitive to the interest of the investigator and seemingly eager to ensure they provided information that the interviewer wanted. “Rosinda” anticipates the interviewer’s interest by suggesting the interviewer wants to know; “You want to ask me where I got it from?”

Ruth defers to the interviewer when she says, “It is you whom I am waiting” in response to the question “Do you have anything else to say?”

A few women spoke of topics that were evidently intended to be heard by someone beyond the interviewer. “Rebecca’s” knowledge and wisdom about the HIV/AIDS situation is evident as she expounds on a range of community issues as she answers the interviewer’s questions. Rebecca addresses a number of social and political topics. Legislative issues include a policy of mandatory HIV testing and advocacy with government officials to secure financial assistance for HIV positive persons. Social issues cover the community reaction and stigmatization of HIV positive persons, neglect of HIV positive women by daughters-in-law and orphans created when both parents die of AIDS. She discusses the economic challenges of managing with HIV. Rebecca’s long digressions highlight what she believes is important and is reflective of speaking to an external audience of elected officials and business people in her role as a community elder.

Demographic information and field notes provided a context for the woman’s words. A review of the demographic information and field notes broadly defined the characteristics of the woman’s life and the interviewer’s impressions. As needed, the women provided additional information to the original researcher that helped to explain, put into context, and provide detail to the story they were telling.

In some cases, a request for additional information came from the interviewer. Ruth told the interviewer she had “given birth ten times,” and “six are the children who are alive.” The interviewer asked Ruth to explain the death of the four children to which Ruth replied, “I used to give birth in the hospital and the child used to die instantly after

the doctor doing his best to save the life of the baby... no one who died when big.” In other instances, the women volunteer information as a means of explaining themselves. “Salome” tells the interviewer, “I have not disclosed {HIV status} to my family because I have a family who really love me so much and when I disclose this information to them, they will break down because my mother is hypertensive. Definitely when I tell her she will have a shock and she will die.” Salome’s motivation in not revealing her status to her parents stems from concerns for their health, not from a fear of rejection.

Additional Thoughts

These HIV positive women living in Kenya were originally interviewed to gather information about HIV risk, treatment and self-management. Although the standard question at the end of the interviews was an open-ended invitation; “Do you have anything else to say?” The most frequent response was “no.” The structured question and answer format of the original research constrained the study participants’ answers to the specific goals of the study. Goffman’s (1954, 1974) work and use of the dramaturgical metaphor postulates that interactions between individuals occur according to perceived roles and accepted rules of behavior. The negative response to an invitation to raise a topic of the interviewee’s choice is, perhaps, reflective of the tacit perception the interviewer controlled the topics discussed. Comments by the interviewer such as, “You have given me most of the information *I wanted*,” underscore the idea the interviews were controlled by the interviewer and limited to the topics the interviewer wanted addressed.

However, consciously or unconsciously, these women employed a variety of techniques to convey their identity in the aftermath of their HIV positive diagnosis and

the changes brought to their lives by this condition. The information they provided about themselves gives testament to the richness of information to be found beyond evidence specific to the aims of the original study.

Specific Aim # 2 Synthesize across the identity stories major themes (what was said), structures (how it was said) and “that something extra” (for whom, in what context, and to what purpose they were generated)

The creation of the interpretive summary for each study participant involved the identification of the theme, the unifying or dominant idea each woman wanted to convey to the interviewer about who she is and what meaning she gives to her HIV positive diagnosis. Women shared commonalities in dealing with external factors such as food insecurity, lack of education, poverty, gender power issues, and so on. However, the women’s responses to their HIV diagnosis were unique and individualized to the circumstances of their lives. Stories of faith and famine; lives derailed or transformed; breakdown of family or recommitment; secrecy and advocacy; and other topics represented the very personal and individualized identity story each woman conveyed. A read of each woman’s personal story is, by itself, instructive of the experiences of women in Kenya post HIV positive diagnosis and could influence the nature and delivery of health care to these women.

For the purpose of developing a more generalized understanding of these women’s experiences, each individual story was distilled to its basic elements and examined for common threads with the stories of other women for the purpose of discerning overarching themes. A matrix was created which cross referenced the

individual story to emerging common overarching themes. As new broad themes surfaced they were added until all the individual stories were categorized in a broader theme.

Interactive Aspect of the Narrative

With few exceptions, the women shared a collective experience with issues of famine and food insecurity, poverty, abandonment by partners, transportation problems, fluctuating feelings of physical well being, stigma, and family instability. The specifics varied but the overall pattern of their lives gave insights into their lives as women in Kenya. Their responses to self-care questions also were very similar. However, within the back and forth of the question and answer format of the interviews, the content of the women's individual identity stories surfaced demonstrating clearly the interactive nature of narrative despite the structured format.

As the women shared their identity stories they used a variety of structural techniques discussed earlier to sidestep the flow of the interview questions. No pattern emerged in the presentation of their story. The women artfully used their conversational skills, sometimes blatantly, sometimes subtly to direct the interviews to topics most significant to them. Despite the rigidity of the interview format, the interactive and performative nature of the dialog was evident. "Veronica's" polite and revealing responses to the interviewer's questions provided valuable insights. Quickly in the conversation Veronica shifts the discussion to the topic of most importance to her i.e. her efforts to conceive a child. Veronica says, "You know I have had problem conceiving for the last four years." The interviewer is drawn to the story of Veronica's efforts to become pregnant. Questions shift from a focus on HIV to topics related to infertility. The interviewer asks, "Do you normally visit a specialist of fertility?" "You have done

hormonal levels?” and so on. The issue of infertility is woven throughout three interviews even as the interviewer moves through the set of prepared questions.

Similarly, the dialogic/performance failed to capture consistency in the audience, purpose or context of the identity story. Variations reflect the story each woman told as they selected audience, purpose or context to support their account of their story.

Rosinda's *A Story of Survival from Famine* illustrates her resourcefulness. Rosinda draws in the interviewer referring to her as “my friend” and flatters the interviewer by comparing her to “My daughter who is educated like you.” Rosinda solicits empathy with shows of altruism asserting, “I have tried to help people since many people have died due to fear of what people would say about them if they are found with the disease.”

Rosinda is not intimidated by any power differential between her and the interviewer.

Near the end of the interview Rosinda asserts her expectations of the interviewer asking, “What can you do to help us for we are sick and we cannot work to earn money?”

Specific Aim # 3 Examine dramaturgical elements (Goffman), dialogic elements (Bakhtin), and performance of identity (Riessman) within the interview transcripts to describe the process by which participants communicated the distinguishing characteristics that defined them as persons.

Researchers who employ dialogic/performance analysis may not and, indeed, need not segregate the analysis into the component parts identified in the third specific goal of this research when doing their analysis of narrative data. Such an effort would be like examining a picture by looking at what was painted, what material and techniques were used to paint the picture and who painted the picture, where and for what reason. The whole of the meaning the picture has for the person viewing the creation could be lost in

the dissection. However, for the purposes of informing novice or experienced researchers about this technique pointing out how Goffman's and Bakhtin's ideas are present and influence the analysis is essential. Additionally, although all the interpretive summaries are reflective of the women's identities, selected examples of performance of identity (Riessman) will solidify recognition of how identity is presented within the interviews. Providing illustrative examples of these elements for researchers interested in using dialogic/performance analysis will assist them to understand the application of dialogic/performance analysis to narrative data.

The influence of the original interviewer or study participant in directing or shaping the socially interactive discussion during the interview speaks to Goffman's ideas about how we control the kind and amount of information we share. This exchange between the interviewer and Joyce illustrates the control Joyce maintains over what she reveals to the interviewer as the interviewer must ask for details and draw out information that may prove pertinent to the original study aims.

Interviewer – “How is your health?”

Joyce – “I am doing well though there is a time I had malaria”

Interviewer – “And what did you do?”

Joyce – “I went to the hospital”

Interviewer – “Where?”

Joyce – “At Logala”

Interviewer – “Is that the place you normally go for your clinic?”

Joyce – “Yes”

Interviewer – “And what did they do?”

Joyce – “They told me that it is normal to get that.”

Interviewer – “Then they gave you medicine?”

Joyce – “They treated me and gave me medicine which I am taking right now.”

In contrast, at another point in the interview, as an addendum to answering a question about her husband’s status, Joyce shares some of her frustration with her husband, revealing insights into her life not the subject of the research.

“He may have the ignorance that the men have, though it is bringing problems.

There is one time when one of the children lost textbooks for school and she was supposed to pay. But when I told him, he ignored and this man is educated and this issue was very important. I felt bad about it. I imagined if I could get money, I would have bought the book and given it to the teachers. You know when you don’t pay a lost textbook; a child cannot go to the next class. And this was very bad for him to ignore such an issue. This child is very bright and I know she will do very well. Now like a person, what can you do?”

The potential presence or evidence that the woman may be speaking in the voice of others (e.g. the doctors) illustrates Bakhtin’s ideas about polyphonics double voicing i.e. hearing the influence of another in our own words. One can hear the voice of the doctor in Pam’s explanation of the effect of medications, “They help the body’s defense system. They support the defense system so it does not go down. Then the body gets strong. And you are not supposed to miss. If you miss the defense system goes down and your body gets worse.” The polyphonic nature of the women’s voices is evident in the women’s responses to self-care questions. Sometimes the woman references the words of the doctor or someone else as “Monica” illustrates, “The doctor advised me to do that

{use condoms}.” Naomi acknowledges, “I was trained in seminars,” and her answers reveal her knowledge of HIV transmission and treatment. More often, the voices of others are evidenced by the similarity of answers the women provide. The consistency of women’s responses to questions about self-care reflects the information they had been given at the clinics or in support groups. Each woman expressed the necessity to eat well, avoid stress, take medications, use condoms or abstain, avoid traditional healers and other activities to maintain good health.

The primary researcher was acknowledged as a person of importance, of higher stature and influence as seen in the following exchange. “Carol” is self-identified as a leader in providing information to others. The interviewer asked her, “And where do you think you got that skill of a leader?” Carol responds, “You gave it to me... When we happen to meet with you, the first time I tend to fear, the second day I see how you are so loving to us and the way you talk to us nicely and the way you leads us here and I say to myself that sister really is a role model to me, I just desire to be a leader like you and that desire pushes me to take part somewhere and the people choose me to lead them.” In some cases this difference in standing creates tension, captured in Bakhtin’s phrase heteroglossia. Rachel firmly tells the interviewer, “I told you that when you go back where you stay, send money to me so as to start a business because it is the one which can help me.” Rosinda almost challenges the interviewer when she says, “The sick needs help from you if you really care about us.”

Carol’s story provides an example of the formative influence of an HIV diagnosis on her evolving identify as both illustrative of Riessman’s thoughts about how identity is

performed within the interview and Bakhtin's concept of the unfinished self. As presented in the interpretive summary:

The psychological effect of the HIV positive diagnosis was significant. Carol discussed "the stigma that made me start hating myself." "It really affects somebody," Carol went on to say, "when it comes to stigma, you feel you want to be alone, eating becomes a problem and you just need to be alone and at times cry from inside." Filled with self-loathing and despair, Carol questioned, "I was feeling like I was not worthy to live..."

Two years post diagnosis, Carol has "adjusted". She "joined the support groups and began to take medicine." As a result Carol "got encouraged and everything is working well..." Carol's advice to other HIV positive women summarizes her personal journey, "One thing is to accept yourself and tell your children and whoever is with you who cannot tell out to anyone. Also one should not sit down but work to get money but learn to get ways of making money." Carol has learned to love herself, "since the worst stigma is self-stigma...and that's the one that kills people not AIDS."

Katherine's story demonstrates the overriding influence of one characteristic, her gender, in her identity. Gender serves as the defining aspect of her identity and the factor that underlies her reactions to life events including her HIV diagnosis. As presented in the interpretive summary:

Katherine's life has been, as she summarized it, hard. Overlaying a life filled with suffering and struggle because she was orphaned; deprived, widowed, threatened, shunned, and victimized is the challenge of dealing with a chronic illness. She is almost matter of fact in declaring, "It is true, I found myself a woman and so I have to cope with

the problems.” Simply, in her view, her life experiences and hardships emanate from her status as a woman.

Conclusion

Dialogic/performance analysis offers the researcher a technique for examining narrative data from a different perspective, i.e. that of the study participant, by focusing on what the participant wants to tell the researcher rather than what the researcher wants to learn. Often, the participant’s story is found mingled in and between the researcher’s questions but can be uncovered if attending to the content and structure and the participant’s efforts to be heard. The participant’s shift of focus or topics may appear tangential or irrelevant to the primary purpose of the inquiry which may result in discarding these data. A second look at the data using dialogic/performance analysis can offer confirmation of prior analysis, new insights and/or rich descriptive stories that give voice to, in this case, the stories of HIV positive women living in Kenya.

Bleakley (2005) examines the role of stories in medical education by discussing the tension between two qualitative approaches in narrative inquiry. One approach involves the researcher analytically thinking about stories and “involves deriving categories inductively from raw data and/or applying such categories back to narratives for explanation or illumination.” (p.535) In the second approach, the researcher synthesizes narrative seeking “a more holistic and integrative understanding of narratives, either empathetically ‘entering’ a given narrative, or creating a story as research product as a way of capturing elements otherwise lost to a structural analysis.” The interpretive summaries developed through an examination of the interview transcripts is one tool for synthesizing the data.

Bleakley (2005) asserts “where analytical approaches to stories may lead to objectifying the patient approaches of synthesis claim to bring researchers and patients closer to the patient’s world through the medium of story – acting – metaphorically – as stethoscope.” (p. 535) Dialogic/performance analysis facilitates a synthesis of narrative data and offers, in Bleakley’s (2005) words, “a powerful way of empathizing with the patient’s experience” (p. 538) and can give voice to patients who might otherwise not be heard. We only need listen to the patient’s voice to transform nursing practice to better meet the needs of our patients.

References

- Axinn, W. G., and L. D. Pearce. *Mixed Method Data Collection Strategies*. Cambridge: Cambridge UP, 2006. Print.
- Boris, L. & P. Stevens (2015). *Critical Review of Selective Literature Exploring the Dialogic/Performance Method of Narrative Analysis*. Unpublished Manuscript. University of Wisconsin Milwaukee, College of Nursing, Milwaukee, WI.
- Boris, L. and P. Stevens (2015) *Giving Voice to HIV Positive Women in Kenya- Findings from a Dialogic/Performance Analysis*, Unpublished Manuscript. University of Wisconsin Milwaukee, College of Nursing, Milwaukee, WI.
- Bleakley, A. "Stories as Data, Data as Stories: Making Sense of Narrative Inquiry in Clinical Education*." *Medical Education* 39.5 (2005): 534-40. Web.
- Bradley, E. H., L. A. Curry, and K. J. Devers. "Qualitative Data Analysis for Health Services Research: Developing Taxonomy, Themes, and Theory." *Health Services Research* 42.4 (2007): 1758-772. Web.
- Brown, L. M. *Raising Their Voices: The Politics of Girls' Anger*. Cambridge, MA: Harvard UP, 1998. Print.
- Emerson, C, and G. S. Morson. Eds.; M. Groden, M. Kreiswirth, and I. Szeman. Baltimore: Johnson Hopkins UP, 2006. Print.
- Ezzy, D. "Illness Narratives: Time, Hope and HIV." *Social Science & Medicine* 50.5 (2000): 605-17. Web.
- Fixsen, A., and D. Ridge. "Performance, Emotion Work, and Transition: Challenging Experiences of Complementary Therapy Student Practitioners Commencing Clinical Practice." *Qualitative Health Research* 22.9 (2012): 1163-175. Web.

- Frank, A. W. "What Is Dialogic Research, and Why Should We Do It?" *Qualitative Health Research* 15.7 (2005): 964-74. Web.
- Hays, M. M., and C. Weinert. "A Dramaturgical Analysis of Shift Report Patterns with Cost Implications: A Case Study." N.p., 2006. Web.
<<http://www.ncbi.nlm.nih.gov/pubmed/17131617>>.
- Kako, P., PhD, RN, FNP, Patricia Stevens, and Anna Galvao. *HIV Transmission Risk, Access to Treatment, and Self Management of Illness over Time: An In-Depth Longitudinal Study of HIV-Infected Women in Kenya*. N.p., n.d. Web.
- Monrouxe, LV, CE Rees, and P. Bradley. "The Construction of Patients' Involvement in Hospital Bedside Teaching Encounters." *Qualitative Health Research* 19.7 (2009): n. pag. Print.
- Riessman, C. K. *Narrative Methods for the Human Sciences*. Los Angeles: Sage Publications, 2008. Print.
- Svensson, A., L. Mårtensso, and U. Hellström Muhli. "Well-being Dialogue: Elderly Women's Subjective Sense of Well-being from Their Course of Life Perspective." *International Journal of Qualitative Studies on Health and Well-Being*, 7 (2012): n. pag. Web.
- Vice, S., *Introducing Bakhtin*. Manchester: Manchester UP, Distributed Exclusively in the USA by St. Martin's, 1997. Print.

CHAPTER 5-MANUSCRIPT 4

GIVING VOICE TO HIV POSITIVE WOMEN IN KENYA-FINDINGS FROM A
DIALOGIC/PERFORMANCE ANALYSIS

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This article reports findings of a secondary analysis of data from a study titled *HIV Transmission Risk, Access to Treatment, and Self-Management of Illness over Time: An In-Depth Longitudinal Study of HIV-Infected Women in Kenya* (Kako, Stevens and Galvao). The specific aims of the original study were to: 1) explore gender roles and HIV transmission risks, 2) examine personal and contextual factors that influence women's capacity to access HIV treatment on a consistent basis over time, and 3) describe the daily behaviors women perform over time to manage HIV/AIDS and maximize their health and the health and well-being of their families. This secondary analysis used a different methodology, dialogic/performance analysis, to explore the impact of an HIV positive diagnosis on the identity and lives of women in Kenya.

Secondary analysis offers a researcher an opportunity to investigate new or additional research questions using an existing data base (Heaton, 2008). New findings can be generated by examining the data through a new research context or from a different point of view (Irwin and Winterton, 2011). The use of an analytical method different from that used in the original research can assist in examining the data with a fresh perspective rather than simply verifying the prior findings by utilizing the same analytical technique and retracing the work of the original investigator. This article, with its focus on HIV positive women in Kenya helps to fill a gap in research involving this population as expressed by Kako and Stevens (2011) "The need for continued diverse methodology research, including in-depth qualitative studies of HIV positive women in a country such as Kenya, is urgent because of the disproportionate HIV/AIDS burden on women in sub-Saharan Africa." (p. 281)

Dialogic/Performance Analysis

A secondary analysis utilizing a different method offers the potential to examine the data from a different point of view that could provide new insights into the lives of these women. I selected to use dialogic/performance analysis to examine the interviews of these women. The dialogic/performance method was identified as a narrative technique by Riessman (2008). Dialogic/performance analysis is a broadly interpretive method. Dialogic/performance analysis examines three elements: theme – the content of a story; structure – the presentation of the story; and dialogic/performance – the purpose, the audience and the context of the story. The method is not as structured as other qualitative methods so variation exists in the application of dialogic/performance analysis in research studies. The specific application of dialogic/performance analysis to the interviews of these women is discussed in depth elsewhere (Boris and Stevens, 2014).

Theoretical Underpinnings

Dialogic/performance analysis is a narrative method whose theoretical underpinnings arise from the work of Erving Goffman and Mikhail Bakhtin. Erving Goffman was a sociologist. His work is heavily influenced by the perspective of symbolic interactionism. This perspective is premised on a few basic ideas that postulate people act toward things based on the meanings they ascribe to those things. Meaning arises out of the social interaction that one has with others and society and the meanings are modified through an interpretive process people apply as they deal with things in their lives (Blumer, 1969). Goffman (1959) was interested in human behavior and people's attempts to influence the impression others have of them by controlling the exchange of information between themselves and another. Goffman used the dramaturgical metaphor to examine and

explain interactions between people i.e. the performances of individuals as a mechanism for understanding the part a person plays, the impression a person wants others to have of them, the control of the amount and type of information revealed to another and other aspects of social interaction.

Goffman asserted people tend to present their best face in times of difficulty such as chronic illness. A person who is interviewed does not just give information. They undertake a performance for the audience in which the person projects a picture of who they are (Goffman, 1974). The speaker controls the amount, type and quantity of information provided to the listener in an effort to convince the listener of their perspective. Thus, an examination of participants' "performances" may yield additional information beyond the awareness of the investigator (the listener) or captured in prior research.

The philosophical work of Mikhail Bakhtin, a Russian literary philosopher and scholar informs dialogic/performance analysis. Dialogism, polyphonics, heteroglossia, and unfinished self are concepts that intermingle in social interactions and influence the development of identity. Dialogism is a complex concept that includes the idea that for dialog between people to be meaningful there must be an exchange of ideas and positions and an openness of participants to be shaped by the interaction in which they are engaged (Frank, 2005). Polyphonics refers to the idea a speakers words reflect the voices of all persons in their past interactions. Heteroglossia is defined as differentiated speech reflecting the tension between one speaker attempting to exert control through their language and the other speaker resisting that control (Vice, 1997). These three literary concepts are linked to the concept of unfinished self. In Bakhtin's view our identities are

never finished but rather are in a constant state of change and evolution. The development of our individual identity according to Bakhtin occurs not in isolation but through our interactions with others (Emerson, 2006).

Riessman (2008) notes that, “The construction and performance of identities,” is a general thematic interest in a narrative inquiry using dialogic/performance analysis. The concept of identity has slightly different meanings in disciplines such as philosophy, sociology, psychology and medicine. Two related but distinct ideas surface in discussions that attempt to pinpoint the definition of identity. One idea focuses on the personal characteristics, the personality of an individual as it persists over time. The other idea suggests identity has a social aspect by tying individuals’ behavioral or personal characteristics to membership in a group (Stedman Dictionary). This later idea relates to another concept, persona, which arises in discussions of identity and tracks Goffman’s view of social interactions. Persona is defined as “the role that one assumes or displays in public or society; one’s public image or personality as distinguished from the inner self” (Stedman Dictionary). In dialogic/performance analysis, identities are treated “as dynamically constituted in relationships and performed with/for audiences.” (Riessman, p.137)

The Study Design

The original study, *HIV Transmission Risk, Access to Treatment, and Self-Management of Illness over Time: An In-Depth Longitudinal Study of HIV-Infected Women in Kenya* (Kako, Stevens and Galvao), aims were to: 1) explore gender roles and HIV transmission risks, 2) examine personal and contextual factors that influence women’s capacity to access HIV treatment on a consistent basis over time, and 3) describe the daily behaviors

women perform over time to manage HIV/AIDS and maximize their health and the health and well-being of their families. This longitudinal study consisted of 1-3 structured interviews with fifty-four HIV positive women in Kenya. Findings from the original primary study have been published (Kako, et al, 2012, 2013).

I started the analysis with the premise that within the interviews the women attempted to tell their stories—who they are and how the diagnosis of HIV positive impacted their lives. Dialogic/performance analysis is a method that allowed me to shift the focus from what I as a researcher wanted to know to what information the women wanted to share about their post-HIV diagnosis identities and lives. This opened the analysis to the possibility of the women offering information that I might not have considered exploring. I approached the data with the broad goal of unearthing each woman's own identity story. I used an expansive conceptualization of identity that included self-conception, social presentation and unique aspects of a person to isolate the women's identity stories. An attempt to unearth the identity story of each participant began with two questions to guide readings of the transcripts:

1. What story was the woman trying to present within the context of her illness, family and community?
2. What information did the woman provide related to the specific aims of the study HIV Transmission Risk, Access to Treatment, and Self Management of Illness over Time; and did that information align with her own story?

After an examination of the theme, structural and dialogic/performance elements in the interviews I crafted interpretive summaries, punctuated with the women's own words, which captured the women's identity stories. I acknowledge the interviews were read

through my own cultural and social lens opening my analysis to the possibility that another investigator may arrive at a different understanding. Riessman (2008) offers a strategy for countering an argument that all potential interpretations of the data are plausible by suggesting “interpretation must be linked to features of the text.” (p. 111) Each interpretive summary was carefully created after an integration of the thematic, structural and dialogic/performance elements that surfaced in the interviews.

Their individual stories are instructive of the HIV/AIDS experience of women in Kenya. Space considerations prevent sharing each of their complete individual stories here. The interpretive summaries created from the interviews of 48 of the original 54 HIV positive women in Kenya can be found in the appendix. Synopses of some of their stories are included here to illustrate a general sense of their experiences post diagnosis. All names used in this report are pseudonyms.

The Pattern of Life

Commonalities in the lives of the study participants were evident. Interviews contained frequent references to famine and food insecurity, poverty, faith in God, abandonment by partners, and transportation problems. The women also spoke of the shared experiences related to treatment for their infection. Directed by the interview questions of the primary researcher, the women spoke of the value of support groups, the reception by staff at the HIV clinic, the stigma associated with their diagnosis and the efforts at self care through commitments to taking medication, eating nutritionally, avoiding stress and using condoms. These commonalities, along with basic demographic information made available from the original study, created the general context for situating the women’s words and segregating their personal identity story.

From the women's own words, a sense of similarity in the significant circumstances and contexts of their lives was revealed. Many women spoke of food insecurity and especially difficulty getting the nutritional food they were advised to eat to maintain their health. "Rosinda" summarizes asserting, "The hard thing for us is famine" and asks, "What are we going to do when the hospital no longer provides food to HIV positive women?" "Jesinda" is widowed and has three children to support. Food security is an ongoing concern especially during the period of drought. She explains the particular concern about food created by her disease, "When you are taking the medicine, you should have enough food since you can take them and they overpower you and you grow weak. So one should have food ready and like when there is famine one cannot have enough food and can take the whole day without food, which means that one has to take the medicine like that and sleep."

Money was an almost universal concern for the women who shared sentiments similar to "Martha" who says the biggest concern is, "Money since when you have money then your life will be good and you will be able to survive." Jesinda answers the question "How much money do you take per month?" by saying, "Many times I stay without getting anything." "Carol", an unmarried mother of two, answers, "It is very little that they are not enough," so she depends on her brother for some financial support. Abject poverty or at the least very limited financial resources forced women to choose between food, medications, education for their children and other activities requiring money. "Katherine" explains the interrelationship of money, transportation and health care by saying, "Getting fare to come here {the clinic} is the problem and it is a must to see them {the doctors}."

In most cases the women acknowledged an unfaithful partner was the source of their infection. Infidelity was tacitly accepted as described by “Baraka”, who, like so many of the women, was infected by her husband. She says, “You know you cannot even know even he goes outside the marriage. Me I just see that he goes to work in the morning, he returns at night.” Not uncommonly the disclosure of their HIV status resulted in the departure of the men. “Roxanne”, a 32 year old mother of two, describes her husband’s abandonment of her, “When he came to the hospital, I told him about it {the HIV positive test} and he disappeared for good and he never came back.” “Joy” relays that, “When I shared {her test result} with my husband he chased me out of the house. I had to leave with my children and I went to live with my mother. I am still living with my mother today.”

Many women referenced a belief in God as a source of strength in their lives. “Everlyn”, a 51 year old widow, maintains, “I have nobody to depend on who can help me” and proclaims, “I only trust in God.” “April”, diagnosed just a year earlier, says, “When I came to know about my status, I thought that the only way to survive is to have faith in God.” For some their faith defined their identity; for others, their faith was less central yet seemingly an important component of their life.

Reading the transcripts, it is clear these circumstances did not generally develop as a result of the HIV positive diagnosis. Famine was familiar to many of the women. Poverty was wide spread. Even if men did not actually abandon their partners, infidelity was commonplace.

An HIV diagnosis, either their own or that of their husbands did, however, compound efforts to deal with the everyday circumstances of their lives. “Rose” explains

how her almost non-existent income made it difficult for her to get transportation to the clinic to care for her illness. She says, “We used to be given 200 Ksh. This money was enough to take me to the hospital and back home”...”When I call my daughter and she does not send the money then it becomes hard for me to attend the clinic.”

“Dorothy’s” husband died prematurely of AIDS. She and her husband had been living near his family, “There was land but according to that family, I was not to stay there.” Dorothy explains, “There are those who follow the traditions... many of them like chasing the wife so as to get the land. So I came from that place and I came here because I had children. I saw that I could not stay there waiting to be killed by these people and I had children.” Her husband’s premature death left her and her three children homeless. Later she learned she was HIV positive making her difficult situation more challenging.

Stigma arising from the fear of HIV was widespread and a situation in their lives the women had not previously experienced. Stigma was reported by the women in various degrees as summarized by “Naomi” who believes people who stigmatize her are, “Those that they feel they do not need you,” but “Others have love.” “Faith” reports, “I have no stigma...when I went back I found I was not alone. There were many people and that encouraged me a lot.” In contrast, “Eve” describes the workplace discrimination experienced by HIV positive persons, “There are those jobs which you expected to apply and get before you tested positive, but now you can not apply and get those jobs.” She continues, “Some bosses will not give you the chance for the job when they know you are positive and they will not tell you the reason. Or in other cases people just get fired from the job when the job knows that you are positive.” Roselyn summarizes, “People have a very negative attitude about HIV so it is hard to share with them.”

As a group, the women were committed to caring for themselves and following the medical advice they were given. The answers to self care questions reflected what the women had been taught at the clinics or in support groups and offered much less variability than answers to questions about their personal circumstances, which typically included statements like - I do not seek care from a traditional healer. I try to eat nutritiously. I avoid stress. I use condoms or abstain from sex. I take my medications without fail.

Women acknowledged the life saving effect of medication as “Martha” expresses, “I feel that I cannot stop because I could have died if it was not for this medicine.” “Cecilian” describes the power of the medications, “Whenever I think of medication, I think of life. Whenever I don’t take the medication, I feel that my life is crumbling down.” “Jacklin” states, “I tell them I will take {medicine} since I want to stay longer on Earth.” This knowledge diminished the burden of life-long daily medication use. Asked about how she felt about taking medicine for the rest of her life Martha gave a typical response, “I feel okay and I don’t imagine of not taking.”

Transmission of the disease through sexual relationships was a universal concern. “Elizabeth” decides the best course is, “I came to know I can’t move with a man without condom.” “Rahab” repeats what she had learned about the best way to avoid infecting others, “When we are being taught, we are advised not to have men and if one happens to get one then she should use condoms.” Other women insisted their partners use condoms. “April” again has a boyfriend but unlike her prior relationships she is now using condoms because, “The other thing is to take care not to infect others in one way or another.”

The women talk about other issues of self care they learned about at the health clinics. “Betty” states it is good to go to the hospital because, “There is advice and we are told to eat well when taking the medicine. One should take porridge and a fruit and eat a balanced diet.” Unlike many of the women, “Beatrice” indicates, “I have enough food to eat because I have planted green vegetables which I normally get everyday to cook. I have chicken that I can cook and eat meat.” “Pam” has learned that, “Taking medications, and eating well and without stress” are the most helpful in managing her condition. Stress can be avoided, she explains, by “Talking to people, or sing Godly songs, take walks.” The self care activities help the women to manage their HIV diagnosis yet there is a tension between the women’s desire to comply with medical advice and the circumstances of their lives that challenge their ability to care for themselves.

Identity Themes

The creation of the interpretive summary for each study participant involved the identification of the theme, the unifying or dominant idea each woman wanted to convey to the interviewer about who she is and what meaning she gives to her HIV positive diagnosis. The women’s responses to their HIV diagnosis were unique and individualized to the circumstances of their lives. Each story is rich with descriptions of their lives and their efforts to manage a serious, chronic disease within the context of life situations that test their strength, resourcefulness and resilience.

Table 1.1 Titles of Interpretive Summaries

Name (Pseudonym)	Title	Name (Pseudonym)	Title
Pam	Trying To Reconcile the Irreconcilable	Veronica	The Quest for a Healthy Child
Rebecca	The Story of the Wise Woman	Lucia	And the Lame Shall Walk
Everlyn	Keeping the Faith	Louise	The End of the Life
April	Changing the Patterns	Purity	Alone and Afraid
Ruth	The Story of the Dream for Education	Roxanne	The Breakdown of Family
Faith	It Takes A Community to Heal	Esther	In the Shadow of Death
Joyce	A Matter of Faith	Eve	The Internship
Naomi	A Family Affair	Miriam	Take Our Lives as Normal
Carol	To Love Yourself	Roselyn	The Burden of Secrecy
Emma	Caring for Others	Sarah	Coming to Terms with Reality
Susan	The Education of Children	Baraka	The Power Struggles of Marriage
Mary	We All Belong to God	Moriah	Stand For Your Rights
Jacklin	A Single Act in the Life of a Couple	Josephine	The Transformation
Elizabeth	Life Will Continue the Same	Mercy	So Many Problems
Pauline	A Double Portion	Lilly	Waiting for the Call
Rosinda	A Story of Survival from Famine	Dorothy	Focusing on the Reality of Life
Rachel	For Each Their Day to Die	Salome	Not Just a Disease
Rose	The Triumphant God	Phillis	He Will Open the Way
Monica	That is Where We Used to Have Problems	Nafula	It Is Obvious
Jesinda	Regrets	Cecilian	The Desire to Procreate
Florence	Divine Intervention	Katherine	Finding Oneself as a Woman
Sue	Continue on With Life	Rahab	Bound By Tradition
Patricia	The Heart of an Entrepreneur	Martha	A Story of Managing a Small Business
Belinda	A Life Derailed	Betty	A Spirit Undeterred

Across the individual stories two general themes emerge when each of their artfully distilled interpretive summaries were examined. Two general themes, each with three sub-themes surfaced. The two general themes are Identity-Defining Experiences and Identity Trajectories.

Identity-Defining Experiences is a category in which the women's stories focus on an aspect of their experience as they discuss their lives following their HIV-positive diagnosis. The sub-themes include Altered Relationships, Matters of Faith, and Persistent Aspirations and Dreams. Altered Relationships discusses women who address

relationships reshaped in the aftermath of a positive diagnosis. Although many women talk generally about people's reactions to an HIV positive person, the identity story of these women primarily focuses on the relationship they have with their spouse or partner or the consequences of losing their spouse. Matters of Faith highlights the stories of women for whom their faith is a characteristic that is inextricable from the core of what defines them as a person. Persistent Aspirations and Dreams describe women who, despite HIV, persevered in pursuing a dream.

Identify Trajectory stories provide a broader view of the women's lives and address the overall direction of their lives in the aftermath of their diagnosis. Life Derailed presents the stories of women who lament the loss of a life they once had and have no vision for a life post-diagnosis. Life Continued describes women who essentially want to believe that HIV is no different than cancer or diabetes and life can continue unchanged. Life Transformed examines a group of women for whom the HIV diagnosis serves as a catalyst to reinvent themselves in a positive and productive way.

In advancing these themes three caveats are offered. First, the women did not neatly fall under one theme. Often there was crossover both across the general themes and the subthemes. Abuya advocates for the empowerment of women in her story of her Identity-Defining Experience as an HIV-positive woman. But, her story is also one of a Life Derailed. Blind and HIV positive, Moriah dreams of maintaining productive employment, yet her story also reverberates with references to her self-identification as a woman of faith. Second, within each theme there are considerable variations and nuances that can only fully be appreciated by reading each woman's identity story. Finally, to a certain extent, these themes are a modest attempt to bring some order and

understanding of the lives of women whose lives are anything but orderly and easily understood. The lives of these women are complicated and challenging as they attempt to balance the demands of their illness with the realities of their life.

Identity-Defining Experiences

Altered Relationships

Many women spoke about the stigma associated with HIV and its impact on their relationships. They spoke broadly about the reactions of family, co-workers, community members, friends, clinic staff and partners. They spoke of being shunned by people in their lives and how they found friendship among people who shared their diagnosis.

Women referenced alterations in relationships in their identity stories and shared challenges related to the stigma associated with HIV/AIDS. Lilly talks about the betrayal by her employer. She encouraged Lilly to be tested but when the test came back positive the employer put her on a medical leave. Years have gone by but Lilly has yet to be called back to work.

Rachel, a 67 year old woman, talks about discrimination in care based on age. She reports, “The widow and the old are left without anything. Like there are those doctors who say they don’t want to treat the old since they are almost dying and of no use.” The discrimination was not subtle. Almost disbelieving Rachel’s statement, she is asked, “They say you are old and you do not need to be treated?” Rachel confirms this and points out, “You have life and you don’t know the time you are going to live.” Rachel implores, “They should give us medicine and food,” and admonishes, “To remember the old women.” For Rachel and other older HIV positive woman, death does not need to be hastened unnecessarily but will come when it is their time to go home.

