

A LEAP OF FAITH:
COLLECTIVE MEMORY WORK INVOLVING HIV/AIDS AND SPIRITUAL COPING

by

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(Under the Direction of Anneliese A. Singh)

ABSTRACT

The World Health Organization (2016) reported an estimated 36.7 million people are living with HIV, among them are the 1.1 million people living with HIV in the US (CDC, 2015). While the health benefits associated with spiritual coping in response to chronic illness are well established by the Centers for Disease Control and Prevention (CDC, 2015), research suggests that access to faith-based supports is complicated by the threat of encountering stigma for people living with HIV/AIDS, due to moral preoccupations involving sexual health and behaviors (Benton, 2008; Ford, 2011; Martinez, Lemos, & Hosek, 2012; Szaflarski, 2013).

Given this potential for encountering both supportive and stigmatizing messages in faith-based contexts, this study used Collective Memory Work (Haug, 1997) coupled with Participatory Video (Lunch & Lunch, 2006) as a framework that explored how eight people made meaning of HIV through spiritual coping. Findings included themes associated with existential questioning, the need for unconditional love, the process of spiritual meaning-making, and acquiring a sense of heightened purpose, oftentimes manifested as a personal call to action through HIV prevention and education efforts. Moreover, this study used participatory video as a

medium to record and share participant stories in affecting change, with an intended audience, in demystifying the complexities of living with HIV while engaging in faith-based supports.

INDEX WORDS: Collective Memory Work, Social Construction, Participatory Video, HIV/AIDS Stigma, Spiritual Coping, Faith-Based Supports

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A Dissertation Submitted to the Graduate Faculty of The University of Georgia in Partial
Fulfillment of the Requirements for the Degree

DOCTOR OF PHILOSOPHY

ATHENS, GEORGIA

2018

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May 2018

DEDICATION

While cleaning out the basement of our small rural HIV/AIDS clinic, a former client's "Letter to the Future" was discovered inside a stack of old dusty boxes, describing a wish to one day safely disclose her HIV status with her beloved faith community. I imagined how different her message might be if she were dealing with a different illness, such as cancer, and how it would compare to the social complexities of living with HIV/AIDS. This dissertation is dedicated to this courageous community of people whose greatest threat is perhaps no longer the virus, but rather the communicable disease of stigma. This dissertation represents my own hopeful letter to the future – in finding a cure.

ACKNOWLEDGEMENTS

First and foremost, I would like to thank God for guiding me in all that I do, including this wonderful opportunity to grow in service to the community. To my supportive wife Michelle and our amazing children Ethan, Amelia, and Rory - the personal sacrifices you have all made during the past 4 years has been the foundation to my success in completing this difficult journey. I love you more than words can express, and I look forward to reclaiming many of the countless hours with you that were dedicated to making this dream a reality.

To Dr. Anneliese Singh, who embodies the spirit of social justice activism. Your influence in my life has been nothing short of transformative. Thank you for instilling and supporting an idea, which began with watching a social justice film and much to my amazement, has somehow resulted in our creating one. To Dr. Natoya Haskins and Dr. Deryl Bailey, thank you for your guidance, support, and encouragement when I struggled to believe that any of this was possible. Each of you has uniquely contributed to my growth in preparing for a future filled with meaningful service, and commitment to making a difference.

And to my inspiring cohort of game-changers, thank you for sharing your personal experiences in helping me to explore the world through multiple perspectives. In just 4 years, you have provided me with life-long lessons in what it means to risk ourselves for the love of something greater. I would not be here without your support. Thanks also to Claire Davis, Jean So, and Margie Gill for your generous gift of time and talent, in helping with this dissertation. I would also like to give my heartfelt appreciation to everyone working at the Gwinnett Campus for always making me feel welcome and part of your family. I will miss seeing you each week.

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CHAPTER 1

THE RESEARCH PROCESS

“Plow me under the ground that covers the message that is the seed” (Sponge-1994)

The task in memory studies is to articulate how personal memories are shaped, cultivated, and situated within our social identities and frameworks (Olick, 2012). As an instrument of transformative dialogue, participatory video (Lunch & Lunch, 2006) coupled with memory work (Haug, 1987, 1997) offers the marginalized and vulnerable a means to share emotional realities as an “extended language,” engaging diverse communities in what is described as *video power* (Velásquez Atehortúa, 2015, p. 327). Du Bois (1903, 2003) forged political partnerships highlighting the “rhythmic cry of the slave” and other marginalized groups using extended language to deconstruct, interrupt, and counter the social injustices affecting the oppressed (p. 178). Civil rights activist Frederick Douglass also recognized the intrinsic value of extended language, describing how African American folk music affects change more readily than “reading whole volumes of philosophy on the subject could do...” (Douglass, 1845, 2003 p. 26). Inspired by the Civil Rights Movement, participatory video research mobilizes diverse audiences with emancipatory ideals (Corneil, 2012), requiring a “leap of faith” in the filmmaking process by extending the power of language to catalyze change (Charbonneau, 2014, p. 227).

Statement of the Problem

Based on the United Nations Global AIDS Update (UNAIDS, 2016), the World Health Organization reported that there are over 36 million people currently living with HIV/AIDS worldwide. Here in the US, the Centers for Disease Control and Prevention (2015) reported that there are approximately 1.1 million people living with HIV/AIDS; African Americans

representing a disproportionate 44% of the total infections. Beneath these figures lie multiple disparities; the criminalizing of HIV promotes new forms of discrimination (Grant, 2013; Martin, 2014; Newman, 2013) where it is often said that stigma is deadlier than the virus itself, when equating illness with blame (Hoppe, 2014). Furthermore, the effects of social stigma undermine the US National HIV/AIDS Strategy (Lazzarini, et al., 2013) calling for increased community partnerships with faith-based organizations (White House Office of National AIDS Policy, 2010). Such dueling realities (Paul, 2007) of disease management and compromised social capital places a significant burden upon people coping with HIV/AIDS and the existential challenges that accompany serious illness (Cottone, et al., 2006).

Background and Need

Du Boise (1903, 2003) described the African American Church as the primary social, economic, and intellectual center facilitating interpersonal relationships leading to socio-political influence; where “the Negro church antedates the Negro home” (p. 140). In his appeal for justice, Booker T. Washington (1900, 2008) also called on the religious community to overcome racial disparity by mobilizing strong Christian leadership in transforming American education and health care systems. In more recent times, Espino (2012) asserted that people of color have insight into uncovering and resolving social injustices surrounding health disparities such as HIV/AIDS, where “inequities and high levels of religious involvement, makes the study of the religion-health connection among African Americans particularly relevant...” (Holt, Wang, Clarke, Williams, & Schultz, 2013, p. 268).

While the health benefits of accessing faith-based communities when confronted with chronic illness are well established by the Centers for Disease Control and Prevention (CDC), National Institutes of Minority Health and Health Disparities (NIH), and the World Health

Organization (WHO), moral preoccupation with sexual behaviors creates tension between faith-based communities and the people affected by HIV/AIDS (Benton, 2008; Cotton, et al., 2006).

But when public health promotion is carried out with faith-based community partnerships intended to increase access to HIV/AIDS prevention, education, and treatment, how do people living with HIV/AIDS make meaning within the complexities of spirituality and sexual health?

Digital storytelling offers an emergent methodology for health promotion and practice (Gubrium, 2009) in rural communities affected by HIV/AIDS, using participant-led decision making as foundational to the filming process (De Lange & Mitchell, 2012). Although Kindon, Hume-Cook, and Woods (2012) encountered legacies of historical oppression resulting from colonial race relations, increasingly, researchers are utilizing participatory videography with “growing recognition” (Labacher, Mitchell, De Lange, Moletsane, & Geldenhuys, 2012, p. 152) in bridging diverse communities (Catalani, et al., 2012; Lunch & Lunch, 2006), where people affected by HIV/AIDS have an opportunity to communicate a collective goal narrative using alternate modes of expression (Sawhney, 2012).

Participatory video collectively reframes questions of power in political, historical, and social contexts where researchers can highlight power, position, and the monopolizing of truth claims from an inside perspective, with the potential for expanding into systemic audiences with meaningful dialogue leading to change (Walsh, 2012). To bring this into perspective, on the 30-year anniversary of Freire’s *Pedagogy of the Oppressed* (1970, 2000), total circulation exceeded 750,000 copies, yet in less than 30 days, a video project from the basement of Kansas Professor Michael Wesch (2007) was seen by over 1.7 million people, translated into 5 languages, and resulted in follow-up lectures occurring at major research conferences on six continents (Catalani, et al., 2012).

Community Tensions

Cotton et al. (2006) reported 41% of participants became more spiritual following HIV diagnosis, yet 1 in 4 felt alienated by a religious group, resulting in 1 in 10 changing their place of worship. In terms of race, this same study found that compared to Caucasians, African American participants felt more spiritual, less judgment in religious settings, and believed spiritual coping extended their lives. Moreover, Jeffries, Dodge, and Sandfort (2008) reported African American men who identified as bi-sexual esteemed religion and spirituality as vital components in their lives, while expressing fear of encountering religious condemnation and homophobia in these same settings. Similarly, in a 10-year longitudinal study, Kremer and Ironson (2013) reported that those who overcame barriers to spiritual engagement were more likely to reap positive benefits such as slower disease progression and longer life, but were paradoxically more at risk for encountering religious stigma.

Purpose of the Study

Fusing memory work (Haug, 1987, 1997) with participatory video (Lunch & Lunch, 2006) illuminates personal engagement between the HIV/AIDS and research community, where the participants become writers, producers, and actors in their own stories for change, resulting in a shifting of power and transformative connection between actors and audience (Velásquez Atehortúa, 2015). By inviting a small purposive group to share their individual and collective memories of spiritual coping following HIV infection, this research aims to collaboratively identify common themes, meaning-making, and creative methods of extending language within a postmodern framework, using film to inspire systemic change toward equitable access to spiritual supports in a small southeast community.

Postmodern Approach to Social Justice

The new American Counseling Association's Multicultural and Social Justice Counseling Competencies (Ratts et al., 2015) reflects a life-long commitment to increasing counselor self-awareness, located within a not-knowing stance of perpetual curiosity (Anderson, 2008). This constructivist posture supports questioning the roles of power and privilege; a belief that intrapsychic identities do not exist in a vacuum, but rather occur within systemic constraints, practices, and language (Pare, 2014). The deconstruction of dominant narratives within the postmodern tradition (Derrida & Caputo, 1997) is central to the collaborative nature and theoretical underpinnings of collective memory work (Haug, 1987, 1997), by generating new knowledge to inform social justice and advocacy (Collins, Arthur, Brown, & Kennedy, 2015), coupled with participatory video in HIV/AIDS communities (Waite & Conn, 2012).

High, Singh, Petheram, and Nemes (2012) highlighted the cooperative and empowering process of participatory video research, leading to "relational and transformative effects" using co-created film as an instrument to leverage dialogical space (p. 36). While deconstructing institutional power affords an opportunity for postmodern counselors, researchers, and activists to reexamine historical events, public policy, and systemic oppression, the question remains how collective memories are recorded and analyzed in a reflexive film making process.

Patrick and Connelly (2013) described the role of reflexive feedback instruments to assess the construct of privilege in multicultural contexts involving race, ethnicity, gender expression, sexual orientation, and religious practices. Similarly, Saltzburg (2007) described pathways for re-authoring narratives among parents of lesbian, gay, and bisexual clients in the coming-out process with cultural sensitivity, against "socially constructed negative laments..." (p. 62), acknowledging the connection between social justice and overall mental and physical

health (Lee, Smith, Jorgensen Henry, & Ryan, 2013). Sen (2009) reported that outcome measures should not just focus on emancipatory endpoints, but rather explore the “comprehensive processes” involving the historical marginalization of racial and ethnic minority groups historically absent from the literature (p. 22). Studies have shown that the reflexive film making process is oftentimes more liberating than the film itself (Lunch & Lunch, 2006; High, et al., 2012) in joining historically marginalized communities in peer support, meaning-making, and personal value systems (Aguilar-Raab, Grevenstein, & Schweitzer, 2015) across the lifespan (Alonso, Jiménez-López, García-Vargas, & Roales-Nieto, 2013).

