Title
What is the role of spirituality in HIV positive adolescents and emerging adults?

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What is the role of spirituality in HIV positive adolescents

and emerging adults?

by

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DISSERTATION

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Dedication and Acknowledgements

I dedicate this work to my husband Jimmy L. Smith who "stood the watch". On April 1, 2008 upon his retirement from the USN, he passed the watch on to those who remained at his duty station and throughout the USN. Little did he know he would assume the watch again. This time he would serve his family faithfully while I attended school. He kept things together in many ways and reminded me to stay focused and to rest when I was pushing myself unnecessarily. I want to thank my sons Isaiah and Phillip Smith for being my biggest cheerleaders encouraging me, giving me rides to and from the airport, and helping out at home. You are such a blessing to me and I love you both so much. I would also like to dedicate this work to my late father, Eugene Tyson, who would tell all his friends I was a doctor when I was in my BSN program. Perhaps he knew then. To my late mother, Doris Tyson, who would tell her primary care physician that I was a better doctor than she was after I completed my NP program. I wish they could have been here to share this moment with me. A special thanks to my sister Reno, brothers Barry, Vincent and Clinton for understanding the lack of phone calls and visits over the course of this educational journey. I would be remised if I did not dedicate this work to my Godparents, James and Freddie Peaco. I really appreciate your love prayers and support. Many thanks to my church family at Faith Tabernacle Church, San Diego, CA for your love, prayers and support. Finally, to all of my wonderful participants who shared their stories making this dissertation possible.

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Abstract

The purpose of this grounded theory study was to theorize about how spirituality may or may not impact HIV positive adolescents and emerging adults, explain how spirituality may or may not influence their treatment, health and mental health outcomes and quality of life for adolescent and emerging adults with HIV, and explore expectations that HIV positive adolescents and emerging adults have for clinicians to address their spiritual needs after diagnosis of a life-altering disease such as HIV. Data were collected from 21 HIV positive adolescents and emerging adult males via individual interviews with three second interviews for a total of 24 interviews. Participants were racially and ethnically diverse with seven of Hispanic descent, six of African American descent, five were Caucasian and three identified as Bi-racial. All were gay with the exception of one perinatally infected young man. Through their experiences living with HIV and prior experiences with organized religion, participants shared their perspectives of how their spiritual beliefs assisted with coping with their diagnosis of HIV as well as decreasing depressive symptomatology and increasing medication adherence. Several common themes were found throughout the interviews and were instrumental in generating a grounded theory: "reconnecting to spirituality as a means of coping with HIV." Participants reported having to re-embrace and re-engage in their earlier held spiritual beliefs and practices as well as hold to on to hope, believe in and claim normalcy and commit to beliefs and practices despite rejection from the church to move them along in this process of reconnecting. Most participants admitted to attending and participating in organized religion in youth but are no longer active participants in an organized religious organization due to stigma from the church regarding their sexual orientation and assumed HIV status. Nevertheless, spirituality continues to play an important role in these adolescent and emerging adults' lives. Understanding the role of spirituality in HIV-infected adolescents and emerging adults may provide new insights on

how clinicians may address these potentially unmet needs. Future research should be done to understand the role of spirituality in HIV-infected females and younger teens.

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Chapter 1: The Study Problem

Introduction

I still remember listening to the children at the Tumaini HIV/AIDS Orphanage singing to us (their American visitors) on my first mission trip to Nairobi, Kenya in 2007. In the lyrics of their song, they said "I know I have HIV and I am going to die but it is O.K. 'cause God is taking care of me". What a profound statement by children who were 4-9 years of age. I was impressed with how much they relied on their spiritual beliefs to help them with their diagnosis of Human Immunodeficiency Virus (HIV) and wondered what that may be like for young people here in the United States (US). Those words never left me and consequently led to my desire to better understand the role of spirituality in HIV positive adolescents and emerging adults.

To better understand this concept here in the US, it was imperative that I understand the impact of HIV in the adolescent and emerging adult population. I also needed to understand the role of spirituality in these young people's lives and how their spiritual beliefs might assist them during a time of development and maturation as well as the influences spirituality may or may not have on adolescents and emerging adults in the presence of a chronic illness. As I searched the literature to increase my knowledge regarding the role of spirituality on HIV positive adolescents and emerging adults, I found very limited data which enhanced my desire to research this vulnerable population.

HIV currently affects more than 73,000 adolescents in the US (Centers for Disease Control and Prevention [CDC], HIV/AIDS Statistics and Surveillance, 2012). At the end of 2009, more than 6.7% of the estimated 1.1 million persons living with HIV were between the ages of 13 and 24 years; more than half (59.5%) of these adolescents and emerging adults were

unaware of their status (CDC, HIV/AIDS Statistics and Surveillance, 2012). HIV is a "youth-driven disease" with 40% of new infections in the US occurring in youth less than 25 years of age, thus ranking HIV as the sixth-leading cause of death among adolescents (Benton & Ifeagwu, 2008, p. 109).

Smith and Denton (2005) suggest spirituality is extremely important to American youth. Although religion and spirituality are important to many adolescents and emerging adults, their religious or spiritual beliefs are often not reflective of their childhood religious socialization (Arnett & Jensen, 2002). Adolescents and emerging adults may either adhere to spiritual beliefs observed in childhood or adopt new beliefs that are congruent with their developing self-identities and world views (Arnett & Jenson, 2002). While there has been increased interest in the effectiveness of spirituality in adolescents as a coping mechanism in chronic illnesses, there has been very little research on its effectiveness in adolescents with HIV. In fact, less than 1% of all the literature on children and adolescents has examined issues on spirituality and religiosity in this population (Shek, 2012). As HIV positive adolescents and emerging adults seek to understand meaning in their diagnosis, the use of their spiritual beliefs may offer hope, support, decrease depression often associated with the diagnosis and an increase in overall well-being for some (Bernstein, D'Angelo & Lyon, 2012, Park & Nachman, 2010).

Statement of the Problem

Adolescents and emerging adults account for approximately 52 million persons of the more than 305 million people living in the US (American Factfinder, 2010). The leading cause of death in this age group continues to be associated with unintentional injury or accident and the leading chronic illnesses are diabetes, leukemia and heart problems. Behaviors that contribute to the leading causes of death and disability among youth and young adults include: "behaviors that

contribute to unintentional injuries and violence, sexual behaviors that contribute to unintended pregnancy and sexually transmitted diseases, including HIV infection, alcohol and other drug use, tobacco use, unhealthy dietary behaviors, and inadequate physical activity" (CDC Youth Behavioral Risk Surveillance Survey, 2010).

Youth accounted for 12,200 new HIV infections in 2010 with 72% (8,800) attributed to male-to-male sexual contact. Reasons cited for the increased spread of HIV in adolescents include 1) older sex partners, 2) unprotected sex, 3) young gay and bisexual men having sex with men, 4) sexual abuse, 5) increase prevalence of sexually transmitted infections, 6) substance abuse, and 7) lack of awareness (CDC, HIV/AIDS among Youth, 2004). Transactional sex, which can be described as having sex in exchange for money, food, clothing, of housing, can also be attributed to the increase in HIV in adolescents, emerging adults and heterosexual men who do not classify themselves as gay (Mustanski, B.S., Newcomb, M.E., DuBois, S.N., Garcia, S.C., & Grov, C., 2011).

It is estimated that 95% of US teens believe in God and religious/spiritual beliefs remain important during emerging adulthood, even when not actually practiced (Arnett 2002; Smith 2005). We know little about the meaning of spirituality in adolescents and emerging adults and how spiritual practices may impact their quality of life and adherence to treatment after a diagnosis of HIV. Assessing the spiritual needs of adolescents and emerging adults who are HIV positive may provide useful insight on the connection between religion/spirituality and health outcomes in this under researched population.

Purpose of the Study

The purpose of this dissertation was to describe HIV positive adolescent and emerging adults' perceptions of spirituality and their expectations of their clinicians and providers in addressing their spiritual needs, if so desired.

The specific aims for this dissertation were (1): To describe the meaning and role of spirituality for adolescents and emerging adults with HIV, (2): To describe the range of factors that influence spirituality in adolescent and emerging adults with HIV, (3): To theorize about how spirituality may or may not impact HIV positive adolescents and emerging adults, including their treatment, health outcomes, depressive symptoms and quality of life and, (4) To explore expectations that HIV positive adolescent and emerging adults have for clinicians to address their spiritual needs.

Grounded Theory method was chosen for this research as it is a method that allows the use of rich inductively-derived data, including detailed description of the participants' views, feelings, actions, and intentions (Charmaz, 2006). Grounded Theory is often used in health research because of its focus on interaction, communication and engagement in the participants' social situation. Interviews, observations, and field notes allowed me to develop a rich description of their perceptions of the role of spirituality in coping with HIV. It also added insight into the world of the participant's coping mechanisms and/or strategies. Using this grounded theory approach, I was able to examine how the inclusion of spiritual practices in HIV-positive adolescent and emerging adults' treatment plan assisted these young men in navigating their diagnosis and promoting better health outcomes and quality of life. I also examined how adolescents and emerging adults who do not ascribe to spiritual beliefs and practices navigated their diagnosis.

Significance

While tremendous gains have been made in treating HIV, the disease continues to be problematic in the US, particularly in minority communities. African-Americans, who represent only12% of the US population, accounted for 44% of new HIV infections in 2011 and Hispanics/Latinos who make up 17% of the US population accounted for 21% of new infections (CDC, HIV Basic Statistics Online, 2014). Although the rate of new infections remains steady, African-American men who have sex with men, ages 13-24, accounted for most new infections (CDC, HIV among Youth, 2014). It is estimated that as many as 60% of HIV positive youth age 13-24 are unaware of their status however, youth accounted for 10,500 or 21% of the 50,200 people diagnosed with HIV in 2011 (CDC, HIV among Youth, 2014). HIV is a "youth-driven disease" with 40% of new infections in the United States occurring in individuals younger than 25 years of age (Benton & Ifeagwu, 2008, p. 109). HIV was among the 10 leading causes of death among several groups of youth in 2002, and as of 2008, HIV is the sixth leading cause of death among adolescents (Rangel, Gavin, Reed, Fowler, & Lee, 2006, Benton & Ifeagwu, 2008, p. 109).

HIV continues to disproportionately affect minorities, including adolescents and emerging adults. Adolescents and emerging adults account for the fastest growing population of newly acquired HIV infection, particularly among African Americans and Latinos (CDC/ DHAP Annual Report Online, 2013). In fact, HIV infections in African American and Hispanic youth accounted for 75% of new infections from 1999-2005 in 33 surveillance areas in the 50 states, the District of Columbia and the US Virgin Islands (Rangel et al., 2006). Among males diagnosed during this time, 74% of all new infections were among men who have sex with men (Rangel et al., 2006). Poverty, access to care, stigma, racism, and lack of age appropriate

facilities to treat adolescents and emerging adults who are HIV positive are among the many challenges and disparities these young individuals face (Magnus et al., 2010). These factors place them at risk for spreading the virus to other young men who have sex with men, straight or bisexual men.

Adolescents and emerging adults are in life stages where they are making efforts to understand who they are, who they may want to become and find a sense of purpose and meaning. This is also a stage of sexual exploration and experimentation (Arnett, 2000; Steinberg, 2011). Adolescents frequently begin sexual experimentation when the brain and its executive functioning are still developing, putting them at increased risk for reproductive health problems (Arnett 2000 & Steinberg 2005). During this period of transitioning into adults, adolescents often take risks without fully weighing the consequences acting sometimes on emotions or heightened levels of arousal (Steinberg, 2005). Having a diagnosis of HIV during this period can present additional challenges for the transition through adolescence and emerging adulthood. A diagnosis of HIV may present new uncertainties for adolescents and emerging adults as many are attempting to find meaning in life and life situations. HIV positive youth are more prone to be lost to follow up care which increases viral resistance due to poor medication adherence (Magnus et al., 2010).

In limited studies in adolescents with a chronic illness, the authors elude to the obvious lack of research in adolescents with a chronic illness, including HIV. There is also a lack of research on this topic in the emerging adult population. Often times, research done in this age group is included in with the adolescent population with a cutoff age of 19 -22 or it is included in with the adult population that often has a broad range that may be as low as 18 and as high as the 80s. These diverse and wide age ranges in the literature make it difficult to impossible to discern

the impact of chronic illness, including HIV on young people. There are also potential regional biases in the literature in that the research that has been done in adolescents and emerging adults with HIV has been limited to the Midwest, south and the east coast therefore, we are unsure of the impact spirituality may have in the lives of populations of patients with a chronic illness in the western region of the U.S. Understanding the experiences and perceptions of adolescents and emerging adults in the western region of the US may also assist in broadening the applicability of spiritual assessments and inclusion of spiritual beliefs in the treatment plans for this population as a whole.

Spirituality is important to young people in America. In Smith and Denton (2005) book, *Soul Searching: The Religious and Spiritual Lives of American Teenagers,* the findings from their national survey suggest 95% of American teens believe in God, 85% state religion is important in their life, over 50% attend religious services at least monthly, and close to 50% admit to praying alone frequently.

The literature on adults infected with HIV suggests those with higher rates of spirituality report better mental well-being, better cognitive and social functioning and fewer HIV symptoms (Trevino et al., 2006). Additionally, lower rates of CD4 cell loss and lower rates of viral load over four years were evident in patients with higher levels of spirituality following a diagnosis of HIV compared to participants whose spirituality decreased following diagnosis (Ironson, Stuetzle, & Fletcher, 2006). A literature review of the role of spirituality in adults and children in certain populations suggests that spirituality is a very effective coping mechanism (Cotton et al., 2006; Trevino et al., 2007; Cotton et al., 2009; Cotton et al., 2012). We have limited understanding of the meaning of spirituality for HIV positive young people. Are there similarities to what we see in adults or are there important distinctions that make them unique?

In particular, we do not know how spirituality may be used to make meaning and/or cope with the illness. To guide our care of young people with HIV, it would be helpful to understand their spiritual beliefs and practices (if any) and if and how they use them to navigate a life-limiting illness.

During adolescent years, one may practice the religious or spiritual beliefs of their parents however, emerging adults may choose other religious beliefs or spiritual practices. With so little understanding of adolescents' and emerging adults' values and practices, there is minimal scientific basis to guide clinical practice. As HIV positive adolescents and emerging adults seek to understand meaning in their diagnosis, understanding the meaning of spirituality for this under-researched population may offer useful insight into the connection between spirituality and health outcomes. Gaining new insights on how adolescents and emerging adults respond to a diagnosis of HIV during a heightened time of social development, as they construct meaning about their spiritual beliefs and their diagnosis, has the potential also to assist clinicians in developing treatment plans inclusive of their spiritual beliefs and practices. It is hoped that these new insights will inform clinical practice and promote better health outcomes among this vulnerable population.

Primarily, the lack of qualitative studies in this area does not allow for increased understanding among clinicians of the subjective and lived experiences of adolescents and young adults with chronic illnesses. With this limited research in adolescents and emerging adults, it is quite possible their spiritual as well as other health care needs are not being fully met. What we also do not know is how this population employs their spiritual practices to assist them in navigating life threatening or chronic illnesses nor do we know their specific religious or spiritual practices.

Increased knowledge of the range of factors that influence adolescents and emerging adults to employ their spiritual beliefs while navigating their diagnosis and treatment protocols may assist healthcare clinicians in developing strategies to meet the spiritual needs in this population. In addition, results will aid in the development of recommendations to facilitate an improvement in the quality of healthcare services for adolescents and emerging adults living with HIV.

Definition of Terms

For the purpose of this dissertation, adolescents and emerging adults were defined by the definitions of Laurence Steinberg and Jeffrey Arnett. Steinberg (2011) defines adolescents as the age range from 10- 21. Adolescence is usually differentiated as early adolescence (about ages 10-13), middle adolescence (about ages 14-17) and late adolescence (about ages 18-21) (Steinberg, 2001). Arnett (2000) posited emerging adulthood (ages 18-25) as a more descriptive later phase of adolescence. Emerging adulthood is a stage that is empirically and theoretically distinct from adolescence and young adulthood and is distinguished by relative independence from social roles and from normative expectations.

For the purpose of this dissertation, the term spirituality was used to encompass beliefs about the meaning of life that underpin one's values and relationship with the world, including but not limited to religious beliefs. Spiritual practices were defined as activities that move the individual towards their personal goal of salvation or a more intimate relationship with their spiritual being or higher power. Those activities include but were not limited to prayer, meditation, chanting, yoga, fasting, reading religious or spiritual materials, attending spiritual services, listening to spiritual music or worship.

Summary

While the body of research on the relationship between spirituality and adolescents and emerging adults with HIV is in its infancy, there is little disagreement that spirituality used as a coping strategy has been found to be effective in decreasing depression, improving overall quality of life, increasing medication adherence and promoting better health outcomes (Woodard & Sowell, 2001; Lorenz et al., 2005; Trevino et al., 2007; Braxton et al., 2008; Cotton et al., 2012; Park & Nachman, 2012). In a study of 45 adolescents with and without HIV, Bernstein et al., (2012) found that the majority of teens (53%) wanted to engage in spiritual discussions when they were just diagnosed with a serious illness, suffering from a long term illness (66%), were seriously ill with the possibility of dying (66%) and 42% of the HIV positive teens wanted their doctor to pray with them.

This grounded theory study on HIV positive adolescents and emerging adults expands our understanding of the meaning and role of spirituality to them along with the factors that have influence on their spirituality. It also provides a theoretical explanation for how spirituality impacts medication adherence, decrease depressive symptomatology, improves health related quality of life and gives guidance to nurses and other clinicians for addressing their spiritual needs.

The dissertation is organized as follows: Chapter 2 is a critical literature review entitled, "Understanding the Spiritual Needs of HIV Positive Adolescents and Emerging Adults", prepared for publication in a journal for nurse clinicians. This literature review provides an overview of the existing literature relevant to spirituality in adolescents and young adults as it may or may not impact their treatment adherence and health outcomes. Chapter 3 presents an overview of the Grounded Theory methodology used in this study, including sampling, interviews, data collection, data analysis coding, categorizing, writing memos and field notes, data interpretation, assessing

and assuring rigor, and identifying limitations to the research. Chapters 4 and 5 are two data-based manuscripts on the findings of this study, prepared for submission for publication. Chapter 4 presents a theory on how adolescents and emerging adults reconnect to their spiritual beliefs and practices after a diagnosis of HIV despite the messages they receive from the church and other places of organized spiritual practices. Chapter 5 is a paper on claiming normalcy as a coping mechanism in the process of reconnecting to spirituality. Chapter 6 is a discussion paper on how the findings of this study add to the state of the science on spirituality and health outcomes in adolescents and emerging adults. Their meaning and significance will be discussed, as well as their implications for nursing practice and future research.

Chapter 2

Understanding the Spiritual Needs of HIV Positive Adolescents and Emerging Adults: A Review of the Literature

Abstract: The role of spirituality in adolescence and emerging adulthood has been understudied. While we are still attempting to understand the importance of spirituality in healthcare, we are challenged with the need to explore this concept in adolescents and emerging adults with HIV who are attempting to navigate the challenges of a chronic illness during a critical stage of development**.** The purpose of this paper is to review the existing empirical literature relevant to spirituality in adolescence and emerging adulthood, including the impact of spiritual practices on treatment adherence and health outcomes in the lives of young people with HIV.

Background: Religion has been identified as being important in the lives of the majority of children and adolescents; however, the association between religiosity and general well-being prior to adulthood has not been given substantial attention.[1] In a longitudinal study of 2,266 patients infected with human immunodeficiency virus (HIV) in the United States (U.S.), Lorenz and colleagues[2] suggest a large majority of HIV-infected patients deem religiousness (65%) and spirituality (85%) to be very important in their lives. There has been very little research on spirituality and HIV in adults and even less on the impact it has on adolescents and emerging adults with HIV.

During the developmental phases of adolescence and emerging adulthood, young people often grapple with the values they hold and what they believe in as a part of identity development. Although religion and spirituality are important to many adolescents and emerging adults, their religious or spiritual beliefs are often not reflective of their childhood religious socialization.[3] Adolescents and emerging adults have unique developmental qualities that influence their understanding of spirituality, decisions about personal and moral values, and enactment of spiritual practices or use of spiritual beliefs as a means of coping making it especially important to assess their perceptions regarding spirituality.