Mary's experience is typical. Mary speaks of the discrimination she felt in her various relationships. She lost her husband to AIDS. Subsequently her brother-in-law, consistent with tribal custom, wanted to have sexual relations with her. Not wanting to spread the infection she refused his advances along with the advances of other men who offered assistance in exchange for sex. Mary declares unequivocally that people in her village, "Stigmatize me. They ask why she goes to the hospital always." The villagers, "Say that one is sick and therefore they ignore you completely. They stop coming at your place completely and cannot help you and you are seen as a nobody." At the clinic where she goes for care she relays that, "Sometimes they take me well and other times bad." Mary, even with her family, is selective about who she tells her diagnosis. Within her own family among those who know, Mary is generally "taken well" but shares that one son claims, "If he can know he is positive then he can go and throw himself in water and drown to die." Mary asserts, "No one intended to get such disease." She concludes her story by declaring people should not be stigmatized based on their illness, "I feel we should be together and know that we all belong to God."

Perhaps, the most poignant stories of relationships redefined came from women who described how the diagnosis altered the relationship with their husbands. This topic was the focal point for their identity stories. Despite the fact that most of the women acquire HIV as a result of the infidelity of their husbands or boyfriends, the men's reactions to the women's announcements of an HIV positive diagnosis were often negative. Monica confides, "When the husband came to know that I was sick, he started beating me until I felt like I was to die." Domestic abuse, abandonment by their partners,

and lack of cooperation in testing or treatment are examples of the pressures and changes brought on the relationship the women had with men in their lives.

Purity maintains that two men left her when they learned she was HIV positive. “When I started getting sick when I was pregnant, that other pregnancy I thought of going for the test,” she states. Her husband’s reaction to the test results, “When he came to know that I was positive, he went.” They had been married only a year and a half. Purity discloses, “The stressful thing was when my husband left me alone. Adjusting to that was very hard for me.” She met another man and lived with him about a year. But, like her husband, he left when learning she was HIV positive. Now she is “staying alone” and raising a child by herself.

Roxanne relays a story of her husband’s ambivalent response to her diagnosis and her own struggle to reconcile his actions. When Roxanne’s husband learned she and their new baby were HIV positive he, “Disappeared for good and he never came back.” Roxanne looked for her husband. She went to her in-laws home. “When the father saw me, he chased me and told me not to step there, the son was not there.” At their home, the husband had, “Took all his things and left my clothes and those for the baby.” Roxanne knew her husband had given her the infection. A few years later he returned. Roxanne explains, “What made my husband to come back to me is that when he went to his place {his parents} and they came to know that he was positive, they said that he was not needed and therefore they wanted him to be burned when still alive since the disease is as a result of a curse.” Roxanne notes that since her husband’s return, “We do not agree to anything.”

In a few instances the impact of an HIV diagnosis brought a couple closer together. Jacklin's story illustrates a shared response to the dramatic adverse consequences to their family when both husband and wife are HIV positive. Jacklin speculates, "I try to imagine if my husband never went outside the marriage, we would not have problems and he would still be working." She wonders, "What he was looking for in that woman that he had to get this bad disease which has no cure." Both Jacklin and her husband are HIV positive. The husband's act of infidelity dramatically altered the life circumstances of Jacklin and her family. Their old life of respectability and financial stability is gone perhaps permanently. They face stigma, food and financial insecurity. Her husband, "Regrets why he did." Her husband told her, "We are going to follow the instructions of the doctor and nothing bad would happen." Together as a couple they are facing the consequences of a life with HIV/AIDS.

Matters of Faith

Many women mentioned God as a source of strength. For some women their faith was an essential component of their identity and permeated their story. Women spoke of their belief in God for help in managing their disease or avoiding the fear of immediate death. Today, when life is hard, April announces, "I tell God to take control since I don't know anything else to do." Everlyn advises other HIV positive women, "She should keep her trust in God and He will help her." Rahab proclaims, "I am born again, and I told them I am no longer bound by traditions." Rose has opened up to the healing power of her God proclaiming, "I depend on faith in God and give Him the first priority." Faith guides Rose's life and death as she declares, "I know I cannot just die anyhow unless God calls me and even this disease has no power to kill me."

Joyce's identity story illustrates the spirituality that is central to several women's stories. As a testament to her faith, Joyce reverently states, "Before I do anything I pray to my Redeemer." Joyce states, "I have a long life to stay," and "I don't see my grave." Her belief is strong and revealed in comments to her children, "Like I talk with my children that Jesus will find some people since when he was being born, he still found people." Her faith sustains her and helps her battle her disease. Joyce reveals, "I pray God when I am sick and He heals me." Joyce's objective is, "I want to be alive when He {Jesus} is coming because I hear He coming soon." "I strengthen myself," she says and, "I tend to think one day God will show me as an example in heaven since I had taken care of myself so much but I got AIDS."

Persistent Aspirations and Dreams

Identity stories of some women were centered on a discussion of their aspirations and dreams that were not connected to their HIV positive diagnosis. Not uncommonly women expressed hope for a cure for their HIV. They recognized medication could treat their illness but was not a cure. Quite often the desire for a cure was discussed in the context of their attitudes toward taking medication for the rest of their lives. This thread crossed several general themes but did not surface as the primary focus of any woman's identity story. The aspirations and dreams that generated an identity story did not arise from the HIV diagnosis. These were dreams that eluded them independent of acquiring an HIV diagnosis. In some cases, that which they sought was a long standing dream. The HIV diagnosis did, however, complicate or move their dream further out of reach.

Veronica wants to have a child but in four years of marriage has not been able to conceive. Veronica reveals the meaning infertility has for her, "Not having the child, it

make me feel like there is something I have not accomplished in life.” The topic of infertility dominates the interviews. Interview questions shift from the questions related to the goals of the original research to questions related to infertility. “Do you normally visit a specialist of fertility?” “You have done hormonal levels?” “And have they checked your husband?” “Have you tried other methods of getting a baby like egg capturing or artificial implantation?”

Veronica and her husband, “Really want to have a child.” A positive HIV status adds yet another dimension to Veronica’s infertility. The standard advice to use condoms when engaging in sexual intercourse is problematic. Veronica further explains, “The doctors told me to wait until the CD4 count goes up because when it is low, I cannot conceive.” She adds, “He {the doctor} told me to wait because you know last year I had an ectopic... I am telling you that I have really stays in this state for a long time.” Both Veronica and her husband are HIV positive increasing the likelihood her dream for a healthy child may be beyond reach.

Eve has concluded she needs to work. Eve relays, “I decided to go and find a job so I can be able to help myself.” To that end, Eve is, “Doing an internship in a manufacturing industry. I got my college certificate and now I am working to get a practicing license.” She expresses her hope, “To me I hope things would be much better for me and my family if I finish my internship and get a job.” As she studies for the certification exam her goal is within sight. The hardest part of being HIV positive to Eve is, “The concern that I may not be able to find a job.” Her concern is substantiated by stories she has heard of people discriminated against because they are HIV positive. She articulates several examples, “There are jobs which you expect to apply and get before

you tested, but now you cannot apply and get those jobs...there are more limited chances for HIV positive people,” and, “In other cases people just get fired from the job knows that you are HIV positive.” Eve further worries that if she secures a job, “I start falling sick I will automatically lose the job.” Eve remains optimistic she will find a job and after that, who knows what may lie ahead. Eve dreams that one day she may even, “Own a chemist shop.”

Susan is herself uneducated. Education of her six children is a priority that overrides other events in her life. Thoughts of famine, death and HIV/AIDS do not interfere with Susan’s desire to have her children educated. Over and over Susan returns in the interviews to the theme of obtaining money for school fees. Susan knows the education of her children offers hope for their future and is needed to advance children’s standard of living. The spread of HIV can be avoided in Susan’s opinion by educating children about HIV/AIDS. From Susan’s viewpoint, the education of children is not just about improving the future; for some children education may mean they have a future. Obtaining sufficient money to educate children is a challenge in Susan’s life. Her illness has compromised her ability to work to earn money for school fees.

Identity Trajectories

Life Derailed

Some women commented, as Jesinda expressed it, “What I had planned in my life is not what happened.” Their identity stories speak to the loss of who they were and the uncertainty of who they might become if indeed they do not succumb to the disease. Women in this group tended to answer the interviewer’s questions with brief, concise responses offering little description or explanation. Their answers were often devoid of

emotion. They seemed consumed with thoughts of if only I had not married, if only I had not had sex, if only I did not have HIV. Their identity was intricately tied to their HIV status.

Jesinda had been working as a maid when she got married. She asked her husband to get tested but he sidestepped the request asserting he, “Took care of himself and was ok.” Life seemed reasonably good. Her husband took care of her and their three children. As Jesinda described their life they, “Used to stay well.” They had earned enough to purchase land and build a house. Then, her husband, “Got sick abruptly and he died.” Her husband’s death from AIDS left her to raise their three young children alone. In telling her story, Jesinda details the numerous ways life is difficult including problems getting medicine, lack of money, stigma and other issues. Jesinda comments, “I grew up in problems and I could not imagine that when I grow up, I would have the same life.” She concludes her story, “At that moment I regretted why I got married because if I was to work as a maid, it would have been better for me since you are given everything.”

Pam’s life is consumed trying to care for herself and her child despite her ill health. She states she is doing well but Pam appears ill. At 30 years of age, she has an 8 year old son and is divorced. Following her divorce, she worked until she became sick. Pam is taking medications and asserts, “My health is improving.” Indeed her 7 kilo weight gain since diagnosis and the fact she has not experienced rashes would seem to confirm her assertion. Yet, she is not symptom free. Pam has had headaches, malaria, TB and pneumonia. She is experiencing diarrhea. Asked what she would need to help her life? Pam responds with, “If there is medication that we can take so that we all get healed so that whoever has repented and decided not to go back to risk behavior, they can stay.”

Pam tries to live a life of repentance, managing the disease as instructed. She tenuously holds on to life with a hope for a cure knowing she may succumb to the disease before a cure can be found.

A few women appeared overwhelmed by the circumstances of their lives and devastated by the additional burden of dealing with their illness. Their thoughts were consumed with the thoughts of death and what would happen to their children. The HIV diagnosis of Louise, her husband and one of her four children meant the end of Louise's life as she knew it. Whatever dreams and hopes Louise had for her family were dashed by the misplaced trust in her husband and the resulting presence of HIV in her family. Louise confesses, "I think so much on these other kids {her three younger children}. How they will go on with education in case I die or the father. I think so much. Nothing else except these kids." Louise discloses her life's focus "I pray that God may help them grow to a stage where they can be independent. It is my great concern how they can live without me."

Belinda's story illustrates an extreme level of despair. Belinda was a well educated, 28 year old. She was, "Very disappointed" to be denied a job when the pre-employment physical revealed she was HIV positive. Post diagnosis, Belinda states, "I felt bad and I started to have new relationships with men and I got pregnant." Belinda worried about her four-year-old-daughter. She offers that since her diagnosis, "I worried much about the future of my child ...I worry about where she will end up." Belinda's objectives were straightforward. She wanted to, "See my daughter grow" and "Be strong...be able to do something for myself." Belinda did not have the opportunity to

fulfill either goal. Her life permanently derailed, she died of AIDS shortly after she told her story.

Life Continued

An HIV diagnosis was just one more issue in their life to deal with for some women. They downplayed the significance of the diagnosis. Miriam reflects, “For real I don’t think of this disease and I don’t take it like a sickness. I take it like normal colds since there is a person who got cancer the time I came to know that I am sick is not alive today, and there is another one with diabetes and is in a lot of pain than me so I don’t think about it.” These women conduct their lives with very little accommodation to their illness.

Miriam, in telling her story, asserts, “So far I do not count myself as sick. I am strong and energetic...I even encourage my husband that we should not count ourselves as sick because there are other people who are more sick than us.” Miriam notes, “One should not think too much about this sickness because when you think so much, you get stigma which is not good at all. One should stay normal like other people.” Miriam holds strongly to her belief that she and her husband, “Just need to take our lives as normal,” declaring, “I know I will die the day God has planned and not because I have this virus.”

Katherine’s life has been, as she summarizes it, hard. Her life is filled with suffering and struggle because she was orphaned, deprived, widowed, threatened, shunned, and victimized. She is almost matter of fact in declaring, “It is true, I found myself a woman and so I have to cope with the problems.” Simply, in her view, her life experiences and hardships emanate from her status as a woman. She cannot change her gender or remove the hardships associated with being a female in her society. Katherine’s

illness is one more challenge as she continues to deal with her life in a male dominated society.

Elizabeth's story dramatically demonstrates this theme. Elizabeth is looking for some help with her life, "I want to tell you that I want you to get someone to marry me who is positive like me." She wants, "To get married to have my own family." She saw a couple, "That married when they are positive and they are doing well." "That is what is in my mind right now and I need that one who is positive like me," is Elizabeth's explanation. She does not know how she will meet an HIV positive man, "That is where I don't understand." There are support groups for men, "But men do not come and if they come, only one or two." An HIV positive diagnosis has caused Elizabeth to briefly reevaluate the way she interacts with men. But, for Elizabeth, with or without an HIV positive diagnosis, "Life will just continue the same."

Life Transformed

A small number of women by necessity or choice embraced their HIV diagnosis and were transformed, emerging post-diagnosis as a new person. The diagnosis served as a catalyst for change. These women were generally talkative and positive in their outlook. Their enthusiasm for their new life was infectious. The following excerpts from their stories provide examples.

Dorothy's identification as a woman was radically altered post HIV diagnosis. Dorothy was HIV positive by her husband. As a woman she felt powerless. "In our society women are always seen as dependants of men," she explains, "We are treated as if we cannot stand by ourselves without the support of men." Her experience dealing with the aftermath of diagnosis taught her, "We can do without men." Dorothy

acknowledges, “For me personally I see that I came a long way to where I am today, and that give me confidence that I can make any decision about my family. I have enough knowledge and ability to make my own decision.”

For Carol the HIV diagnosis initially plunged her into a period of depression caused by the stigma associated with the illness. Filled with self loathing and despair, Carol questioned, “I was feeling like I was not worthy to live.” Two years later as a result of treatment, support groups and self care activities her outlook was entirely different. Carol reports, “I have no stigma at all and the people in the community have accepted me and chosen me to be a leader.” In her capacity as a community leader, she provides support and advice to other HIV positive women.

Josephine tested HIV positive after her boyfriend died presumably of AIDS. She initially entered a two year period of depression and despair. In her words, “I knew I was going to die and join Rick. I did not want to live at all.” She initiated action to commit suicide by drinking poison. But, her story does not end in death. Her six-year-old daughter interrupted her suicide plans. Josephine’s sister took her to the hospital. A social worker noticed Josephine, “Was not okay” and took her for counseling. This was the start of Josephine’s transformation. With the help of counseling and a support group Josephine, “Started looking at life at another angle” and saw herself, “More beautiful than ever before.” Today Josephine works as a peer counselor at the clinic where she receives care. The interviews contain long passages where she describes in-depth her work as a peer counselor. Her enthusiasm for the work is evident as she discusses plans to expand her outreach efforts.

Patricia had thoughts of suicide. Her husband left to marry another woman. She was jobless. Her life turned around when a woman with breast cancer befriended her and took her for counseling. Patricia tells her story which reveals an entrepreneurial spirit that has thrived since her diagnosis. Forty-three-year-old Patricia is the mother of two children. The household consists of eight people – her dead brother’s two children and the two sons of another brother, her mother, her daughter and granddaughter.

For income, Patricia states, “These days I sell porridge in the market place.” She raises goats to, “Keep them for the December holidays” when she can earn 8500-9000Ksh per goat. Patricia sells shoes on the days she is not at the market. She knows that when she buys shoes for resale, “The more you buy the more the profit.” She explains, “I have these goods and in the middle I keep charcoals at home and I sell to villagers.” Patricia buys “Charcoal with sacks” and “I buy at 400Ksh and I sell it at 700Ksh.” She prefers to “Be mobile” because when, “You rent the shop then the city council licenses...they include a lot of things which consume your money.” With money from a loan Patricia took a risk – “I go to Gikomba open air market and I buy T-shirts and I iron them and I go round selling.” Her understanding of business is evident in her risk taking, knowledge of business regulations, timing of market conditions, selection of products and sale location, and turning a profit.

The Unfinished Self

Goffman (1963, p. 68) notes “there is a popular notion that although impersonal contacts between strangers are particularly subject to stereotypical responses, as persons come to be on closer terms with each other this categorical approach recedes and gradually sympathy, understanding and a realistic assessment of personal qualities takes its place.”

These women's stories offer insights into the array of issues they face managing a chronic and expensive medical condition. I was impressed by their resilience and strength in attending to their health needs while simultaneously navigating the challenging circumstances of their lives. Riessman (2008) points out that "readers are inherently part of the interpretive process, bringing their positioned identities and cultural filters to interpretation" (p. 131). My hope is that I have faithfully shared the circumstances of these women's lives and their responses thereby contributing to an enhanced understanding and a more realistic assessment of their personal qualities by giving wider voice to their experiences as HIV positive women in Kenya.

Frank (2005), a proponent of dialogic research writes, "Here we get to the key question for qualitative research: what can one person say about another? Research is, in the simplest terms, one person's representation of another" (p.966). Bakhtin's concept of the unfinished self enters into the study of these women's stories by my acknowledgement and understanding that a person's identity is not fixed in any one representation of their words. In a secondary analysis, the researcher, i.e. the listener/recipient of the story as presented in the interview transcript, has no opportunity to dialog with the study participant. The researcher only knows that in some way that may not be immediately evident, they are changed by the experience of interacting with the interviews or put another way, the interviews contribute to the ongoing evolution of their self. "In Bakhtin's dialogic ideal, the research report must always understand itself not as a final statement of who the research participants are, but as one move in a continuing dialogue through which participants will continue to form themselves, as they continue to become who they may yet be" (Frank, 2005, p.966-967).

Conclusion

Frank (2005) writes “one story calls forth another, both for the storyteller him or herself, and from the listener/recipient of the story. The point of any present story is its potential for revision and redistribution in future stories. This principle of perpetual generation means that narrative analysis can never claim any last word about what a story means or represents. Instead, narrative analysis, like the story itself, can only look toward an open future” (p.967).

The her TED Talk (http://www.ted.com/talks/chimamanda_adichie_the_danger_of_a_single_story/transcript), the writer Chimamanda Ngozi Adichie, who grew up in Nigeria, talks about the danger of a single story. She explains that people expect writers to have difficult childhoods, but in fact, her childhood was happy and filled with love and laughter. Yet, she also acknowledges grandfathers died in refugee camps, she grew up under a repressive military government and her family’s finances could not keep pace with the escalating costs of many foods. She says “all of these stories make me who I am. But to insist on only these negative stories is to flatten my experience and to overlook the many other stories that formed me. The single story creates stereotypes and the problem with stereotypes is not that they are untrue, but that they are incomplete. They make one story become the only story.”

Any time we attempt to understand someone’s story we must guard against concluding it is their only story. Dialogic/performance analysis is another method to understand the stories of these women in a more complete way and thus base interventions on a broader understanding. Dialogic/performance analysis, a dynamic method of analysis, pays homage to the influence of time and contextual factors on an

evolving identity, a changing story, while still attempting to find meaning in the experiences of the study participants at the intersect of their interactions with the researcher. That meaning, and our understanding of it, may not, likely will not, remain fixed. That meaning and our understanding of it, may or may not have applications to others in circumstances similar to those of the participants in this study. Nevertheless, dialogic/performance analysis gives voice to these women's experiences supplementing the findings of the primary study from which these data were drawn, and giving life to the statistics so often used to drive efforts to effectuate change.

Reference

- The American Heritage Stedman's Medical Dictionary*. Boston: Houghton Mifflin, 1995. Print.
- Boris, L. and P. Stevens (2014) *Meeting the Challenges of Conducting a Qualitative Secondary Analysis*, Unpublished Manuscript. University of Wisconsin Milwaukee, College of Nursing, Milwaukee, WI.
- Blumer, H. *Symbolic Interactionism: Perspectives and Method*. Englewood Cliffs, NJ: Prentice-Hall, 1969. Print.
- Emerson, C., and G. S. Morson. Ed. M. Groden, M. Kreiswirth, and I. Szeman. Baltimore: Johnson Hopkins UP, 2006. Print.
- Frank, A. W. "What Is Dialogic Research, and Why Should We Do It?" *Qualitative Health Research* 15.7 (2005): 964-74. Web.
- Goffman, E. *Frame Analysis: An Essay on the Organization of Experience*. New York: Harper & Row, 1974. Print.
- Goffman, E. *Stigma; Notes on the Management of Spoiled Identity*. Englewood Cliffs, NJ: Prentice-Hall, 1963. Print.
- Goffman, E. *The Presentation of Self in Everyday Life*. Garden City, NY: Doubleday, 1959. Print.
- Heaton, J. "Secondary Analysis of Qualitative Data: An Overview." *Historical Social Research* 33.3 (2008): 33-45. 2008. Web.
- Irwin, S., and M. Winterton. "Debates in Qualitative Secondary Analysis: Critical Reflections A Timescapes Working Paper." *Timescapes Working Paper* No. 4

(2011): n. pag. Web. <<http://www.timescapes.leeds.ac.uk/assets/files/WP4-March-2011.pdf>>.

Kako, P., PhD, RN, FNP, P. Stevens, and A. Galvao. *HIV Transmission Risk, Access to Treatment, and Self Management of Illness Over Time: An In-Depth Longitudinal Study of HIV-Infected Women in Kenya*. N.p., n.d. Web.

Kako, P.M & Dubrosky, B. (2013). Exploring the lived experiences in HIV positive Kenyan Women. *Issues in Mental Health Nursing*. 34(3),150-157.

Kako, P. M, Kibicho, J., Mkandawire-Valhmu, L., & Stevens' P.E., Karani, A. K. (2014). Advocating for HIV Prevention and Care: A Critical Role for Older Women Living with HIV in Rural Kenya. *SAGE Open*. April-June 2014: 1–9.
Doi: 10.1177/2158244014532277.

Kako,P.M., Wendorf A.R., Stevens,P.E., Otto-Salaj, Ngui, E. (in review)“Contending with Psychological Distress in Contexts with Limited Mental Health Resources: HIV-Positive Kenyan Women’s Experience.” (Issues in Mental Health Nursing)

Mkandawire-Valhmu, L., Kako, P.M., Kibicho, J.W. (2012). Personal Perceptions of the character of God as narrated by East African women living with HIV. *Journal of Christian Nursing*, 29(3), 2-10.

Mkandawire-Valhmu, L., Kako , P.M., Kibicho , J.W., Stevens, P.E. (2013). The innovative and collective capacity of low-income East African women in the era of HIV/AIDS: Contesting western notions of African women. *Health Care for Women International*. 34(3-4), 332-350.

Riessman, C. K. *Narrative Methods for the Human Sciences*. Los Angeles: Sage Publications, 2008. Print.

"Transcript of "The Danger of a Single Story"" *Chimamanda Ngozi Adichie: The Danger of a Single Story*. TED Talks, Oct. 2009. Web.

http://www.ted.com/talks/chimamanda_adichie_the_danger_of_a_single_story/transcript.

Vice, S. *Introducing Bakhtin*. Manchester: Manchester UP, Distributed Exclusively in the USA by St. Martin's, 1997. Print.

CHAPTER 6: SUMMARY AND IMPLICATIONS

Introduction

This chapter summarizes the contributions of my research to methodology in the social sciences, the discipline of nursing and the field of HIV care. Additionally, this chapter discusses implications for nursing practice, outlines areas ripe for further research and explores some recommendations for policy changes.

Overview

Chapter One

Chapter One introduced the problem of a lack of methodological guidance in qualitative research especially in the context of conducting a qualitative secondary analysis (Miles and Huberman, 2002; Bishop, 2007; Gladstone, et.al, 2007; Leech and Onwuegbuzie, 2008; and, Long-Sutehall, Sque and Addington-Hall, 2010). To fill this void, a study using the dialogic/performance method of narrative analysis was applied to interviews of HIV positive women in Kenya in a qualitative secondary analysis. The analysis provided opportunity to explore the methodology of both dialogic/performance analysis and more generally qualitative secondary analysis. The significance of this work to expand the toolbox of qualitative researchers by providing methodological guidance includes optimizing the use of data that was costly or challenging to obtain; generating new findings from data that may have been overlooked, facilitating interdisciplinary collaboration, adding diversity to medical research approaches and improving the quality of results by triangulation of findings obtained using multiple types of analysis.

Dialogic/performance analysis is an infrequently used technique in health care research. The first chapter provided a brief summation of Riessman's (2007)

conceptualization of dialogic/performance analysis as a broadly interpretive technique that includes components of thematic, structural and dialogic/performance into a distinct and separate analytical method. The method is built on the philosophical works of two major intellectuals of the 20th century, Mikhail Bakhtin and Erving Goffman. The major concepts from their works that infuse dialogic/ performance analysis were discussed. These include Goffman's (1959) use of the dramaturgical metaphor combined with Bakhtin's ideas of dialogism, heteroglossia, polyphony and unfinished self (Emerson, 2006).

Knowledge of research concepts is essential to designing a new study. Additionally, secondary analysis presents challenges specific to conducting research that reuses data (Doolan and Froelicher, 2009). Each research technique has methodological challenges specific to the technique, data, and study design. The specific issues and challenges to conducting this secondary analysis of interview data using a dialogic/performance method include conceptualization of the study, selection of a research question, ensuring suitability of the data set, addressing context, relationship to the original researcher, and ethical considerations. Although discussed separately, these challenges are intertwined in the research process. These challenges were outlined in Chapter One.

Chapter Two

Chapter Two offered a critical review of selected literature that focuses on research studies that have utilized the dialogic/performance analysis method including three foundational studies Riessman (2008) used to introduce dialogic/performance analysis and three more recent examples that have cited dialogic/performance analysis as the basis

for their research. Commonalities in the application of dialogic/performance analysis to narrative data were identified. Distilled to the essential elements, research using dialogic/performance analysis requires the investigator to relinquish preconceived ideas to be open to whatever meaning or understanding can be derived from a narrative of individual or group identity. The examination of data demands an acknowledgement of the interrelationship of researcher and study participant and its impact on findings. The content of the narrative; how the story is told; and to whom and for what purpose the story is told characterizes the tri-part approach to dissecting the data. The findings reported are rich with the words and behaviors of study subjects. Distinct sections of a research study are often indistinguishable as the discoveries are discussed intermingling purpose, methods, and findings. This guidance can be helpful to a novice researcher or an experienced research who seeks to expand their qualitative techniques toolbox.

Chapter Three

Chapter Three reframed the conceptualization of qualitative secondary analysis in a manner that undermines arguments that the challenges of conducting qualitative secondary analysis cannot be overcome sufficiently to produce valid, trustworthy findings. The use of dialogic/performance analysis opened the research to a number of specific challenges that could potentially undermine the credibility and soundness of the research. These challenges included conceptualization and coherence of the study design; fit of research question to existing data set; suitability of the data set; context; contact between researchers; data analysis; and informed consent, confidentiality and anonymity. Chapter Three offered an explanation of how these challenges were overcome in this

research and serves as guidance to other researchers on how to design and conduct a sound qualitative secondary analysis study.

Other researchers using different qualitative methods to conduct a qualitative secondary analysis may face similar or different challenges. Two thoughts from this chapter can be generalized to any qualitative research effort. First, the fundamental nature of qualitative research is that there is not a right or wrong interpretation of the data. Each interpretation, each report of findings represents a different understanding of a phenomenon and serves to highlight the complexity of human interaction. The measure of the quality of the research effort lies in the soundness of the process to arrive at the findings. An accounting of the decisions and processes used in the study methodology enable other investigators to evaluate the strength, credibility and soundness of findings whatever analytical technique is employed.

Second, both primary and secondary research studies have problems that need to be addressed in the design and conduct of the study. It is a mistake to think secondary analysis involves problems primary research always avoids (Hammersley, 2009). Certain types of problems are more likely to arise on one side or another of the primary-secondary divide but problems are not restricted to one side. The tendency for certain issues to surface on one side or another of the divide alert researchers to the issues they need to address. Researchers facing the challenges of conducting a sound research study involving secondary analysis will need to confront the issues within their own study design that could undermine the soundness of the research. This is no different than the care needed in designing a primary study.

Chapter Four

Chapter Four illustrated the application of dialogic/performance analysis to interviews of Kenyan women who are HIV positive. The analysis examined the thematic, structural and dialogic/performance aspects of the interviews. Deviating from the usual approach of a researcher seeking answers to specific questions, I approached the data from the perspective the women wanted to tell their own story about their experience but were constrained by the format and structure of the primary study. This approach opened the research to unearthing information that a researcher might not have even conceived of exploring.

The thematic aspect focused on the content of the women's stories. Particularly definitive or poignant passages, emphasis on a certain aspect of their lives, addressing topics not specifically queried, and drawing a picture of their identity were content areas that served to direct me to the story the women wanted to tell about who they were and how their HIV experience shaped their identity. The structural aspect examined how the women told their story. The women employed numerous devices to convey the story they wanted tell. These included raising topics spontaneously outside of the interview questions, deviating from the intent of the interview question, directing comments to an external audience, providing significantly more detail that included information extraneous to the interview question and repetition of topics. The dialogic/performance component examined the context of the story through an examination of the demographic information provided and passages within the interview that gave an understanding of the context. Other aspects of this component include to whom the discourse was directed and for what purpose. Attention to the women's words revealed clear requests for food, money, children's educational expenses, business loans or other items that suggest a

perception that participation in the research might yield immediate tangible help for conditions in their lives.

Illustrations of dramaturgical, dialogic and performance of identity elements were provided to help researchers unfamiliar with dialogic/performance analysis understand this method. Examples of the women's control of the kind and amount of information they revealed to the interviewer evidenced one way the dramaturgical element was operational in the interviews. The similarity of the women's responses to self-care questions revealed the manner in which their voice incorporated the voices of others illustrating polyphonics - one of the concepts of dialogism evident in the interviews. The overarching influence of one characteristic, her gender, on the narrative of one woman is one example of the performance of identity element. The philosophical foundation arises from the symbolic interactionism work of Goffman (1959) and his use of the dramaturgical metaphor; Bakhtin's (Emerson, 2006) work in literary theory and concepts of heteroglossia, dialogism, polyphonics and unfinished self; and, Riessman's (2007) amalgamation of these ideas into a narrative analytical method, termed dialogic/performance analysis, that focused on performance of identity. Evidence of these elements ground dialogic/performance analysis to the underlying philosophical foundation of this method.

Chapter Five

The fifth chapter presents the findings of analyzing transcripts of interviews with HIV positive women in Kenya in a secondary analysis using dialogic/performance analysis. Some background information about dialogic/performance analysis and ideas of Erving Goffman and Mikhail Bakhtin that form the philosophical foundation for the method are

concisely summarized to orient the reader with a basic understanding of this narrative analytical technique. A brief explanation of the study design was provided as a prelude to understanding the research findings.

A review of the commonalities in the lives of the study participants offered a general context for situating the women's words and segregating their personal identity stories. The interviews contained frequent references to famine and food insecurity, poverty, faith in God, abandonment by partners, and transportation problems. The women also spoke of the shared experiences related to the treatment for their infection; the value of support groups, the reception by staff at the HIV clinic, the stigma associated with their diagnosis and the efforts at self care through commitments to taking medication, eating nutritionally, avoiding stress and using condoms. The similarities in these topics and the demographic information provided by the original researcher or the women themselves framed the general situation these women faced as an HIV positive woman in sub-Saharan Africa.

Their individualized and unique responses post HIV diagnosis to the particular circumstances of their lives are captured in the identity stories found in the appendix. Their identity stories are rich with their own words and descriptions of their lives coping with a chronic serious illness while dealing with the challenges of their day-to-day existence. Synopses of some of their experiences are used to explore the commonalities of their lives and illustrate general themes that emerged.

General themes that capture the women's experiences are offered to capsule the experience of these women. This is done with the full realization that the identity stories often overlap several themes, and the variations and nuances found in each of their stories

can only fully be appreciated by reading each woman's identity story. Six general themes surfaced.

Self-Identification is a theme introduces the stories of women who self-identify with a characteristic that is inextricable from the core of what defines them as a person. Aspirations and Dreams describe women who, despite HIV, persevered in pursuing a dream. Relationships Redefined discusses women who address relationships reshaped in the aftermath of a positive HIV diagnosis, primarily focusing on the relationship they have with their spouse or partner or the consequences of losing their spouse. Transformation examines a group of women in whom the HIV diagnosis serves as a catalyst for these women to reinvent themselves in a positive and productive way. Life Derailed discusses women who lament the loss of a life they once had and have no vision for a life post-diagnosis. Life Continues addresses women who essentially want to believe that HIV is no different than cancer or diabetes and life can continue unchanged.

Implications for Nursing Practice

There are two areas to consider when addressing the implications for nursing practice that flow from this study. One level is the implications from what we learned about HIV-positive women in Kenya. The second area examines the implications of lessons learned about the application of dialogic/performance analysis to narrative data as a methodology to be used in health care research.

Caring for HIV Positive Women

The stories these HIV-positive women tell about how an HIV-positive diagnosis shaped their identities and impacted their lives accentuates the need for nurses to look at the whole person when providing care. The women were not defined by their HIV-positive

diagnosis. It was an aspect of their life that jeopardized their interactions with others and drained their already limited resources. Their stories are a testament to their resourcefulness and resilience. Nurses learn to take a history from a patient, do a physical assessment, educate patients, treat patients, administer medications and monitor therapeutic outcomes. Much of what nurses do is dependent on an understanding of the patient's needs. This understanding is developed, in part, through knowledge of the particular disease process. However, as these women's stories indicate a nurse's knowledge of HIV/AIDS alone is insufficient to effectively provide nursing care to these women. The nurse must combine understanding of the disease with understanding of the patient and help the patient to build on their strengths to overcome their health struggle.

As the women were being interviewed, they controlled the type and amount of information they provided in response to the interviewer's questions. A nurse cannot assume patients always answer questions fully and completely thereby providing all the information relevant to the patient's care. The patient passes their response to the nurse through filters of trust, privacy, expectations, and need-to-know, that determine how much and what the patient wants to reveal. Patients may be reluctant to share information about all the measures they are pursuing to treat their condition if they know certain activities may be inconsistent with the treatment advice provided by health care experts. The nurse's sensitivity to the cultural and social practices, skill in building trust and openness to hear what the patient says will impact the information the nurse has to guide her care and influence the nurse's effectiveness.

There were numerous times when the women appeared to use the questions to provide information about a different topic. They inserted seemingly unrelated

information. They went off on tangents. They talked at great lengths about topics that were not asked about. With the pressing time demands most nurses experience it might be easy to discard this kind of information as irrelevant. Yet, not only was this information relevant, this information was arguably the very information the women wanted the interviewer to know about who they are and how they are managing their disease. As nurses we must attend to information patients provide, weigh its importance and incorporate this knowledge into care provided.

Impacting Nursing Practice Using Dialogic/Performance Analysis

This study provides some guidance to novice or experienced researchers in the methodology of applying dialogic/performance analysis to narrative data. The method is dynamic and flexible but adherence to a few basic guidelines renders this a technique that can be learned. Dialogic/performance analysis, based on the experience of applying this technique to narrative data of HIV-positive women in Kenya, is best used in conjunction with other methods of data analysis. The strength of the method lies in providing a different perspective i.e. that of the study participant, in an effort to either broadly explore or understand a phenomenon of interest or provide rich, descriptive detail to data examined by other means, qualitative or quantitative. Further research in areas of interest to nurses and the nursing profession using dialogic/performance analysis can bring a different perspective to the research and thus contribute to expanding the body of knowledge on any topic under scrutiny.

By virtue of education and experience, nurses, physicians and other providers of services to people who face an assault to their well being are the acknowledged experts on the care and treatment of health care issues. Based on information gathered and patient

diagnosis, we make assumptions about the care needed by the patient. We focus on completing the tasks associated with the treatment plan. However, our effectiveness in our duties is, in part, dependent on the information we can gather from those in our care. All too often time demands make it difficult to spend adequate time listening to our patients.

One event, one interaction with a person can alter the way we practice nursing. We know this in other areas of life. Frances Scott Key, after witnessing the bombardment of Fort McHenry, was moved to write the *Star Spangled Banner*. Florence Nightingale, inspired by her nursing experience during the war in the Crimea, focused her work establishing nursing as an activity that required a sound knowledge base acquired through standardized training.

