The Health Implications of Spirituality for Persons Living with HIV

By

Maxime Charest

Supervisors: Dr. William Morrow and Dr. Tracy J. Trothen

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Abstract

This essay explores the relationship between spirituality and health for persons living with HIV (PLWH). In

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Introduction

While it may not often be characterized as such, HIV could be defined as an existential illness. The virus affects an individual holistically, and has an impact on various aspects of their lives. Some of the most evident changes are biological: HIV impacts the immune system directly and can increase the chances of being diagnosed with a host of other conditions; HIV medications have multiple side effects, including some that can alter an individualÕs appearance; and HIV even has the ability to insert itself into a personÕs very DNA. Other changes are psychological: a person with HIV may experience changes in the way they perceive themselves and others; persons living with HIV (PLWH) often experience depression, anxiety, and various other mental health conditions in higher proportions than the general population; and medications also have side effects that can initiate or exacerbate some of these mental health conditions. Add to this the pervasive societal stigma of living with the illness, changes in relationships with family, friends, and partners, as well as the high costs of medication and difficulty with finding suitable employment that many PLWH experience, and few facets of a PLWHÕs life seem not to be impacted by this illness.

reviewed here are from the United States, as this is where the majority of research in this field is being conducted currently. Additionally, the relative availability of antiretroviral therapies (ARTs) means that most people who are diagnosed with HIV can treat it as a chronic illness, and few people these days have their illness progress to the point of AIDS. As such, research in recent decades has shifted from end-of-life care to a focus towards healthy living and aging with HIV, and this is the facet of the illness that is of interest for this essay.

An estimated 75,500 and 1.2 million people are currently living with HIV in Canada and the United States, respectively.[1] Since the introduction of ARTs in the 1990's, many PLWH are living longer and healthier lives; yet, the prevailing stigma surrounding the virus still have an impact on their mental and physical health. Fear of disclosure can leave an individual isolated and alone to cope with their illness, and many do not know who they can turn to for support following their diagnosis. One dimension of coping with HIV that has received increasing attention in the past 20 years has been the importance of spirituality for many individuals living with HIV. What the literature shows is that many people reflect on their spirituality following their diagnosis and, as with most other medical conditions, it seems as though spirituality and the health of PLWH are connected intimately. While there is growing evidence that spirituality is an important dimension of coping for many PLWH, most physicians have yet to fully incorporate the existential dimension of living with HIV in their care for this community.

This essay reviews some of the literature to date on the spirituality of PLWH. The emphasis will be on Christianity as the vast majority of research in this field to date has been conducted with reference to the Christian tradition. Chapter 1 focuses broadly on how individuals with HIV

[1] ÒHIV in the United States:.00003 12 575.9999 768 r6r Q n /Cs1 cs 0 0 will be on Chris cs 0 0(i) (

experience and define their spirituality. There is a wealth of literature that looks at HIV, spirituality and health, the various spiritual changes that individuals go through after an HIV diagnosis, as well as the impact that spirituality has on psychological and physiological health. In Chapter 2, I focus more specifically on one aspect of spiritual coping, namely PLWHÕs relationships with God. I use insights from the psychology of religion field and suggest that attachment theory may be a useful analytical framework to explore and analyze these

Chapter 1

Spirituality for Persons Living with HIV

Introduction

Recent decades have seen a proliferation of research on the intersection between health and spirituality. What seems evident from the wealth of accumulated knowledge in this field is that these two aspects of individualsÕ lives are often interwoven intricately. In the last two decades, since the introduction of ARTÕs in 1996, a growing number of PLWH are able to manage HIV as a chronic illness, and scholars have shifted their focus to living and aging well with the virus. Research has also begun to focus on the link between HIV and spirituality, and how this facet of PLWHÕs lives impacts and relates to their health. What the past 20 years of research tell us is that health and spirituality are also connected intimately for PLWH. Considering HIV can have an impact on so many aspects of an individualÕs life, such as their mental and physical health, finances, relationships, and identity, it only makes sense that it would also have an impact on their spirituality.

This chapter reviews some of the literature to date on HIV and spirituality. As the reality of living with HIV has changed drastically since the introduction of ARTs, only studies that were published since 1996 were included in this review. While it would be important to look at the wider context of religious communities and congregations and their responses to the HIV epidemic, this chapter focuses more specifically on the spirituality and spiritual changes of individuals diagnosed with HIV. I first discuss some of the difficulties with finding an adequate definition of spirituality as well as finding suitable measures to quantify this elusive construct. I then talk about the impact a diagnosis of HIV can have on an individual by exploring some of the spiritual changes PLWH go through following their diagnosis. Finally, I discuss the variety

of ways that PLWH cope with their illness spiritually, as well as how this relates to their mental and physical health. Considering the broad impact that this illness can have on an individual, I argue that it is important, if not necessary, to recognize the spirituality of PLWH.

