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The Lived Experiences of HIV+ Community Health Workers Serving HIV+ Clients

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Abstract

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MPH, Walden University, 2010

BA, Spelman College, 1989

Dissertation Submitted in Partial Fulfillment of
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Doctor of Philosophy
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Abstract

Numerous studies have focused on the effectiveness of community health worker (CHW) programs in producing positive health behaviors and health outcomes for the clients CHWs serve; however, there has been a gap in the literature regarding how the health of HIV + CHWs is impacted by their jobs. A phenomenological design was used to gain insight into the lived experiences of HIV+ CHWs (HIVCHW) who provided services to HIV positive clients. Fifteen HIVCHW were recruited using criteria and snowball techniques. Data were collected via audio recorded personal interviews regarding respondents' perceptions of their work and how it impacted their own health and wellbeing. The data were organized by hand creating charts with pen and paper. Lazarus's theory of stress and coping was used to understand the data and aided in the analysis. The key findings indicated that while the majority of participants had an overall positive perception of the experience of being HIVCHWs, they also indicated that being a CHW impacted their health and well-being. Stress and stressful situations were among the impacts most often referenced by the study participants. The study is socially significant because it may offer the workforce of HIVCHWs empowerment to selfadvocate for tools such as stress and time management training and mentors to support healthy work-life balance. In addition, this study may help to prevent or reduce rates of adverse health outcomes such as pain and burnout that HIVCHWs reported experiencing.

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Dedication

I affectionately dedicate this dissertation to the memory of my parents, Matthew W. Simmons and Mary E. Simmons. This dissertation has been the most intricate project upon which I have ever embarked. I know I was able to persevere through this process by recalling one of my mother’s mantras: All things are possible with God. I believe their spirits were with me every step of the way and that they are proud angels in heaven smiling down on me. I dedicate this dissertation to Delores Marshall, a heroine in the fight against HIV/AIDS, who was the inspiration for the study.

Acknowledgments

I thank the Almighty God for keeping and guiding me through this endeavor. To my immediate family—husband Sidrowe, sons Campbell and Nathaniel, and daughter Savannah—who had to stay quiet and tiptoe by me as I read and wrote: I love you all! Thanks for putting up with me for the last 5 years. You are now free to make as much noise in our house as you would like. To my friend and now colleague, Dr. Latoya Callender, I appreciate your support and thank you for pushing me beyond my naive expectation of this process. I express my sincerest gratitude to Dr. Richard Jimenez for the many roles he served during this process, but especially for chairing my dissertation. You are the epitome of a professor and public health professional. To my other committee members, Dr. Faith Foreman and Dr. Thron, thanks for your guidance and support in helping me to complete this project. To my family and friends who proofed a paragraph or chapter, printed an article, offered a word of encouragement, or texted me in the middle of the night to make sure that I was up writing and not asleep at my laptop, my heartfelt thanks go out to you, as earning a doctorate requires a village to achieve.

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Chapter 1: Introduction to the Study

Introduction

The healthcare workforce is facing a growing demand for health services for varying reasons, including but not limited to the fluctuating burden of disease, an aging population, expectations and advances in health technology, and increasing patient knowledge (Centers for Disease Control and Prevention [CDC], 2015). A *community health worker* (CHW), a paraprofessional who serves at the community level, acts in multiple roles to address a health challenges, diseases, and health promotion activities (CDC, 2015). CHWs are progressively acknowledged as an essential part of the health workforce, and they help to meet healthcare goals (World Health Organization [WHO], 2007).

In this study, I explored the lived experiences of CHWs living with human immunodeficiency virus (HIV)/acquired immunodeficiency syndrome (AIDS) (HIVCHWs) who’s clients are people living with HIV/AIDS (PLWHA) and who conducted HIV prevention activities. The individuals who served as CHWs and their clients were peers. The HIVCHWs were available to educate and navigate PLWHA through a sometimes difficult maze of everyday life issues, as well as more complex bureaucratic policies that could hinder them from receiving the care they needed (The White House, 2012). There is a limited amount of data on the impact that the role of CHW has on the well-being of HIVCHWs. Because the CHW profession is predicted to grow, there is a need to explore this phenomenon from the perspective of the HIVCHW.

The potential positive social change impact of this study may occur through the HIVCHWs' perceived state of their own health they will be empowered to identify and self-advocate for tools needed for healthy work-life balance.

In this chapter, I summarize research literature related to CHWs, describe the gap in knowledge about HIVCHWs, and discuss the need for this study. I also provide evidence of consensus that the problem is current, relevant, and significant to the CHW profession, and I identify a meaningful existing gap in the research literature. I explain the purpose of the study by describing the research paradigm, the study intent, and the phenomenon. I state the research questions. I identify the theoretical framework as well as concisely state its concepts and explain how it relates to the research questions and study approach. I provide a concise rationale for selecting the qualitative tradition and methodology to examine this phenomenon. Further, I offer definitions of key concepts and terms in the study that have multiple meanings. Finally, I describe the assumptions, limitations, and delimitations of the study; suggest the significance of the study; summarize the chapter; and provide a transition to Chapter 2.

Background

CHWs are referred to by many titles, as noted by the California Association of Community Health Workers (2015), including but not limited to *peer counselor*, *lay health advisor*, and *outreach worker*. According to the CDC (2015), CHWs are members of the same communities in which their clients live and work, thereby following the lay health worker model. Therefore, CHWs support the United States in achieving health goals at the local level. The WHO (2007) suggested that the CHW lay health worker model has at least a 50-year history. According to Findley et al. (2012), in New York, CHW programs have proven to be effective. CHWs have been used to achieve improved health outcomes for clients with a variety of illnesses, such as cancer and diabetes (Staten et al., 2004). Additionally, research has shown that people who suffer from chronic illnesses, such as diabetes (Shah, Kaselitz, & Heisler, 2013), cancer (Bone et al., 2013), and HIV (Kenya et al., 2013), which are linked to CHWs, have obtained and maintained the support needed to achieve healthy quality of life. I selected both CHWs and the profession of CHW as constructs for this study.

According to Jaskiewicz and Tulenko (2012), CHWs link people to services for family planning, HIV/AIDS, and environmental health. The researchers discussed that CHW programs were scaled up, and some CHWs had even more job responsibilities. The researchers noted that establishing harmony within CHWs' work setting improved the output of the services provided by CHWs. Therefore, they noted that it was essential to consider the characteristics that influenced CHWs' productivity during program design and implementation (Jaskiewicz & Tulenko, 2012). In this study, I focused on HIVCHWs holistically by exploring their lived experiences. While previous research has focused on the efficacy of CHWs, there has been a limited amount of information on the impact the role of CHW has on the well-being of the HIVCHW. There is a need to explore this phenomenon from the perspective of the HIVCHW.

Problem Statement

Although extensive research has been conducted on CHWs, little has been known regarding how HIVCHWs perceive the impact of the role of CHW on their health and well-being. As the CHW profession gains increasing importance and scope, there is a need to learn directly from HIVCHWs about their lived experiences in order to better understand what impact, if any, working as a CHW has on their health and well-being. Shreedevi (2013) suggested that while every employed person experiences stress; work-related stress is prevalent in the healthcare field. This work-related stress affects a person's mental and physical well-being (Shreedevi, 2013).

Slocum-Gori, Hemsworth, Chan, Carson, and Kazanjian (2013) administered a self-reported instrument using validated scales to understand the complex relationships among compassion satisfaction, compassion fatigue, and burnout within the hospice and palliative care (HPC) workforce. Slocum-Gori et al. suggested that there is a need to improve policy and programs to support HPC professionals and to improve compassion satisfaction. While burnout has been highly researched in a variety of serving professions, more research is needed (Slocum et al., 2013). Rossi et al. (2012) conducted a health questionnaire with 260 staff who participated from community-based mental health services in Verona, Italy. The goal of their study was to evaluate burnout, compassion fatigue, and compassion satisfaction. Prior to their study, little research had focused on the physical, cognitive, and emotional outcomes of providing mental health care (Rossi et al. (2012). Rossi et al. found the stress level to be high for people who provided care to individuals with multifaceted mental health needs. They also suggested that these results were beneficial in helping health administrators to acknowledge characteristics that influenced workers' quality of life as well as factors that negatively and positively impacted workers' duties (Rossi et al., 2012).

Atukunda and Constance (2013) conducted a quantitative study of healthcare workers at 18 HIV health facilities. The study participants completed a stress questionnaire. The researchers concluded that when working with patients living with HIV/AIDS, healthcare workers developed healthy lifestyle habits and engaged with colleagues, family, and friends. Atukunda and Constance (2013) also suggested that workers pursued compassionate interactions with colleagues and ensured work-life balance.

These studies provided evidence from disciplines similar to CHW that the role of the job impacted workers' health and well-being. A review of research articles substantiated a gap in the body of knowledge on the impact the role of CHW has on HIVCHWs. Consequently, exploring the lived experiences of HIVCHWs from the perspective of HIVCHWs was relevant and significant to the profession of CHW. This is in-line with studies conducted by other researchers examining similar caregiver disciplines, such as nursing and counseling. I sought to learn directly from HIVCHWs about how they perceived their role as CHWs impacting their well-being. These data led to increased knowledge about the needs of CHWs.

Purpose

The purpose of this phenomenological study was to explore the lived experiences of CHWs who live with HIV/AIDS, are employed to provide support to other people who live with HIV/AIDS, and conduct HIV prevention activities from their unique perspectives. According to Harris and Larsen (2007), there is a need to examine the perceived benefits of peer counseling from the peer counselor's perspective. In this study, participants identified their experience as involving stressful encounters and discussed how they handled such situations. These data provide some insight from the perspective of HIVCHWs on how the role of CHW impacted their well-being.

Research Question

The primary research question for this study was the following: What are the lived experiences of HIVCHWs? I developed a series of prompt questions to guide the discussion if needed during the interviews with participants. The research questions are described in detail in Chapter 3.

Theoretical Framework

I utilized the theory of stress and coping (TSC) as the theoretical foundation (TF) for this study. Lazarus (1966) initially presented TSC as a transactional phenomenon dependent on how a person perceived a stressor. According to Lazarus, there are three major theoretical propositions of TSC: (a) the primary appraisal; (b) the secondary appraisal; and (c) coping (Lazarus & Folkman, 1987). I used TSC to validate and interpret this study’s results. TSC was the best TF for this study because it related to well-being, and it was a useful procedure to follow to classify circumstances (Lazarus & Folkman, 1984). I provide a more detailed explanation of TSC in Chapter 2.

Nature of the Study

I used a qualitative tradition, phenomenology, for this study. According to Trochim (2006), researchers gather qualitative data in an effort to understand the lived experiences of people. As explained by Polkinghorne (2005), a qualitative approach allows study participants to express their life experiences and perceptions of the phenomenon being studied.

Researchers utilized qualitative phenomenological methodology to gather rich, thick descriptions of a particular situation or event. Senden et al. (2015) used a qualitative interview design to discover the lived experiences of older cancer patients and family caregivers, as well as their interaction. Additionally, Lawton et al. (2015) conducted a qualitative study of employees to reveal how the job impacted employees emotionally. Similarly, Chan, Walker, and Gleaves (2015) explored students' lived experiences of smartphone usage through a phenomenological approach. In addition, Algood (2014) described the lived experience of hospice workers who used a phenomenological method; by conducting interviews with the hospice workers, Algood described the phenomenological experiences identified by the workers in their own words and processes of thought.

In this study, I used the qualitative phenomenological approach to identify the key concepts of the CHW and the profession of community health work. I explored the lived experiences of CHWs living with HIV/AIDS, who had clients also living with HIV/AIDS, and who conducted HIV prevention activities. I conducted audio recorded structured interviews with 15 participants using open-ended questions. I opened each interview with the general primary research question and then asked additional prompts, as needed. I explored how participants perceived the role of CHW affecting their well-being. I analyzed the data from the transcribed audio recordings with the assistance of a research assistant.

Definitions

The following are definitions for the main concepts and constructs for this study:

Community health worker (CHW): According to the American Public Health Association (APHA, 2014), a community healthcare worker:

> is a frontline public health worker who is a trusted member of and/or has an unusually close understanding of the community served. This trusting relationship enables the CHW to serve as a liaison/link/intermediary between health/social services and the community to facilitate access to services and improve the quality and cultural competence of service delivery. A CHW also builds individual and community capacity by increasing health knowledge and self-sufficiency through a range of activities such as outreach, community education, informal counseling, social support and advocacy. (para. 1)

Profession of CHW: According to the Bureau of Labor Statistics (BLS, 2014), CHW:

> is an occupation in which individuals in local communities promote healthy behaviors, conduct outreach for medical personnel or health organizations to implement programs in the community that promote, maintain, and improve individual and community health. May provide information on available resources, provide social support and informal counseling, advocate for individuals and community health needs, provide services such as first aid and blood pressure screening, and collect data to help identify community health needs. (para. 6)

Well-being: A state of being healthy, comfortable, or happy and total social, physical, and mental health, and not just being without infirmity or disease, indicates well-being (WHO, 1948).

Human immunodeficiency virus (HIV): Virus that negatively impacts the immune system of human beings (Whitsitt, 2009).

Acquired immune deficiency syndrome (AIDS): Advanced stages of HIV (American Academy of Family Physicians, 1988).

Assumptions

The assumptions that I made in this study were primarily based on the phenomenological research design. For example, I assumed that I could apply epoche of natural attitude while conducting this study. As such, I assumed that I could remove my previous knowledge of CHWs. Therefore, I expected that I could avoid biases affecting the findings of the study, as explained by Wertz et al. (2011). I assumed that participants who identified themselves as living with HIV/AIDS did so based on a clinical diagnosis. Additionally, I assumed that the responses of the study participants were true, correct, and reflective of their perceptions.

Delimitations

I focused on HIVCHWs and not on HIVCHWs' impact on the health outcomes of PLWHA that they served. I did not explore how situations impacted the well-being of the HIVCHW when those situations were not related to the role of CHW. These issues were important; however, they did not fall within the scope of this study, which explored the lived experiences of HIVCHWs.

Limitations

The limitations of this study included the sampling techniques. The criterion research sample was developed through a snowball technique. I made efforts to have a diverse group of study participants; however, the risk of gender, income, and racial partiality may have existed because of the demographics of the sample. I considered the potential for researcher bias as a limitation. I ameliorated this limitation by using the bracketing process, which I discuss further in Chapter 3. Although this study explored the perceptions of many HIVCHWs, the results of this research apply only to the individuals who participated in this study and, therefore, may not be reliably generalized to other individuals.

Significance

This study contributes to the field of community health work by addressing the problem of not knowing the perceptions of HIVCHWs regarding how the role of CHW impacts their well-being. The findings of this study are instrumental in contributing the perspective of the HIVCHW to the body of knowledge regarding the quality of life of HIVCHWs. This study’s findings provide CHW stakeholders such as the CDC, public health departments, HIV community organizations, medical care providers, and any entity that considers using CHWs, with data that may advance the practice and policies of CHWs. This was accomplished by hearing directly from the HIVCHW regarding their experiences with organizational policies and practices that support personal and professional satisfaction. The potential positive social change impact of this study is that the workforce of HIVCHWs is empowered to identify and self-advocate for tools needed to support a healthy work-life balance as well as prevent or reduce rates of possible adverse health outcomes among HIVCHWs.