Not all nurses are researchers, but there is a lesson for all nurses in the basic precepts of dialogic/performance analysis. Patients control the kind and type of information they share based on our responses to them. Patients have a story of what is meaningful to them beyond the test results, the medications and treatments, and the prognosis. We, as care providers, are as much changed by our patients (consciously or unconsciously) as we change the trajectory of our patients' lives. Openness to really listening to our patients and hearing their stories can cause us to care more and potentially alter the way we practice nursing.

Areas for Future Research

Nursing Practice - The Experiences of HIV-Positive Women

The women who spoke in this study articulated how their identity and lives were shaped by their HIV diagnosis. These women were from a pool of women who sufficiently

overcame the potentially stigmatizing affects of an HIV diagnosis and sought testing and treatment for the disease. In the course of describing their experiences, they also identified factors that profoundly impacted their ability to manage their illness. Food insecurity, transportation, lack of support from family, limited income, religious activities, employment practices and medical policies were issues raised over and over by these women. The women in the study confronted the challenges of their daily lives and accommodated the testing and treatment actions needed to preserve their health. The issues the women in the study faced may offer insights into factors that prevent some women from taking proactive steps to avoid potential threats to their health and seek testing and treatment if indicated. The repetition of these issues suggests that their role and impact on the identification and treatment of HIV-positive women has not been fully explored. These topics represent some of the pragmatic issues the women in the study mentioned that can serve as a focus of future research.

Beyond the Pragmatic

The women's individual stories raise questions beyond the pragmatic that invite further exploration through research. The women's experiences in the aftermath of their HIV positive diagnosis and their reactions varied considerably. The circumstances of their lives did not seem to account for the resultant differences in their reactions to their diagnosis and management of the illness post diagnosis. One woman, facing chronic poverty or food insecurity, manifests despair and defeat succumbing to the disease; while another woman, in similar circumstances, rose above such life challenges and in the process maximized her well-being. What accounts for these differences? Specific

research questions that might yield information to answer this question and with that knowledge reshape the approach to treating HIV-positive women include:

- What factors shape women's responses to their HIV diagnosis?
- What role do personality traits such as resilience or resourcefulness play in shaping women's responses to their HIV diagnosis and success in managing their lives post-diagnosis?
- Are there tangible, identifiable actions health care providers, including nurses, can take to enhance women's internal strengths to manage their disease?
- What is the relative influence of nurses or health care providers, friends, families, and neighbors in helping women diagnosed HIV positive to manage their chronic condition in a manner that optimizes health and well-being?
- Are there specific portions of a standardized care plan for the treatment and management of HIV that can or need to be tailored to maximize women's coping and response to treatment?

Methodology Research on Dialogic-Performance Analysis

Utilization of any research methodology is dependent, in major part, on the understanding of how the methodology should or can be applied to the data and the credibility of the resultant findings. This study demonstrated the viability of dialogic/performance analysis as a tool to be used in a secondary analysis. Further research that adheres to the guidance provided from this effort will confirm the adequacy of the instructive and illustrative value of this guidance and lend credibility to the use of dialogic/performance analysis in health care research.

Dialogic/performance analysis offers flexibility in its application. The experience with dialogic/performance analysis use with this particular data set suggests that the method is best viewed as a supplement to other methods of analysis of the data. This can be done either using dialogic/performance analysis as an initial method of exploring a phenomenon providing direction for more focused research based on findings or using this method to provide rich, descriptive information to complement findings from a more directed research question or structured analytical method. Research examining the effectiveness of dialogic/performance in a primary study in health care is another opportunity to solidify the use of this method in health care research. An increase in the use of this method in health care research will confirm the value of this method in contributing to the knowledge base of health related topics.

Qualitative Secondary Analysis

This study explored the challenges of using dialogic/performance analysis in a secondary analysis. The quality of the findings is a function of overcoming challenges inherent in conducting any research but particularly challenges that arise in qualitative secondary research. Further research that assesses challenges to conducting secondary analysis using qualitative approaches other than as dialogic/performance analysis will also strengthen the argument that issues of context, adequacy of the data set, relationship of researcher to study participant, etc. do not preclude a sound study that yields credible, informative results.

Policy Implications

Managing the Public Health Issue

If nothing else, this study highlights the multifaceted complexity of addressing the chronic health needs of HIV-infected women in Kenya. Clearly, after hearing these women tell their stories, the spread of this disease and the adequate treatment of individuals infected with HIV is not isolated to the medical resources available. Socio-cultural determinants as well as financial resources (both of the individual and the country) are intertwined in efforts to address this public health issue. My limited knowledge of HIV/AIDS, health care in Kenya and relevant social, economic and political characteristics of the country, render it presumptuous to think that any policy modifications I could suggest would radically improve testing and treatment for HIV/AIDS of women in Kenya.

The women themselves offer specific modifications to address the concerns of HIV/AIDS patients. Rebecca, one of the study participants, explains that some people do not want it known they are HIV-positive because “this sickness is really hated by so many people.” However, medication is given at the clinics in a central place so everyone knows someone’s HIV status. To encourage people to avoid hiding their status and come for treatment Rebecca suggests “they should avoid giving medicine at a central place. They should gather people for a seminar or workshop to educate them on disease and this will reduce fear.” Immersed in personally confronting a host of factors that determine ability to obtain care, some women in the study advocated for specific actions e.g. mandated testing, free medications, economic support for infected women, etc. While perhaps they are more qualified than I am to assess the need for, and suggest specific

policies to address the public health situation, the recommendations lacked the critical examination needed to determine desirability and feasibility, likelihood of achieving desired outcomes, cost effectiveness, and avoidance of undesirable consequences.

Secondary Research

This research study demonstrates the power of a secondary analysis to add to the body of knowledge of health care topics and, therefore, supports calls for the increased use of qualitative secondary analysis. Irwin and Winterton (2011, p. 2) note, “Secondary analysis is an established practice within quantitative research and there is a drive towards extending qualitative data re-use and analysis.” A policy to require a secondary analysis of all qualitative data sets, although seemingly desirable, is simplistic but perhaps is a direction to move.

Research efforts in the United Kingdom identified some of the challenges of establishing a practice of qualitative data storage and reuse analogous to that which exists in quantitative research. The Economic and Social Research Council (ESRC) is a United Kingdom (UK) organization for funding research on economic and social issues. The ESRC mission includes support for research, training and development opportunities for researchers, expansion of the UK data infrastructure and supporting methodological developments <http://www.esrc.ac.uk/about-esrc/what-we-do/index.aspx>.

Timescapes: an ESRC qualitative longitudinal study, examined through seven primary research projects, the dynamics of personal relationships and identities and how these are forged, sustained, discarded or re-worked through the life course and across the generations. The projects focused on siblings and friendships in childhood; the unfolding lives of teenagers; motherhood across generations; men as fathers; work/life balance in

families with young children; grandparenthood and social exclusion; and the lives of the oldest generation. Collectively the projects explored the impact of the passage of time on the “biographical, historical and generational unfolding of lives, how individuals perceive past, present and future, and how they constructed and overwrite their biographies, both personally and collectively, in relation to wider historical processes” (ESRC).

The secondary examination of data both within and between projects in the Timescapes work spawned a strong methodological component that gave rise to the Timescapes Secondary Analysis Project <http://www.timescapes.leeds.ac.uk/secondary-analysis/timescapes-secondary-analysis-project.html>. The goals of this project centered on developing methodological insights around secondary analysis working with one data set and across qualitative data sets “to explore the scope for extending the analytic reach of qualitative evidence.”

The methodological insights derived through the work of the Secondary Analysis Project offer a compendium of issues that need be addressed to expand secondary analysis of qualitative data sets. Setting aside debates about epistemological concerns about context, researcher presence and the like there remain practical considerations that must be addressed. Provided here is just a sampling of issues and questions discussed in the Timescapes Secondary Analysis Project working papers that arise if an expansion of qualitative secondary analysis is required or encouraged.

Storage of data:

- Where will the qualitative data sets be stored?
- What will be stored – transcribed transcripts or the original interviews? How will storage of items that cannot be digitalized be handled?

- How will the cost of storage be managed?

Policies by institutions or funding sources:

- Should researchers only be allowed or funded to collect new data if it can be demonstrated that no archived data set is suitable?
- Should researchers be required to make their data sets available to other researchers?
- Should researchers always be required to craft informed consent documents to allow for the re-use of the data in a secondary analysis?
- What levels of access should be allowed?

Cataloging data sets:

- What information is needed to understand the nature of the data set for future researchers to determine if a re-use of the data set is suitable for a secondary research project?

Ethics:

- How is data in the archive protected?
- Should the primary researcher control who may have access to their data?

Qualitative secondary analysis can supplement findings from a primary study through the addition of rich descriptive information potentially not captured in the initial research and/or by generating new findings. These uses and others such as validating results of the primary study are widely acknowledged as legitimate and valuable purposes for conducting qualitative secondary analysis (Irwin and Winterton, 2011; Corti, Day, & Backhouse, 2000). However, the obstacles that discourage the use of qualitative secondary analysis must be addressed. This brief sampling of the myriad of troublesome

issues that discourage a broad based approach to facilitating qualitative secondary analysis calls for more reasoned and measured efforts. Corti and Thompson (2004, eds. Seale, Silverman et al, p. 299) conclude “there is a well established tradition in social science of reanalyzing quantitative data. Nor is there any logical intellectual reason why this should not be so for qualitative data. However, among qualitative researchers there is no similar research culture encouraging the reanalysis of data collected by other researchers.” Better education about qualitative secondary analysis at the doctoral level, enhanced collaborative intra- and interdisciplinary research efforts that reuse data sets and institutional policies that support secondary analysis are measures that can create a research culture that facilitates the proliferation of secondary analysis.

Novice and experienced researchers need to educate themselves about the purposes and analytic tools for conducting secondary analysis. Dialogic/performance analysis is just one of the analytical tools that can be used. To be sure, there is “methodological skepticism about secondary analysis” (Van den Berg, 2005, p. 1) characterized by lively debates about context, confidentiality, validity and other aspects of the research process. As was demonstrated in this research effort, researchers will likely craft their secondary analysis with an eye toward addressing the issues most salient to their particular research purpose and methodology anticipating what critics might deem the weaknesses or flaws that could undermine the research effort. Hammersley (2010, p. 2) argues that “the problems with re-use of data highlighted by the critics are not restricted to it: they also occur in some kinds of primary research,” and cites as an example primary research that involves collection of data by one researcher and analysis by another. Knowledge about the potential benefits and pitfalls of conducting secondary

analysis will enhance the quality of the resulting effort and potentially bring greater clarity to primary research efforts.

Increased collaboration within disciplines and between disciplines at the outset of planning a research project can forestall some of the issues that are problematic in a secondary analysis. Modifications in informed consent procedures, changes in sampling criteria and data collection, agreements about re-use of data, data security and storage, and other practical or logistical considerations that impede re-use of data can be examined and resolved through collaborative planning with an understanding the data will be used beyond that proposed by the principal investigator.

A call for increased collaboration and proactive planning for multiple uses of a data set calls into question the distinction between primary and secondary analysis. Windle (2010) states “primary analyses address a specific set of objectives outlines before the data are collected” (p. 322) and secondary analysis is “analysis of an existing dataset to address a different research question.” Hammersley (2009) speaks to the distinction between use and reuse of data acknowledging there are more purposes for conducting secondary research than contained in Windle’s definition. Hammersley argues absolute differences between primary and secondary analysis are lacking.

Contemporaneous discussions between researchers on proposed research on a topic of common interest does not alter the conclusion the data will be re-used. Proactive discussion to maximize use of the data is beneficial to all parties and need not get bogged down by intellectual debates on whether to categorize the research as primary vs. secondary.

Institutions, both higher education and businesses, can enhance collaboration and facilitate access to data bases by the development of policies that are designed to foster these activities. For example, work done for tenure or promotion may require at least one project that involves interdisciplinary collaboration. Interdepartmental meetings or correspondence designed to share research interests and activities can encourage collaborative work. A repository for data sets on the institution servers and guidelines for storage, access, use and confidentiality can be established. Windle (2010) notes that many investigators lack access to original clinical databases thereby diminishing the use of databases for secondary analysis. High fees for use of the data or inadequate information about the conduct of the primary study are potential causes of lack of access that can be influenced by institutional policies. Perhaps some institutions have already moved in this direction and can be developed further as a multi-pronged approach to encouraging qualitative secondary analysis.

Conclusion

The significance of this research is threefold. First, the stories of these HIV-positive women in Kenya contribute to our understanding of the experience of living with a chronic, stigmatizing health condition. Their stories explore the complexities of living as an HIV person and celebrate the resourcefulness and resilience they display in the face of adversity. Any one story can be a catalyst for modifying our approach to supporting women who are HIV positive. Collectively the stories address the myriad of reactions to a diagnosis of a chronic illness and offer numerous areas for future exploration.

Second, this research offers methodological guidance on the use of dialogic/performance analysis in health care. The philosophical underpinnings of this

method and an assessment of characteristics of common to the application of this method to narrative data discussed in this research provides the methodological guidance so often lacking in qualitative research. Dialogic/performance analysis is an approach to the exploration of a phenomenon that shifts focus from what the researcher wants to know to the perspective of the study participant thereby opening the possibility for findings previously unimagined.

Third, this research posited a conceptualization of qualitative secondary analysis that recasts qualitative secondary analysis as a viable approach to maximizing the use of data. Every research methodology, qualitative or quantitative, involves discretionary decisions and overcoming methodological challenges to achieve a valid, trustworthy result. Qualitative secondary analysis has, for too long, been avoided because it was perceived as fraught with insurmountable challenges. This research demonstrated how these challenges can be overcome within the context of doing a secondary analysis using dialogic/performance analysis by careful attention to the factors that could undermine such research.

Frank (2005) writes “one story calls forth another, both for the storyteller him or herself, and from the listener/recipient of the story. The point of any present story is its potential for revision and redistribution in future stories. This principle of perpetual generation means that narrative analysis can never claim any last word about what a story means or represents. Instead, narrative analysis, like the story itself, can only look toward an open future.” (p. 967) Researchers should feel confident they can move forward into the future adding to knowledge with qualitative secondary analysis and dialogic/performance analysis.

References

- Bishop, L. "A Reflexive Account of Reusing Qualitative Data: Beyond Primary/Secondary Dualism." N.p., 30 May 2007. Web. <<http://www.socresonline.org.uk/12/3/2.html>>.
- Corti, L., A. Day, and G. Backhouse. "Confidentiality and Informed Consent: Issues for Consideration in the Preservation of and Provision of Access to Qualitative Data Archives | Corti | Forum Qualitative Sozialforschung /forum: Qualitative Social Research." N.p., 2000. Web. <<http://www.qualitative-research.net/index.php/fqs/article/view/1024>>.
- Doolan, D. M., and E. S. Froelicher. "Using an Existing Data Set to Answer New Research Questions: A Methodological Review." *Research and Theory for Nursing Practice* 23.3 (2009): 203-15. Web.
- Emerson, C., and G. S. Morson. "Mikhail Bakhtin." *The Johns Hopkins Guide to Literary Theory and Criticism*. Eds. Michael Groden, Martin Kreiswirth and Imre Szeman. Second Edition 2005. The Johns Hopkins University Press. 25 Jan. 2006.
- Frank, A. W. "What Is Dialogic Research, and Why Should We Do It?" *Qualitative Health Research* 15.7 (2005): 964-74. Web.
- Gladstone, B. M., T. Volpe, and K. M. Boydell. "Issues Encountered in a Qualitative Secondary Analysis of Help-Seeking in the Prodrome to Psychosis." *The Journal of Behavioral Health Services & Research* 34.4 (2007): 431-42. Web.
- Goffman, E. *The Presentation of Self in Everyday Life*. Garden City, NY: Doubleday, 1959. Print.

- Hammersley, M. "Can We Re-Use Qualitative Data Via Secondary Analysis? Notes on Some Terminological and Substantive Issues." *Sociological Research Online* 15.1 (2010): n. pag. Web.
- Huberman, A. M., and M. B. Miles. *The Qualitative Researcher's Companion*. Thousand Oaks, CA: Sage Publications, 2002. Print.
- Irwin, S., and M. Winterton. "Debates in Qualitative Secondary Analysis: Critical Reflections A Timescapes Working Paper." *Timescapes Working Paper* No. 4 (2011): n. pag. Web. <<http://www.timescapes.leeds.ac.uk/assets/files/WP4-March-2011.pdf>>.
- Irwin, S., and M. Winterton. "Timescapes: An ESRC Qualitative Longitudinal Initiative." *Timescapes Secondary Analysis Project* ». University of Leeds, 2011. Web.
- Leech, N. L., and A. J. Onwuegbuzie. "Qualitative Data Analysis: A Compendium of Techniques and a Framework for Selection for School Psychology Research and Beyond." *School Psychology Quarterly* 23.4 (2008): 587-604. Web.
- Long-Sutethall, T., M. Sque, and J. Addington-Hall. "Secondary Analysis of Qualitative Data: A Valuable Method for Exploring Sensitive Issues with an Elusive Population?" *Journal of Research in Nursing* 16.4 (2011): 335-44. Web.
- Riessman, C. K. *Narrative Methods for the Human Sciences*. Los Angeles: Sage Publications, 2008. Print.
- Riessman, C. K. *Narrative Methods for the Social Sciences*. London: SAGE, 2007. Print.
- Seale, C., G. Gobo, J. F. Gubrium, and D. Silverman. "Qualitative Research Practice: SAGE Research Methods." *Qualitative Research Practice: SAGE Research Methods*. Sage Publications, 2004. Web.

Van den Berg, H. "Reanalyzing Qualitative Interviews from Different Angles: The Risk of Decontextualization and Other Problems of Sharing Qualitative Data | Van Den Berg | Forum Qualitative Sozialforschung / Forum: Qualitative Social Research." N.p., 2005. Web. <<http://nbn-resolving.de/urn%3Anbn%3Ade%3A0114-fqs0501305>>.

"What We Do | ESRC | Economic and Social Research Council." *ESRC News*. Research Councils UK, n.d. Web. <<http://www.sociology.leeds.ac.uk/research/projects/timescapes>>

Windle, P. E. "Secondary Data Analysis: Is It Useful and Valid?" *Journal of PeriAnesthesia Nursing* 25.5 (2010): 322-24. Web.

APPENDIX: INTERPERATIVE SUMMARIES

Trying To Reconcile the Irreconcilable

Despite her statements affirming she is doing well, Pam appears ill. At 30 years of age, she has an 8 year-old son and is divorced. Following her divorce, she worked until she became sick. When she became sick, she returned home and now lives with her parents, younger siblings and son. She reports that “I was staying at home, it was very hard even to get one shilling it was hard.” But, her parents “put up a business for me” selling vegetables. With the money she earns she claims “usually when I need something I can get it.” She has reestablished a life for herself but her life is punctuated with reminders of her illness.

Diagnosed two years ago, Pam was sick for more than a year before she got tested for HIV. She summarized her symptoms and health care experience during that year by stating, “before I knew {of her HIV status} I used to go to the doctor they would tell me I have pneumonia, they treat me, they would tell me its chest problem, they would give me medications...they did an x-ray and I was told I had TB, they gave me medication multivitamin but my feet had problems, I had numbness so that I could not even walk. Any time I would attempt to walk I would have much pain and they were swollen.” Pam thought something was wrong but attributed her symptoms to not having enough blood. Testing for HIV offered Pam some hope. She reported she was not shocked by the result of the test. After she learned of her HIV positive status she claimed, “I was happy because I knew I could be better because now I knew what was wrong, now I can take medications.”

Pam faithfully takes her medications because she knows medications “help the body’s defense system; they support the defense system so it does not go down. Then the body gets strong, and you are not supposed to miss. If you miss the defense system goes down and your body gets worse.” “Taking medications and eating well and without stress” are the most helpful in managing her condition. Stress can be avoided, she explains, by “talking to people, or sing godly songs, take walks.” Support groups, brothers who work and support her, counseling, eating properly and a belief that “nothing is hard with God” sustain her life with AIDS.

Pam asserts, “My health is improving.” Indeed her 7 kilo weight gain since diagnosis and the fact she has not experienced rashes would seem to confirm her assertion. Yet, she is not symptom free. Pam has had headaches, malaria, TB and pneumonia. She is experiencing diarrhea. She speculates that her stomach is hurting and she is having diarrhea because of her diet – “I have a stomach problem of diarrhea every time I eat something. I don’t know after I eat food I keep asking myself is it the cabbage, or is it because I mixed with avocado, so I don’t know what it is.” She lacks an appetite. Further, she is not free from discrimination against people with AIDS. Pam claims, “Now people think as it is common, it is like having diabetes or high blood pressure.” She is, however, selective about disclosing her disease for she says, “you know when you are sick and people know about it, they start discriminating against you.”

Asked what she would need to help her life? Pam responds with “if there is medication that we can take so that we all get healed so that whoever has repented and decided not to go back to risk behavior, they can stay.” Pam recognizes that the medications do not cure AIDS. Her thought is that if “we take the medication we can be

healed. But, we have belief that we will be healed because they say it can take 30 years.”

In her final thoughts, she almost pleads with government officials of health care “I would tell them to give us better medications that would heal us. You know the medications we are taking they help support the body defense system to kill the virus, if by any chance there could be a medication that can kill the virus from the body, they should give us that type of medication so that we can be healed.” Pam tries t` o live a life of repentance, managing the disease as instructed. She tenuously holds on to life with a hope for a cure knowing she may succumb to the disease before a cure can be found.

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The Story of the Wise Woman

The story of Rebecca is told in two parts. Each part illustrates the knowledge and wisdom she has gained in understanding HIV/AIDS. Part one is an in-depth examination of her own experience as a person positive for HIV for 17 years. Part two demonstrates her knowledge of the impact of HIV/AIDS on people within the broader context of her community. Rebecca is a 56 year-old widow who is so well loved by her family and community she was made a village elder.

In part one Rebecca shares her story. She only learned of her HIV status after the hospital encouraged her to be tested following the death of her husband. Although he died from AIDS, Rebecca had not known that was the cause of his sickness. Rebecca shared the news of her positive status with her children but they, like others she would encounter in the ensuing years, had difficulty understanding because, in her words, “they could not believe it since it was strange to them...you are doing well and you looked

good.” She had “sick pancreas” when her husband died and thought she might also die. However, Rebecca recovered and she states, “I do get sick just normally but I have never been sick as in I go for admission. I get the normal sickness like malaria, headache which is not severe.”

Rebecca attributes her good health primarily to two factors. Her children “really take care of me” and her God “gives me life and joy to live.” She believes, “because many have died but I don’t die so it is God.” But, she does go on to cite a number of self care activities. Rebecca attends a support group once a month at the hospital, she eats well, she uses herbal medications and she prays to “our Heavenly Father.” Rebecca has not had her CD4 count checked nor is she on medications. As she explains, “you were only checked CD4 count when you are so sick so as to start medicine and like me I don’t get sick so I have not been checked.”

Rebecca loved her husband “so dearly and not because we had anything or riches but from my heart.” At his death, the custom was for her husband’s brothers to inherit her. The brothers stigmatized her and they did not value her because she was HIV positive. Instead, she remained with her children. Other men pursue her but she had “decided to stay without one.” She told men she was positive but sometimes had to be very assertive in thwarting their advances. Men, she decided “really are tiresome.”

Part one ends in a broad discussion of problems in her home that include unemployed sons, an unmarried son, and no money to finish building the house as money was used to buy food during the famine. Rebecca also begins to display some of the knowledge and wisdom she has acquired about HIV/AIDS. In answer to the question

about what she would tell an HIV positive woman her advice is to take medicine, abstain completely, listen to counselors and not work so much. But these answers are only provided after gauging who initiated the conversation and what the hospital had told the hypothetical woman.

The focus of part two of Rebecca's narrative shifts to a dialog, in which Rebecca answers specific questions posed by the interviewer. The questions cover Rebecca's personal experiences, advice she would provide to other HIV positive women and community issues related to the prevalence of HIV. Rebecca repeats she has not had her CD4 count checked, she does not take medications and she engages in self care activities such as eating properly and avoiding men. She adds that she has "friends who are sick like me and I share with them my problems," and also that "one should not work so hard to avoid getting sick." In response to a question about her experience at the hospital, Rebecca outlines the benefits of receiving advice from doctors, meeting other HIV positive women and recognizing, "I was not dying as fast as I thought." Of other HIV positive women, Rebecca shows great sensitivity and tact as she states, "I can see a person with symptoms and she does not know and I can start with my story and I cannot go direct but tell her the good thing of getting tested and if she agrees to go for the test then I can take her and I become her teacher at all times when she needs me."

Rebecca's knowledge and wisdom about the HIV/AIDS situation is evident as she expounds on a range of community issues as she answers the interviewer's questions. Rebecca addresses a number of social and political topics. Legislative issues include a policy of mandatory HIV testing and advocacy with government officials to secure financial assistance for HIV positive persons. Social issues cover the community reaction

and stigmatization of HIV positive persons, neglect of HIV positive women by daughters-in-law and orphans created when both parents die of AIDS. She also discusses the economic challenges of managing with HIV.

Personal loss and HIV infection led to a dramatic shift in Rebecca's life and in response she not only became an expert in her own care but was transformed into a knowledgeable and wise woman in her community.

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Keeping the Faith

Everlyn, a 51 year-old widow maintains, "I have nobody to depend on who can help me," and proclaims "I only trust in God." Her husband, a mechanic, died about three years ago. An accident left him with "an injury with a spinal cord." Everlyn's husband knew he was positive for HIV but did not tell her. Everlyn "came to know that he was sick afterwards." So when she became sick, "they took me to the hospital. I was examined and found with the virus." Her husband was the only man with whom she had been sexual. She suspects he had "girlfriends". Eleven years have passed since her diagnosis. The youngest of her five children is just 13 years old and the three small children of a divorced daughter stay with her. Everlyn "stay with my children and my God who created me," managing as she can with her limited education and income. Her source of strength is "from God" because "without God the disease makes you weak, and at times you feel like not waking up but God gives you the strength to continue when you pray."

Money is limited. Everlyn claims that faced with this disease "it is hard to get a job to do" in part because of stigma and in part because of limited stamina. Everlyn

confesses “I used to work so hard from morning till night and from there I can go fetch some water. I used to love work but now when I became sick I stopped since my body is weak.” After two hours of work in the fields Everlyn is “so tired and thirsty” she needs to “go back home and take something. That is the biggest challenge I face.” Everlyn laughs as she discloses, “I do get daily bread but to have money in the pocket, I don’t have.”

In times of famine Everlyn reports, “I used to work casual jobs, and out of the money we get we used to get food.” If there was no food at all, Everlyn states, “we used to sleep like that.” Everlyn knows of women who trade sex for food - “When there is famine some women go to places without telling the children where they have gone to and they come at night with food and they don’t work and they have not worked any casual job.” Everlyn has not engaging in such behavior. Her religious beliefs inform her actions. She believes “God never lets us be ashamed...I tell HIM to come down for my needs and in the process I can get a person pass by” who shares food with her and her children.

Money is needed for food but it is also needed for medicine. Everlyn reports that “the money we used to get for buying medicine is not there at the moment so one is forced to get money by yourself for the medication.” Medicine, transportation to the hospital, blood test, CD4 count are some of the costs associated with being HIV positive. Everlyn states the situation, “when you go to the outpatient in Muthale they do not give you free medicine and you pay like any other patient, the project of Homecare does not pay for us anymore. If one goes there with no money then she will not be treated.” Everlyn describes peoples effort to obtain care with limited financial resources “if you fail to get the money they give you on debt that is payable...on going back, they cannot

give you another day without paying for the first debt...so we have problems getting the medicine.”

Everlyn has a plan for addressing this problem. “If I can get a business, it can help me a lot to eat well and pay for the medicine without strangling.” This idea has potential as there are funds for women to start businesses. Yet, there are significant risks. Everlyn divulges that “here we have some that will give maybe 5000 Ksh, but when one goes home she decides to buy food instead. So you don’t really meet the target of the business and later if you don’t pay that money, the woman take whatever you have to compensate the loan. So people fear the loans due to that.”

There are other risks as well. Everlyn tells how “we had started making soap but after we made the soap and it was sold, we were not given the money.” She and the other woman making soap do not know where the money went. “We have been so sick but other people are taking advantage of us.” Everlyn explains, “We used to bring the money here and this money is not audited neither given to us. They take the money. For example the money we used to be given here for fare and trainings, we were told that the money is over which we believe is not the case.”

Everlyn outlines the basic problem. “You can get money for the food and you fail to buy the food just to get the medicine.” For Everlyn, the distinction between food and medicine has blurred “with time I thought of taking them {medicine} just like the normal food since when you have taken them you are strong and healthy.” Her faith prevents Everlyn from viewing the choice between money for food or medicine as a dilemma. As she advises other HIV positive women, “She should keep her trust in God and He will

help her.” “If we can get someone to sponsor the women to have their own businesses then this can be marvelous and how we pray that one day God will hear our prayers and answer us accordingly,” Everlyn concludes. Everlyn’s life and approach to her disease is a testament to her faith.

LLB 01182011

Revised 09052011

Changing the Patterns

Today, when life is hard, April announces, “I tell God to take control since I don’t know anything else to do.” April, a 43 year-old single mother of an 18 year-old daughter and a 16 year-old son, has had a diagnosis of HIV positive for about a year. Her daughter is married. The son lives with her as she explains, “he got an accident (the cart fell on him) that the whole body was damaged so this affected his brain and he never performed well in his final exam and this boy used to be very clever before all that happened. When you see him walk, you can think he is drunk because he walks staggering. I normally take him for clinic.” Her current reliance on God is relatively new as she describes, “When I came to know about my status, I thought that the only way to survive is to have faith in God.”

April became sick but treatments for typhoid or malaria were ineffective. She became sicker and developed diarrhea and vomiting. Her sister took her for blood work. April tested positive for HIV and her CD4 count was so low she was started on ARVS. Sickness was not new to April for she explains, “I used to get problems like I could be sick always, malaria and so much to my chest.” A chest X-ray revealed nothing, “but later when I went to see the doctor and explained how I used to feel. I was told that it was

asthma.” April was given medication and states, “but I don’t completely get well and I still have problems.”

A second change that occurred with diagnosis is that April “booted the partner that I had and I stopped associating with him.” Sex, she had been counseled, “Adds to the sickness.” April had been with her male partner “a long time...like one year.” He was one in a series of men for as April tells, “I used to get a friend, and dismiss after sometime and get another one.” April again has a boyfriend but she is now using condoms because “the other thing is to take care not to infect others in one way or another.” April “uses the ones for women that they do not understand what is happening and if it is a person that we trust each other then he can use the one for men.”

Sex was not always about the satisfying of physical needs for April. April sometimes used men to get money. As April explained in her own words, “there before I used to do that when I had not known my status. You see I was suffering and I did not have any man to take care of me and I was not married so if a man came to me and gave me money I would not hesitate to take it.” Condoms were used “sometimes but not always and I could not believe there is AIDS.” The money would be used to pay for food. April gets “casual jobs to continue with life” but confesses the family income “cannot be enough for my needs.”

Food security has been an ongoing issue for April. April tells of times when the little money she had “can buy food for supper only and one cannot get satisfied.” She describes, “There was once one year when there was a lot of famine and the baby could not breastfeed well.” In the past year, April discusses the hardest thing “it is working

since I am never strong.” Again she references food “although I like working and you know now there is famine, so when you don’t eat, you get problems and feel weak.”

April relays the second half of her story. She reports, “I am doing well” and there have been “changes in life”. April has been “taking the medicine and not getting sick.” She is also “taking care not to get other sicknesses” by “staying clean and eating well and using a net not to be bitten by mosquitoes.” There are other things she does to continue to feel well “for example when you get bad news; you don’t put them in mind as we have been told. Instead she likes “to sing and laugh and anything that was in mind goes away.” April goes to the clinic every other month to get medicine. She does not find it difficult to see the doctor and states, “If I have a problem I don’t hide but I explain to the doctor and he treats me and I get well.” The doctor “advises us on nutrition” so April “try so hard to eat a balanced diet.” April has discontinued her use of herbs and seeking care from a witchdoctor.

A big change has occurred in April’s working life. April reports she is working in her brother’s hotel. April recognizes that “many people are not yet informed about the disease and therefore they end up mocking the ones who are positive but there are others who take it normal.” Customers of the hotel, however, apparently do not know she is HIV positive and thus the business has not seen problems employing her. April explains that to work at the hotel “they only require a letter from the ministry of health and I have it.” The health officer knows her status thus April says “so I have no problem only that I should be careful.”

April's life is not what it once was. The pattern of her life post HIV positive diagnosis has changed from the life she knew prior to diagnosis. Steady employment, condoms, medication and a deeper relationship with her God are just a few of the changes she discusses.

April summarizes her story to an interviewer by saying, "I wanted to tell you that when we started talking and asking these questions, I have learned some things through the questioning method and things that can help me in my life." Perhaps for April, the knowledge she is gaining will continue to change her life just as her HIV diagnosis forced changes. Despite her HIV diagnosis April affirms a commitment to her son "I will continue taking care of him and taking him for the clinic and I am trusting God for his healing that one day he will be well. I am hopeful that I will stay for a long time and therefore take care of him." The changes April has made in her life might just be enough to permit her to live a very long time and care for her disabled son.

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Revised 09082011

The Story of the Dream for Education

Early in the narrative, Ruth sets the backdrop for her wandering musings about her nine-year experience being HIV positive. One of seven children, "we never got education we wanted." At 51 years old, the mother of six children with additional responsibility for other children, she has a very limited income to pay for food let alone school for her children. She believes firmly in the value of education asserting, "The most important

thing is education, if there is no education there is no peace.” Ruth states unequivocally, “for every woman, she cries for the education of the children.”

Between the bookends of comments emphasizing the value Ruth places on education she tells her HIV story. Ruth’s husband’s first wife was “unfaithful in the marriage, she brought this disease.” Ruth cares for the woman’s three children. The husband “never sent a cent to help us.” He also refused to be tested for HIV. Ruth’s husband “does not come home.” He lives and works in another city where he has a girlfriend, returning there after a period at home when Ruth told him “we cannot meet without a condom and he refused.”

The husband does not hide the fact he is living with another woman. Ruth asks him if “that is why he does not send money for the kids to go to school.” The husband replies, “that kids get education depending on how their mother is giving service to the father,” Ruth told him “to go away for he will do what he feels he can do. And if he wants me, he must use a condom.” Rather than trading unprotected sex for money for the education of her children Ruth “make basket for sell, I also make liquid soap and *panga* soaps which we were shown how to make them. One has to work hard.” Ruth confesses, “That’s how I get money but little as in it cannot educate a child.” Ruth clearly conveys to the interviewer “the hardest thing is to educate the kids.”

Ruth articulately covers a series of topics ranging from frustrations with her husband, stigmatization, self help treatments, money, orphans, marital infidelity, HIV transmission and other issues related to HIV/AIDS. Discussion is, in part, in response to questions from the interviewer, in part almost a free flow of thoughts. She describes her

four miscarriages, “You know when you have still birth you get pregnant so fast.” Ruth tells her experience as a second wife. The first wife, “Yes she went for good and so he married me. This time he was working at Mombasa and before long they were together again with the woman. Because of the gift that God has given me for patience I said I will stay and let them stay in town. Because this woman was unfaithful in the marriage, she brought this disease. She died in the year 2000 in July and I was left with her children.”

The husband, Ruth says, refuses to use condoms “he calls them belts and he says he cannot put on seed governors.” Ruth talks about stigma “it’s like they heard people with AIDS do pierce fruits and inject the virus inside. So they really stigmatize us and people think it is gone but it’s there.” She talks about the children orphaned by parents who died of AIDS “not 100 nor 200 but so many orphans. Even some have no grandparents.” Ruth discusses the disease process, “When you are positive the white cells are eaten up and you become weak.” Ruth’s understanding of HIV/AIDS confirms her statement. “I went for a seminar and we were taught many things.”

In the second interview, Ruth describes a series of adverse events that occurred between interviews. Ruth has been having a stomach ache but the dream of an education for her children is not forgotten. The doctors recommend an X-ray but Ruth states “I lack money.” Despite her lingering stomach pains she goes on to say “I also had a hard time that my child passed and wanted to go to school and I did not have money.”

Numerous events in her life that require money have befallen her. Her wayward husband returned home with a dog bite but “we could not raise the money” for an injection. She reports “she don’t see the doctor since seeing the doctor is money.” She

has no money for medicine, no money for fare to the hospital. She wishes she had money to find a lost son.

