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The Impact of Being a Community Health Worker on People Living with HIV/AIDS

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Abstract

Multitudes of research have focused on the effectiveness of community health worker (CHW) programs in producing positive health behaviours and health outcomes for the clients CHWs serve; however, there is much less literature regarding how the health of CHWs living with HIV (HIVCHW) are impacted by their jobs. A phenomenological design was implemented to gain an understanding of the lived experiences of 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 most of the 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 was completed in 2016 and is relevant and socially significant in 2020 and beyond, because it may offer the workforce of HIVCHWs empowerment to self-advocate 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, while ultimately promoting resilience.

Keywords: HIV; CHW; AIDS; Community Health Workers

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).1 A community health worker (CHW), a para-professional who serves at the community level, acts in multiple roles to address a health challenges, diseases, and health promotion activities (CDC, 2015) [1]. 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) [1], 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.

CHWs are progressively acknowledged as an essential part of the health workforce, and they help to meet healthcare goals (World Health Organization [WHO], 2007) [2]. This study 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) [3]. There is a limited amount of data on the impact that the role of being a CHW has on the well-being of HIVCHWs. As 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.

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) [4]. Additionally, research has shown that people who suffer from chronic illnesses, such as diabetes (Shah, Kaselitz, & Heisler, 2013) [5], cancer (Bone, *et al.*, 2013) [6], and HIV (Kenya *et al.*, 2013) [7], who are linked to CHWs, have obtained and maintained the support needed to achieve a healthy quality of life.

This study contributes to the field of HIV/AIDS and 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 HIV/AIDS and CHW stakeholders with data that may advance the practice and policies of HIV/AIDS and 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.

Methods and Materials

The study conducted used a qualitative phenomenological design. The study 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). 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 without a legal representative. 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.

Organizations that employ HIVCHWs, agreed to place information flyers about the study in their offices. 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. The flyer also listed the primary investigator's (PI) name and telephone number for the participants to contact to express interest in participating in the study.

When contacted by potential participants, an inclusion criteria screening interview over the telephone was conducted to identify whether the person met the inclusion criteria. If the person met the inclusion criteria, the following information was explained: the purpose of the study, the voluntary nature of participating, the interview would be audio recorded, and all information would be kept confidential. Interviews were scheduled during a timeframe and in a location that was most convenient for the participant.

An interview protocol was used to guide the in-depth interviews with the participants. Questions were developed based on the study's main research question (What are the lived experiences of HIVCHWs?) and probing questions were 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? The main questions followed by probing questions to gain the most descriptive and accurate data from participants were asked (Rubin & Rubin, 2011) [8]. An audio recorder used to ensure that the responses and perspectives of the participants were properly recorded for accurate transcription.

A pilot study was conducted with two study participants. This allowed the PI to test for issues and problems that might occur during the main study, and to confirm the validity and refinement of the research questions and tools (Kvale, 2007) [9]. However, no adjustments were required of the protocol and data collection tool.

The interview protocol consisted of the following steps: explained the purpose of the study, provided an informed consent form for the participant's review and signature, discussed items in the consent form as they related to ethical principles of autonomy, beneficence, and justice, reminded the participant that the interview would be audio recorded, informed the participant of the anticipated interview time, notified the participant that this would be the only contact of the study unless clarification of a response was needed, ask for permission to contact the participant via telephone if that was necessary, asked if the participant understood, had questions, and agreed, answer any questions and ask the participant to sign the form, lock the forms a desk drawer, turned on the audio recorder, tested it, and started asking the questions. Upon completion, advise the participant that the interview was over, issue the participant the incentive, ask the participant to sign for the incentive, and turned off the audio recorder. After the participant leaves make notes in the journal about the interview, document nonverbal communications, and personal feelings about the interview.

Data collected for this study was by conducting confidential, anonymous in-depth interviews. The way in which the respondents told their stories was based on how the questions were asked. The same interview protocol, open-ended opening questions and follow-up prompt questions were used with each participant, as Gall, Gall, and Borg (2003) [10] noted that structured interviews encouraged participants to express their perspectives and experiences. Data were collected from participants from one-on-one interviews using opened-ended questions. As explained by Munhall (2007) [11] the main goal was to obtain a better understanding of the lived experience. Upon interviewing 15 participants, no new meanings or themes emerged from the data. Therefore, saturation had been reached and the interviews ceased.