Summary

In this chapter, I described the qualitative phenomenological study that I conducted to explore the lived experiences of CHWs living with HIV/AIDS who served clients living with HIV/AIDS and performed HIV prevention activities. The constructs of CHWs and the profession of CHW provided the background for the scope of this study. I addressed the problem of not knowing the lived experiences of HIVCHWs for the purpose of exploring how HIVCHWs perceive the role of CHW impacting their well-being. I conducted in-depth interviews to collect data from 15 HIVCHWs. The TSC served as the theoretical framework and assisted me in understanding the data. Findings from this study contribute to the gap in the literature with respect to perceptions of HIVCHWs. This study adds to the existing evidence that CHWs will continue to influence the health of their communities. Implications for positive social change are through the HIVCHWs' perceived state of health. HIVCHWs may be empowered to identify and self-advocate for tools needed for a healthy work-life balance. The potential for positive social change resides in the HIVCHW's empowerment to identify and self-advocate for tools needed for a healthy work-life balance, possibly resulting in more effective services for clients. I identify literature relevant to this study in Chapter 2.

Chapter 2: Literature Review

The purpose of this phenomenological study was to explore the lived experiences of community health workers (CHWs who live with HIV/AIDS (PLWHA) and are employed to provide support to other PLWHA in addition to working in HIV prevention. The subjects of this study were CHWs who lived with HIV, who served people also living with HIV/AIDS, and who conducted HIV prevention services (HIVCHW). There was a limited amount of data in the literature from the perspective of CHWs with regard to how their professional role affected their health and well-being. According to Harris and Larsen (2007), there has been a need to examine the perceived benefits of peer counseling from the peer counselor's perspective. I explored the lived experiences of CHWs who lived with HIV, served clients living with HIV/AIDS, and conducted HIV prevention activities.

According to Murray and Ziegler (2015), much of the research that has been conducted on CHWs has focused on strategy and policy change instead of the actual lived experiences of the CHW. Murray and Ziegler conducted a qualitative study that allowed CHWs to share their experiences in regard to their lives and careers. The participants discussed the challenges that they faced in their professional role; however, they did not discuss how the challenges affected their health, if at all. Harris and Larsen (2007) contended that using CHWs to work with PLWHA was becoming increasingly viable in prevention efforts with positive treatment options; however, they acknowledged that little research had focused on the perceived benefits of the use of CHWs from the perspectives of clients receiving services and CHWs. In a qualitative study, Harris and Larsen collected data from 12 participants who were diagnosed as HIV positive. Nine of the participants were CHWs, and 11 of the participants received CHW services. Both the CHWs and the clients discussed the benefits of giving and receiving services; however, little data were collected regarding actual experiences of the role of CHW influencing CHWs' personal health. The researchers recommended that further research be conducted to explore the CHW role in more depth.

I begin this chapter with a review of the search methods and terms I used to obtain articles that provided background for the study. I follow this with a discussion of the TF for this study. Studies related to the topic addressed the history of CHWs, CHW models, and the effectiveness of CHWs. The chapter also contains concepts found in the literature and an explanation of how the study contributes to the existing body of knowledge and fills in a knowledge gap relating to this phenomenon. I conclude with a brief transition to Chapter 3.

Literature Search Strategy

I conducted a thorough review of the literature by searching the websites of government and nongovernmental organizations, such as the CDC, District of Columbia Department of Health (DCDOH), WHO, Robert Wood Johnson Foundation (RWJF), Kaiser Family Foundation (KFF), National Institutes of Health (NIH), and APHA, as well as CHW Central and Google Scholar. An extensive search in the Walden University library involved the following databases: ProQuest Central, Ovid Nursing Journals (full text), Academic Search Complete/Premier, Expanded Academic ASAP, SAGE online journals, PsycINFO, PsychiatryOnline, Education Research Complete, Education (SAGE full text), Science Direct, CINAHL and MEDLINE Simultaneous Search, CINAHL Plus (full text), MEDLINE (full text), SocINDEX (full text), PubMed, Nursing and Allied Health Source, Health Sciences (SAGE full text), Health and Medical Complete, Management and Organizational Studies (SAGE full text), Walden Dissertations, and the Networked Digital Library of Theses and Dissertations. Additionally, the libraries of Howard University, University of Maryland, MedStar Washington Hospital Center, and University of the District of Columbia were explored. I searched the databases for literature on community health using the different titles CHWs are called in numerous combinations with terms such as *HIV*, *quality of life*, *well-being*, *history*, *model*, *types*, *health-related quality of life*, *effectiveness*, *cost*, *paid volunteer*, *training*, *programs*, *impact*, *health outcomes improvements*, and *success*. Additionally, where data were limited, as was the case when I sought articles written from the perspective of the CHW, I asked professionals in the field of study for suggestions of other names used to describe CHWs, as well as for recommendations concerning leading researchers in community health work and other venues where a search result might yield some data for this literature review. Specifically, the APHA, CHW Section, and CHW Central were identified as possible resources to ascertain information.

Theoretical Foundation

I used the TSC as the TF for this study. Lazarus (1996) initially presented the stress theory as a transactional phenomenon dependent on how a person perceives a stressor. According to Lazarus, there are three processes of stress. The *primary appraisal* is the process in which an individual is able to perceive stress. The *secondary appraisal* is the process of being mindful of possible responses to the threat. *Coping*, the third step outlined in the theory, relates to how the response is executed.

Lazarus’s stress theory was expanded to include two types of coping responses, emotion focused and problem focused (Lazarus & Folkman, 1987). An individual may use an *emotion-focused coping response* to lessen negative emotional responses such as fear, embarrassment, and anxiety related to stress. When the source of stress is beyond a person’s control, emotion-focused coping may be a practical option. Emotion-focused tactics include ignoring the problem and praying for guidance and strength. Emotion-focused coping tends to focus on the arousal caused by stress, rather than focusing on the problem itself, and it does not provide long-term solutions (McLeod, 2009). In contrast, *problem-focused coping response* involves tackling the causes of stress in a realistic manner that targets the problem or stressful situation that created stress. As a result, it directly reduces the stress. Techniques of problem-focused coping include evaluating pros and cons, taking control, and information seeking. These strategies are aimed to eliminate or diminish the root of the stressor. According to McLeod (2009), emotion-focused and problem-focused coping are methods of coping with stress. The effectiveness of the methods depends on the circumstances, the type of stressors, and the particular individual.

Stress and coping theory was among the 10 most-used theories in multiple publications in the field of behavioral change by several authors from 1999 through 2005 (Glanz et al., 2008). More recently, Lim et al. (2011) conducted a qualitative study that described daily coping and stress experienced by 23 nurse participants, whom the researchers recruited using the snowball technique. Lim et al. (examined the participants’ experiences in their personal and professional lives. The researchers noted that the interaction between personal and professional life played a major role in nurses' experiences of stress and coping. The participants reported that stress levels might have been reduced by using family support and effective stress management techniques.

Lim et al. (2011) recommended identifying methods of coping as a means to reduce turnover and achieve a healthy workforce. Similarly, Kerr et al. (2011) interviewed 42 HIV test counselors from an AIDS service organization to investigate the factors that caused stress and the techniques that countered stress. Although the nature of the study was exploratory, the researchers noted that the findings suggested that the well-being of the participants might have been increased by better training standards and a stronger support base. Lim et al. (2011) recommended future research using quantitative methods to determine the factors that indicate stress and techniques to cope with stress. This study could inform the CHW field, in that it may be instrumental in developing interventions to prevent burnout in HIVCHWs who serve as HIV test counselors.

Lim et al. (2011) and Kerr et al. (2011) selected TSC as a theoretical framework and used phenomenology to analyze data collected from interviews to understand the experiences of healthcare workers. The central concept of *appraisal* in Lazarus and Folkman's model is defined as the "the process of categorizing an encounter, and its various facets, with respect to its significance for well-being" (Lazarus & Folkman, 1984, p. 31). Both problem-focused and emotional-focused coping efforts influence outcomes, such as perceived well-being and symptom reporting (Lazarus & Folkman, 1984). Lazarus (1999) advocated for the use of qualitative approaches to analyze coping theories. The constructs of the TSC could be used as a blueprint to analyze the phenomenon of the lived experiences of HIVCHWs, more specifically how CHWs perceive that experiences as CHWs impact their health.

Literature Review

I explored the phenomenon—CHWs who live with HIV/AIDS, serve clients also living with HIV/AIDS, and conduct HIV prevention activities (HIVCHWs)—by collecting qualitative data directly from HIVCHWs about the situations they encountered while serving in the role of CHW. In this study, I investigated how the HIVCHWs identified and coped with the various situations they experienced in their professional lives.

I selected CHWs and the profession of CHW as constructs for this study. The constructs provided the background knowledge for me better to understand how the study participants responded. The definitions of a CHW by advocates such as APHA have been broad. I understand that these broad definitions have been intended to satisfy multiple end users. Therefore, I found it necessary to include the CHW as a variable in this study. In this study, I sought data about the impact that the occupation of CHW had on HIVCHWs' well-being. The occupation of CHW was the second variable for this study. The BLS (2015) of the U.S. Department of Labor predicted that the CHW occupation would grow at a rate higher than the average rate for all occupations, at 21% between 2012 through 2020. I first obtained a description of CHWs and CHW occupations. Next, I collected and interpreted data; explored the phenomenon, HIVCHW; and answered the research question, "What are the lived experiences of HIVCHWs?" According to WHO, more can be learned in relation to CHW programs; however, there is existing knowledge.

Therefore, I selected CHWs and the profession of CHW as the variables for this study.

According to Cabral et al. (2014), the 2010 Patient Protection and Affordable Care Act included an assertion that CHWs are important members of the healthcare workforce. Cabral et al. (conducted a qualitative study in which they interviewed 44 mental health peer specialists who operated in ways similar to CHWs. They also interviewed clients and supervisors of the CHWs. Data were reviewed by the entire team to identify themes using a consensus coding approach. The focus of the questions was the role of the peer specialist in the care team; however, both the peer specialist and the clients expressed the importance of their shared experiences. Although this study solicited the perspective of the CHW, it did explore how the CHW’s well-being was impacted by serving as a CHW.

In another qualitative study about CHWs, Becker et al. (2004) suggested that for disadvantaged communities, CHW programs may be among the most effective methods of health promotion and education. Becker et al. conducted a study to evaluate relations between program advocates and clients and developed a survey instrument to assess the CHW intervention strategy and individual empowerment within the context of the program. One of six questions asked of 26 advocates during four focus groups, which were conducted during a 2-week period, was “How do you think your role as an advocate has affected your clients? How do you think your role as an Advocate has affected you?” The researcher created a database by using analytic software designed for text data. The three major themes emerged were the importance of forming bonds between advocates and their clients, the resources that were available to the clients, and the ability of the advocates to become proactive their clients, after the interviews were transcribed, entered into the database and coded. Again researchers sought the perspective of the advocate. However, they failed to explore a link between the role of the advocate and the advocate’s well-being.

I explored the lived experiences of HIVCHW utilizing a qualitative research tradition, phenomenology. Draucker (1999) explained a core belief of hermeneutic phenomenology was its usefulness in finding significance and meaning of lived experiences. This study used the broader view of phenomenological research similar to what Caelli (2000) explained that the study participants expressed, insightful interpreted of their previous experiences. Valle et al. (1989) characterized this view of phenomenology as seeking descriptions from a personal perspective of the individual.

As a result of my literature search, three concepts emerged from the body of identified research that investigated CHWs. First, CHWs have a long history, which dates back to the 17th century when there was a shortage of doctors in Russia (Perez & Martinez, 2008). Second, Models of CHWs, as Urban (2014) identified a plethora of models and roles of CHW and CHW Programs. The effectiveness of CHWs was the third concept that I identified during the literature review. As Perry and Zulliger (2012) noted interventions utilizing CHWs have demonstrated positive impacts in changing the health behaviors and the health outcomes of people living with various illnesses. Although, there were numerous articles and studies on various topics as it related to the CHW, it appeared that how HIVCHWs perceive the impact that the role of CHW has on their quality of life, health, and well-being remained to be studied when I began this research.

Community Health Workers

History

The role of the CHW can be traced back to the 17th century, when there was a shortage of doctors in Russia (Perez & Martinez, 2008). Lay health workers, also known as *feldshers* or *barber surgeons*, were trained to provide care to military employees (Kenyon, 1985) and to low-income populations. As the role of CHW training became formalized, the practice spread to places such as China in 1930, where CHWs were known as *barefoot doctors* (Newell,1975), as well as Latin America, where they were known as *Promotores* (Witmer et al., 1995). Their common role was to provide health resources to populations whose members would not be able to access or afford care otherwise (Richter et al., 1974). CHWs emerged in the United States in the late 1960s, where they were part of the Great Society domestic program. Their public health mission was to improve education, promote equality, and protect the environment (Johnson, 2006). They also served under the Federal Migrant Act of 1962 and the Economic Opportunity Act of 1964, which provided federal funds for outreach efforts to low-income neighborhoods and migrant worker camps. The first official CHW programs included the Columbia Point Housing Project and a program that catered to American Indian and Alaskan Native communities (Witmer, 1995). Although CHW programs started to decline in the 1970s, CHWs and their supporters united with the APHA to create the New Professionals Special Primary Interest Group (SPIG). This collaboration conducted activities to protest the many terms used to label CHWs, including *paraprofessional*, *subprofessional*, *nonprofessional*, *auxiliary*, and *aide* (APHA, 2014). During the 1980s, CHW programs mushroomed in the aftermath of the Alma Ata Declaration, which began by stating that "health is not merely the absence of disease or infirmity, but the complete mental, physical, and social well-being, a fundamental human right, and the attainment of the highest possible level of health is a most important world-wide social goal" (WHO, 2007). Additionally, the Act suggested that all governments, despite their differences, collaborate on global health issues (WHO, 2007). CHWs were used to accomplish these goals. CHW programs began to cater to migrant and seasonal farmworker communities in the 1990s (Hunter, 2004). Since the 1990s, CHW programs have continued to grow. In 2010, the U.S. Department of Labor recognized community health workers as an official labor category (Office of Management and Budget, 2009). The 2010 passage of the Patient Protection and Affordable Care Act, Public Law 111–148, sec 5101, 5102, 5313, 5403, and 3509, also known as Obamacare, afforded additional integration of CHW programs into the health care system (Patient Protection and Affordable Care Act, 2010; Shah, 2014). Ingraham et al. (2011) suggested that the events in this timeline moved the CHW field forward to gain national recognition; however, consensus on the data regarding the impact of CHW impact remained elusive.

Workforce

Over the years, there were several attempts to clarify the CHW profession. The

Comprehensive 1998 Community Health Advisor Study was conducted which utilized CHW surveys and organizational case studies. As the results of the study seven CHW core competencies were developed (Rosenthal et al., 2011). The Department of Health Resources and Services Administration (HRSA) conducted a study called the Community Health Worker National Workforce Study in which over 500 CHWs participated (HRSA, 2007). The study yielded data from CHWs pertaining to personal and professional characteristics to better define the occupation. The 2010 National Community Health Worker Advocacy Survey (NCHWAS) was initiated to further support previous efforts to comprehend the professional roles of CHWs and to clarifying aspects of CHW training, and job activities across demographic characteristics, geographical regions, and different types of work settings (Ingraham et al., 2011).