The dream of educating her children is almost, but not entirely, lost coping with these other situations that demand money. After a long discourse on the role of the pastor, Ruth summarizes the kind of support he offers. She states, “You see I can tell my pastor my problems, but he likes attacking us saying if one has no money, should not bother to take the child to school and should let her go to work as a maid. Can you go back there?” Near the end of part two Ruth concludes, “So from the time I got sick, it is only that *samba* that I got and I ask God to pour the rains to get money to look for my son who got lost or educate my girl. I pray for strength. So money is a problem.” Ruth retains the dream to educate her children.

As Ruth’s story continues in a third interview she reports, “I have not been feeling well and I thank God for enabling me to come today otherwise I would not have come since I have been experiencing health problems.” Her stomach aches have increased, limiting her ability to work. She outlines her efforts to obtain care. “Let me tell you,” she says, “it is hard to get money here since the school fees is waiting for me....so I imagine where I can get that money to buy the medicine.”

“Nothing is able to go on well however how much you try, you move backwards,” Ruth laments. “This sickness,” she tells us has brought losses because it causes you to have a bad relationship in marriage.” The impact on children of HIV/AIDS she concludes, “I can start with what I see in my family because it has affected the education of these children so much.”

Her dream to educate her children is not lost but the dream grows more distant as her health deteriorates.

LLB 10132010

Revised 09082011

It Takes a Community to Heal

Faith says, “I was suffering a lot and the doctors used to tell me that it was malaria, other times typhoid and no one used to tell me.” Her sister was concerned about her ongoing illness. The sister “counseled me first with good words,” then told Faith that “she told me wanted to go and see the doctor first concerning.” The sister first visited the VCT centre and told Faith to come the next day.

At the hospital the doctors asked her what she would do if she was found to be HIV positive. Faith responded, “I told them that I would do nothing and I will accept myself to stay with the disease in the body.” The doctors agreed to test her and “found that I was sick.” Her sister came to support her telling Faith “not to pity myself for there are so many people who are sick and don’t feel anything.”

It was not a surprise for 36 year-old Faith to learn she was HIV positive. Faith claims, “I can’t tell how I got it,” and that “I never used to see anything” that would indicate she may get the virus. But, her husband of twelve years died four years before her own diagnosis. Like her, “My husband got sick for a long time. When we go the hospital we used to told that he was suffering from typhoid, other times malaria until he

left me.” Faith thought she would “go very fast” but “found that God was with me.” The hardest part of being HIV positive Faith offers is “I started having trust with my God.”

The marriage between Faith and her husband was, at times, difficult “we took some time without coping with one another and used to leave him and go to my home place.” The husband would drink and sell what little food they grew to buy alcohol. When confronted about his actions, Faith reports “when you ask him anything, he becomes like wasps and starts to beat you.” At one point Faith returned to her parents’ home for a month. She went back to her husband only after her husband pleaded with her parents. Faith’s mother-in-law provided the protection needed for Faith to stay with her husband near his parents. The mother-in-law “was so tough to him that I could hide under her,” Faith remarks.

The husband’s parents continued to be involved in Faith’s life even after their son died. When Faith received her own diagnosis, “I explained to the parents of my late husband. They regretted why they did not know they would have taken him for test.” Faith’ stayed “together with the parents,” suggesting “my mother-in-law has been holding me there.” The father-in law wanted Faith to leave Faith speculates because of the land but “he has cooled down” after a sister-in-law intervened and “told him to come out of my way.”

To avoid potential transmission to others, Faith has stopped being with men. Faith maintains, “I have given my body to God and I told him that the husband to the widow is Jesus and I stay like that.” Church attendance is an important activity in Faith’s life. She asserts she is welcome at church and has never experienced stigma among the

congregants. “I have never heard since I go to church frequently and even when there is a duty to do they put me somewhere.” Stress is avoided by a morning ritual “when I wake up in the morning I pray first.”

When food is in short supply Faith thanks “God for the whole of last year when there was famine, I used to see people come to bless me with some food and therefore we have never slept like that.” Faith told people in her area, “I could not do hard work like digging and so they put down my name to be getting help.” The Catholic Church runs a program to assist people. Faith describes the program “like my place we have a group of digging the path and I told them that I had no strength to do that work and the only strength I have is to dig for my children. I told them that I am sick and they took my part.” Although Faith did not have the strength to contribute to the group “they are given, I also get.”

Faith holds that “the people at home know how to stay with me.” This helps her to manage her disease. She has three children in their teens. Her daughter “was at first scared,” but Faith explained to her, “It was very important for me to be tested since right now I would have died long time.” The daughter shared, “how she feels to see me around.” Faith did not immediately tell her younger children she was HIV positive. By the time she did tell them her health had improved one child questioned the truth of her revelation “she seemed to be wondering how it can be true that I have been sick but the other one told her that it is true that I am sick and that is why they see me taking medicine at all times.” Faith comforts the children telling them “that I will not die until I will take care of them until I see my grandchildren.”

Faith's family has helped her. Her sister arranged for her to be tested. The sister provided money for both medicine and a CD4 test. The sister encouraged her. Today Faith exclaims, "When I see my sister I see her as my second God." When Faith first started taking HIV medicine "I thought about them so much that I was to take them until death and my sister comforted me and told me to stop thinking and if anything arises then I should share it with her."

The sister from time to time helps Faith with money. Faith's mother helps "a lot" and a brother "I also have a brother who goes to help me to plow."

People at the medical clinic treat Faith well. She was comforted by the people she met at the clinic. "When I went back I found that I was not alone, there were many people and that encouraged me a lot." What helps Faith to stay positive "is by going to the groups...when everybody is contributing I get encouraged." Faith was initially afraid to tell people her HIV status "I used to fear but I stopped this with time and I got courage." The courage came from her experience receiving medical care "I was counseled and given encouragement and when I meet with the other people, I feel okay." Now if Faith sees someone who appears to be sick she willingly discloses her own status and encourages them to go for testing. "I used to counsel them and tell them that I was a victim, and I came to know when I went for the test."

Faith experience with HIV is a departure from most people in her country who feel outcast and compelled to hide their status. Faith states, "I feel everything is okay" claiming "because I have no stigma." Her life is characterized by support from her in-laws, family, children, church and community. From her years of illness and initial

diagnosis to her day to day existence today, Faith has enjoyed the acceptance and nurturance of people in her life. Perhaps this factor as much as the medicine she takes is responsible for her to be able to happily assert, “I am doing well.”

LLB 09182011

A Matter of Faith

As a testament to her faith, Joyce reverently states, “before I do anything I pray to my Redeemer,” and thus she began her story. Her faith is shared by her husband who, although he is not trained, is a pastor in the A.I.C. church. Joyce is a 39 year-old mother of three. She also cares for two children of a distant family member who were orphaned when their parents died of AIDS. Her husband works in Nairobi while Joyce stays in Kutha with the parents of her husband. Her husband works for a paint factory and comes home monthly. Prior to the birth of her last child, both Joyce and her husband worked with a combined income of 12,000Ksh. But, Joyce was diagnosed HIV positive during her last pregnancy three years ago and due to illness was “forced to come out of work to take care of this child.” Today their family income of 5,000 Ksh is less than half of what it was. Nevertheless, money does not seem to be a major strain. Joyce has assured the children she will pay for their education and the family tithes to the church.

Joyce’s husband and children test negative for HIV. In 2004, Joyce reports, “I was pierced by a nail at the right leg.” She did not receive immediate treatment and her leg swelled. Two years later she was having continuing problems with her leg and was diagnosed with tetanus. Joyce concludes, “I suspect I got the disease from there because I never went outside my marriage.” Joyce’s husband told her “he must be a carrier and to

be negative does not mean that you don't have the disease. He said that was no problem and he would take care of me." Her husband is quiet and disclosing to him can be difficult as "one feels isolated." Joyce says of her husband, "I am the only one positive in our family but I pray that I stay for a long time. I like when he is strong like that because her is in a position to take care of the family." Her children, however, do not yet know of her HIV status as she claims, "I have not yet told my children since they have not reached the age of being told."

Joyce's account of her life as someone who is HIV positive is summarized with the following statement; "I read the Word of God and see how people suffered and I truly know that this is a trial to prepare me for the journey to heaven." Initially, Joyce was quite sick. During the birth of her last child she reports, "I had an over bleeding and the body was weak for around six months." Her weight dropped to 29 kilos, her CD4 count at 203 was very low. Joyce told her kids "that they should have confidence in life since God is there and I am still alive." She made a covenant, she explains, because of her frail health after delivery.

During the period of extreme illness, Joyce thought she was going to die very fast. Joyce learned through counseling and the training at seminars that a person can live a long time HIV positive. This realization proved to be a turning point for as Joyce says, "When I came to know that there is life ahead I started coping with the disease." She was started on ARVS and faithfully takes her medications. She attends support groups. She and her husband use condoms. Joyce works as a community worker advising others about HIV/AIDS. Her former employer is courting her to return to work. She uses a bicycle for exercise. The stress she felt that her youngest child might be HIV positive has dissipated.

Joyce's goal now is "my determination is to reach 1300 to see whether I will read negative." If Joyce's health starts to deteriorate, "I pray God when I am sick and He heals me."

The most difficult part of being HIV positive is, in Joyce's experience "the ignorance of people." She encounters ignorance as a community health worker. She explains, "There is a lot of ignorance and some say there is no AIDS these days. Some refuse saying that when we take them we are given money in exchange which is just a prober gander." She "tells people to go for VCT but they don't believe whether I am sick. They refuse completely." The churches provide differing information about HIV/AIDS. Joyce comments, "I have seen a great difference between a catholic and a protestant. A catholic knows that one can get this sickness through so many ways but a protestant knows only one way and whenever they are talking about it, I just keep quiet because I know the truth about this disease."

Joyce has also personally experienced people's ignorance. In her weakened health state she felt "many people mocked me a lot." Even as her health improved Joyce felt "they still undermined me" and questioned "why since I love them." Her religious convictions carried her as she exclaimed, "I thank God for His care despite the ignorance."

Today Joyce states, "I have a long life to stay," and "I don't see my grave." Her belief is strong and revealed in comments to her children "like I talk with my children that Jesus will find some people since when he was being born, he still found people." Her faith sustains her and helps her battle her disease. Joyce objective is "I want to be

alive when He {Jesus} is coming because I hear He coming soon.” “I strengthen myself,” she says and “I tend to think one day God will show me as an example in heaven since I had taken care of myself so much but I got AIDS.”

LLB 10272010

A Family Affair

“The father was the first to start having problems,” 31 year-old Naomi tells us, “he used to be sick always.” About five years earlier her husband was “so sick that he could do nothing.” He decided to be tested and, “when he came back he told me that he was found with the virus so he told me that the following day we would go for the test.” The results of the test revealed “we were all found positive.” Speculating Naomi suggests they were infected because “maybe my husband who was unfaithful when he was working.” Today Naomi reports, “He is doing well” and confides “he is alive due to medicine; he would have died by now.” They were counseled “on how to stay and join support groups for encouragement.”

Others in her family did not fare so well. Naomi and her husband had five children. The second born died at age four. Naomi describes the situation; “she used to have chest problems and other times used to swell the whole body...we did not know what was the problem.” Another child, their fourth, died at one-and-a-half years of age. Prior to her death “she was suffering from diarrhea and vomiting.” “If I knew my status,” Naomi laments, “my children would not have died.” With her last pregnancy Naomi “was aware of my status together with my husband.”

Naomi does not know if her youngest is HIV positive or not as he is too young. “The child had not yet been examined since we had told that the test was to be done when the child would be one year and eight months.” Naomi and her husband had been using condoms until “it is that time I needed to have a child and from that time we don’t risk.” During her pregnancy Naomi “did not miss clinic” and was told she would be “given some medicine to take the time of labor.” The hospital also “gave the baby the first medicine.” The youngest child has been examined twice but Naomi was told “the baby will take until the last test.” So far Naomi and her husband “were told the baby is ok.”

Naomi and her husband work casual jobs to earn money to support their family. They also get money “from selling our livestock when the need arises.” But she admits, “It cannot be enough because you cannot use it to educate a child.” “Where to get money and food,” Naomi confesses is the hard thing to cope with when one is HIV positive. Her husband told family members of their HIV positive status “in case he dies.” People have proven supportive of them. “They take me so well that my kids cannot sleep hungry...they help me,” she confides.

The next time Naomi is interviewed we learn she is pregnant again. She “did calculated and saw that I had two boys and one girl and therefore if I could get another girl then it would be better. I said if I get a girl then it is better but if I don’t get then I will stop there.” Naomi wanted family planning but by the time she saw the doctor, “I had already conceived and he told me that I cannot abort.” Naomi had not been taking medicine for HIV but, “I started this time when I am pregnant.”

Naomi considered an abortion. She relayed the story of another woman. “There was another woman who gives a medicine for aborting when it is two months, and I went home and thought about it and so that I can abort and die and leave the other kids so I saw there was no need and this woman needed 500Ksh to do the abortion which I did not have, and so I said let me wait and give birth then I can family plan well.” Naomi and her husband were not using family planning when she conceived “I was using my mind.” They were using condoms “I could use and other times I don’t so when I stopped is when I got pregnant”. They had been receiving condoms for free but “where we were taking they got finished.” After the birth of their child, Naomi “will be given an injection ...once every three months” to avoid pregnancy Naomi.

Worries are not far away. “You think of the disease and you want a solution to the sickness and it is not there and there is no cure also so you really wonder what to do.” Naomi confides, “You tend to think that any time you may grow weak and go.” But, the family has learned through support groups, counseling and experiencing the losses in their life as Naomi says, “Came to know how we would take care of one another.” The husband and wife attend support groups together. At home, “we are there with my husband and we assist each other.” Their sixth child, another boy, was born just a few weeks before the last interview with Naomi. Asked about being HIV positive and bringing up children, like all mothers, Naomi responds, “one should take care of the children and bring them up well.” As a family Naomi tells us “we are still continuing life.”

LLB 09132011

To Love Yourself

The realities of life are challenging for Carol. At twenty-five years of age she is a single mother of four-year-old twin daughters. Carol is, in her own words, “a girl not yet married so I have no man.” Without a husband, she is the primary support for herself, her children and her mother. Asked how much money she gets each month, Carol reports, “we get very little because it is like me who looks for the money.” Carol did reach form two in school but she explained her source of income this way; “we make soaps that we sell and get money. This money is taken back in the office and the little that remains it is the one I use.” A sister-in-law also stays with them while Carol’s brother, the woman’s husband, works in another city. Money is “very little that they are not enough,” and so Carol states “my brother gives me support also.”

Two years after the birth of her children, Carol “got the boyfriend.” It is not clear if, at the time, the boyfriend knew he was HIV positive but Carol does know he is HIV positive because “he takes medicine.” Carol “started getting sick always.” A person from an HIV support group encouraged her to get tested “so as to know her status.” She tested positive and knew definitively the boyfriend was the source of the infection. The father of her children “was not sick” since as Carol explained, “I would have been told during the clinic so I was negative,” when the children were born. Indeed, the children are negative for HIV. Further, Carol knew she “had not moved with another person” other than the boyfriend.

The psychological effect of the HIV positive diagnosis was significant. Carol discussed, “the stigma that made me start hating myself.” “It really affects somebody,”

Carol went on to say, “when it comes to stigma, you feel you want to be alone, eating becomes a problem and you just need to be alone and at times cry from inside.” Filled with self loathing and despair, Carol questioned, “I was feeling like I was not worthy to live.”

Now two years post diagnosis, Carol has “adjusted.” She “joined the support groups and began to take medicine.” As a result, Carol “got encouraged and everything is working well.” Carol learned that “one cannot die neither is it the end of life when recognized with the virus.” “Just following the advice of the doctor and taking the medicine as required” are essential elements for good health, as she learned. Carol developed an understanding of what it means to be HIV positive. Her approach to other women who speculated about their HIV status; “I give her hope by telling her that it is like any other disease and she should not worry and it is like malaria which also kills so it is nothing to worry and tell your people about it and follow the instructions of the doctor and stay well and take care of the kids.”

Carol helped herself. “I started eating well and I was put on medication and my mother encouraged me to keep on going to the clinic for checkups. I ate well and I got healed completely.” At the thought of taking medicine the rest of her life Carol acknowledges, “It is good since it is keeping us alive. We tend to develop a positive attitude towards the medicine.” She attends support groups. If she meets a man, she insists they would use condoms.

The change in Carol’s attitude was dramatic as she gained knowledge and felt healthier. She believes one should “have courage that everything is possible.” When

asked if she feared anything in her home she replies, “I don’t and I have no stigma at all and the people in the community have accepted me and chosen me to be a leader.” In her capacity as a community leader, she provides support and advice to other HIV positive women. One issue Carol sees women struggling with is “how to get money.” Carol herself struggles. “The thing that gives me problems is where to get money since I am single.” She asserts that women “need to wake up and know how to look for money that the children cannot sleep without food and they are not sent home due to school fees.” During times without rain when there is famine, money allows women to sustain themselves and their children.

One challenge she faces as a young woman “is making decisions who stick to so as to marry in future.” Carol desires “a good person whom I will explain to him my status and we plan ourselves. The life we have today is knowing how to plan things whether you are sick or not.” Giddily she reveals, “I believe that I will have a wonderful wedding,” and she dreams of having “one child, a boy”; “when I will give birth I will get with my husband” and not be raising the children alone.

Carol has not entirely avoided the stigma associated with HIV/AIDS. Initially the people at home “they could not like to share anything that I used, it was like stigma but it went with time and these days they feel good when I am health.” Her own brothers, however, continue to stigmatize her pushing her to leave the home she lives in with her mother and “to build at my own place.” Hurt by her family’s reaction to her HIV positive status she verbalizes “I really feel so bad, so bad and I take heart because of my children and I say if I had no child I would go to work that particular moment but I cool down and I try to cope with the problems for my children to go to school.” Within the broader

community the response to “sick people” varies. “They are hated” but then Carol qualifies her statement; “also it depends with how you stay with the people.” At the hospital “they take me well on the side of the community we understand.”

Based on her own experience, Carol’s advice to other HIV positive women summarizes her personal journey “one thing is to accept yourself and tell your children and whoever is with you who cannot tell out to anyone. Also one should not sit down but work to get money but learn to get ways of making money.” Carol has learn to love herself “since the worst stigma is self stigma...and that’s the one that kills people not AIDS.”

LLB 0112011

Caring for Others

Emma felt sick and sensed “it’s not a normal sickness”. She told her husband they “should know what is wrong” so she could “stop being tortured by sickness.” To her surprise, she tested HIV positive. Confident that neither her husband’s sexual behavior nor her own is the source of the virus, she speculates that she was infected by an injection. “Now that is when injections needles were being boiled...not like now they are being opened from the paper,” leading Emma to conclude “I don’t think there is any other thing that might have caused the disease.”

At 68 years old, Emma’s husband is significantly older than his 35 year-old wife. Together they have four children. They also are raising three other children whose mother died from AIDS. In Emma’s words “I am with them three as orphans since one was left when seven days [old] only.” Emma is encouraged “that my husband never stigmatized

me or kept me aside at all.” Her husband told her that “this disease does not affect somebody due to carelessness or neither is it your will.” The doctor advised the husband to “stick with me because if it were him who was sick, than would not leave him.” Emma reports that “now due to those reasons, I found things so easy for me.”

Emma downplays the affect of her diagnosis on her family “it has not done so bad since I thank God my husband is negative,” and “I don’t feel bad since the kids were tested and tested negative.” Still she laments “but in my heart I know that am still bringing up the children but I will not reach the age of our grandmothers.” At the clinic Emma learned “that we can stay even for thirty years living positively” and by then “some will have finished school and gotten a job and started to help the others in school.”

When first diagnosed three years ago, Emma worried and “asked myself if I happen to get sick what about my children and the way they are small.” “You know,” she says “that when a person is positive has many needs and needs a lot of care.” “I told God give me strength to take care of this child” she beseeched. Emma takes care of herself by taking medications, eating as advised and other measures. Three years after diagnosis Emma almost forgets she is sick stating “when am taking [medications], I start remembering that am sick but after that I forget.”

Emma is able to care for the children and has developed a method of protecting them from becoming HIV positive. She opted not to tell the children of her HIV positive status. “I see them in school learning well with organized mind” she explains “so feel when I tell them they might get into it saying ‘after all, my mother has it’.” Emma also takes practical steps to avoid transmission of the disease to her family. “Because I don’t

want to transmit the virus to my children and my husband...I looked for my own bathing stone and I have my own bathing scrub which I keep very far...I have my own basin and the other people theirs” and ”I looked for my own bathing towels.”

Caring is not restricted to her immediate family. As a community worker, she goes to villages and teaches villagers about HIV/AIDS. She explains her expansive approach to the work “when am going, I don’t just aim at the sick person only but any house.” There are many facets to her work. Part is advising parents to teach their kids to take care of themselves. She gives “a lot of advice for the person to choose how to take care of himself or herself.” Emma’s practical approach recognizes that “if the person is of unduly character” they may choose to stop or continue doing what they are doing.

Emma’s passion and compassion for her work as a community worker is evident. She recounts the numerous concerns expressed by the persons afflicted with HIV/AIDS including “crying about school fees,” “where to get food,” inability to work when taking medications and overall feeling “stressed due to many thoughts.” Stigmatization and fear are highly sensitive issues she helps people to navigate. She shares information with people and states “my happiness is that after the advice if the person wants to ask me questions”. Emma reports that some people are “very tough and hard to talk to,” whereas others “are very happy. They say that its better you have been taught this work in order to help me.”

The source of Emma’s strength to “continue to be alive” and carry out her work caring for others is, in her words “it is only God...If it were not for God—If I tell God to give me strength.” She adds another source of strength is “following the advice of the

doctor.” She feels the stress of caring for her children. Emma is realistic about her work caring for others as a community organizer. Yet, her enthusiasm and optimistic outlook about life can be heard as she describes a life of caring for others.

LLB 12272010

The Education of Children

Children have been a central focus in Susan’s life for as long as she remembers. Susan confides that as a child “there were problems since we were born thirteen of us and life was very hard.” Her mother was “very hard working, and whoever wanted to go to school was going. But with me I never because I was the first one and they forced me to work as a house girl so as to help those in school.” The money she earned was used to pay school fees for her siblings. Education of her children is a priority that overrides other events in her life. Obtaining sufficient money to educate children is a challenge in Susan’s life complicated by her HIV positive diagnosis.

Forty-seven year-old Susan and her husband have six children. The youngest is 15 when Susan first tells her story. Susan cares for another child. “There is one child who was left there by my sister and she went for good.” Additionally she has a two-year-old granddaughter. Susan and her husband now use condoms. Her husband “told that we should use a condom when having sex...he said because am sick so I don’t infect you with the disease.”

“My husband is the one who started being sick, and I did not know what he was suffering from,” says Susan. “We stayed around four years without telling me,” but as Susan began to have symptoms her husband “would give his medications” to her. Susan

remarks that “I used to hear about the disease and say that it will never get me since I was married and faithful to my husband.” Susan discloses, “By bad luck he was a drunkard,” which presumably led to indiscrete behavior. Susan reports she and her husband “stay well at peace with each other” after they openly discussed with each other their HIV positive status.

The husband was hospitalized for two months prior to his death. When interviewed again later Susan describes that time. Susan says she “used to stay with him here without even going out of the hospital compound.” But, “there were so many things that were going wrong at home because only the children who were there alone and there was nobody to take the duties there. There was need for money...the children needed school fees and food because this time there was famine.”

Thoughts of famine, death and HIV/AIDS do not interfere with Susan’s desire to have her children educated. Over and over Susan returns to the theme of obtaining money for school fees. Asked the things she does to continue with good health Susan replies, “You see you must do something that can support you so I buy green vegetables and go to sell them and I get some money which I use to pay fees.” In response to a question about how government officials can help HIV positive women Susan replies the “need” is for “school fees.” To “live well” Susan belongs to a “group which we called Children Education Fund whereby we contribute money and lend to people.” She describes this group as “a self help group for school fees.” The impact of health compromised by HIV on Susan’s ability to obtain money for school fees is summarized “if I were not sick I would go far and work to get money.”

Susan understands the impact of HIV on the education of children goes beyond an appreciation of her limited ability to work to earn money for school fees. In response to a question exploring what would help both grownups and children Susan says, “I think educating each other can bring improvement.” Small children she explains “have not gotten education and a family and they get this disease then it becomes a real problem.” She provides an example “like I have seen another boy from the neighbor who is sick and he is in school and he is always sick and out of school which affects his education.” HIV/AIDS “has brought so many downfalls since the children who have been left by the parents are in problems.”

Children are infecting children Susan says. “They are there like young boys and girls in school since there are children who get medicine and some do not know and they are having sex with those who do not have.” The community, she says, should advise children “to avoid sex before marriage and there is nothing else since if they do not do that then the disease may reduce.” Susan also believes children “need to be advised to take the test but many say that they do not have the sickness. Yet they have been tested and they are positive, they are sick, vomiting and they cannot eat at all. Others have the medicine at home and they say that they will pray and get healed and God will heal them.” She adds that, “before marriage they should be examined or tested.”

Susan laments how times have changed. “There used to be rain and people used to get the advice of the older ones especially the youth but these days they do not hear the parents. Children used to fear and respect the older people.” Susan explains what she thinks has changed. “It is the knowledge which has reduced due to too much learning

since they want to know beyond what they have been taught. There before they could be taught something and they get it and it sinks but these days there is nothing like that.”

Susan has developed an appreciation for the importance of education “you see the women of those days were not educated and they did not know the need for education but these days they have seen the fruits of education.” Susan knows the education of children offers hope for the future and is needed to advance children’s standard of living. The spread of HIV can be avoided in Susan’s opinion by “I think advice to the young children.” From Susan’s viewpoint, the education of children is not just about improving the future; for some children education may mean they have a future.

LLB 082892011

We All Belong to God

Mary is uncertain how she became infected with HIV. Her husband died eight years before she was diagnosed. It is possible her husband died of AIDS. However, she declares “I do not know how I got the disease because even if my husband had it we don’t know since we were not told. And when we asked we were not told.” Mary received her diagnosis three years ago.

Forty-eight-year-old Mary has five children. The two oldest children are married. Three children live at home with Mary. She states she does not have a monthly income and she only has money “when I am given.” This creates problems paying for food, education expenses for her children, transportation to health appointments, fees to attend support groups and other items that require money. Mary explains that when life is very hard in terms of money “I try to cope with them and try to borrow money from other

people.” Fortunately her in-laws and adult children give her money. Her children, Mary reveals, “really take care of me and they don’t like me working at all.”

Mary tries to take care of herself. She consistently takes her medications because she recognizes that “I take knowing I will be well.” She tries to eat well which is a challenge with her limited money. Mary knows she needs to have good food to maintain good health. On the advice of the doctor, she stopped using herbal medicines.

Mary acutely feels the impact of an HIV diagnosis on her relationships. Mary hopes to prevent the spread of the disease by refraining from sexual activities. When her husband died his older brother came to her wanting to have sexual relations as was the tribal custom telling her “the wealth of the brother is not going to stay there without anybody.” Mary told the brother her husband never told her of this expectation prior to his death so she was not going to stay with him. Mary believes this is the reason many in her husband’s family shun her. Mary divulges “I think they want me to sleep with them so as to help the children.” She has had to tell other men in she is not interested in sex asserting “I do not know what killed my husband so I did not want him.” Her commitment to preventing the spread of the disease impacts her ability to get support she needs.

Asked about how the villagers respond to her, Mary declares unequivocally that “people stigmatize me. They ask why she goes to the hospital always.” She knows they think she is going to spread the disease to them. Villagers do not necessarily know if someone is HIV positive although infected people may tell their families. Mary confirms that even in their homes some people are stigmatized. The villagers “say that one is sick

and therefore they ignore you completely. They stop coming at your place completely and cannot help you and you are seen as a nobody.” In response to the stigmatization Mary asserts “I comfort myself by saying that my children will be there for me and care for me.”

When Mary first learned of her diagnosis, Mary told her older children and in-laws. She reports “they took me well.” The in-laws even took her to the hospital and paid the hospital bills. While some of her children know of her diagnosis but she did not want to tell other family members because, as she explained “they have stigmatized me even before I tell them.” Mary’s children take care of her “but those other people in the family, they don’t. They exclude me completely.” Even among her children, their reaction to HIV is mixed. Her daughter faithfully reminds Mary to take her medications. Cautioning her son about ways to prevent contracting HIV, he responds by saying “if he can know he is positive then he can go and throw himself in water and drown to die.” Mary reaffirms her message to take care to avoid the disease and offers encouragement and hope to people who test positive.

Mary finds friendship among the people she meets at the clinic or in support groups. She declares “the positive ones are my friends.” The HIV positive people she meets at clinic are the best people to talk to because “he is like me.” Mary goes to support groups which she finds helpful as people “share a lot and one feels that she is not alone.”

At the clinic where she goes for care she relays that “sometimes they take me well and other times bad.” Mary is asked what she would tell the doctors and nurses concerning the people with HIV/AIDS and how they should handle these people. Mary

responds “I can tell them to handle us like any other person, no one intended to get such disease. They should not stigmatize us and take us like we are not of use since anybody can get this disease.” Although asked specifically what she would tell health care providers, Mary doubtless would say the same thing to other people in her life if she had opportunity. She summarizes her belief that people should not be stigmatized based on their illness by declaring “I feel we should be together and know that we all belong to God.”

LLB 01192015

A Single Act in the Life of a Couple

Thirty-two-year-old Jacklin speculates, “I try to imagine if my husband never went outside the marriage, we would not have problems and he would still be working.” She wonders “what he was looking for in that woman that he had to get this bad disease which has not cure.” Both Josephine and her husband are HIV positive. Fortunately, their four children, ages four to fourteen, have all tested negative.

Jacklin has been married sixteen years. For a period of four years, her husband was working in Mombasa. He came home every three months, “but it came a time when he finished a year.” He did, however, continue to send money to support his family. During the year-long absence, he “started being sick.” He told Jacklin that “he was suffering from chest problems” and, rather than come home, asked her to meet him in Nairobi. Jacklin continues the narrative; “When we met he told me that he was sick chest, and he had been examined and found with TB, and later he thought of going for test since

he was getting sick continuously and vomiting and his body was losing energy. Later he had pibbles all over his body and he went to the hospital.”

Jacklin’s husband was diagnosed with HIV/AIDS and began medication. He encouraged Jacklin to also be tested. Initially she tested negative but she exclaimed, “It is impossible that you are positive and I am negative.” A repeat test at a different clinic was positive. Following medical advice, Jacklin’s and her husband took their children to be tested. The negative test at the first clinic was confirmed with testing at a second clinic. Jacklin was scared “thinking how our kids would survive.” But her husband told her, “we are going to follow the instructions of the doctor and nothing bad would happen.”

Jacklin’s husband was reluctant to come home and tell his parents. He did come home and, “when he told them, it happened the way he had said that they kept us aside and saw us as nothing and not worthy to be there.” The father-in-law was “scared” and “said that he was going to give us land that was very far.” So Jacklin and her family “shifted to that land”. Jacklin explains today, “We are in our own place with our compound with my husband and children.”

Jacklin’s family used to “get money when things were good when he was working in Mombasa.” Today Jacklin gets “casual jobs of digging benches.” She digs a lot but her husband cannot help “since he was very sick before he came to know he had no energy.” The money is used to buy maize and beans to eat that day. “The other foods that are energetic, we don’t get” Jacklin explains. Jacklin divulges, “The following day we go to work again and we get money to use that day.” Generously Jacklin’s sister told her “instead of getting many problems and you have children, whenever I get even if its

1000Ksh I will be giving you. And because I know that your husband will be okay, we shall agree on how you will refund some.”

Jacklin and her husband take medicine, go to the clinic and attend groups. Jacklin asserts, “I don’t hide am sick AIDS and I take medicine.” Disbelieving, other people tell her “a person with HIV/AIDS does not look so good like me”. Jacklin divulges, “In my area there are so many people” that she can see are sick. Jacklin encourages people to go for testing “but they tell me they fear to come.” Despite her encouragement to be tested people have “no turned up.” Exasperated she says, “I really don’t know how they can be helped.” For Jacklin, knowledge of her HIV status opened the door for treatment. She tells people she takes medicine “since I want to stay longer on earth.”

The husband’s act of infidelity dramatically altered the life circumstances of Jacklin and her family. Their old life of respectability and financial stability is gone perhaps permanently. Instead they face stigmatism, food and financial insecurity. Still Jacklin believes her husband “did so good to tell me.” Her husband “regrets why he did whatever he did if he knew such a disaster would happen.” Jacklin summarizes the impact “now I can’t tell you that it has done well to the family but I say thanks since there is medicine that we are taking.” As the husband grows stronger taking the medicine, he is hoping to go back to work. Jacklin believes “God will release a medicine to cure.” Whatever happens, together as a couple they are facing the consequences of a life with HIV/Aids.

LLB 08192011

Life Will Continue the Same

Elizabeth seemed untroubled by an HIV positive diagnosis. She had been sick over a two year period “I get malaria then it is cured. Chest problem, then it is cured. Then headache, then I continued like that.” Her body was itching and “some black marks started coming out of my body.” The doctor discussed testing with her asking her if she would feel anything if she was found to be sick. Elizabeth responded, “I told him no because I needed solution for problem and how I can be cured.” When she was told she was HIV positive she “never got scared.”

Forty-seven-year-old Elizabeth does not know how she became HIV positive. “I got it—people say the disease is got from having sex—from a man and a woman.” “I think I got it that way,” she concludes. Since becoming HIV positive, “I came to know I can’t move with a man without a condom,” because Elizabeth says “I was told by the doctor.” Elizabeth asserts she had a husband but it is unclear what happen to him stating, “We collided with those people where I was married.” Elizabeth and her children went to stay with her parents and later, when the parents died, the children lived with her brother’s wife.

The story continues as Elizabeth recounts, “When my kids were big I went to Mombasa. It is where I used to stay working there.” When she was young she lived in Mombasa for three years. “I used to work and in the evening I go for commercial sex work,” she confesses. She does not say how much money she received in exchange for sex. She clarifies her situation. “I used to behave that way before but not these days.” Elizabeth does believe the casualness of her past sexual contacts led to her contracting

HIV. She tends “to think that I got from men because one thing I am not married and we used to move with men without using condoms.” “Men really refuse,” to use condoms she declares, “but that time I did not know I used to tell them it was okay.”

Elizabeth says of the man she is seeing now “the one I move with does not refuse...because I told him my status.” Other men approach her “but I don’t show any interest,” she states. Telling the men no if they refuse to use a condom and feigning disinterest allows Elizabeth to avoid telling them she is sick. The difficulty telling people of her HIV positive status is “one thing you fear people to see as an adulterer because many people associate it with prostitution.” Instead she tells men, “that I don’t want since we were told that when you move with men they will add more viruses to you but if you avoid then you can stay and get healed.” Elizabeth is a little skeptical as she adds, “I don’t know how true it is.”

“There is a doctor who said the disease should be your friend,” Elizabeth says adding, “And you should love it”. Queried about aspects of life as an HIV positive woman Elizabeth answers briefly with little emotion or explanation. She does “suggest one should be examined even if one doesn’t want.” Her rationale is that “if one is aware of his or her status can stay a good life.” The person who is HIV positive but does not know their status “will be going transmitting the disease.”

Elizabeth is looking for some help with her life “I want to tell you that I want you to get someone to marry me who is positive like me.” She wants “to get married to have my own family.” She saw a couple “that married when they are positive and they are doing well.” “That is what is in my mind right now and I need that one who is positive

like me,” is Elizabeth’s explanation. She does not know how she will meet an HIV positive man. “That is where I don’t understand.” There are support groups for men “but men do not come and if they come, only one or two.” An HIV positive diagnosis has caused Elizabeth to briefly reevaluate the way she interacts with men. But for Elizabeth, with or without an HIV positive diagnosis, “life will just continue the same.”

LLB 09232011

A Double Portion

Thirty-year-old Pauline’s religious beliefs shape her life and her experience as an HIV positive woman. Relatively well educated, Pauline had a good paying job as a supervisor in a security firm in Nairobi. She had a boyfriend she had been seeing for almost two years. Then, she became sick. She returned to her childhood home and explained, “When I came here I was suffering from TB.” The second time she was tested for HIV the results were positive. Pauline had been sick for more than a year. Her condition was so poor she spent one and a half months in the hospital.