Client Worldview

Paré (2014) suggested that personal and collective identities are constructed in social interactions, communities, and through mass media and symbols. Sharing this emancipatory spirit, participatory video is an empowering process that inspires people to respond differently; rather than internalizing historical and oppressive forces, it creates opportunities for identity development using film as an instrument to challenge, interrupt, and transform local concerns (High, Singh, Petheram, & Nemes, 2012). Using the extended language of film, researchers can juxtapose dueling visual realities; images of a cancer clinic (Appendix A) conspicuously identified within the same communities where HIV/AIDS clinics exist in relative obscurity (Appendix B); where African Americans encounter civil war commemorations (Appendix C) while walking to and from the HIV clinic, under the threat of punitive HIV/AIDS criminalization laws (Areola et al., 2015; Francis & Francis, 2013). By visually sharing such rich and sharply contrasting images, the participants’ worldview is extended beyond the one-dimensional limits of text, providing emotional insight and collaborative exchange with participants as expert

contributors to socially constructed identities and diverse worldviews (Collins, Arthur, Brown, & Kennedy, 2015).

Social Media as Change Agent

Under an overarching constructivist paradigm, the client's synthesis of inner and outer worlds holds potential to construct possibilities for personal growth between client and clinician, actors and audience (Anderson, 2008). At the systemic level, integrating person-centered and postmodern theory provides transformative utility in public policy, health, and international affairs (Rogers, 1961; Gergen, 2001; Iversen, Gergen, & Fairbanks II, 2010). Low, Brushwood-Rose, Salvio, and Palacios (2012) reported digital video provides enrichment to qualitative participation in voice, authorship, and representation using collaborative research methods as alternatives to traditional process. Both collective memory work and participatory video espouse "a strong emphasis on cultivating participation that recasts traditional relations of power" by renegotiating the roles commonly associated with hierarchical research practices (Haug, 1987; Low et al., 2012, p. 54) in an active, recursive, and engaging process of meaning-making, leading to transformative action within a "pocket of objectivity" (Cottone, 2007, p.194).

Stakeholders

Live Forward (formerly AIDS Athens) is a 501(c)(3) non-profit inspired by a 1987 grassroots response to the HIV/AIDS epidemic, beginning with a community forum at the University of Georgia. Their mission involves serving the unique needs of the HIV/AIDS community while striving to change societal attitudes toward the over 1.1 million Americans living with this disease, using creative approaches to public education and HIV/AIDS prevention, including the extended language of film.

Under the auspices of Live Forward, this author serves on the Advisory Board for Care Project Monroe as well as the North Georgia AIDS Consortium. Our services encompass ten counties of rural Georgia where 42% of our clients are women, and of this group, 91 % have the virus under control. In terms of marginalization, 79% of clients live below the poverty line, however 93% are in stable housing after one year in our program (2014-2015). Live Forward currently has community partnerships with the University of Georgia, Sister Love, the Foodbank of Northeast Georgia, the Georgia Department of Community Affairs, and the Athens-Clarke County Housing and Community Development Department.

Positioning of the Researcher

As a child, I used to visit the local library and sit in a quiet corner of the basement where my favorite books were kept; *The Adventures of Curious George* (Rey, 1941). As much as I enjoyed hearing these stories, it was the time spent with my mother that made me feel so happy. I remember how good it felt to sit on her lap and laugh at all the trouble this little monkey got himself into, despite his good intentions. His endless supply of curiosity inspired the lens through which I experience life, in search of meaning, fun and adventure.

Throughout my childhood and adolescence, my inquisitive nature continued to grow; in exploring my natural environment, making friends, and questioning the everyday occurrences within a small rural community. Although I got along well with peers, I never felt completely comfortable in group settings, as I had yet to discover which group to identify with. During this time of adolescent development, I began to realize that my curiosity and adventurous spirit might be valuable in the public safety domain where I ultimately forged a strong sense of identity working alongside fellow firefighters.

This new family was curious in and of itself; a group of nonconformists thriving under the auspices of a paramilitary organization. How strange! Within the firefighting culture, my personal relationships were galvanized in collective experiences and memories of traumatic events. I found it interesting how each of us returned from a shared event with completely different realities, and how our memories remained pliable; collectively reshaped while having coffee back at the fire station. Working in this dangerous occupation also garnered each of us a sense of public appreciation; the archetypal heroes romanticized in books, television, and films. Everyone should enjoy this much appreciation, because we are all courageous in surviving our respective challenges. However, while serving in this esteemed micro-community, I experienced something that would forever change my personal and professional identity; testing positive for the human immunodeficiency virus (HIV).

Words cannot begin to express the impact this event had on my life. I spent countless hours awake and alone each night, searching the internet for signs of hope in the form of a cure. This became an exercise in futility, as I encountered story after story of people still dying from AIDS, and worse still, ostracized from family and friends when they were most needed. I began to question how my own family and friends would respond if I were to disclose my HIV status to them, particularly inside the hyper-masculine culture of the fire service.

While looking down at my positive saliva test with raised eyebrows, the clinician asked if I “forgot to mention” a male to male sexual encounter, or secret history of intra-venous drug use. She repeated the question, emphasizing that this information would remain confidential and not be shared with anyone. I was not accustomed to having my integrity questioned like this, which only added to my sense of shock, disbelief, and growing resentment for this newly assumed

identity. W. E. B. DuBoise (1990) described this *double consciousness*; the tensions of seeing yourself through the eyes of those who misperceive you.

One of the existential dilemmas surrounding this illness is “why me?” Following a large fire, I would take a moment inside the fire engine to close my eyes in silent gratitude for another positive outcome, reinforcing my belief that a benevolent force is watching over us. But when faced with HIV, I began questioning my faith. It is hard to describe the irrepressible sadness and abject fear that accompanies HIV. I became afraid to shave, cough, or sneeze near my children. I even avoided the basement of our home, equating it with funerals, burial, and death. I resented this disease, the people associated with it, and questioned how God would allow this to happen.

After a month of sleepless nights and shameless self-pity, I began living in the present, and it was within this spiritual framework that I began to make meaning. It is somewhat ironic that six weeks after testing positive for HIV, I was retested at an infectious disease clinic and learned that I did *not* in fact have the disease. The odds of receiving a false positive test are reportedly 1/1000, so while this news was a tremendous relief and restored my faith, it also resulted in feelings of survivor’s guilt (Nader, 2014) where I found myself wanting to unlearn everything this experience taught me. But over time, I began to believe that this experience happened for a reason and with the knowledge I gained from it feel awakened and appreciative.

As a heterosexual married man, I realize that I am not the first person who typically comes to mind when thinking about HIV. But who is this person? I began volunteering in a small community clinic in the southeast where I learned that HIV is not limited to the public’s perception of gay white men. I encountered people of color, including many African American women, who represent a disproportionate number of new HIV infections where accessing health care, housing, and spiritual supports is extremely complicated.

The Centers for Disease Control and Prevention (2015), reported that African Americans account for 12% of the US population yet represent 44% of new HIV infections. This is due to many factors, including loss of social and financial supports, along with living in an environment where unprotected sexual contact is far less forgiving compared with other parts of the country (Women's Research Initiative on HIV/AIDS, 2014). In response to these formidable challenges, coupled with my growing sense of curiosity, I wanted to learn how people living with HIV/AIDS make meaning of this illness through spiritual coping, as well as what it means to access faith-based communities.

CHAPTER II

REVIEW OF THE LITERATURE

“Check my vital signs, to know- I’m still alive and I walk alone” (Green Day, 2004)

Despite a confluence of research in support of spiritual coping in response to HIV/AIDS (Cotton et al., 2006; Jacobson Jr., Luckhaupt, Delaney, & Tsevat, 2006; Kudel, Cotton, Szaflarski, Holmes, & Tsevat, 2011) as well as the potential for encountering religious stigma when accessing it (Munoz-Laboy et al., 2011; Palar, Mendel, & Derose, 2013), the literature is relatively silent surrounding the process of engagement between people living with HIV/AIDS and their faith-based counterparts (Abara, Coleman, Fairchild, Gaddist, & White, 2015; Derose, et al., 2014; Taylor, Chatters, & Brown, 2014). Using the University of Georgia Library System, and drawing from over 700 research databases, little was found describing how the process of spiritual engagement can be increased between HIV/AIDS and faith based communities, beyond the health benefits associated with coupling them.

This need for communicating the unique existential concerns of the HIV/AIDS community with faith-based supports might seem obvious, yet in reviewing the literature, there is surprisingly limited research focusing on this contextual process where social, political, and cultural responses to sexual health behaviors conflict and converge (Muñoz-Laboy et al., 2011). Edwards (1993) reported that drawings obtained from patients following initial diagnosis revealed disorganized and fractured images, indicative of a common biographical struggle in which the virus “permanently ruptures the afflicted person’s sense of body and time” (p. 325). More recently, Alexias, Savvakis, and Stratopoulou, (2016) further illustrated the oftentimes

disruptive embodiment of HIV/AIDS and how physical changes in health result in complex identity management. However, in terms of emancipatory research, both memory work (Haug, 1987, 1997) and participatory video (Lunch & Lunch, 2006) are emerging in the literature as a transformative instrument that critically engages “intimate spaces...and half-spoken truths” (Low, Brushwood-Rose, Salvio, & Palacios, 2012, p. 52) toward collective empowerment, by providing a context where members most at risk in the HIV/AIDS community have not enjoyed equal footing in promoting research interests and community engagement based on their own strivings (Conn, Modderman, & Nayar, 2013).

The Need for Community-Building

In reviewing the literature surrounding public health promotion, recent studies have indicated a positive correlation between the physical and emotional benefits of spiritual coping for people affected by HIV/AIDS (Kudel, Cotton, Szaflarski, Holmes, & Tsevat, 2011). While a large majority of participants reported identifying with an organized religion (Cotton et al., 2006), little is known about the process of safely disclosing their status within community support settings (Elopre, et al., 2016), including faith-based, given the fundamental difficulty in “setting oneself up for rejection in the process of seeking attention and support” (Adam, Corriveau, Elliott, Globerman, English, & Rourke, 2015, p. 392).

Despite such risks and social complexities, the potential benefits surrounding personal engagement between faith-based and HIV/AIDS communities is well supported in the literature. In the Presidential National HIV/AIDS Strategy (2010), former President Barack Obama called for a commitment from faith communities to assist in a coordinated response to the unique challenges posed by the HIV/AIDS epidemic. This report explicitly acknowledged the challenges in accessing community-based supports, including clergy, in striving for increased personal

interaction with people willing to disclose and demystify HIV/AIDS in community-based settings. Jacobson Jr., Luckhaupt, Delaney, and Tsevat, (2006) also reported that spiritual coping contributes to meaning making and high levels of life satisfaction for people living with HIV, underscoring the significance of safely accessing faith-based communities for support. But how are messages communicated by the faith-based community in promoting sexual health and education, and how does it influence the spiritual coping and meaning-making of people affected by HIV/AIDS in a multicultural world?

Multicultural Beliefs

Reflected in the literature, Black churches are historically among the most dominant and influential institutions, comprising more than 80% of all African American church members and largely associated with the Civil Rights Movement (Lincoln & Mimiya, 1988; Taylor, Chatters, & Brown, 2014). While ethnic minorities represent a disproportionate number of HIV/AIDS infections, religious involvement continues to play a key role in the culture (Holt, 2013). The community of African American Christians has turned to the church for psycho-social support during serious personal and emotional challenges involving existential questions, beginning with the harsh realities of slavery (Hardy, 2014). The faith-health connection in research suggests that involvement with faith-based communities improves emotional functioning while decreasing depressive symptoms associated with HIV (Holt, Wang, Clark, Williams, & Schulz, 2013).