In 2014 the Arizona Prevention Research Center, Zuckerman College of Public Health, University of Arizona was funded through a grant from the CDC to conduct an online survey of CHWs. Each of these studies were relevant, as they validated the CHW occupation.

The 2014 National Community Health Worker Advocacy Survey (NCHWAS 2014). The on-line survey was available in English, Korean, and Spanish and distributed to CHWs via local, state and national CHW professional associations, allies and programs. Of the 1,995 respondent to the on-line survey, 1,858 self-identified as a CHW, and 1,757 respondents who were eligible to complete the survey.

Hispanic/Latino race/ethnicity accounted for the largest percentage at 45, 89% of the respondents were female and 11 percent were males. The mean age of the CHWs as

45, ranging from 20 as the minimum to 77 as the maximum age. The major of the CHS's who responded to the survey had a college degree. One thousand seven hundred and fifty-seven respondents were eligible to complete the survey. According to Arizona Prevention Research Center, University of Arizona the 2014 National Community Health Worker Advocacy Survey is the largest on-line survey of CHW ever conducted.

The US Department of Labor BLS estimates that there are approximately 47,880 CHW employed in the United States. The BLS reports that Individual Family Services, Local Government, and Outpatient Care Centers are the industries with the highest levels of employment for CHWs. According to BLS Chicago-Joliet-Naperville, IL., Los Angeles-Long Beach-Glendale, CA., New York-White Plains-Wayne, NY-NJ., Boston-Cambridge-Quincy, MA., Baltimore-Towson, MD., and Washington-Arlington-Alexandria, DC-VA-MD-WV are the Metropolitan areas with the highest employment levels of CHWs.

Training

As described by HRSA (2007), CHW have gained knowledge and skills to do their jobs through formal and informal venues such as on the job, online, direct service agencies, colleges, and state certification training programs. To develop competencies skills directly related to their work tasks CHWs often participate in on-the-job training programs that improve capacities of CHWs and enhance their standards of practice. Trainings are administered informally by an experienced CHW or health care provider through mentoring or formally by the coordinator of the CHW program. Many rural CHW programs have created their own policies and regulations in regards to educational and training curricula from existing resources and best practices. For instance, Perez, et al. (2006) reported on an effective program developed to train and integrate CHWs into ongoing programs at community organizations. The Northern Manhattan Community Voices Collaborative empowered health promotion in underserved communities. There was a 16%-20% increase in CHW competency for selected skills of the 1,504 CHWs were trained. The CHWs facilitated health insurance enrollment for about 30,000 individuals, assisted 8,000 children to become completely immunized, and supported 4,000 families improving asthma management (Perez et al., 2006).

Community colleges offer Formal CHW training programs, the opportunity to earn continuing education credits, academic credit and gain skills needed for career advancement (HRSA, 2007). Love et al, (2004) reported the results of their evaluation of the first college credit– bearing CHW certificate program in the United States. They identified three main outcomes guided their assessment of the efficacy of the program: retention, career outcomes, and student proficiency. From 1995 to 1998, the retention rate was deemed successful at 84% and double the class size. The second test of the certificate programs was to assess rate of finding fulltime employment or if current CHWs were awarded promotions. A total of 85% of those surveyed reported a positive career outcome. Pre and posttest were administered at the beginning and end of the program. From 1997 to 2000, a third of the participants received a passing grade of the pretest and over three quarters obtain a passing grade on the posttest. Respondents attributed their accomplishment to their completion of the CHW certificate (Love et al., 2004). State level certifications legitimize and recognize the profession of CHW, as well as created the possibility for organizations to obtain reimbursement for insurance for services rendered by CWs (HRSA, 2007).

According to HRSA (2007) because each community has different needs there is no standard CHW training program. Brownstein et al., 2005 suggest using adult learning techniques that are inclusive, empowering, and focused on lived experiences similar to the popular education method established by the Brazilian educator and writer Paulo Freire. Additionally, CDC recommends that CHW training programs adapt existing materials from Federal and State agencies to ensure the CHWs are equipped with the necessary skills to serve the target population (CDC, 2014).

Regulations

CHWs have started to integrate into the health care system as the result of Obamacare (Shah, 2014); however, there are no federal laws that regulate CHWs. As of 2012 the District of Columbia and 15 of the 50 states have some form of regulation pertaining to CHWs in effect on the state level (CDC, 2013). These CHW state regulations are based on Anthony et al., 2009 recommended categories; infrastructure, professional identity, workforce development, and financing of issues that proposed laws should address.

AK, CA, DC, MD, MA, MN, NM, NY, OH, OR, RI, TX, UT, VA, WA, WV represents the 16 states that have enacted laws as of December 2012, that require or authorize total or partial recommendations to some extent or degree (CDC, 2013). These data are subject to change, as the state of Florida has joined the states that have enacted regulation after the CDC published the data in the table. On January 27, 2015 Members of the Florida Legislature, the Florida Certification Board, and the Florida Community Health Worker Coalition jointly announced Florida's first credentialed CHWs. According to the Florida Certification Board, CHW is a profession that is anticipating a 25% increase by the year 2022 and the professional credential brings workforce development and accountability to the CHW profession.

Models of CHW

CHWs report that employers require them to have communications, computer, interpersonal, organizational, and possible many other employable skills (HRSA, 2007). Qualities such as, ethical principles and core values of access, acceptance, advocacy, excellence, learning, partnership, self-determination, social justice, strength, trust and unity guide the work ethics of CHWs (MACHW, 2014). In addition to mastering vendible skills, professional work ethics, and decent values, a person can qualify as a CHW by having a common ethnic, linguistic, cultural or experiential connection with the population in which they serve. Additionally, having the same health condition as those they are serving is one of the most popular ways that CHWs can connect with the population in which he or she serves. These statements are reinforced by Necek and Sabatier (2003) note that culturally competence is an important characteristic or CHWs.

There are six standard CHW Program Models commonly used in the U.S. CHW programs could have characteristics of any combination of those six models. The purpose of the models is to the guide CHW responsibilities. The Lay Health Worker Model consists of CHWs that are considered members of a target population who share social, cultural and economic characteristics. In this model, they are also referred to as Peers.

West et al. (2011), used a lay health educator's model in a study weight loss intervention that was successful. Similarly, Small (2013) gathered outcome measures from randomized controlled trials pooled outcome measures obtained by Lay Health Workers yield significant improvements in self-management behaviors.

CHWs that render direct health services collaborating with medical professionals are characterized as the members of the Care and Delivery Team Model. Celletti et al. (2010) found that CHWs were valuable in the health workforce shortage, during a study with key informants. Likewise, Brownstein et al. (2011) concluded that CHWs have the likelihood to fortify the framework of health care delivery. The Care Coordinator/Manager Model utilizes CHWs to help people who have complex health conditions to navigate through the health care system. These CHWs are also known as Navigators. As explained by Taveras (2014), Navigators were used in a childhood obesity research demonstration study, and for enrolling individuals in health insurance during the open enrollment of the ACA implementation (Lang, 2014). CHWs, which have been with delivering education to a target population, are a part of the Health Education Model. Shortell (2013) discuss the use of CHWs, Health Educators and other providers in addition to physicians to obtain health and wellness. The Society for Public Health Education (SOPHE) also explains that CHWs work in tandem with other health educators to serve clients (SOPHE, 2014). The Outreach and Enrollment Agent Model has similar functions as that of the Health Educator model, however, with greater outreach and enrollment responsibilities. The Outreach and Enrollment Agent Model was used in 2013 to educate individuals about Obama Care to enroll individuals in health care plan (Lang,

2014) According to Lichtveld and Arosemena (2014) CHWs were used to collect data, and to disseminate information in the field during the aftermath of the oil spill in the Gulf of Mexico. CHWs that build community support for new activities and encourage community action are part of the Community Organizer and Capacity Builder Model. Ingram et al. (2013) expound on how CHWs pursue advocacy activities by conducting policy and system changes efforts. Additionally, Shah et al. (2014) denote possibilities to promote a policy, research and advocacy plan. CHW models are not always mutually exclusive, thus allowing for customizing CHW program design to serve specific needs.

Table 1 matches the Six CHW Models with the corresponding main Job Functions. These are standard based on HRSA; however, it is not unusual for certain aspects of models, job functions, and characteristics to be combined, depending on what is expected of the CHW (HRSA, 2007).

Table 1

Six CHW Models and Main Job Functions Under Each Model

Model	Job functions/characteristics
Lay/peer	To bridge the diverse populations they serve and the health care system
Care and delivery team	To render direct health services in collaboration with a medical professional. They may measure blood pressure and pulse and provide first aid care, medication counseling, and health screenings, among other basic services

Care coordinator or manager	To assist individuals with complex health conditions and navigate the healthcare system case management strong understanding of the health care system and resources available in their community
Health educator	To deliver health education to the target population related to disease prevention, screenings, and healthy behaviors
Outreach and enrollment	To conduct intensive home visits, deliver psychosocial support, promote maternal and child health, conduct environmental health and home assessments, offer one— on-one advice, and make referrals. To help individuals enroll in government programs
Organizer and capacity builder	To promote community action and garner support and resources from community organizations to implement new activities. CHWs may also motivate their communities to seek specific policy and social changes

Effectiveness of CHW

Obesity and smoking are risk factors for chronic diseases such as diabetes, cardiovascular disease, and cancer. The literature has data on the effectiveness of the utilization of CHWs in different roles of interventions and programs that address the previously mentioned risk factors and diseases. The research suggests that organizations such as the American Association of Diabetes Educators support the role that CHWs play in Diabetes Prevention (AADE, 2011). According to Philis-Tsimikas et al. (2004) recognized that in addition to improving diabetes-related outcomes, CHWs are essential in sustaining cost-effective care, reduction of missed appointments, treatment adherence, and allows the physician to focus on acute care.

Norris (2006) investigated the use of CHWs in diabetes care through computerized searches. The results showed the CHW's clients served gained knowledge, reported positive changes in lifestyle and self-care, and improved physiological.

Collinsworth et al. (2013) conducted a qualitative study that evaluated the effectiveness of a diabetes self-management education (DSME) program, which was led by CHWs. Collinsworth et al. (2013) sought to understand how and primary care providers (PCPs) and CHWs collaborate to provide total patient care for people who have diabetes care. Collinsworth et al. (2013) interviewed Seven PCPs and five CHWs via semi and concluded that when CHWs are a part of a health care system’s care coordination strategy, which can play a variety of roles in helping patients overcome barriers to diabetes control. The success was based a quantitative pre- and post-assessment of change in the results of patients who participated in the program, with whom the CHW work. The systolic blood pressure readings and A1C of these patients were significant improved one year after the baseline measurement.

Hurtado et al. (2014) evaluated a CHW conducted curriculum, use to identify and manage cardiovascular disease risk factors. The findings indicated an increase in CHWs clients’ knowledge as well as an increase in readiness for positive behavior change. In a phenomenological study, CHWs were used to link citizens within the community to health service delivery systems for a breast and cervical cancer health promotion program (Mayfield-Johnson, Rachal, & Butler, 2014). The data from the research suggested that

CHWs are useful in preventing and managing programs resulted in desired outcomes in chronic health issues. This study also resulted in an increase of the CHW’s knowledge on the cancer.

Andrews et al. (2012) conducted a study that used nurses and CHWs to reach African American women who participated in a smoking cessation intervention that was conducted in subsidized housing developments. The CHWs were instrumental in recruiting the 15 program participants. Andrews et al. (2012) suggest the CHWs provided social support and self-efficacy training with the cessation intervention process in women who hold like beliefs. Once a week for six weeks nurses conducted education and behavioral counseling for a group, and at week 12 they perform a review session. They measured abstinence rate at baseline week 1, week 6, and week 12. Upon analyzing the data, abstinence rates at weeks 6 and 12 were 80% and 73%, respectively, and the 2-month sustained abstinence rate was 60% (Andrews et al., 2012). These data show a significant progression for social support and self-efficacy scores (Andrews et al., 2012). The researchers concluded that partnering with CHWs is viable tactic to assisting low socioeconomic African American women access smoking cessation programs (Andrews et al., 2012).

Obesity prevention and management programs are areas in which CHWs are being utilized, as is in the randomized controlled trial conducted by Goin et al. (2014). One goal of Goin et al. (2014) study was to examine how Steps to Growing Up Healthy, obesity prevention program, was impacted by monthly phone call or home visits by a

CHW. For the study two bilingual/bicultural CHWs certified by the Central Area Health Education Center, Inc. were hired and provided training (Goin et al., 2014).

Islam et al. (2013) used a randomized controlled trial among Korean Americans which explored the impact and feasibility of a pilot CHW intervention program in order to improve health behaviors and promote diabetes prevention. Forty-eight Korean Americans who were at risk for diabetes and lived in New York City (NYC) were placed in either the treatment or control group. The treatment group received six two-hour workshops held by trained, bilingual Korean American CHW on diabetes related risk factors. The researchers examined for changes over six months including mental health. The data exhibited ways in which CHWs can influence outcomes. Although the primary focus of this study was diabetes, these results demonstrate that CHW can be successful in improving mental health among the Korean American population in NYC (Islam et al., 2013).

The above article highlights that CHW have been effective in contributing the desired health, outcomes. The literature also suggests that CHWs have been shown to be effective in reducing healthcare costs Fedder et al. (2003), Johnson et al. (2012) and Felix et al. (2011). According to Mirambeau et al. (2013) even though there have been studies that focused primarily on program costs, very few studies provided a comprehensive analysis of those costs. From October 2010 through September 2011, Mirambeau et al. (2013) conducted a detailed analysis of costs of the Northeastern Vermont Regional Hospital Community Connections (NVRHCoCo). The program employed two CHWs who focused on improving the quality of life of all 27,000 residents in the hospital service area. The researchers established a data collection team consisting of a program evaluator, a health economist, a hospital administrator, and a health scientist. The researcher explains the tool they created and the method they employed may allow for a full, comprehensive assessment of a CHW program’s cost based on itemized items from actual financial records for the program. The researcher suggest that their approach may also serve as a useful approach and a helpful reference for others seeking to conduct a systematic cost analysis of CHW programs their programs (Mirambeau et al., 2013).

According to Perry and Zulliger (2012), “CHWs are the world’s most promising health workforce resource for enabling health systems in resource-constrained settings to reduce the burden of disease from severe, readily preventable or treatable conditions. They are the most promising health workforce resource because there is an abundant supply of potential recruits”.

Gap in Literature

A literature search for research published since 2009 specifically related to the perspective of CHW about the impact of the CHW role has on their health produced a plethora of articles. Javanparast et al. (2011) conducted a qualitative study to document CHWs' perceptions of their role within rural communities and their contribution over time to health improvements. Wiggins et al. (2009) conducted in-depth interview with five CHWs to explore their views on how the use of popular education effects the CHWs and their communities. Boyd et al. (2011) conducted three focus groups in which 16 CHWs, to discuss the performance of staff who serve that needs of pregnant women with mental challenges; however, a scan of the articles, like the samples above, show that although most of the articles were from the perspective of the CHW, the articles were not about the impact of CHW role has on the CHW's health. Therefore, the identified gap in the literature is the perspective of the HIVCHW regarding how the role of CHW impacts their quality of life, health, and well-being.