Religion and spirituality are very important to many adolescents. [4] In the book, Soul Searching: The Religious and Spiritual Lives of American Teenagers, a national survey found the majority of American teens believe in God (95%), deem religion important in their life (85%), attend religious services at least monthly(> 50%), and admit to praying alone frequently (50%).[4] Spirituality may be an indicator of well-being and religious affiliation and practices such as prayer may be common among patients with HIV infection.[2] The level of spirituality/religion (practices) in adult patients with HIV has been associated both directly and indirectly with

feeling that life was better after a diagnosis of HIV. [5] This is can further be explained by the causal effect of ones' increase in spirituality/religion improves relationships, self-esteem, health beliefs which in turn leads to medication adherence and improved health outcomes. [5]

The meaning of the word "spirituality" may vary individually or culturally in the context of life-changing events such as HIV/AIDS.[6] Religiosity and spirituality are often used interchangeably, however, one does not have to belong to a religion to practice spirituality or to hold particular spiritual beliefs. Spirituality is defined as "of, relating to, or affecting the human spirit as opposed to physical things, of or relating to religion or religious belief".[7] Spirituality can further be defined as "a belief in a higher power operating in the universe that is greater than oneself, a sense of interconnectedness with all living creatures, an awareness of the purpose and meaning of life and the development of personal absolute values". [8] A commitment to any of these aspects may be deemed spiritual. Religiosity is described as the organized expression of the sacred and is measured by the importance of religion as evidenced by such practices as service attendance, frequent prayer and/or meditation, and belief in God. [9]

Purpose of the Review

The impact spirituality may have on adolescents and emerging adults with HIV has been understudied. The purpose of this paper is to review existing empirical literature relevant to spirituality in adolescence and emerging adulthood, including the impact of spiritual practices on treatment adherence and health outcomes in the lives of young people with HIV. First, the importance of spirituality in young people with HIV will be discussed. Second, studies on the impact of spirituality on mental health and psychosocial well-being in HIV will be critically analyzed. Finally, the role spirituality plays in HIV treatment and outcomes will be discussed.

Literature Search Strategy

A literature search was done using the following databases: PubMed, PsychInfo, PsycArticles, Sociological Abstracts and Cumulative Index to Nursing and Allied Health Literature (CINAHL). The aim of this search was to identify studies that addressed the spiritual concerns or perspectives of adolescents and emerging adults with HIV in their efforts to cope with their diagnosis. The age range of subjects that were the focus of this review was 10-25 years old. For the purpose of this paper, adolescents and emerging adults will be defined by the definitions of Laurence Steinberg and Jeffrey Arnett. Steinberg[10] defines adolescents as 10 - 21years old. Arnett[11] defines emerging adults to include late teens through the early twenties, 18-25. The overlap between the two developmental groupings may be explained by the years' corresponding to the college years.[11] Studies were included for review if they met the following criteria (a) inclusion of adolescents and or emerging adults (defined as ages 10 – 25 years); (b) inclusion of a diagnosis of HIV; (c) inclusion of spirituality and health outcomes; (d) on U.S. samples and written in English.

The mesh terms used in combination were religion, spirituality, adolescents, young adults, emerging adults, HIV, and chronic illness. PubMed yielded 4472 articles with three relevant articles found that will be critiqued in this paper. Excluded articles addressed concerns of adults with HIV or focused primarily on HIV in other countries. Articles were also excluded if they only contained the mesh term HIV and did not address spirituality or the spiritual concerns or perspectives of the participants in their ability or efforts to cope with HIV. PsycArticles yielded 36 articles however, they, too, were not found relevant as they did not address spirituality in HIV positive participants and or concerned perspectives from adults in other countries. Sociological Abstracts did not yield any articles. PsychInfo yielded six articles

and CINAHL yielded 347 however, after applying the inclusion process outlined above, no new articles were identified.

A hand search was conducted from the reference list of the articles found relevant. Twenty-four articles were found with nine identified for use in this literature review. There were no new studies found from this hand search. Due to the limited studies related to the specific population of interest, articles critiqued included the role of religion/spirituality in adults as many of these studies included emerging adults within the age range of their studies. For example, Lorenz et al (2005) studied adults, ages 18-45+, thus including a subset of emerging adults in the sample. This resulted in nine studies for this review which are detailed in a supplementary table (see Table 1). First, those studies that offer the unique perspective of young people with HIV will be critiqued. This will be followed by a critique of the remaining studies that encompass the age range of young people from 18-25 years old in their studies that cover the range of adults to age 55 and greater.

Findings

Importance of Spirituality in Young People with HIV

Within the nine studies reviewed, five studies broadly examined the meaning of spirituality for young people with HIV and its impact on their lives with this illness.[2,6,12,13,17] Bernstein and colleagues'[12] used a cross-sectional design to determine if adolescents found it acceptable to have their physicians explore their spiritual beliefs as part of their medical care. The findings suggest a majority of teens (53-66%) wanted to discuss spiritual concerns when initially diagnosed with a serious illness, suffering from a long-term illness, recovering from a serious illness, and if seriously ill with the possibility of dying. Further, 59-62% of adolescents

with or without HIV desired to engage in spiritual discussions with their doctor so the doctor would better understand them and how their beliefs influence how they deal with being sick.

Casarez and Miles[13] descriptive qualitative study analyzing semi-structured interviews collected from a larger longitudinal study of parental caregivers of HIV positive infants, used content analysis to understand the role of spirituality in 38 African American mothers with a mean age of 22 years old. The findings demonstrated the importance of spirituality in African American women and found spirituality to be a cultural strength. The women perceived God to play a major role in their lives as an authority figure. They deemed God in control of all aspects of their lives inclusive of their ability to live and cope with their diagnosis of HIV.

Lorenz et al.[2] sought to understand the importance of religiousness and spirituality in patients with HIV using a cross-sectional, longitudinal design in a cohort of 2266 patients, including those ages 18-45+ years of age. Using a 4 item religiousness scale (Cronbach alpha = 0.84) and a 5 item spirituality scale (Cronbach alpha = 0.84), their study affirmed the importance of religion and spirituality in that 70% and almost 90% respectively, indicated that religion and spirituality was very or somewhat important. Woodward and Sowell[6] explored the spiritual perspectives of 21 HIV-infected women using a descriptive qualitative design with semi structured interviews. The focus was on participants' perspectives on managing HIV. They consistently expressed they were able to deal with having HIV/AIDS because of God's influence in their lives and felt they would not be able to accept living with HIV infection without the help of God.

Spirituality may present with a negative impact on those with HIV as well. Some adolescents with HIV may personally view religion or spirituality as a weapon of destruction for excommunication, rejection, condemnation, and damnation.[14] This perception is explained by

some adolescents' belief that AIDS is a punishment from God because of their sexual orientation and the stigma associated with HIV/AIDS.[14] In a cross-sectional, longitudinal study with 429 participants, Trevino et al.[15] findings suggest participants with low or moderate spiritual struggle scores (<11; 67.9% of total sample) experienced an increase log CD4 of 0.13 while those with high spiritual struggle scores (>12; 32.1% of total sample) experienced a decrease in log CD4 of 0.01 points. These small, but significant findings indicate those with higher spirituality CD4 increased while those less spirituality showed losses in CD4. (The goal of therapy is to maintain a CD4 cell count greater than 500).

Black men who have sex with men that are HIV positive may face the stigma of their disease coupled with stigma and homophobia from their church.[16] In a qualitative study, Foster et al.[16] found the salient theme of struggles of homophobia and stigmatization at traditional black churches. This type of stigmatization led to 50% of the participants disconnecting from organized religion.

Spirituality, Mental Health and Psychosocial Well-Being

Having a diagnosis of HIV can contribute to major depression. Basu, Chwastiak and Bruce[17] found that the lifetime prevalence of Major Depressive Disorder in HIV-infected adults ranges from 4%-45%. Spirituality has been associated with a decrease in depression and an increase in overall well-being in those who participate in some form of religious or spiritual practice.[15] Spiritual struggle however, leads to lower levels of psychological, physiological, social and spiritual well- being.[15]

In a cross-sectional design study of 308 HIV positive black women age 18 – 51 years old, Braxton et al.[18] sought to understand the role of spirituality in sustaining their psychological

well-being. The findings from this study suggest spirituality may play a critical role in Southern Black women's psychological well-being.

Woodward and Sowell[6] sought to understand the spiritual perspectives of 21 HIV-infected women using a descriptive qualitative design with semi structured interviews. When asked their perceptions on managing HIV, participants consistently expressed they were able to deal with having HIV/AIDS because of God's influence in their lives and felt they would not be able to accept living with HIV infection without the help of God.

Spirituality and HIV Treatment and Outcomes

In the Lyon et al.[14] randomized control study on spirituality in 40 HIV-infected adolescents and their families (40 parents, surrogates or caregivers), findings indicate that adolescents who believed HIV to be a punishment scored lower on spirituality and adherence to Highly Active Antiretroviral Therapy (HAART). Park and Nachman[19] used a cross-sectional design to study the link between religion and HAART in 20 HIV-infected youth. Youth, ages 14-22 years old, with perinatally acquired HIV who self-classified as having higher rates of religious practices, were found to have greater adherence when compared with those whose religious beliefs were lower. Those with higher religious beliefs scores (measured by an unspecified tool developed by the researchers) had significantly greater adherence than those with lower scores (3.46 vs. 2.34, $p < 0.05$). As previously stated, in the Trevino et al.[15] cross-sectional longitudinal study (N= 429), low or moderate spiritual struggle scores (<11; 67.9% of total sample) had a direct correlation with log CD4 levels of 0.13 while those with high spiritual struggle scores (>12; 32.1% of total sample) had average decreases in log CD4 of 0.01 points. Although small, this significant finding indicate those with higher spirituality CD4 increased while those less spiritual showed losses in CD4.

Discussion

The literature review, though on a limited number of studies, provided insight on the spiritual care needs of young people with HIV. Although several researchers concluded there was a need for such findings in young people with chronic illnesses[20,21] there are still few studies that have addressed these concerns. Findings from these studies support the notion that the impact spirituality has on the lives of adults as well as adolescents with HIV are generally positive.[14,17,19] The state of the science to date support several key findings, including associations between spirituality and increased medication adherence, coping skills, and levels of CD4, a physiologic indicator of disease state, as well as decreased depression associated with HIV.

There were several strengths in the studies included in this body of literature. The longitudinal studies demonstrated good sample retention, from 77- 86% over time. The measurement tools, the Brief Multidimensional Measure of Religiousness/Spirituality-adapted to measure spirituality and the Pediatric Quality of Life to measure health-related quality of life, have been used successfully in adolescents and report good internal consistency and well-established reliability and validity. There was good reliability, validity and internal consistency of the tools used to measure spirituality, coping and depression. The following tools were used to measure quality of life, coping, spirituality and depression: Medical Outcome Study (MOS-36) (Cronbach alpha = 0.89) to measure quality of life, Way of Coping scale (Cronbach alpha = 0.76), Center for Epidemiological Studies Depression scale (Cronbach alpha = 0.92) and spirituality scale (Cronbach alpha = 0.78). This range gives confidence that there is good internal consistency and reliability among all measurement tools used.

Using Whittemore[22] criteria for evaluating qualitative research, the three qualitative studies, [6,13,16] were found credible and met the rigors of qualitative inquiry. Negative and positive spiritual experiences were reported and participant's responses were transcribed verbatim. Although the findings of the Foster et al.[16]study is not applicable to all genders, it offers insight on the role of spirituality and religion in black men who have sex with men's treatment and compassion for others and how this may be used for preventive HIV efforts within the community at large. Woodard and Sowell[6] and Casarez and Miles[13] findings are not applicable to all races, ethnicities or genders, but do affirm the importance of considering and supporting spiritual beliefs in caring for African American women with HIV. Collectively, these studies support that spirituality and religion play a significant role in the life of African Americans, especially when dealing with a chronic or life limiting illness.

Study design was a notable limitation as most studies were cross-sectional and only measured spirituality at one moment in time, thus eliminating the possibility of determining causality.[2,6,13,15,18,19] Another limitation of this review is the limited number of studies that focused specifically on the spiritual needs of adolescents and emerging adults with HIV. Studies with adult samples that included emerging adults were reviewed to glean the emerging adult perspective. Some were specific to the age range of emerging adults; however, some included an age range of 18 years old well into the 40's and 50's. This wide range makes it difficult to capture the true perspective of emerging adults as their perspectives are often not singled out in these findings. The limited studies on adolescents had sampling issues which limited the generalizability of the findings. The sample sizes ranged from 20 to 45.[19] When using a study sample size this minimal, there is the potential for the sample not to be representative of the wider population. Samples often reflected homogeneity, for example, in a demographic variable

or single region of data collection. Findings, therefore cannot be generalized or considered applicable to all ethnicities, regions of the country or to those who do not have access to care.[6,13-19] These studies did not have comparison groups thus, limiting the ability to assess possible differences in religion/spirituality in HIV positive and HIV negative participants. Spiritual beliefs may present differently in the presence of a chronic illness such as HIV.

Despite measurement strengths in some, several studies had issues with measurement tools. The 5-item spiritual tool used in the Lorenz et al[2] study on religiousness and spirituality among HIV infected Americans reached a ceiling effect, preventing clarification of the relationship of spirituality with patient characteristics. Spirituality is individualized, develops over time and may not have been defined in the self-perceived tool which may have allowed for various interpretations. Lyon and colleagues'[14] study on spirituality in HIV-infected adolescents and their families used only one measure to assess spirituality and therefore limits the validity and reliability with a single item measure. All of the studies used self-report measures which may introduce bias in the study. Social desirability from self-report measures can decrease validity of findings as participants may not accurately report sensitive or personal information or report what they perceive the researcher is looking for. However, there is essentially no way to measure spirituality other than with the use of self-report measures.

Implications for Research and Practice

The conceptual framework of the nursing profession is based on a holistic care model. It incorporates a holistic, family centered approach to the delivery of care. This is often evidenced through active listening, the showing of genuine unconditional acceptance, the use of humor and humility and the inclusion of beliefs and practices in care, including those of a spiritual nature.[23] Although there may be a lack of acknowledgement, spirituality has underpinned the nursing

profession. [24] The nursing professions' basis of healing is steeped in rich traditions of religion that focus on service to others. [25]

The role that spirituality plays in the lives of HIV positive adolescents and emerging adult remains unclear. The very limited research in adolescents and emerging adults suggests that spirituality may be important in improving health related quality of life, overall well-being, promoting medication adherence and decreasing depressive symptoms. This work, however, must be expanded and replicated with larger, heterogeneous samples. However, these studies fail to distinctively or individually address emerging adults. There are more than 52 million adolescents and emerging adults in the U.S.[26] HIV continues to disproportionately affect minorities and young men who have sex with men. Understanding the perspectives of young people in regions across the US will maximize the applicability of these findings. Without a full representation of the US population, we are unsure of the nature of the spiritual needs of adolescents and emerging adults and how clinicians and providers might best meet these needs. Additionally, most of the participants were male; therefore a gap in the knowledge of the importance of spirituality in HIV positive adolescent and emerging adult females continues to exist.

Understanding the role of spirituality in the experience of adolescents and emerging adults living with HIV may provide insight and guidance for providers and clinicians in their efforts to meet the spiritual needs of patients. Some evidence suggests that spirituality has or promotes positive outcomes in healthcare. Although there are no concrete answers as to how, why, and who will benefit from exercising their spiritual practices in the presence of their disease, the literature suggests that for many, it has proven to be an effective coping mechanism and navigational tool.

In a study of 45 HIV-infected and non-infected adolescents, Bernstein et al.[12] found that not only did the majority of teens (53%) want to discuss spiritual concerns when they were initially diagnosed with a serious illness, suffering from a long term illness (66%), or were seriously ill with the possibility of dying (66%) but; 42% of HIV positive teens wanted their doctor to pray with them as well. This study is believed to be the first to ask adolescents if they wanted their healthcare provider to pray with them. Increasing the knowledge of clinicians of adolescent and emerging adult perceptions and expectations regarding their spiritual beliefs can offer new guidelines for addressing the unmet needs of those who practice spirituality and deem it to be a very important aspect of their life. Additionally, there was no mention of advanced practice nurses in the literature yet, there is a consensus that providers in general are not very comfortable assessing spirituality with patients. In a classic study by Anandarajah and Hight[27] approximately 64 percent of physicians were found to believe in God compared to 91 percent of patients. Although there are tools available to provide guidance, for example the Hope, Organized Religion, Personal Spirituality/practices, and Effects on medical care end of life issues (HOPE) questionnaire and formal spiritual assessment tools, there is reluctance to address the spiritual needs of patients.[27] The need to incorporate spiritual assessment in nursing and medical schools is evident if clinicians are expected to address their patients' spiritual concerns. This gap will continue to serve as a barrier in the patient/clinician relationship when patients deem their spiritual practices critical in their ability to move towards a state of wellness or in making end-of-life decisions.

Conclusions

While there has been great interest in the effectiveness of spirituality in adolescents and emerging adults as a coping mechanism in chronic illnesses, there has been very little research on its effectiveness in young people with HIV. There is clear evidence from the literature that higher levels of spirituality influence positive outcomes and a higher health related quality of life. It has also been demonstrated to reduce depression when faced with a chronic illness. Adults as well as adolescents have been shown to adjust better and employ better coping strategies with higher levels of spirituality. The literature strongly suggests a positive correlation between health outcomes and religion/spirituality. However, religion/spirituality may be a painful factor, especially if viewed as punishment.[12]

There is still much that we do not know in this area yet, it is very encouraging to know there is growing interest in discovering the unknown. Adolescents rate spirituality as being very important with as many as 50% of teens in the U.S. reporting participation in spiritual practices weekly.[4] How important is spirituality to adolescents and emerging adults who are faced with a chronic illness such as HIV? When should clinicians have these discussions with their adolescent and emerging adult patients? Is it really appropriate for clinicians to have these discussions with their patients? These are all questions that we really do not have answers to and further research will help to provide evidenced-based guidance to better incorporate spirituality into clinical practice, when appropriate. It is important that we keep in mind the relevance of their religious/spiritual needs in our assessment of young people. However, knowing the importance of religion/spirituality in chronic illnesses for many, may be beneficial in assisting clinicians and providers to act on these suggestions with referrals to chaplains and other spiritual leaders when assessing adolescents and emerging adults. Although we may never understand the

relationship between spirituality and medicine, we must be cautious in minimizing its role in the coping process for adolescents and emerging adults with HIV.

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Table 1: Spirituality and HIV in Adolescents and Emerging Adults

Investigator(s), Year Journal	N	Sample	Study Design	Major Findings	Strengths	Weaknesses
Bernstein, D'Angelo, & Lyon, 2012. An explanatory study of HIV+ adolescents' spirituality: will you pray with me? *Journal of Religious Health*	N= 45	19 HIV positive Adolescents, 26 HIV negative adolescents Ages 12-21, mean age 17.2 years. Female = 28 male = 17 African America = 36, Hispanic =2, Caucasian =3, Other = 3	Cross-Sectional	1) The majority of teens did want to discuss spiritual concerns when just diagnosed with a serious illness (53%), when suffering from a long-term illness (66%), if recovering from a serious illness (60%) and if seriously ill with the possibility of dying (66%). 2) Adolescents with or without HIV desires to discuss spiritual concerns with their doctor so the doctor would better understand (62%) and so the doctor could understand how their beliefs influence how they deal with being sick (59%). 3) HIV adolescents were more likely to endorse feeling Gods' presence (Mean = 3.95 versus 2.83), more likely to feel they were part of a larger force (Mean = 2.58 versus 1.69), and more likely to feel at times that God had abandoned them (Mean = 1.63 versus 1.15).	1) Pediatric Quality of Life Inventory tool with established reliability and validity (Ped QoL). 2) Brief Multidimensional Measurement of Religiousness/ Spirituality (BMMRS) reports good internal consistency.	1) Small sample size of primarily African American 2) Insufficient power to find statistically significant differences. 3) Convenience sample. 4) Volunteer bias skewing data toward higher spirituality levels due to nature of voluntary participation in the study and failure to collect data on those who declined to participate. 5) Participants may represent those adolescents who are most comfortable discussing spirituality.

*Adult studies were included to glean information about emerging adults.

Investigator(s), Year Journal	N	Sample	Study Design	Major Findings	Strengths	Weaknesses
Foster, Arnold, Rebchook, & Kegeles, 2011. "It's my inner strength": spirituality, religion and HIV in the lives of young African American men who have sex with men *Culture, Health & Sexuality*	N=31	15 HIV positive males 16 HIV negative males, African American males, Age range 18-30 years of age	Qualitative	1) Spirituality remains important in the life of HIV positive and negative MSM. 2) Homophobia and stigmatization remains prevalent in the black church 3) Black MSM face challenges with their sexual identity and the being Christian.	1) Affirms stigma associated with HIV in the African American community and church. 2) Good retention. 3) Affirms importance of spirituality in the life of HIV positive and negative Black MSM.	1) The study was done in one metropolitan area of the US and therefore is nor representative of the perspectives of Black MSM in other regions of the US. 2) There was no direct correlation identified for why the men left the church. 3) There is no evidence to support Black MSM leaving the Black church or all churches.
Lyon, Garvie, Kao, Briggs, He, Malow, D'Angelo, & McCarter, 2010. Spirituality in HIV-infected adolescents and their families: FAmily CEntered Advance Care planning and medication adherence *Journal of Adolescent Health*	N= 40	20 HIV positive Adolescents (14-21), 18 decision making surrogates =/> 21 Female = 23, male = 15 African American = 35, Caucasian = 2, American Indian/Alaskan = 1	Randomized Control Trial	1) The intervention affected spirituality while confirming the hypotheses of an association between the belief that HIV is a punishment from God and low adherence to medication, but not between spirituality, adherence, or the stage of illness. 2) Between-group differences in Meaning/Purpose and Faith Subscales were statistically non-significant at baseline. 3) FACE adolescents' mean score for meaning/purpose increased, but the mean spirituality score of the control group increased significantly (p= .045). 4) On the faith subscale, FACE adolescents' scores	1) Longitudinal, prospective, randomized clinical trial design. 2) Excellent retention all participants completed study. 3) Theoretically guided hypotheses. 4) Multilevel modeling analyses.	1) Secondary analysis restricts causality 2) Self-report measures. 3) Only one spirituality measure. 4) Validity and reliability of a single-item measure.