Given these intersections of health, faith, and culture, Szaflarski et al. (2006) emphasized the need to educate clinicians about the important role of spirituality in the repertoire of coping strategies for their patients using faith-based, community partnerships that specifically engage in HIV-related services (Abara, et al., 2015). Coleman, Tate, Giddist, and White (2016) also argued for relationship-building between HIV/AIDS and faith-based supports, particularly African

American, where it was reported that having intimate knowledge of someone living with HIV/AIDS reduced the risk of perpetuating stigma. But how do we enter and support such intimate conversations when facing the very real possibility of encountering HIV stigma?

Walsh (2012) reported that HIV/AIDS workshops using Participatory Video helped to “unlock taboos and open up spaces for discussion that is otherwise left silent” (p. 250) as participants identify community audiences to share their local concerns (High, Singh, Petheram, & Nemes, 2012). Based on this emerging body of literature in support of community-building at the intersection of faith and public health, De La Cruz, Davies, and Stewart (2011) reported diverse community-based partnerships are needed among spiritual service providers in promoting health education, disease prevention, and reproductive counseling, yet tensions continue to exist between faith-based communities and people affected by HIV/AIDS.

Palar, Mendel, and Derose (2013) found an overwhelming number (82%) of urban religious organizations perform health-related ministries, however, very few engage specifically in HIV-related services. Munoz-Laboy et al. (2011) also reported that moral preoccupations are leading to the continuing stigmatization of people living with HIV/AIDS when attempting to access spiritual supports. Despite the potential threat for encountering stigma, Hardy (2014) reported that African American Christians may feel more comfortable accessing pastoral counseling over traditional therapeutic services, yet many faith-based leaders remain uncomfortable discussing sexual behaviors, with a steadfast belief that virtue is the best form of HIV prevention (Ford, 2011).

Similarly, Benton (2008) proposed that faith-based communities are poised to counter discrimination and stigma associated with HIV, yet these same institutions place vulnerable people, such as the newly infected, at risk for added emotional harm. Szaflarski (2013) also

noted that while spiritual coping in response to HIV/AIDS correlates with optimism, healthy behaviors, and increased social supports, it also can be negatively framed in religious contexts as a deserving punishment from God. In the Latino community, Martinez, Lemos, and Hosek (2012) reported the potential for both stressors and supports to occur in faith-seeking contexts, where the newly-diagnosed place a heavy emphasis on spiritual beliefs in coping with HIV. Instone and Mueller (2011) also reported that faith-based reproductive messages influence HIV-positive Latina women, who reported feeling less likely to use contraception based on their spiritual practices and beliefs. These studies underscore the need for better communication and coordination between sexual health promotion and faith-based constructions of HIV/AIDS (Isler, Eng, Maman, Adimora, & Weiner, 2014).

Despite such conflicting studies in the literature, faith-based organizations have vast social and political capital, placing them at the forefront of social transformation. The Institute of Development Studies (2015) endeavors to attain equality in growth-fostering relationships where people affected by public health concerns can elevate their voices using the extended language of participatory video (Catalani et al., 2012; Mitchell & de Lange, 2012). This reflects an epistemological belief that social progress is possible when community engagement messages are easily decoded within a fabric of complex and increasingly mobile relations (Lyotard, 1984).

HIV/AIDS Representation

Historically, the literature suggests that language is used to both emancipate and marginalize minority communities, including dominant narratives surrounding HIV/AIDS (Arreola et al., 2015; Francis & Francis, 2013; Grant, 2013; Gagnon, Phillips, & O'Byrne, 2014; Hoppe, 2014; Martin, 2014; Newman, 2013). Shaw (2012) interrogated this gap between participatory ideals and the realities of applied practice, where institutional funding risks

constricting the scope of participant decision-making to “becoming puppets” between complex and contradictory agendas (p. 227). However, reflecting on their use of Freirean pedagogy, LaFlamme, Singeton, and Muir (2012) reported that participatory video provides a “catalyst to build more equitable relationships between less and more powerful groups” (p. 287), using research translated in every day, common language, accessible to a vast spectrum of stakeholders (Johnsen & Christensen, 2008; Hays & Singh, 2012; Mignon et al., 2014). By integrating collective memory work with participatory video, participants have the freedom to critically expand the theoretical framework of the process (Haug, 1987, 1997), leading up to the creation of a collaborative film, community screening event, and selecting a targeted audience.

Lemaire and Lunch (2012) emphasized this need for logical frameworks in conducting and monitoring participant-developed goals throughout the participatory video process. Integrating collective memory work within this process will provide the structure leading up to a self-represented research collaboration. Self-representation in the HIV/AIDS community is a formidable challenge, however exemplifies the Live Forward mission statement aiming to “enhance and enrich” the members we serve, while seeking “to change societal attitudes” toward HIV stigma (AIDS Athens, 2016). Similarly, Olivier, De Lange, Creswell, and Wood (2012) reported that participatory video provided space where participants could see themselves as having local expertise, while creating images that leave a lasting effect on selected audiences. By collaboratively designing research activities in partnership with members of the community, researchers capitalize on local resources sharing a vested interest in the transformation of public perception surrounding HIV/AIDS.

Self-Representation using Participatory Video

Thanks to recent medical advances in Highly Antiretroviral Therapy (HAART), HIV/AIDS continues to transition from a terminal illness to a manageable disease. These benefits, however, are predicated on strict adherence to life-sustaining medications, positively correlated with spiritual coping (Ironson, Kremer, & Lucette, 2016; Kremer et al., 2015; Van Wagoner et al., 2016; Vyas, Limneos, Qin, & Mathews, 2014). For people living with HIV/AIDS, gaining access to non-judgmental social and spiritual supports is inherently complicated, given positive and negative experiences continue to occur (Trevino et al., 2010).

While critics argue that participatory video remains difficult to define (Thomas & Britton, 2012), it is widely accepted that this reflexive process is centered on cultural representation; to empower groups toward being heard rather than *giving voice*, ultimately promoting an extended language leveraging “the creative genesis of new modes of collective expression” (pp. 208-209). This creative process leads to a transformative (film) product by highlighting the entanglements of inner and outer expression; where “the producer is a group rather than an individual...to affect social change” (Thomas & Britton, 2012, p. 219).

Participatory video also responds to community-building as a health advocacy and promotional methodology (Warren, Knight, Holl, & Gupta, 2014), providing members of the HIV/AIDS community with an opportunity to identify and share personal concerns, including communities known to be under-resourced and ethnically diverse, including those having a disproportionate number of children living in poverty (Warren, Knight, Holl, & Gupta, 2014). This completed film reflected group consensus, local insight, and intentionality in dissemination using on-line as well as community engagement events. This resulted in an increase in critical

knowledge among participants, as well as acquiring significant knowledge in community activism, photography, and videography skills (Warren, et al., 2014).

Under the umbrella of Action Research, participatory video offers an emerging creative methodology to “vividly portray” multicultural experiences that bridge diverse communities in personally meaningful collaboration (Chávez et al. 2004, p. 395). By creating an intimate space between diverse communities, participatory video method coupled with collective memory work capitalizes on reflexive storytelling enhanced by images, music, and raw emotional narratives that engage local stakeholders and strengthen community networks, having the potential for extending to larger audiences through social media (Lunch & Lunch, 2006).

Linking the Past with the Present

Throughout the literature, collective memory work holds a strong persuasive bond in areas of social establishment, including political, economic, and religious institutions (Durkheim, 1915; Durkheim & Swain, 2008; Halbwachs, 1950; Johnson, Singh, & Gonzalez, 2014; McGowan, 2016; Olick, 1999; Kansteiner, 2002). The persistence of these established cultural and social traditions reflects the influential role of collective memory; a process of linking the past with present histories (Olick, 2014), just as the participatory video process reframes questions of power in political, historical, and social contexts (Walsh, 2012). While collective memory provides intergenerational social cohesion, for these very same reasons, it reflects a hierarchical commodity system, filled with successful “memory makers” as architects of dominant discourse, contrasted with lesser known memory failures, working in opposition as actors in the struggle to reconstruct the past, as it pertains to the future (Kansteiner, 2002, p. 179). However, it is through this process of confronting, challenging, and expelling historical myths, that significant and transformative change occurs (Freire, 1970).

Collective Memory and Social Stigma

Much of HIV/AIDS stigma is perpetuated in the construction of rumor. Fine's (2007) work tells us a great deal about rumors, describing them as nearly synonymous with collective memory; both vying for credibility in a common belief system, in contrast to government controlled public health discourse surrounding infectious disease. As recounted by Fine (2007), "Collective memory is rumor served cold" (p. 7); connecting historical events such as Leprosy with modern day HIV/AIDS. The present need to overcome stigma perpetuated in rumor (Lazzarini, et al., 2013) reflects how society and perhaps even its viruses are socially stratified in research and policy making. Fine (2007) suggested that rumor increases in direct proportion to state ambiguity, just as audiences favor personal accounts of HIV/AIDS over institutional discourse. This helps explain how marginalized communities who encounter systemic oppression often harbor widespread distrust in public health domains. Similarly, rumors serve the purpose of updating collective memory, formed in the constant tensions between trust and judgment communities (Fine, 2007), where accessing spiritual supports by members of the HIV/AIDS community are historically voiceless in the literature (Conn, Modderman, & Nayar, 2013).

Collective Memory and Spirituality

There appears an intrinsic relationship between moral code and spiritual systems of collective classification, where all religions reflect "truth" within the social cohesion they provide (Durkheim, 1915; Durkheim & Swain, 2008). This fundamental belief in multiple realities shares a postmodern framework, where no spiritual beliefs are "false" but rather collective representations on equal footing. Durkheim (1915) argued these systems work in constant tension, discerning the sacred from the profane. Under these dueling realities, there are of course inclusions and exclusions, perpetuated in collective memory, where no two categories

have been as historically and “radically opposed to one another” (p. 41). This dichotomy is further cemented in legal tradition, as religious freedom protects discriminating narratives, often targeting sexual behaviors and minority groups just as public health fears lead to criminalizing HIV/AIDS (Encarnacion, 2017; Grant, 2013; Martin, 2014; Newman, 2013).

Credited with developing collective memory while working with Durkheim, Halbwachs (1950) asserted that physical objects serve as important symbols, both meaningful and interpretive, providing groups with stability and local custom, where people tend to change much faster than the brick and mortar surrounding them. When confronted with public health threats such as HIV/AIDS, these iconic symbols remain fixtures of stability and comfort, insulating communities from “the gravest national, political, or religious events” where life continues “as if nothing had happened,” (Halbwachs, 1950, pp. 2-3). These symbols are also anchored within segregated spatial and spiritual frameworks, where slavery is captured in collective memory, separated not by the people, but by their differences in power.

Despite renewed interest in these cultural histories, Kansteiner (2002) criticized collective memory research for focusing too heavily on cultural events and memory production, while failing to reflect on the subversive audiences, cast as “memory consumers” (p. 179). While it makes sense that commodified tension between past and present history privileges the memory makers (Kansteiner, 2002), the spiritual needs of the HIV/AIDS community may be bridged in the production of a social “media of memory,” by the consumers themselves (p. 90). Under the umbrella of action research, participatory video methodology has increasing presence in public health promotion; developed as a democratic, community-based instrument (Catalani et al., 2012), that responds to the unique challenges of marginalized groups, promoting social justice

“beyond the group immediately involved, including dialogues with policymakers” (Wheeler, 2009, p. 13).