It is not clear if Pauline’s faith is strengthened by, or newly found with, her diagnosis. It is clear that religion is a stable force in her life that shapes her reaction to and view of events in her life. She politely answers many questions about her experience as an HIV positive woman and her life.

“It is not easy but I have hopes. God is able and he can also heal me.” Pauline talks about possibly going back to her position at the security firm “maybe the end of this year.” She thinks about starting her own business rationalizing, “if you take it easy you can still survive and you can still do your own business.” She believes she could

successfully run a shop because “I had gotten a job in a shop and I was running it well and the owner was happy about it so I can do that.”

In Pauline’s personal life she speaks of getting married “if I can get a husband.” Pauline describes the ideal candidate for marriage. “It is good for one to get a person of your category who is positive and one in this case has to be open minded and getting a person who is no positive then it is not good.” She thinks that “when I will be well I will have one child” but to first take a precautionary step to “ask the doctor first” because “I don’t want to mess up.”

Pauline’s life but not her faith was forever changed by her positive HIV diagnosis. Her poor health forced to leave a relatively good job. Her boyfriend remained behind when she moved home. She depends on the goodness of her family to provide for her needs. She suffers from the HIV infection and medication side effects in addition to other illnesses. Pauline experiences the stigma commonly endured by people HIV infected. Her life turned upside down yet she retains hope for the normalcy she enjoyed. “Most of the times,” she says “I keep on praying and I have accepted my status.” She would tell others that “one can live a long life and believe God that everything is possible through Jesus Christ.” She dreams of a life with a husband, a business of her own and even a child but asserts. “I know the way I can stay.” “For now,” Pauline says “I want to trust upon God. Most I trust God for his healing.”

Pauline’s faith sustains her today and supports her belief for the future that one day she “can be well.” Pauline relays the basis for her faith. “I read the Scriptures like where Job suffered and he lost everything, and when God started to refund him. Then he

got double portion of what he had lost and even his health was back to normal. So, God is able to do anything to your body until it is back to normal.” Pauline maintains that “I have accepted that I am sick but am trusting God for His healing. I do hope everything is possible with God.” Pauline’s unwavering faith is her source of hope and strength as she waits for her double portion.

LLB 12232010

A Story of Survival from Famine

At 61 years of age, Rosinda is one of the oldest study participants and among the poorest. Eight years have elapsed since her diagnosis, but for Rosinda events are not linked to a calendar or passage of time as evidenced by her inability to recall when her children were born. The chronology of her experience with HIV is lost as she weaves a story of survival. Rosinda provides a performance for the interviewer meant to secure assistance for her and other HIV positive women Rosinda has befriended. She tells the interviewer near the end of the interview “the sick needs help from you if you really care about us.” Rosinda emphasizes to the interviewer “I have told you the truth,” as if to highlight her early assertion that famine, not HIV, is the “hard thing.”

Rosinda starts and stops her description of her life with HIV. Sometimes she resumes the HIV story in response to specific questions; “Did they take your CD4 count?” Other times she returns to the story anticipating what the interviewer wants to know “you want to ask me where I got it from?” Rosinda provides seemingly scripted answers to the interviewer’s questions. In responding to the question, “Do you fear to give out this virus to another person?” Rosinda asserts she “cannot give it out” to men

because “there is no one of them I have moved with since I got this disease.” To the question, “How has this disease affected your family?” Rosinda states “it has brought loss in my family.” But, she fails to elaborate on the loss and instead speaks of her experience going to the hospital. “I am given 500Ksh to use as fare and lunch, which is a lot of money when one is not sick.” Almost as an afterthought Rosinda adds, “But I thank God that I am alive.” Rosinda describes the HIV story in brief factual terms that provide a broad overview of her symptoms and interactions with healthcare providers.

Early in the interview Rosinda begins the story of survival. She draws in the interviewer calling her “my friend.” Rosinda flatters the interviewer comparing her to “my daughter who is educated like you,” or to the mistress of her husband who is described as “somebody smart like you.” Rosinda attempts further to solicit empathy from the interviewer with shows of altruism. Rosinda asserts, “I have tried to help people, since many people have died due to fear of what people would say about them if they are found with the disease.” The story of survival is interspersed with references to her work with other HIV positive women. Rosinda’s approach to a woman who is diagnosed HIV positive is to “call her my friend and welcome her and congratulate her for going for the check up.” Near the end of the interview Rosinda asks, “What can you do to help us, for we are sick and we cannot work to earn money?”

Extensive discussion is devoted to family. She explained her inability to identify how long she was married is because she is “not educated” and points to having grandchildren as old as the interviewer in support of a long marriage. Her husband died a few years earlier presumably of AIDS. Rosinda described her husband as “very immoral when it came to women” but denied that he beat her. The husband had a relationship with

another woman whom he lived with in another city and thus “he never at all used to come home” But, Rosinda was able to get money from him or he would buy cooking oil or “all what I needed” if she visited where he lived.

Rosinda bore ten children but two died in an accident. She provides details of their marital status, spouses and children. One girl comes to Rosinda for help while the others “have no problem.” When Rosinda “started having problems” she was encouraged by “my daughter who is educated” to go for testing. At Genesis, a health care facility, Rosinda “found help here like we would be given money and food.” She stayed “until Genesis was like it was not doing well.” At various times “groups” gave money to patients or supplied medicines for free. Periodically Rosinda would turn to her children for support. While they would not give her money, they would take her shopping for food.

Rosinda is told by the clinic she is “doing well,” and because her medications are free, she is able to consistently take them. She is constantly in search of a means to obtain food but so far has been able to piece together support from family and organizations involved in HIV/AIDS care and treatment. Thus, Rosinda asserts, “I feel I am going well and satisfied with myself.”

LLB 10132010

For Each Their Day to Die

Rachel is a 67 year-old woman. Her age apparently makes her somewhat unique among the HIV/AIDS population for as she says, “the old people are not many but the young ones are so many.” She is unsure of her monthly income because any money she receives

is from “selling ropes and *kiondos* (weaving baskets).” Her education is limited to “literacy education for two years” because her witchdoctor father “refused us school saying we would go to graze his cattle.” At 19 years old she married and bore six children. Her children are grown and married thus she declares, “I only have my husband now and we are all who is sick.”

As the first wife, Rachel shared her husband with a “co-wife” – a second woman her husband had also married. Rachel explains that prior to diagnosis “I got sick malaria so much until I finished three years.” She could not walk properly and sought answers. Her rationale to be tested for HIV was “since my thoughts were showing me of knowing our status considering that we were three.” The doctor told her, “They do not talk of that disease to avoid people being shocked and commit suicide.” She dismissed this concern by explaining, “I cannot commit suicide since I had grandchildren.” When further queried about why she was not afraid, Rachel responded, “I was a person just like anybody else...and I know one day I will die my day of dying.” Rachel knew that if she tested positive, “there was medicine to take so as one to stay a little bit longer.”

The co-wife refused to be tested. Rachel’s husband did get tested and was found HIV positive. The source of the infection is not clear. Rachel’s thoughts about how she got the disease are expressed as, “I don’t know since I hear from the counseling that one can get through many ways but I cannot really know how it infected me.” The relationship between Rachel and her husband remained amicable despite the diagnosis. In Rachel’s own words, “we stay well and at peace. We were tested and kept quiet and we never blamed each other neither the other wife.”

Rachel believes, “this disease was not made for anybody but the devil brought it. It is a trial to any person who has it.” She asserts, “this disease has so many problems whether you eat or not.” Rachel laments, “it has not done me good since the way I was working is not the way I work.” Still, from the time of diagnosis two years earlier, Rachel declares “there was no problem instead we sat down and imagined how we could get help.” She provides several examples of the help they received including free medications and food. “We got help,” Rachel states “since we eat despite the normally problems that we have.” God, Rachel claims, is the source of her strength.

Rachel displays a relatively sophisticated understanding of HIV as evidenced by her understanding of topics such as modes of transmission “getting sick may be caused by three things” and proper method for taking medicine “if one takes the wrong way, he/she can die.” Her knowledge was obtained through counseling and support groups. Rachel adheres to the plan of care. Condoms to reduce transmission are unnecessary as she and her husband “said that we will rest since we are old until the time God will call us,” and she refuses the advances of other men. She receives support from “a friend who understands me.” Rachel does not “see anything hard” in going to a doctor. She goes to the hospital to receive medicine, to get tested and to receive treatment for an illness like malaria. She does not see witchdoctors or use home remedies. She knows to eat well “to get food to eat is very important” but confesses food is sometimes difficult to obtain especially given her limited financial resources. Rachel finds strength avoiding stress. “I avoid getting annoyed since we have been educated on that.” Rachel ties this advice to her religious beliefs; “even if you do something to me, I don’t take them weight since

even the Bible teaches us not to get annoyed the whole day, it also teaches us to forgive one another. So you tell God to forgive us and have courage and hope in God.”

Between the first and second part of Rachel telling her story, Rachel’s husband of 48 years died. The cause of his death is unclear as Rachel says, “I don’t think he died because of the sickness but you know each person has got a day to die, since he had the medicine and I was taking care of him well.” Rachel’s reaction to her husband’s death reflects her deep faith, “I told God that I will not stand on his way, let him go where God prepared for him. I told God to give me courage until the last day since each who is created will once go back home. So when your time to go reaches, you must go home.”

Stigma, fear, lack of support, and discrimination are generally not a part of Rachel’s HIV experience yet she is acutely aware that for others these factors shape their reality. She speaks of women “like those daughter-in-law who do not give their mothers-in-law food.” Of these callous relatives, Rachel believes they should “get a curse since they should take care of their mothers.” She knows of women who seek financial support. “The sub-chief takes the names and takes them to the office in charge,” determining “those with small kids are getting help,” and “the widow and the old are left without anything.” As a member of a group of women, Rachel says, “I used to look at them and know that some of them were sick,” but they refused to be tested. With great understanding and compassion, Rachel told the doctor “to stop following them since they know the truth” for she knew “they fear to be seen they were sick.”

Rachel acknowledges the adverse impact advancing age and widowhood has on accessing health care for HIV positive woman. She reports, “The widow and the old are

left without anything. Like there are those doctors who say they don't want to treat the old since they are almost dying and of no use." The discrimination is not subtle. Almost disbelieving Rachel's statement, she is asked "they say you are old and you do not need to be treated?" Rachel points out, "you have life and you don't know the time you are going to live." Thus Rachel advocates for HIV positive older women such as herself. She demands to "go tell them we want money to do business so as to stop suffering." Rachel asserts the main things people like her need are "food and clothes to wear which can give one stress." Rachel implores, "They should give us medicine and food," and admonishes "to remember the old women." For Rachel and other older HIV positive women, death does not need to be hastened unnecessarily but will come when it is their time to go home.

LLB 01102011

He Will Open the Way

Born into a "poor family" in which, "my parents were not able to educate me so I was forced to stop...I mean they were jobless," thirty-seven-year-old Phillis turned to marriage. Twelve years later her husband died. Phillis did not know why her husband died, but "did not have the confidence to be tested since I knew that he had been bewitched."

Phillis explains what happened after her husband's death. "There are some things at our home whereby when a man dies and leaves a wife, she gets mistreated by the other people, and when I saw that I never followed so much because when he died, the relatives were there and they took him together with everything that he had." Phillis states "there

was land but according to that family I was not to stay there.” She explains, “Many of them like chasing the wife so as to get the land. So I came from that place, and I came here because I had children. I saw that I could not stay there waiting to be killed by these people and I had children.”

Phillis had four children. Her youngest, the only boy, died a year before her husband died. Her husband’s family “because he died they have no concern with the girls. You know they used to say that the boy was to make me go back there, but because he died then I cannot go back since girls have no place in the family.” Phillis “decided to come back to start life a fresh and get daily bread.” “You see since my husband died, I did not have a job,” and Phillis goes on to explain, “I was forced to look for a job and therefore my brother told me to give him the children to relieve me so as not to have stress.”

Six years after her husband’s death Phillis learned she was HIV positive. She started to have unexplained symptoms. “When I was walking, I was like a lame person. So I wondered what was happening, but I was treated until I was well. So I said to myself that my children needed help than ever before, and so I decided to go and take the test so as to know my status.” Her initial reaction when told she was HIV positive “I was shocked.” She described how “my heart beat and I wondered how my children would get education. I grew thin within two days and I thought of many things, and I even thought of taking poison to die but I thought of my children and who will take care of them.” When Phillis learned of the many other people who were also HIV positive she “thought to myself what is the use of taking poison to die alone for nothing and I am the mother and the father. If I die the children will suffer and I stopped that thought.”

Phillis' focus of concern is “money is a big problem” not her diagnosis. Phillis met HIV positive people who “have really taken long and are still taking the medicine.” She shifted her thinking. “So I thought also about where to get money and a job. I start thinking so hard.” Her story is about “getting a job where I can pay the house rent, send some money at home and pay school fees for the children. I normally say that because I never went to school, I don't want my children to miss to go to school.” The HIV diagnosis impacted little her quest to secure the needed funds.

Phillis reports earning about 200Ksh per day, “but since December I have not gotten a place but I go at Nairobi west for one day only.” She gets additional money from a married man she is seeing. “He helps me with money and he divides the money in my presence until I tell him not to give me until he has cleared his things” and provided for his wife. She sends money to her brother who is watching her two youngest girls. Phillis has not told her brother her HIV status. “It is a must I tell my brother who is staying with my children the only thing holding me is money. If I get money then I will go and we sit down and I tell him.” Her oldest daughter is attending a day school. Phillis stays with the daughter. “In my house,” Phillis relays “I have no problem with food since when I work on Saturday, I buy enough *unga* (flour) but the problem is house rent and sending money home.”

The daughter attending school asked Phillis, “how she could get school fees but I told her that God knows where to get the money from because the same God who opened a school for you is the same one to open a way for money to come.” Phillis suggests that to continue well “one can do business or one can open her own work and continue with it.” Phillis does not have a plan to secure her financial future. She believes “when you

trust in God, He opens a way for you.” Phillis says, “I like doing my own work and get money.” What work she can obtain and how she will get money remains a mystery because, as Phillis says, “I cannot know because Gods plan is not man’s plan.” Thus she continues, “To pray to God because he is the one who created me, He knows me and He cares for me and there is a day He will open a way for me and I will succeed.”

LLB 08272011

The Triumphant God

Rose summarizes the preeminence of God in her life “I know that even if trials come I will never be shaken and God is above all and He is in control.” Rose made a conscious decision “I have decided to stay a righteous life until the day God has planned to take me.” As a 50 year-old woman, Rose’s four children are adults with lives of their own. She lives in a rural area. Rose explains her lack of education other than literacy education “the men in olden days never wanted girls to go to school.” Lack of education and perhaps other factors account for her extremely limited income.

The HIV infection was acquired “through my husband” for Rose knows her husband “used to keep so many women.” She does not dwell on the issue. Her husband died when “the disease was not as famous as it is today.” Rose became sick a few years after her husband’s death but was not tested for 15 years when she became sick again. The doctor advised her to get tested telling her “not to worry if the results would be positive” and in response Rose “prayed to God to do his will.”

Life has been difficult yet Rose is noted to give a “happy presentation.” She relays several examples of the kinds of challenges that beset her life. Rose worked so hard weeding the garden until “I worked so much until my CD4 count was down” to 31 and she had lost 7 kgs. A persistent cough is cause for concern. Rose anticipates being tested for tuberculosis the next time she returns to clinic. With a very limited income, Rose finds it difficult to attend clinic to see the doctor. Lack of income and food insecurity, especially during times of famine, are constant aspects of her life.

It is not clear when Rose became a woman of faith placing trust in God above all. Rose faced many trials guided in her response to each challenge by her understanding of the work of God in her life. At her husband’s death, she was left with four small children to raise on her own. People, “even the mother” told her to find someone. She resisted on the belief “I saw there was no need of moving here and there since the Bible says when two are joined together no one can put them asunder” and “because we loved each other when my husband was alive I could not get married again.”

Rose does not minimize the impact of her diagnosis. In response to the question how has the disease affected the family Rose says “it is bad since my husband died” and she goes on to say she “cannot do some things” because of illness. Yet, Rose’s faith is evidenced in all aspects of her life including her attitude toward her HIV-positive diagnosis. Rose acknowledged the importance of taking medications because it “sustains my life” yet asserts “I trust in God so much because even when I am taking the medicine, I pray first for the will of God to be done.” When overwhelmed by stressful thoughts Rose claims she has a person to share those thoughts with but returns to her faith “other times I listen to the radio, a channel called *Biblia Husema* which preaches the Word of

God and on listening, I get settled.” Rose describes her interactions with doctors “the doctors are very good because they listen to me as I explain and I have seen God touch them to handle me very well.” Alone in her home, Rose is not afraid stating people fear her “because of prayers and people say I am born again.”

Rose’s faith is unbroken by the potentially devastating impact of a chronic illness such as HIV infection. Over and over she makes comments such as “I know that God has the power to heal any disease and therefore I trust in Him” or “I trust in God any time I get sick.” If Rose could talk to other women about her experience she would tell them HIV “is just a virus which is not a disease. I can tell them that they are only sick in mind and if they can open up their minds and see clearly then they can live healthy.” Rose has opened up to the healing power of her God proclaiming “I depend on faith in God and give Him the first priority.” For her, no power, no earthly occurrence is greater. Faith guides Rose’s life and death as she declares “I know I cannot just die anyhow unless God calls me and even this disease has no power to kill me.”

LLB 03152014

That is Where We Used to Have Problems

Monica is HIV positive. She “suffered for three years before I came to know the real problem, since I used to get sick frequently.” She was so sick initially she was “admitted for months since I was being given food through the mouth.” Her health is stable on medicine. “I am doing well and no one can know whether I am sick.” By “eating well, and for my children and fare to go for medicine,” her stress will be minimized and Monica believes she will be able to “continue to stay with this virus.”

Monica is forty-four years old and married. The couple's four children are adults. Her husband does not work as "he is the kind of men who drink so much." On her limited income, Monica tries to help her children and would like for them to have some land. "Very few know that I am sick," she says. The children are among those who know of her HIV status. They are supportive of their mother "my son told me to take the medicine and all shall be well, and I felt a change and I was encouraged."

The infection was probably acquired from her husband. Monica knows that, "From the time he married me, I have never had any other man." Monica mentions, "The time I was getting married to him, I was a girl." She does not know with certainty of her husband's infidelity "you see you can't tell and because of this problem, it means that he used to have them." Her husband accused her "he started chaos saying it is me who knows where I got all those problems." He will not use condoms. "He said that he would not use such things and it means that I am not good and I told him yes because the doctor advised me to do that." Her husband also refused to get tested. "That," Monica concludes "is where we used to have problems with him."

Monica and her husband are estranged. She explains, "I got sick, he brought chaos and I went back at my place where I take care of the children." Monica discloses, "We never used to cope well." When the husband "came to know that I was sick, he started beating me until I felt like I was to die." Monica dismisses the domestic violence. "A drunkard has so many problems."

She asserts she will not go back to him "because this person wants the things I was refused by the doctor." Specifically, her husband wants sex, but "I was told he

should use a condom but he refused.” Monica’s life has been permanently altered by her husband’s actions but her life, her future is now in her hands.

LLB 09162011

Regrets

Jasinda announced, “What I had planned in my life is not what happened.” Her husband died in 2004. “If it was my wish, my husband should be alive even today.” They were married for only seven years when her husband “got sick abruptly and he died.” Jasinda was left to raise three young children. She laments, “I wished that we grow old and see the success of my children,” our family “would be big but now life was affected so much” she explains.

Jasinda and her husband “used to stay well.” They were faithful to each other, “no one went outside we stayed the two of us.” Her husband, she reports “used to take care of us.” Life was improving for the family. “Before he died he had bought a land and we had build a house and so we had gone to stay there.” They lived “at the new place for one year when he passed away,” and that is where Jasinda and her children continue to live.

The impact of her husband’s death on Jasinda’s life and those of her children has been dramatic compounded by the fact that Jasinda and one child tested positive for HIV. “My life has been so hard,” states Jasinda. Jasinda discusses some of the factors that make life hard. The HIV positive diagnosis means “like you need to take medicine and to cope with taking medicine always.” Going for medicine is “a lot of work” because “where to get the medicine is not near and one has to get fare to go there.” The children, Jasinda tells us, “need education and there is no money and this lowers their rate of

study.” Food security is an ongoing concern especially during the period of drought. She explains the particular concern about food created by her disease. “When you are taking the medicine, you should have enough food. Since you can take them and they overpower you, and you grow weak. So one should have food ready, and like when there is famine one cannot have enough food and can take the whole day without food, which means that one has to take the medicine like that and sleep.”

People’s reaction to knowledge of her illness varies. Jasinda told her mother. “It was not easy for her but she kept quiet.” Her mother proved supportive. “She really comforted me and she told me that if one continues with the medicine can be very stable.” In contrast, sometimes Jasinda experiences people’s negative reactions. “Some stopped being the people I knew and some things they used to do to me, they stopped. They start fearing you.” She continues, “You can see them discussing how they are going to help people but they don’t include you.” Jasinda acknowledges some people say, “Those with AIDS should not be given the medicine but instead they should die so that the disease can stop spreading.”

Jasinda states that money is difficult to earn. “Many times I stay without getting anything...like now there is a drought and there are no casual jobs.” Stigma associated with HIV compounds efforts to secure employment and undermines self esteem. Jasinda describes a recent experience working in the garden for another woman. “While I was working in the garden, she refused me from bathing using her basin since I was sick and I would infect her with the disease.” Jasinda replied, “I told her that the disease is not spread that way.” Jasinda still feels the sting of this discrimination. “I felt bad since up to now she has never changed, and she keeps on spreading the rumor.”

Jasinda acquired the infection “through my husband since before he died he had been examined and found positive. But he was in a bad state to be helped.” Jasinda elaborates on the transmission of HIV to her. “I knew myself that I was faithful and when my husband died. I heard his sisters say that they had advised him to go for the test and he refused, and the girl who had infected him they knew her. This girl was working in Mombasa, and she found my husband, who did not have a wife by then, and they married and she was sick. They stayed for some time and they parted then I was married by him.” The girl died a short time later. Jasinda divulges, “The last minute when he was so sick, I took him to the hospital and I told the doctors to test him.” The doctors refused to tell Jasinda the results of the test, but “when we went home I asked him and he never hid it and he told me that he was found positive.” Her husband did not want people to know of his HIV positive status. “He told me if I am asked by people what he was suffering from; I should tell them that it was TB.”

Based on her own experience Jasinda believes, “women should take care like when I was getting married-if it were like today I would have gone for a test which is free today. One should be tested and if they are sick they can stay together and lead a good life through the advice of the doctor.” Jasinda believes firmly “people should be tested and try to be faithful to each other” and these actions would help spread the transmission of HIV.

Jasinda thinks back to her childhood and remembers that as a child, “there was a problem because we used to stay with our mother alone. Our father used to be there but working in time though he never used to send money at home at all.” Jasinda summarizes, “I grew up in problems and I could not imagine that when I grow up, I would have the

same life.” “I had told my husband,” Jasinda states “that we needed to have the test if he wanted to marry me, and he told me that he had taken a lot of care and he was okay.” If her husband had consented to a premarital test, “I say that if my husband knew this, he would have taken the medicine and he would not have died today.” Unfortunately, her husband did not agree to be tested and was HIV positive at the time they married. As a result, Jasinda and one of her three children acquired the HIV infection. Thus Jasinda concludes, “at that moment I regretted why I got married because if I was to work as a maid, it would have been better for me since you are given everything.”

LLB 09082011

Divine Intervention

Thirty-two-year-old Florence divulges that “this disease stopped my family.” Florence “was young and we married with my husband.” The husband had been married twice before his four-year marriage to Florence. At the time he died, Florence recalls, “When I looked him die that time he had signs of having been infected with this disease.” Florence continues, “After that this husband died and left me when I was pregnant. Later this child never survived also.” Florence’s seven-month-old baby died of pneumonia, “but the child had been infected by this disease,” and Florence “did not know” at the time. Florence developed a swollen leg that was unresponsive to treatment. Initially the doctor was reluctant to test “for the VCT test since he thought that I would be shocked.” Florence’s retort was “if God had planned that I would die of AIDS then there is nothing I could do.” Florence tested HIV positive. Thus, in a few short years, she lost her only child, husband and marriage and was infected with a chronic, life threatening disease.

Florence was quite sick, yet “those parents-in-law never wanted to take me to the hospital.” Florence “left that place where I was married and went back to my home.” Her father took her to the hospital. The expectation was that Florence would return to her husband’s family. Florence refuses. “The problem that makes me not go back is that when my husband died, the brother said he would inherit me like it used to be in olden days and due to my status, I cannot do that.” The relative who would inherit her already had a wife and children, and Florence knew that, “if it was to be like that the whole family would die.” She never did return to her husband’s family.

The initial reaction to the HIV positive diagnosis was for Florence to develop “self stigma.” She “started thinking what to do” and “thought of neither attending the clinic nor going for the group.” Florence’s story of loss, sadness, despair and hopelessness might have ended here were it not for an intervening hand. The doctor encouraged her to attend groups and gave her the fare to the hospital. Florence reports that “when I went there I found out that I was not alone and I was encouraged. And the other day I joined the support groups and from there I was okay.” She added, “From the time I came to know that I was positive I welcomed God in my prayers.”

Today Florence is doing well. She says “thank God so much for I came to know...because if I had not known, I would have infected many people.” Florence does not have problems accessing treatment unless “you fail to attend the appointment well.” She follows the doctor’s instructions. She eats well. She attends groups meetings. Witchdoctors are a “waste of money” but she does use aloe vera “to clean up the blood.” Medication is taken without fail for Florence knows “it is keeping my life” so she “put a lot of effort in taking the medicine.”

With knowledge, support, treatment and a belief that “with prayer all things are possible,” Florence was able to rewrite her story. Instead of succumbing to her earlier losses and yielding to the power of her disease, Florence embraced life. Today Florence educates other people, telling HIV positive women “step by step” which “helps them to absorb the story in a better way.” She feels good when counseling HIV positive children as others do not know how to talk with the child. Florence helps “the children to grow in faith.” Explaining, “There is no need of infecting another person,” Florence talks about adopting a child. Florence offers a captivating, positive outlook on life, a transformation she might suggest is attributable to divine intervention.

LLB 01232011

Continue on With Life

Sue was tested for HIV three times at three month intervals. She states that, “I got sick and when I went to the hospital, I was examined and I did not believe it.” She also did not believe the second test. The third time, “I told my husband we go at Kalali Hospital that we may know the truth when we are together.” Sue continues, “We were tested and we got the results that we were all positive, but he agreed to stay with me the way I am.” Sue’s reaction to her diagnosis was disbelief. “I was shocked since when you have not believed is hard to cope with it. When you believe in something you can stay and cope with it and no stress. So I believed I will die just like those other people who don’t have it.” Sue discloses that “when I came to know I was first scared but I comforted myself that I was to stay just like those who don’t have.”

Twenty-nine-year-old Sue is the mother of three children ages 3, 5 and 7. The children are negative. Sue was tested for HIV during her last pregnancy but was negative. She does not know how she contracted the disease. “I cannot say since I know that I was faithful but don’t know about him {her husband} since he used to work and sometimes at night and other times during the day.” They use condoms but this is not new, as they had used condoms “as a way of family planning.” Sue had not been with a man prior to her marriage nine years earlier. One of the hardest things for Sue is “about thinking so much about my husband, I try to avoid it.”

Diagnosed just five months earlier, Sue’s CD4 count was low so she was started immediately on medications. Sue reports, “I can’t say that I am bad the way I started the medicine.” She uses a mobile phone alarm to remind her to take the medicine. The reaction of other people who may see her taking medicine is not of concern to Sue as she knows “this disease has caught up with me and I cannot remove it and if there is anything that can help me to stay for long, than I can do it.” She offers “my faith in God I know with this medicine, I will stay.”

According to Sue, the HIV diagnosis has not changed their lives. As Sue describes, “things are normal and even him he has not changed the way we stayed.” Sue confides she has not ruled out the possibility of more children. She continues, “Things can change due to lack of money but on the side of sickness, he has remained the same.” Her mother encourages her to have hope. The in-laws and others who know of her diagnosis “take me well” as do the people at the clinic where she goes for care. Sue describes the impact on her family, “The effects are few but we will rectify them” without elaboration.

Life, however, is not the way it was prior to their diagnosis. Sue takes measures to protect her children from getting the disease. Sue's husband is not working. Their limited income is derived from Sue's sale of vegetables. The money is used to "pay the house rent, and educate the children." Sue claims, "The only thing that gave me problems is stress for money." Monthly she goes to the clinic. At the clinic, "there is a doctor who prays for the people." As Sue elaborates, "We pray together so as to start the treatment." There is a cost for the medicine, the doctor, the blood work and the transportation to the clinic. Lack of money for transportation to town prevents Sue from attending support groups. Sue believes that "if I can get somewhere to get money to pay school fees for my children" then "there is no problem."

Perhaps Sue is experiencing some denial about the impact a positive HIV diagnosis will have on her life and that of her family. Or, perhaps the advice she gives to other HIV positive women; "stop getting worried whether to die or not, since when one is sick and thinks of this disease she cannot live," captures her life philosophy. Sue relays that "the first time I took the medicine; they told me that it was not for cure but to reduce the virus in the body." Once she started taking medicine, Sue expressed her hope. "I stopped thinking so much, and I want to stay the way I was before I got this disease." She adds, "I want to bring up my children, even if God will take me, they will be big." Sue takes the medicine, "to reduce the virus and continue with life" – a life she hopes "I can live like the others who are free."

LLB 01242011

The Heart of an Entrepreneur

Patricia's husband, a teacher, decided she was not educated enough and he wanted to be with another teacher. Married for seven years, eventually Patricia and her husband separated, and he married the teacher with whom he was having an affair. Patricia knows her husband is HIV positive and knows that his second wife died of AIDS. Patricia has had an HIV positive diagnosis for eleven years. Patricia's diagnosis came as a result of problems she was having with a pregnancy that ultimately ended in a miscarriage. She recalls, "you know those days they were disclosing to people very badly." Patricia was told, "You know mama, you have that dangerous disease which is killing people here and that is why your pregnancy came out."

Patricia is vague about dates but speaks of a "partner" after her separation. She no longer has a partner, "because the partner used to move so much." Patricia developed gonorrhea and then syphilis. The boyfriend was HIV positive. She and her partner were advised to use condoms but he refused. Patricia explained the partner's thoughts on the use of condoms. "The person will be so mad that now I am with you, and I don't move with anybody else. Now you have to be like my wife so I don't have to use condoms and I use them with prostitutes." Patricia does not speculate about how she became HIV positive.

In a matter of fact manner, Patricia describes her response to the HIV diagnosis. "After just hearing the word AIDS and the way it was affecting people, you know we could see people being buried in nylon papers in the village," Patricia begins and then continues "so the first thing which jumped into my mind was now that I will be buried in

that paper and then, I was just thinking of death.” She immediately stopped working. Patricia confides, “I even tried suicide twice.” She discusses with detail her attempts to end her life. Patricia’s husband announced his intention to marry the other woman so Patricia separated from him. Jobless, separated and diagnosed with a life threatening disease “what flashed in my mind was death.” She was so distraught, “I even thought of killing my children instead of leaving them behind.” Patricia’s justification was, “The news all over the radio were going like there were so many orphans because of this HIV and AIDS, and I could not understand how I would leave my children with all those problems.”

Patricia was not working and as a result “we used to sleep hungry,” and “my mind was totally mixed up.” The people who gave her the diagnosis, “those ones they never counseled me.” She “could not tell people because of the way people were being stigmatized in the village.” Patricia believed, “my only solution and the only answer was to commit suicide.” Fortunately Patricia met a woman who befriended her and took her for counseling. The woman had breast cancer and “showed me {Patricia} the breast cancer which made her to be cut her breast.” Patricia thought, “She had a wound and yet she was living. So I wandered with her and she was still living. This encouraged I so much.” Patricia reports, “I thank God because I opened up to that person, that lady.” Patricia reflects on how times have changed. She states, “These days they have changed. In the other one we used to even regret. People used to die in the clinic and even the receptionist never used to care and talk bad.” “These days,” Patricia says “you like the handling and I even encourage people to come here.”

Early in the narrative Patricia begins telling her own story which reveals an entrepreneurial spirit that has thrived since her diagnosis. Forty-three-year-old Patricia is the mother of two children in their early twenties. The household consists of eight people – her dead brother’s two children and the two sons of another brother, her mother, her daughter and granddaughter.

For income, Patricia states; “These days I sell porridge in the market place.” This is not, however, her only source of income. She raises goats. She is just feeding the goats to “keep them for the December holidays,” when she can earn 8500-9000Kshs per goat. Patricia sells shoes on the days she is not at the market selling porridge. She knows that when she buys shoes for resale, “the more you buy the more the profit”. She explains, “I have these goods and in the middle I keep charcoals at home and I sell to villagers.” Patricia buys “charcoal with sacks,” and “I buy at 400Kshs and I sell it at 700 Kshs. She prefers to “be mobile” because when “you rent the shop then the city council licenses...they include a lot of things which consume your money”. With money from a loan Patricia took a risk – “I go to Gikomba open air market and I buy T-shirts and I iron them and I go round selling.” The list of products she has sold seems endless. Her understanding of business is evident in her risk taking, knowledge of business regulations, timing of market conditions, selection of products and sale location, and turning a profit.

Patricia also has a sophisticated understand of business and charitable resources. She talks about a loan from the Kenya Women Finance Trust to “assist me to sell shoes and I do some other businesses”. The wholesale shops are at the Kenya Bus Services. Patricia was “trained a bit by the Christian Children’s Fund,” which she explains is an

NGO. Trained as a community health worker, she helps villagers get food “from the DOS office”. The USAID “used to give us porridge,” she says. Patricia is “attached to another CBO called Uhai,” a welfare group. She uses her knowledge to help HIV positive women receive medical care and “to make her {the other woman’s} life stable”.

Patricia is articulate and informative telling both her experience with HIV/AIDS and her own story. The dominance of her own story in her narrative is clear. Patricia has been shaped by her HIV experience but she is not defined by her disease. At her heart, Patricia is an entrepreneur using her sophisticated understanding of business, local and international resources and law to secure what she needs. She readily shares her knowledge with other HIV positive women. Patricia acknowledges these women face many problems. Yet her own experience leads her to advise other woman “to stand firm...to be strong and bring up her children and she should know that it is not the end of everything”. Patricia believes that a woman “should accept herself and know that she has her own life to stay and she can live like any other woman in the nation in the whole world.” Patricia is living proof this philosophy is successful.

LLB 01302011

A Life Derailed

Belinda is a relatively well educated, 28 year-old, single mother of a little girl. She lives with two brothers and three sisters but “they cater their own food.” Her retired parents live in another village. A year ago a herpes infection caused her to become sick so she quit her job. She is currently not working.

Five years ago, Belinda applied for a job as a customer service representative in Dubai away from her home—a position “where they pay better.” Her plan was to work and “pay for college.” Along with the application was a requirement for a medical examination. The results, as she reports, were “when I took the medical test I was found to be positive.” Prior to her diagnosis, HIV/AIDS was not something she thought about. “I really did not care. I was dealing with various people not knowing I was risking myself.” As evidence, she admits she did not routinely use condoms. The inability to secure the customer service position was “very disappointing” for Belinda “because it was a lost opportunity.” She laments, “I already spent a lot of money to apply for that job and I cannot be eligible anymore.” Her track to a well paying position that would allow her to pursue a college education was seriously damaged.

In response to the news of her diagnosis she states, “I felt bad and I started to have new relationships with men and I got pregnant.” Belinda views her daughter “as a source of strength” in her life. Although Belinda reports her daughter is doing fine, her four-year-old has not been tested for HIV. Belinda took medications “before and after delivery” and did not breastfeed her daughter presumably to reduce the risk of infecting her.

Belinda suggests, “I have accepted and I adjusted my status. Because I come here it shows my acceptance of the status that I am infected but I want to live.” Her actions, however, fail to demonstrate the life style changes that facilitate a long, relatively healthy life as a person HIV positive. Her use of ARV medications has been inconsistent. “When I take the medicine it kind of come back when I swallow,” she explains. She reports, “the

ARVs are giving me side effects like diarrhea, vomiting.” The diarrhea and stomach aches she experiences are “driving me crazy.”