Health Effects of CHW

I surveyed the literature for data on the health outcomes of people who are employed as CHWs. Ge, Fu, Chang, and Wang (2011) published an article containing self-administered questionnaire that was completed by 1,694 CHWs in northeast China's Liaoning Province. The questionnaire assessed the correlations of job satisfaction, stress and burnout among CHWs. The results of the questionnaire also strengthened the evidence that stress and burnout were negatively associated with higher job satisfaction. I found few data about the health effects of CHW. Therefore, I also searched the literature for work burnout and fatigue in occupations similar to CHW such as social workers, nurses, mental health counselors, and clinical staff caring for sick and terminally ill patients. I identified a qualitative study conducted by Lawson (2007) of 501 counselors, who were members of the American Counseling Association. Lawson notes that the wellness of Counselor has a direct impact on the quality of services clients receive; however, little is known about the overall wellness of counselors. The purpose of Lawson's research was to explore the wellness and wellness strategies of counselors. The counselor's responses suggested that although they have areas of concern, they are mostly healthy and content with their work (Lawson, 2007). Lawson concluded that the survey established the importance of exploring counselor wellness, deficiency, and approaches for sustaining wellness in this perplexing field. In the proposed study, I hypothesize that working as a CHW takes the same toll on health experienced by other related workers. While (Ge et al., 2011 & Lawson, 2011), demonstrates that exploring the wellness of healthcare workers is valid and important, their studies also confirm the rationale for the proposed study

Conclusion

The purpose of this study was to explore the lived experiences of HIV community health workers (HIVCHWs) from their perspective. This chapter includes a descriptive narrative of the research methodology of the qualitative research study. Also included in this chapter is the rationale for this method of inquiry. I clarify my role as the researcher and address potential bias. I describe the sample population and methods of recruitment, data collection methods, and study analysis. An account of the actions taken to secure ethical assurance and protection of human subjects for the study closes the chapter.

Chapter 3: Research Design

Study Design and Approach

I conducted a qualitative phenomenological study to explore the lived experiences of HIVCHWs, specifically regarding the impact the role of CHW has on the well-being and quality of life of the HIVCHWs who live with and serve others who live with HIV/AIDS. I began data collection with one primary research question: What are the lived experiences of HIVCHWs? The qualitative tradition was appropriate for my study, as explained by Tong et al. (2007), in that qualitative research may be used to examine complicated phenomena encountered by health care providers, clinicians, consumers, and policymakers et al. Creswell (2007) explained that quantitative research methods are limited in comparison, as they are used to illuminate or determine relationships between variables. Phenomenology, narrative, grounded theory, case study, and ethnography are the five main approaches to qualitative methodology as explained by Creswell (2012). I employed a phenomenology approach in this study. According to van Manen (1990), hermeneutical phenomenology is applied to research oriented toward lived experience. Phenomenology is also an interpretive process in which the researcher makes an interpretation of the meaning of the lived experiences (Moustakas, 1994). I considered using narrative because it involves stories about lived experience and researchers use it to analyze and understand those stories (Pinnegar & Daynes, 2006). I did not select a narrative study because narrative is geared toward the life of a single individual.

A phenomenological approach was suitable for my study because I sought to describe meaning for several individuals based on their lived experiences of a concept or phenomenon (Creswell, 2006). Chunlestskul et al. (2008) used a qualitative phenomenology study to explore the lived experience of family members of patients in the intensive care unit. The researchers conducted in-depth interviews with six family members and analyzed the data using qualitative thematic analysis, which resulted in four main themes. The study concluded with the researchers collecting relevant insight from family members’ views on how they found ways of dealing with the situation. The researchers noted that these data proved relevant to clinical practice (Chunlestskul et al., 2008). Additionally, Hanks (2008) explored lived experiences using qualitative phenomenology. Hanks conducted 90-minute semistructured interviews with three medical-surgical registered nurses. His research question guided the interviews. He analyzed the data and identified themes. His findings increased the body of knowledge surrounding nursing advocacy as practiced by nurses (Hanks, 2008). The use of a phenomenological inquiry method by Hanks (2008) and Chunlestskul et al. (2008) to described lived experiences demonstrated that it was appropriate and supported my decision to use phenomenology. I used the TSC as a guide for understanding and interpreting the data in this study.

Role of the Researcher in Data Collection

I developed a protocol to identify and qualify study participants, gather and interpret perceptions and personal experiences of the study participants, and remain flexible (Creswell, 2013). My role as the researcher was that of an observer. I asked the research question, and I followed up with probing questions as necessary. Although the field of CHW was of interest to me, I did not have any power over the potential participants, as I did not supervise or instruct CHWs, nor did I interview any CHWs with whom I had professional of personal relationships. According to Creswell (2012), a researcher is obligated to set aside his or her prejudgments. I controlled potential personal bias in the data collection and interpretation processes by using the bracketing process as defined by Creswell (1998) as a process of researchers recognizing their opinions and biases. Creswell suggested that researchers reveal their positions on phenomena to the reader and then bracket or suspend those researcher biases as the study proceeds. Chenail (2011) suggested conducting a pilot study to address possible bias. I conducted two pilot interviews that served as a pilot study, allowed for review and correction of bias in the instrument, and provided me practice in conducting the interviews. I provided the participants with $10 cash and $5 cash to reimburse them for the cost of transportation to the interview and as a token of appreciation for participating in the study.

Methodology

The primary aim of this qualitative study was to investigate the lived experiences of HIVCHWs. I used criteria and snowballing sampling strategies. Patton (2001) defined using more than one strategy as combination or mixed purposeful sampling and suggested that it accomplished several goals. Criteria sampling satisfied the need for participants to meet specific inclusion requirements (Patton, 2001). Because one of the inclusion requirements was of a sensitive nature, asking people who met the criteria to ask other people they knew who met the criteria to participate in the study (i.e., snowballing; Patton, 2001) was a useful approach to sampling for this study.

The selection criteria for inclusion in this study stipulated that participants needed to (a) be currently employed as CHWs (b) self-identify as living with HIV/AIDS (PLWHA) (c) serve clients who are PLWHA (d) conduct HIV prevention activities (e) be at least 18 years of age (f) have previously worked as a CHW (g) agree to being audio recorded, and (h) have the mental capacity to sign an informed consent (see Appendix G) without a legal representative. I developed an inclusion criteria screening tool as part of the recruitment and interview protocol (see Appendix A).

I sought to obtain quality information by interviewing 15 HIVCHWs for this study. According to Benner (1994), an adequate sample size is reached when interpretations are clear and observable. When no new meaning or themes emerged from the data, I reached saturation and ceased to conduct interviews.

I obtained permission from the community research partners, organizations that employ HIVCHWs, to place information flyers about the study in their offices. I ensured confidentiality of the community research partners by referring to them as CP1 and CP2. I also obtained permission to place flyers in two additional community research partner locations in the event that I did not recruit enough participants from the first two organizations. I referred to the additional community research partners as CP3 and CP4. I have attached the letters of intent to cooperate as partners in Appendix B. The flyers contained a brief summary of the purpose of the study and the inclusion criteria, along with a request for volunteers to participate in the study. The informational flyers also included a request to pass the study information along to others who might meet the criteria for participation in the study.

I listed my telephone number as the method for participants to contact me to express interest in participating in the study. I have attached a copy of the information flyer in Appendix C. When I was contacted by a potential participant, I conducted an inclusion criteria screening interview over the telephone to identify whether the person met the inclusion criteria. If the person met the inclusion criteria, I reviewed the purpose of the study and informed him or her that participation was voluntary, data would be audio recorded, and all information would be kept confidential. I scheduled an interview during a timeframe and in a location that was most convenient for the participant. I offered my private office as a meeting option. My office was located in northeast

Washington, DC. It was secured, accessible via public transportation, and compatible for physically impaired individuals; however, if that was not convenient for study participants, I met them at a location of their choice.

Data Collection Tool

I acted as the primary data collection tool for this study. I used an interview protocol (see Appendix D) to guide the in-depth interviews with the participants. I developed questions based on the study’s main research question (What are the lived experiences of HIVCHWs?) and probing questions that I asked only when the participant did not expound and add information that was needed. Examples of probing questions are as follows: What about that encounter was stressful? How did you handle that situation? How do you feel the role of CHW impacts well-being? I asked the main questions followed by probing questions to gain the most descriptive and accurate data from participants (Rubin & Rubin, 2011). I used an audio recorder to assure that the responses and perspectives of the participants were properly recorded for accurate transcription. I conducted a pilot study that confirmed the validity and refinement of research questions and tools (Kvale, 2007). These instruments allowed for data collection in a thorough examination, as suggested by Polkinghorn (2005), in order to rigorously study the experiences of the participants.

I developed the list of interview questions based on the research questions, purpose, and theoretical framework of the study. The interview questions were appropriate for the phenomenological qualitative method of this study. Qualitative studies conducted by Calman, Brunton, and Molassiotis (2013) and Roberts et al. (2013) exploring lived experiences involved similar questions.

Data Collection Methods and Rationale

I collected data for this study by conducting confidential, anonymous in-depth interviews. I asked the same open-ended opening question and follow-up prompt questions with each participant, as Gall, Gall, and Borg (2003) noted that structured interviews encouraged participants to express their perspectives and experiences. I audio recorded the interviews. I collected the data in my private office, which was located in northeast Washington, DC. It was secured, accessible via public transportation, and compatible for physically impaired individuals; however, when that was not convenient for study participants, I met them at a location of their choice. Creswell (1998) suggested selecting up to 10 study participants who have experienced the phenomenon of interest. If I had not recruited at least 15 participants or reached saturation within the 2-week period, I planned to create an additional 2-week data collection schedule and recruit from organizations FU1 and FU2. I did not find this necessary. If, for some reason, the research assistant or I had not understood the participants' response, I planned to notify the participant via telephone and collect clarification data. I did not find this necessary. I considered conducting focus groups to collect more data in a short amount of time; however, in light of the study participants' positive HIV status, one-on-one interviews provided privacy to the study participants.

Pilot Study

I prepared for the actual study by conducting a pilot study. I recruited the pilot study participant through snowballing. I identified four organizations that hired HIVCHWs and recruited participants for the study from these organizations and through word of mouth for this phenomenological study. I conducted one-on-one in depth interviews with 15 study participants. I asked CHWs to refer other CHWs to participate in the pilot study. The pilot study was an important stage in preparing for the main study. The protocol for the pilot mirrored that of the main study (see Appendix E.). After receiving permission from the Walden Institutional Review Board (IRB) to collect data, I conducted a pilot study with two study participants, through which I gained practice and tested for issues and problems that might occur during the main study.

The protocol for the pilot study was followed. I met the study participant at the agreed-upon location. If the location of the meeting was my office, I greeted the study participant at the front door of the building and introduced myself. I escorted the participant to my office, pointing out the restroom on the way. I asked about the participant's comfort as it related the room temperature and offered water, coffee, or tea. I explained the purpose of the study and provided an informed consent form for the participant's review. I discussed items in the consent form as they related to ethical principles of autonomy, beneficence, and justice. I also reminded the participant that the interview would be audio recorded. I informed the participant of how long I anticipated the interview would last. I notified the participant that this would be the only contact we would have for this study unless I needed to clarify a response. I asked if it would be alright for me to contact the participant via telephone if that was necessary. I asked if the participant understood, had questions, and agreed. I answered any questions and asked the participant to sign the form. I locked the forms in my desk drawer. I turned on the audio recorder, tested it, and asked the questions. Data were collected from participants from one-on-one interviews using opened-ended questions. As explained by Munhall (2007), the main goal was to obtain a better understanding of the lived experience. The way in which the respondents told their stories was based on how I asked the questions. I took written notes on nonverbal communications during the interview. Upon completion of the interview, I asked if the participant had questions for me. I advised the participant that the interview was over. I gave the participant the incentive, asked the participant to sign for the incentive, and turned off the audio recorder. After the interview was over, I made notes in my journal about the interview. I documented nonverbal communications and my personal feelings about the interview.

The main purpose of the pilot study was for me to gain practice in administering the interviews and with the interview process. During the pilot study, I identified any weaknesses, limitations or flaws, and limitations within the interview design. As noted by Kvale (2007), I made needed revisions before implementing the actual study, which is the purpose of a pilot study, in order to refine how I asked questions to get specific information. I did not need to revise my protocol and data collection tool. Therefore, I did not need to collaborate with my committee and submit revised materials to the Walden IRB for expedited review and approval to conduct the main study. As suggested by

McNamara (2009), the preparation stage helps a researcher achieve maximum benefits from a research study.

Data Analysis

I used a phenomenological approach to analyze the data collected from the one-on-one interviews and allow the materialization of concepts and themes. The overall phenomenological data analysis consisted of coding, categorizing, and making sense of the essential meaning of the phenomenon. I hired a professional transcriber to transcribe the audio tapes. I analyzed the data by using a process described by Kleiman (2004). To gain a sense of the big picture, I listened to the interview in its entirety. In an effort to divide the data into significant parts, I deliberately listened to each of the interviews two more times. I organized sections by research questions and similar focus and determined which ones were essential to the study. I assigned codes, which I describe in more detail in Chapter 4. I justified my descriptions upon another review of the raw data to substantiate the accuracy of my findings. After a thorough analysis of my data, I conducted a critical analysis of my work within my research study.

I assured rigor and validity of the study by having one research assistant (RA) independently code and analyze the interviews. I required that the RA sign a letter of confidentiality (see Appendix F) prior to handing the data. We corroborated and compared notes. Where we identified any discrepant cases, as a validity strategy we reviewed the audio recording and transcript to resolve the discrepancy.

I did not follow the customary scheme of phenomenological analysis with the assistance of a qualitative software package such as NVivo 10. I manually organized the data using pen, paper, note pads, and color markers. I created charts, developed codes, discovered themes, connected themes, and analyzed and reported data (Creswell, 2011). I did not identify the names of participants during the analysis. Pereira (2012) suggested that in order for phenomenological research to appear valid, it must at least undergo rigorous and appropriate procedures that provide insight in terms of plausibility and illumination about a specific phenomenon.

Issues of Trustworthiness

I put controls in place to assure the trustworthiness of the study. I addressed internal validity by working with a research assistant to analyze the data. As noted by (Denzin, 1978 & Patton, 1999) this type of analysis is called analyst triangulation which allowed for comprehending the data from various perspectives. I made entries in a reflexive journal after each interview. According to (Lincoln & Guba, 1985) recording the reasons for methodological decisions establishes confirmability and address researcher bias. Additionally, I did not find it necessary to member checks to clarify and confirm particular aspects of the data. As explained by (Lincoln & Guba, 1985) member checks engage individual from whom the data were initially collected and this establishes credibility in the study.