Investigator(s), Year Journal	N	Sample	Study Design	Major Findings	Strengths	Weaknesses
				decreased slightly while the control scores significantly increased from a mean of 44.27 to 49.57 (p=0.002). 5) Youth living with HIV/AIDS who persisted in beliefs that HIV was a punishment from God had lower spirituality scores (p=.05) and poor HAART adherence (p=.04) than those who did not have this belief.		
Park & Nachman, 2010. The link between religion and HAART adherence in pediatric HIV patients *AIDS Care*	N=20	Female = 7 Male = 11 Age = 14-24 Caucasian = 8 Black = 9 Asian = 1	Cross-sectional	1) Average depression score was higher in those with poor adherence than in those with excellent adherence. 2) Tools assessing depression as a reason for non-adherence may not be helpful in adolescents with HIV. 3) Average religious practice score was higher in those with excellent adherence than in those with poor adherence although the value was not significant (2.66 vs. 2.23 p = 0.46)	1) Affirms that teenagers will not always be up front with their providers. 2) Youth that self-classified as having higher rates of religious practices more often had excellent adherence as compared with those whose religious beliefs were lower.	1) Self-report measure leads to potential for social desirability bias. 2) Religious and spiritual used interchangeably. 3) Adherence measured over three days.
Braxton, Lang, Sales, Wingood, & DiClemente, 2008 The role of spirituality in sustaining the psychological well-being	N= 308	African American Women in Southeastern, US	Randomized Cross-sectional	1) Participants with lower spirituality scores had higher levels of depressive symptoms. 2) Religiosity and spirituality were found to be protective	1) Addresses the prevalence of psychiatric disorders in HIV positive women.	1) Cannot be generalized to other populations living with HIV/AIDS, (only measured women).

Investigator(s), Year Journal	N	Sample	Study Design	Major Findings	Strengths	Weaknesses
of HIV- positive black women *Women and Health*				against negative consequences of stress and beneficial in promoting psychological well-being. 3) Using a 3 step hierarchical linear regression, with spirituality added in the final step, accounted for a significant increase in the overall variance explained by the model (R square change =0.01, F change = 4.17, significant F change = 0.042). 4) Reliability of measurement tools – Medical Outcome Study quality of life scale – Cronbach alpha= 0.89, Ways of Coping scale – Cronbach alpha = 0.76, Center foe Epidemiological Studies Depression scale- Cronbach alpha = 0.92 and Spirituality belief scale – Cronbach alpha = 0.78	2) Offers implications for further research in Black women. 3) Good reliability of measurement tools.	2) Cannot be generalized to all women with HIV, (recruited only African American women). 3) The depression scale used is indicative of symptoms and cannot be translated into a measure of clinical depression. 4) Spirituality was only assessed at one point in time. 5) Self-report surveys lead to social desirability bias.
Casarez & Miles, 2008 Spirituality: a cultural strength for African American mothers with HIV *Clinical Nursing Research*	N= 38	African American Females = 38	Qualitative descriptive involving secondary data analysis	1) The benefits of relationship with God = decrease worrying for self and child. 2) Staunch belief in God's control over their lives. 3) Spirituality as a cultural strength. 4) Spiritual practices increase faith – prayer, reading Bible, church attendance.	1) Good retention 2) Affirms importance of considering spiritual beliefs when caring for African American women with HIV.	1) Interviews did not focus directly on spirituality and spiritual practices. 2) Study done on women in the Southern US where Christian traditions are strong for African Americans. 3) Cannot be generalized to women in other regions of the US or those who do not adhere

Investigator(s), Year Journal	N	Sample	Study Design	Major Findings	Strengths	Weaknesses
				5) Insight on the meaning and importance of spirituality to African American women.		to any particular religious affiliation.
Trevino, Pargament, Cotton, Leonard, Hahn, Caprini-Faigin, & Tsevat, 2007. Religious coping and physiological, psychological, social, and spiritual outcomes in patients with HIV/AIDS: cross-sectional and longitudinal findings *AIDS Behavior*	N = 429	Male = 367 Female = 62 African American = 226 Caucasian = 203 Christian = 316 Jew = 7 Muslim = 5 Other = 12 None = 50 Undesignated = 40	Cross-sectional Longitudinal	1) Positive religious coping was associated with positive outcomes. 2)Positive religious coping was a significant predictor with scores increasing on average by 0.80 3) Spiritual struggle was associated with negative outcomes. 4) HIV mastery scores increased by 3.53 in participants with low or moderate spiritual struggle and scores decreased in participants with the highest spiritual struggle by 14.00 points. 5) Center for Epidemiological Studies-Depression 10 scores decreased in participants with low to moderate spiritual struggles by 0.33 points and increased by 1.29 points in participants with highest spiritual struggle scores. 6) Participants with low to moderate spiritual struggles had a mean increase in CD4 of 0.13 points and those with	1) Good retention and follow up at 76.7% 2) Multi-site recruitment 3) Longitudinal study design. 4) Affirms that positive religious coping is synonymous with positive outcomes including greater self-esteem and spirituality.	1) The sample size was limited to Caucasians and African Americans with primarily Judeo-Christian religious affiliations therefore, cannot be generalized to individuals of other ethnicities and religious denominations. 2) Data was collected at East coast and Midwest locations and therefore cannot be generalized to other regions of the country. 3) Participants had access to state –of-the-art HIV/AIDS treatment and cannot be generalized to individuals who do not have access to treatment or who are not benefiting from treatment. 4) Potential for recall bias.

Investigator(s), Year Journal	N	Sample	Study Design	Major Findings	Strengths	Weaknesses
				highest spiritual struggles had an average decrease by 0.01 points. 7) Spiritual struggle leads to lower levels of psychological, physiological, social and spiritual well-being. 8) Positive religious coping leads to greater well-being.		
Lorenz, Hays, Shapiro, Cleary, Asch, & Wenger 2005. Religiousness and spirituality among HIV-infected Americans *Journal of Palliative Medicine*	N= 2266	Male = 1609 Female = 657 Caucasian = 1156 African American = 702 Hispanic = 317 Other = 68	Longitudinal Cross-sectional	1) Sixty-five percent of participants affirmed that religion was somewhat or very important in their life. 2) Eighty-five percent affirmed that spirituality was somewhat or very important in their life. 3) Seventy-two percent sometime or often rely on religious or spiritual means when making decisions. 4) Women, non-whites and older patients were more religious and spiritual. 5) Participants in regions other than the western US reported higher religiousness.	1) Sample size 2) Reliability of measurement scale – measured two dimensions; religiousness and spirituality. Both reported Cronbach alpha of 0.84.	1) Ceiling effect of spirituality measure – used only one measurement tool. 2) Questionnaire did not include items to parse the impact of religiousness and spirituality in ways that may be important to understand their importance in practice. 3) The survey did not explore patient's expectations of how the findings could be implemented in their interactions with their providers.
Woodard & Sowell, 2001. God in control: women's perspectives on managing HIV-infection	N=21	Age 18-55+ African America = 18 Caucasian =3 Baptist = 11 Methodist = 3 Other = 5	Qualitative Grounded Theory	1) Consistently expressed belief that God's influence in their lives allowed them to deal with HIV/AIDS. 2) Faith in God's ability to intervene in their lives was an	1) Offered perspective of underserved women. 2) Offered insight on use of applying spiritual beliefs in medicine.	1) Not generalizable to women in other areas –Study done in North Carolina. 2) Convenience sample of poor women thus not generalizable

Investigator(s), Year Journal	N	Sample	Study Design	Major Findings	Strengths	Weaknesses
Clinical Nursing Research		None =2		important force in helping them live with HIV/AIDS. 3) Church attendance was less important than other spiritual activities such as praying, or talking directly to God. 4) Anger at God for their illness. 5) Modern medicine as an adjunct to spiritual beliefs. 6) God uses doctors and give them wisdom and knowledge to care for the sick (HIV-infected). 7) Benefits in having a spiritual life – getting peace, being happy, easing stress and worry, and decrease in pain. God described as a constant companion, trusted confidant, problem solver and guardian.	3) Shared expectations of patients from providers.	to women who are not impoverished.

Chapter 3

Chapter 3: Research Design

The purpose of this chapter is to describe the research design used in this dissertation to elucidate the lived experiences of adolescents and emerging adults living with HIV, specifically to explore the influences of adolescent and emerging adults' spiritual beliefs and practices on the experience of their disease. A brief overview of grounded theory will be discussed followed by the specific procedures used for this study, including sampling, data collection (interview and field notes) and data analysis (coding and memos). Issues of theoretical saturation as well as study limitations and ethical issues will be presented. Finally, I will discuss my personal positionality in the research and steps taken to assess and assure rigor throughout data collection and analysis.

Grounded Theory

Grounded theory is one of many qualitative research methods. Grounded theory uses rich data: detailed description of participants' views, feelings, actions, and intentions. Grounded theory is often used in health-related research because of its focus on interaction, communication and engagement in participants' social situations. Grounded theory is similar to other methods of qualitative research in its mode of data collection which uses interviews, field notes, documents (e.g., letters, diaries, autobiographies, biographies, newspapers and other media materials), and videotapes (Strauss & Corbin, 1990). Unlike other methods of qualitative research, grounded theory places emphasis on theory development (Strauss & Corbin, 1990).

Grounded theory methodology is a two-part process that involves generating a theory and conducting social research (Glaser, 1978). In grounded theory approaches, theory is generated from existing data or from data as they are discovered. Grounded theory methodology does not require the researcher to enter the study with a hypothesis but rather, the researcher should

remain open to themes that emerge from the data (Strauss & Corbin, 1990). As described by Charmaz, (2006), grounded theory methodology is a systematic method for collecting and analyzing qualitative data that allows for flexibility while constructing theories grounded in the data themselves. Grounded theory is not standardized or packaged but rather guidelines and processes that assist the researcher in building a theory about a phenomenon (Charmaz, 2006).

This study used a constructivist grounded theory approach which allowed participants to construct meaning and actions in their situations. Constructivists seek to understand how participants' "construct meanings and actions in specific situations" (Charmaz, 2006, p. 130). Charmaz explains that constructivist grounded theorists engage in this process by getting as close to the experience as possible while knowing they are unable to replicate the experience of the participant (Charmaz, 2006). Constructivists seek to understand how participants' "construct meanings and actions in specific situations" (Charmaz, 2006, p. 130). To better understand the spiritual needs of adolescents and emerging adults with HIV, it was important to allow them to construct personal meanings about their spiritual believes and how these beliefs may have assisted them in coping with their chronic illness. Understanding the individual spiritual meanings and needs of adolescents and emerging adults may provide useful insight for clinicians and providers in their efforts to address these often unmet needs.

Pilot Study

From December 2012 to March 2013, I conducted a pilot study, consisting of 13 individual interviews and two second interviews of emerging adult males who were HIV positive living in a metropolitan area in the Western United States (US). The sample consisted of six Hispanic males, three Caucasian males, three African American males and one Bi-racial male between the ages of 19-25. Most participants denied being affiliated with an organized religious

organization at the time of this study, but identified as Christian or having a Christian upbringing, including being raised in a home that practiced or participated in organized religion. Participants shared both negative and positive experiences of using their spiritual beliefs to assist with coping with their diagnosis. They also shared experiences of real and perceived stigma from the church because of their sexual orientation.

To better understand how adolescents and emerging adults employ their spiritual beliefs while coping with a chronic illness, one must also have an understanding of the importance of spirituality in the lives of young people. Understanding these unique qualities became a part of my research and helped to generate theory around their spiritual beliefs as a coping strategy.

Sample

In keeping with grounded theory methodology, participants for both the pilot and the larger dissertation study were recruited using purposive and theoretical sampling. In grounded theory, it is thought that a sample size should consist of 20-30 participants for a well-saturated grounded theory study (Creswell, 2007). Purposive sampling allowed me to consciously select participants who had a range of characteristics or experiences relevant to the study (Charmaz, 2006). The characteristics that guided the purposive sampling included within the age range of 13-25, able to speak and understand English, and HIV positive. Youth age 13 to 25 years account for 26%, or 1 in 4, of all new HIV infections (Centers for Disease Control and Prevention [CDC], HIV among Youth 2014). Youth, 13 -24 year olds, accounted for 12,000 new HIV infections in 2010 (CDC, HIV among Youth 2014). These statistics provided rationale for the age range of the target sample. Participants were required to read and understand English, as the consent forms and interviews were provided and conducted in English. Participants who were not in the designated age range, unable to speak or understand English, who were not HIV positive, were excluded from the study.

Later in the process of data collection, theoretical sampling allowed me to select events, information or participants for what they may have contributed to the developing theory to refine and saturate categories until no new themes emerged from the data (Charmaz, 2006). For example, in the initial phase of data collection, my sample consisted primarily of Hispanic males. A decision was made to recruit at a second site that served a large African American population. This resulted in two more African American male participants, enhancing racial diversity across the study and allowing comparison across race to be conceptualized. A second theoretical sampling decision was made after having recruited 15 male participants. All efforts to that point to recruit female participants were unsuccessful and therefore a decision was made to limit theorizing to only males with the knowledge that further research would need to be done to verify or challenge my conceptualizations with samples that included females.

Twenty-one adolescent and emerging adult males who identified as Christian and/or had Christian upbringing participated in this study. They were aged 17-25 and were recruited from two clinical sites in Southern California that served adolescents and young adults with HIV/AIDS. Participants were recruited via flyers posted in the two clinic sites. Providers in the clinics also informed eligible participants of the study and provided my contact information to them such as phone number and email address. A written consent was obtained from participants aged 18 and older and parental consent and participant assent from participants younger than 18 years old. Each participant was given a copy of the consent. Three females were approached regarding participation in the study, but each declined for unknown reasons. One male patient agreed to participate in the study, but did not show up for the scheduled interview. Five younger adolescents were approached as well but also declined for reasons unknown (see Table 1).

Ethical Issues and Human Subject Concerns

Ethics, a critical component of qualitative quality, is not merely a process in research (Tracy, 2010). The Institutional Review Board (IRB) mandates procedural ethics which protect participants from harm, deception, guarantee privacy and confidentiality, and ensures informed consent has been obtained (Tracy, 2010). During the research, care was taken to maintain privacy, participant confidentiality, and to not cause harm either physically or mentally. Ethical procedures and principles were also adhered to with coding, sampling and writing the accounts of the participants. Only participants that met all inclusion criteria were allowed to participate in the study. All interviews were transcribed verbatim thus, presenting the detailed accounts of participants' reflections on their experiences of living with HIV.

There is always a concern for potential harm to participants in any research. Interviews with participants were conducted in a private, confidential setting. Participants were informed of their rights as research participants, and of measures taken to protect their privacy. Participants were informed that as a Mandated Reporter, I was required to report whenever financial, physical, sexual or other type of abuse had been observed or suspected, or when there is evidence of neglect, knowledge of an incident, or an imminent risk of serious harm. Anonymity and privacy were maintained by securing paper and electronic documents and use of a pseudonym in presentations or publications of their direct quotes. Paper study records were secured in a locked file cabinet. Electronic study records were secured via password protection and encryption. Field notes and transcripts were de-identified and participants were assigned a study code that was securely stored separately from the research records to maintain anonymity as well as confidentiality.

Interviews

A semi-structured interview guide was designed to address the specific aims of the study. The interview guide was informed by the literature and changes were made based on learning from the pilot study. Broad open-ended non-judgmental questions were asked to encourage participants to share their experiences of living with HIV and how their spiritual beliefs may or may not have assisted them with living with HIV. An interview guide with eight primary questions and twenty-nine secondary questions was prepared (see Appendix A). Broad open-ended questions were asked to elicit participants' responses to their diagnosis of HIV, their experiences of living with HIV, their spiritual practices and how their spiritual practices may or may not impact their diagnosis of HIV. Additional questions were asked as themes came from the participants' response. Care was taken to not force data but rather elicit the experience of the participants through their own story. Participants' responses were also verified with them for interpretation.

Observations

In a grounded theory study, data may also be gathered through observations. The researcher may feel uncomfortable with some of the things observed and their personal views may hinder their ability to acknowledge the perspectives of all participants from many dimensions (Creswell, 2007). Some of the challenges of observational data collection are remembering to take notes, accurately recording quotes, not being overwhelmed by the data and not being able to narrow the data down in time (Creswell, 2007). There are many roles the observer may assume during research. The researcher may participate in an active role, passive role, from the outside, limited interaction observant, active control or participant observer. There

are drawbacks to each role and the role assumed is dependent on what the researcher is hoping to gain from the observations.

While collecting data for this study, I assumed the role of limited interaction observant. This allowed me to gather data from participants' non-verbal actions as well as their interactions with clinic staff. In this observational role, I gained better insight as to why participants were willing to share stories of their experiences of spirituality as it related to their diagnosis. They found the clinic staff to be very warm, caring and concerned about them. Clinic staff were inclusive of participants' spiritual beliefs and saw me as someone who was interested in putting a voice to their stories.

I took structured field notes on all observations and used them later in my data analysis (for the field note structure, see Appendix B).

Data Collection and Analysis

Each interview was conducted in a location that provided openness to talk, and yet maintained confidentiality. Interviews ranged from fifteen minutes to one and one half hour in length. Twenty- one young men, aged 17-25, were interviewed with three receiving second interviews on other occasions. The purpose of the second interview was to verify information and to expound on some information received in the initial interview. Field notes on observations were taken directly following the interviews. Interviews were audiotaped and transcribed verbatim in English to prepare for data analysis. Data were collected until theoretical saturation was achieved. Theoretical saturation occurs when no new themes or properties emerge from the data and no new revelations come forth about the emerging theory (Bryant & Charmaz, 2007).

Data collection and analysis occurred simultaneously through interviews, observations and field notes (Charmaz, 2006; Holloway & Wheeler, 2009). Grounded Theory techniques were used to analyze the data. Grounded theory coding consists of phases: "an initial phase involving naming each word, line or segment of data followed by a focused, selective phase that uses the most significant or frequent initial codes to sort, synthesize, integrate and organize large amounts of data" (Charmaz, 2006, p. 46). Coding essentially provided a way for data and theory to connect for the purpose of generating theory with explanatory power (Jeon, 2004). Transcripts were coded using Atlas ti, a qualitative data analysis tool.

The data were coded using the three major types of coding in grounded theory methodology: open, axial, and selective coding. In open coding, the data were broken down, examined and compared to extract similarities and differences while placing the data into categories (Strauss & Corbin, 1990). In initial coding (open coding), I paid attention to analytic ideas that were further explored in data collection and analysis while remaining open to developing conceptualizations emerging from the data (Charmaz, 2006). There were as many as 340 open and in vivo codes. Some examples of early codes included: "I am normal", "It's just something I live with", "HIV does not define me", and "a pill to survive".

Axial coding was the second step in the coding process and reflected the systematic process I used of putting data back together, connecting categories based on conditions, context, action/interactions and consequences of what was extrapolated from the data (Strauss & Corbin, 1990). I categorized groups of concepts that shared similarities such as disclosing, stigma, spiritual experiences – negative and positive, medication adherence, and experiences of living with HIV. Categories contained clusters of data that needed to be further broken down into subcategories for further refinement (Saldaña, 2009). Categories, as explained by Bryant and

Charmaz (2007) emerged from close analysis of the data and provided a deeper level of extracting data. Categories not only helped me to understand the aspects or characteristics of the phenomenon but also provided practical, everyday meaning to the phenomenon (Bryant & Charmaz, 2007). Categories had certain attributes that were unanimous to each concept and each concept of the category possessed all or most of the attributes (Bryant & Charmaz, 2007). In grounded theory, categories are concepts of the story (Charmaz, 2006).

Groups (such as African Americans and Hispanic or adolescents and emerging adults) were compared and contrasted to uncover prominent or recurring themes in relation to their stories and responses to interview questions. Through coding and constant comparison of data, codes and themes emerged which laid the foundations of category building. As categories emerged I coded incidents from the data and compared these incidents to previously coded data and with incidents that had not been coded. For an example, "just something I take a pill for," "I have to take a pill every day," "I have to survive over a pill" and "I just take a pill" were categorized as *"a pill to survive"* and insurance issues, medications, frequent medical visits and uncertainties were categorized as *"challenges of HIV."* Another example would be; "no different," "same life stressors", "no physical reminders" and "don't feel any less" were categorized as *"the normalcies."*

The final step of coding was selective coding-- the process where I systematically made relationships between the core category and other categories. Categories and their relationships were identified, verifying these relationships while other categories that need further development were filled in (Strauss & Corbin, 1990).