Defining Spirituality

Scholars of religion have been attempting to find an adequate definition of religion and spirituality for well over a century. There are numerous schools of thought with different views concerning what is at the core of these two constructs. It would be impossible to perform an exhaustive exploration of the various ways that scholars have defined spirituality and religion historically and currently, even within the spirituality and health literature specifically. As such, this section will focus mainly on the writings of Harold G. Koenig and Kenneth I. Pargament, two of the leading experts in this field.

Koenig distinguishes between definitions of spirituality and religion for research versus clinical purposes. He argues that while clinical definitions must be very broad in order to reflect the variety of ways that people might define and experience their spirituality, research definitions

Koenig also discusses how, in the past, religion was a much broader concept, yet, in recent decades, there has been a movement towards viewing religion and spirituality as distinct phenomena.[4] So much so that some scholars have even begun to view anything to do with religion as institutionalized, dogmatic, closed, and negative, while spirituality is seen as individualized, flexible, open, and good.[5] This dichotomy, however, may bias scholars against more traditional forms of worship and faith, such as going to church, or may make us overlook the importance of faith communities for those who are spiritual. It can also make us forget that these constructs are not entirely distinct and that many individuals identify with either, neither, or both. In a study on long-term survivors and other PLWH, for example, half of the sample identified as spiritual but not religious, 33% identified as both, 8% as religious but not spiritual, and 10% as neither.[6] This demonstrates that these categories are not as rigid as some make them

provides sample items from some of the most widely used scales which seem to measure positive mental states and well-being rather than spirituality specifically.[8] The Spiritual Well-Being scale, for example, which has been used in a multitude of studies, has two subscales, Religious Well-B

capture a different aspect of spirituality, reducing spirituality to nothing more than these processes does not accord with current empirical evidence, and also risks alienating patients or clients if they do not feel that their worldview is being taken seriously.[13]

The two components of Pargament's definition of spirituality, the act of searching and the meaning of the sacred, are both equally important. This search implies an active component, as Pargament sees spirituality as more of a process or a pathway

reverence, or negative feelings such as fear, revulsion, and dread.[19] These strong emotions can ignite a passion for or incite individuals to prioritize the sacred in their lives. As Pargament explains, ÒPeople feel drawn to, experience a thirst for, or are even grasped by the sacred, and as a result they begin to invest more and more of themselves in sacred objects.Ó[20] The sacred can act as a kind of organizing force, and serve to integrate seemingly disparate and contradictory pieces of an individualÕs identity into a cohesive whole.[21] Not only that, but people also tend to invest more of their time and more of themselves into what they consider sacred. Sacred objects can also be used as a source of comfort and strength in times of need. ÒThus, upon discovery, the sacred becomes a resource that can be accessed through life.Ó[22] Hence, while it is true that almost anything in an individualÕs life has the potential to be sanctified, what is considered sacred is usually held onto dearly, is associated with strong emotions, and can often act as an organizing pattern around which people may build their lives.

In his discussions on spirituality and coping, Pargament also distinguishes between spiritual coping and spiritual struggles. In times of stress, individuals will often turn to their spirituality to help them cope with adverse life events.[23] Spiritual coping can take many forms and serve many functions. ÒSometimes people can find support when other forms of social support are hard to come by, ultimate explanations when the events of the world seem incomprehensible, and a sense of control when life seems out of control.Ó[24] Sometimes, however, life events can push individuals beyond their spiritual coping capacities, which is usually when they will experience spiritual struggles. Spiritual struggles, according to Pargament, Òrefer to

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[19] Kenneth I. Pargament, *Spiritually Integrated Psychotherapy*

tensions, questions, and conflicts centering on sacred matters.[25] In these cases, spirituality and spiritual coping methods may be transformed and integrated, often followed by a new period of spiritual conservation.[26] Some individuals, however, are unable to resolve these struggles, and choose to "disengage from the search for the sacred, temporarily or permanently".[27]

Throughout this essay, various terms are used such as the transcendent, the divine, a higher power, and God. These terms, while similar in some ways, are not entirely interchangeable. The transcendent can refer to an ultimate reality, gods and goddesses, or whatever lies beyond this world. The divine refers mainly to gods and goddesses, and more specifically God in monotheistic traditions, but many also believe that a piece of the divine is within all of us. A higher power or entity can refer to gods and goddesses, such as HaShem in Judaism, and also an all-encompassing entity, such as Brahman in Hinduism. For Christians, these terms refer most often to the Christian God, and so for the purposes of this essay, the transcendent, the divine, and a higher power/entity will be used to refer to the Christian God specifically.