Human Rights Protection Measure

Prior to data collection for the pilot study and the main study, I applied for approval to collect data from the Walden University Institutional Review Board. To uphold the highest ethical standards, ethical assurance of participants’ confidentiality, privacy, and informed consent had precedence during the study. I protected the participants’ identity, by conducting the interview in my private locations. I assigned each participant a unique identifier that only I know how to decode. I required the participants to sign a consent form, which listed the participants’ rights. I also verbally notified the participants of their right to refuse to answer any questions, and withdraw at any point during the study. I informed the study participant that in addition to myself, the research assistant, the dissertation committee members, and the transcriber would have access to the data. I included the list of individuals with access to the study data Appendix I. I encrypted the data and am the only person with the password. I will destroy the data five years after the study is completed. As explained by (Oliver & Barr, 2014), ethical research procedures were developed to minimize potential mental, emotional, or bodily harm to research study participants.

Summary

In this chapter, I described in great detail the design, approach, and methodology for the qualitative phenomenology research study. The method and the approach were appropriate for the study as it sought to examine human experience (Polkinghorne, 2005). I labeled my role as researcher as an observer in this research study. I identified the data collection tools of in-depth one on one interviews and explained the rationale for the interview questions. I defined the recruitment procedures. I expounded upon protocol for both the pilot and main study. I justified the data analysis process and validated the trustworthiness of the data analysis and confirmed how I protected the study participants’ human rights. Upon approval of the proposed study, I collected data, which I analyzed and discussed in Chapter 4. Following in Chapter 5, I interpreted the findings of the data collection and made recommendations for future research.

Chapter 4: Results and Outcomes

This study’s purpose was to explore the perceptions of HIVCHWs regarding the impact their job as an HIVCHW had on their well-being. Results of the study may serve to inform stakeholders invested in the CHW field. I conducted a pilot study with two individual HIVCHWs. The intention of the pilot study was to serve as a test run of the main study. For the main study, I then conducted in-depth one-on-one interviews with 15 individual HIVCHWs. The participants shared firsthand personal experiences and perceptions of how their well-being had or had not been impacted by their job as a HIVCHW. The primary research question for this phenomenological study was the following: What are the lived expectances of HIVCHWs? This chapter includes a description of the pilot study, the setting for the in-depth interviews, demographics of the study participants, and the study findings.

Pilot Study

For the pilot study on December 9 and 16, 2015, I conducted individual in--depth interviews with two different HIVCHWs. The pilot study offered me the opportunity to practice interviewing participants and to determine whether my research questions and interview guide were appropriate tools to gather data for this study. The pilot study participants provided answers to the main research questions and the probing questions while discussing their experiences as HIVCHWs. Upon review of the pilot study, I determined that I needed to do a better job at keeping the participants focused on the main research question. I did not find it necessary to make any changes to my originally proposed study protocol as a result of the pilot study.

Setting

I conducted the interviews in my private office and the homes of study participants at their request. I began each interview by reading the informed consent form (ICF) to the participant. The ICF disclosed the purpose of the study, researcher's responsibilities, and the rights of the participants. I reminded the participants that the interviews would be recorded from beginning to end. I disclosed to each participant my past employment as a CHW and expressed the respect that I have for the CHW field. In building this type of rapport with the participants, I hoped that they would be more open about their experiences and perceptions.

Participant Demographics

The two pilot study participants and the 15 individual HIVCHWs who were interviewed were all currently or previously employed as CHWs and were living with HIV/AIDS. Every study participant completed a demographic form. The purpose was to collect data on age, gender, level of education, marital status, and income. The amount of time served as a HIVCHW, type of training received, size of case load, services provided, and affiliation to a professional or formal CHW organization were collected from each participant.

Age

The ages of the participants ranged from 39 to 70 years. The mode age was 49 years. The median age was 57 years. The mean age was 55 years.

Gender

The gender makeup of the study participants was as follows: Of the 15 participants, 13 (87%) were female, and two (13%) were male. See Table 2 below. Table 2

Frequency Distribution of Study Participants by Age and Gender (N = 15)

Age	Male	Female	Total
Mean age	60	50	55
30-39	0	1	1
40-49	0	4	4
50-59	1	4	5
60-69	1	3	4
70-79	0	1	1
Subtotal	2	13	15
Percent	13%	87%	100%
Total	2	13	15

Education

The majority of the participants—87% (*n* = 13)—had graduated from high school; 27% (*n* = 3) did not graduate from high school. In terms of higher education, four participants (27%) held a college degree, and one (6%) had earned a graduate degree. Some participants selected more than one answer. See Table 3.

Table 3

Education Level Distribution of HIVCHWs (N = 15)

Education	Count	Percent
Did not complete high school	3	27%
High school diploma/GED	13	87%
College graduate	4	27%
Graduate degree	1	7%

Marital Status

Most of the study participants—53% (*n* = 8)—had never been married or were living with a partner. Twenty percent (*n* = 3) were currently married. Twenty percent (*n* = 3) of the participants identified as widowed. Thirteen percent (*n* =2) of the participants were divorced, and seven percent (*n* = 1) reported marital status as separated.

Income

The average income reported by 33% (*n* = 5) of the study participants was in the low range of less than $10,000. One of the participants indicated earning in the high range of $60,000 or more. Three (20%) indicated earning a salary between $40,000 and $49,000. Two CHWs reported $50,000 to $59,000 as their annual salary, while one reported a salary in the $20,000 range.

Time Worked

Of the 15 respondents, 10 (67%) currently worked as HIVCHWs, and 5 (33%) previously worked as CHWs. The amount of time that the study participants served as HIVCHWs ranged from 4 months to 18 years. Three HIVCHW worked for 10 years, which was the mode. The median was 6 years, and the average time working for all participants was 7 years. See Table 4.

Table 4 *Study Participants by Time Worked as a HIVCHW (N= 15)* Years' work as HIVCHW	Count	Percent
0-1 year	2	13%
2-5 years	5	33%
6-10 years	4	27%
10-17years	3	20%
18 or more years	1	7%
Mean	7	
No longer CHW	5	33%
Total	15	100%

Training

The type of training available to prepare individuals for a CHW career varies throughout the world. One (7%) respondent identified online training as the method of CHW training received, while two (13%) participants expressed that they did not receive any training. Five (33%) of the CHWs had attended a certificate program, whereas six (40%) study participants mentioned being given on-the-job training and seven (47%) reported having participated in classroom training. See Table 5. Table 5

Study Participants by Type of Training Received

Type of training	Count	Percent
Online	1	7%

No training	2	13%
Certificate program	5	33%
On the job	6	40%
In classroom	7	47%

Case Loads

The actual case load size varied from HIVCHW to HIVCHW. The range was from zero to 55. The average number of clients for the HIVCHWs who responded was 18, and the median was 16. The mode was 15. The types of services provided by the study participants were as varied as the case load sizes.

Services

Prevention was the service provided by 12 or 71% of the study participants. Food service and help with errands were indicated by 7 or 41% of the respondents. In addition, 14 or 82% explained that they provided other service including but not limited to accompanying clients on doctor visits and health education tasks, such as discussing laboratory results. See Table 6. Table 6

Study Participants by Services Provided to Clients

Services provided	Count	Percent
Prevention	11	73%
Food services	7	47%
Help with errands	6	40%
Other services	12	80%

There are professional organizations that provide support and advocate for CHWs. Of the participants interviewed, five (33%) indicated that they were members of such organizations, and nine (60%) reported not being associated with any such groups. One (7%) of the HIVCHWs referenced being a member of a professional organization not related to CHWs. All 100% of the study participants were of the Black/African American race and resided in the metropolitan Washington, DC area.

Data Collection

In Chapter 3, I described the research design, the procedure for collecting data, and the evidence of quality for this study. In the in-depth audio recorded interviews, I gathered the data by asking my opening general question: “So tell me, what it is like working as a community health worker?” That question prompted the HIVCHWs to describe how they felt about being CHWs. Most of the HIVCHWs stated terms that were either favorable or adverse. This led to broad banter that I found it necessary to make more focused. Therefore, when the study participants mentioned words that I thought would provide more insight on the study questions, I asked prompting questions such as “So, can you talk about that a bit more? Can you tell me more about that?” To ensure that I comprehended what the HIVCHW was saying, I asked additional prompting questions, such as the following: “So, if I am understanding correctly, [paraphrase what participant said]—is that right?” If a HIVCHW used a term that could be interpreted in many ways, I asked, “What does that mean?” For example, a HIVCHW said that she had been hurt by a situation that she encountered. Therefore, I asked, “What does *hurt* mean?” for clarification. In addition, when some of the HIVCHWs were less forthcoming in responding to the opening questions, I used specific additional prompting questions, such as “What is a day like in your life as a CHW?” or “So tell me, does working as a CHW affect you in any way?” If a participant indicated stress or other adverse impact, I asked, “How do you handle the situation?” If participants did not mention adverse impact on their own, I prompted them in a subtle way, by asking, “So, can you talk a bit more about the role of CHW and your well-being?” See Appendix D. I followed the proposed methods accordingly. There were a total of 17 participants for this study, consisting of two participants in the pilot study and 15 participants in the actual study. All of the participants for both the pilot and actual study shared their experiences and perceptions in relationship to the impact the job of HIVCHW had on their well-being. This was done by way of audio recorded in-depth interviews. The participants of the pilot study also expressed their opinions on the effectiveness and understanding of the research questions in gathering data sought. From December 2015 through February 2016, I interviewed a total of 17 study participants in my office, in their home, or at locations where they felt comfortable. Some of the interviews were done in my office, the study participants’ private offices, or in the privacy of participants’ homes or cars. I used a voice recorder to document the interviews. I took written notes while the participant was speaking when situations arose to remind me to clarify a statement or word. I also made notes when the HIVCHW demonstrated some emotion or behavior when explaining a situation during the interview. I debriefed after each interview by reading my notes and adding notes as needed. The interviews lasted for a total of 416 minutes. The shortest interview was 8 minutes long, and the lengthiest interview was 69 minutes in duration, for an average interview time of 25 minutes.

Data Analysis

I analyzed the data by arranging the data on large sheets of paper, using a color coding system to group data into themes. I listened to the audio-recorded interviews three times each. The first time, I listened to the interview in its entirety and took general notes. This helped me to identify the voice tone expressed by the study participants when responding to the questions.

The second time, I listened to the interviews, paying close attention to the responses the participants gave to the first question during the interview: What is the lived experience of HIVCHWs? On a large sheet of paper that I titled *experience*, I listed every descriptive word the study participants stated as they responded to the question, *What is it like being a HIVCHW?* I listed these nine words and phrases on a sheet of paper and grouped them into two columns titled *positive* and *negative*.

The third time, I listened to the interviews with a concentration on what the study participants communicated in relation to how being a CHW affected their well-being. In a notepad, I labeled 15 pages with each HIVCHW's unique identifier on the top of the page. As I listened to a particular HIVCHW, I recorded on his or her specific page every word used to describe the impact that being a CHW had on his or her well-being. Next, I created a handwritten table entitled *impact*. It consisted of 19 columns. The first column was labeled *code*, columns 2 through 18 had one of each of the study participant's unique identifiers, and column 19 was labeled *total*. I transferred the words recorded on the pages from the notepad that described the impact of being a CHW on participants' well-being to create the rows for the table, and I removed duplicated words. I identified 25 words and phrases, which became the codes for this study. I next created a table consisting of 19 columns and 26 rows, on which I recorded which participants used which words by placing a check mark on the row with the word under the column of the participant, and I totaled each row. The research assistant (RA) listened to the recordings and confirmed that I accurately identified in the experience and impact tables the terms the study participants stated during the interviews.

As this study involved exploring the impact of being a CHW on HIVCHWs' well-being, I developed a broad set of themes based on elements related to well-being and created a chart called *themes*. It had six columns and 16 rows. The first cell of each row had one of the themes in it, and the columns were titled *All themes*, *Combined with*, *Eliminated*, *Codes/words/phrases*, *Final themes*, and *Comments*. I placed each of the codes in the cell of the themes that it best fit. The RA completed the same exercise, and we compared our tables. I modified the themes based on our comparison of the themes table. This handwritten method of organizing the data was time consuming and perhaps not as automated as NVivo; however, it was most useful and allowed me to organize and ultimately analyze the collected data.

Evidence of Trustworthiness

To ensure that the data collection process adhered to the ethical considerations set forth by Walden University, I collected the data according to the procedures outlined in my proposal that was approved by the Institutional Review Board (approval number 12-

02-15-0155984). Evidence of trustworthiness in this study was demonstrated by analyzing the data with a research assistant to address internal validity. (Denzin, 1978 & Patton, 1999) described this process that allows for understanding of the data in many ways as analyst triangulation. I employed the multiple analysts' method of triangulation, by working with the RA during data analyses. My goal here was not to validate what the participants were saying, as much as it was to allow the participants to have a voice and to allow their perspective to be heard. The RA and I did not always achieve a consensus. The purpose of working with the RA was to see the data in multiple ways. I believe we accomplished this goal as there where encounters where we interrupted the data differently. For instance, with the code we did not always select the same themes for each code; however, after reviewing to data again we agreed that it was acceptable for the code to apply to multiple themes.

Results

To explore the lived experience of the HIVCHW, I asked each study participants what is it like to be a CHW? I allowed them as much time a necessary to expound upon their experiences. I listened for key words that could further define their experiences. The terms love, good, and rewarding were the most commonly referred, as nine, 53% of the HIVCHWs use these terms to describe their experiences. The term love was used to describe the experience by three 20% of the study participants. Two, 12% of the HIVCHWs describe the experience as rewarding. Four, 24% explicitly cited good when then they responded to this questions. As an example; Participant 2 said; "Being a CHW is rewarding work." While, Participant 3 said; "I love being a CHW', and Participant 7 said; “Being a CHW makes me feel good” are direct quotes from the study participants. These other descriptors; fulfilling, fruitful, challenging, satisfying, learned a lot, and negative were stated by at least 1, 6% of the of the HIVCHWs. Participant 14; stated “being a CHW was a negative experience”, while Participants 9 and 11 did not describe their experience as either favorable or adverse. I categorized these data into groups that appeared as experiences that were favorable, adverse or neither. I entitled the favorable group theme Positive. I named the adverse group theme Negative and the group that did not describe the experience as either favorable or adverse, I grouped it in the neither theme. See in Table Number Seven, I summarize the opinions of the study participants on their experience of being a HIVCHW.