Although Strauss and Corbin identified the preceding three major types of coding in grounded theory, Charmaz (2006) suggested another form of coding, theoretical coding.

Theoretical coding identifies relationships between categories developed with focused coding and provides cohesiveness to the analytic story while moving the story in a theoretical direction (Charmaz, 2006). Theoretical codes encompass all the codes and categories the researcher has identified in their initial grounded theory analysis (Saldaña, 2009)

Concepts were identified from the most salient categories that emerged. Concepts are considered the foundation of grounded theory research, as they are grounded in the data, which provide a means for discussing a phenomenon while attempting to understand the phenomenon (Morse et al., 2009). Concepts are groups of categories that are related to other categories, have explanatory and predictive power or serve as explanatory borders around categories, provide conceptual understanding about the relationships among categories, and are able to move the analysis forward and bring insight to the analysis (Charmaz, 2006).

Theoretical coding allowed me to move from general themes about the data to theoretical constructs (Saldaña, 2009). Some of the theoretical codes that were instrumental in generating a theory were: making meaning of HIV, coming to terms with HIV, reconnecting to spirituality, living with HIV and "I am normal."

Memos

Memos and field notes were written as soon after each interview as possible about developing conceptualizations. Memos allowed me to analyze the data throughout the process to assist with generating a theory. Memos serve the following purposes: (a) allow the researcher to engage in open dialogue (give voice to and formulate ideas) about the data with themselves (b) offer explanation and definition of properties and characteristics while clarifying analytic processes, (c) encourages the researcher to analytically distance themselves from descriptions about the phenomenon and on to their thoughts and ideas about what is happening related to the

phenomenon, (d) allows the researcher to record what they think or feel is happening with the data and where it is leading which may be used for future data collection and analysis, (e) aid in coding and categorizing data, (f) provides a space for ideas that may be used in analysis, (g) identify patterns and properties in situations that may not have otherwise been obvious to the researcher (e) are useful in generating theory about the phenomenon (Bryant & Charmaz, 2007). Memos keep the researcher actively engaged in the data while making constant comparisons, constructing categories or simply writing whatever comes from the data for immediate use or use in the future as the theory emerges (Charmaz, 2006).

A particular memo that comes to mind and kept me actively engaged with the data was one started early on entitled "Normal". I was not expecting to hear participants refer to their lives being normal with a diagnosis of HIV. Being normal was described as not having any physical disabilities or a disease that resulted in outward physical manifestations such as the effects of cancer. Being normal meant having the same life responsibilities as others such as paying bills and maintaining employment or being a student. This concept carried forward into later, iterative memos and became obvious to me that "believing in the normals"- not appearing different from others while taking medications and without physical disfigurement- was instrumental in assisting them with reconnecting with their spiritual Beings, providers and practices. I will share parts of those memos to give a better understanding of these young men's thoughts around HIV and normalcy.

For the purpose of this dissertation, normal was defined as a state of health that affords one the ability to function at a level that is equal to his or her peers in the presence of daily medications and the absence of outward physical signs of disfigurements.

Participant #1 and #3 compare HIV to cancer and depression. In participant #1 second interview lines 467-473; ***"Yeah, cuz usually, HIV people with…we don't' feel pain, we don't feel, I guess the only pain we go through is depression because you start thinking, about it like 'oh my God, I'm this and that' and people with cancer go through worse because they go through chemo, they lose hair, they have to be in the hospital,…us…HIV people…we have medicines that keep us in a good health".*** *If you don't feel pain from a disease, does that make you normal? Even the pain of depression does not often times show physical signs so by all rights, his statement seems pretty accurate. Participant #3 states in lines 103-104;* ***"I am not scared of it because there are people that have worse things out there like cancer you know".*** *There is nothing that says he is different. With cancer, there may be disfigurement, scarring, wounds, or loss of hair of none of these things are visible with HIV. This is echoed in participant #3 statement in lines 130-133;* ***"Aside from that I don't feel any different. I don't feel any less healthy. I don't feel any less like I can't do anything like it sets me back because it doesn't. I am like I am still alive and well, strong and still with great color {chuckle}. So like, um, I 'm o.k. you know".*** *Participant #7 states pretty much states the same as he describes when he was first diagnosed in lines 79-81;* ***"I kind of saw it coming. It was more of how to educate my parents about it so that they wouldn't be so worried. But, I still felt normal".*** *Participant #2 described normal as having the same concerns and life stressors as everyone else. This is brought out in his statement in lines 115 – 117,* ***"I have it. No big deal, I am still normal, like I still work, I still stress out about money situation like every other person you know what I mean, there is no difference".*** *Does having HIV exclude you from the everyday stressors of life such as food, shelter, utilities, clothing, and having to provide for your basic needs? Participant #4 see the key to normalcy is taking care himself which he describes in lines 130-*

133; ***"They know that I'm going to take care of myself, which I do. Then everything should be perfectly fine. I'll have a normal, healthy and happy life".*** *Participant #15 thinks the opposite. He feels that taking HIV medications makes one abnormal as described in lines 403-404;* ***"Because normal to me is living a day to day kind of life because not everyday someone has to take an HIV medication".***

Saturation

Following the interpretation of data, I worked with my dissertation committee to determine whether theoretical saturation (Charmaz, 2006), that is, a sufficient understanding of the role of spirituality in adolescents and emerging adult males with HIV experiences who identified as Christian and/or had Christian upbringing had been achieved, or if more sampling, data collection and analyses were needed. Theoretical saturation occurs when no new codes, categories or concepts emerge through the process of constant comparison of the data (Bryant &Charmaz, 2007). Saturation was determined when I was able to achieve both thick description and when thick explanation had been achieved (Holloway & Wheeler, 2009).

Rigor

Assessing qualitative research for quality has been an interest for years with concerns not only in quality but also in the relevance of the findings ability to impact quality of care and treatment for patients and caregivers (Long & Godfrey, 2004). Debates have long centered on quantitative epistemology and methodological issues of qualitative research, more specifically, the difficulty of establishing validity (Whittemore, Chase & Mandle, 2001).

Rigor was maintained through careful attention to reflexivity, interview quality, systematic sampling, data-driven coding, and member validation (Whittemore, Chase, & Mandle

2001). Rigor assesses whether or not the conclusions drawn by the researcher are trustworthy in qualitative research. Rigor is assessed by credibility, authenticity, criticality and integrity as primary criterion and may also be assessed by secondary criteria such as vividness, creativity, thoroughness, congruence and sensitivity (Whittemore, Chase, & Mandle 2001).

As a Christian nurse with deep spiritual beliefs, I remained open and exposed myself to different forms and expressions of spiritual beliefs and practices, including non-belief, before, during, and after data collection. I wrote iterative reflexive memos on my potential assumptions and biases about spirituality to continually assess how these may have impacted data collection, analysis and interpretation. Memos and field notes were written after each interview to reflect on personal experiences. I refrained from sharing my spiritual beliefs with participants to decrease social desirability. The reflections were reviewed as compared with the data to assure they were not embedded in the analysis. Additionally, the data were checked by committee members to assure my personal spiritual beliefs, feelings and experiences were not embedded in the analysis. As a family nurse practitioner with experience in interviewing adolescents and emerging adults in clinical practice, I was very conscious of my role as researcher from that in clinical practice and was careful not to bring any assumptions about this age group to the research. Also, I was careful to not share any information about my Christian experiences as a youth, my underprivileged upbringing or any personal experiences with HIV and the church with participants.

Credibility assesses if the findings of the research are reported in a way that is believable to the reader. Open-ended questions were used to leave the response open to the participants' experiences (Charmaz, 2006). I provided honest reporting of positive and negative experiences. Interviews were recorded and transcribed verbatim. In later interviews, developing concepts

were shared with participants for verification and to be sure the findings were not from my perspective. I also restructured my interview guide, asking open ended questions themed around the developing concepts. Finally, dissertation committee members reviewed the identified categories and overarching themes and theorizing that emerged from the data. To ascertain that the findings thickly expressed life experiences of the participants, expert guidance and oversight was provided.

Limitations

Every effort was made to enroll any male or female adolescent and emerging adult into the study. However, this was not possible, as some HIV positive adolescents and emerging adults chose not to participate. For this reason, only male participants aged 17-25 were recruited to the study and theorizing was limited to this gender and age group. The sample consisted of 21 males who had or were exposed to some type of Christian upbringing and one male who was not exposed to organized religion but was familiar with such Christian-identified spiritual practices as praying, reading spiritual books and meditation. None were of other faith traditions such as Muslim or Jewish. As a result, the findings from this study do not represent the impact of spirituality on the lives of young HIV positive females and younger adolescents. Nor do the findings represent the impact of spirituality on the lives of young HIV positive males and females who are of a faith tradition other than Christian. The findings from this study are representative of young Christian men who have sex with men in the Western region of the US. I worked closely with my faculty mentors and all recruiting agencies, organizations and churches to make certain that the aims of this study were fully understood in relation to the parameters of the final sample. In an effort to ensure a range of adolescents and emerging adult experiences, I

paid particular attention to achieving a sample with a range of variation in their types of beliefs and experiences.

Despite study limitations, I implemented a research design with systematic procedures to maximize its rigor. Theory development was carefully constructed using a sample with clear parameters on demographics and spiritual beliefs and practices. In sum, this study was one of the first studies in the western region of the United States to describe the role of spirituality in Christian male adolescent and emerging adults who have sex with men and are HIV positive.

Table 2:

Sample

(*N=21*)

Age:	**Mean**	**SD**
17-25	22.19	2.32
	N	%
Race/Ethnicity:		
Hispanic	7	33
African American	6	28.5
Caucasian	5	23.8
Bi-Racial	3	14.3
Sexual Orientation:		
Homosexual	20	95
Heterosexual	1	5
History of Abuse: Sexual, Physical, Substance		
Sexual	6	28.6
Physical	2	9.5
Substance	11	52.4
Religious Affiliation	**Youth**	**Current**
Catholic	43%	29%
Baptist	29%	14%
Lutheran	4.7%	0
Non-denominational	14%	14%
Church Experience	9.5%	0
Spiritual	0	43%

Chapter 4

Reconnecting to Spirituality: Christian-identified Adolescents and Emerging Adult Young Men's Journey from Diagnosis of HIV to Coping

Abstract: Spirituality is important to holistic health, yet little is known about its impact on young people with HIV. To address this knowledge deficit a grounded theory study used semi-structured interviews of 20 Christian-identified adolescent and emerging adult gay males and one perinatally- infected male. This study revealed that, to cope with HIV health issues, participants used a process of reconnecting with their spirituality. In order to successfully reconnect with their spirituality, study participants reported a need to re-embrace and re-engage in spiritual practices, hold onto hope, believe they are normal and commit to beliefs and practices despite rejection from the church.

Reconnecting to Spirituality: Christian-identified Adolescent and Emerging Adult Young Men's Journey from Diagnosis of HIV to Coping

Adolescents and emerging adults are at a crossroads in development where their psychosocial characteristics and functioning propel them into adulthood. They are growing in independence from their parents and families, seeking and making close interpersonal relationships, and developing a more sophisticated sense of self-identity. Part of one's identity formation for many young people is the development of personal values, including spirituality or personal spiritual beliefs and practices.

When a young person is faced with the diagnosis of a life-altering disease like HIV during this time of tremendous psychosocial change, it is important to understand the many facets of life it impacts, as well as those areas which can assist him/her to make meaning of the diagnosis and live a new life with a chronic illness. Spirituality is one area that is important to explore to better understand its place in the lives of young people with HIV: how it may help them, how it may hinder them, and how clinicians can better integrate spirituality into holistic HIV care for adolescents and emerging adults, when appropriate.

This paper will present the central findings of a grounded theory study that aimed to describe the spiritual perspectives of HIV positive adolescents and emerging adults and their expectations of their clinicians and providers in addressing their spiritual needs, if so desired. First, literature on the importance of spirituality in adolescence, HIV in adolescents (its prevalence and what puts them at higher risk and contributes to increased transmission in this age group), and the impact of spirituality on people with HIV will be reviewed. Second, study methods will be presented. Finally, the process of reconnecting to spirituality in young Christian-

identified men with HIV is articulated as a central finding of the study. Implications for clinical practice are discussed.

Background

HIV currently affects more than 73,000 adolescents in the United States (Centers for Disease Control and Prevention, [CDC], HIV/AIDS Statistics and Surveillance, 2012). The CDC (2014) estimates that 60% of youth 13 – 24 years of age are unaware of their HIV status. Reasons cited for the increased spread of HIV in adolescents include having older sex partners, unprotected sex, young gay and bisexual men having sex with men, sexual abuse, an increased prevalence of sexually transmitted infections, substance abuse and lack of awareness (CDC, 2012, HIV among youth). Transactional sex, which can be described as having sex in exchange for money, food, clothing, or housing, may also be a factor in the increase in HIV in adolescents, emerging adults and heterosexual men who do not identify as gay. Thus, young Black men who have sex with men (MSM) may participate in survival sex because of factors related to needing shelter or drug money, underemployment or unemployment, lower socioeconomic status, or trust in older MSM who are in many cases unaware of their own HIV status (Harawa et al., 2008).

Of the more than 305 million people living in the United States, adolescents and emerging adults account for approximately 52 million people (17%; American Factfinder, 2010). During their transition into adulthood, these young people often take risks without fully weighing the consequences of their actions, sometimes under the influence of strong emotions or of heightened levels of arousal (Steinberg, 2005). Not surprisingly, adolescents and emerging adults are at increased risk of being infected with HIV and other sexually transmitted infections. Indeed, among youth – emerging adult risk behaviors that contribute to this age group's leading causes of mortality and disability, the CDC lists "sexual behaviors that contribute to unintended

pregnancy and sexually transmitted diseases, including HIV infections" (2013, Youth Risk Behavior Surveillance).

Importance of Spirituality in Adolescents and Emerging Adults

Although spirituality is important to young people in America, fewer than 1% of research studies have explored religion, religious development, spirituality, or spiritual development in children and adolescents (Roehlkepartain, Benson, King, & Wagener, 2005). Moreover, in many cases, investigations described as focusing on young adults have included older adults (i.e., 18-65 years of age and sometimes older) in study samples. This mixture of age groups in study samples obfuscates estimates of the number of research studies that have specifically investigated spiritual needs of young adults. However, important findings have emerged from extant research. A national survey of 3290 American adolescents reported that 95% of the respondents stated belief in God, with an additional 85% stating that religion is important in their life, over 50% reporting attending religious services at least once a month, and close to 50% stating they pray alone frequently (Smith & Denton, 2005). Adolescents report usually beginning a relationship with God or a higher power when they are 12-20 years old (Park & Nachman, 2010). Although many adolescents practice the religious or spiritual beliefs of their parents, emerging adults may choose other religious beliefs or spiritual practices (Arnett & Jensen, 2002).

Spirituality has many definitions that usually focus on individuality and refer to good or positive experiences (Koenig, 2011). Among these definitions, spirituality has been described as entailing belief in a higher power in the universe, feeling a connection to all living creatures, an acknowledgment that life has purpose and meaning and having achieved personal values (University of Maryland, Ehrlich, 2013, "Spirituality," para 1). In this paper, the term

spirituality will be used to encompass beliefs about the meaning of life that underpin one's values and relationship with the world, including but not limited to religious beliefs.

Impact of Spirituality on People with HIV

Spirituality may be an indicator of well-being. Religious affiliation and practices such as prayer may be common among patients with HIV infection (Lorenz et al., 2005). The level of spirituality/religion (as measured by affirmation of spiritual or religious belief or engagement in spiritual or religious practices) in patients with HIV has been associated both directly and indirectly with feeling that life was better after a diagnosis of HIV (Szaflarski et al., 2006). Higher levels of spiritual practices have been associated with better mental well-being, better cognitive and social functioning and fewer HIV symptoms (Trevino et al., 2006). In a 4-year longitudinal study with 100 HIV-positive participants, Ironson, Stuetzle, and Fletcher (2006) found that participants reporting an increase in spiritual practices following an HIV diagnosis had lower rates of CD4 cell loss and viral load increase when compared to participants whose spiritual practices decreased following diagnosis. The investigators hypothesized that their findings resulted from medication adherence associated with health-related quality of life in the presence of higher levels of spiritual practices. In light of these findings, understanding the religious and spiritual perspectives of patients with HIV and how religion and spirituality relate to challenges they face may be beneficial for clinicians caring for HIV-positive patients (Lorenz et al., 2005). Accordingly, increasing clinicians' awareness of the importance of spirituality and/or religion in patients with HIV should be a clinical focus (Szaflarski et al., 2006).

Adolescents and emerging adults have unique developmental characteristics that influence their understanding of spirituality, decisions about personal and moral values, and enactment of spiritual practices or use of spiritual beliefs as a means of coping. As HIV-positive

adolescents and emerging adults seek to understand meaning in their diagnosis, the use of their spiritual beliefs may offer hope and support, ameliorate depression and strengthen their overall sense of well-being. In addition, from an improved understanding of the spiritual needs of adolescents and emerging adults who are HIV positive clinicians may gain useful insight into the connection between spirituality and health outcomes in this under-researched population.

Methods

Design

To better understand adolescent and emerging adult spiritual beliefs and practices in the context of a chronic illness such as HIV, this research used a constructivist grounded theory approach. According to Charmaz (2006), the constructivist grounded theorist seeks to understand how participants "construct meaning and actions in specific situations" (p. 130). This application of grounded theory generated new understandings of how adolescents and emerging adults appraise the meaning of HIV. Grounded theory also helped to explain how their spiritual beliefs guide adolescents and emerging adults in this appraisal in a way that is meaningful to them.

Eligibility and Recruitment

To qualify for study participation, adolescents and emerging adults had to be (a) at least 13 years of age and no older than 25 years old (b) have a prior diagnosis of HIV infection; (c) be able to read, speak, and understand English.

At both clinic sites, the study's investigators attempted to recruit all male and female adolescent and emerging adult patients who met inclusion criteria. Clinic staff approached potential participants at the time of their scheduled appointments. Flyers were also posted throughout the clinic area. Those participants who agreed to take part in the study (N=21) were

given the contact information of the study's principal investigator. All participants gave written informed consent. In addition, participants who were minors (i.e. younger than 18 years of age) provided both participant assent and parental consent. The study was approved by the University of California, San Francisco, Institutional Review Board.

Data Collection

Data were collected between December 2012 and February 2015 from two HIV clinical sites in metropolitan cities in the western United States. One of the clinics was at an academic medical center that served approximately 100 adolescent and young adult patients (male, 80% and female 20%). The other clinic, in an underserved community, had approximately 20 patients who met eligibility criteria for participation in the study. Two participants were recruited from this clinic.

Data were collected via face to face interviews with 21 male participants; three of these participants had second interviews to elaborate, clarify, and /or verify themes and developing conceptualizations (N=24 interviews). Interviews ranged from 16 minutes to 90 minutes. A semi-structured interview guide was designed to address the specific aims of the study while asking general (i.e. broadly worded) open-ended, non-judgmental questions about the participants' experiences of living with HIV and how their spiritual beliefs may or may not assist them with living with HIV. The interview guide consisted of eight primary questions and 29 secondary questions. As themes emerged from the participants' responses, additional questions were added to the interview guide. Interviews were audio recorded and all of the interviews were transcribed verbatim; the majority were transcribed by the study's primary investigator, and the remaining studies were transcribed by a professional transcriptionist.

Data Analysis

Data were analyzed from 24 interviews transcripts (21 participants, 3 with second interviews), field notes and memos. After all interviews were transcribed, they were coded. The data were coded using grounded theory's four major types of coding: open, axial, selective and theoretical.

Open Coding. During *open coding*, the data were broken down, examined and compared in order to identify similarities and differences while categorizing the data (Strauss & Corbin, 1990). While conducting open coding, I attended to analytic ideas that were further explored in data collection and analysis, and I developed concepts that emerged from my developing understanding of the data (Charmaz, 2006). The open coding process generated over 340 open and in vivo codes. Some examples of early codes included: "I am normal," "It's just something I live with," "HIV does not define me," and "a pill to survive."

Axial Coding. *Axial coding,* the second step in the coding process, reflected the systematic process I used for grouping data, linking categories based on associative relationships and derived conclusions from analysis and re-synthesis of data (Strauss & Corbin, 1990). I categorized groups of concepts that shared similarities such as disclosing, stigma, spiritual experiences – negative and positive, medication adherence, and experiences of living with HIV. Categories contained clusters of data that needed further classification into sub- categories for additional refinement (Saldaña, 2009). As explained by Bryant and Charmaz (2007), categories emerged from close analysis of data and enabled a deeper level of data extraction. Categories not only clarified understanding of the phenomenon's aspects and characteristics but also provided practical, everyday meaning to the phenomenon (Bryant & Charmaz, 2007).