McGowan (2016) identified an equal opportunity to enter, interrupt, and transform systems of memory-making using iconic symbols from the feminist past, as instruments of persuasion for changing the future. While critics contend that collective memory is inherently ambiguous and contrary to objective truth claims (Olick, 1999), McGowan (2016) argued that collective memory symbols provide continuity for activists in connecting past oppressions with current concerns that “transcend individual and collective differences” as powerful instruments for change (p. 8). But how does collective memory work support the spiritual coping practices of people living with HIV/AIDS, at the paradoxical crossroads of religious tradition *and* change?

Constructing Transformative Events

Bloustein (2012) used visual images to evoke “what has not been previously stated or even consciously recognized by the participants themselves” (p. 119) in the process of creating an anti-oppressive research instrument (Wiebe, 2015). In the spirit of democratized research, findings are disseminated to broader and more diverse audiences using everyday language where it has potential for lasting change (De Lange & Mitchell, 2012; Johnson, Singh, & Gonzalez, 2014; Lewin, 1946). Such creative products inspire social influence (Runco & Kim, 2011), where social media has potential to “impact and persuade an audience to change the way it thinks” (p. 537) by constructing transformative events where “Society as a whole will gain much more from research...” (Runco, 2007, n.p.).

While Freire (1970) argued for raising critical consciousness, this alone does not complete the transformative link between knowing and doing social justice work. Johnson, Singh, and Gonzalez (2014) amplified voices from transgender, queer, and questioning high

school students by fusing collective memory work with creative film documentary. As a social justice instrument, this study was original, and fitted to the explicit needs of the participants, using historical factors capturing the emotional immediacy of participants' personal narratives, purposefully disseminated as a public service message.

The use of collective memory “storyboards” facilitates the emergence of important themes that frame the entire film production before it ever begins, as an initiation into the creative and collaborative process. Labacher et al. (2012) used storyboarding in performing an HIV/AIDS health promotion film to illustrate creating and disseminating “intimate knowledge” as an instrument of change where participatory video garners “growing recognition” in research addressing the HIV/AIDS epidemic (p. 152). Similarly, De Lange and Mitchell (2012) used visual methodologies in researching sustainability in rural communities impacted by HIV/AIDS; proving a useful model in exploring how people living with HIV/AIDS make meaning of the disease and how it impacts the role of spiritual coping in their lives. Each of these studies support participant-led, decision-making as foundational to the film-making process. Using this democratized research, De Lange and Mitchell (2012) have produced several short videos using a No Editing Required (NER) format, compositing them into a larger film to address “issues that require more than a once-off intervention” to inspire active engagement between diverse communities, where “we see great potential in the afterlife of participatory video” (De Lange & Mitchell, 2012, pp. 326-327).

CHAPTER III

METHODOLOGY

“All the stolen voices, will someday be returned” (U2, 2014)

Research suggests that both positive and negative experiences are encountered by people living with HIV/AIDS in faith-based settings (Benton, 2008; Cotton, et al., 2006). Using the qualitative participatory action methodology, collective memory work, this study will explore how adults living with HIV/AIDS make meaning of their illness, as reflected in their memories of spiritual coping. There are 3 phases of this method; beginning with individual written memories surrounding an important topic, the group process of collectively reframing individual memories, and finally the production of a community film, to elevate voices of participants in a rural HIV/AIDS clinic making research accessible to community members, practitioners, and members of the clergy in a “common language to which everyone can relate” (Haug, 1987, p. 3). It is important to note that the proposed study will take place in an area commonly referred to as the Bible Belt, where Christianity is embedded in the everyday fabric and culture of this region.

Fusing Collective Memory with Participatory Video

Integrating collective memory work and participatory video is not unique (Garde-Hansen, Hoskins, & Reading, 2009; Mistry et al., 2014; Recuber, 2012; Rothberg, 2004) however, it uniquely responds to the need for exchange-learning between communities of unequal power (Snowden, 1983) by acknowledging collective faith traditions, the physical spaces they occupy (Durkheim, 1915), and the existential challenges surrounding those confronted with serious health disparities (Salant & Gehlert, 2008). In the context of HIV/AIDS, participatory video and

collective memory work are silent in the literature, where participant co-researchers encounter “the reality of racism, poverty, heterosexism, and other forms of oppression” (Smith, Bratini, Chambers, Jensen, & Romero, 2010, p. 409).

Collective Memory in Social Movements

Collective memory plays an important role in social movements (Olick, 1999) supporting an underlying belief that knowledge, narratives, and social influence are value-laden rather than value-neutral. This constructivist framework is particularly relevant in the HIV/AIDS community, given “religious representations express collective realities...” (Durkheim, 1915, p. 38). As part of the feminist movement in Germany, Frigga Haug (1987, 1997) developed collective memory work as a social constructionist method to remove barriers between experience and theory, recasting traditional research from researcher-subject, to intersubjective processes (Onyx & Small, 2001). Therefore, collective memory assumes group and setting influence each other, leaving impressions translated into spatial terms, where habits are grounded in physical (religious) settings that are resistant to forces of change (Halbwachs & Coser, 1992).

As an extension of memory work, participatory video capitalizes on visual representations to communicate rich descriptions of memory data. Durkheim (1915) proposed “...the first representations that man made of the world and himself were of religious origin”, where subordination serves to “make one sacred and the other not”, perpetuating a hierarchical distinction that underscores the rationale for this critical research pedagogy (pp. 38-41). Freire (2000) characterized critical consciousness as not a self-achievement but rather a collaborative action from which transformational research (Creswell, 2014) emerges in a democratic change process. As a movement, participatory video supports social justice in HIV/AIDS settings (Mitchell & De Lange, 2012) by producing and circulating knowledge toward increasing public

awareness, policy, and social change. This reflexive process highlights everyday life, inner longings, and “half-spoken histories” (Low, Brushwood-Rose, Salvio, & Palacios, 2012, p. 52), contributing to an understanding of the meaning made of HIV/AIDS and the role of spiritual coping among those affected by the disease. Such reflexive feedback embodies constructivist values driven by the meaning-making process (Aguilar-Raab, Grevenstein, & Schweitzer, 2015) while “collapsing categories of data to tell a story of the group” (Hays & Wood, 2011, pg. 89).

The Fogo Method

As Director of the Extension Department at Memorial University Newfoundland Canada Donald Snowden began filming the people of Fogo Island in their opposition to a government resettlement policy aiming to relocate indigenous fishing communities. Commonly referred to as the Fogo Method, this body of democratized research was inspired by the Civil Rights Movement, illustrating an ethical “mode of public action” where community filmmaking provided policy makers “a chance to better know the people they were making decisions about...” (Corneil, 2012, pp. 21-26). The Fogo Islands initiative resulted in a landmark cooperative between the Canadian National Broadcasting Service (CNB), national policy-makers, and the Fogo Island fishing communities who persuaded the Canadian government to not only honor their traditional culture, but to protect it by investing in its local fishing industry. Following Snowden’s successful bridging of communities having unequal power, the Fogo Method was applied in multiple research initiatives where it has since become known as participatory video (Lunch & Lunch, 2006).

As a political instrument, counselors join participants confronting social injustices at the systemic level (Lee, Smith, & Henry, 2013) where researcher and researched are “equal participants both behind and in front of the camera” (pp. 440-446). However, at the intersection

of HIV/AIDS and collective memory, participatory video explores multiple identities within a social media context (Luttrell, Restler, & Fontaine, 2012), where emancipation occurs in the filmmaking process (Dougherty and Sawhney, 2012) through “the generation of empowerment” (Bühlmann, Fehr, Hälg, & Lehmann, 2012, p. 4).

Participatory videography provides a unique opportunity for sharing “diverse images and voices” that respond to power differentials, providing participants historically absent from research with the dialogical space for credible self-advocacy, scientific inquiry, and social justice activism (Chávez, 2004, p. 397) contextualized in the HIV/AIDS community (Olivier, De Lange, Creswell, & Wood, 2012). The overarching question guiding this qualitative inquiry is: How do people living with HIV/AIDS make meaning of their illness through spiritual coping practices? And secondly: This study seeks to illuminate what it means to navigate faith-based settings given the possibility of encountering both positive and negative messages.

Research Team

Consistent with memory work and the participatory video method, the participants in this study are co-researchers in the collective analysis of memory data by calling on their everyday experiences. In addition to the participants, the research team will consist of (1) researcher, serving in data collection, transcription, and film production (1) Project Coordinator from Live Forward, serving in participant recruitment, film setting, and transportation coordination (1) member from the University of Georgia’s Innovative Technology Department, serving as technical film advisor, (3) external reviewers serving as a critical reflection team, having extensive background in the HIV-AIDS community.

Sampling Procedures and Participants

This researcher will recruit 5-7 participants using purposeful sampling (Hays & Singh, 2012) throughout northeast Georgia by advertising at all Live Forward outreach centers. The criteria for participation is (1) having a positive HIV status, (2) current and active participation in spiritual coping practices, (3) willingness to engage in collective memory work as a collaborative group process with this researcher, (4) and a willingness to publicly share personal reflections surrounding spiritual coping practices in the making of a community film. Participants will be between the ages of 21 and 75 years. Training in Participatory Video and recording ethics will be provided at the start of this project, using *Insightshare: A Rights Based Approach to Participatory Video: toolkit* (Benest, 2010).

Simultaneous Data Collection and Analysis

There are 3 specific phases to collective memory work (Haug, 1997). Following informed consent and discussing incentives, the first phase involves inviting participants to write about one positive and one negative memory that impacted their spiritual coping practices while living with HIV. Preferably, these narratives will be 1-2 pages, typed in third-person, seeking as many details as possible of a memory scene, absent of personal significance or interpretation. The narratives will then be collected, copied, and redistributed to the participants as a complete set, to be read during the focus group sessions, scheduled at Live Forward.

The second phase of data collection begins with a semi-structured focus group using critical discourse analysis (Haug, 1997) as participants will be invited to read each individual narrative, share opinions and ideas about each other's memories, and identify possible similarities and/or differences while exploring and identifying themes (Johnson, Singh, & Gonzalez, 2014). The focus group will be digitally recorded and transcribed, serving as the

second level of memory data, with researcher sharing in the creative production of knowledge, reflecting personal experience within the social whole (Haug, 1997).

The third phase of data collection and analysis involves comparing individually written memories (phase 1), to generative meaning-making, themes, and collective memories (stage 2), and exploring how the stages conflict and converge, paying attention to the (spiritual) politics of language in a collective editing process (Haug, 1997). Process journals, research notes, and individual composite reflections will be assembled and grafted onto a single storyboard, in the development of a capstone participatory video. During this phase, ongoing peer debriefings, member checking, and critical group process will serve as triangulation of data. Given the goal of this research is to explore the meaning of spiritual practices when confronted with HIV/AIDS, the film editing process will ensure the accuracy of memory data in the voices of the participants. Ideally, the final edited film will then be shared in community screening event.

Trustworthiness

While LaFlamme, Singleton, and Muir (2012) reported that participatory video catalyzes equitable partnerships between less and more powerful groups, Yang (2012) cautioned that power differentials also exist between participants and researcher, requiring an ongoing commitment to self-interrogation of power relations (Plush, 2013). This concern will be addressed using external critical reviewer(s) Adriane Brown, Office Manager Live Forward Monroe; Dr. Corey Johnson, University of Waterloo; Dr. John Kiweewa, St. John Fisher College; and Fr. Desmond Drummer, the Catholic Diocese of Atlanta.

This researcher will closely monitor all stages of this project, maintain a reflexive journal, oversee data collection and storage, and conduct recursive member checking and peer debriefings with respect to the accuracy of qualitative data during this reflexive film process.

By combining collective memory work with participatory video, participants will be able to interact with written, spoken and visual data based on their own interpretations and experiences. Participants will collectively analyze written and video data for accuracy and triangulation using collective memory analysis (Haug, 1987, 1997; Johnson, Singh, & Gonzalez, 2014). In addition, text captions, music, and other creative media may be inserted within the film, to add aesthetic quality, strengthen credibility, validate lived experience, and triangulate the qualitative domains that “look at the social world from multiple angles” (Olivier, De Lange, Creswell, & Wood, 2012, p. 142).