Table 7

Participants' Assessment Description

Participants' Assessment Description	Participant number	Comment
Positive	1	Love being a CHW
Positive	2	Love giving to community
(These study participants made specific comments that suggested their experience as a HIVCHW was favorable.)	3	I've learned a lot
	4	Rewarding
	5	Makes me feel good
	6	It's fruitful
	9	Enriching and rewarding
	10	Good
	12	Good
	13	Fulfilled
	15	Love it
Negative (This study participant comment implicitly indicated that the experience was negative.)	14	Felt good about being a CHW It was a negative experience
Neither	7	
(These study participants did not comment either way, positive or negative)	8	Long journey with ups and downs
	11	

During the in-depth interviews, the study participants either volunteered terms related to how being a CHW impacted their well-being or I prompted for the information. The terms used were; stress, burnout, tired, exhausted, sick, forgetful, not concentrating, pain, worry, lose sleep, anxiety, do not eat, irritated, frustrated, neglect, draining, care for their clients’ first, medical adherent, trauma, eating healthy, guilt, overwhelmed, putting clients’ first, transference, and hurt. I use these data to identify the twenty-five codes for this study. The words; stress, burnout, and tired were mentioned by more study participants than other words and phrases. They were mentioned by seven (41%), five (29%), and six (35%) of the participants respectfully. For instance, Participant 3 stated “sometimes it can be stressful”. Burnout was mentioned by Participant 9. The participant described a time when attempting to do too much lead to forgetful. The participant said “my supervisor said I was burnout”. The terms *medical adherence* and *eating healthy* were referenced by two of the study participants each and were referenced in a positive manner by one of the participants and negative by the other participants. As an example, Participant 10 stated “that when the job became stressful you would stop taking care of yourself…sometime you would stop taking your meds.” Whereas, Respondent 7 suggested that she is Medically Adherent because she wants to set a good example for her clients. Participant number 6 explained that the knowledge she gained from being a CHW inspires her to eat healthy foods. In contrast, eating healthy was referenced in a negative fashion by Participant 13 who said “I was not looking out for myself…not eating properly”. I listened intently to not only the terms stated by the respondents but in what context the term was presented. This allowed me to group these data of codes in groups or themes of positive impact or negative impact on the health and well-being of the HIVCHW. In table 8, I list the words and phrases that the HIVCHWs used to describe the impact being a CHW has on their health and well-being. I used these term and phrase as code for this study.

Table 8
Listing of Codes Developed From Participant Comments

Codes	# of study participants that code	Negative impact	Positive impact
Stress	7	7	0
Burnout	5	5	0
Tired	6	6	0
Exhausted	1	1	0
Sick	3	3	0
Forgetful	2	2	0
Not concentrating	1	1	0
Pain	1	1	0
Worry	2	2	0
Lose sleep	3	3	0
Anxiety	1	1	0
Do not eat	3	1	0
Irritated	1	1	0
Frustrated	2	2	0
Neglect	4	4	0
Draining	2	2	0
Care for their clients' first	5	5	0
Medical adherent	2	1	1
Trauma	1	1	0
Eating healthy	2	1	1
Guilt	1	1	0
Overwhelmed	3	3	0
Putting clients' first	4	4	0
Transference	2	2	0
Hurt	1	1	0

As this study is exploring the impact of being a CHW has on HIVCHW's well-being, I developed a broad set of themes based on the elements related to well-being. The

16 themes were; mental, emotion, physical, positive, negative, other, academic, professional, intellect, family, social, spirit, financial, environment, cultural, and empowered. I placed codes in the cells on the theme table where it best fit. For instance, in the cell physical on the theme table, I entered the codes; tired, sick, pain, lack of sleep, exhausted, don't eat, neglect, draining, medical adherence, eating healthy.

The RA matched codes with themes as well and we compared notes and identified overlapping themes. I eliminated the themes, Other, Academic, Professional, Intellect, Family, Social, Spirit, Financial, Environment, Cultural, and Empowered. Some of these themes did not have any codes under them for instance; Environment, Cultural, and Empowered. Therefore, I eliminated them. The themes that were referred by the HIVCHW in a very similar fashion, I combined such as Family, Social, and Spirit with negative, since the HIVCHW referred to them in a negative manner. As an example, Participant 4 described how working as a CHW had a negative impact on her social life. She stated that it took her away from spending time with family, friends and attending church. Themes referenced by the HIVCHW in a positive way were combined under positive, as an example, Academic, Professional, and Intellect. Study Participant 7 discussed that being a CHW impacted her academic, professional and intellect positively by affording her the opportunity to attend conferences and take trainings. Financial was described as both negative and positive. For instance, Participant 4 described a positive impact being a CHW had on her financially, she said; "I didn't have an issue with it financially" …" I was making good money". Participant 14 described an opposing experience of how being a CHW impacted her financially, she said; "I never got paid", therefore, I eliminated theme financial it as well. I combined mental and emotion into one theme entitled Mind. I changed the theme Physical to Body. I no longer needed a theme called Other as every code fit under one of the remaining themes. I moved from 16 themes down to four by first eliminating themes that did not have corresponding codes. Second, I combined the themes that were similar in meaning and had the same codes under them. This deduction resulted in four themes from the data, Mind, Body, Positive, and Negative emerged from the data.

Summary

From January 2016 through February 2016, I interviewed a total of fifteen study participants for 310 minutes. The shortest interview was eight minutes and the lengthiest interview was 36 minutes in duration, for an average interview time of twenty-one minutes long. The data were collected directly from the HIVCHW, therefore 100% of the data were from the perspective of the HIVCHW. In the beginning of the data collection process, it took me longer to get enough data that I felt comfortable, there for I allowed the study participant to talk and talk. I obtained pertinent data from the thirty-seven minutes' interview where for example Participant 1 said: “experienced stigma”. I became more skilled in focusing and identifying keys term stated by the participant to probe for them to convey more data related to the research questions. In comparison the data I obtained during my shortest interview, which was in a location where I felt unsafe. Therefore, I quickly gathered data to answer the research questions. For instance, in the eight-minute interview with Participant 4 who said, “I loved being a CHW, “It’s more positive than negative impact”. I believe these data are as relevant as the data yield during my lengthiest interview. Therefore, I have included the data gathered form all of the interviews in my analyst. After listening to each interview three times each, I developed four themes related to how the HIVCHWs perceive their experiences while being a CHW.

The purpose of this study was to explore the lived experiences of the HIVCHW, to obtain their perceptions about how working as an HIVCHW impacts their well-being and conceivably use the data gathered to provide recommendations that perhaps may contribute to inform and advance the CHW profession. Under the Theme-Mind all nineteen, 100% of the codes were presented by the study participants as negative. Of the ten code under the Theme-Body two, 20% were present as negative and positive and other eight, 80% were presented as negative; however, all 100% of the study participants expressed from their perspective their lived experience as a HIVCHW. Each of the study participants, 100% encounter adverse situation while in the role of CHW, that impacted their health and well-being; however, of the 15 HIVCHWs that participated in this study one, 7% of the HIVCHWs shared that being a CHW was a negative experience. As an example Participant 14 said; “I love what I did . . . Being a CHW was a negative experience”. Three (20%) of the HIVCHW interviewed did not label their experience as a CHW either way negative or positive. I collected data from 11 (73%) of the respondents qualifying their experience as HIVCHW with favorable terms. In Chapter 5, I will include my interpretation of the research results, limitations of the study, and recommendations for further research.

Chapter 5: Conclusion

Introduction

The purpose of this phenomenological study was to explore the lived experiences of CHWs who are living with HIV/AIDS and are employed to provide support to other people living with HIV/AIDS (HIVCHWs). I conducted audio recorded in-depth interviews with 15 HIVCHWs to yield data regarding how being a CHW impacted their health and well-being. The intent of this study was to explore the perceptions of the HIVCHWs, thus addressing a gap in the literature and providing a basis for future studies from the perspective of the HIVCHW.

All 15 of the study participants perceived that being a CHW had an impact on their health and well-being. The first question was the following: “What is it like being a CHW?” Eleven (73%) of the study participants described their experience of being a CHW with positive attributes. In direct opposition, one study participant described the experience of being a CHW as negative, while three of the HIVCHWs did not offer an overall perspective on their experiences as either negative or positive. In the responses to the question “How does being a CHW impact your health and well-being,” stress and stressful situations were mentioned by seven (47%) of the study participants. A research assistant and I created 25 codes from the data that were collected as the HIVCHWs described what it was like to be a CHW. From the 25 codes, a research assistant and I developed four themes based on how the CHWs described their experiences. I titled the themes *mind*, *body*, *positive*, and *negative*.

In addition to the above summary of the key findings of the study in this chapter, I provide a detailed interpretation of the findings related to the theoretical framework. I describe the study's limitations and offer recommendations for further research on the HIVCHW. I explain the study's potential for positive social change. I conclude this chapter with my reflections on the study.

Interpretation of Findings

In Chapter 2, I discussed peer-reviewed literature related to the phenomenon of interest, CHWs. More specifically, I provided information about the history, training, models, job roles, regulations, and effectiveness of CHWs. The results of this study confirm two of the concepts that emerged from the literature review, training and models. The HIVCHWs who participated in this study were trained through a variety of methods, similar to what was found in the literature. As described by HRSA (2007), CHWs have gained knowledge and skills to do their jobs through formal and informal venues such as on-the-job training, online learning, direct service agencies, colleges, and state certification training programs. The study participants, when responding to the questions regarding training on the demographic form, indicated the following; One (6%) respondent identified online as the method of CHW training received, while two (13%) participants expressed that they did not receive any training. Six of the CHWs attended a certificate program, whereas eight study participants mentioned being given on-the-job training and eight reported having participated in classroom training.

In addition, the HIVCHWs in this study provided many different services to their clients. Prevention was the service provided by 12 or 71% of the study participants. Food service and help with errands were indicated by seven or 41% of the respondents. In addition, 14 or 82% explained that they provided other services including but not limited to accompanying clients on doctor visits and health education tasks such as discussing laboratory results. Therefore, this study validated a study conducted by Urban (2014) that identified a plethora of models and roles of CHWs and CHW programs.

The data collected from this study revealed findings similar to those of a qualitative study conducted by Lawson (2007), in which counselors' responses suggested that although they had areas of concern, they were mostly healthy and content with their work. I found that 15 (100%) of the study participants described at least one negative impact on their health and well-being related to being a CHW, and 14 (93%) of the study participants described their experience of being CHWs with positive attributes. Even though none of the other concepts from the literature—for example, history, regulations, and effectiveness of CHWs—were identified in the data that were collected from the participants in this study, they were not disconfirmed.

The results in Chapter 4 indicate that the HIVCHWs perceived that they encountered job-related stressors that impacted their health and well-being. These results align with the tenets of Lazarus and Folkman's (1984) TSC as presented in Chapter 2. Seven (47%) of the participants stated that they experienced stress while working as CHWs, and six (40%) of the participants said that they experienced burnout. The HIVCHWs stated that they perceived these encounters as having adverse effects and creating stressful situations and lifestyles for them. Negative perceptions by the

HIVCHWs of situations such as stress and burnout are in line with the first tenet of Lazarus and Folkman’s TSC, primary appraisals. The study participants discussed how they found methods to handle these stressful situations. This is in line with the TSC’s secondary appraisal process of being mindful of possible responses to threats.

Coping, the third tenet of the theory, relates to how the response is executed. Lazarus and Folkman’s (1987) TSC includes two types of coping responses, emotion focused and problem focused. The HVCHWs disclosed eight approaches that they used to cope with what they encountered while working as CHWs. Seven were related to emotion focus, and one was related to problem focus. The study participants stated that they used the following seven emotion-focused techniques: pray, meditate, talk to friends, talk to professional therapists, relax, watch television, and play with pets. As explained in the TSC, these types of emotion-focused responses do not necessary resolve the problem but address emotion associated with the stress. Identifying additional resources for clients was the one problem-focused coping response the HIVCHWs in this study stated that they used. By finding a tangible way to resolve the problem, they were able to eliminate the stress. The explanation of the results reveals how each of the aforementioned tenets of the TSC applied to this study, as well as how the data compared with the published literature.

Limitations of the Study

This study had numerous limitations. The generalizability of the study was a limitation. Although this study explored the perceptions of multiple HIVCHWs, the results of this research can only apply to the individuals who participated in this study and therefore cannot be reliably generalized to any other individuals. The criterion research sample was obtained through the snowball technique. While I hoped my study sample would represent a diverse group of study participants, the risk of gender and racial bias may exist, as the 15-person cohort was 100% African American and majority (87%, *n* = 13) female. Although I made every attempt to suspend my personal judgment by journaling after each interview, there still may have been potential for researcher bias as a limitation. The study participants communicated retrospective self-reports of their experiences of being HIVCHWs, which could not be validated ethically or practically.

Recommendations

In this study, I explored the lived experiences of the HIVCHWs with a sample that was 100% African American and majority (87%) female. I recommend that future studies be conducted on the lived experiences of HIVCHWs that include more men and individuals of different races. Additionally, a different geographical area might yield a different sampling demographic more representative of the population of interest. This study did not explore the specific job duties that caused stress. Therefore, future studies could be conducted to determine which elements of the job cause stress. Future studies should be conducted to explore how the stigmatization associated with HIV impacts CHWs’ health and role. More qualitative studies should be conducted with CHWs as participants because it is important to learn directly from CHWs about their experiences. Lawson (2007) made a similar recommendation, stating that there is a need to examine the perceived benefits of peer counseling from the peer counselor’s perspective. These recommended studies may serve to provide a better understanding of the experiences of

HIVCHWs, which may lead to standardized training and regulations for CHWs in an effort to help them provide the best quality of care to their clients and themselves.

Implications

This study’s implications for positive social change involve HIVCHWs’ perceived state of health. HIVCHWs may be empowered to identify and self-advocate for tools needed for healthy work-life balance. This may promote self-efficacy, aiding HIVCHWs in achieving a healthy quality of life for themselves and their clients. Thus, there are implications for positive social change at both the individual and family levels. The results of this study could inform organizations that hire and train CHWs. The data provided by the HIVCHWs could inform the development of training methods and content. Hiring agencies could use the findings when creating duties and responsibilities in job descriptions of CHWs. Organizations like the community partners for this study that hire and train CHWs, such as The Women’s Collective and DC Care, could benefit from this study by incorporating consideration of the needs of CHWs into their hiring and training practices. Local and national organizations that advocate for and recommend guidelines and policies that impact CHWs could also use the data collected from this study. The APHA CHW Section may find the information from this study useful when suggesting best practices that could improve the CHW occupation. The results of this study could be incorporated into policies such as the Affordable Care Act, when recommending the use of CHWs in the delivery of healthcare. Government agencies such as the Centers for Medicare and Medicaid Services could benefit from these data, as they provide guidance regarding rates of pay for reimbursing for CHW services. The implications from the data in this study may lead to increased knowledge about the needs of CHWs and the development of policies that sustain the CHW profession.

Conclusion

The CHW occupation is expected to grow at a rate of 21%, a rate faster than average for all occupations, from 2012 through 2020 (BSL, 2015). It is essential that personnel within this occupation are studied. It is vital to further discover and comprehend the perceptions of CHWs in relationship with their whole being. This study represents an important phase in the exploration of how HIVCHWs perceive that being a CHW impacts their health and well-being. The findings of this study are consistent with previous literature on CHWs, as participants suggested that overall they were pleased with their experiences of being a CHW, even as it sometimes had adverse effects on their health and well-being. It is essential to further explore and understand the perceptions of HIVCHWs using a larger and more diverse sample. As one of the most used theoretical frameworks, TSC was the most appropriate for analyzing the data. The findings were in line with the tenets of the TSC.

References

Algood, C. (2014). *Using a phenomenological approach to explore lived experiences of hospice workers* (Doctoral dissertation, Capella University). Retrieved from ProQuest. (3611227)

American Association of Diabetes Educators. (2009). Community health workers in diabetes management and prevention. *Diabetes Educator, 35*(3), 48S-52S.

American Public Health Association. (2014). *About community health workers: CHW section history*. Retrieved from http://www.apha.org/membergroups/sections/aphasections/chw/about/

American Public Health Association. (2015). *Community health workers.* Retrieved from http://www.apha.org/apha-communities/member-sections/community-healthworkers

Andrews, J. O., Tingen, M. S., Jarriel, S. C., Caleb, M., Simmons, A., Brunson, J., & Magwood, G. (2012). Application of a CBPR framework to inform a multi-level tobacco cessation intervention in public housing neighborhoods. *American Journal of Community Psychology*, *50*(1-2), 129-140.