Groups were compared in order to discover prominent or recurring themes in relation to their stories and responses to interview questions. Such comparisons included, for example, comparisons of African American groups with Hispanic groups and comparisons of adolescents with emerging adults. Coding and constant comparison of data, enabled identification of codes and themes; these codes and themes in turn laid the foundations of category building. As categories emerged I coded incidents from the data and compared these incidents with previously coded data and with incidents that had not been coded. For an example, phrases such as "just something I take a pill for," "I have to take a pill every day," "I have to survive over a pill," and "I just take a pill" were categorized as "a pill to survive" and similarly, phrases such as "insurance issues," "medications," "frequent medical visits," and "uncertainties" were categorized as "challenges of HIV." The phrases "no different," "same life stressors," "no physical reminders" and "don't feel any less" were categorized as "the normalcies."

Selective Coding. The third step of coding was *selective coding* – a process in which relationships between the core category and other categories were systematically identified. Categories and their relationships were identified, verifying these relationships while other categories that need further development were filled in (Strauss & Corbin, 1990).

Theoretical coding. *Theoretical coding,* the fourth type of coding, allowed me to move from general themes about data to theoretical constructs (Saldaña, 2009). Theoretical codes that were instrumental in generating a theory included (but were not limited to): "making meaning of HIV," "coming to terms with HIV," "reconnecting to spirituality," "living with HIV," and "I am normal."

As soon as possible after each interview, memos and field notes were written about developing conceptualizations. The use of memos enabled me to analyze the data throughout the

process to assist with generating a theory. Memos were iterative, thus enabling me to build upon them as new concepts arose from the data.

Data were collected and analyzed until theoretical saturation was achieved (i.e. when no new codes, categories or concepts emerge through the process of frequent comparison of the data; Bryant &Charmaz, 2007). Specifically, I collected and analyzed data until (a) I sufficiently understood the role of spirituality in Christian –identified adolescent and emerging adult males with HIV experiences (Charmaz, 2006); or (b) I recognized there was no need for additional sampling, data collection, and analysis. Saturation was determined when I was able to generate both thick description and thick explanation (Holloway & Wheeler, 2009).

Assuring Credibility

Rigor was maintained through careful attention to reflexivity, interview quality, systematic sampling, data-driven coding, and member validation (Whittemore, Chase, & Mandle 2001). To decrease social desirability, I refrained from sharing my spiritual beliefs with participants. In addition, the data were checked by other members of the research team to ensure my personal spiritual beliefs, feelings, and experiences were not embedded in the analysis. As a family nurse practitioner with experience in interviewing adolescents and emerging adults in clinical practice, I was very conscious of differentiating my role as researcher from that of a clinician; also I was careful to not introduce personal assumptions regarding this age group into the research process- including data analysis.

I provided honest reporting of positive and negative experiences. As noted earlier, interviews were recorded and transcribed verbatim. In later interviews, developing concepts were shared with participants for verification and to be sure that the findings were not biased by my perspective. I also restructured my interview guide, asking open-ended questions related to

developing concepts. Finally, co-authors reviewed the identified categories and overarching themes and theorizing that emerged from the data.

Results

Study participants, 20 Christian-identified gay males and one perinatally infected male, ranged in age from 17 to 25 years. No participant self-identified as transgender. Seven participants self-identified as Hispanic, six as African American, five as Caucasian and three as bi-racial. Of the participants who enrolled in the study, 47% were Catholic, 28% Baptist, 9.5% Non-Denominational Christian, 9.5% were exposed to organized religion in childhood, and one participant was Lutheran. Fourteen percent admit to attending spiritual services regularly, 38% attend occasionally and 48% do not attend services but maintain some form of spiritual practices such as praying or reading religious material. Ten participants, (48%) completed at least one year of college, 38% were in or completed high school, 14% did not complete high school and one participant obtained a GED.

Findings from this grounded theory study focus on the important social process that young Christian-identified men (in this study, mostly gay and one heterosexual) use to reconnect with spirituality to provide meaning for their illness as well as strategies they use to cope with its day-to-day manifestations. First, I will discuss findings related to participants' history with spirituality, religious practices, and church. This will include their current context for spirituality and in particular, stigma and rejection they experience from their church, and sometimes families. The central process of reconnecting to spirituality is presented using an explanatory matrix to organize dimensions of reconnection and their relationships. Conditions that contribute to reconnection, strategies they use to reconnect, and outcomes of reconnection they describe will be presented.

Family History and Current Context of Spirituality

All participants were exposed to organized religion at a very early age however, one participant was given the option to not attend organized services as organized religion was a cultural norm for his father only. Participants spoke of being baptized in church, attending youth services and Catechism classes. Family prayers were mentioned as shared traditions at meals and during crisis such as an ill family member or loved one. Participants also spoke of being reminded by their parents and/or grandparents to "always have faith and believe in God". Some shared how this family value would be the catalyst to keep the family strong after disclosing their diagnosis of HIV.

The church was not seen as welcoming as these adolescents and emerging adults had hoped. The sin of premarital sex, homosexuality and the stigma associated with HIV continues to be a factor separating the church and the homosexual community (Foster, Arnold, Rebchook, & Kegeles, 2011). While some churches are in acceptance of their sexual orientation others, especially African American churches, have held on to foundational principles. In this study, African American adolescents and emerging adults were more likely to state that they were stigmatized by church and family because of sexual orientation and HIV status than were their Hispanic and Caucasian peers. African Americans and Hispanics in this study were more likely to rely on their spiritual faith and practices than were their Caucasian peers; participants who were raised in Catholic, Baptist, and Christian or Non-Denominational were equally likely to rely on spiritual belief and practices to cope with adversity. Most (81%) participants felt their HIV status was the result of their own doing and not "following God's plan" as opposed to "punishment from God."

Many participants expressed painful experiences associated with church views that denounced homosexuality and implied HIV was a punishment from God. They faced or feared rejection and stigma from organized religion, their churches, and sometimes their families. It can be quite confusing to hear a message that God loves you and created you the way you are and another message that He hates homosexuals. Participants #13 and #17 had the following to share about the church and feeling rejected.

P #13: "And I haven't been to church in a while — long time because every time I go to the church, the person's personal test — the preacher, whoever is testifying at that time, will change the testimony from the personal testimony or to whatever they're speaking about to the Sodom and Gomorrah thing. And I have a really good feeling that the — I mean the Bible's been rewritten numerous times. And who's to say what's been taken out of its — who's to say what's been added into it, you know? I just feel that I didn't come to church to be judged. Nobody should be judging me but the Lord, and if He's not worried, you know?"

P #17: "I don't think my church family would accept me, well they would accept me but, I feel there would be a lot of judgment in the church house if I were to tell them about my status. … I feel that if I were to go and tell my pastor or probably tell someone, I feel that I would get looked at. Maybe cause it's just me that I feel that the stigma is just (inaudible) on HIV and the church community and it's just so much that, and the church area or the spiritual belief is so much judgment around that thing that I don't think that you should have been, you know if you wasn't gay you wouldn't have got it. Or you know, I think that a lot, even for my family, I feel that if you are gay, that you are automatically going to get something and I don't, I think that would be hard to come out for the church family as well cause they have a lot of judgment."

Despite these negative reactions from the church, most participants in the study continued to believe and participate in their spiritual practices to help them cope. However, one participant removed himself from the church he once attended due to the negativity. Participants #7 and #21 describe their decisions about the negative responses from the church below:

P #7: "Because I was raised to follow what the Bible was going to say and in the Bible it says that God doesn't accept homosexuality and that took a while for me to cope with but then, I guess I've found ways to just keep going. Even though it says it in the Bible I don't pay attention much to it but just try to live my life best I can being a Christian."

P #21: "I stopped going, not cause those ignorant people, and not cause they started saying all those things about from the church and everything and I didn't want to make, I didn't want to make a big out of a house of God you know? I didn't want to make something that people were going to keep on talking about so I just decided to move myself aside."

Participants spoke of being given a choice to continue to participate in the spiritual practices they grew up on in childhood such as church or religious service attendance or youth group service. Many chose to not attend and for some, a decision was made by the family to not attend organized religious services. This disengagement from faith practices is typical of adolescents and young adults. During this disengagement, some speculate that they may return to their spiritual practices when they have a family or have fully matured into adulthood. Participant #8 and #12 describe their experience of walking away from their spiritual practices or disengaging in the church in the following statements:

P #8: "Yeah, when I was younger, it was mandatory. I didn't have a choice but I would say when I reached like 13 or so was when I had a choice whether to go or not. And being you

know a 13 –year- old you know it's like I'm not going to church, I going to hang out with my friends you know, and this and that so."

P #12: "I was brought up Catholic and, um, so, there was always this sense of you know, God and you know, right and wrong, and heaven and hell, and stuff like that, and, um, so, that was my childhood and I kept having that ingrained into me until I was old enough to kind of make up my own mind when I was like about 11 or 12. I was like, you know, I'm kind of just going to have a few too many disagreements with the Bible and I'm going to kind of do my own thing, and that's kind of where I — I — I went on like a — I was devouring books of different religions and spiritualties—"

These young men were exposed to organized religion during childhood and left the church during adolescence for various reasons including their sexual orientation.

To better understand of how this process may have occurred for these young men, I will share stories from their perspectives. An example of questioning one's faith is found in statements by participants #1 and #5:

P #1: "(Pause) Um, I really don't know what to believe in {chuckle} I really don't have, I mean I do but then it's like I don't. Its' like, its' like I don't, I really don't know what to say about that."

P #5:" He's supposed to be there for you. He's supposed to look out for you. You know what I mean. He's your over-looker person, and then I became homeless, and for two of the years that I have been homeless, I still went to church, and I still believed in God, and then it kept getting worse, and worse. More things happened, and more things happened, more things happened, and now I have so many things that are wrong with my body. It's messed up, and He's supposed to look out for you, and take care of you. That shouldn't happen."

The feeling of guilt, shame, and hopelessness related to being HIV-positive lead some to relinquish their spiritual practices. Participants #15 and #20 experienced trauma growing up. With the addition of the diagnosis of HIV infection, they were left with very low self-esteem and substantial shame and guilt about their status. The following are excerpts from their interviews:

P #15:" I just keep on f—g my life you know. F—g up my life and it's like you know like why can't I just be a normal person that's HIV negative that's doing normal things you know? What are normal things —? O.K. fine it's not a death sentence but I still have, I know that I cannot wake up one morning and not have it you know, um, so maybe there is some days that again it's o.k. for me to live a normal life, normal life as in some days I like to live like I don't have HIV, not take my meds you know. Um, because I feel like um, maybe I shouldn't be taking this because that might be a better way for me to cope with my HIV so I can forget about it."

P #20: "Lots! Very, like I don't feel, I feel a lot guilt, lot of shame. You hit right on it, you hit it right. Like I don't, I don't, I am sorry but it's kind of hard for me to give people eye contact. I don't know. I think about my past every day. I wake up and I really wish I could restart everything but I can't. I don't know."

Central Process of Reconnecting with Spirituality

Figure 1, presents an explanatory matrix that is structured from the perspective of adolescents and emerging adults who reconnect to spirituality after disengagement from their earlier practices due to rejection and stigma. Reconnecting to spirituality was chosen as the central process because this theme explained what was happening in these young men's lives. During adolescence, a large portion of young people decide to either adhere to the spiritual beliefs they were brought up with or develop their own spiritual beliefs which are typically based on their environment and self-identity (Arnett & Jenson, 2002). This process of developing new

beliefs may also entail abandoning prior spiritual beliefs. Reconnecting to spirituality described how these young HIV-positive men moved from being disengaged in their faith and beliefs to re-embracing and re-engaging in their beliefs and practices through a recommitment to their spiritual practices and in some instances, a return to their spiritual practices.

Conditions that Contribute to Reconnection

For these young men who identified as Christian and/or who had Christian upbringing, reverting back to what got them through difficult situations in the past was a common theme. Although none of the participants indicated that they currently attended or participated in organized religion, they spoke of organized religious upbringings and how they remembered that in difficult times and in difficult situations, they relied on their Christian spiritual practices such as praying, meditating, reading spiritual books, believing, trusting and having faith in a higher power or Being, and seeking spiritual counseling to get them through.

This reconnection occurred for many after their diagnosis as they were reminded of what helped them to cope with difficult times. For some, this reminder came from family members; for others, the reconnection process entailed simply returning to their source of hope. Participant #2 describes a conversation where his father reminds him to trust God:

P #2: "I found out November 2nd that I had it. Um, and that same day, right before, right after getting the news, like seconds right after, my dad had called me, he told me like" "everything is going to be fine, everything is going to be O.K." I am like what are you talking about? He was like, "I don't know, I just got like, I just got like a feeling that is something is not right". He like, "just remember, he's like leave it in God's hand". He like, "just pray and don't ever lose your hope and faith."

Participant #6 describes his experiences of reconnecting with the Catholic Church but is searching to find a place where he may fit in;

P #6: "I being going to church. I been going to Catholic Church. There certain things I don't agree with so I am kind of like. There was a list of approved churches in here so I am trying to see which one I wanted to go to. So I said maybe I could try something new. I want to try something new. The catholic one, I don't agree with certain things you know, and so I am trying to belong to a church or maybe that is just a way of trying to believe in God but I do have spirituality apart from that."

Reconnecting served as a reminder to some to take their medications and to do things necessary to preserve their health. Here, reconnecting is defined as the process of returning to one's spiritual beliefs and practices to the extent that existed prior to disengagement that provides personal worth, value, hope and peace. During this journey, certain conditions placed these young men in a situations where they would consider making this reconnection. What was at stake and what was the cost? Some of the salient conditions included; questioning their faith and beliefs, disengagement from faith practices, feelings of guilt, shame, and/or hopelessness associated with their HIV status and rejection from the church. To make these reconnections, the study participants would have to re-embrace and re-engage in their spiritual practices. They would also have to hold on to this hope in a belief that they are normal human beings and to be committed to their beliefs and practices despite rejection from the church.

Strategies to Reconnect

Many of these young men have accepted these conditions or moved past them to begin the process of finding strategies to assist with reconnecting to their spiritual beliefs. Some have re-engaged with their places of worship or with youth groups. They have begun to pray and read

spiritual books. In doing so, they have found hope and describe the feeling that they are normal. Some even believe in their spiritual beliefs and practices despite rejection from the church. These actions occur over time but are instrumental in finding strategies to reconnect to their spiritual beliefs.

Participant #2, a 20 year-old male, had not been to church for 12 years prior to his diagnosis. He had this to say about re-embracing his beliefs and practices;

P #2: "I won't sit here and lie to you and say I that I pray every single day and what not, but I do wake up, give Him thanks for another day. Thanks for our daily bread and during the day, I forgot the name of this, (using hands makes a cross from chest to forehead and from shoulder to shoulder), I pray–"

I: "You do your prayer, your cross?"

P #2: "Yea, my cross, my Catholic cross. Um, and right before I go to sleep, I thank Him for another day, and just hope to wake up the next day with good health and that's it."

Participant #3 states that he does not attend church as he once did but remembers what his family has always taught him, just pray and have faith. He tells of a time when he allowed his faith to fade and what brought him around.

"So um, my grandma has always taught faith in my mom. My mom has always taught faith in me. Because my mom always told me "Just pray whatever you need, just stay strong and the mother will help you, the virgin will help you". She's always told me that. Like, when I was little every time we would sit down for dinner it would be like "thank the Lord for dinner" or "thank the Lord" after we eat or for anything you know".

"What happened to your faith? Why are you being so negative and why are you always looking down? Why don't you look up anymore"? And so it kind of just like hit me and I was like

wow! I really did let go of my faith. I wasn't praying like every time I went to a church. I wasn't like putting my faith where it needed to be. I kind of just forgot about it for that little bit. And that was my worse times. As soon as I realized it, like things started to turn around and that's when I started getting things working out for me like when I was getting my own place and I started like, me and my boyfriend got off drugs and like we were doing good".

Some participants took things a step further and re-engaged with their faith practices by going back to traditional places of worship or joining spiritual groups. I will share participants' #16 and #17 experiences of re-engaging.

P#16: "Um, (pause) because um, the Bible study that I recently became a part of, I don't know if you have heard of them before but it's um it's a group that called themselves like the Black Israelites."

I: "I've heard of them."

P #16: "They've kind of help me understand it a little better and understand why certain things happen in life in general."

P #17: "Yes, I am using my spiritual way more. I been calling on Him and I been going to church and praising Him and asking for understanding of what I've got."

As participants begin to engage in these activities, they are able to find strategies to further assist them in this process of reconnecting. Some of the strategies that have been identified by these young men are (a) recommitting to spiritual practices – (praying, reading spiritual books, and church attendance), (b) seeking spiritual guidance, (c) reengaging with faith community and (d) practicing personal and community forgiveness. Some examples of these strategies are given below:

Recommitting to Spiritual Practices- *P #2: "After finding out, I have gone to church, I have gone maybe like a good seven/eight times in the past year which is not that much but a big difference from like a five to ten year gap…. the times I've gone to church and has made me feel that way where I come out of church feeling like no problems, no stress, no nothing and that's something I could use every Sunday, and also, to get build my relationship closer to God."*

P #18: "and then spiritual strength I try to do a bit of meditation as well as I read on spiritual practices and things about the Bible. All sorts of things to try to strengthen my spirit in a way, so yeah."

P #20: "I pray, um, I pray and um me, I started to think that He answers to me in my dreams if I am lucky to even sleep cause I don't like to sleep. My dreams are pretty bad. I pray a lot even though sometimes I feel likes He's not listening, I still pray cause what if it's leaving it on His voice mail or something."

Seeking Spiritual Guidance- *P #13: "I always talk to my aunties and, you know, my other aunties and other cousins about God and stuff like that. And I asked them, like, why does He allow us to, you know, go through so many things in life that are so, like, what is the word that I'm looking for? Um, so hurtful and down putting to the spirit?"*

P #17: "Well, I do think I can only do this for myself but I do go there and I ask, I talk to Him about health issues and other things and um, and I am not ready to um, to give out that information just yet but I have a good support system at home and I go to church, it seems like the family. It's always open doors and I feel like that's the place that I miss. And it's O.K. to go there and cry, it's O.K. to go there to be happy there and I just go there for a lot of praying, yea. And it has actually turned my life around. I've been more church involved."

Reengage with Faith Community – *P #6: "Well, the other time that I was trying to choose a church, I actually asked her about like hey, what are you and your husband think, which one should I go to cause I got a Baptist or protestant or all these different ones. They were like well just choose from one that doesn't have a particular name or just one that is more open. I was like well I don't want to show up in a church and know that I have to dress in a certain way or like you know so then I just didn't want to show there and not know what's up, so just go to one that's more open."*

Personal and Community Forgiveness – *P #8: "And I remember I broke down once because I was like ah, so many pills and this and that. You know blaming myself, but once again I uh, you know, lifting my head up high and knew things would get better so I am totally fine with it now.*"

Outcomes of Reconnection

Many participants have found hope through their spiritual beliefs. In doing so, this hope has assisted with them in reconnecting to their spiritual beliefs and practices. As an example I will share participant #11's and participant #15's description of how spirituality has given them hope.

P #11: "And, spirituality helps me, you know, ease the pain and help me realize, "Well, you know, look at all the medications. You know, look at there's a person who was just cured, let me tell you," you know? And, it's like, there's hope, you know? And, I feel like if I wouldn't have anything to hope for, I probably would have committed suicide by now, you know?"

P #15: "It does. It helps me in many ways because, it's, it helps me cope with life. It gives me hope. I know that it, I know that someone is again looking out for me and someone wants the best interest, you know has best interest for me you know."

Believing that one is normal makes it easier to maintain spiritual beliefs and to participate in spiritual practices. Not having disclosed one's status to the church certainly facilitates assimilation with the congregation. Many of the study participants found it easy to believe they were normal but faced challenges in the church because of their sexual orientation. Some of the thoughts that the participants shared regarding normalcy and not being different are very interesting perspectives. If any of these young men were among you in church, how could one argue that they are not normal? Participant #9 and #11 said the following about being normal;

P #9: "I like to have fun. I like to go out. I'm a normal human being. I like to do what normal people like to do, I guess."

P #11: "Um, I would say I'm like any other normal person. I don't see myself different from a person who doesn't have HIV just because, you know — Yeah, I'm a normal person."

While participants #7 and #13 felt they were being rejected by the church because of their sexual orientation, they continued to believe in their spiritual beliefs and practices and how they may and have assisted them in coping with their diagnosis.

P #7: "Because I was raised to follow what the Bible was going to say and in the Bible it says that God doesn't accept homosexuality and that took a while for me to cope with but then, I guess I've found ways to just keep going. Even though it says it in the Bible I don't pay attention much to it but just try to live my life best I can being a Christian".