Limitations

There are many limitations in the proposed study. Having a variety of faith-based institutions located within a given community, and their respective theological beliefs and practices, this research is intentionally broad in scope. This qualitative research focuses on the subjective experiences of a relatively small sample of participants located in a rural setting, and is not intended to represent all members of the HIV community, nor favors any one religious community over another. Rather than seeking truth claims, collective memory work is concerned with destabilizing and reconstituting memories formulated in individual and group processes requiring active engagement from all group members while striving for consensus (Onyx & Small, 2001).

In the visual research domain, High et al., (2012) reported that participatory video has been applied to social change more often in community settings rather than inside academia, suggesting that academia struggles to define this innovative research medium that questions social experiences, in mobilizing and supporting voice through collaborative quality. Moreover, the post-production screening process in this study is an important but missed opportunity for

measuring the effects of the film between participants and their targeted audiences (Waite & Conn, 2012).

Ethical Concerns

Participants may feel distrustful of the medical community, given the historical exploitation of minority groups in the shadows of Tuskegee, and widespread distrust concerning HIV/AIDS needle exchange programs (Gamble, 1997). However, democratic research methods respectfully explore cultural narratives embedded within participant communities (Rowell, Polush, Riel, & Bruewer, 2015). To ensure the protection of clients' interests in this research project, this researcher will provide a memorandum of agreement (MOA) to maintain the integrity, scope, and ownership of the research project, particularly helpful to protect participants when potential turnover of staff is an issue. Multicultural considerations are another important issue throughout the research process; particularly when discussing race, religion, sexual behaviors and health.

All research involving human subjects is subject to an institutional review board (IRB), as our responsibility to ensure any risks to participants is minimized using informed consent related to personal health and sexual behaviors around the topic of HIV/AIDS. This topic is particularly sensitive, given once a participant discloses this personal information, there are no methods to retrieve it or reinstate privacy. The National HIV/AIDS Strategy (2010), reported "...there is too much social stigma that seeks to assign blame to people who acquire HIV" (p.36). Given this unfortunate reality, recruitment will be limited to adult participants who are at least 21 years of age and consent to having their stories shared in a co-created film documentary. Hayes and Singh (2012), pointed out it is sometimes inappropriate to maintain the anonymity of participants given the goals of quantitative research, particularly when seeking thick descriptions

of data collection and analysis. This research will employ informed and ongoing consent, whereby participants will have the option to withdraw from the research at any time. Since this documentary will serve as an instrument for affecting positive change in community-based settings, participants will have an opportunity to fully discuss any concerns surrounding public disclosure of their HIV status in making this film.

CHAPTER IV

RESEARCH FINDINGS

“And in the end, we shall achieve in time the thing they call Divine” (Spacehog, 1995)

A total of eight participants were recruited for this study, each of them professing a Christian faith orientation. Assignment to the focus groups (2) was largely based on participant preference, in making attendance in this study as convenient as possible. Following a brief informational film and overview of the study, an informed consent letter was distributed and read out loud to the participants, allowing time to answer any questions related to the study. Following informed consent, the participants were asked to write a story describing one positive and one negative experience that impacted their faith or spirituality while living with HIV, paying attention to the quality of detail while avoiding overly autobiographical descriptions. The anonymous reflection papers were then distributed among the participants and read out loud on camera, ensuring that the papers were read by someone other than its author to create an emotional distance and to depersonalize the text (Haug, 1997).

Group members were then asked to explore and identify common themes, differences, and similarities related to spiritual coping across the reflection papers, while a facilitator from the University of Georgia listed their critical text analysis on a bulletin board in the front of the room. Following a lengthy and oftentimes rich discussion, the participants worked toward achieving consensus on which items should remain on the list (similarities, differences, themes), which might be missing from the list (vacuums or silences), and the significance or meaning attributed to each of the collective themes generated in the focus group discussions.

Collective Analysis

The following section describes the major themes revealed through the collective analysis of the participants during the focus groups along with the creative synthesis of the researcher. Based on the research questions and the two stories written by each participant, the key findings reveal specific elements surrounding how people living with HIV make meaning of their illness through spiritual coping practices. Other findings included what it means to navigate faith-based settings given the potential for encountering both positive and negative messages. Based on the research questions focused on the role of spiritual coping, and the two stories written by each participant, the themes reflected personal life experiences characterized by (1) existential questioning (2) the need for unconditional love, (3) spiritual meaning-making and (4) a personal call to action. The following section provides examples that describe each of these themes.

Existential Questioning

Upon learning of their positive HIV status, each of the participants described an existential questioning process that reflected thoughts associated with identity and death. For participants such as Patricia, the diagnosis was compounded by her having lost other loved ones to this same disease: “I got a call in 4 days telling me to come and see the doctor. And I got the news. I felt as if my life was over. I had family to die with AIDS.” For each of the participants this existential process appeared inextricably linked with faith, just as Dennis described during this initial reflection:

I remember walking away from the medical office in a daze. My eyes blurry with tears, my face red and hot. The hall was crowded but I could hear the echo of my own feet. My life was changed long before I knew it officially. The hollow gut wrenching ache had grown from my stomach to my heart. I was not invincible and now I knew it. What was

going to happen next and how do I reconcile the blessings I have received with the lack of gratitude I have shown? Have I pushed it too far with my life? I cried myself to sleep that night, fearing not for myself, but for those who loved me. Would their faith remain?

My self-doubt led to a plunge into alcohol and drug abuse that lasted for three years.

Although denomination was not a focus nor a common theme in this study, both Dennis and Patricia discussed a process of “church shopping” while seeking faith-based supports promoting messages that “relates to my life.” Szaflarski (2013) reported the need for developing appropriate spiritual/religious-based interventions for people living with HIV/AIDS. Robert’s experience also spoke to this need, given he encountered faith-based messages equating his illness with sin:

I spent the afternoon in shock, denial, questioning myself, crying and feeling shameful. I went to my church that night looking for answers. At 7:30 pm Bible study started. I cried all during praise and worship. At 8:00 pm I literally was drug off the alter and taken to the prayer room. At 9:00 pm I finally told the elders I was HIV-positive. At 9:01 pm I was being prayed into hell for being gay, in sin, etc. [I’m straight]. Those prayers coupled with the stigma...the diagnosis drove me into the deepest depression ever. I even entertained thoughts of suicide.

For Greg, a feeling of urgency accompanied his existential process, catalyzed by the recent loss of his partner:

You know the hardest part for me, you know, once they said the whole positive thing was like you know, when my 22-year old ex died in my arms, that was like six weeks after he went to the hospital. And so, I figured okay, I’ve got like six weeks [left to live]. You know, and then I was mad at myself because I cried the first day...

During this initial stage of critical discourse analysis, the participants noted how their existential questioning process was a common starting point in the memories, as Andrew reflected: “I think we all questioned ourselves...our lives. You know, our being...somewhere in there we questioned it.” While this process of existential questioning manifested differently between each of the participant’s stories, the following exchange revealed a deeper understanding of theological differences, achieved through a unified sense of humility:

Andrew: I agree with you but living in this world, the reality is not everybody are believers.

Patricia: Oh no (agrees), by no means.

Dennis: Some believe in something else...

Andrew: Right. But with that being said, I think whatever you believe in is greater than you-
that’s where you draw your strength from.

Dennis: Right. Amen...

Andrew: ...and that’s how we make it through.

An interesting analysis of faith and language was beginning to develop among the participants, demonstrating their collective synthesis of meaning-making within a multicultural framework.

Greg posed the following reflection to the group, suggesting how common messages transcend diverse cultures and belief systems:

But the problem is, that nobody ever thought that, maybe our higher power comes to us in a way that *we* can understand. You know, maybe that’s Pentecostal, maybe that’s Baptist, maybe that’s Buddhist, maybe that’s Hindu... I mean maybe that’s how they can be reached by *their* higher power, which is *our* higher power.

The Need for Unconditional Love

Although many of the participants described having existential questions as a starting point in their stories, it should be noted that this was time and again an ongoing process of what might best be described as memory management (Tung, Lin, Zhang, & Zhao, 2017). In other words, collective memory work provided an opportunity for the construction of new meaning, through the negotiation of perceptions, when open to reinterpreting past experiences (Haug, 1987, 1997). Many of these past experiences conveyed a paradoxical relationship between the threat of stigma and the need for unconditional love, as Dennis offered in this reflection:

I have made a decision to have myself tested while I was incarcerated...so my diagnosis came from the medical staff of the detention center. And I don't know if the isolation of the detention center didn't cause more anguish for me, or less for the fact that I was separated from my life and the people and the next issue—which is having to confront the folks that I love about the diagnosis. And I called my mother first, and there was absolutely no doubt in my mind that...that she would be supportive.

This discussion involving unconditional love shifted to include race and faith-based supports, as Tracy added:

Because people are looking...for a place to go to be comforted, and African American people—they look for the church...But then, church can also make you not want to go back to church.

For Greg, this need for unconditional love meant something very different from Tracy:

...when that moment like when I found out like I'm Prego [infected]...the *last* place that I thought about was going to church because like at that moment, I do not need to be around any judgmental people. I mean, you know, at that moment I needed to have

somebody inspire me to say you know something? Okay, yeah you got this [HIV], but this is not going to define you, that this is just gonna be a part of you.

DuBoise (1990) described the tensions of seeing yourself through the eyes of those who misperceive you as a *double consciousness*. Bryant described a similar awareness in this reflection: “But you know, I mean...people, when you, when you call yourself their friends you got a friend. Okay but one of the things you find out through HIV positive or AIDS you know, that everybody gonna cut you a little thin.” Greg shared a similar double-mindedness, linking the past with the present:

...it's the *stigma* that now you're not one of the regular people. Now you're positive, which means you know, like you may as well have the Bubonic Plague. You know, like they just look at you different. Like you're not good enough.

Similar with Bryant and Greg's experiences, Tracy described how the threat of stigma negatively impacted her ability to maintain valuable social supports:

And then when you find out that you have a diagnosis, everybody is talking about it, as such a bad thing. You don't want to tell that friend, because you don't know if you're going to have that friend or not.

This critical discourse analysis shifted to what it means to have *friends*, given many of the participants described the vulnerabilities of identifying and disclosing to people whom could be trusted with potentially stigmatizing information. This issue was settled in the familiar ethos of love, as Robert pointed out; “And that goes back to love and unconditional love.” For Patricia, this tenuous process of HIV disclosure inspired a reconstruction and definition of family; “You find who your friends are...or your real *family*. I mean just because you're sharing a blood line don't necessarily mean that make you family now. You know what I mean?”

During this collective analysis of stigma, love, and acceptance Bryant pointed out the irony:

People looking at you like you know, you're a menace to society and all that. But you never know, you might be going down the road one day and something could happen to you, and I might be the one to save you.

Adding to Bryant's sense of irony, Tracy described how stigma became a barrier to engaging in authentic relationships and the damaging effects that resulted from "wearing a mask":

...in my mind, I'm saying okay, I know now that I'm never gonna have a relationship. So, I built these defense mechanisms...in order *not* to have a relationship. And I remember one time, this guy who really liked me, he was a negative guy, and I ended up telling him I had mental health issues. But then as time went on, I found out I *did* have some emotional issues.

Within these tensions of accessing unconditional love versus the risk for encountering stigma, the focus group arrived at a creative synthesis of reflections in addressing the needs of the newly diagnosed:

Greg: I would be 100% for like doing extra funding so that when they tell you that you're [HIV] positive, they immediately hand you tickets to Club Med. And then whisk you by helicopter right over there where you have like a week where you cannot talk to any of your friends, family, nothing! I mean, have some intense counseling right there, where they just basically...

Tracy: That makes sense to me.