While she is given the ARV’s, other medications, including those to manage the side effects, she would have to purchase from a pharmacy. Her brother has helped in the past as Belinda “cannot afford to buy now.” Advised to go to a support group, she cites her inability to pay the fare as a reason she does not routinely attend. She summarizes her situation. “It is hard because the family has to support me financially to buy the medicine, and whenever I go to see the doctor they ask me what did he say. It affects me personally. As I get sick I feel like I am a liability to my family.” Only Belinda’s one sister knows of her HIV status although she admits, “I have to tell my brother, he must know it.” Asked what is really helping her to live, Belinda responds, “I will say the Lord, and my sister who is now becoming a nun supports me spiritually. So when I have doubt in the Lord she encourages me.”

Belinda worries about her daughter. Since her diagnosis she offers, “I worried much about the future of my child, and before I started taking the medicine I feel sick and worry much about her future...I worry about where she will end up.” Belinda’s current objectives are straightforward. She wants to “see my daughter grow” and “be strong...be able to do something for myself”. Belinda did not have the opportunity to fulfill either goal. Her life permanently derailed, she died of AIDS shortly after she told her story.

LLB 12302010

The Quest for a Healthy Child

Veronica is a twenty-nine-year-old, college educated, married woman. She has a business selling handbags and her husband is a manager. Finances are stable and Veronica does not comment on food insecurity common to people in her world. Both Veronica and her husband tested HIV positive. Veronica is on medication but her husband's CD4 count was adequate without the need for medicine. She does not attend support groups as recommended by the doctor. She shared with a close HIV positive friend her diagnosis but otherwise has not told her extended family of her medical condition. She prefers to confide in her husband. Veronica confirmed her husband had an affair but refuses to speculate how they became infected. Veronica describes her relationship with her husband as "normal". He was cooperative in being tested, remaining with her following their diagnosis. He appears to be a source of support.

Articulate and candid, Veronica shares her knowledge of HIV and its impact on people's lives in response to queries. She discusses the stigma associated with the diagnosis vividly disclosing the situation of a woman ostracized and neglected by her family until she died. Women are, according to Veronica, "the breadwinners as in they look for food for their children. So when they are affected, it is a very big blow to the children and the society at large." She speaks of women's efforts to obtain money for food. Veronica addresses the care she is receiving and makes recommendations for improving access to medical care. She comments on the government's role in addressing the prevalence of HIV/AIDS and emphasizes the importance of educating young people about the disease.

Questions are answered openly and politely providing valuable insights into the impact of HIV/AIDS in Veronica's world. However, very quickly in the conversation Veronica shifts the discussion to the topic of most importance to her i.e. her efforts to conceive a child. Veronica says, "You know I have had problem conceiving for the last four years." The issue of infertility is woven throughout three interviews. The interviewer is drawn to the story of Veronica's efforts to become pregnant. Questions shift from a focus on HIV to topics related to infertility. "Do you normally visit a specialist of fertility?" "You have done hormonal levels?" "And have they checked your husband?" "Have you tried other methods of getting a baby like egg capturing or artificial implantation?"

Factually Veronica relays her efforts to become pregnant. In the ten year period of sexual activity she became pregnant only once. Veronica's elation quickly dissipated. "I was so happy only to find that it was an ectopic. I was so sad. I am telling I started having pain and I had to be brought here by ambulance." The surgery to address the ruptured ectopic pregnancy not only resulted in the loss of the pregnancy but also the loss of the fallopian tube further complicating efforts to become pregnant.

A positive HIV status adds yet another dimension to Veronica's infertility. The standard advice to use condoms when engaging in sexual intercourse is problematic. Veronica and her husband "really want to have a child". The medical staff modifies their advice. Veronica relays her understanding. "When I come here they tell me that I should count days, like from day ten to twelfth. I should not use a condom for they speculate those days to be fertile days, but if I don't conceive then from the fourteenth day I should continue using the condom." Veronica further explains, "The doctors told me to wait

until the CD4 count goes up because when it is low, I cannot conceive.” She adds, “He {the doctor} told me to wait because you know last year I had an ectopic. So he told me to wait for some time and I am telling you that I have really stays in this state for a long time of ten years.”

Three years later during the third interview, Veronica comments to the question about conceiving a child. “It is like we are giving up. We have tried but we have not succeeded.” Discussion of infertility dominates the third interview. In contrast to the assertion plans for pregnancy have been abandoned, Veronica talks at length of various aspects of infertility and conceiving when one is HIV positive. Veronica reports the results of a medical scan of her reproductive organs and her desire to review the report more in depth with the gynecologist. The feasibility and cost of alternative methods to conceive is explored. Veronica verbalizes stories of HIV positive women she knows who have had children. Veronica presses the interviewer for information and the interviewer, in turn, encourages Veronica to speak with the doctor.

Veronica reveals the meaning infertility has for her. “Not having the child, it make me feel like there is something I have not accomplished in life.” Despite years of infertility, Veronica and her husband still hope for a child. The challenges of conceiving, however, are overshadowed by the concern and hope that she could bear a child who is HIV negative. In her own words, “my worry was that I was asking them {the doctors} whether I could get a negative baby because with a positive baby...” Yes Veronica wants a baby, a baby whose own life is untouched by HIV.

LLB 01202014

And the Lamé Shall Walk

Forty-seven-year-old Lucia is HIV positive. Asked how she got the disease she verbalizes, "That is where the problem lies." Lucia explains, "Because I have like nine years without seeing a man (having sex)." After separating from the father of her only child, "I got another one so I don't know." She offers an alternative source of infection. Lucia explains, "there is a tooth here I was being removed and it cut." She continues, "It was done half way and later it was to be uprooted again after everybody else had been attended to. So I think that's what brought the problem for me." "I think this tooth that I have been removed is the cause of it all," she concludes.

Lucia tells us she is uneducated. "My father thought if I go to school, I would not get married." But she never did get married. The reason she did not get married she asserts is, "I did not like the life I was brought up with," so she "decided not to get married, so I thought one child was good for me." Her 24 year-old son lives with her. She describes their relationship since her diagnosis; "there has been no change instead we are so close than before." "Me and my child," she states "we keep on encouraging each other."

Lucia has felt the effects of stigmatization. She reports, "Yes my mother, my sisters have done away with me. Before they used to come to visit me but these days they don't." Lucia has known discrimination her whole life. "One evening when I was three years when I got sick," she says "I was admitted like three months and nothing was found-neither polio not it stayed like that." While the nature of her disability is not clear she is described as lame and recently started using a wheelchair. The signs of

discrimination are clear to Lucia. “You see the signs; if someone used to come and she doesn’t, used to care about you and he doesn’t you just know she has discriminated you.” Lucia suggests she is accustomed to discrimination because of her disability, “The disabled are targeted because they are not profitable and depend on others.”

Lucia presents as tearful and almost desperate for treatment. Lucia politely answers questions about her experience with HIV but her tears have another origin. Lucia has a growth on her neck. Initially she was told the growth was cancer that metastasized from her uterus. However, after further testing, the uterus was found to be cancer free. Lucia then was sent to be followed by an ear, nose and throat specialist. During the initial hospital stay, “I was tested, and the results showed that I was positive.” Uncertainty remained about treatment for the neck growth. “They have not yet know since they have taken blood samples and next month I am coming to be taken x-ray.” The growth Lucia pronounces “is very painful,” but otherwise her health “has been okay.” Her focus is on “the way this growth will be treated” because, as she explains, “it has blocked my ways. I don’t go anywhere.”

The next time Lucia is seen she maintains, “My health has not been so good. This tumor has been giving me headache.” Testing confirmed that the growth on her neck is cancerous. She alleges the doctors “have taken me very slowly since February they have been telling me to wait” although “this tumor is really growing.” Lucia is on medication for HIV. The doctor’s plan, as she understands, “now the doctor said I can use medicine and it is finished but I was told they must examine me.” The doctors want “to see how much strength I have to take the medicine.” The treatment options as Lucia outlines them, “but they will check to see whether to dry it with a machine or take medicine only and

another for applying.” Lucia finds the whole situation “tiresome.” She has experienced a growth for seven years. “Sometimes this tumor disappears and we tend to think that it is over but it comes up again.” The doctors say, “They cannot find any other disease.” The strain is reflected in her demeanor as she muses about what is keeping her going. “I am stagnant at the moment and I don’t know what now.”

About five months later Lucia is seen again. The change in her is dramatic. She seems happy and optimistic. People in the community “kept asking what it was, it doesn’t heal, they thought of many things so saying its witchcraft, curse so many things but I said God is the only one who knows”. The neck growth is now visibly smaller. Lucia summarizes what transpired. “The wound swelled and became a big wound.” “The doctors,” however, she divulges “have been defeated and say its cancer they don’t know.” The doctors do not offer a treatment so Lucia “stayed and let I heal on its own because doctors say its cancer.” The transformation Lucia maintains is because “I accepted myself and trusted God will heal me, and when I believe I will be healed the things reduce. I started regaining good health and happiness.”

People in her church have helped her spiritually but Lucia has not told them her HIV status. Just as she believes the power of God healed her neck wound “I believe I will get well”. Her pastor encourages her faith. “He said God is able, nothing is impossible to Him, If he can resurrect the dead? What is impossible to him?” Lucia announces, “I tell God I will not stay on drugs forever, if he can resurrect the dead what else will defeat him? I will not stay on drugs forever, He will do something and I will be healed and I will be a testimony to others.”

Lucia brings to mind the story from the Book of Matthew in the New Testament. Men brought a paralyzed man to Jesus. When Jesus saw their faith he told the man to get up take your mat and go home. The man got up and went home. Lucia's HIV positive status is not a concern as she asserts, "let me tell you since I got saved, it has not been a problem." "These days," Lucia knows "there are treatments and if one can eat well can stay for long." By faith, Lucia believes her neck wound was healed and by faith she believes she will be cured of AIDS.

LLB 09142011

The End of the Life

The diagnosis of HIV positive is not even a year-old for 40 year-old Louise. Louise is a married mother of four children. Her husband is "an association police"... "they don't have so much salary." She supplements the family income selling second hand clothes although, "these days, things are not doing well." Louise's first reaction upon hearing the news of her diagnosis was, "me I saw death has reached...the way we used to take HIV as death." She felt stressed. The stress was compounded by the concurrent HIV positive diagnosis of her husband and youngest child.

Louise's youngest child became sick with an illness initially attributed to allergy. His unresponsiveness to treatment led to testing. "When the child was examined was told that he had the sickness," Louise says and the doctor recommended testing for both parents. Louise's husband initially refused to be tested but with increasing weakness and at her urging he eventually went for testing and, like their son and his wife, he tested positive. When she told her husband she and the youngest child "were sick, he did not

believe but I saw from his reactions that he knew something.” She said, “I could ask him and I fail to get a satisfying answer to my questions.” Louise exclaimed, “I did not know that I would get such a disease since I was not moving outside. So I really wondered where the sickness came from.”

Louise could not fathom she would become HIV infected, “because I trusted him so much and I wouldn’t imagine him moving outside.” Following her diagnosis Louise only told her husband stating, “I was very annoyed and we just used to discuss it with my husband.” Louise “started giving out my clothes to my sister” so certain was she that she “knew that was my time of passing on.” Encouraged by the doctors, she regained strength and her health. The damage to Louise’s relationship to her husband was significant. She explains, “I felt so bad and I said let him marry another woman if that was the case because I was really blaming him for bringing the sickness to the house.” However, Louise decided “to just stay and take care of my children.”

Louise and her child are doing well. She attends support meetings, takes her medicine consistently, tries to eat well and avoids stress. Her husband was very sick before his diagnosis and treatment but is sufficiently recovered to be working. They remain together but Louise insists he uses a condom when they engage sexually. For now, the family is maintaining their health and has adjusted to the changes required because of the impact of HIV on their lives.

In reaction to her diagnosis Louise stated, “I did not have any happiness. I saw it like it was the end of the life.” Whatever dreams and hopes Louise had for her family were dashed by the misplaced trust in her husband and the resulting presence of HIV in

her family. Louise maintains that, “I used to have many thoughts but I stopped because when one has many thoughts in mind, she/he gets stress.” However, she confesses; “I think so much on these other kids {her three younger children}. How they will go on with education in case I die or the father. I think so much. Nothing else except these kids.”

Indeed, the HIV diagnosis for her and other family members was the end of Louise’s life as she knew it. She easily accepts going to the clinic for treatment knowing “I get my life from here.” At the clinic, Louise asks the doctors and nurses “to tell us when there is any good news coming up.” “Everybody,” she verbalizes, “wants to be completely healed.” Louise fully understands the medicines she takes daily are not a cure. Thus, Louise discloses her life’s focus and biggest worry. “I pray that God may help them grow to a stage where they can be independent. It is my great concern how they can live without me.”

LLB 01262014

Alone and Afraid

Twenty-eight-year-old Purity relays her story in brief, concise answers to questions. Her responses are devoid of emotion. Her HIV positive diagnosis came two years earlier. She is dealing with the challenges of being a single parent of a small child while simultaneously experiencing the ill health resulting from HIV infection and malaria. Alone and without resources, thoughts of how to manage her situation dominate her thinking.

Purity was not always alone. She had a husband and a child. “When I started getting sick when I was pregnant, that other pregnancy I thought of going for the test,”

she states. Her husband's reaction to the test results "when he came to know that I was positive, he went." They had been married only a year and a half. Purity discloses, "The stressful thing was when my husband left me alone. Adjusting to that was very hard for me." She met another man and lived with him about a year. But, like her husband, he left when learning she was HIV positive. Now she is "staying alone."

Purity bore three children. The birthdates and fathers are not clear. Purity states two children died. The two children were small when they died because "one had six months and the other one was ten months." She elaborates, "You see when the two children died; I was so scared that I would also go but these days, I am okay." Purity has another small child – a girl who is HIV negative. She is raising the child alone.

Knowledge of Purity's HIV diagnosis is only known by a friend who is also HIV positive. Purity does not attend support groups. Purity's reluctance to tell people is based on her assertions that people "will hate" her and gossip about her. She explains that people think HIV and AIDS is a "very bad disease" and "they think you have been doing prostitution." Her mother and sister live upcountry and are unaware of her illness. One day, she maintains, she will tell her mother-when the time is right. But for now, Purity manages the stress of her illness and single parenthood primarily by herself.

Purity is receiving treatment including medications. Her initial fears of dying were mitigated by counseling as she remarks, "I used to fear before but when I was done counseling and guidance, I stopped fearing." Purity's concerns have shifted to caring for herself and her child. She states, "I think too much about my life and this child and how I am going to stay." Her illness forced her to quit working as a hairdresser. Purity gets

money when she is well enough and is able to get work doing laundry and other casual jobs for others. At times she does not have enough money for food so she must “go and borrow from the shop and pay back when I get money.”

Alone and with few resources, Purity’s health suffers she thinks due to stress. “It is because I have no work and I have a baby.” The hardest part of the disease for Purity is “a lot of stress that is pressing me.” A job would help Purity but also create childcare challenges while she is at work. Purity claims she would tell a newly diagnosed woman, “We can talk how we are going to help each other.” In particular, Purity believes women want to know about “good baby caring.” Women with this sickness Purity explains, “they think so much about your life and how they are going to leave your children.” For the moment, Purity’s support system is limited primarily leaving her to manage the challenges of single parenthood and her health alone.

LLB 01262014

The Breakdown of Family

When Roxanne first began her story she was 32 years old with two small children; a six-year-old and a 5 month old baby. Her husband abandoned them about a year earlier when Roxanne was three months pregnant. Roxanne divulged, “When this one fell sick and was admitted here and the baby was tested to check the problem.” Roxanne’s husband came to the hospital and Roxanne told him both she and the baby tested HIV positive. The doctors wanted the husband to be tested. The husband refused and “disappeared for good and he never came back.” Roxanne looked for her husband. She went to her in-laws home. “When the father saw me, he chased me and told me not to step there, the son was

not there.” At their home, the husband had “took all his things and left my clothes and those for the baby.” Roxanne was “so shocked.”

Roxanne declares, “The person who gave me was my husband since when we were marrying, we tested and we had no problem.” She discloses that, “I had a problem with my husband since he was a mechanic and he loved women so much.” With a limited education and no husband to support her, Roxanne has few options. She discloses, “I have no parents to help me.” Roxanne sought help from her sister but “she abused us” and “told me not to go at her place. Her children may get it.” Other people, Roxanne knew “see it a bad disease and that you were not faithful when in marriage.” Only at the clinic did Roxanne find she was treated well.

At the clinic, Roxanne is given ARVS and other medicine. “They examine us then they treat if there is any disease,” she continues. The clinic also checks her CD4 count. Roxanne does not use home remedies, nor is she treated by medicine men or traditional healer. Since her husband left, Roxanne reports “I have never been with any man.” She has not joined a support group.

When first diagnosed, Roxanne “was counseled by doctors, I got encouraged.” She also says, “I encourage myself. I pray God to give me the strength to bring up these kids since I don’t know why I got the disease.” Abandoned by husband and family, shunned by people in the community Roxanne believes, “I have no one else who can help me except God.” Roxanne struggles to get money doing casual jobs but admits, “The hardest thing is money since many a times I don’t get jobs.” Roxanne’s desire is “if God can give me good job, I get money to start a business.”

Roxanne returns an unspecified time later and continues her story. In response to a question about the status of her health Roxanne responds simply “I am still there.” She is having some problems with her legs. “They are paining so much, and I am not able to wear shoes, and even when I am walking I have problems.” The doctor is trying her on a new medication. Roxanne’s health has changed as she describes, “I used to get sick at all times” and now “I don’t get sick so much.”

At this point, Roxanne has been sick for four years. She believes that to continue living, “one thing is to avoid many thoughts and then take control of your body by not moving with men.” Additionally, eating well is cited as an important factor. Roxanne articulately tells the problems she faces trying to do these three things. In her words, “the problem when one is sick and is in the midst of the family members, they try to stigmatize you. They say that you have no value to them and you need to be burned and stay away from them. Now you see someone like me, I have no family.....when one has a problem like me, she/he gets a lot of problems.” In contrast, Roxanne’s husband “escaped” and “when he was going, he didn’t know that he had the disease and he is the one who brought the disease.”

Roxanne’s husband has, however, returned to her. Roxanne explains, “what made my husband to come back to me is that when he went to his place {his parents} and they came to know that he was positive, they said that he was not needed and therefore they wanted him to be burned when still alive since the disease is as a result of a curse.” The husband, when he returned “was in fear because the way he left me was different from the way I am now. And he found when I have changed and he wondered how I was and I told him that the way I told you is the same way I am.” The husband thought, “The way I

used to get so sick, he thought that he would find when I am in a very bad state and it was not that way.” Roxanne’s health was much better than the husband anticipated.

Since the husband’s return, Roxanne and her husband “we do not agree to anything.” They “came together in January, and we are not together so much since I still ask him why he ran away. And he knew that problem and I was left alone with the children for two years.” The husband tells her “to cool down.” But Roxanne remains bitter “you see that I still have pain in my heart since he is the one who brought in this problem. And when I asked him, he was so harsh and he escaped. So why should I listen to what he says and he wants to pressurize us.” Roxanne also has memories of the beatings she received. “He is the kind of a person who is with girls at all times and when you ask him he starts to beat you.” Asked if she fears something bad may happen to her when Roxanne is in her own house Roxanne replies, “You see because of the children, I try to think that in case of something happening to me and the children are small who will take care of them. That is the fear that I have.”

The period her husband was absent was difficult for Roxanne. She maintains that “getting strength when you are alone is hard especially when you are alone because when my husband escaped and I had no parents to rely on then I lost hope in life. I had no friend and I didn’t know where to go but the person who helped me is the doctor.” The doctor “gave me advice and encouraged me, and I got strength and I stopped fearing.”

Roxanne’s life has changed. “The kind of friendship” she knew with members of her community “has changed.” Her health is better. Roxanne has friends who give her support. Roxanne says, “I normally tell God that He is the one who knows and He is the

provider, and therefore I don't lack food even if I don't go for work." However, she says; "God always gives me work." She now has her own business selling vegetables. Roxanne highlights the significance of having her own business. "You see when one is doing the business it will be easy to educate the children and pay house rent and she has no problem. And she cannot think of having men around her. Her mind is in the business and stops thinking about men totally and the business becomes the husband." Her husband has returned but his place in the family, like Roxanne herself, is changed.

LLB 02022011

In the Shadow of Death

Forty-one year-old Esther learned of her own HIV positive status when she took her young child to the hospital for pneumonia. The child "got admitted in Kalali hospital and then they tested him and found to be positive." Esther was then also tested and found to be positive. She felt bad "because I was wondering when did I turn positive and I was attending the maternity clinic when I was pregnant and they never told me." The child was started on medication. Three years later, based on blood tests and the advice of her doctor, Esther started taking medicine

Esther's husband of 20 years was "from Sudan, and when I got the last baby he probably knew he was positive and decided to walk away." He never told Esther his status nor knew her status. "Even when he left I did not know," Esther states. Yet, she believes she acquired the infection from him "because I now remember him taking medication like this ones, and I was not aware by then that they are for HIV."

Esther finds the strength to keep going as a HIV positive woman “is mainly the church as I believe the word of God.” The church has helped Esther to realize “that we are all going to die whether we are infected with HIV or not.” This attitude seems to underpin Esther’s approach to dealing with her HIV positive situation. She maintains that at the time of diagnosis, “I started panicking and being shocked, but now I come to reality and just living like a normal person.”

Life has changed. But, from Esther’s perspective, the change is a result of her husband’s departure. “Life has been hard since my husband went in 2006 and when he was there I never used to work. I was staying at home and he was providing everything but when he went I started to work which was so hard for me.” She declares, “I just feel like all men are bad people. Like the way my husband just left without even telling me what is going on that was not fair.” Left alone to raise four children, her HIV positive diagnosis has made “life more difficult because like in my case now my husband left me alone with the children and I do not have a job so that is a heavier burden on me.”

Esther’s income varies. When she gets called for a casual job she does it and gets paid trying to earn enough for their basic needs. She confesses that sometimes “we sleep without food.” When Esther has not eaten she takes her medicine, “but I feel like I want to vomit.” The need for money for food and medicine and the need to work to obtain money create conflict.

Twice a month Esther must go to the clinic to get medicine for herself and her child. Many potential employers tell her “they cannot give me offs every month.” She summarizes the conflict she feels; “like the time of taking the medicine from the hospital

is hard because may be I have someone who has called me to go and wash for her. So I get confused on what to do since these are two issues coming at the same time and they are all important.”

Esther claims, “Nothing has changed since I have not told any person.” She has not told friends, siblings, parents or even her children. The hardest part of telling others of her status is “how to start to explain to them, and how they are going to feel about it because when you tell one, everybody will know.” People in Esther’s world “know the disease {HIV} as a killer disease.” She tells the story of her female cousin. The cousin developed the disease, and upon returning home was “built a house that was outside the homestead.” There she lived alone. Esther explains, “The community regarded this as bad omen to the community and if not taken seriously, the community would be affected. They believed that people would start dying slowly even starting from that day.” Esther has not been stigmatized “because they don’t know.”

Esther suggests HIV positive women should “accept it and continue with life because this is just a disease like any other disease. Because since the time I came to know I have seen people die of accident but us we are alive.” Esther states she would advise other HIV positive women to “be courageous because death is certain for all of us whether we tested positive or not. Each of us will die one kind of death or another.” She would also ask women to “be encourage them that HIV is not an immediate killer as people think you can still live longer with HIV.”

Thoughts of an immediate death punctuate the façade of normalcy. Esther fears to tell her mother and daughter because they “may think that I am dying.” Medicine may

keep some people who are HIV positive alive for 20 to 30 years but death is a reality for others. She worries about the availability of medicine “since we are to use it for the rest of our lives-what if one day we woke up and this medication are no longer available what are we going to do?” She has concerns about the misuse of medicines because it “can be dangerous to our health if we do not follow the doctor instructions.”

Esther “also worry about my children. How are they going to make it without me being around to help them and they are still young?” Esther has begun preparing her children for her death. She relays, “I teach them how to live even without me,” and “I tell them such like things but they don’t know the reasons as to why I tell them such things.” She acknowledges she is instructing her children. “Yes, so as to get used to it that one day I may not be there. And how they should survive in case I die.” The specter of death is real. As Esther divulges, “Living with fear and worry all the time, it’s like I am just waiting for my day.” For Esther, “everyone will die the day God has planned,” but that day might just come sooner rather than later for someone who is HIV positive.

LLB 0822011

The Internship

Twenty-eight-year-old Eve feels the weight of caring for her large family. In addition to their own two children, Eve and her husband are caring for her younger brother and sister and a cousin. Both Eve and her husband are HIV positive. Eve’s husband “is working as a clerk at the treasury office.” But Eve reports, her husband is so sick he is bedridden. Eve states, “Currently I am not working. After college I got married and I started feeling sick.”

The HIV diagnosis made during her second pregnancy came as a surprise to Eve because “on the last pregnancy I was negative, and I have not gone out of my wedlock since then.” Initially her husband suggested she may have been infected at the hospital during the birth of her first child. Eve wanted to question the hospital and spoke of potentially suing them for carelessness. She relays that “when my husband saw that I was serious about it, he felt sad and started to explain to me that he had other relationship before, and that is how he got infected.” Eve’s husband knew he was HIV positive but “he was afraid to share” that news with his wife. The husband, Eve explains, “Wanted one of us to die.” And therefore he would never have to confess. Eve forgave him and acknowledged they continue to live together. Resigned to the situation, Eve summarizes her thoughts; “there is nothing we can do at this point, it happened, we just have to look forward.”

Lack of sufficient money is a problem for the family. Eve confesses, “There is a lot of strain because the cost of living is high, and we have a big family. But we try to live the best we can with the little we earn.” Eve discusses the difficulties women face in her community where women “are regarded as nobody in the family, as in they have to do every work that is available in the house. A woman is suppose to be there just to be seen but not to be heard even if she is very bright with good ideas. It does not matter to the men and this is happening even today. It does not matter whether you are a person who can perform.” Men are the breadwinners, however Eve notes, “They provide when they want but when they are not in their moods, they withdraw and stay away and in that case the woman suffers.” The men sometimes do not even leave money for food for their families. Eve’s thoughts about the financial dependency of women have evolved for she

states, “Now I think it is important for both the woman and the man to be working so as to provide because a man will not provide everything for you. A woman must work in the house and this will improve the lifestyle of living. A man cannot satisfy all your needs so a woman needs to work.” Eve relays, “I decided to go and find a job so I can be able to help myself.” To that end, Eve is “doing an internship in a manufacturing industry. I got my college certificate and now I am working to get a practicing license.” Eve’s husband “has been supporting me all through and providing for the family. He is good because he buys food and takes the children to school.”

Eve divulges, “I can say that it {HIV} has really changed my life so much. It has worsened it because the way I had planned my life is not the way it came.” The hardest part of being HIV positive to Eve is “the concern that I may not be able to find a job.” Her concern is substantiated by stories she has heard of people discriminated against because they are HIV positive. She articulates several examples; “there are jobs which you expect to apply and get before you tested, but now you cannot apply and get those jobs...there are more limited chances for HIV positive people,” and “in other cases people just get fired from the job knows that you are HIV positive.” Eve further worries that if she secures a job “I start falling sick I will automatically lose the job.”

Eve controls her worries. “To me HIV is not a killer disease. We just live with it and it depends on how you take it and life will continue. You just make it your friend and life will continue.” She takes her medicine faithfully. “You see one thing I know is that I am taking care of my life so I take them with a lot of keenness. I prefer taking them because without them there is no life.” She also knows “there is also people with worse diseases as I tend to think like cancer and diabetes.”

Although she has many concerns about the uncertain future, Eve remains optimistic stating she tries to “take everything in a positive way and have hope for the best things to happen.” She expresses her hope; “to me I hope things would be much better for me and my family if I finish my internship and get a job.” As she studies for the certification exam her goal is within sight. And after that, who knows what may lie ahead. Buoyed by stable health and a job, perhaps one day Eve may even “own a chemist shop.”

LLB 01312014

Take Our Lives as Normal

Miriam’s husband had been very sick for a year and was not getting better despite treatment. He decided to be tested for HIV. When his test proved positive he encouraged Miriam to be tested. Despite her seemingly good health, she consented to testing and learned she was HIV positive. Miriam and her husband accepted their diagnoses. Miriam says “we never blamed each other and even me I never said anything like where did it come from, no and we are staying together in harmony.” Their relationship has changed. Miriam finds her husband treats her better than during the days when he was drinking and seeing other women.

It has been three years since her diagnosis and Miriam still asserts “so far I do not count myself as sick. I am strong and energetic...I even encourage my husband that we should not count ourselves as sick because there are other people who are more sick than us.” She declares “one should have courage and take this sickness normal and better than cancer and diabetes.”

Miriam is 45 years old and has three grown children. Both Miriam and her husband work. Her husband is a businessman and finds his income fluctuates. She raises chickens and sells the eggs. Their combined income allows them to pay school tuition for their son and granddaughter, support their two unemployed daughters and pay their own living expenses. Miriam laments that her college educated daughters are unable to find employment. Miriam and her husband are able to avoid private medical care although they also receive medical care at a clinic that specializes in HIV/AIDS care.

Miriam regularly takes multivitamins and Septrin®. But, unlike her husband, she has not yet been started on ARVS. She never uses traditional medicines explaining “I wonder how they can come up with the cure while professional doctors could not come with the cure.” Her husband insists they use condoms. When asked about any home remedies Miriam replies “I just eat well, vegetable, fruit, milk and eggs.” Miriam does not attend support groups for people with an HIV/AIDS diagnosis. However, Miriam has a group of friends she meets with, and they “eat together and laugh and no one can know whether we are sick. We share many things and stories.” Her self-care efforts have so far maintained her good health.

Miriam notes “one should not think too much about this sickness because when you think so much, you get stigma which is not good at all. One should stay normal like other people.” People in the community “really stigmatize you even your own people.” Thus Miriam has only confided her diagnosis to her children and husband excluding even her own parents. She explains that “when people know that you are positive they will not step at your place. They will even keep off from you.”

Miriam points to the availability of medication and health care as two reasons for her assertion that the disease progresses when people neglect themselves and lose hope with life post diagnosis. Miriam declares “I would dare say that HIV positive people who let the stigma and the disease to knock them down is that they allow that to happen to themselves.” She says “I say the problem that you get is you who want it since you have brought it in your mind. The thing is to have in mind that is positive and think what you can get.” Miriam holds that “some problems are brought about by us relaxing and not wanting to work.” Miriam tends to think women should start their own businesses. She speaks in depth about her own positive experience starting and operating a business. She advocates for women to receive assistance in establishing their own business so they can achieve financial stability and independence. Miriam concludes that the important point when faced with challenges including challenges associated with this disease is to “be active and when you do like that you will prosper and live.”

Miriam maintains “one needs to have courage so as to live long. Once cannot die before her/his days on earth are over and therefore one should have courage in life. A person was born one day and will die one day because death is a must to all.” Hard work is required “to get everything” which, from Miriam’s perspective, includes working hard to take care of yourself to prevent the progression of the disease. Miriam’s advice to others about how to stay well includes “stay happy and go to laugh with people and if not so put on music and listen to it. If it praise and worship then worship in your house. When you have finished your work put on a song and listen. Eat and sometimes even relax and sleep and don’t put your thoughts about this sickness.” Miriam holds strongly

to her belief that she and her husband “just need to take our lives as normal” declaring “I know I will die the day God has planned and not because I have this virus.”

LLB 01192015

The Burden of Secrecy

Forty-year-old Roselyn limits what she discloses about her experience as an HIV positive woman. Roselyn’s fear in disclosing her HIV positive status is obvious in her numerous references to maintaining the secrecy of her status. Her fear in discussing her status could be related to the fact Roselyn and her husband have a business “selling cloth” which helps to “pay for rent and cover our living expenses.” Additionally, and perhaps more likely her reticence is related to the stigma associated with HIV/AIDS. Roselyn expresses her stance. “I do not like to share with other people...I do not want to share with people because they always have a negative attitude toward HIV positive people. Like when I was sick they started talking negatively of me. So it is better not to share with people.”

Roselyn acknowledges, “The most difficult thing is to share with other people the fact that you are positive. People have a very negative attitude about HIV so it is hard to share with them.” People “see HIV as a killer disease and hence they do not want to associate themselves with HIV positive people.” Roselyn knows, “If you share with a few people they do not keep it to themselves. Before you know they told other people and everybody will know about it.” Roselyn is not willing to risk experiencing the perceived or actual adverse consequences of disclosing her HIV status.

No one knows Roselyn’s HIV status except her husband and sister. Roselyn’s relationship with her husband improved when she found out she was HIV positive. Her

husband also tested HIV positive and as a result their relationship “even became better than before. He sympathized with me and he was so sorry about it.” Roselyn’s sister had accompanied her for testing. Roselyn and her sister are “great friends and very close to each other.” The sister, on hearing the news of Roselyn’s HIV positive status, was “positive and understanding.”

The burden of secrecy does, however, affect relationships Roselyn has with others including her three children. She has not taken her children to be tested. The children have learned about HIV/AIDS in school and told Roselyn “there is no cure for it.” This statement causes Roselyn to “wonder how I could break the news and tell them to go for the test. It is very hard for me.” Of telling her family Roselyn says, “I have not told my family yet... simply because of knowing their attitudes and perspectives in life. As members of the family, I know what they think of positive people so I just saw it is not fit to share with them at this point.” Her reluctance extends to speaking with other women who may be HIV positive. She maintains that “I can talk to them to go for the test but I don’t tell them that I am positive... I have not yet had a breakthrough to tell out my status.”

The burden of keeping her HIV status a secret impacts Roselyn’s treatment for her illness. Roselyn became quite sick and was sent for HIV testing. She was not given the results immediately so as she says, “I went and tested but when I took back home and I ignored the whole idea.” Her long delay in returning to the clinic to learn the results of the test necessitated a retesting. The positive test was followed swiftly with the initiation of treatment. Roselyn has not joined a support group to help her handle life as an HIV positive woman. She explains, “They told me about it but I still have that fear... I just

hold that fear of how people talk bad about me being positive.” She even expresses an initial fear of visiting the clinic “because I just did not want people to see me coming for they will know that I tested positive.”

Roselyn found the HIV positive diagnosis “hard initially because people have a negative attitude, and they did not want to accept people who are infected as ordinary people-like people who are suffering from other diseases”. Her reluctance to disclose her status deprives her of the support that would help her manage the challenges that come with living with a chronic disease. One day Roselyn claims she will open up and be more forthright in telling people about her HIV positive status. She holds however, “I will first consult my husband to know whether to tell anyone or keep it. My husband fears to be known his status. We are waiting for that time when we will be free.” With a business that depends on support of the public, that day of freedom may not come for a long time.

LLB 03152014

Coming to Terms with Reality

Sarah is newly diagnosed as HIV positive. She is divorced from her husband and father of her children because he was having affairs. She heard that one of the women he was having an affair with was HIV positive. At the time of his death, Sarah heard the cause of death was meningitis. Sarah has not had sexual relations with anyone until very recently so believes she acquired the HIV infection from her husband. Sarah had been tested during her pregnancy with her second child but tested negative. Later the child became quite sick and was found to be HIV positive. Sarah was also offered testing and learned she had the infection. Sarah advises people who find themselves in a similar situation

“Pray for God to give us strength to accept the reality because it does not help anymore to point fingers that this person is infected or not.”

Sarah cohabits with her boyfriend. Her youngest child lives with her, while the older child lives with Sarah’s mother. Sarah works as a housekeeper in a guest house but her income is very limited. Her living arrangement is beneficial because the boyfriend pays the rent and food allowing her to use her income for transportation costs to work and assist with supporting her extended family. The availability of sufficient funds to eat good food and cover her other expenses is an ongoing challenge. Although Sarah has not told her boyfriend of her diagnosis, the boyfriend actually initiated use of condoms and “is fine with it.”

Sarah has not revealed her diagnosis to many people. Nevertheless she states “I know other friends who are infected and they encourage me. They do not know that I am infected but the way they talk to me it encourages me.” At the clinic where Sarah receives care she reports the staff is very encouraging. One doctor in particular has been helpful. Sarah relays she “found a male doctor who encouraged me” by disclosing his own HIV diagnosis. He told Sarah she should be attending seminars to gain knowledge, listen to other people and ask questions. Sarah’s work schedule makes it difficult for her to attend support groups yet she asserts “what encourage me is the fact that I am not the only one infected.” The encouragement of others has and the knowledge she has gain has positioned Sarah to “encourage myself” when stressful thoughts surface in her thinking.