Anthony, S., Gowler, R., Hirsch, G., & Wilkinson, G. (2009). *Community health workers in Massachusetts: Improving health care and public health*. Boston, MA: Massachusetts Department of Public Health Community Health Worker Advisory Council.

Arosemena, F. A., Fox, L., & Lichtveld, M. Y. (2013). Reproductive health assessment after disasters: Embedding a toolkit within the disaster management workforce to address health inequalities among Gulf-Coast women. *Journal of Health Care for the Poor and Underserved*, *24*(4), 17-28.

Atukunda, R., Peter, M., & Constance, S. S. (2013). Care for the caregiver: Stress relief and burnout among health workers in HIV care. *Global Journal of Medicine and Public Health*, *2*(1), 1-7.

Benner, P. (Ed.). (1994). *Interpretive phenomenology: Embodiment, caring, and ethics in health and illness*. Thousand Oaks, CA: Sage.

Bone, L., Edington, K., Rosenberg, J., Wenzel, J., Garza, M. A., Klein, C, Ford, J. G. (2013). Building a navigation system to reduce cancer disparities in urban black older adults. *Progress in Community Health Partnerships: Research, Education, and Action, 7*(2), 209-218.

Boyd, R. C., Mogul, M., Newman, D., & Coyne, J. C. (2011). Screening and referral for postpartum depression among low-income women: A qualitative perspective from community health workers. *Depression Research and Treatment, 2011,* 1-7.

Brownstein, J. N., Bone, L. R., Dennison, C. R., Hill, M. N., Kim, M. T., & Levine, D. M. (2005). Community health workers as interventionists in the prevention and control of heart disease and stroke. *American Journal of Preventive Medicine, 29*(5), 128-133.

Brownstein, J. N., Hirsch, G. R., Rosenthal, E. L., & Rush, C. H. (2011). Community health workers "101" for primary care providers and other stakeholders in health care systems. *Journal of Ambulatory Care Management, 34*(3), 210-220.

Bureau of Labor Statistics. (2014). *Standard occupational classification.* Retrieved from http://www.bls.gov/soc/2010/soc211094.htm

Bureau of Labor Statistics. (2015). *Occupational outlook handbook: Community health workers.* Retrieved from http://www.bls.gov/ooh/community-and-socialservice/health-educators

Caelli, K. (2000). The changing face of phenomenological research: Traditional and American phenomenology in nursing. *Qualitative Health Research*, *10*(3), 366-377.

California Association of Community Health Workers. (2015). *APHA CHW policy.* Retrieved from http://www.cachw.org/policy/

Calman, L., Brunton, L., & Molassiotis, A. (2013). *Developing longitudinal qualitative designs: Lessons learned and recommendations for health services research. BMC Medical Research Methodology*, *2013*(13-14), 1-10.

Celletti, F., Wright, A., Palen, J., Frehywot, S., Markus, A., Greenberg, A., ... Samb, B. (2010). Can the deployment of community health workers for the delivery of HIV services represent an effective and sustainable response to health workforce shortages? Results of a multicountry study. *AIDS*, *24,* S45-S57.

Centers for Disease Control and Prevention. (1985). Revision of the case definition of acquired immunodeficiency syndrome for national reporting—United States. *Morbidity and Mortality Weekly Report*, *34*(25), 373-374.

Centers for Disease Control and Prevention. (2015). Community health workers. Retrieved from http://www.cdc.gov/dhdsp/pubs/docs/chw_state_laws.pd

Chan, N. N., Walker, C., & Gleaves, A. (2015). An exploration of students' lived experiences of using smartphones in diverse learning contexts using a hermeneutic phenomenological approach. *Computers & Education, 82*, 96-106.

Chenail, R. J. (2011). How to conduct clinical qualitative research on the patient's experience. *The Qualitative Report, 16*(4), 1173.

Chunlestskul, K., Carlson, L. E., Koopmans, J. P., & Angen, M. J. (2008). Lived experiences of Canadian women with metastatic breast cancer in preparation for their death: a qualitative study: Part II-enabling and inhibiting factors; the paradox of death preparation. *Journal of Palliative Care, 24*(1), 16.

Clark, V. P., & Creswell, J. W. (2011). *Designing and conducting mixed methods research.* Thousand Oaks, CA: Sage.

Collinsworth, A. W., Vulimiri, M., Schmidt, K. L., & Snead, C. A. (2013). Effectiveness of a community health worker-led diabetes self-management education program and implications for CHW involvement in care coordination strategies. *The Diabetes Educator, 39*(6), 792-799.

Community Health Worker Network of New York City. (2012). *Health professionals pioneers changing the face of health care.* Retrieved from http://www.chwnetwork.org/resources-materials/chw- training/

Creswell, J. W. (2002). *Educational research: Planning, conducting, and evaluating quantitative*. Upper Saddle River, NJ: Prentice Hall.

Creswell, J. W. (2007). *Qualitative inquiry & research design* (2nd ed.) Thousand Oaks, CA: Sage.

Creswell, J. W. (2013). *Qualitative inquiry and research design: Choosing among five approaches.* Thousand Oaks, CA: Sage.

Creswell, J. W. (2013). *Research design: Qualitative, quantitative, and mixed methods approaches*. Thousand Oaks, CA: Sage.

Draucker, C. B. (1999). The critique of Heideggerian hermeneutical nursing research. *Journal of Advanced Nursing, 30*(2), 360-373.

Fedder, D. O., Chang, R. J., Curry, S., & Nichols, G. (2003). The effectiveness of a community health worker outreach program on healthcare utilization of west Baltimore city Medicaid patients with diabetes with or without hypertension. *Ethnicity and Disease, 13*(1), 22-27.

Felix, H. C., Mays, G. P., Stewart, M. K., Cottoms, N., & Olson, M. (2011). Medicaid savings resulted when community health workers matched those with needs to home and community care. *Health Affairs, 30*(7), 1366-1374.

Findley, S. E., Matos, S., Hicks, A. L., Campbell, A., Moore, A., & Diaz, D. (2012). Building a consensus on community health workers' scope of practice: Lessons from New York. *American Journal of Public Health*, *102*(10), 1981-1987.

Glanz, K., Rimer, B. K., & Viswanath, K. (Eds.). (2008). *Health behavior and health education: Theory, research, and practice.* Hoboken, NJ: John Wiley & Sons.

Gorin, A. A., Wiley, J., Ohannessian, C. M., Hernandez, D., Grant, A., & Cloutier, M. M. (2014). Steps to growing up healthy: A pediatric primary care based obesity prevention program for young children. *BMC Public Health, 14*(1), 1.

Hanks, R. G. (2008). The lived experience of nursing advocacy. *Nursing Ethics, 15*(4), 468-477.

Harris, G. E., & Larsen, D. (2007). HIV peer counseling and the development of hope: Perspectives from peer counselors and peer counseling recipients. *AIDS patient Care and STDs*, *21*(11), 843-860.

Hunter, J. B., de Zapien, J. G., Papenfuss, M., Fernandez, M. L., Meister, J., & Giuliano, A. R. (2004). The impact of a promotora on increasing routine chronic disease prevention among women aged 40 and older at the US-Mexico border. *Health*

Education & Behavior, 31(4), 18S-28S.

Hurtado, M. (2014). Knowledge and behavioral effects in cardiovascular health: Community health worker health disparities initiative, 2007–2010. *Preventing Chronic Disease, 11*, 1-9.

Ingram, M., Schachter, K. A., Sabo, S. J., Reinschmidt, K. M., Gomez, S., De Zapien, J. G., & Carvajal, S. C. (2014). A community health worker intervention to address the social determinants of health through policy change. *The Journal of Primary Prevention, 35*(2), 119-123.

Islam, N., Nadkarni, S. K., Zahn, D., Skillman, M., Kwon, S. C., & Trinh-Shevrin, C. (2015). Integrating community health workers within Patient Protection and Affordable Care Act implementation. *Journal of Public Health Management and Practice, 21*(1), 42.

Islam, N. S., Zanowiak, J. M., Wyatt, L. C., Chun, K., Lee, L., Kwon, S. C., & Trinh-Shevrin, C. (2013). A randomized-controlled, pilot intervention on diabetes prevention and healthy lifestyles in the New York City Korean community. *Journal of Community Health, 38*(6), 1030-1041.

Jaskiewicz, W., & Tulenko, K. (2012). Increasing community health worker productivity and effectiveness: A review of the influence of the work environment. *Human Resources for Health, 10*(1), 1.

Javanparast, S., Baum, F., Labonte, R., & Sanders, D. (2011). Community health workers' perspectives on their contribution to rural health and well-being in Iran. *American Journal of Public Health, 101*(12), 2287-2292.

Johnson, L. B. (n.d.). *Great Society speech.* Retrieved from http://coursesa.matrix.msu.edu/~hst306/documents/great.html

Kleiman, S. (2004). Phenomenology: To wonder and search for meanings. *Nurse Researcher, 11*(4), 7-19.

Kvale, S. (2008). *Doing interviews*. Thousand Oaks, CA: Sage.

Kenya, S., Jones, J., Arheart, K., Kobetz, E., Chida, N., Baer, S., ... & Carrasquillo, O. (2013). Using community health workers to improve clinical outcomes among people living with HIV: A randomized controlled trial. *AIDS and Behavior, 17*(9), 2927-2934.

Lang, H. (2014). Narrow networks: The need for enhanced guidelines and transparency. *Annals of Health Law Advance Directives, 24,* 112-136.

Lawson, G. (2007). Counselor wellness and impairment: A national survey. *The Journal of Humanistic Counseling, 46*(1), 20.

Lawton, J., Kirkham, J., White, D., Rankin, D., Cooper, C., & Heller, S. (2015). Uncovering the emotional aspects of working on a clinical trial: A qualitative study of the experiences and views of staff involved in a Type 1 diabetes trial. *Trials, 16*(1), 1.

Lazarus, R. S. (1966). *Psychological stress and the coping process*. New York, NY: McGraw Hill.

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping.* New York, NY: Springer.

Lazarus, R. S., & Folkman, S. (1987). Transactional theory and research on emotions and coping. *European Journal of Personality, 1*(3), 141-169.

Levine, D. M., Becker, D. M., & Bone, L. R. (1991). Narrowing the gap in health status of minority populations: A community-academic medical center partnership. *American Journal of Preventive Medicine*, *8*(5), 319-323.

Lincoln, Y. S., & Guba, E. G. (1985). Naturalistic inquiry (Vol. 75). Thousand Oaks, CA: Sage.

Love, M. B., Legion, V., Shim, J. K., Tsai, C., Quijano, V., & Davis, C. (2004). CHWs get credit: A 10-year history of the first college-credit certificate for community health workers in the United States. *Health Promotion Practice, 5*(4), 418-428.

Massachusetts Association of Community Health Workers (2014). *Who are community health workers?* Retrieved from http://www.machw.org/

McLeod, J. (2009). A framework for the practice of embedded counselling: The significance of the story. In S. Trygged and S. Larsson (Eds.), *Counselling i Socialt Arbete.* Stockholm, Germany: Gothia Forlag.

McNamara, C. (2009). General guidelines for conducting interviews. Retrieved from http://managementhelp.org/businessresearch/interviews.htm

Mirambeau, A. M., Wang, G., Ruggles, L., & Dunet, D. O. (2013). A cost analysis of a community health worker program in rural Vermont. *Journal of Community Health, 38*(6), 1050-1057.

Moustakas, C. (1994). *Phenomenological research methods.* Thousand Oaks, CA: Sage.

Munhall, P. L., & Munhall, P. (2007). A phenomenological method. *Nursing Research: A*

Qualitative Perspective, 4, 145-210.

Murray, M., & Ziegler, F. (2015). The narrative psychology of community health workers. *Journal of Health Psychology, 20*(3), 338-349.

Nemcek, M. A., & Sabatier, R. (2003). State of evaluation: Community health workers. *Public Health Nursing, 20*(4), 260-270.

Newell, K. W., & World Health Organization. (1975). *Health by the people.* Retrieved from http://apps.who.int/iris/bitstream/10665/40514/1/9241560428_eng.pdf

Norris, S. L., Chowdhury, F. M., Van Le, K., Horsley, T., Brownstein, J. N., Zhang, X., & Satterfield, D. W. (2006). Effectiveness of community health workers in the care of persons with diabetes. *Diabetic Medicine, 23*(5), 544-556.

Oliver, W., & Barr, S. (2014). Ethical research practices: FAQs. *Journal of Dance Education, 14*(2), 43-44.

Pattenden, J. F., Roberts, H., & Lewin, R. J. P. (2007). Living with heart failure: Patient and carrer perspectives. *European Journal of Cardiovascular Nursing, 6*(4), 273-279.

Pereira, H. R. (2012). Rigour in phenomenological research: Reflections of a novice nurse researcher. *Nurse Researcher, 19*(3), 16.

Pérez, L. M., & Martinez, J. (2008). Community health workers: Social justice and policy advocates for community health and well-being. *American Journal of Public Health, 98*(1), 11-14.

Perez, M., Findley, S. E., Mejia, M., & Martinez, J. (2006). The impact of community health worker training and programs in NYC. *Journal of Health Care for the Poor and Underserved, 17*(1), 26-43.

Perry, H., & Zulliger, R. (2012). *How effective are community health workers? An overview of current evidence with recommendations for strengthening community health worker programs to accelerate progress in achieving the health-related Millennium Development Goals.* Baltimore, MD: Johns Hopkins Bloomberg School of Public Health.

Philis-Tsimikas, A., Walker, C., Rivard, L., Talavera, G., Reimann, J. O., Salmon, M., & Araujo, R. (2004). Improvement in diabetes care of underinsured patients enrolled in project dulce A community-based, culturally appropriate, nurse case management and peer education diabetes care model. *Diabetes Care, 27*(1), 110-115.

Polkinghorne, D. E. (2005). Language and meaning: Data collection in qualitative research. *Journal of Counseling Psychology, 52*(2), 137.

Quinn, P. M. (2002). *Qualitative research and evaluation methods.* Thousand Oaks, CA: Sage.

Richter, R. W., Bengen, B., Alsup, P. A., Bruun, B., Kilcoyne, M. M., & Challenor, B. D. (1974). The community health worker. A resource for improved health care delivery. *American Journal of Public Health, 64*(11), 1056-1061.

Robert Wood Johnson Foundation. (2008). *Qualitative research guidelines project.* Retrieved from http://www.qualres.org/HomeTria-3692.html

Rosenthal, E. L., Wiggins, N., Ingram, M., Mayfield-Johnson, S., & De Zapien, J. G. (2011). Community health workers then and now: An overview of national studies aimed at defining the field. *The Journal of Ambulatory Care Management, 34*(3), 247-259.

Rossi, A., Cetrano, G., Pertile, R., Rabbi, L., Donisi, V., Grigoletti, L.,...& Amaddeo, F. (2012). Burnout, compassion fatigue, and compassion satisfaction among staff in community-based mental health services. *Psychiatry Research, 200*(2), 933-938.