Greg: where you can just like, have that emotional thing. Because believe me, like you walking in the house right after you got that news [diagnosis], and then all of sudden somebody

says; “what’s wrong?” Now you tell them and now *they’re* crying. Like hold on, this is *my* chance for a freak out!

As a Christian Pastor, Robert brought a unique perspective to this collective analysis of stigma by highlighting the complexities of disclosing on an individual, familial, and community level:

...actually, there’s a lot of folks with HIV. Other people have dealt with it. But to your point, I didn’t have anybody to call. I couldn’t call mom or dad because what would they think? I couldn’t call my friends because oh my God, you know, although they were out partying with me or doing whatever, I couldn’t do *that*. I had no one to call you know, so...I went to the church because they have to have the answer. Only to get there, and find out that they were the problem. But the church isn’t the one with the answer; I had to go to the One that created the answer.

Delving into collective memory work, the participants began mining for what it means to engage in faith-based communities and the motivations behind accessing them. Greg provided this creative metaphor:

But I think that you know, one drawback that churches have is that you know, it’s kind of like joining the union. You know, you join ACLU or ACI or whatever it is. And right away you’re looking for the health benefits, you’re looking for the vacation time, you’re looking for this, we’re looking for that...but people don’t recognize that is all coming with a cost. You’re going to pay into that. You know, you’re paying into your insurance, now I’m not talking about financially I’m talking about in terms of living that whatever church, faith, that you have. Whether you’re Buddhist, or Christian, or Catholic, or Jewish, or Episcopalian, or whatever. You know, to not just be showing up to just like get

the benefits, and throw a twenty in the collection basket, but actually make that deposit in there. To make that like an amazing experience.

This tension between sexual health and institutional messages is a growing area of concern for developing appropriate systems-level HIV supports (Coleman, Tate, Gaddist, & White, 2016). Having experienced financial security as well as periods of homelessness, Greg highlighted how his newly ascribed identity is communicated within the “politics of language” (Haug, 1987, p.9):

I’ve been praying for years that I could get health insurance. You know I could never afford it. Yeah even when they had the Affordable Health Care thing, you know? You need insurance? We can help you with that. Dentures? Yeah Dude, we got you covered. I mean, really? So, all I had to do was be Prego and be a pariah to society and I could get all the free health care I needed?

Robert related how his former stigmatizing attitude toward the HIV community also began to collide with his present sense of identity, occurring within minutes of diagnosis:

But we always throw stigma on the world, but we never talk about the self-stigma. I hadn’t experienced a lot of stigma, yet there’s only two people in the room [when diagnosed]. But by the time I walked out of that room, self-stigma sort of kicked in. ...and then being heterosexual, as I had like coupled with the HIV positive diagnosis, and now people are gonna think I am gay, or they’re gonna think that I’m a drug addict, or they gonna think I’m this or think...all of that.

Unlike Robert, Tracy appeared less concerned with perceptions surrounding her sexual orientation, however she and Robert shared a similar internalization of stigmatizing messages: “the church telling me, you won’t have no relationship with a woman with HIV...it made me feel some kind of way. So, the self-stigma, the self-denial that I had, you know I had on a mask.”

Fine (2007) suggested that rumors concerning public health occur in direct proportion to the level of mistrust over government discourse, particularly among marginalized communities. The participants in the present study appeared to support such claims, as they collectively negotiated how HIV stigma, and the rumors surrounding this disease can impact the construction of self:

Bryant: I mean you can look at me and tell I got HIV. You know what I'm saying? You ain't gonna make me no different. Look here, all you gonna do is make me stronger, that's all.

Robert: What the hell you talking about? HIV doesn't have a pattern, a look. But that becomes cliché because somebody came up with it for a t-shirt or put it on a billboard or whatever, and then *that* becomes, becomes a thing. That ain't *our* thing. And I think you [Greg] said it best in reference to it's just a *part* of us. And it's such a small part, of what makes us up but we give it so much power. It just, it literally takes over our life. Well, I wanted to be a chef, now I got HIV...How come you still can't be a chef *with* HIV?

In a similar exchange, the power of such self-stigmatizing messages revealed the potential for becoming a self-fulfilling prophesy, shared by two of the participants:

Tracy: I just refused to accept the fact that I could have a healthy relationship with somebody, whether they was negative, whether they were positive. But for years, I just created scenarios, and I begin to believe the scenarios.

Robert: ...and we do have a tendency to get around other like minds, but those other like minds are wearing masks as well. So that ain't no more healthier for us than sitting in a room by ourselves.

Although the participants described having different religious affiliations, practices, beliefs and experiences, their need for receiving unconditional love was ultimately gained through a process of personal surrender to what was collectively defined a universal "Source" or Higher Power. In

analyzing the prevalence of stigmatizing messages within each of the stories, Robert provided this insight in capturing the spirit of the group consensus: “I definitely heard love in all the stories. The need for it. And it seemed in our own need, that *we* had more Christ than the folks we went to get our need fulfilled.”

Differences in Support

The church holds special significance in the African American and Latino Community, where the social climate surrounding HIV, testing, and messages becomes a significant factor (Bogart, et. al 2015). As an African American woman, Tracy added this insight; “...when we’re hurting, the first place, even if you just believe just a little bit, the first place (that) people want to go to, or think they should go to is the church.” But for Terrance, an African American man, the church was not his only source for unconditional love. Living alone and without family in the area, Terrance described how he overcame the loss of family supports through an active participation in the HIV community, and what it means to acquire his socially-constructed support system:

...went to a lot of groups and meetings, learned about stuff...met a lot of people that got HIV and AIDS and stuff like that...so I’m glad I got someone to talk to or something to do, so if I get depressed or something. Like mostly the days, I’ll hop on a bus and just ride around, which can clear my head. I like coming up here [HIV clinic] ...they’re good at keeping me upbeat, upbeat up here. It’s real positive over here.

The focus groups revealed an appreciation for these individual differences in the collective construction of meaning. For Robert, a middle-aged African American who serves as a Pastor, these differences and their potential for meaning-making occur in the context of faith:

I don't want to be around like-minded folks, because we having the same conversation over and over. I want to get around other folk, or whatever that talk about the sand and then the hand being open so I can stop sitting over hear clenching my hand...talking about I got HIV, I look like HIV, this, that, and the other. And I can start walking with my hand open to receive what He has for me.

Greg acknowledged a difference in how people respond to HIV compared with other illnesses:

...before you go sit there telling anybody, you got to have your shit together I mean, cause first of all, when they get that devastation news...you have to be prepared for what's coming back to you. You know, is it going to be admonishment? Is it going to be them looking at you like pity? Like you know, if somebody says like the cancer word? You're like, cancer oh my God! They have cancer! You know...maybe I don't want to be in a position of where at that moment somebody's feeling sorry for me. Maybe I need somebody that can inspire me to be better. To get healthy.

For Patricia, family was a continuous source of unconditional love, where being heard is synonymous with healing:

Just that ear...just somebody to express what *I'm* feeling. What I'm going through...to be with you, and to just connect with me for these few minutes I need to release something. I need to let it go now. And to not hold onto it and take me into a dark place. I don't want to go into darkness...I want to stay where I am or go further you know, on another level...towards positivity. But not having nobody; I don't want to know what it feels like. I don't want to know. All I can do is imagine because I don't know what it feels like because I've always had them there.

Other participants in the focus group were shaking their heads, appearing not as comfortable in disclosing with family, as Andrew pointed out the contrast between stories this way:

There's a difference in here in listening to everybody choose to disclose the way everybody else does...or don't do. So, I think that's a difference. I mean I told some of my family, I haven't told all of my family. You know. All my *family*...family. I don't go around telling all my friends, you know.

Bryant suggested that despite these differences, there were also similarities: "And what got me, what I heard too, was the love and, and things in your life...the Lord will send you friends down. It might not be the church people, but He will send you friends down and everything." This began a new course of analysis in defining the different meanings attributed to love, as Robert suggested: "And I think we probably need to expand the definition of love to be a God thing or unconditional love because...I *love* cookies. I love my mamma different than I love cookies." Such humorous exchanges appeared helpful to the participant's increasing comfort with one another, leading to a deeper level of sharing. This gave way to a collective acknowledgment in linking the present with the past, as Tracy added:

Yeah and I was thinking on the side that you're coming from...because if you read the Bible, and the stories in the Bible, from genesis to revelation, everybody had a diagnosis. Do we actually know what that diagnosis is? So, to eliminate people, or to not love a person that's been diagnosed with HIV within the church. In my mind, and in my heart, what type of church is this? What are they operating on? When everybody's supposed to love everybody...it gets back to unconditional love.

Building on this growing group consensus, both positive and negative messages were revealed, as Bryant described the effects of stigma: "Living with HIV changed my life by going to church,

because people think that living with HIV and AIDS is going to rub off on them...people look and stare at you, don't want to shake your hand." Similar with Bryant's story, Andrew described encountering religious condemnation in his church and the effect it continues to have on him:

He continued going to church and one day, he heard the Pastor preaching on homosexuality; that those living that life was bound for hell. He also heard of other members saying homos get that AIDS virus because they are homos and God hates them. Well needless to say, he was torn apart. He did not know what to do. Go to church, not go to church. Serve God, not serve God. And needless to say-to some degree, he is still bothered by this [sermon] 16 years later.

Taylor, Chatters, and Brown (2014) reported on the primary role of the African American Church and the important social processes that influence participation within it. This participation comes with the risk for encountering stigmatizing messages, and the potential for secondary disclosure of HIV status, as described by Tracy:

People don't want to go and tell their friends. And the first thing some people do is the comfort zone...is the church. And the comfort zone for me was the church until they just like you know, kicked me to the curb.

The participants consistently discussed what it means to disclose, calling into question the motivations for doing so, how they themselves respond to someone else's disclosure, and the possibility that disclosure signals something unspoken:

Andrew: but you do have those that just outright hey...like a flag waving. I mean, I was in the shelter one time with this guy and he looked at me and like; hey you know, I'm gay and I'm HIV positive....and I'm like wow, I don't even know you. And why do I need to know that?

Patricia: But you know I'm gonna take that just the way...from what you just said. There's that ear. Hear me? There's that ear. That's...that's what he's looking for [someone to talk to].

For most, disclosure itself remained a difficult and ongoing process of assessing personal risk against the need for increasing social supports. While most of the participants described this process as complicated, Patricia shared how disclosing her status helped make meaning of HIV:

We decided my friend and family and myself that Athens was close to my girls and had the best care for me...I got medicine and joined groups. I today am very active in my church and living forward. I am living without thinking of dying.

While Patricia found social support that helped her make meaning of living with HIV, Greg described the very real fears of losing valuable social supports in the wake of HIV disclosure. Despite this fear, Greg shared how the potential to lose social supports co-existed with a shift in his attitude and his further development of resilience:

Okay because you got one friend that blocks you, that disses you, that ain't gonna talk to you no more because you just told him you got some disease that you weren't looking to get in right? All a sudden, if you got five [friends] and you lose one that's 20% of your network support for you know, those emotional days you just can't handle it. You need phone calls, right? So, every time I get one of them people that block me, die on me, disappear on me, tell me that they're never talking to me again, I add ten new people in my life.

While the participants revealed a need for unconditional acceptance within their chosen faith, this same critical analysis was turned inward, describing differences between faiths and the need for personal accountability in promoting religious tolerance. In a very practical sense, Dennis related this need within the HIV/AIDS community using an all faiths perspective:

My wife is Wiccan and all my friends said there's no way a Southern Baptist and a Pagan are gonna make it! [laughter]. And because my father spent so many years in interfaith human relations work, with a national organization...we went to you know a Methodist Church on Wednesday night, and Synagogue on Friday, and a Greek Orthodox Church on Saturday morning, and Presbyterian on Sunday morning..., really learning the history behind religion in general, and God and everything. It's worked out in our relationship.