Both mother and child are being treated. Initially Sarah was on multivitamins and Septrin® but later she started on ARVS. Sarah was shocked at the idea of taking

medications for the rest of her life. Sarah found support from other women. “I get encouraged through what my fellow women tell me. They talk to me and at last they reveal that they are sick the same way. They tell me how they started taking the ARVS and how hard it was but they got used to them. This gives me the courage to continue taking the medications.” She does not use traditional or herbal medicines and restricts home remedies to the use of garlic and pepper.

Sarah’s acceptance of her situation slowly evolved. She reports that initially she was very shocked by her diagnosis. Sarah confides “I started thinking of how my husband was not faithful in our marriage...I was bitter about him but it happened and there is nothing else I can do at this point but to follow up using medication to lengthen my life to be able to support my children to grow up.” She claims “I came to term with reality.” Reinforced by what she has learned about HIV/AIDS and encouraged by others who are HIV positive she clings to this new reality that requires her to consciously attend to her health needs. Sarah concludes with “we just pray that God will continue to give us strength and courage to live and accept the reality.”

LLB 01242015

The Power Struggles of Marriage

Baraka is a married, 35 year-old mother of four children. She learned she was HIV positive when she took her then four-year-old child to the hospital. Her child started coughing, was not eating and was not walking. The child was tested and found to be HIV positive. The child was also found to have tuberculosis after a relapse in her health a month later. The hospital asked Baraka and her husband to be tested. Her husband

refused telling Baraka “that illness is for me and my child...he does not have that illness.”

Baraka believes “it is better for me to take the medications.” She voices her frustration with her husband’s refusal to be tested. “So it’s like if I am taking the medication and he is not using, at night we are together, you see the medication will not work.” The doctor went to their home and spoke to her husband who then agreed to be tested the next day. Baraka is “ready to start the medications,” but will wait for her husband to be tested first.

HIV is a disease Baraka did not think she would get because “since I was married to this man I have never gone outside my marriage.” “That is why,” she says “I want him to be tested so that I can know how it came about.” The husband claims “he does not move around outside.” But Baraka knows “even wealthy people move around outside.” She cannot confirm he is unfaithful; “you know you cannot even know, even he goes outside the marriage. Me I just see that he goes to work in the morning, he returns at night.” Still, she knows men “can say they are going to work but he does not go to work.”

Baraka knows she was not HIV positive during her last pregnancy. Yet her child is HIV positive “just when the child was walking that’s when we went she was tested and was found to be positive, so even now I am surprised.” Baraka asserts, “I don’t even know where she got it from.” The explanation is offered to Baraka that there is a window for testing when one may miss knowing but she does not grasp the significance stating, “I was tested for everything, they found nothing.” Baraka’s fervent hope is her husband

will cooperate. “To help her {the child} to be healed, even me to help me, I pray to God even my husband if he has it, he start taking the medications and not refuse them.”

“I just want to take the medication,” Baraka repeats several times. Take the medicine “so that I can start feeling better,” and “so that my life can continue well for a while,” she states. She knows that “even this medication, it helps reduce the virus a little but it is not a cure for ever, it is a must you die.” Baraka wants to take the medication, and “I just stay with that my husband.” “That is why,” Baraka concludes “I find he is disturbing me before I start that medication.” Her husband is supposed to go for testing, but Baraka will not let him go by himself. “I cannot let him go by himself because even me I want to hear, what he will say to there. If he does not want to use medications, he should take condoms to use.” If her husband at least was tested and willing to use condoms she would be able to take medications knowing they would be more effective.

Efforts to push her husband must be handled carefully. Baraka maintains, “I try to be very humble when I am talking to my husband because if I talk with him strongly, he gets annoyed and starts to fight me.” She denies he has been physically abusive claiming, “He only hits with his mouth.” Later in the discussion Baraka confesses she and her husband used “to fight at all times.” When she would refuse sex because he would not be tested or use condoms he would beat her. Her husband threatened to rape her “he used to threaten but I used to run away.”

Baraka’s husband agreed to be tested, but “changed his mind” telling her “he can’t leave his job and not go to work just for a test.” That night he wanted to have

unprotected sex with her. She refused and in response “he now wanted to beat me. I ran outside and slept at my neighbor.”

After a second argumentative night she fled to her sister’s house for a week. Her sister intervened and “talked with him slowly and wanted to know the cause of the fight.” The husband explained Baraka did not want to have sex with him and that Baraka “wanted him be examined by force which is bad.” Her sister encouraged him to go for testing or permit Baraka to have CD4 testing and start on medications. But the husband “said that he did not want medicine in his house and instead I should go home and stay there.” Baraka replied “it was better for me to go home and start taking the medicine. Let him stay and he can marry another wife if he wanted.”

Baraka continues her story reporting, “My problem was to get my husband to the right line and I have struggled until I won him.” Her success is a testament to her perseverance, courage and skill. She explains how she convinced him to go for testing. “He used to want to have sex with me without the condom but I used to refuse and after I refuse, he could go to his girlfriends. Until it reached one day when he called me and talked to me telling me that he would want to have a test and start attending the clinic.” The husband again made excuses to avoid being tested, again demanded unprotected sex. Baraka “refuse then he decided to kick me this side and I run away to his younger father.” The father talked to him but the husband still refused. His sister Monica then “talked to him slowly and he accepted to go for the test, just the other day and today he has taken the second test.”

The aspect of being HIV positive that was most problematic for Baraka was her husband's refusal to cooperate with diagnosis and treatment. Once he was convinced to be tested and get treatment, "I started showing him love than ever before." Baraka tells her husband, "I tell him that we are already old to start new life with youngsters and we ought to love each other so much since we are also sick. I tell him to unite together to have a wonderful life together." Baraka reveals, "I normally cheat him like that so as to follow the doctor's rules." Baraka has done well to help her husband, her child and herself with a disease that threatens the whole family.

LLB 09172011

Stand for Your Rights

Moriah weaves several related threads through her HIV story. Her HIV story shares commonalities with other women. She doesn't know how she became HIV positive, but "I can think to be one of the two possible instances." During the birth of her last child she lost a lot of blood and was given a blood transfusion. She continues, "The second one is my husband. My husband was not very faithful in our marriage." Moriah's husband died of HIV, and "after the burial I started feeling sick of pneumonia. So I went to hospital and got tested, and that is when they confirmed I am HIV positive." Her CD4 count was low and thus she began ARVS immediately after diagnosis.

Moriah and her husband "really never discussed the issue, but he was always very sympathetic of us and the predicament he put his family in." She describes her husband as "so concerned about us and very supportive." His expressions of concern were accompanied by actions as he "made a lot of changes on family properties to make sure

they were transferred in my name.” Moriah concludes, “We did not have any issues with him. He really felt attached to all of us.” Despite the relatively respectful manner of Moriah’s husband, Moriah picks up the thread of women’s rights and security in marriage at the end of her telling her HIV story. The whole issue of husbands “re-infection” of wives because of the men’s refusal to use condoms is an issue for Moriah “about women rights, HIV positive women rights in marriage.” Moriah explains, “A man may test positive and he do not tell the wife. He do not even use protective measures, so they do not even think of saving the wife. So the women rights are violated and women in a marriage are suppressed.”

For Moriah, the violation of marital rights was mediated in part by her husband’s measures to ensure transfer of property to his wife at his death. Additionally, by the standards common in her community, Moriah is well educated with a comfortable income. Her work as an occupational therapist provided an independent source of income for her to support herself and her four teenage children upon her husband’s death.

Although Moriah had only told her family, when she started to have skin symptoms and a weight loss people at work suspected her diagnosis. Coworkers would wash their hands after shaking hands with her. She would bring food to share with coworkers, and “they would take the food just symbolically but they do not eat.” Moriah reached a point “where I just wanted to be an introvert...I just wanted to stay in my house.” Moriah “did not want visitors or any company.” Her fear was that “who ever come to visit me is coming to spy.” Moriah slipped into “a low or silent depression.” After 19 years of experience, “working in the same department with the same people,” her employer retired her “on medical reason.”

The exact medical reason Moriah was “retired on medical grounds” was not clear. HIV robbed Moriah of her husband but also her sight. As she explains, “I think I had some visual problem. It is something in our family trait but when I got infected with HIV it made it worse and I lost my sight.” She sought treatment at an Institute for the Blind, “where I was treated but could not restore my sight.”

Moriah takes up another thread to describe in depth her fight to retain her ability to support herself and her family. Moriah’s articulate argument on appeal was that “the fact that I lost my sight does not mean I cannot continue to do my job. I still have my skills and my mental capability has not been impaired.” The institution was unmoved by her argument. Moriah continues, “one day I just waked up and decided to go the minister of health office and present my appeal case.” The minister of health reviewed her retirement letter and all the appeal letters and listened to Moriah “explain to him my case.” The minister said “he do not see why they do not assign me other related jobs like doing massage.” The minister “talked to the management of the institution,” and Moriah was “redeployed back to work.” Moriah summarizes her fight to return to work. “I had to stand for my children, because if I give up who are they going to lean on? They will start feeling the gap of their father and fall into a trauma thinking about him.” In her new capacity she provides counseling services and massage for children with autism. She is going to learn a new computer software program to enable her to document her own notes.

Moriah faced many hard situations since she tested HIV positive. She lists the challenges; “one major hardest thing is to be laid down from my job for medical grounds, the other one is losing my sight and losing my husband.” Her faith as a Christian “really

grew when I was retired from job.” After much soul searching, “I came to realize I need divine intervention.” Moriah prayed to God; “I know you promised you are not going to leave widows in need and somehow the Lord just provided by touching somebody or by opening a window of opportunity.” Armed with this faith Moriah just knew “I have to stand for my rights without giving up.” Moriah’s message to other women, molded by her own difficult experience; “being HIV positive is no the end of everything, God still loves you, you still have your human dignity, you still have your life, and you still have your rights as a citizen.”

Note: the demographic chart puts Moriah’s age at 51 but in the interview she states her age is 48.

LLB 01272011

The Transformation

The lines of demarcation in the life of 30 year old Josephine are clear. The immediate period prior to her HIV positive diagnosis was marked by great happiness that was overshadowed by the mysterious death of her fiancé. Josephine was “living in a luxurious place.” She was educated to the college level. She had an eight-month-old daughter. The fiancé, Rick, was a “well-to-do person.” Josephine heard stories about her fiancé’s family and was told “the mother belonged to a group of devil worshippers.” Rick did not want Josephine involved in the cult suggesting Josephine and the baby would be a “sacrifice.” Rick was being recruited to join the cult. He was clearly fearful that “the mother can do anything to him,” and spoke about what Josephine should do if “anything happens to

him.” One evening Rick went out. Two-and-a-half weeks later, his body was found in the river.

Rick had experienced coughing and other symptoms of illness prior to his disappearance. Josephine started to experience rushes, blisters and night sweats similar to Rick. She recalled a conversation with Rick about his involvement with a woman who later died of HIV/AIDS. Josephine “gathered courage and planned for a test” so she could know her status. When she received the news of a positive HIV status, Josephine did not “feel anything at all.”

Josephine entered a two-year period of depression and despair. In her words, “I knew I was going to die and join Rick. I did not want to live at all.” She was given the ARVS medication but took it erratically at one point skipping a whole month. But Josephine was not dying and relayed, “I thought I was to die very fast. Instead I grew very healthy and strong.” She bought poison to commit suicide. As she was mixing the poison, she was interrupted by her then six-year-old daughter. The daughter was “suspicious” and almost miraculously Josephine reports the daughter “prayed for me and immediately the solution poured to the floor...I decided not to take the poison in any other day.”

Josephine’s sister took her to the hospital. A social worker noticed Josephine “was not okay” and took her for counseling. This was the start of Josephine’s transformation. With the help of counseling and a support group Josephine “started looking at life at another angle” and saw herself “more beautiful than ever before.” Josephine identifies herself as a peer educator at the clinic where she receives care.

The transformation is so dramatic people often do not believe Josephine when she tells them she is HIV positive. The passion for her work as a peer counselor is evident. She speaks extensively about her plans to develop support groups in every church detailing her activities to make that a reality. The HIV education Josephine proposes to take place in churches is not just targeted at people who know they are HIV positive but is for everyone with the goal of empowering people to be tested, provide support to persons who are positive and reduce the spread of the infection.

Josephine speaks realistically of the challenges of working with HIV positive people. She expounds extensively on the difficulties of getting people to disclose their status to their sexual partners. She admits, “The worst of it, which I don’t know what we are going to do with is disclosure.” Josephine details some of the cases of non-disclosure she has encountered in her work as a peer educator. Her skill, her compassion, her knowledge are clearly noticeable in her description of her work.

Stigma is another topic that Josephine discusses in depth from both her personal experience and her experience working with others who are HIV positive. Josephine relays that stigma in the church is “very high, and that is why I decided to empower people by teaching them and organizing for groups.” Josephine also knows the financial struggles for many people with HIV. Candidly she relays her own situation of lacking money to pay for her daughter’s school. She received an offer of sex for money – a common exploitation faced by poor women who are HIV positive. Josephine did not succumb to this method of obtaining money declaring “I was not ready to sell my body due to money.”

The enthusiasm Josephine shows for her work as a peer educator is infectious. Her work, not her disease, defines her. She maintains that doing peer education “is very nice, and it is the one that is putting me in position to know that I have a lot to do because I meet with many people and when I tell them what I went through, when I get some who are in denial, I talk to them and the moment they accept, I feel good and I just want to be here.” The transformation from a woman on the verge of suicide to a person actively engaged in life is reaping benefits for Josephine and for those people whose life she touches.

LLB 06222013

So Many Problems

Thirty-five-year-old Mercy faces many problems. Her problems started well before her HIV positive diagnosis seven years ago. Her marriage to an unfaithful husband was permeated by domestic abuse. She explains their relationship. “That time when we were together, we had many problems. He used to go out and accuse me of going out, but I used to tell him that I cannot go out...when he comes home he used to give me slaps accusing me of going out.” His jealousy drove him to continually question where she went and who she was with and led to accusations that their youngest child was not his. Even as Mercy cared for him in the final period preceding his death from AIDS, he was very difficult. Mercy reports it “seemed as if his mind was not okay.” Mercy offers, “Yes I really suffered. Even this time he was sick he used to ask me tough questions.” If Mercy’s husband had had the strength Mercy states “if he could get a stick, then he could

have beaten me.” To defend herself, Mercy “used to stand very far that he could not beat me.”

Undoubtedly, Mercy was infected with HIV from her unfaithful husband. Sickness that was not responsive to treatment is responsible for her proactive request to be tested. Mercy accepted the results of the test “with courage” and accepted her status. She did not have any physical problems and started taking medicine. Her emotional adjustment to the diagnosis was more difficult. Mercy reveals “I took a lot of time, and I was so stressed almost to fall on the way, and I thought that if I was to continue that way then I would die very fast and I stopped. I said that sickness gets a person and God so that he will be with me since the devil brought it to me.” Mercy concluded, “So I thought about it and I said to myself, let me stay with the disease as if it was mine. I said I will stay until God wants to take me home.”

Mercy’s husband’s death ended one problem but brought a new problem. Mercy relays one significant challenge she faced. “People at home were saying that my husband died of AIDS and so I was also sick.” Mercy states, “These people wanted to take my land ... they were saying why should I have the land and soon I am going to die.” Like vultures waiting for an animal to die, Mercy describes the situation. “Those people were just counting the days for me. They used to come and check whether I had died.” Mercy took them to court to maintain ownership of the land because, as she told her neighbors, “even if I am going to die I have children who can do farming.”

Mercy’s health is relatively stable and she routinely takes medication and is seen at the clinic. Mercy’s health is “not bad only the eyes that have problems...they itch and

pain this other area itch on the upper side so much.” In the past she had boils all over and some rushes but now reports she is okay. Yet, she cannot escape her diagnosis and the impact it has on her life. Her neighbors “take me bad with a lot of mockery.” The stigmatization isolates her so, as she states, “I stay like I am, alone.” Her chronic disease has also robbed her of strength. “But now I have no strength to do all that {work in *shamba*} and I cannot even work casually when I need money so it is a real problem.”

Overwhelmed with other problems, today Mercy does not dwell on her HIV positive status. Poor, minimally educated with sole responsibility for three children once her husband died life has been a struggle. Food insecurity is ever present. When the rains do not come so Mercy can grow food, money to buy food is scarce. Family members have not been especially supportive, “even getting tea from the family members was a problem.” Mercy has had other health problems. Both hands were broken after she fell. The mosquito netting tore and she developed malaria.

The children help Mercy as they can. Educating her children is a real problem. Mercy declares, “I have so many problems with school fees...this is due to lack of money.” One child was unable to take the final exams due to lack of money to take the test. Two children finished class eight at the same time but there was only enough money to send one of them for further education. Mercy still struggles for money to help the second child finish school. The children created other problems for Mercy as well. “Like food is a problem and so many other problems about the children since no one else who can help them except me.”

Despite the problems, Mercy's life has changed since her diagnosis. She reveals, "I stopped pitying myself as I used to do." Mercy divulges that she used to cry when neighbors talked about her, "but it came a time when I was so depressed," she decided to not let others bother her. She believes that when the other people see how her children cooperate with her, the others feel ashamed.

Mercy's children are one source of support and help. So too is her belief in God. When she has too many problems, her approach is to "get into prayer and pray God and tell him to give me all the ways that are right for me." An HIV positive infection is just one more problem in Mercy's life, yet not a problem that will defeat her. She sums up her philosophy; "there are many problems and I don't think problems can ever come to an end but I take them out of mind and get into prayer and God takes away some things."

LLB 06222013

Waiting for the Call

Lilly is calm and brief in her discussion of the implications an HIV positive diagnosis has had on her life. She states, "My life is not the same like when I was well," and cites "now am taking the drugs I never used to take," as the major change since diagnosis. Lilly fully acknowledges, "If the drugs were not there I don't know where I would be. Maybe I would be dead." Yet when asked the hardest thing that has happened since she found out she is HIV positive Lilly succinctly states "nothing".

Thirty-four-year-old Lilly conducts her life making matter-of-fact adjustments because of her HIV positive diagnosis. Disclosure of her condition to her family was taken from her hands. Lilly's uncle had assisted her in obtaining employment. When the

employer “found out that I was positive she told my uncle. And my uncle told my dad.” Lilly maintains, “I didn’t blame my uncle because he was worried, he thought I would die. The one I blame is my boss.” Similarly, her father, “His reactions were not bad. Not that he reacted badly, what has affected him is only worries. He is worrying about my status.” Lilly tells others of her medical condition as she deems appropriate.

Lilly is the mother of two small children. Lilly did not want a second child but her ex-boyfriend wanted a child. Despite the fact both were HIV positive, Lilly conceived and delivered her second child. She disclosed to the hospital her status. “I never hid it, and I said it clearly in the hospital I delivered in. I told them I am positive and when I got the baby, he was taken to nursery and he was given drugs.” The baby is HIV negative. Lilly does not want any more children and does insist on condom use. Of men she says, “If I get somebody who is ready we agree, I can get married if he is the right person.”

The part of her life that has changed, in Lilly’s view “it’s just that I accepted myself. My status. I felt like there is nothing to be feared.” Lilly summarizes the discussion as an HIV positive woman. “I have said are the ones that have been disturbing me. The worries of being positive, lack of income.” She has accepted the commitment to lifelong medication and doctors appointments. “The hard thing is when you are not free and you have the appointment and you can’t stay like two to three days and I feel worried to miss the clinic,” Lilly says but then adds, “But I have to try my best and come. It becomes a commitment.”

Lilly does admit, “I lost my job and since that time, life has been very hard.” The theme of financial security, an income of her own, underscores her story of life as an HIV

positive woman. “Since I lost my job, I don’t get somebody to support me,” explains Lilly. She does washing and other odd jobs but complains, “It’s hard or at times you have worked for somebody and he doesn’t want to pay you. Or he under pays or he simply doesn’t respect you. At time I don’t feel like doing that job.” When she was working Lilly “would have friends and if I tell them I have problem they give me money.”

Lilly conveys with little emotion the betrayal of an employer who encouraged her to be tested for HIV. The employer noticed her 10 kg weight loss and encouraged her to go for testing. The employer offered Lilly to “feel free if am positive she can help me. If you negative I can help you with medication, I be okay.” Lilly took the test results to the employer “because I trusted her. Because she said she will help me and I knew she cannot such me because she is the one who encouraged me to go.” The employer put Lilly on a medical leave. Lilly tells what happened at the end of the medical leave. “I went back after the leave, and she told me I was not well. But I was well, despite my status, I was ready to work, but she said she has no problem with me but when I will be ready to call you back, you just come. That was in 2006.”

In Lilly’s own words the benefit of an income is “you are independent in doing your things than depending on somebody. You become financially stable.” She has been “thinking of getting something to support me at least in income.” Lilly laments, “just to get a job to do even if it business to do. It’s not that I expect anything at the end of the month so I have to do something to eat. I depend on support from people.” How Lilly will achieve financial security is unclear. Lilly claims, “Now days the discrimination is not there like in the past because of the wide education on how to live with HIV positive people and how they will live with the virus. It has improved.” When it comes to work,

however, Lilly bears witness to discrimination against HIV positive people. Lilly has been ready to work but years have gone by without her former employer calling her back to work as she said she would.

LLB 08232011

Focusing on the Reality of Life

Dorothy conveyed the shock she felt when 10 years earlier she received an HIV positive diagnosis. “I was so shocked because I never thought of such a predicament in my life.” She was 19 at the time, married, pregnant with her second child. Her husband worked “with the Telecom Company.” During a prenatal visit she was tested and found positive. “I did not know what to do,” she says “I went to visit my husband at work and tell him about the test result.” Her husband brushed away the news “saying that is a lie, the clinic people always tell a lie. The city council does not have proper equipment so they must be lying.” Dorothy did not return to that clinic but instead “went to private clinic where they just attended me for ordinary maternal clinic until I delivered and they did not even take my blood test.”

Six years later, Dorothy’s husband died. Dorothy “started wondering what happened to him, and I started getting sick myself so I went to hospital and started me with treatment.” By this time she had had two more children. Dorothy asserts that her husband knew he was HIV positive, but “I come to know later that he knew about it but he never told me.” Dorothy is certain she became infected by her husband and described him as “a lavish and a luxurious person, he leaves home on Friday and come back on Monday spending time with women.”

Her status as a woman left Dorothy in a difficult situation. She tells the story. “When my husband passed away, his relatives came and took everything he left for us even the carpet.” She was legally married to him, and he had a will. Despite this, Dorothy relayed, “we did not get anything. His employer at one time wanted us to go and get the benefits but they wanted me to go with my mother-in-law. However, the way I saw my mother-in-law behaving, I decided it is not worthwhile to fight with them so I did not go. I just let them take whatever they were given.” The in-laws justified their actions, as told to Dorothy, “they demand is their son money and they are the ones who helped him in a form of bribery to get the job so they need their money back.”

With her four children, Dorothy turned to her older sister for help. Her sister took the family in until they could pay for their own home and “financed the merchandise” for a small shop Dorothy runs. Dorothy sells vegetable and fruits which “help to pay for food and rent. You know it help me to keep busy and cover me from the shame of borrowing from others.” The big challenge, Dorothy admits “is the whole struggle of making end meet.” Her big need “will be a way to help to expand my business; to be able to stock it with enough inventory so as to earn more profit to sustain the family needs.”

The challenges are indeed big. Dorothy reports the older two children are negative but the younger two “I believe the two children are infected.” The third child, a seven-year-old, “is not feeling well, he is sick and weak,” but he does not take medications. The youngest child, now four years old, “is taking medication.” “It is really hard,” Dorothy says “especially when you have children who are sick and I feel weak myself to be able to help them. I am the only parent left and it is hard to meet the needs of the family by myself.”

Dorothy describes the turning point in her life as an HIV positive woman, “when I was tested I admitted that I was infected, and the doctor gave me counsel so I felt comforted. And when I look around and see other infected people I console myself that I am not alone and I better just admit the reality and get the help I need.” To keep herself healthy Dorothy engages in a number of activities. If she gets sick, “I just go to the hospital and get treatment.” She does experience ongoing health problems. “My main problem is headaches which are continuous which do not stop. Also I have dental pain and chest pain,” for which she has sought medical care. She regularly takes ARV medication setting “the alarm on my phone at 9.00 in the morning and at 9.00 in the night” to remind herself. She tries to “eat healthy food as much as I can afford.” And, Dorothy continues to attend support groups.

The HIV positive diagnosis was “a big blow to my family.” Dorothy told her older sister and mother who said, “nothing really, just encouragement that I continue to use medication and take care of myself.” Dorothy has developed a new relationship with a man. Despite his lack of awareness about her diagnosis he is cooperative in using condoms because Dorothy does not want to have any more children. However, the relationship is not always supportive of Dorothy’s struggles to provide for her family. Dorothy confesses, “When he is sober he is ok. I can talk and chat nicely with him, and I feel like I am with my partner but when he drink he turn wild.”

The reality-Dorothy’s life changed dramatically as HIV positive first her husband, then her and finally two of her children. “In our society women are always seen as dependants of men,” she explains “we are treated as if we cannot stand by ourselves without the support of men.” Her personal experience has demonstrated to her “we can

do without men.” Dorothy acknowledges, “For me personally I see that I came a long way to where I am today, and that give me confidence that I can make any decision about my family. I have enough knowledge and ability to make my own decision.” Today Dorothy declares, “So I just now feel like life as usual, and I do not get shocked when I think about it or when somebody tell me I am positive.” Dorothy knows people will talk about her and her family. People, she says, “will talk about it no doubt on that, but as long as the patient accepted the reality of their status the people talk really does not matter.” Dorothy’s reaction to what people may say summarizes her life today. “Personally I did not care whatever they talked about all I was focusing was the reality of my life.”

LLB 02232011

Not Just a Disease

Thirty-nine-year-old Salome is very articulate. Questions about her life are answered in clear, lengthy, detailed descriptions providing an insight into her unique experience as an HIV positive woman. Nine years ago Salome was considering marriage and starting a family. “What happened” she tells us is “I met a man who wanted to marry me but we agreed that we had to go for a checkup first. So it was during the check up that I turned positive, so the marriage could not go on in that basis so I declined. So from that time everything I had planned for my life changed.”

Salome describes in great detail the manner in which the doctor told her the results of testing. Her potential husband, “funny enough knew the doctor. So the doctor gave him the information before she gave me. The doctor disclosed my status to the man

without my knowledge, and by the time I was getting for the results and even when I was being cancelled, already the man had known that I was positive without my conscience.” Salome relays her thoughts “After that I felt -- I could not move on with that relationship since the man had already gone. So I had to restructure my life and start all over again and I decided to look for where I could get support.”

The diagnosis caused Salome to feel so down “I was contemplating suicide.” Nine months after diagnosis Salome was started on ARVS. She says “this was like God gave me a second chance to live so I am living on. ARVS is like the second chance that God has given to live so I don’t mind because I can move on with my life.” Salome finds the thought of taking medicine the rest of her life “stressing, you can’t imagine that this is something that you are taking the whole of your life time.” Today Salome says the medicine “it is okay for me to take until the time I will be told that cure has been found. That is when I will take the cure and get healed.”

A person living with HIV/AIDS is “really stigmatized” and faces “discrimination at the work place when the boss knows that you are positive.” College educated, Salome has a diploma in “human resource, management and labor management.” At the time of her HIV positive diagnosis, Salome was working “but due to the fact that the work environment was too stressful for me so I had to resign because I had my health to take care of and a job, but the job was too stressing and I preferred my health first.” Today Salome reports “I am not working now, I work as a volunteer.” She explains “We don’t get a salary and I cannot really quantify that this is the much I get per month. And an average is zero because sometimes a whole month goes without anything. I am a volunteer, I don’t earn, I just work until time to go home.”

Salome describes the way in which she does get money. “Sometimes when you help someone who is down, when they come up they support you. Sometimes they can give you something for appreciation. Someone gives you 100Ksh for appreciation.” She muses “Funny enough I am a sole breadwinner and I stay with my siblings. I have two brothers and three sisters and then I have my mother whom I have to take care of because of old age and my father also who is old and they are both hypertensive. Another one is diabetic but here I am jobless working as a volunteer so you can imagine sometimes you get home, there is nothing to eat and everybody sleeps hungry. So I find that it is a bit difficult because you cannot provide.” Salome cites her parents’ health problems as the reason she has not disclosed her status to her family “because I have a family who really love me so much and when I disclose this information to them, they will break down.”

Salome describes other aspects of living with HIV. She discusses her work as a volunteer “I talk to fellow people who have turned positive like me and they do not know what to do next. I get them what to do, how to take the follow up, they need to go to the hospital, and they need to adhere to treatment, the importance of nutrition and joining therapy groups or support groups and the work of support groups.” She explains side effects of taking medicine “the fats were being deposited in the chest and the stomach and you would realize that the two parts were growing. But the other parts of the body remained thin and when they changed the drug, I am doing fine now.” She discusses the role of the church “spiritual guidance, I pray a lot and I get involved so much in church activities and I also get a lot of teachings from the Bible, from the church, and that’s what keeps inspiring me.” Salome is comprehensive and informative answering questions about life as an HIV positive woman.

Salome's struggle with HIV has solidified and given a focus to her views about the vulnerability of women in her country. Her thoughts about the HIV epidemic are cast within a much wider context of human rights and empowerment of women. Her personal experience is that "women in my home are really respected and in our families, it is women who have uplifted families." She recognizes this is "specific for my family." In the community women "are not involved in policy making. They are not also involved so much in politics." Therefore, issues of rape and domestic violence and other "women issues really are not in the forefront and therefore women continue lacking behind in terms of policy making level in terms of education, in terms of you know the standard of living, you find that women are down because they are not supported. They are not involved in most of activities only within the family level but not within the community level or the national level."

Salome believes the involvement of women is essential "in policy making which is very important to avoid women lacking behind and especially those who are HIV positive. You find that the HIV positive woman are not involved in policy making so you find that at policy making level, the HIV positive woman has no say. They are not involved at all." The way to slow the spread of the HIV/AIDS epidemic Salome maintains "it is empowerment on human rights, income generating projects, have small scale businesses and education, educating the young girls, educating the elderly about HIV and how to care of themselves not to get infected."

HIV/AIDS is more than a disease for Salome. HIV/AIDS is the result of a gender imbalance that robs women of independence and power thus denying them their basic human rights. Salome offers a lengthy discourse that outlines the female childhood

experience emphasizing lack of access to education and inability to develop marketable job skills. For Salome “is all about supporting women and involving them in income generating activities, making women self reliance and independent.” Salome summarizes the cycle. “Vulnerability is brought by poverty and it in turn brings HIV because you need money, and you are given conditions that you have sex with him and then the outcome is not pleasing.”

“The empowerment should be done at all levels in the life of a person and these life skills are very important” asserts Salome. Medicine as described by Salome ‘it is like food and you have to take the ARVS since you know that it keeps you alive.’ But, the ultimate cure for the HIV/AIDS epidemic in Salome’s view lies elsewhere. Salome concludes “so is all about empowering women and HIV will stop spreading because they will be able to negotiate and they will be able to take care of themselves and practice safer sex and then we will have a society that is HIV free.”

LLB 08262011

It Is Obvious

Nafula provides very little information beyond the facts of her life. She is of the Luhya tribe and speaks in Bunyore. Nafula and her husband have been together 14 years. She and her husband have three girls and one boy ages, “14 years, 10, 6 and one-and-half.” The husband “works with an Indian.” Nafula does “casual jobs.” She cooks for an Indian but report, “I get very little since the casual job that I go is only for Saturdays only.” “God is the one,” who gives Nafula spiritual strength.

In a detached, concise manner Nafula relays the events leading to her HIV positive diagnosis. Nafula believes she acquired the virus following a miscarriage. “There is a time I was washed the uterus,” she says. Although the procedure was performed in a clinic by a doctor, Nafula discloses, “I don’t trust the tools they used,” implying the instruments were not sterilized. Nafula denies other behaviors that may have been the source of her infection. A month long illness some time later drove her decision to get tested.

Upon receiving the news of the HIV positive test Nafula maintains, “I did nothing.” She neither did anything nor felt anything but claims, “I went back to the house and life started.” Nafula “took no time” to adjust to her diagnosis and asserts, “You know once you know it and accept yourself then you feel okay and nothing will change.”

Maybe from her perspective little has changed in Nafula’s life. Nafula does now take ARVS medications, but “there is nothing hard since it has not affected me at all.” She summarizes attendance at support groups “it is good.” She told her husband her diagnosis. “He went for a test and he is negative...he did not say anything.” “Nothing,” she states has changed in her relationship with her husband. Her relationship with her HIV negative children “has not changed.” Her children and others in her family see her taking medicine. They know what the medication is for but “say nothing.” From Nafula’s view, HIV/AIDS “is not the end of life.” She would advise other HIV positive women, “she should not be worried about it since there are so many people who are dying without even the AIDS, due to accidents and others dying in the hospitals. So she should not think but continue with life until the day reaches for her to go.”

Nafula understates the challenges of her life. She reports there are no hardships in her life. Pressed for further information, Nafula admits the hardships are “just the obvious but not big ones.” An example of a hardship Nafula faces is, “You know I cannot be employed because I see that it would be hard to go for the medicine. I mean to go every month to ask for permission to go for the medicine.” In regards to food security, Nafula alleges, “it is obvious you face problems,” but denies days when she sleeps without food.

In Nairobi where Nafula now lives, “people are used, and no one is concerned about other person’s affairs, but in up country everybody knows you. And when you go for VCT, they talk about you at all times.” In her area of her birth, “they know that when one has this disease, is just going to die and that is the end.” People would “just prefer to die and not go for VCT.” Nafula explains the view of HIV where she is from. “Men believe that women are the main carriers because when something bad happens, it is women who are blamed.”

Stigmatization of women goes beyond being HIV positive. In her home women face problems just being women. “Some communities take them as valueless like kids.” Nafula has experienced the impact of discrimination against women. Her brothers went to school but she never went to school. “There are some who do not educate them, and they just know that they are getting married but they value the boys.” Women face a particular kind of discrimination Nafula discloses, “Like men circumcision which is the work of men as it is in some communities.” In her life Nafula has known the struggle of being HIV positive and of being a woman. The struggle continues even today. Nafula hesitantly tells of the abuse she experiences when she and her husband “collide.” The fact that Nafula experiences abuse at the hands of her husband “is obvious in the house.”

To live longer, women need “To have courage since life is full of struggle.” The prevalence of gender based discrimination is so widespread that for Nafula it is hardly worth mentioning. The obvious needs no explanation. Instead she accepts her life as a person HIV positive but even more so, as a woman, knowing “I have passed a lot but God is still protecting us.”

LLB 08282011

The Desire to Procreate

The HIV positive diagnosis was a surprise to twenty-seven-year-old Cecilian especially because her husband tested negative. The husband was sick so, in Cecilian’s words, “we decided to go for a test. This was very shocking, and I did not believe it that I was found positive and he was negative. It was a tormenting moment for me because he was the one who was unfaithful. I was so confused but after two months, I came back to my senses.” In retrospect, Cecilian was convinced she had acquired the HIV virus from her only other sexual partner. Prior to her marriage, Cecilian had a boyfriend who became sick with “malaria” and subsequently died.

After the initial shock and confusion, Cecilian seemed to take the diagnosis in stride. She sought medical care. She routinely took her medicine. Cecilian tried to eat well and stay active. Cecilian recognized the “stigma is very high and therefore it is very important for one not to disclose about it to everyone.” However, her mother, sister and brother knew her medical condition and were supportive.

Cecilian’s husband “was supportive at first but after one year he changed.” His change was not entirely a consequence of the HIV diagnosis. As Cecilian explained, “He

realized that I could not bore him children, and secondly I was living positively so he thought of getting an alternative, which was to get another woman who would be able to bore him children and that is what he exactly did.” The husband, Cecilian reported, “Used to leave me there without any food and I was sick and he could not show any concern.” When she became stronger he told her to go.

The couple was separated for more than a year. The husband returned telling Cecilian she “was very important in his life,” and he “could not do with” her. The husband did not return alone. He brought his pregnant girlfriend on the premise he would be happy with the baby in the house. This did not prove to be true. He apologized to Cecilian. Cecilian says, “He told me that with or without a baby, he would stay with me and he promised to support me.” Although the husband does not always provide financial support, Cecilian claims he supports her morally summarizing, “when I am sick he is there for me and he reacts very quickly.”

The desire to procreate remains strong and overrides concerns about the transmission of the HIV virus. When the couple got back together, Cecilian’s husband told her “that he loved me so much and he was ready for anything and if it meant death, then let it come. Therefore he made that there is no need of using a condom.” Cecilian’s husband knows the consequences of not using “control measures” but Cecilian asserts, “He has taken the risk.” Although not directly addressed, one consequence of failure to use birth control is pregnancy.