P #13: "Because a lot of people say that, growing up in the Bible, they say that this, the HIV, is supposed to be one of the plagues for homosexuality. That was just what I was taught in the Bible. I don't believe it— I do. I've actually been wanting to go back to church. I just don't know which church to go to. I don't want to go into church where they're always talking about homosexuality."

When these adolescent and emerging adult males are able to grasp and hold on to these strategies, they are able to return to their spiritual practices, reconnect with their spiritual being and places of worship, find hope and a sense of self-worth. They are, despite the challenges they face with their illness and within the church, finding ways to reconnect and stay connected to their spirituality as it provides support, hope, increases self-worth, and gives them something to believe in.

Discussion

In this grounded theory study of 21 HIV- positive adolescents and emerging adults, reconnecting to spirituality emerged as the most salient process in coping with HIV. Most participants in this study referred to their spiritual being as "God" while other referred to their spiritual being as a "higher power." Although some participants received negative messages from the church regarding their sexual orientation or their illness being considered a punishment from God, they all spoke of their experiences with spirituality and the impact spirituality has on their ability to cope with their HIV status. Spirituality offered hope to many participants, increased medication adherence, decreased depression, and provided an overall feeling that they were able to live with HIV. The findings from this study support the findings in Lorenz and colleagues (2005) study on 2,266 HIV-infected adults which suggest religiousness (65%) and spirituality (85%) were very important in their lives. The findings also support the notion that those who practice spirituality are able to accept their diagnosis because of the influence of God or their spiritual being (Woodward &Sowell, 2001).

Some participants' abandoned organized religion during youth but reverted back after their diagnosis. Others continued their spiritual practices such as prayer and reading spiritual books. Some participants expressed having a desire to attend organized religious services but

feared stigmatization from the church because of their sexual orientation and HIV status. The findings from this study support the notion that spirituality is important in young people's lives, especially when diagnosed with a chronic illness (Bernstein, D'Angelo & Lyon, 2012; Smith & Denton, 2005). The findings also affirm that spiritual practices are important in helping to cope with HIV (Woodward &Sowell, 2001) and spirituality is a cultural strength for many who are HIV -infected (Casarez & Mills, 2008).

Clinical Implications. Although the majority of American patients and physicians agree that spirituality is important, 80% of patients stated that their physicians rarely or never discuss spirituality with them (Anandarajah & Hight, 2001). Over half (57%) of the adolescents and emerging adults in this study stated that they wanted their providers to address their spiritual needs during their clinical visit or to provide services at the clinic to address their spiritual needs. Participants in this study believed a more trusting relationship with their provider may develop if their spiritual needs were discussed or addressed during visits. Clinicians can began this relationship early on by assessing the spiritual needs of patients at the initial visit and reassessing these spiritual needs with any changes in their disease process or life situations that have potential consequences on health outcomes. Additionally, clinicians can take an active role as a listener, referring patients to a Chaplain, Priest, Pastor, or other spiritual advisor culturally suited to address their spiritual needs. More research on the spiritual health needs of HIV- infected adolescents and emerging adults is needed to translate these findings into clinical practice in a way that is relevant and effective when deemed appropriate.

Limitations. Every effort was made to enroll any male or female adolescent and emerging adult into the study. However, this was not possible, as some HIV- positive adolescents and emerging adults chose not to participate. For this reason, only male participants

who were 17-25 years of age were recruited to the study and theorizing was limited to this gender and age group. As a result of our inability to recruit young HIV-positive females and younger adolescents for study participation, findings from this study do not represent the impact of spirituality on the lives of other groups. There was only one heterosexual participant, so findings cannot be considered to be representative of the heterosexual male experience. Nor do the findings represent the impact of spirituality on the lives of young HIV positive males and females who are of a faith other than Christian. In an effort to ensure a range of adolescents and emerging adult experiences, I paid particular attention to recruiting a sample that represented a diversity of beliefs and experiences.

Despite study limitations, I implemented a research design with systematic procedures to maximize the study's rigor. Theory development was carefully constructed using a sample with clear parameters regarding demographics and spiritual beliefs and practices. In sum, this study was one of the first studies in the western region of the United States to describe the role of spirituality in Christian-identified male adolescent and emerging adults who have sex with men and are HIV positive.

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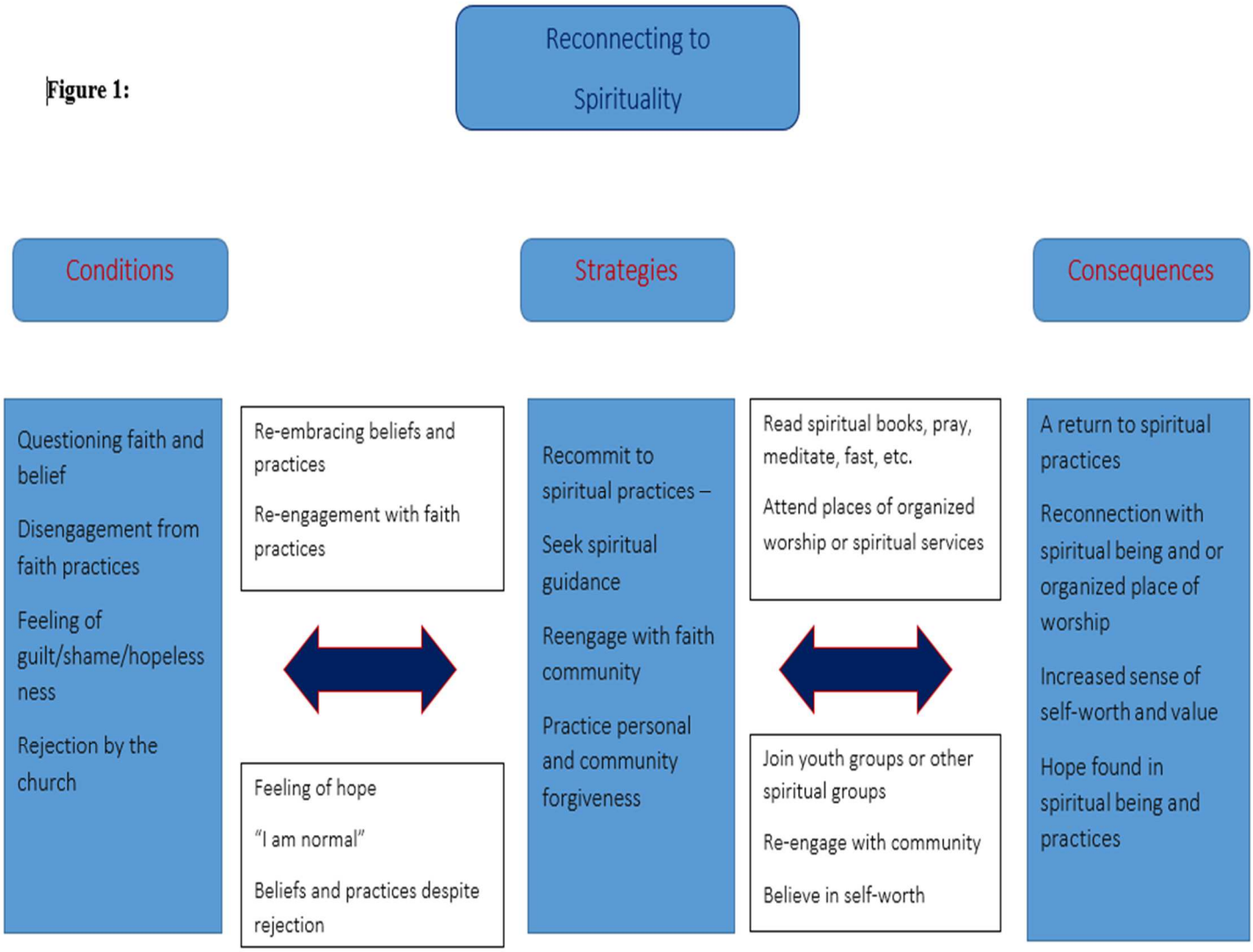
Figure 1:


Reconnecting to Spirituality
Conditions
Strategies
Consequences
Questioning faith and belief
Disengagement from faith practices
Feeling of guilt/shame/hopelessness
Rejection by the church
Re-embracing beliefs and practices
Re-engagement with faith practices
Feeling of hope
"I am normal"
Beliefs and practices despite rejection
Recommit to spiritual practices –
Seek spiritual guidance
Reengage with faith community
Practice personal and community forgiveness
Read spiritual books, pray, meditate, fast, etc.
Attend places of organized worship or spiritual services
Join youth groups or other spiritual groups
Re-engage with community
Believe in self-worth
A return to spiritual practices
Reconnection with spiritual being and or organized place of worship
Increased sense of self-worth and value
Hope found in spiritual being and practices

Chapter 5

"I am Normal": Claiming normalcy in Christian-identified HIV-infected adolescent and emerging adult males

Abstract

In a grounded theory study to describe HIV positive adolescent and emerging adults' perceptions of spirituality and expectations of their providers in addressing their spiritual needs, "I am normal" was a salient theme. The research used a constructivist grounded theory approach to allow participants to construct meaning of living with HIV from their perspective. Twenty-one HIV- infected males were interviewed to elucidate their understanding of HIV from their perspectives and experiences. Claiming normalcy after diagnosis was a key process defined as seeking a state of health that affords one the ability to function at a level that is equal to his or her peers in the presence of daily medications and the absence of outward physical signs of disfigurements. Being normal was instrumental in assisting these young men to cope with their diagnosis. These findings offer insight on how claiming normalcy may promote better overall health outcomes.

"I am Normal": Claiming normalcy in Christian-identified HIV-infected adolescent and emerging adult males.

Adolescents and emerging adults are in life stages where great emphasis is on understanding who they are, who they may want to become and finding a sense of purpose. Having a diagnosis of HIV during this period can present additional challenges for the transition through adolescence and emerging adulthood. Additionally, a diagnosis of HIV may present new uncertainties for adolescents and emerging adults as many are attempting to find meaning in life and life situations. Hoekelman, Adam, Nelson, Weitzman, and Wilson (2001) suggest adolescence is described as period of identity development which usually occurs in the context of peer groups that may predispose them to various high risk behaviors, such as substance use and unprotected sexual activity, putting them at risk for negative health outcomes such as HIV (Hoekelman, Adam, Nelson, Weitzman, & Wilson, 2001). Cognitive development continues in emerging adulthood and a key feature of this period is identity explorations in the areas of love and work, explorations in intimate relationships become more serious and work experiences become more focused on preparation for adult work roles (Arnett & Jensen, 2002).

The purpose of this study was to describe HIV positive adolescent and emerging adults' perceptions of spirituality and their expectations of their clinicians and providers in addressing their spiritual needs, if so desired. The central process of "reconnecting to spirituality" and its dimensions and relationships is described elsewhere (Smith, Kools, Blanchard, Dawson-Rose & Butler). In exploring the specific aim to describe the range of factors that influence spirituality in adolescents and emerging adults with HIV, the overarching theme of normalcy emerged that these young men found as a way of connecting to the church, community, their spiritual beliefs

and roots and everyday life. This paper will focus more deeply on the important process of claiming normalcy that was generated from the in vivo code of "I am normal."

Background

Adolescents and emerging adults account for approximately 52 million of the more than 305 million people living in the United States (17%; American Factfinder, 2010).

Adolescence, ages 10 – 21 years, is usually differentiated as early adolescence (about ages 10-13), middle adolescence (about ages 14-17) and late adolescence (about ages 18-21) (Steinberg, 2011). In a more recent conceptualization, Arnett (2000) posited emerging adulthood (ages 18-25) as a more descriptive later phase of adolescence, accounting for continued changes in the brain that effect behavior and affect. Emerging adulthood is a stage that is empirically and theoretically distinct from adolescence and young adulthood and is distinguished by relative independence from social roles and from normative expectations. "Emerging adulthood is a time of life when many different directions remain possible, when little about the future has been decided for certain, when the scope of independent exploration of life's possibilities is greater for most people than it will be at any other period of the life course" (Arnett, 2000, p. 469).

Sexual risk taken during these developmental periods may put younger people at higher risk for sexually transmitted infections such as Human Immunodeficiency Virus (HIV). HIV is no longer considered a "gay white man's disease" but rather a "youth-driven disease" with 13 - 24 year olds accounting for 26% of all new infections in the United States in 2010 (Benton & Ifeagwu, 2008; Centers for Disease Control and Prevention [CDC], HIV among youth, 2014). HIV as the sixth leading causes of death in adolescents (Benton & Ifeagwu, 2008) and as many as 60% of adolescents and emerging adults infected with HIV are unaware of their status (CDC, 2014).

While adolescents and emerging adults account for approximately 17% of the population in the United States, adolescents and emerging adults accounted for 26% of all new HIV infections 13 -24 year olds from 2008 -2010 (CDC, HIV Among Youth, 2012). Additionally, young gay and bisexual men accounted for approximately 72% of all new HIV infections among youth between 2008 – 2010 representing a 22% increase in this age and gender group (CDC, HIV among Youth, 2012).

The CDC (2014) cites several reasons for the increased rate of infections in adolescents and emerging adults which include; (a) trust of older sex partners who may be unaware of their HIV status, (b) unprotected sex, (c) young gay and bisexual men having sex with men who may be HIV-infected or unaware of their status, (d) sexual abuse, (e) increase prevalence of sexually transmitted infections, (f) substance abuse which may also lead to unprotected sex, and (g) lack awareness of HIV prevention interventions. Mustanski, Newcomb, DuBois, Garcia, and Grov, (2011) explain that this increase in HIV may be attributed to some adolescents, emerging adults and heterosexual men who do not classify themselves as gay, participating in transactional sex, sex in exchange for food, money, clothing, or housing. A diagnosis of HIV as a young person may present multiple challenges as developmentally, adolescents and emerging adults face the challenges of fitting in and being accepted, and making and sustaining friendships and relationships, and very importantly, developing a solid sense of self.

Methods

A constructivist grounded theory approach was taken for this study, allowing the researcher to get as close as possible to the experience without being able to replicate the experience (Charmaz, 2006). Rich inductively-derived data, including detailed description of the participants' views, feelings, actions, and intentions were collected to better understand the

spiritual needs of adolescents and emerging adults with HIV. It was important to allow young men to construct personal meaning about their spiritual beliefs and how these beliefs may assist them in coping with their chronic illness. Theory was generated from data as they were discovered and used to explain how young men perceive spirituality and used their beliefs and practices to cope with having HIV.

Sampling

Recruitment. Participants had to be at least 13 years of age and not older than 25 years of age and have a prior diagnosis of HIV to be eligible for the study. Potential participants were approached by clinic staff during their scheduled appointment at one of two clinics in two metropolitan cities in the western United States. Additionally, flyers were posted throughout the clinic areas with information about the study and contact information. To participate in the study, participants had to speak and read English as consents and interviews were in English. Efforts were made to recruit a range of adolescents and emerging adults who met inclusion criteria.

Sample. A purposive sample of 21 Christian-identified HIV-infected males agreed to take part in the study. All were gay with the exception of one heterosexual, perinatally infected young man. The participants ranged in age from 17-25 years old with a mean age of 22. They self-identified as Hispanic (7), African-American (6), Caucasian (5) and Bi-racial (3). Despite concerted efforts to recruit females and younger adolescents, none agreed to participate. In total 11 young people (younger adolescents and females) declined to participate.

Written parental consent and minor participant assent was obtained for participants less than 18 years of age. All participants 18 years old and older gave written consent. The Institutional Review Board of the University of California San Francisco granted approval for the study.

Data Collection

Consistent with the constructivist grounded theory approach, data were collected through ongoing interactions with participants and thus, provided a richer, deeper understanding of the participants' life and experiences of living with HIV (Charmaz, 2006, Hallberg, 2006). Data were collected through semi-structured interviews and field notes taken during each encounter with participants. The first author interviewed and audio recorded 21 male participants in face-to-face interviews. Second interviews were done on three participants for clarification, verification or elaboration of developing themes or concepts. Interviews were scheduled at a mutually agreed upon location providing privacy and convenience for participants. Interviews were not less than 15 minutes and no longer than 90 minutes. The semi-structured interview guide consisted of general (broadly-worded) open-ended non-judgmental questions designed specifically to explore the participant's experiences of living with HIV and how their spiritual beliefs may or may not impact their ability to live with HIV. There were eight primary questions, 29 secondary questions and as themes emerged from analysis of participants' responses, additional questions were added to the interview guide. All interviews were transcribed verbatim from the audio recordings with the majority transcribed by the study's primary investigator and the remaining studies transcribed by a professional transcriptionist.

Field notes were started during the interview and completed as soon after the interview as possible. These field notes enabled me to compare data that I may have otherwise missed (such as participants' affect during the interview or emotional responses to questions) and provided space for notations on future data that needed to be collected.

Data Analysis

Coding is a process of grounded theory that helps the researcher define what is happening in the data while attempting to understand its' meaning (Charmaz, 2006). Segments of the data were labeled with a name that described, categorized, summarized, and accounted for the data (Charmaz, 2014). I used multiple levels of coding to code the interview transcripts- open, axial, selective, and theoretical.

Open coding. During *open coding*, I identified concepts as they developed, examined them for similarities and differences while placing them into categories (Strauss & Corbin, 1990). I remained open to developing concepts that emerged from the data while also attentive to analytic ideas that were further explored in data collection and analysis (Charmaz, 2006). This coding process generated greater than 340 open and in vivo codes, including - "HIV is better than other diseases", "I am normal", "Not as bad as thought", and "life is better."

Axial coding. I used *axial coding*, to put the data back together by categorizing and connecting categories to make relationships (Strauss & Corbin, 1990). Concepts that shared similarities were grouped together into categories. As an example, stigma, church views of homosexuality, personal responsibility, HIV punishment, and hypocrisy of church were important categories. As categories emerged from the data, I coded these incidents and compared them to previously coded data and with incidents that had not been previously coded. As an example; disclosing status, fear of acceptance, stigma, and relationship challenges were categorized as "second coming out". Another example would be; no physical disfigurements, better than other diseases, still do same things and I am not dying were categorized as "I am normal." Groups within the sample (such as African American and Caucasians and adolescents

and emerging adults) were compared and contrasted. The groups were compared to identify salient themes in regard to their stories and responses to interview questions.

Selective coding. *Selective coding* involved systematically identifying relationships between the core category and other categories. After categories and their relationships were identified, I verified these relationships and filled in other categories that needed further development (Strauss & Corbin, 1990).

Theoretical coding. The fourth and final stage of my coding process was *theoretical coding.* This stage of coding allowed me to move from general themes about the data to theoretical constructs (Saldaña, 2009). Theoretical codes that arose in the data included: making meaning of HIV, coming to terms with HIV, reconnecting to spirituality, living with HIV and "I am normal." Explanatory matrices were used to organize concepts and their relationships into a theoretical story.

Memos were written throughout the process of data collection and analysis. All memos were iterative, therefore enabling me to build upon them as new concepts developed from the data and assisted with generating a theory.

In grounded theory, the aim is to collect and analyze data until theoretical saturation occurs, that is, no new codes, categories or concepts occurred through constant comparison of the data (Bryant &Charmaz, 2007). With a sample size of 21 participants and a total of 24 interviews, I reached saturation with a sufficient understanding of the role of spirituality in gay Christian –identified adolescents and emerging adult males with HIV. The data from this sample offered both thick description and thick explanation of these adolescent and emerging adult young men's experiences of living with HIV inclusive of their spiritual beliefs (Holloway & Wheeler, 2009).

Assessing Rigor

Rigor assesses if the findings of the study are trustworthy in qualitative research (Whittemore, Chase, & Mandle 2001). The descriptions of the participants' spiritual experiences were reported verbatim and a broad definition of spirituality was used to prevent bias from my own spiritual beliefs. Negative spiritual experiences of participants were also reported. I was careful to not share my spiritual beliefs with participants to decrease social desirability. To assure my personal feelings, spiritual beliefs, experiences and potential biases were not embedded in the analysis, other members of the research team reviewed and discussed interviews and products of analysis with me. In my clinical role as a family nurse practitioner, I often interview adolescents and emerging adults. I paid very close attention to my role as researcher, differentiating it from that of clinical practice, and took extra precautions to not introduce personal assumptions about this age group in the research process.

I reported both positive and negative experiences of participants from the data as all interviews were transcribed verbatim. As concepts developed, they were shared with participants in later interviews for verification and to assure the findings accurately reflected the perspectives of participants and not my own perspective. Finally, co-authors reviewed the data to ensure the identified categories and overarching themes and theorizing actually emerged from the data.

Findings

The central theory of the study was the process of *reconnecting to spirituality*. Participants spoke repeatedly of reverting back to or relying on their spiritual beliefs and practices from youth to assist them with coping with their diagnosis of HIV. Participants were reminded by family members that in difficult times during their youth, they (as a family) relied

on their faith to sustain them and get them through those difficult times. Although many participants admitted to having abandoned their places of organized religious worship and practice, many have found solace in reconnecting to their spiritual beliefs and practices and some have actually returned to organized religion. Further details on this theory and its development are reported elsewhere (Smith et al.).