Rubin, H. J., & Rubin, I. S. (2011). *Qualitative interviewing: The art of hearing data.* Thousand Oaks, CA: Sage.

Sadler, G. R., Lee, H., Seung-Hwan Lim, R., & Fullerton, J. (2010). Recruiting hard-to- reach United States population sub-groups via adaptations of snowball sampling strategy. *Nursing Health Sciences, 12*(3), 369–374. doi:10.1111/j.1442-2018.2010.00541.x

Schachter, K., Ingram, M., Jacobs, L., De Zapien, J. G., Hafter, H., & Carvajal, S. (2014). Developing an action learning community advocacy/leadership training program for community health workers and their agencies to reduce health disparities in Arizona border communities. *Journal of Health Disparities Research and Practice, 7*(2), 3.

Senden, C., Vandecasteele, T., Vandenberghe, E., Versluys, K., Piers, R., Grypdonck, M., & Van Den Noortgate, N. (2015). The interaction between lived experiences of older patients and their family caregivers confronted with a cancer diagnosis and treatment: A qualitative study. *International Journal of Nursing Studies, 52*(1), 197-206.

Shah, M., Kaselitz, E., & Heisler, M. (2013). The role of community health workers in diabetes: Update on current literature. *Current Diabetes Reports, 13*(2), 163-171.

Shortell, S. M. (2013). Bridging the divide between health and health care. *The Journal of the American Medical Association*, *309*(11), 1121-1122.

Shreedevi, D. (2013). Stress management among health care professionals: It's not stress that kills us, it is our reaction to it. *International Journal of Research, 1*(3), 37-48.

Slocum-Gori, S., Hemsworth, D., Chan, W. W., Carson, A., & Kazanjian, A. (2013). Understanding compassion satisfaction, compassion fatigue and burnout: A survey of the hospice palliative care workforce. *Palliative Medicine, 27*(2), 172-178.

Small, N., Blickem, C., Blakeman, T., Panagioti, M., Chew-Graham, C. A., & Bower, P. (2013). Telephone based self-management support by 'lay health workers' and 'peer support workers' to prevent and manage vascular diseases: A systematic review and meta-analysis. *BMC Health Services Research, 13*(1), 1.

Society for Public Health Education. (2014). Complementary roles and training of health education specialists and community health workers. Retrieved from http://www.sophe.org/CHW_vs_HealthEd_final.pdf

Staten, L. K., Gregory-Mercado, K. Y., Ranger-Moore, J., Will, J. C., Giuliano, A. R., Ford, E. S., & Marshall, J. (2004). Provider counseling, health education, and community health workers: The Arizona WISEWOMAN project. *Journal of Women's Health, 13*(5), 547-556.

Taveras, E. M., Marshall, R., Kleinman, K. P., Gillman, M. W., Hacker, K., Horan, C. M.,...& Simon, S. R. (2015). Comparative effectiveness of childhood obesity interventions in pediatric primary care: A cluster-randomized clinical trial. *The Journal of the American Medical Association Pediatrics, 169*(6), 535-542.

Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care, 19*(6), 349-357.

The White House. (2012). *Fighting HIV/AIDS in Washington, DC*. Retrieved from https://www.whitehouse.gov/blog/2012/07/25/fighting-hivaids- Washington-dc

Trochim, W. (2006). *The research methods knowledge base*. Retrieved from http://www.socialresearchmethods.net/kb/

Urban Institute. (2014). *Care Works: The community health workers project*. Retrieved from http://www.urban.org/features/careworks-community- health-worker-project

U.S. Department of Health and Human Services. (2015). *Key features of the Affordable Care Act.* Retrieved from http://www.hhs.gov/healthcare/facts-and-features/keyfeatures-of-aca/

U.S. Department of Labor Bureau of Labor Statistics. (2009). *Standard occupational classification, 21-094.* Retrieved from www.bls.gov/opub/mlr/2013/05/art3full.pdf

Valle, R. S., King, M., & Halling, S. (1989). An introduction to existentialphenomenological thought in psychology. In Authors (Eds.)

Existentialphenomenological perspectives in psychology (3-16). New York City, NY:
Springer.

Van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy*. Ontario, Canada: State University of New York.

West, D. S., Bursac, Z., Cornell, C. E., Felix, H. C., Fausett, J. K., Krukowski, R. A.,...& Beck, C. (2011). Lay health educators translate a weight-loss intervention in senior centers: a randomized controlled trial. *American Journal of Preventive Medicine, 41*(4), 385-391

Wiggins, N., Johnson, D., Avila, M., Farquhar, S. A., Michael, Y. L., Rios, T., & Lopez, A. (2009). Using popular education for community empowerment: Perspectives of community health workers in the Poder es Salud/Power for Health program. *Critical Public Health*, *19*(1), 11-22.

Witmer, A., Seifer, S. D., Finocchio, L., Leslie, J., & O'Neil, E. H. (1995). Community health workers: Integral members of the health care work force. *American Journal of Public Health*, *85*(8), 1055-1058.

World Health Organization. (2007). *Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference*. Retrieved from http://www.who.int/governance/eb/who_constitution_en.pdf.

Appendix A: Criteria Screening Tool

Please answer Yes or No to the following questions. Must answer yes to each criterion.

	Inclusion criteria	Yes	No
a	Are currently employed as a community health worker?		
b	Do you serve clients that are living with HIV/AIDS?		
c	Are you at least 18 years of age?		
d	Do you agree to being audio recorded during the interview?		

Meets inclusion criteria	Ask to participate	Does not meet inclusion criteria

Recruit code: ______________________________

Appendix B: Sample Letter of Cooperation From a Research Partner

Organization X
Contact
April 24, 2015

Dear Phronie Jackson,

My organization agrees to cooperate with you for your study and agrees to authorize you to post flyers on bulletin boards and information table. Individuals' participation will be voluntary and at their own discretion.

We understand that our organization's responsibilities include: making informational flyers available to potential study participants. We reserve the right to withdraw from the study at any time if our circumstances change.

I confirm that I am authorized to approve research in this setting and that this plan complies with the organization's policies.

I understand that the data collected will remain entirely confidential and may not be provided to anyone outside of the student's supervising faculty/staff without permission from the Walden University IRB.

Sincerely,
Authorization Official
Contact Information

Walden University policy on electronic signatures: An electronic signature is just as valid as a written signature as long as both parties have agreed to conduct the transaction electronically. Electronic signatures are regulated by the Uniform Electronic Transactions Act. Electronic signatures are only valid when the signer is either (a) the sender of the email, or (b) copied on the email containing the signed document. Legally an "electronic signature" can be the person's typed name, their email address, or any other identifying marker. Walden University staff will verify any electronic signatures that do not originate from a password-protected source (i.e., an email address officially on file with Walden).

Appendix C: Informational Flyer

Be part of an important confidential Community Health Worker (CHW) Research Study

Let your voice be heard!

Are you a Community Health Worker and are HIV positive?
Are you 18 years of age or older?
Do you serve clients that are living with HIV/AIDS?
Would you agree to be audio recorded during the private interview?
(**No personal identifiers will be used for any part of this study**) If you answered yes to all of the above criteria you are eligible to participate in a study about HIV Community Health Workers.

If you know of someone who may be eligible to participate in this study, please feel free to refer him or her to me.

The purpose of this research study is to explore the lived experiences of Community Health Workers who are living with HIV/AIDS to gain their perspective on how the role of CHW might impact the HIVCHWs well-being.

Participation in this study is completely voluntary.

All information will be confidential and no names will be used to report data. This re be conducted by Phronie Jackson, Walden University Ph.D. candidate.

Participants will be reimbursed for travel to the interview site (or I can come to you) and a $10 cash as a token of appreciation for participating in the study.

To learn more about how you can help with this study, please call or email Phronie Jackson at
Telephone: xxx-xxx-xxxx
Email: Phronie.jackson@xxxxxxx.xxx

Appendix D: Interview Questions

Opening General Question:

So tell me what is it like working as a Community Health Worker?

Prompts:

So can you talk about that a bit more?

So if I am understanding correctly……. was I right?

What does …. mean?

Additional Specific Prompts:

What is a day like in your life as a CHW?

So tell me, does working as a CHW affect you in any way?

Can you tell me more about that?

If they indicate stress or other adverse impact, ask the following question.

How do handle the situations?

If they don’t mention adverse impact on their own, prompt in a subtle way.

So can you talk a bit more about the role of CHW and your well-being?

So if I am understanding correctly……. was I right?

What does …. mean?

Appendix E: Protocol for Pilot Study

Step number	Step	Description	Time
1	Prepare room for the interview prior to interview before participants arrive	Set up desk, chairs, place privacy plaque on door, set up 2 audio recorders (one for backup) provide water	15
2	Welcome	Introduce myself will ask about their comfort offer them water, coffee or tea	10
3	Informed Consent	Explain the purpose of the study, provide participant with an informed consent form for their review. I will discuss items in the consent form as they relate to ethical principles of autonomy, beneficence, and justice. remind participant that I will audio record the interview. I will inform them of how long I anticipate the interview will last. I will notify them that this will be the only contact we will have for this study, unless I need to clarify a response. I will ask if it will be alright for me to contact them via telephone if that is necessary. I will ask them if they understand, have questions, and agree. I will answer their question and ask them to sign the form. I will lock the form in my desk drawer.	30
4	Demographic Data Collection	Give demographic data collection sheet for completion	10
5	Interview	I will turn on the audio recorded, test it Ask opening question Follow up prompting questions as necessary. Upon completion of the interview, I will ask if they have questions for me. I will advise them that the interview is over.	45 - 60
6	Tokens of Appreciation	I will give them the gift of appreciation, ask them to sign for the gift and turn on the audio recorder.	5
7	Debrief	Journal my own notes immediately following the interview and after the participant has departed.	15

Appendix F: Confidentiality Agreement

Name of Signer:

During the course of my activity in collecting data for this research: "The Lived Experience of the HIV Community Health Worker" I will have access to information, which is confidential and should not be disclosed. I acknowledge that the information must remain confidential, and that improper disclosure of confidential information can be damaging to the participant.

By signing this Confidentiality Agreement, I acknowledge and agree that:

1. I will not disclose or discuss any confidential information with others, including friends or family.
2. I will not in any way divulge, copy, release, sell, loan, alter or destroy any confidential information except as properly authorized.
3. I will not discuss confidential information where others can overhear the conversation. I understand that it is not acceptable to discuss confidential information even if the participant's name is not used.
4. I will not make any unauthorized transmissions, inquiries, modification or purging of confidential information.
5. I agree that my obligations under this agreement will continue after termination of the job that I will perform.
6. I understand that violation of this agreement will have legal implications.
7. I will only access or use systems or devices I'm officially authorized to access and I will not demonstrate the operation or function of systems or devices to unauthorized individuals.

Signing this document, I acknowledge that I have read the agreement and I agree to comply with all the terms and conditions stated above.

Signature: **Date:**

Appendix G: Consent Form

You are invited to take part in a research study of the perceptions of Community Health Workers who are living with HIV. The researcher is inviting current and former community health worker, who are living with HIV. Individuals must be at least eighteen years of age to be in the study. This form is part of a process called "informed consent" to allow you to understand this study before deciding whether to take part.

This study is being conducted by a researcher named Phronie Jackson, who is a doctoral student at Walden University.

Background Information:
The purpose of this study is to explore how working as a community health worker, might impact the health and wellbeing of community health workers who are themselves living with HIV.

Procedures:
If you agree to be in this study, you will be asked to:

- Participate in one in-depth interview that will last for approximately 90 minutes
- Agree to being audio recorded during the interview

Here are some sample questions:
Could you tell me what it is like being a community health worker?
Please describe a day in your life as a community health worker who is living with HIV/AIDS?

Voluntary Nature of the Study:
This study is voluntary. Everyone will respect your decision of whether or not you choose to be in the study. No one at this organization will treat you differently if you decide not to be in the study. If you decide to join the study now, you can still change your mind later. If you agree and start the interview, you can stop the interview at any time.

Risks and Benefits of Being in the Study:
Being in this type of study involves some risk of the minor discomforts that can be encountered in daily life, such as stress. Although unlikely, the topic of our conversation may cause some stress or discomfort

The study's potential benefits are possible policy and practice improvement in the profession of community health work. Community health workers and their employers may identify the need to equip community health workers with additional or different skills and resources to better cope with situation encounter on the job. As the result of hearing the perspective of the community health worker, training and regulation of community health workers could be developed based of the findings of the study.

Payment:
As a token of appreciation for participating in the study, participates will receive $10.00 cash and be reimbursed up to $5.00 in cash for transportation to the interview. The thank you gift will be distributed immediately following the interview. They may keep the token even if they decide to stop the interview.

Privacy:
Any information you provide will be kept confidential I will not use your personal information for any purposes outside of this research project. Also, I will not include your name or anything else that could identify you in the study reports. Data will be kept secure in a file that can be opened only with a code that only I will know. Data will be kept for a period of at least 5 years, as required by the university.

Contacts and Questions:
You may ask any questions you have now. Or if you have questions later, you may contact me via telephone. If you want to talk privately about your rights as a participant, you can call Dr. Leilani Endicott, the Walden University representative who can discuss this with you. My Walden IRB approval number is 12-02-15-0155984 and it will expire on December 1, 2016. I will give you a copy of this form to keep. Please keep this consent form for your records.

Statement of Consent:

I have read the above information and I feel I understand the study well enough to make a decision about my involvement. By signing below, I understand that I am agreeing to the terms described above.

Printed Name of Participant	______________________________
Date of consent	______________________________
Participant's Signature	______________________________
Researcher's Signature	______________________________

Appendix H: Demographic Data Questionnaire

1. How old were you on your last birthday _____________ (Write exact age)
2. Marital Status
___ Now married
___ Widowed
___ Divorced
___ Separated
___ Never married

___Live with Partner

3. How many years of formal education have you completed?

_______ (Write number in) (Here they may indicate any range 2 or 16 or 20 and you can ask for specifics below.)

Did you graduate from high school?
Yes
No

Did you graduate from college?
Yes
No

Have you completed a graduate level degree?
Yes
If Yes, Write in degree________
No

4. Gender
___ Male
___ Female
___ Transgender male to female
___ Transgender female to male

5. What was your total household income after taxes for 2014?
___ Less than $10,000
___ $10,000 to $19,999
___ $20,000 to $29,999
___ $30,000 to $39,999
___ $40,000 to $49,999
___ $50,000 to $59,999
___ $60,000 or more

6. How long have you worked as a Community Health Worker? _________
Months ___________ Years_____________

7. What is the size of your current case load? ____________

What types of services do you provide to clients?
Prevention
Food services
Help with errands
Other_____________________________________

8. What type of training CHW training did you receive?
______ None

______ on the job from another worker not in a classroom
______ classroom/workshops/seminar a week or less
______ certificate/college month or longer
______ on-line internet/distance learning

9. Are you a member or participate with a CHW network, association or support group
_____Yes
_____ No

Appendix I: Individuals With Access to the Study Data

The following individuals will have access to the study data.

The researcher: Phronie Jackson

The research assistant: TBD

The researcher’s dissertation committee members: Dr. XXXXXXXXXX and Dr. XXXX
The transcriber: TBD