In five years, Cecilian has not become pregnant. Her primary doctor has advised her to see a gynecologist. At the time Cecilian tested HIV positive she “became so afraid

of bad news” she did not investigate her infertility. Cecilian’s doctor advised her to “have courage.” Now Cecilian feels “ready to go” and learn why she has not been unable to conceive. The cost of a specialist is paid for by the recipient of services and is prohibitively expensive for Cecilian. Financial concerns are, in Cecilian’s assessment of her life the hardest thing she is facing right now. What money she earns pays for her HIV medications leaving little to cover the cost of care of a gynecologist. HIV is “not the road to death” in Cecilian’s opinion as she views the diagnosis as something “you learn to life with.” Yet, the diagnosis and its impact on her health and her finances complicate her desire to provide her husband the child he wants.

LLB 06152013

Finding Oneself as a Woman

Katherine begins her story with the pronouncement, “I was an orphan.” She relays the events. “Yes, my mother died when I was eight years old, and I was the one who was left with the young ones. And according to African Traditions, a girl child was to stay at home and take care of the children, and this was due to down looking the girl child. When now my mother died, she left behind me and two other boys who I was made to take care of, so I did not get time to go to school.” She hesitates; “and if start explaining how my life is...” and simply concludes, “it is hard.”

Katherine was married young and within four years bore 3 children. Her husband fell sick and, as a last resort to identify his illness, was tested for AIDS. He tested positive as did her youngest child. Two years later they both died within two months of each other. Around that time she also gave birth to a fourth child. Her husband’s family knew

by the manner in which their son was buried that he died of AIDS. In response, Katherine reports, “When his family saw that, they hated me and saw that I was cursed because I had AIDS.” She knows she got the virus from her husband because “I had never had another man before marriage.” Despite this, “When he died, the family members chased me and they dismantled the house and I went back home to my home place and when I went there, there was no space for me since I was an outcast and I was not accepted by anybody so I came to Nairobi.” Looking back, Katherine realizes, “they chased me, and I think that I am better than if they accepted me because they would have given me a man to inherit me,” thus spreading the disease. However, as a widow she had three children to care for with no family support.

Initially Katherine worked building sports grounds. However, “when I got tired with the hard job of construction, I started a business of selling *omena*.” Political violence disrupted her business. She had spent a significant sum of money buying three sacks of *omena* and was traveling with her goods back to where she had her business. Katherine tells what happened. She was on a bus and “there are some people who came in and they pretended to be the police and stopped the bus and they told us to come out. And that time they lit fire in the bus, and that time I had *omena* three sacks and I had consumed 30,000Ksh, and it was burned all of it and they never bothered us ... They did not have any concern with us neither beating us. They escaped after burning the bus.” Katherine “failed to understand where I would go,” and turned to the support group where she told them what had happened. She describes the members of the support group as friends and tells how, despite the prevalence of post-election violence, “We were eating together.”

Another major hardship punctuated Katherine's life. Following a decade of abstinence after the death of her husband, Katherine explains how she was "cheated by a man." The man told her "that he has married me, and he took me and I agreed since I had no home, and I said if I get married to the man then he would build a home for me at his place." Four years later she stopped receiving care for AIDS. "I saw that I am healed and no need of going to the clinic because I had gotten a husband and I thank God for him since he was negative." "Chaos" developed in the house. The man refused to use condoms but because of her insistence burned her "things for doing business," and hit her in the head with a stick. Violence escalated and Katherine found "even he wanted to kill me with a knife, and I escaped running to the police station." The matter rests with the courts. One man gave her AIDS. The second man wanted to kill her. Devoid of optimism that a third man would be different Katherine maintains "what I am praying now is God to help me and lift my business that I will be able to buy a *shamba* and build a house with my children."

Katherine returned to treatment. She takes medication, talks with counselors, attends clinic, eats well and avoids stress. When she gets distressing thoughts she turns to "another woman and the only one who I like sharing with her." Katherine calls her sweetheart because "whenever I call her, she normally comes and we talk until I feel settled." Discrimination because she is HIV positive is a reality that she faces but more troublesome are problems she faces because she is a woman. Women, she explains, "are taken as inferior and they have no say." "When they see me right now when I have no husband," she goes on to say, "they tend to think that I am a prostitute and I am nobody."

Confidently she asserts, “We will cope with those challenges since we found ourselves as women.”

The composition of Katherine’s family changed through the years. She declared herself an orphan a second time. “I have been left as an orphan because my brothers died” – the brothers she cared for when her mother died. The brothers “left their children and they died together with their wives,” so Katherine was left to raise the orphaned children. Katherine’s own daughters “gave birth to one child each and they escaped from home,” leaving Katherine to raise her grandchildren. In a matter-of-fact manner Katherine tells how she became responsible for yet another orphan. “I found a baby in a green bag and had not yet been cut off the umbilical cord...he is called Benjamin Ombama.”

Katherine’s life has been, as she summarized it, hard. Overlaying a life filled with suffering and struggle because she was orphaned; deprived, widowed, threatened, shunned, and victimized is the challenge of dealing with a chronic illness. She is almost matter of fact in declaring, “It is true, I found myself a woman and so I have to cope with the problems.” Simply, in her view, her life experiences and hardships emanate from her status as a woman. She cannot change her gender or remove the hardships associated with being a female in her society. Katherine’s final advice to women living with HIV/AIDS is “to accept herself, to follow the clinic and remove stress.” Katherine’s role as a mother raising five children is the bright spot in her life. Thus despite the challenges she is able to declare, “I thank God since my life is full of bringing up babies.”

LLB 05192011

Bound by Tradition

Rahab feels the conflict between tribal traditions and her life as an HIV positive woman who is a born-again Christian. She was widowed at age 34 when her husband of just three years died of AIDS. She is a single parent responsible for both her ten-year-old son and one of her sister's three children. The children were orphaned when both parents died of undisclosed illnesses.

She reports she gets no money each month to support her and the children although, "sometimes someone may call me for a casual work like washing and other times I sell groundnuts at the road." Rahab has also joined "merry-go-rounds which we go and buy food and divide them amongst us." The group buys food and shares the contribution between the members "each week we give to two people, on Tuesday and Friday and we get only one item like sugar."

Approximately one year has passed since Rahab learned of her HIV positive status. She was with a man who became sick and was hospitalized. Rahab does not believe he knew he was HIV positive. "I think he did not know because when he was tested, he was shocked and due to that shock he run mad and was seriously sick. And later he was admitted at the hospital where I used to come and see him all the time." The doctors encouraged her to go for the test and "when I went there I was found positive also." The doctors also encouraged her to attend a class "where there was counseling and so many other teachings about the disease." She "came to know that everybody whether sick or not will one day die, and that one can live positively."

Rahab and the man were in the early years of their marriage. They were preparing their life together and a move to her husband's village. Her husband "did not have any house. We were preparing to build the house and we had bought the things for building." Her in-laws did know she had married their son; "they knew me and I used to go there to visit them." Nevertheless, she did not tell her in-laws the cause of her husband's death, and "they have not come to me to tell me anything but it is something they know."

Rahab explains her husband's family "are *Luo* people. They have their own traditions concerning a widow. Though I have not seen them do that, but their traditions state that when a woman is left, you have to stay there until you get another man so as to release you." The in-laws "really want me back, and they keep on calling me to go back because from the time we buried my husband, I have never gone back there and therefore they keep on calling me to go and settle as the wife of the deceased." Rahab puts them off by telling them "if they want me they should organize to build the house for me."

The decision not to move to her in-laws home as tradition dictates is explained by Rahab. "I am born again, and I told them I am no longer bound by traditions." She also refused to bury her husband according to tradition. "I told them I was not to do any ritual for the dead because my church does not allow me to do such like things." Were they anyone else, Rahab's in-laws might have insisted on their tradition rights and claimed her as their woman. Rahab does not believe they will as she divulges, "Yes, I am their woman, but even them they are born again Christians who do not at all follow the traditions."

“I feel that I am free,” is the emotion evoked by the thought of taking ARVS medications for the rest of her life. Rahab does not find it difficult to take the medicine. “I take as I have been instructed to do,” and “I put vibration in the phone that is the alarm which reminds me the time go take the medicine.” She gets medicine from the clinic and is given counseling and information as needed. Rahab does not use herbal medicines or go to traditional healers. She has not been with a man since her diagnosis. Rahab admits, “I don’t think much that I have the sickness, and I use the medicine and I try to avoid being idle. And I don’t stay alone, I go to friend to chat, and I only remember when that I am sick only the time I am taking the medicine.”

Rahab confesses, “You see this child that I have, I got when I was at my place before I got married.” She reveals she sometimes has too many thoughts of the ramifications of her HIV positive status. She remarks, “You tend to think so much, and when something small like colds or malaria attack you then you can die very fast.” The hardest thing Rahab has faced since her diagnosis is “this child since he belongs to me only because the father who bore him disappeared.”

Rahab explains the customs of her people. “A child is not supposed to be given land at my place unless he gets good education and buy land for himself. My parents will not stay always with them and when they die then my boy gets into problem because they know that he does not belong there.” The possibility of her son moving to “his father’s place” is non-existent unless “if he himself {the father} comes claiming for the child then he will be given.” Unless the absent father comes to the mother’s home and “explain that he wants the child.” Rahab’s son would have no place to live if she dies of AIDS. Rahab laments, “I think like if I am not there then the child will suffer.” While Rahab avoided

the dictates of the traditions of the Luo people, Rahab has not escaped the concerns she has about her son and the position tradition would place him in were she to die of AIDS.

LLB 02222011

A Story of Managing a Small Business

Martha is a 27 year-old mother of two children who was diagnosed HIV positive four years ago. She is married to a man who is physically abusive and fails to financially provide for his family. Her performance narrative occurs in two acts. Act One is her work supporting herself and her children. Act Two is about the relationship of Martha and her husband and how the relationship disrupts her small business. The interview about Martha's HIV status is a thread that ties the two acts together. The descriptors of her illness serve to accentuate the story of her struggle for survival in the context of domestic abuse and managing a small business. The narrative is supplemented with facts that speak to her skills and resilience.

Act One begins with Martha's statement her husband "does not help me and he was stuck outside with other women and when he gets the salary, he spends it with other women. And I had to look for a way of getting money to buy food, and if I don't work then we don't eat." Martha tells the story of how she established a business to support herself and her children. While pregnant with her second child, she was tested and found to be positive for HIV. She gradually came to realize her husband knew he was positive but had not told her. In Act Two, Martha claims not to know how she got the disease but such detail is not relevant to her story. A period of illness after diagnosis caused her to be so sick "she could be in and out of the hospital." Her husband began "sleeping outside

three to four days.” He beat her, explaining he wanted to marry someone else. Over time Martha asserts, “I could not know where he was, and he could not even help me at all.” Desperate, she turned to friends to “help me with food and life,” but ultimately developed a business selling maize.

Initial success was halted by a month-long hospitalization and three-month recovery. Determined to provide for her and her children, Martha restarted the business only to have her husband break the charcoal oven and cooking pot. Her husband “wanted her to go away and that why he took everything and he went away.” Once again friends helped. These setbacks in the business created by Martha’s husband foreshadow the dominant theme of Act Two. She could recover from her illness and restart her business but her husband’s abusiveness and the beatings were more persistent.

Act Two begins with a rare discussion between Martha and husband. The husband is insistent Martha give him money purportedly to pay school fees for the children. The interviewer cuts short that segment and redirects to the nominal topic of the performance—HIV. Martha is quite vocal in musing about the possible source of her illness, sharing her beliefs about the effect of the disease on her family and describing a serious bout of illness. Martha has not had sexual relations with anyone but her husband. A dialog between interviewer and Martha quickly addresses a series of issues related to self care. “When you think of taking this medicine the rest of your life, what do you feel?” The response, “I feel okay and I don’t imagine of not taking.” Asked about the hardships of coming to the clinic, Martha responds, “I don’t see anything hard since I am staying here at Kalali.” Queried about the use of condoms, Martha explains, “I don’t wait for him to ask.” Her quest for independence through her work and growing her own

vegetables gives a picture of a self-reliant person who knows how to care for herself and her children despite her illness.

Martha is able to shift the focus to the dominant theme of her husband's disruptive behavior in a question about women "getting into problems of getting this disease because they are trying to earn living?" This question provided an entree for Martha to discuss her concerns about her husband. Martha claims, "I had such a heart, but what my husband was doing made me to have a negative mind towards men." Her husband "liked women so much even young girls." He was physically abusive; in her words, "I have been beaten so many times." He refused to help her get treatment at the hospital despite the fact he had an insurance card. The hospital, friends and her family encourage her to report him to the police.

The drama is intense, yet the ending of this performance narrative banal. Martha proclaims, "I see that if I work hard and the business does well then I will stay like that since I have no otherwise." Her husband has convinced her that "there is no place that I can take him." So, she tells him "that I only spare him and respect him," emphasizing to him she depends on "that *jiko* (charcoal oven) to care for the children." Martha explained to her husband, "My like is in the business that I am doing." Her children and her ability to care for them with her business, not HIV, is the major theme of her performance.

LLB 10132010

A Spirit Undeterred

Betty's no-nonsense, practical outlook to life is reflected in her response to her HIV positive diagnosis. She acknowledges she does not know how she became infected. A

woman suggested she get tested because she was sick all the time. She did not resist the idea because as she says, “it was good for me to be examined since there was no payment to be made.” Betty reports, “I was not shocked and therefore I was given the medicine, and I started taking right away.” The benefits were evident as she declares, “there is a great change since I don’t get sick like the way I used to get sick.”

In the little bit of information Betty provides about her life it is difficult to discern how much her approach to life is a product of her innate personality or simply a philosophy developed by her life experiences. Uneducated, married at seventeen and the birthmother to nine living children and two who have died, Betty’s life revolved around caring for her children and her husband. Fortunately her husband had a stable position working for Kenya Power and Lighting. The focus in her life on others continued after the death of her husband. She earns money “[I]sell things in my shop, and I buy tomatoes and cabbages for sale, and when I am called for any casual job, I normally attend to it and earn money.” The money she uses to educate her children.

Calmly Betty relays her experience as an HIV positive woman. She discloses the affect of HIV on her family. “There is no one who is affected because I took them for test and they were found negative.” Her family “they take me well, and they try so much that I don’t fail to get food that I need.” Her children pay for a boy to help her farm. Routine trips to the clinic, vigilance taking medications, abstinence, avoidance of stress, prayer and other activities mark her relationship with her HIV positive diagnosis. Asked the hardest thing she has experienced being HIV positive she claims, “There is nothing and it is better this time that I know because if I had not yet known that I am positive then I would have spread the sickness.”

Betty is not fearful of something bad happening because of her diagnosis. “I don’t fear anything.” She approaches the possibility of stigmatization straightforwardly. The people in the village she says “know that people are sick and normally I tell them that it is better me who is aware of my status than them who do not know. They ask me whether I am sick, and I tell them yes.”

Perhaps more than anything Betty’s comment about her mother reveals the foundation for her approach to life. Betty relays, “I never found my father because he was already dead. I found my grandparents and my mum. I used to see problems, but my mother was there for us and we survived.” Betty is aware of the challenges to being a woman in her culture. She unequivocally states, “There isn’t a woman who has never been beaten by her husband.” Betty believes, “why should they be beaten instead they should be corrected with a word of mouth.” The husband “remains the head of the family and therefore there is nothing to do to him.” Her own protective stance was “to be a coward in that when I am told a mistake, I don’t repeat it again. I used to tell them the mistake before he asks me. Even when a child asks permission after doing a mistake, do not beat the child.” Yet, with her mother as female role model, Betty asserts, “there is nothing I cannot say.”

Betty knows the impact of HIV/AIDS. “It has done disastrous thing like many people have died and left families empty with just children there surviving. People left quarreling and if a partner dies, they may separate.” Betty doesn’t share much of what defines her life but her approach to what life brought her way is clearly articulated. Her pragmatic approach to the disease, similar to her approach to other challenges in her life, calls for open discussion, liberal testing and measures to protect ones health. Her request,

simple and practical like the rest of her approach to managing her life and her diagnosis is for “medicine that can heal us completely so as to stop taking the medicine.”

LLB 05212011



Lenore L Boris, JD, MS, RN

HIGHLIGHTS OF QUALIFICATIONS

COMMITMENT | SERVICE | LEADERSHIP | INTEGRITY

Self-directed problem solver, outcome oriented professional

Excellent communication, negotiation, facilitating and interpersonal skills

Diverse experience in leadership and project management positions

Dedicated to maintaining a reputation built on quality, service, and uncompromising ethics

EDUCATION

- University of Wisconsin - Milwaukee, College of Nursing - Milwaukee, Wisconsin
PhD (Nursing), Successfully defended dissertation on April 9, 2015
- University of Wisconsin, School of Law - Madison, Wisconsin
Juris Doctorate September 1984 - December 1986
- Syracuse University, College of Nursing - Syracuse, New York
Master of Science September 1989 - May 1996
Focus in Community Health Nursing
- California State University - Hayward - Hayward, California
Bachelor of Science - Nursing September 1975 - December 1978

- University of Wisconsin - Milwaukee - Milwaukee, Wisconsin
Bachelor of Science - Secondary Education August 1971 - August 1974
Degree encompassed a broad Social Studies major and an English minor

MILITARY EDUCATION

- Air War College (by correspondence) - July 2004
- Nursing Service Management for Air Reserve Components - August 1996
- Flight School - May 1984
- Nursing Service Management (by correspondence) - May 1983
- Squadron Officer's School (by correspondence) - September 1982
- Battlefield Nursing - July 1982
- Military Indoctrination for Medical Service Officers - March 1980

PROFESSIONAL EXPERIENCE

Civilian Experience

Associate Dean September
2005 - present

SUNY Upstate Medical University,

Clinical Campus at Binghamton, 425 Robinson Street, Binghamton, New York 13904

Responsibilities and Accomplishments include:

General Branch Campus Administration

- Manage daily operations of the Clinical Campus and three remote locations. Oversee purchasing, payroll, personnel, inventory, space and facility issues, equipment, information technology, maintenance, housekeeping and parking.

Budget

Responsible for the \$ 3.5 million Binghamton Campus budget.

- Develop financial resource allocation plans based on program needs and requests
- Manage the State budget account, DDF (IFR) accounts, Research Foundation accounts (including MSG generated), FSA accounts, Upstate University Foundations Clinical Campus accounts (restricted funds/endowments), and specific extramural SUNY Research Foundation projects and grants
- Monitor, review, approve and sign-off on all expenditures and receipt of income

Responsible for the approximately \$ 1 million budget for operation of the Dr. Garabed A. Fattal Community Free Clinic.

- Approximately 2/3 of budget is in-kind services (e.g. waiver of lease for clinical spaces) and 1/3 is direct cash expenditures for staff salaries, medical and office supplies and pharmaceuticals
- Monitor, review, approve and sign-off on all expenditures and receipt of income

Medical Service Group

- Manage expenses, payouts, insurances, election process, individual faculty contracts and audits for the 2-3 faculty physicians who are members of the Binghamton Campus medical faculty practice plan.
- Sign-off on MSG accounts/ Research Foundation account generated by MSG coverage

Affiliations and Contracts

- Oversee conceptualization and development of new clinical affiliation agreements, renewal of existing affiliations agreements and contracts, and resolve implementation problems. Binghamton Campus has affiliations agreements with fourteen clinical

facilities and twelve contracts with facilities in addition to contracts for Internet service, office equipment servicing, janitorial services, etc.

- Activities include negotiating the terms of, drafting new language and/or revising existing affiliation agreements or contracts language.

- These agreements range from major hospital clinical affiliates such as United Health Services, Inc., with four hospitals and 25 outpatient clinics, to specific educational rotations at educational and clinical affiliates such as the Broome County Public Health Department or private physician practices.
- Contracts include services such as Information Technology support for the Binghamton Campus, telephone and internet services, utilities, office equipment servicing, etc.

Ambulatory Clinic

- Administrator of the Dr. Garabed A. Fattal Community Free Clinic. This primary care clinic has provided physician visits and prescription medications to approximately 3,000 medically uninsured adults, during more than 15,000 patient visits in the past five years
- Oversee all administrative issues: space, liability, personnel recruitment, purchasing of pharmaceuticals and supplies
- Created a fund raising program that has successfully provided a positive cash flow and generated a reserve fund of monies sufficient to maintain clinic operations for 18 months

Academic Program: Teaching and Administration

- Teach the Practice of Medicine III - a course designed to teach communication skills and explore ethics issues with 3rd year medical students.
- Staff the Research Committee which coordinates an annual research poster session in conjunction with Binghamton University and United Health Services Hospitals, Inc.
- Member of the Educational Policies Committee and Executive Committee of the Site Directors. Both groups have interrelated responsibilities of planning, implementing and evaluating the 3rd and 4th year clinical program at the Binghamton Campus.

- Participated in the 2011 re-accreditation of the SUNY Upstate College of Medicine by the Liaison Committee on Medical Education. Member of the self study team that evaluated faculty involvement and administration for Binghamton Campus.

Faculty and Staff Recruitment and Management

- Recruit, hire, evaluate and manage a staff that consists of twelve administrative positions, seven professional positions, and 35 part-time hourly employees
- Oversee the physician faculty that includes 2 full-time faculty, 125 part time (.01-.45 FTE) paid faculty and approximately 325 voluntary faculty. Activities include recruitment/application processes (search committee composition), including national searches, affirmative action concerns, advertising content and position descriptions with immigration and visa issues if relevant. Recently concluded a search for an Associate Dean - Academic Affairs
- Faculty and staff are represented for collective bargaining which impacts the hiring, termination and management of the Binghamton Campus workforce

Intra-Institutional Relations

- Work with various administrative departments on the Syracuse parent campus as needed, including but not limited to Office of the President, Upstate Administration, Accounting, Human Resources, MSG offices, Research and Grants Administration and Academic and Student Affairs as required.
- Represent the Binghamton Campus on various task forces and school-wide committees including Admissions Task Force, Industrial - Higher Education Relations Policy Review, Regional Expansion Task Force, Medical College Assembly, Student Health Committee, and Faculty Assembly

Community Relations/Information Dissemination

- Liaison to community health-care organizations such as Rotary, legislative committees and county government, public health department, local health and welfare agencies, professional groups (medical, dental, nursing societies), community health leadership, political appointees and

politicians, electronic and print media for purposes of information dissemination and publicity.

- Member of the steering committees of the Broome County Health Department development of the Community Health Assessment 2010-2012 and 2013-2017
- Founding Board member for the creation of the Hope Dispensary of the Southern Tier, an organization providing reduced or no cost medications to the un- or under-insured in New York's Southern Tier
- Board Member, Health Workforce New York, a 501c# organization dedicated to health workforce development in the central New York region
- Board Member, Rural Health Network of South Central New York
- Served on the Central/Finger Lakes Regional Advisory Committee for the New York State Health Benefit Exchange in 2013
- Southern Tier Rural Integrated PPS – part of Core Steering Committee overseeing the submissions of the planning grant application, the application grant submitted in December 2014 and the implementation plans due May 1, 2015-03-28
 - Planning Grant – Wrote section 4 Project Selection and helped review the whole application for consistency prior to submission
 - Application Grant – Lead on development of the Workforce Section and participated in development of Sections on Community Needs Assessment, Cultural Competency/Health Literacy and Project 11. Reviewed other sections such as finance, projects as part of team assembling grant for submission.
 - Implementation Phase –
 - Member of the Steering Committee overseeing the development of the STRIPPS Implementation Plans.
 - Leading the Workforce Team and writing of the workforce implementation plan. Participating in writing the implementation plans for Cultural Competency/Health Literacy and Project 11. Continue work with Community Health Assessment Team with stakeholder panels.
 - Chair of the PAC and the PAC Executive Council

Academic Appointments:

Clinical Assistant Professor, Department of Family Medicine.....July 1, 2011 - present

SUNY Upstate Medical University

Adjunct Clinical

Instructor.....January 2006 - present

Binghamton University, Decker School of Nursing,
PO Box 6000, Binghamton, New York 13902-6000

Adjunct Experiential Faculty..... September 2008 - present

NURSING LABOR RELATIONS REPRESENTATIVE..... May 2001 - September 2005 **New York State Nurses' Association**

11 Cornell Road, Latham, New York 12110

- Negotiated, drafted and managed collective bargaining agreements for registered nurse bargaining units varying in size from 5 members to 450 members
- Negotiated public and private sector contracts for nurses working in hospitals and schools
- Conducted labor-management meetings and grievance hearings
- Addressed issues related to nursing practice and contract implementation

INTERNAL ORGANIZER (NURSE).....May 1998 - May 2001 **Public Employees Federation**
AFL-CIO

1168-70 Troy-Schenectady Road, Albany, New York 12212-2414

- Addressed multifaceted concerns of 9,000 registered nurses employed by New York
- Responsible for the development and oversight of major labor-management, legislative and public relations initiatives to highlight and resolve nursing practice concerns
- Advocated for nurses with officials from the New York State Office of Mental Health, Office of Mentally Retarded and Developmentally Delayed, Corrections and other state agencies

- Provide information/ advice on a broad range of nursing practice and legal topics
- Serve as liaison on nursing issues between the Public Employees Federation and other collective bargaining organizations including the New York State Nurses' Association, Service Employees International Union and American Federation of Teachers

FACULTY COURSE CHAIR.....November 1994 - March 1998
Nursing
Avenue, Troy, New York 12180

Samaritan Hospital School of
2215 Burdett

- Implemented a new practical nurse program within an Associate Degree nursing school affiliated with Hudson Valley Community College
- Developed all course objectives, lesson plans, clinical assignments, selection of course materials and other learning activities
- Provided all classroom and clinical instruction

LABOR RELATIONS REPRESENTATIVE.....September 1987 - September 1992
New York State Nurses' Association
11 Cornell Road, Latham, New York 12110

- Negotiate, draft and service collective bargaining agreements for registered nurses bargaining units varying in size from 3 nurses to 1,000 nurses
- Negotiated public and private sector contracts for nurses working in hospitals, public health, schools and free standing dialysis facilities
- Analysed health care facilities budgets and costed out contracts
- Address issues related to nursing practice and contract implementation

REGISTERED NURSE.....Various time periods

Clinical experience as a per diem and staff nurse in the following settings:
 Medical/surgical, obstetrical (including labour & delivery, postpartum and newborn nursery), geriatrics, community health nursing and neonatal intensive care units.

Military Experience

COLONEL (retired)

UNITED STATES AIR FORCE NURSE CORPS.....November 12, 1979-

November 13, 2007

- 28 years of service (8 years active duty and 20 years Reserve)

**ADJUNCT CLINICAL INSTRUCTOR..... February 2006-
November 2007**

United States Air Force Reserve, Uniform Services University of Health Sciences, Bethesda, Maryland

- Assist with special projects such as the development of Policies and Procedures in the Graduate School of Nursing

**COMMANDER.....February 2003 -
September 2004**

United States Air Force Reserve - extended active duty, 439 Air Base Clinic, Westover Air Reserve Base, Chicopee, Massachusetts

- Commander of 29 medical personnel activated in support of *Operation Enduring/Iraqi Freedom*.
- Ensured activated Reservists were medically qualified for deployments, monitoring health status of members ill or injured during active service and processing medical packages for fitness of duty determinations.
- Oversight for the delivery of services to 1200 activated Reservists and 1200 traditional Reservists as well as transients. Including sick call, immunizations, drug testing, fitness for duty determinations, line of duty actions, RCPHA, activation/ deactivation processing, mobilization/ demobilization processing.

**NURSE ADMINISTRATOR..... September 1997 -
February 2006**

United States Air Force Reserve, 439 Aerospace Medical Squadron, Westover Air Reserve Base Chicopee, Massachusetts

- Responsible 65 member Nursing Service Unit. Responsible for the immunizations, drug testing, fitness for duty determinations, line of duty actions, and annual health screenings for a base population of about 2,700 Reservists.
- Oversight of Unit's Laboratory, Continuing Education program for nurses and medical technicians, Infection Control and Medical Provider Credentialing.
- Officer in Charge for two Health Service Inspection visits (analogous to JCAHO).
- Member of Executive Committee.
- Commander of a 35 member Medical team that provided primary health care to 8000 persons during a Humanitarian Mission to Guatemala in May 2000

**CLINICAL NURSE..... September 1991 -
December 1997**

United States Air Force Reserve 439 Aeromedical Staging Squadron, Westover Air Reserve Base Chicopee, Massachusetts

- Trained to provide patient care to wounded or sick airman transiting the aeromedical evacuation system at the points of entry and exit from the system if Unit called to active duty.
- Additional duties included Assistant Chief Nurse, Unit Training Coordinator and Unit Quality Officer. Member ASTS Task Force – a Reserve wide group to examine policies and functioning of Aeromedical Staging Squadrons

FLIGHT NURSE September 1987

- August 1991

United States Air Force

Reserve 74th Aeromedical Evacuation Squadron, Westover Air Reserve Base

Chicopee, Massachusetts

- Trained to provide patient care to wounded or sick airman transiting the aeromedical evacuation system while patients are in-flight if Unit called to active duty.
- Flight examiner, flight instructor, and disaster preparedness officer.
- Deployed for Operations Desert Shield and Desert Storm.

FLIGHT NURSE.....September 1984 -

August 1987

United States Air Force Reserve,

63rd Aeromedical Evacuation Flight, O'Hare ARFF, Chicago, Illinois

- Trained to provide patient care to wounded or sick airman transiting the aeromedical evacuation system while patients are in-flight if Unit called to active duty.
- Unit Quality Assurance Officer and Medical Plans Officer
- Project officer for Health Service Inspection visit (analogous to JCAHO).

FLIGHT NURSE..... February 1984 -

August 1984

United States Air Force

Reserve, 32nd Aeromedical Evacuation Squadron, Kelly Air Force Base

San Antonio Texas

- Trained in provision of patient care to wounded or sick airman transiting the aeromedical evacuation system while patients are in-flight if Unit called to active duty.
- Assigned to Unit Training Section.

STAFF NURSE..... October 1982 -

October 1983

Active duty United States

Air Force United States Air Force Hospital, Incirlik Air Base, Adana, Turkey

- Managed and monitored ante-, intra- post-partum patients and newborns.

- 10 deliveries a month of active duty dependents.
- Supervised medical technicians.

NURSING EDUCATION COORDINATOR... .. **December 1981 – September 1982**
*Active duty United States Air Force,
 United States Air Force Hospital, Wurtsmith Air Force Base
 Oscoda, Michigan*

- Developed, implemented and monitored a comprehensive inservice and continuing education program for nurses and medical technicians.
- Chairperson of the Nursing Education and Nursing Quality Committees.

STAFF NURSE..... **September 1980 – December 1981**
*Active duty United States Air Force, United States Air Force Hospital, Wurtsmith Air Force Base
 Oscoda, Michigan*

- Managed and monitored the ante-, intra- and post-partum patients and newborn in a facility with approximately 30 deliveries a month of active duty dependents.
- Supervised medical technicians and civilian nurses

NURSE INTERN..... **April 1980 – September 1980**
*Active duty United States Air Force United States Air Force Medical Center, Wright-Patterson Air Force Base
 Fairborn, Ohio*

- Provided basic patient care through rotations on pediatrics, orthopedics, obstetrics and step-down intensive care units.

AWARDS AND HONORS

- **Recipient Brigadier General Beverly A. Lindsey Administrative Excellence Award - 2002**
 - *Six out of eight years as Nurse Administrator the squadron was selected as the Best Aerospace Medical Squadron in the Air Force Reserves over 22 other units.*
- **Awarded "Officer of the Year " 100 bed ASTS - 1995.**

Meritorious Service Medal – 2 devices
 2 devices

Air Force Outstanding Unit Award –

Air Force Overseas Short Tour Ribbon

Combat Readiness Medal

Air Force Commendation Medal

Air Force Training Medal

Air Force Longevity Service Award – 4 devices

National Defense Service Medal

Air Force Achievement Medal

Armed Forces Reserve Medal – 2 devices

DATE OF RANK

- Commissioned – 10 November 1979
- First Lieutenant – 10 September 1980
- Captain – 10 September 1982
- Major – 10 May 1996
- Lieutenant Colonel – 10 May 1999
- Colonel – 1 April 2005

PUBLICATIONS

Castner, J., Grinslade, S., Guay, J., Hettinger, A., Young Seo, J., and Boris, L. (2013). Registered nurse scope of practice and ED complaint-specific protocols. *Journal of Emergency Nursing* (39) 5, 467-473. doi 10.1016/j.jen.2013.02.009

"Commentary on Young, A. (2009). The legal duty of care for nurses and health professionals. *Journal of Clinical Nursing*, 18(22), 3071-3078. doi 10.1111/j.1365-2702.2009.02855.x

Boris, L.L. (2007). Chapter 2 The Legal and Ethical Context of Practice. In Harkreader, H., Hogan, M., & Thobaben, M. (Authors), *Fundamentals of Nursing – Caring and Clinical Judgment (3rd ed.)*, (pp. 16-43). St Louis, MO: Elsevier Saunders.

Boris, L.L. (2004). Chapter 2 The Legal and Ethical Context of Practice. In Harkreader, H., & Hogan, M. (Authors), *Fundamentals of Nursing – Caring and Clinical Judgment (2nd ed.)*, (pp. 15-41). St Louis, MO: Saunders.

Boris, L.L. (2000). Chapter 2 The Legal Context of Practice. In Harkreader, H. (Author), *Fundamentals of Nursing – Caring and Clinical Judgment (1st ed.)*, (pp. 21-41). St Louis, MO: Saunders.

Boris, L.L. (2000). Unit 57 Leadership/Work Transition. In White, L. (Author), *Foundations of Nursing – Caring for the Whole Person*, (pp. 1528-1544), Albany, NY: Delmar Publishers.

Boris, L.L. (1989). Staying Clear of the Law. In Glover, S. (ed.), *Performance Evaluations*, (pp. 29-37). Baltimore, MD: Williams and Wilcox.

Published a monthly article on nursing issues in *The Communicator*, the Public Employees Federation magazine for their 54,000 members from May 1998 – May 2001.

RECENT PRESENTATIONS

“Fostering a Lifelong Commitment to Service”. Keynote speaker at the Rural Health Service Corps (AmeriCorps) member recognition showcase, Binghamton New York (2012)

“The Dr. Garabed A. Fattal Community Free Clinic – Broome County’s Healthcare Safety Net”. A Binghamton University Lyceum Presentation, Vestal, New York (2012).

“The Dr. Garabed A. Fattal Community Free Clinic- where we have been, where we are, what is ahead”. A presentation about the Dr. Garabed A. Fattal Community Free Clinic for the Resident Speaker series at Good Shepherd Village at Endwell(2011).

“Moving Forward on Health Care Reform – A discussion Forum: Designing a Structure of Health Care Reform Implementation in New York State”. A three person panel discussion about implementation of Health Care Exchanges in New York. Sponsored by the Health Care for All New York Statewide Coalition to inform Assembly members Donna Lupardo and Clifford Crouch and Governor Cuomo’s regional staff, Kevin McCabe and community members, Binghamton New York (2011).

"What is Happening in Health Care Reform". One of three presenters to the League of Women Voters of Broome and Tioga Counties, Vestal, New York (2011).

"Neighbors Caring for Neighbors". A presentation about the Dr. Garabed A. Fattal Community Free Clinic to the Park Methodist congregation (2010).

"The Healthcare Safety Net in Binghamton". A presentation about the Dr. Garabed A. Fattal Community Free Clinic to the Alliance of the Broome County Medical Society (2008).

"Accessing Healthcare". A presentation to the League of Women Voters of Broome and Tioga Counties, Vestal, New York (2009).

"Labor Unions and Nursing". A presentation to Binghamton University Nursing Students, Binghamton, New York (2007).

"Expanding Capabilities for Patient Care". A presentation about the implementation of a computer based data management program for the Dr. Garabed A. Fattal Community Free Clinic to the Advocates for Upstate Medical University, Syracuse New York (2007)

"The Dr. Garabed A. Fattal Community Free Clinic". An informational presentation to the Rotary Club of Binghamton, Binghamton New York, (2006)

PROFESSIONAL ORGANIZATIONS AND AFFILIATIONS

- Wisconsin Bar Association
- Reserve Officer's Association
- Sigma Theta Tau, Eta Nu Chapter
- Registered Nurse licensed to practice in New York