A striking finding in the analysis was the extent to which participants discussed their process of claiming normalcy in their lives in the face of HIV and their conceptions of a normal self. The participants gave various descriptions of how their lives are equal to that of their HIV-negative peers.

The concept of "I am normal" was prominent through most of the interviews, so much so that it quickly became an overarching theme in my analysis. Participants expressed this concept in the following ways: "I don't feel any different", "I am still normal", "I am like any other normal person", and "I am no different." This concept was verified in later interviews when participants were recruited via theoretical sampling. The interview guide was changed to add questions that would elicit participants' perspectives on the concept of feeling normal with a diagnosis of HIV.

As I began to listen to their stories that were steeped in their perspectives of feeling and being normal, I began to understand what normal means to adolescents and emerging adults who are HIV-infected. Claiming normalcy afforded these adolescents and emerging adult males the ability to reconnect with their communities, peers, spiritual beliefs and practices and places of organized worship without fear of being stigmatized. Additionally, claiming normalcy, instilled in them a sense of being able to live a life equal to their HIV negative peers thus, reducing the risk of being stigmatized or ostracized. During data analysis, I paid attention to the conditions, strategies and consequences that are involved in the process of claiming normalcy. An explanatory

matrix outlining the dimensions of claiming normalcy and their relationships is presented in figure 2.

What does normal mean to these young people who are living with such a devastating disease? Using the perspectives of the participants, I defined claiming normalcy as affirming that one has a state of health that affords him the ability to function at a level that is equal to his peers in the presence of daily medications and the absence of outward physical signs of disfigurements. So who gets to decide what is normal? Is that a decision that is made by the individual living with the disease state or by others in the social milieu? What are the other qualifications or underlying characteristics? These are all questions that assisted in formulating a definition of what is normal for these adolescents and emerging adults and how they claim it for themselves. Participants compared their lives with HIV to those with diabetes and cancer. They spoke of having the same responsibilities as everyone else in society such as work, paying bills, attending school/college, or providing a place to live for themselves and maybe others. Normal or feelings of abnormality may best be decided by the individual who has the disease as was by these adolescents and emerging adults. Participants in this study often spoke of not feeling or looking any different than anyone else. This paper will discuss the conditions, strategies and consequences that were related to the process of claiming normalcy.

Conditions

Several conditions were identified that could facilitate or block one's ability to claim normalcy. Conditions identified were: disclosing status vs. keeping private, stigmatizing vs. supportive responses by others and health status.

Disclosing status vs. keeping private was a decision each participant made around revealing or not revealing one's HIV status to family and friends. Participants in this study were

open with disclosing their status among family and friends. However, African American participants were less likely to disclose to their family citing reasons such as "homosexuality is not as accepting in the African American community," "stigma," and "don't want to be a burden on my family" as reasons for not disclosing. Some participants disclosed their status to those whom they felt they could trust only to be betrayed and later stigmatized by others. For them, not disclosing would have spared the stigma, shame, guilt and in some instances, family separation. All participants in this study received support from their providers, counselors or social workers to assist with challenges associated with their status including decisions around disclosing. The following statements by participants' #4, and 9 are examples of disclosing status vs. keeping private.

P #4: "They took it well, I guess, as well as they could take it. They're supportive of it. They don't ever bring me down on it and rarely ever mention it too much to be honest. It's just the same thing to them. It's just something that I take pills for and go to the doctor."

P #9: I didn't want anyone to know. I mean, I told — I told a few close friends, and then I — when I tried to tell family, the whole family found out, so that was upsetting to me. Yes. Everyone found out. Friends found out in the neighborhood I grew up. Family, everyone in my family, and I mean everyone, found out. And it was uncomfortable to be around family, so I kind of moved away from — I have — I haven't seen my family in months."

Keeping one's status private or having one's HIV status exposed in the manner described by participant #9 may potentially hinder claiming normalcy.

Stigmatizing vs. supportive responses. Responses of significant others to having HIV either invoke painful thoughts or emotions or convey a message of genuine concern and support. The stigma associated with HIV continues to be evident in the church as well as mainstream

society today. Due to stigma, HIV-infected adolescents and emerging adults often do not get tested which leaves many unaware of their status, do not access or are lost to medical care, are less adherent to medications and often do not participate in treatment and prevention programs (Fielden, Chapman, & Cadell; 2011). In this study, some participants spoke of experiences of stigmatization from the church when disclosing. As a result, one participant left the church which he had attended for many years. Other participants spoke of supportive responses from family and friends when disclosing. Participants #11 and 20 describe their experiences with stigma and support in the following statements:

P#11: "Mm-hmm. Um, I would say I'm like any other normal person. I don't see myself different from a person who doesn't have HIV just— Yeah, I'm a normal person"

P #20: (Referring to his partner) "He's the first guy that ever, that seen a lot of value in me. I don't know why and I don't know what it is he sees. Uh, I love him a lot. He helped me a lot."

Claiming normalcy may foster a sense of not being viewed as different from others. Claiming normalcy may also decrease the likelihood of being stigmatized because of ones' HIV status. Adolescents and emerging adults may be able to transition through life just as their peers without the additional challenges of social acceptance that often comes with disclosing one's HIV status in claiming normalcy. Claiming normalcy may also decrease depression associated with HIV as found in this study, participants lived very active lives and reported less depressive symptomatology associated with their status, when they believed they were normal or no different from their peers.

Health status was defined by participants as having an illness that does not present with visible signs or symptoms. Participants in this study compared their diagnosis of HIV with other

chronic illnesses such as cancer and diabetes. Most participants described having HIV as being better than having diabetes in than "it is much easier to control HIV." Other participants described the side effects of chemotherapy and the disfigurement of certain cancers to be worse than having HIV. Participant #3 explains this when sharing advice from his grandmother in regard to his diagnosis and his niece who has cancer;

"…she's not normal either and she has it worse than you. She has to live plugged into her, a thing to her kidney for the rest of her life you know."

Participant #8 shares his thoughts about having HIV and diabetes in the following excerpt;

"…diabetes could be worse than AIDS or having HIV cause that's just what my doctor told me. That's like the first thing they told me. Like it's not a, not a death sentence and diabetes is actually harder to control, to manage than uh HIV now a days so."

Unanimously, participants felt they were in overall great health and often forgot their HIV status until they had to take their medications. An individual's perception of his overall health status has the potential to impact whether or not they feel normal and can contribute to society or if they are dependent or a burden to society. Participants' #14 and 16 are in school, work, and/or tutor while effectively managing their disease. Excerpts from their interviews read as follows:

"I am a, uh, I work as a math tutor at a math learning center, I also am looking to finish my college degree, a bachelor's degree in mathematics."

"I work as a Kindergarten teacher assistant and I also work for an after school program as a coach. I coach football, basketball and soccer. Um, because um, I'm in school to become a, I want to be a family attorney but also I am getting my AA degree in child development to work

with children and eventually I want to open up a youth center to help children that doesn't have support at home or that's been through a lot cause by me working with the kids I learned a lot."

Strategies

Participants employed several strategies to claim normalcy. Those strategies included seeking meaning in their diagnosis, believing in self, and engagement in social life. With the use of the strategies, participants were better able to feel that they were normal and leading a normal life.

Seeking meaning in diagnosis was defined by participants as seeking personal value and meaning in their HIV status. Many participants admitted to being cautious, using condoms and being in monogamous relationships. For some participants, IV drug use/abuse or sexual assault was the reason for their status. Yet another participant, perinatally infected, would have many questions as to why in trying to make meaning of his diagnosis. While participants #3 and #17 had difficulties in accepting their diagnosis, participant #3 came to understand his life purpose in being HIV-infected. The following excerpt shares the struggles of participants #3 and #17 in finding meaning for their HIV status;

P #3: "For a month I was like, I want to die. Why does God hate me so much? I thought I was going to be O.k... I was like what did I do wrong? What did I do so wrong? And then coming time passing to where I started to understand, to be more comfortable with myself, I started realizing that I got HIV to protect myself from the war, from whatever else is going on. I am here because I saved a life. I saved two people's lives, my best friend and my husband. My husband was addicted to Crystal Meth and I changed his life. Finally, I brought him into a home you know. My parents didn't have nowhere to go so I asked them, come live with me you know and it all just worked out."

P #17: "I feel, I ask myself why would he give this to me. But then I say well, I had a choice too and did whatever I did and I feel, sometimes feel punished because I have and sometimes I don't. I 'm a lot confused of why cause I was so safe and uh you know not really knowing who did I get it from. Um, it has me question God sometimes on it as well."

When participants in this study were able to find meaning in their diagnosis of HIV and not view it as personal suffering, they were better able to accept their diagnosis and claim normalcy. In taking ownership and responsibility for decisions made, participants felt developmentally they were maturing and becoming responsible adults much like their non-HIV-infected peers. This moved participants along the process of finding meaning and claiming normalcy.

Believing in self is defined as having self-confidence that one has the ability to live with HIV. Although participants' initial reactions ranged from shock to disbelief, most (86%) came to accept their HIV status as something they can live with. In doing so, participants garnered a sense of belief that they were living a normal life with the exception of having a chronic illness.

P #14: "I know that you know that with the technology we have today, with the medicine that we have today um, I can live a pretty healthy life. And um, I don't have to worry about my death being imminent upon me. I feel like I can cope with the realization that HIV is not a critical you know it's' just a chronic illness that is upon me so."

Engagement in meaningful social relationships was defined by participants as going out with friends and family or having friends and family over to their apartment for dinner, parties or other social gatherings. Most participants (86%) in this study had active social lives. Those participants that were not as actively engaged socially were less active due family

dynamics unrelated to their HIV status or were new to the area. Participants described their social lives as follows:

P #9: "We're kind of wild crazy party people, yeah. Mmm. I like alcohol. I like to party. I like to have fun. I like to go out. I'm a normal human being. I like to do what normal people like to do, I guess."

P #19: "Um, I think I'll probably get into more dating when I am in my thirties too. I want to start doing that when I am a little more stable with money. Right now I am more worried about myself than anything else. Like I focus on my career and how I am doing, my pumpkin carving party tonight {chuckle} you know."

These young adolescents and emerging adults' social lives are reflective of the typical social life of most of their peers who are HIV-infected or not. Participating in these activities gives them a sense of normalcy and disclosure of status is neither a requirement or exclusion criteria.

Consequences

There are consequences to claiming normalcy. However, not all consequences were positive and these outcomes were on a continuum. The outcomes or consequences were dependent on how participants moved through the process of claiming normalcy. Participants in this study spoke of times since their diagnosis of feeling poor self-esteem and other times feeling a positive sense of self-worth. Other outcomes identified were being engaged versus being disengaged in workforce, school, church and social life, and poor versus better health outcomes related to diagnosis.

Positive sense of self-worth and value is defined by participants as feeling good about oneself and believing that HIV does not define nor mean the end of your life. Participants in this

study believed their diagnosis often served as the catalyst that created change from high risk behaviors or moved them forward in pursuing personal goals.

P #16: "Um, now it's a day, I know that it's not the worst thing in the world cause they have, you have to eat a, live, try to live a healthy lifestyle to help you get better — Um, it's just something I have to keep taking my meds to get better so, I guess it's a part of me — And every day of my life I go, like I tell myself like this is not the end, this can't stop me cause I am still living. I am not dead yet so I won't let this be the reason why I do die."

Participants in this study found it was possible to live with HIV as opposed to dying for HIV. Living with HIV offered hope and a sense of normalcy.

Engaged in workforce, school, church and social life is characterized as being actively involved in the church, currently enrolled in school with a career goal that will lead to a career, socially interactive with peers and classmates and/or gainfully employed. Participants did not disclose their status to peers in school or the workplace for fear of stigma or being fired. Being able to engage in work, attend school, attend church and social activities afforded participants the normalcies of everyday that their peers enjoy without having to necessarily disclose their status. Participant #14 describes how he managed these things.

"Um, I also am looking to finish my college degree, a bachelor's degree in mathematics and hopefully that will occur sometime soon — But I also work so I have um, working in the afternoon um, if I don't have any appointments I work — And um, its' just um, I went out with them at my church to eat some dinner and we had a great time and it's very supportful , very uh, it's not exactly spiritual its' just friends getting together and enjoying time together and knowing that you all care about God and God cares about you and all that good stuff so."

When participants were able to participate in the normalcies of everyday life, the process of claiming normalcy was achievable.

Better health outcomes related to diagnosis. Participants in this study described their lives as better in multiple ways since their diagnosis. They were not claiming that it was good to have HIV, however they reported that their diagnosis led to some improvements in their lives namely, they had health insurance, dental care and housing. Therefore, participants defined better health outcomes related to diagnosis such as having undetectable viral loads, healthier diets, exercise programs and less depressive symptoms related to HIV. Participant #11 provides his perspective of a healthier life after diagnosis.

P #11: "I don't see myself different from a person who doesn't have HIV just because, you know, well, in a way we are different just because, well, we have the HIV, but a person with HIV what they -- I've noticed, they tend to have a better lifestyle as in they eat healthier . They go to the gym. They take care of themselves, you know. They're being healthy. They're doing healthy things, you know, being spiritual, gym, eating healthy. There's all these things that they, they do, so that they're body could, you know, have more strength to fight off this disease, you know."

In addition to medication management, treatment regimens and the uncertainties of HIV, disease management often require lifestyle modifications including daily physical activity (Bosworth, 2006). Participants viewed their lives as normal and equal to that of their HIV-uninfected peers. While their peers joined the gym to increase muscle mass, they joined for better health outcomes related to their HIV status.

Poor self-esteem is defined by participants, as not feeling self-worth or value. This was most often experienced during initial diagnosis. However, one participant continued to struggle

with low self-esteem. He had feelings of shame and guilt about how he became HIV-infected. This was evident during the entire interview as he could not maintain eye contact. He states;

P #20: "It affected me pretty, I already thought low of myself. But um, it affected me pretty bad. I um, it made me actually, when I first found out I used to tell myself, like I am nasty like, just ewe! Like, I just tell myself negative, very negative things."

Other participants in this study used the word contaminated to describe how they viewed themselves after becoming HIV-infected. This feeling of being contaminated devalued their worth as being productive citizens as well as one participant described no longer having the option to join the military and fight for his country. This excerpt from his interview gives an account of his thoughts;

P #18: "Well, just that I feel a bit contaminated in a way and I shouldn't feel that way but there is just a lot of things that HIV uh, can hold you back from— The military was something that I was thinking about, can't do that now. So it, like there's a lot of things I'm like f—k, it's holding me back. So, it's like I am a contaminated being and have, like you know, there's nothing I can do for my country anymore you know."

Such feelings of low self-esteem have the potential to hinder one's ability to cope with their diagnosis of HIV and claim the normalcies that may increase their self-esteem and ability to cope with their HIV status.

Disengaged from work, church, and social life is referred to by participants as removing oneself from a place or setting where he feels he is not accepted or stigmatized because of sexual orientation or the assumption of HIV status. Participants in this study that were stigmatized or felt unwelcomed often spent time participating in activities that did not require multiple players or participants. Additionally, African American participants were more likely to

express stigmatization from church, community and those in their social environments and therefore more likely to disengage from organized religion and social activities.

P #5: "I used to go to church, and then it became used to, like I don't do it anymore — Well, I'm homeless. I don't live with anybody. A typical day for me is killing time until I go to two youth programs, and one starts at 12:00 and the other starts at 5:30. And the one at 12:00 is just pretty much playing video games, and all that stuff, and then the one at 5:30, you can take a shower, get clothes or shoes, and then I go to sleep after that one. The one at 5:30 ends at 8:00. So, that's pretty much my day."

P #13: "And I haven't been to church in a while— long time because every time I go to the church, the person's personal test —the preacher, whoever is testifying at that time, will change the testimony from the personal testimony or to whatever they're speaking about to the Sodom and Gomorrah thing."

While these young men chose to disengage from the church, spirituality remained important in their lives as does with many African American men who have sex with men (Foster, Arnold, Rebchook, & Kegeles, 2011). Although some participants chose to disengage from church, they continued to participate in spiritual practices such as praying, reading spiritual materials and listening to spiritual music. They considered these practices to be a part of having a normal life.

Poor health outcomes related to diagnosis, relates to medication resistance, depression or increased fatigue often associated with HIV. Participants described their experiences below in the following below;

P #12: "Everyone, literally, f–king everyone keeps telling me that I need to be on a pill and I know that I probably should, but I don't want to and that's my decision and I feel that

everyone should respect my decision, because it's my body and I don't have to do anything I don't want to do . If I want to just let this virus take hold and run its course, that's my decision, and I'm allowed to do that. You know, that's not necessarily what I'm gonna do, but you know, I'm— I just— I'm doing my own thing right now and it's a bit unconventional and everyone disagrees with it, but I don't know."

P #20: "Because it, my life right now, it's kind of hard to remember and it's unhealthy for you to take them once here and once there. Cause when I first got my medicine, I was doing it, I was taking it fine but then a lot of stuff was stopped, stuff was happening and I kind of forgot and my body was aching and it actually, cause I already got some resistance. My body could gain more resistance by me taking meds like one here, one there."

Several participants in this study described the concept of a life relegated to the unpleasant task of a daily medication regimen to be anything but normal. This could certainly hinder one's ability to claim the normalcies that have been identified by some as a strategy to cope with their diagnosis of HIV.

As stated by one participant in this study, one challenge adolescents may face in taking Highly Active Antiretroviral Therapy (HAART) is that of forgetting. Coupled with forgetting, may be the associated fear of disclosure and not fully understanding the need for medications. Just as adolescents often take risks without fully weighing the consequences with sexual behaviors, these risks may spill over in to health related circumstances as well.

Believing in and claiming normalcy affords one the opportunity to live with HIV with enduring the stigma, shame and guilt often associated with having this condition. Participants in this study were able to cope with their diagnosis and live with HIV by claiming normalcy.

Although some encountered isolated incidents of stigma, overall, they could live a life relatively free of stigma.

Discussion

The overarching theme of "I am normal" and its related process of claiming normalcy was evidenced across interviews in this grounded theory study to understand the spirituality in HIV-infected adolescents and emerging adults. Claiming normalcy and thus, being normal connected these adolescents and emerging adults to their spiritual beliefs, places of organized religion, their community and gave them a sense of value in their everyday life. Feeling normal provided a feeling of hope and empowered them to live with HIV. Participants were able to interact with peers in places of work and school as well as the community providing the social connection that is so important during this developmental stage (Steinberg, 2011). The invisible scars of HIV (i.e. depression associated with HIV, pain of rejection) enabled participants to harmonize with peers without revealing their status. This feeling of normalcy offered a feeling of being able to live with HIV.

Some participants however, did not find their lives to be normal with HIV. HIV may limit a persons' ability to choose certain career options or travel to certain locations. HIV also reduces the individual to a life of daily medications and lifelong monitoring. Having a chronic illness with limitations and restrictions does not render always one's life as normal.

The findings in this study are similar to findings in a study on 78 adolescents with cancer. Hendricks-Ferguson (2007) used a cross-sectional descriptive design to study hope and spiritual well-being in adolescents with cancer and found adolescents reported their cancer diagnosis and treatment restricted their lifestyle. Cotton et al. (2009) studied religious coping in 48 adolescents with Sickle Cell Disease (SCD) and 42 parents of adolescents with SCD and found 31% and

36% of adolescents questioned why this (SCD) happened and God's love for them. This may be interpreted as a form of questioning normalcy especially during a time of heightened peer social relationships and development.

The findings from this study support the notion that acceptance and not being perceived as different is very important in the lives of adolescents and emerging adults (Steinberg, 2011). The findings also highlight the importance of peer relationships to adolescents and emerging adults (Steinberg, 2011). Participants talked about interactions with family, cousins, classmates, and people in general without the fear of being stigmatized but rather feeling like a part of the group or like they belonged, "like everyone else."

Clinical Implications

Acknowledging and reinforcing the normalcy in adolescents and emerging adults who are HIV-infected may be of benefit in assisting them to cope with their diagnosis and promote overall better health outcomes. Stressing the impact of claiming normalcy, as it allows HIV – infected adolescents and emerging adults to function at levels equal to their non-HIV-infected peers, may increase compliance to care and medication adherence as well as decrease depressive symptomatology associated with HIV. Claiming normalcy instils a sense of being able to "live with HIV" for participants in this study.

Acceptance and relationships are a priority for adolescents and emerging adults. Having a safe place where adolescents and emerging adults can express their concerns about acceptance, peer pressure and living with HIV is also important. Clinicians should take opportunities on every visit to address these issues and make referral appropriately to ensure the potentially unaddressed social needs of their patients are being met. Participants in this study were able to live with HIV in the presence of feeling they were normal or claiming normalcy. Future research

should investigate the psychological impact HIV has on adolescents and emerging adults during a heightened time of physical, and psychosocial development. More specifically, research on the impact that feeling normal while HIV-infected has on health outcomes is needed with the findings translated into clinical practice in a way that is age appropriate and relevant to optimize social development during adolescence and emerging adulthood for those who are HIV-infected.