And we have a family Bible sitting on the coffee table, and an ankh on the wall.

Following a discussion of these differences in support, and balancing the risks of disclosure, Robert pointed out a common theme: "And then His love is you know unconditional. That regardless of the HIV, regardless of substance abuse, regardless of whatever, that that (love) was always there for us."

Spiritual Transformation

A particularly interesting finding in the collective memory work was the ability to ascribe both a negative and a positive meaning to the same exact experience, albeit at different points in time. In other words, a painful memory is not fixed, but has the potential to become transformed into a positive memory, based on a process of post-reflection and spiritual meaning-making.

Greg provided an example of this paradoxical relationship between the past and the present:

It's weird but I think a negative experience *was* the positive. I have, like most, asked God for things. I found myself 'please Godding' over and over. Sometimes the answer is yes. But yes has a price. There are no freebies. I prayed for things and got a house, car, TV's, and things. And that's all I had. No friends. No one to care. No one to care about. Then I prayed for love and someone to care about. The answer [to the prayer] was yes. So, I

loved someone who brought out the best in me. But that love was temporary and he died in my arms. But [it's] the cost of a gift, because it taught me how to love.

This theme of spiritual transformation was collectively named *God Love* and reflected a need to “Make room for God” in order to receive his blessings. It should be noted that the participant’s faith was not the result of having been diagnosed with HIV, but rather was enhanced by an ability to make meaning of illness through a spiritual framework. Maintaining this stance of openness to receive spiritual guidance and blessings became the seeds for humility and spiritual transformation. Patricia revealed her sense of humility in this reflection:

Gets heavy, it gets heavy but you know your biggest strength comes from Him [points to the ceiling]. That’s where your biggest strength come from. You can think you’re doing it by yourself, but you’re not! Everything that you do is through the grace and the mercy of Him. It’s important to understand that. You know, because it will get you through a lot of mess...and this world can be cruel...But if you just hold onto that one thing that’s always going to be, with that strength that you need. And that’s Him.

While Patricia’s account suggests an overarching reliance on faith, Tracy’s provided a more specific example of spiritual transformation within her process of disclosure:

I still had the mask on. And I just did not want to remove it because I was so afraid of the scars until my ladies told me and then God told me, just remove the mask and let it heal...You will be okay.

Despite these differences in the meaning made of God in each of the participants lives, there was a common thread surrounding the need for accessing faith-based supports as Bryant pointed out:

“The best part of all ...we are all God’s children so that what make me keep going on. I’m not

going to let people stop me getting the Lord in my life.” This making room for God also added value to the quality of personal relationships in a time of need, as Patricia recalled:

I left the doctor and went to see my best friend; he told me we were going to get information on this thing and he would always be with me. I prayed for an answer. I told my children and they said they loved me and the work began. I became very sick. My T cell count was 17 and my viral load was very high.

In reaching a consensus, the participants described their collective memories as being different in many respects, but also similar in their effect on the individual in experiencing a spiritual transformation. Tracy provided this analysis: “And then out of all of the stories, everybody had to find their own way. Through faith. Through the church.” For Patricia, this searching was a process of trial and error:

I’ve been to lots of churches. And I find that you know, you have these “preachers” per se that are coming in to like giving you just what you can read yourself in the Bible. But explain that to me. How can I relate that to my life?

This linking the past with the present needs of the participants was as unique as the individual, yet with varying speed and degrees of comfort, this *journey* as it was collectively named, gave way to an elevated sense of faith and hope at the end of the individual and collective stories.

While this mental shift was different from one participant to the next, virtually everyone’s journey ultimately led to the same destination in the form of gratitude, acquired largely through unconditional love and faith. Robert provided this insightful summary: “Just as each of us drove to the clinic taking a different route, each of us are all here...we ultimately arrived at the same destination, to be here and participate in this film.”

Spiritual Gratitude

In collectively analyzing the different stories following diagnosis, many participants arrived at what was collectively defined as an *attitude of gratitude*; a product of existential questioning, the need for unconditional love, the personal experiences leading to spiritual transformation, and a heightened sense of spiritual gratitude. Dennis shared this memory while pushing back tears:

My fear came in telling the woman I was sexually active with, and had been for over 2 years unprotected, who has 3 children. And the possibility that the disruption in their life would've been monumental. She is to this day still HIV negative, by the grace of God.

While most of the participants found meaning through their church communities, Greg's spiritual gratitude was constructed in the observance of God through nature, linking childhood memories with creative metaphor:

I remember, you know when we used to...like my parents used to go to my grandmother's house in Ocean City in New Jersey. We'd go on the beach, and I always liked to every summer grab like a big handful of sand...and I'd hold it as tight as I could possibly hold it. And the harder I held it, the faster it [sand] came out.

Robert: That's right, right.

Greg: You know, it's funny. Like all of a sudden when you open your hand, you know, what stays in stays in. And it allows others to help themselves. But it also allows for more to go in.

For Dennis, gratitude came with having a supportive family which he also attributed to God:

I'm truly, truly blessed and it made my experience easy. I have never hid the fact that I was HIV positive, because I know that God, and my wife, and my mother...and my

father-in-law of course, I have their love, their absolute admiration and support. And they have faith in me and quite frankly, the rest of it's superfluous.

Whereas most of the participants expressed gratitude for the continued support of their families, Terrance remained silent. When the others had finished talking, he provided the group with an insightful message, challenging the presumption that family supports are universally available:

All the family I got is my aunty. That's all I got left one aunty here...And when I tell her [HIV status] she was like okay, and nothing changed...The main thing, you got to have a support system. You gotta have somebody to talk to and stuff. If you don't you're gonna be lagging behind.

Having a large and supportive family, Patricia provided an interesting juxtaposition of what family means to her before and after diagnosis:

...a lot of us probably took our families for granted...in various ways. But when we came across this situation [HIV] and our family was bam, right there for us. It's like, you look at it in a whole different, you...you take a whole different outlook on how good you need to be with your family...

An interesting component of spiritual gratitude was what became known as *Holy Spirit Moments*. Greg related the spiritual significance of this experience during a period of homelessness:

But the only thing I really valued out of everything I owned was just the pair of crocks. So, missing that right one...oh my God! Was that like the end of the world. Like I could deal with everything else being taken; that house gone, the car, you know everything. Ah but that right crock man, that meant everything.

But you know, it was funny how right after that happened, as soon as I gave up, that's when the miracle happened. A lady at a church bought me a brand-new pair of shoes.

And my friend, two days later gave me her shower shoes. So, basically, I was made whole in that department. But I didn't even get to the best one yet. A week later another miracle happened. I met a man at the homeless shelter who was missing his right leg. So, I was thinking about this, you know, for a second there like, like Dude like while I'm freaking out because I am missing my right crock, here's a guy who's missing his right leg. And then a lightning moment hit. All of a sudden with tears in my eyes, I gave him my left crock. You know why I gave it to him? Because sometimes in life, we spend so much time worrying about what we lost, that we forgot what we gained.

Tracy: And I really liked your story because you took us on a, on a real journey...But I got in [the metaphorical car] because I was curious of where he was going. So, the journey that he took us on, all that time, he was searching. And in the midst of that, he said the Holy Spirit. Now with all that chaos, in his searching and the tid bits, the Holy Spirit just said okay, it's his time to feel this. Right? Out of everything that's going on...So, I just decided I was gonna stay in the car. And the ending was like I get it...through a crock!

Robert: Through a *left* crock!

Transformative Actions

During the focus groups, participants discussed how their unique experiences surrounding HIV provided a sense of purpose and with it, having more influence than previously realized. While each participant attended to this personal influence differently in advancing HIV/AIDS prevention and education, it is important to note how this process manifested within the actions of this participatory video project; using visual arts to creatively represent and amplify voice *with* rather than *for* the HIV community (Teti, French, Kabel, & Farnan, 2017). For Patricia, having spiritual gratitude comes with a commitment to share in an active voice:

I have no problem because I have personally seen the change in at least one person's life as a result of hearing my story...because they been doing things that I knew could lead to what I'm going through. And I loved and I revealed, you know? And with no hesitation I revealed, and I'm like you don't need to do that. You don't need to have this [HIV] be a part of your life. And today, I see her every Sunday in church.

In a similar vein, Greg made meaning by demonstrating how his actions reflect a shift from his own needs to providing for the needs of others:

I realized when I had everything, I had nothing and now that I have nothing, I have everything. So now my faith has changed. I ask now: What can I do for you? How can I inspire? And how can I make you smile? By getting those answers, my physical needs and emotions got met and I now feel blessed.

Throughout the focus groups, many of the participants shared how their negative stories became the inspiration for meaning-making and the motivation for their transformative actions. This coupling of pain with purpose informed each of their respective approaches to social justice activism, in promoting HIV/AIDS education and prevention. Robert exemplified what it means to transform his painful memory into a passionate call to action:

Fast forward 8 years. I am now a pastor. (I) train churches and faith based organizations all over the country on public health ministry and around social justice issues. My personal testimony has reached 73 million through TV, radio, print, and billboards. My church and ministry works in marginalized communities and deals with HIV, with sex workers, with substance use and homelessness. Literally we transform ministry, minds, lives and souls through my mantra which is help, hope, and heal. I am also a Life Coach,

Counselor, Consultant and Author. I answered the Call. I'm walking in my Purpose. And Living my Destiny.

Clearly Robert's transformative actions led to him to the ministry, taking an active and public role in addressing access to quality spiritual supports at the systemic level for members of marginalized communities. However, for other participants such as Dennis, transformative action manifested in a sense of the responsibility for simply sharing his story with others:

My mother has always been very proactive with her children. She was the first person I called after my diagnosis. She kindly reminded me of my faith and God's love for me, not to mention her own. To everything there is a purpose, she would say. My diagnosis was a *life* sentence, not a death sentence. Use this to drive your faith, make you stronger, and teach others. Her faith in me and her spirit of compassion showed me even through the worst of times, love prevails.

For Greg, transformative action was summed up in this humorous reflection: "And you know, as life starts happening and you know sometimes God kind of shakes you up a little bit, and if you're real lucky he'll give you the foot in the ass." Tracy described her transformative action as more closely resembling that of Robert; involving community activism to remove barriers in housing and faith-based supports: "I do know through my teaching and faith with reading God, Creator of All ... Love is universal."

Robert expounded on this faith-based perspective using personal experience in the church:

...with most faiths, in the work that I do, they do not have an issue with the disease. They have an issue with the *dis*-ease. If that makes sense. Those things that's uncomfortable, are the things that we have trouble making comfortable. So, we don't know how to react. Ain't nobody in the room was okay with getting a diagnosis of HIV

because *we* didn't know how to respond to HIV...I'm speaking from an all faiths perspective not just the, the church perspective. That we have to begin sharing stories, to help them with the dis-ease piece of it.

Although it was never discussed by the participants, a second silence or vacuum occurred within the construction of vicarious meaning-making. Patricia shared how her transformative actions involved disclosing to a stranger at church and the subsequent meaning she continues to make from this validating experience:

And I don't see her doing the things that she was doing prior to me sharing my story with her. So, you see a difference? I feel as if I saved her life. I don't know how she feels. I know that she took heed to what I was saying because she's doing different. But I personally feel as if I saved her life. And I feel good about that because I would not ever want anybody to go through what I'm going through, or what I've been through getting to where I am today.

It is also interesting how participation in the focus groups was itself a transformative action, occurring in a real-time construction of meaning-making, as Robert commented:

He [God] uses that...the church is a building. We went to a church...the church was right there when I got HIV, Him being the church. With you, you, you [pointing] wherever that moment that all of that was, He was there. So, He knew, He knew before we even stepped into it, He knew that we were going to be here. He knew what Michael was going to go through, all that stuff was already orchestrated or whatever. And part of that, okay I need to bring Tracy into the room with Michael, and I need to bring this one, and I need to bring that one, because that's what our assignment is.