Data Analysis

The demographics of the 15 persons cohort sample was 100% African American and 87% female. The data collected from the one-on-one interviews were analyzed by using a phenomenological approach to allow the materialization of concepts and themes. The Theory of Stress and Coping was the guiding framework for understanding and interpreting the data in this study. The overall phenomenological data analysis consisted of coding, categorizing, and making sense of the essential meaning of the phenomenon. The audio recordings of the interviews were transcribed professionally. The data were analyzed by using a process described by Kleiman (2004) [12]. To gain a sense of the big picture and to divide the data into significant parts, the recorded interviews were listened to multiple times. The transcripts were organized into different sections by research questions and similar focus to determined which ones were essential to the study, and codes were assigned. To justify codes a second review of the raw data was conducted to substantiate the accuracy of the original findings. A thorough and critical analysis of the data to assured rigor and validity of the study was conducted by a research assistant (RA) as well as the PI. The RA and PI independently coded and analyze the interviews. The PI and RA corroborated and compared notes. Where discrepant cases were identified, as a validity strategy the audio recording and transcript were reviewed again to resolve the discrepancy. The customary scheme of phenomenological analysis with the assistance of a qualitative software package such as NVivo 10 was not utilized. The raw data was manually organized by using pen, paper, note pads, and color markers. Charts were created, codes were developed, themes were discovered and connected. This was the overall data analysis procedure from which a data report was established. The participants identity was not revealed

during the data analysis. Pereira (2012) [13] 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. Controls were in place to assure the trustworthiness of the study. Possible internal validity was addressed by working with a research assistant to analyze the data. As noted by (Denzin, 1978 & Patton, 1999) [14] this type of analysis is called analyst triangulation which allowed for comprehending the data from various perspectives.

Results

To explore the lived experience of the HIVCHW, each study participant was asked what is it like to be a CHW? They were allowed as much time as necessary to expound upon their experiences. The PI 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 they responded to the 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 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. These data were categorized into groups and entitled as Positive, Negative, or Neither theme.

Table 1: Participants' Assessment Description

Participants' Assessment Description	Participant number	Comment
Positive	1	Love being a CHW
Positive	2	Love giving to community I've
(These study participants made	3	learned a lot Rewarding
specific comments that	4	Makes me feel good
suggested their experience as a	5	It's fruitful
HIVCHW was favorable.)	6	Enriching and rewarding
	9	
	10	Good
	12	Good
	13	Fulfilled
	15	Love it
Negative	14	Felt good about being a

(This study participant comment implicitly indicated that the experience was negative.)		CHW It was a negative experience
Neither	7	90
(These study participants did not comment either way, positive or negative)	8 11	Long journey with ups and downs

Table 2: 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

During the in-depth interviews, the study participants either volunteered terms related to how being a CHW impacted their well-being or was 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. These data were used 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 led to forgetfulness. The participant stated "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". The investigator listened intently to not only the terms stated by the respondents but in what context the terms were presented.

This allowed the grouping of these data of codes in groups or themes of positive impact or negative impact on the health and well-being of the HIVCHW. As this study is exploring the impact of being a CHW has on HIVCHW's wellbeing, a broad set of themes based on the elements related to well-being was developed. The 16 themes were; mental, emotion, physical, positive, negative, other, academic, professional, intellect, family, social, spirit, financial, environment, cultural, and empowered.

The RA matched codes with themes and compared notes with the PI to identified overlapping themes. As the result the 16 themes were reduced down to four by first eliminating themes that did not have corresponding codes. Second, by combining 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. From January 2016 through February 2016, a total of fifteen study participants were interviewed 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.

Discussion

The data collected from this study revealed findings similar to those of a qualitative study conducted by Lawson (2007) [15], in which counselors' responses suggested that although they had areas of concern, they were mostly healthy and content with their work. This study 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. The responses of the study participants 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) [16] TSC. 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 HIVCHWs 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 necessarily 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.

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 the PI hoped that the 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. Al-

though every attempt to suspend the personal judgment of the PI 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.

Conclusion

This study 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) [15] 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. 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 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 practic-

es 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.

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.

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