Limitations

This study has several limitations. The study was open to adolescent and emerging adult males and females however, some HIV-infected adolescents and emerging adults chose not to participate. With only male participants who were within the age range of 17-25 years of age recruited into this study, this limits theorizing to this gender and age group. The findings from this study do not represent the perspective of living a normal life with HIV from younger adolescents and females as a result of our inability to recruit from these two groups. Additionally, we were able to recruit only one heterosexual participant and therefore the findings are not representative of the heterosexual male experience. Finally, all participants were from Christian faith traditions or backgrounds therefore, our findings are only applicable to HIV-infected adolescent and emerging adult Christian-identified males. Creative recruitment strategies to capture the perspectives of other young people are needed in future studies to increase the applicability of findings.

Although the study had several limitations, the research design was implemented with systematic procedures to maximize its rigor. In sum, this study highlights the impact that one's perception of their disease state has on their ability to cope with their disease process. Moreover, it provided evidence that claiming normalcy impacts HIV-infected adolescent and emerging adult males' ability to remain socially connected to their communities. This is the first study to

describe the impact of the concept “I am Normal” and the process of claiming normalcy from the perspective of adolescents and emerging adults who are HIV-infected in the western region of the United States.

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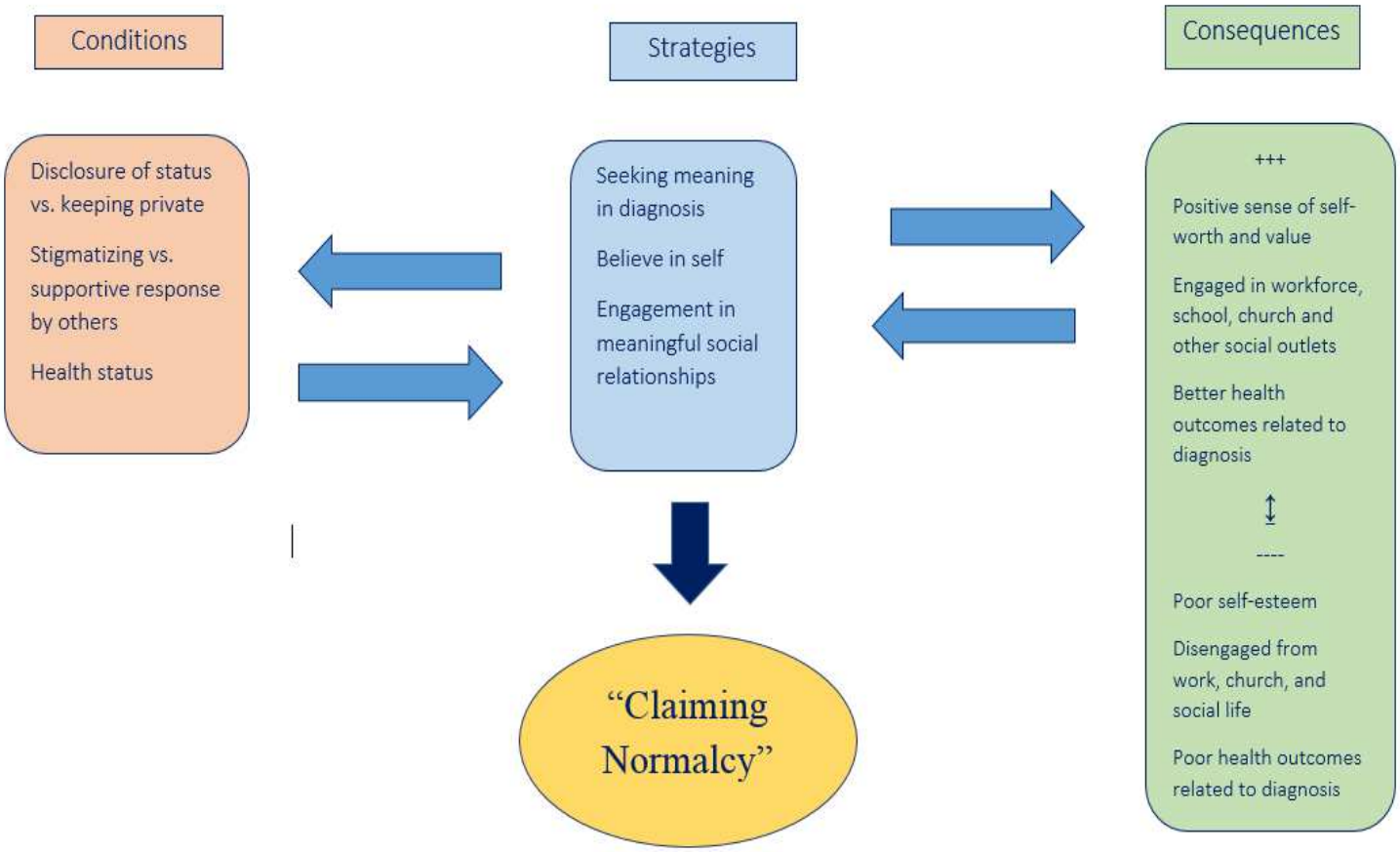
Figure 2: **I Am Normal**



Chapter 6: Discussion and Implications

Spirituality played a very important role in the lives of these adolescent and emerging adult HIV-infected males. While adolescents and emerging adults often disengage in organized religion, they may not completely abandon their spiritual beliefs and practices. This was found to be true of participants in this study. Participants spoke of reasons for leaving the church at a young age which included sexual orientation, questioning faith, peer pressure and relations, feelings of rejection from church and feelings of guilt and shame. However, after their diagnosis of HIV, all participants in this study reconnected to God, a higher power or spiritual being to cope with their diagnosis. Several participants were reminded through the spiritual practices of praying to take their medication. Participants were reminded through conversations with family members and situations within the family that their spiritual beliefs were what has always kept them strong during difficult times and this situation, their HIV diagnosis, would be no different. But not all would find this reconnection a smooth transition. African American adolescents and emerging adult males in this study were more likely to describe being stigmatized due to their sexual orientation at home and in the community. Additionally, African American participants described feeling more stigmatization from church than their peers (Foster et al, 2011).

Believing they were normal was one of the central themes identified in the process that assisted participants with reconnecting to their spirituality. Normal was defined from the perspective of participants in this study and comprised physical as well as cognitive components. Normal was defined as a state of health that affords one the ability to function at a level that is equal to his or her peers in the presence of daily medications and the absence of outward physical signs of disfigurements. Participants viewed themselves as normal in that they had the

same responsibilities as their non-HIV-infected peers such attending school, working, paying bills, attending church and other social gatherings and functions.

While very few participants admitted that they are currently actively engaged in organized religion, they have held on to their faith and spiritual practice from childhood and relied on this faith to help through the difficult times and challenges associated with their diagnosis of HIV. Participants described how prayer, holding their cross, believing in something bigger than themselves, and believing in a higher power has given them hope, reminded them to take their medications (Park & Nachman, 2010), reduced their depression (Basu, Chwastiak, & Bruce, 2005; Braxton, Lang, Sales, Wingood, DiClemente, 2008), provided protection and made a way when there seemed to be no way possible for them to achieve the things required to do well with their diagnosis. Participants also shared how in spite of the negativity or hypocrisy from the church (Foster, Arnold, Rebchook, & Kegeles, 2011), they have chosen to believe and hold on to their faith. For them, believing is better than the alternative of not believing. Some participants believe their spiritual being allowed them to become infected with HIV as a way of saving them from other things such as drugs, homelessness, transactional sex work, and maybe even war. Other participants believed their diagnosis was the result of their actions, not doing or following the plans that God had for them.

Participants spoke of how their parents, grandparents, aunts and even other siblings were instrumental in shaping their spiritual beliefs. Often during difficult times and situations in childhood, they experienced or saw firsthand how their parents or grandparents relied on their spiritual beliefs to get them through the difficult times. Some participants shared their experiences of disclosing to their parents and grandparents who in turn reminded them that they have always relied on their spiritual beliefs in difficult times to get them through and this would

be their source of strength now. Others continue to participate in their spiritual practices such as wearing a cross, reading spiritual books, and praying as a reminder of the things they had been taught about their spiritual faith.

Most participants believed their life with HIV was normal and used that strategy to help them cope. Participants spoke of how they too had the same responsibilities in life as most others such as paying bills, supplying food for the family, work, pursuing a college degree and maintaining an active social life to avoid the stigma associated with HIV. Other participants felt their life was not normal with HIV. They felt HIV limited the things they could do in life such as have a family, join the military and travel to certain countries.

The findings from this study are consistent with the limited studies on adolescents with HIV in that adolescents and emerging adults were open to their providers praying with or for them (Bernstein, D'Angelo & Lyon, 2012) and spirituality is important in the lives of adolescents and emerging adults especially when coping with a chronic illness (Cotton et al., 2009, Cotton et al., 2012, Ironson, Stuetzle & Fletcher, 2006, Lyon et al., 2011, Smith & Denton, 2005). Other findings consistent with previous literature are that those who are HIV positive and practice spirituality feel less depressed (Basu et al., 2005) and report more adherence to medications (Park & Nachman, 2010). Participants also felt they were able to cope with their diagnosis because of their spiritual beliefs (Woodward & Sowell, 2001).

Significance

It is estimated that less than 1% of research on children and adolescents address their spiritual or religious issues (Shek, 2012). However, one national survey documented that 95% of teens in the United States believe in God and religious/spiritual beliefs remain important during emerging adulthood, even when not actually practiced (Arnett & Jensen, 2002; Smith & Denton,

2005). Oftentimes research on emerging adults is collected within adult populations (18 – 65 years of age and older) making it difficult to parse out the perspectives of this age population. All participants in this study were gay except one and had some exposure to Christianity during childhood. After their diagnosis of HIV, a reconnection to their spiritual beliefs and practices was found to be instrumental in offering a sense of hope and that one can live with HIV.

Participants in this study were open to their clinicians and providers praying with or for them. Some participants suggested their relationship with their clinicians and providers could be enhanced if they knew their clinicians and providers had similar or the same spiritual beliefs as they would be more trusting of them. Participants also wanted their clinicians and providers to have spiritual discussions with them and include their spiritual beliefs in their plan of care. Spirituality offered the participants in this study hope that they could live with HIV, decreased depressive symptoms associated with HIV, increased medication adherence and promoted an overall sense that life was better after diagnosis of HIV.

Adolescents and emerging adult young men who have sex with men (MSM) are often faced with the challenges and struggles of integrating spiritual or religious beliefs with their sexual orientation in the presence of condemnation from those in their spiritual places of worship or the church (Kubicek et al., 2009). Participants in this study faced those same challenges. However, when participants did not reveal their HIV status within their church community, they were accepted, were not stigmatized, and were able to openly practice their spiritual beliefs in organized places of worship—their perceptions of normalcy allowed them to participate in spiritual community and to be in control of self-disclosure which protected them from potential rejection and stigma. Participants in this study found claiming the normalcies and assimilating with their peers at work, school and within their community reduced the stigma associated with

HIV. The findings from this study will add to the limited body of knowledge on the spiritual needs or adolescents and emerging adults and aid in addressing the unmet spiritual needs of HIV-infected adolescents and emerging adults.

This study is believed to be the first to explore the concept of "I am Normal" in HIV infected adolescents and emerging adults in the United States.

Limitations

The findings from this study are representative of HIV-infected adolescent and emerging adult Christian-identified males who have sex with men in two clinics in the western region of the United States. Every effort was made to recruit females and younger adolescents however, we were unable to recruit in this gender and age range. Female participants were approached for the study but declined to participate for reasons unknown. Additionally, there were very few females at each site as females may not test for HIV as often as males and consequently may not access care after diagnosis. Diagnosis of HIV is often discovered when testing for pregnancy or other sexually transmitted diseases. Thus, the findings do not represent the spiritual experiences of HIV-infected females who may be more spiritual that their male peers (Lorenz et. al., 2005). Clinic staff also approached five younger adolescents (13 – 16 years of age) who declined to participate for reasons unknown as well. Therefore, the findings in this study represent the perspectives of 17-25 year old males. We were only able to recruit one heterosexual male thus, the findings do not adequately represent the perspectives of the heterosexual male experience. All participants in this study were exposed to a Christian upbringing or familiar with Christian-identified spiritual practices such as reading spiritual books, praying, or listening to spiritual music and did not represent a faith other than Christian. The findings from this study represent

young, gay Christian-identified adolescent and emerging adult males in the western region of the United States.

Implications for Nursing

As HIV continues to disproportionately affect adolescents and emerging adults, minorities and the underserved, implementation of services and clinics geared to towards caring for this population should be explored. Mustanski and colleagues (2011) suggest the lack of clinics that cater primarily to adolescents and emerging adults may be instrumental in the spread of HIV as this young adult population often does not seek care and treatment in clinics that cater to older adults. For this reason, some adolescents and emerging adults are lost to care and are unaware of their HIV status, thus potentially infecting others. Participants in this study expressed appreciation for having a treatment home that catered to the concerns of their health as well as developmental milestones, such as need for privacy and making personal decisions while navigating their diagnosis of HIV. Clinicians can take an active role advocating for teens or young adults in HIV clinics that are more welcoming, inviting and better prepared to meet the health care needs and concerns of this age population in an effort to decrease the spread of new HIV infections.

Participants in this study often spoke of the need, from their perspective, to educate youth about the seriousness of HIV. Most participants felt it was their obligation to educate other teens on how not to become HIV infected and described a real need in the education system to better prepare teens to protect themselves from HIV and other sexually transmitted diseases. The findings from this study correlate with the suggestions from the CDC that better education about HIV transmission is warranted in schools (CDC, 2012, HIV among youth). Clinicians are in

unique positions and should take every opportunity to educate adolescents and emerging adults about sexually transmitted diseases, including HIV during routine physicals and screenings.

Understanding the role of spirituality in the experience of adolescents and emerging adults living with HIV may give insight and guidance for clinicians in their efforts to meet the spiritual needs of patients. Clinicians caring for the HIV population may benefit from understanding how patients perceive religiousness and spirituality and how these factors relate to challenges they face in everyday life (Lorenz et al., 2005). Religious affiliation and practices such as prayer are very common among HIV positive patients as spirituality is an indicator of well-being (Lorenz et al. 2005). An adolescent's spirituality is instrumental in decreasing anxiety and depression associated with HIV status (Lyon et al., 2011). A thorough spiritual assessment on intake and periodically during treatment by clinicians on their adolescent and emerging adult patients may be appropriate to assess their current spiritual status and to refer to spiritual advisors if they are desirous may be beneficial in meeting their spiritual needs.

Increased knowledge of the range of factors that influence adolescents and emerging adults to employ their spiritual beliefs while navigating their diagnosis and treatment protocols may assist clinician in developing strategies to meet the spiritual and health needs in this population. This new knowledge may also may assist clinicians in providing treatment specific care that encourages the use of spiritual beliefs in practices while optimizing health outcomes for Christian-identified HIV positive adolescents and emerging adult males.

Implications for Future Research

Some evidence suggests that spirituality has or promotes positive outcomes in health. Although there are no concrete answers as to how and why and who will benefit from exercising their spiritual practices in the presence of their disease, the literature suggests for many it has

proven to be an effective coping mechanism and navigational tool. However, the very limited qualitative studies on spirituality and HIV do not explore the relationship in adolescents and the perspectives of emerging adults is captured in the often wide range of adults age 18-65 and older, making it very difficult to parse out their experiences.

While there has been increased interest in the effectiveness of spirituality in adolescents as a coping mechanism for the stressors associated with chronic illnesses, there has been very little research on its effectiveness in adolescents with HIV. Although every effort was made to recruit a robust sample, we had difficulty recruiting a full age range of adolescents and young adult participants which makes it difficult to know and understand the spiritual perspectives of these subpopulations when faced with the challenges of HIV. Future research should be done to understand the perspectives of other groups of adolescents who are HIV-infected and we need to continue to find creative ways to recruit difficult to recruit young people, such as teen group meetings, via social chat rooms for HIV-infected youth, camps or other social outings for HIV-infected youth, or via incentives targeted towards this age group population.

In the limited research that addresses the spiritual needs of adolescents with a chronic illness, it is suggested that females are more spiritual than males (Lorenz et al., 2005). Because we were unable to recruit in this age and gender, it is impossible to know and understand the role of spirituality in females who are HIV-infected. Future research should be done to specifically address the spiritual needs of adolescent and emerging adult females who are HIV-infected.

Additionally, having a primarily homogenous sample of twenty gay males and one heterosexual male, we are unsure of the spiritual needs of HIV-infected heterosexual adolescents and emerging adult males. We were also unable to recruit from a faith other Christian and

therefore future research should be done to explore spiritual needs in HIV positive adolescents and emerging adults who are of other faith or spiritual traditions.

Conclusion

The findings from this study using grounded theory methods provided rich a description and explanation of how spirituality has been instrumental in feeling that life is normal and being able to cope with having HIV for emerging adolescents and adult males. It also provided a theoretical explanation for how one may reconnect to earlier spirituality after disengagement in response to an HIV diagnosis and learning to live with this condition. The flexibility of grounded theory allowed for and encouraged the participants to tell their stories in a way that was meaningful to them yet provided insight on how others may benefit form employing their spiritual beliefs as a mechanism for coping with HIV. Participants in this study felt their spiritual beliefs offered hope and made it possible to cope with their diagnosis. Some of the participants in this study have reconnected with their spiritual beliefs and places of organized religion. Some are still struggling to come to terms with their diagnosis and self- forgiveness for what they perceive as their own responsibility for contracting a disease. This study provided an avenue for participants to share intimate stories of their journey to healing which they described should be a part of their treatment plan. In addition, results from this study will aid in the development of recommendations to facilitate an improvement in the quality of healthcare services for adolescents and emerging adults living with HIV.

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Appendix: A - Interview Guide

University of California, San Francisco

"Understanding the Role of Spirituality in Adolescents and Emerging Adults with HIV"

Thanks so much for agreeing to meet with me and participate in this interview! I'd like to take a moment to remind you what this study is about. I am interested in learning about and describing the role of spirituality in assisting adolescents and emerging adults to navigate a diagnosis of HIV. I want to know how you think spirituality has assisted you, or not, in your day to day experiences while living with HIV. I also want to know what it is about your spiritual beliefs that make a diagnosis of HIV better or worse for you. I am not here to judge. I am here to learn from you about your experiences.

I understand that living with a chronic illness such as HIV can be difficult, so if at any point you feel uncomfortable or need to take a break, please let me know. This is also meant to be like a conversation, so please feel free to include any information that you think of, even if it doesn't necessarily answer the specific question that I've asked. Before we get started, do you have any questions or thoughts?

1. Please tell me a little about yourself.
   -Who do you live with?
   -What is a typical day like for you?
   -Do you consider yourself spiritual and why?
   -What does it mean to you to be spiritual?
   -What are your spiritual beliefs and how do they play a part in your life?

2. Please tell me a little bit about your experience of living with HIV.
   -What did you know about HIV prior to your diagnosis?
   -When and how did you find out about your HIV status?
   -What was this like for you?
   - What where your thoughts when you were told of your status?
   -When you think about your HIV status, what do you think about?
   - Have your feelings and thoughts about HIV changed since your diagnosis?

3. What helps you feel physically and mentally strong?
   -How have you learned to handle your diagnosis of HIV?
   -Have you ever employed your spiritual beliefs to assist you in understanding your HIV status?
   -How did that help?

4. Do you consider yourself spiritual and why?

-Tell me about the role of spirituality in assisting you to come to terms with a diagnosis of HIV.
-What is it about spirituality that makes a difference in the way you cope with your illness?
-What does spirituality means to you as a young person with a chronic health problem?

5. What do you feel is the role of your healthcare provider in addressing your spiritual needs?
   -What are your expectations from your provider in addressing your spiritual needs?
   -What is the role of your support persons in addressing your spiritual needs?
   -How might your provider meet or address your spiritual needs?

6. What are your plans for the future?
   -What have people told you or what do you believe your life will be like because you have HIV?
   -What role do you see for spirituality in your life now and in the future?

7. Tell me about how your views may have changed since you were diagnosed with HIV?
   -What advice would you give to someone who has just discovered that he or she is HIV positive?
   -Is there anything that you might not have thought about before that occurred to you during this interview?
   -Is there anything else you think I should know to understand how your spiritual beliefs help you live with HIV?

8. Is there anything you would like to ask me?

Appendix B:

Field Notes- Observation Guide

Date:

Time:

Place:

Description of Field Site:

Who:

Description of overall flow of interview:

Key highlights:

Five main issues:

Describe any problems:

Did any new information, concepts, events emerge in today's interview:

Summarize any information you failed to get:

Clues: What struck you as being disturbing?

Summarize what needs follow-up and why:

Data Appraisal:

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