CHAPTER V

DISCUSSION

“Am I a part of the cure or am I a part of the disease?” (Coldplay, 2003)

This study began with the questions: (1) How do people make meaning when confronted with HIV/AIDS and (2) How does living with HIV impact spiritual coping, given the possibility of encountering both positive and negative messages? Over the course of this collective memory work and critical text analysis (Haug, 1997), the participant’s individual and collective memories were negotiated and reconstructed in the process of consensus-building. Participants in this collaborative process shared common and oftentimes painful memories when first diagnosed with HIV; themes of death and existential questioning were accompanied by tensions in personal identity, spiritual beliefs, and accessing social supports during a time of extreme vulnerability.

For many participants in this study, the contrast between pre-diagnosis and post-diagnosis identities was striking; the data emanating from the focus groups revealed a process of socialization which began with the reconstruction of self. This inner process was collectively expressed by participants as a clear demarcation between former and present values, separated by date of diagnosis, and the meaning made of this life-changing event through a spiritually grounded framework. As one participant candidly noted, “nobody can do HIV for you.” Similarly, development in resiliency took place in response to HIV and the existential challenges that accompany it; participants described forming new meanings of faith, family, and personal relationships, foregrounding the risks and benefits of disclosing health status while feeling vulnerable to further stigmatization. Positive memories included themes of unconditional love,

increased quality of social supports, and finding purpose through a strengthening of faith and personal conviction, oftentimes expressed in the context of HIV/AIDS community activism.

This collective memory work study further revealed that living with HIV is an ongoing process of memory management, where meaning-making included an acknowledgment of painful memories and the choices made in reframing them. Within this process of realigning personal values, many, if not all, of the participants described personal experiences involving a closer relationship with God euphemized as *Holy Spirit Moments*, resulting in the construction of transformative meaning and a higher purpose in serving others. It might be said that participation in the present study was itself a leap of faith, as new insights concerning the role of spiritual coping and healing were generated in real-time and on camera; deemed an act of confronting and addressing the social disease of stigma.

Meaning Made of HIV/AIDS

In the present study, there remained a choice in the meaning made of living with HIV; expressed through the collective memory process of negotiating and reconciling the meaning of faith, health, and personal identity. The participants described developing an emotional shift from fear and resentment of HIV/AIDS, to acquiring a profound sense of gratitude, nested in the ebbs and flows of connecting more deeply with a higher power. It is important to acknowledge that HIV/AIDS was not the cause of the participant's faith, but rather led to a galvanizing of such preexisting convictions. Coming to consensus on God, love, friends and family became primary targets in this critical and collective analysis, discerning how these words are used, what they mean, and how the participants collectively negotiated memories at the intersection of God, health, and existential meaning-making.

In this process of collective memory work, participants also shared rich personal stories that included encountering stigma in faith-based settings, recalling unexpected punishing messages rather than the empathic supports in which they were seeking (Szaflarski, 2013). Conversely, the participants explored the relatively silent role that self-stigma played in their ability to engage in faith-based supports, and how stigma whether real or perceived resulted in the same negative consequences. Overcoming this self-fulfilling prophecy became a defining moment for many of the participants in reconstructing a sense of agency, leading to a greater appreciation for faith through the positive reframing of experiences (Kremer & Ironson, 2013). This reframing oftentimes resulted in the development of a socially constructed family in meeting the participant's need for unconditional love and support, particularly important when biological family or faith-based supports were missing or compromised.

Religion as Collective Reality

As an early pioneer in sociology and the development of memory studies, Durkheim proposed that religious representations express collective realities, "rich in social elements" (p. 38). The participants in the present study constructed memories rich in the social elements of faith, love, and meaning-making. Within these basic components of religious life, Durkheim asserted that a church is more than a building; it represents a moral community, that casts judgments as an "eminently collective" institution, where *action* is at the core of both religious beliefs and society, when functioning to "act upon moral life" (pp. 46-49). However, the participants in this study responded with their own collective action in the construction of counter-narratives to stigmatization, illuminating how access to religious communities following diagnosis was often complicated by moral preoccupations involving sexual health. Moreover,

this study literally and creatively speaks to this concern through the voices of the participants as captured on film, promoting conversations for change with an intended community audience.

Memory Consumers

Kansteiner (2002) suggested that while memory work focuses on important cultural events that may produce lasting memories, the role of the memory consumer is an oftentimes overlooked aspect of this research. Rather than focusing exclusively on faith-based leaders, members of the congregation were identified by the participants in this study as potentially important memory consumers for this participatory video. In other words, the congregation as well as the clergy was deemed responsible for perpetuating HIV stigma, and yet remained a valuable resource in promoting HIV/AIDS prevention and education (Abara et al., 2013). In the present study, six of the eight participants identified as African American and their rich personal stories continued to underscore the primary role of the African American church in their lives. While critics of qualitative research such as this are quick to point out a lack of generalizability, Haug's assertion (1997) that the social and systemic forces acting upon the individual makes a strong argument for the significance of stigma in the present study. Other research further supports this claim, given the potential for reducing stigmatizing attitudes among congregants may promote prevention and testing, particularly among African American and Latino Christians (Bogart, et al., 2015), who are disproportionately affected by HIV/AIDS (CDC, 2015).

While there is little debate surrounding the benefits of spiritual coping when confronted with serious health concerns, the literature suggests that researchers work toward making church leaders aware of the unique existential challenges posed by HIV/AIDS in reducing the threat of stigma. In a practical sense, this same research implies that the solution is "out there" waiting to be addressed with clergy, faith-based leaders, and members of the congregation. However, this

study suggests that the healing process begins with participant reflexivity (Bloustien, 2012), allowing for the development of meaning-making and a deeper connection with faith through spiritual coping.

Film as Empowerment

The coupling of participatory video with collective memory work provided an innovative approach to voicing the concerns of the participants. It might be said that participatory video is an innovative pedagogy of the oppressed, offering diverse communities an opportunity to amplify voice by linking local concerns with systemic audiences. The present study highlighted the collaborative application of visual narratives, images, and music through *horizontal filming*, formed in the spirit of partnership (Corneil, 2012; Teti, 2012). This de-stabilization of power facilitated genuine participation; providing a transparent view of the participant's representation as performance (Low, Brushwood-Rose, & Palacios, 2012), inherently political in sharing with an intended audience the social complexities of living with HIV/AIDS.

This “right of participation” is at the heart of the participatory video process, where the collaborative bridging of knowledge across diverse communities, such as HIV/AIDS and faith-based communities, can inform decision making at local, national and global levels “...in the voice of the people most affected” (Plush, 2013, p. 82). Throughout the discussion groups, voice, gesture and even the use of humor facilitated difficult discussions surrounding sexual health, faith, and the meaning made of these life-changing experiences. Given the need for practitioners, researchers, and advocates to reach beyond the classroom and clinic, the democratic ideals of participatory video coupled with the constructivist framework of collective memory work appear to uniquely embody the pursuit of multicultural and social justice advocacy.

Waite and Conn (2012) suggested that achieving change between participants and their intended audiences comes with understanding problematic relationships, and creating counter narratives surrounding difficult themes without producing them in the company of powerful others. In the present study, embedding HIV statistical data within the participatory video was deemed particularly relevant in highlighting such problematic relations, contextualizing the problem to strengthen credibility, validating the lived experiences of the participants, and triangulating qualitative domains (Olivier, De Lange, Creswell, & Wood 2012). This multidimensional, creative process leads to confidence-building, whereby the participants and researcher can communicate with faith-based communities to “construct new knowledge and use it to challenge one another’s assumptions” (Sawhney. 2012, p. 179).

Implications for Practice, Research, and Advocacy

The creative synthesis of collective memory work and participatory video may provide practitioners, researchers, and advocates with insight into creatively addressing the existential challenges surrounding life-changing health concerns and a means for addressing them with systemic audiences. Similarly, this study highlights the important role of socially constructed supports, which may be enhanced, if not created, in the colorful fabric of community mental health and research. The use journaling, reflection, and engaging in multicultural faith-based discussions were vital to the present study and were only be possible under a climate of Rogerian conditions, characterized by transparency, empathy, and unconditional positive regard (Rogers, 1961). Tragically, the lack of these non-judgmental conditions was the grist for some of the most troubling of memories expressed by the participants in this study, particularly when occurring in the context of help-seeking and faith. Given the Rogerian conditions have a longstanding history of crossing into multiple domains such as health care and public policy, perhaps their continued

advancement into faith-based settings can be supported by practitioners, researchers, and advocates in the continued pursuit of multicultural and social justice advocacy.

Study Limitations

There are several limitations in this study. Recruitment took place under the auspices of a relatively small HIV service provider, and as a result, some of the participants were familiar with one another prior to engaging in the focus groups. Similarly, while every attempt was made to include persons meeting the criteria and expressing interest in participating, it remains possible that some of this agency's clients were not fully aware of the study and therefore not included. Individual differences in level of education between the participants though anticipated, may have had an influence on the length or detail of their written reflection papers. This concern however was mitigated by explicitly deemphasizing the role of grammar and punctuation, in favor of capturing memory data in the participant's chosen style of writing.

In addition, this study does not claim to be an account of facts and events but rather the interpretive experiences of people living with HIV and the role of faith in their lives. While the present study was explicitly collaborative in design, the requirements of a doctoral program and the framework of an Institutional Review Board (IRB) are not subject to a shared partnership. However, the completed participatory video will be shared with participants as an outgrowth of this study, in the collaborative spirit in which it was created.

Recommendations for Future Research

Creating a legacy of HIV prevention and education was a universal motivation for the participants in this study. LaFlamme, Singleton, and Muir (2012) reported that the use of participatory video provided additional opportunities to explore and communicate visual histories while building a cultural archive for future generations to explore and reference.

Maintaining participatory video archives will support future research, particularly in ascertaining the impact of social justice initiatives over the course of time as reflected in institutional policy, practice, and HIV prevention and education efforts. Utilizing assessment instruments that gauge the impact a film has on an intended audience would further advance such efforts, while providing researchers with valuable insight into developing appropriate social justice initiatives.

Hardy (2014) reported on the help-seeking behaviors among African American Christians, suggesting that the Black Church affords a unique platform in addressing social injustice. However, the present study suggests that there is little control over the possibility of encountering stigmatizing messages faith-based settings. Munoz-Laboy et al., (2011) also reported a lack of interdenominational dialogue among faith-based leaders where the spiritually engaged are more likely to encounter the negative effects of stigma. These studies, coupled with the collective memories in the present study, highlight the need for researchers and practitioners to integrate appropriate spiritual supports involving the development of spatial interventions to facilitate settings where spiritual discussions can safely occur, including the community mental health setting, in bringing faith-based supports to a protected space.

Differences in social supports, spiritual beliefs, and how these were accessed were found to influence the help-seeking behaviors of the participants in the present study. The primary role of the African American Church for many of the participants was consistent with the historical significance of this institution and the potential benefits associated with linking clients with this vast social capital. Such differences reflect the importance for counselors, educators, and activists to develop programs using a multicultural framework. Identifying and addressing gaps in accessing social supports is also important, as even the participants in the present study were not immune to overlooking such differences in each other's lives. To overcome these challenges,

counselors, supervisors, and educators can capitalize on the increasing use of technology to impact the construction of knowledge, through the dissemination of research in a multimedia world.

Conclusion

The quality of faith and personal relationships following HIV diagnosis were described as much deeper and more valued compared with life before HIV diagnosis. Interestingly, and at the heart of the research question, is that HIV unexpectedly provided a catalyst to personal insights, meaning-making, and a realignment of values that ultimately led to acquiring a profound sense of purpose; an anointment or “calling” as most of the participants described becoming involved in HIV/AIDS community activism, focusing on sexual health education and prevention, while demonstrating what it means to live with HIV by sharing their stories through community film.

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APPENDIX A



APPENDIX B



APPENDIX C