Changes in Spirituality after HIV

An HIV diagnosis can be a traumatic event. People who are diagnosed with the virus will often reflect on their life, and for many, this also causes them to reflect on their spirituality. Many people who are diagnosed with HIV report changes in their spirituality following their diagnosis. These changes can be either positive or negative, although fortunately, for most, the news of an HIV diagnosis is an

also in their lives more generally[28]. However, there are a substantial minority of PLWH who experience spiritual struggles and negative spiritual changes after being diagnosed. These transformations in PLWHÕs spiritual lives are associated with psychological and physiological changes as well. This section explores changes in individualsÕ spirituality following an HIV diagnosis, as well as their associations with psychological and physiological outcomes.

A few studies have shown that many people report changes in their spirituality following an HIV diagnosis. For example, in a qualitative study with a sample of twenty PLWH, all of

For PLWH who report positive changes in their spirituality, this can have positive effects on both their mind and body. In one study, those who had reported a positive spiritual transformation after their diagnosis had a lower rate of viral replication and CD4 cell loss, as well as decreased symptomology and mortality risk.[35] Other benefits included less distress, more positive and active coping strategies, positive religious coping, and benefit finding. In another study, an increase on the Functional Assessment of Chronic Illness Therapy-Spirituality-Expanded (FACIT-SpEx)

often mention a period of spiritual struggle, particularly right after their diagnosis, which had forced them to re-evaluate their life, priorities, and spirituality.[40]

An HIV diagnosis can be more than a trigger for spiritual change, it can also bring larger changes in an individualÕs life. In one study, one quarter of participants reported that HIV was the key positive turning point in their life, leading to positive changes in their attitudes, behaviours, self-views, and spiritual beliefs.[41] Another eleven percent of those participants saw HIV as the key negative turning point in their lives, which was associated with negative changes in the same four categories. For most, the direction of this turning point was also associated with the direction of their change in spirituality (i.e., those who reported HIV as a key positive turning point had an increase in spirituality, while those who reported it as the key negative turning point had a decrease in spirituality). Once again, these changes were not entirely one dimensional, however; some of those who reported as HIV the key positive turning point also reported some negative spiritual changes, such as viewing God as more judgemental than they did before, and some of those who qualified it as their key negative turning point reported positive changes in their spirituality as a result of being diagnosed with HIV. Some of the factors that were associated with viewing HIV as a key positive turning point include isolation, hopelessness, loss of self-esteem and self-acceptance, or more simply, Òhitting rock bottomÓ before their diagnosis.[42]

In a follow-up study, Lutz, Kremer, and Ironson sought to explore further the experiences of those who had a positive spiritual transformation after their HIV diagnosis.[43]

sample of their initial sample and interviewed them about their experiences. One of their most interesting findings was that, unlike spiritual transformations following traditional spiritual experiences, the spiritual transformation triggered by HIV was not sudden, but rather gradual.[44] As in another study,[45] many participants described their spiritual transformation as a journey.[46] This fits well with PargamentÕs definition of spirituality as a search for the sacred, which implies an active component in the way individuals experience their spirituality.[47] Lutz, Kremer, and Ironson also described what they termed this as Òthird *of care taking*Ó

Various Ways of Coping with HIV Spiritually

In terms of the third theme, almost all participants believed that God was benevolent and had nothing but a positive

chapter, I turn my attention more specifically to PLWHÕs relationships with God, and offer attachment theory as a useful analytical framework to explore these relationships.

Chapter 2

Attachment Theory, Relationship with God, and HIV

relevant to the topic. A more exhaustive and systematic review of the literature would be warranted, but is beyond the scope of this portal. I argue that attachment theory is a useful analytical framework to look at this dimension of spiritual coping for PLWH.

Crash Course on Attachment Theory

John Bowlby and Mary D. Salter Ainsworth jointly developed attachment theory beginning in the 1950Õs.[76]

relationship can be characterized as an attachment, everyone generally has a few people in their lives with whom they form an attachment bond. The style that an infant initially develops with its caregiver is not immutable, and to a certain extent can change throughout the lifetime based on contextual and environmental factors, as well as events such as accidents or illness.[82]

It is important to highlight the dyadic and dynamic aspect of this relationship. In an attachment bond, both partners are active in the maintenance of proximity to reduce anxiety felt by separation or traumatic events. Neither mother nor infant holds the sole responsibility of sustaining an attachment relationship. Attachment style can be influenced both by perceptions of the self, as well as perceptions of others. Someone with an insecure attachment style can hold a negative model of the self but positive model of others, a negative model of others but positive model of self, or a negative model for both.[83] For many people diagnosed with HIV, who may be unsure who they can turn to for support, a relationship with God may provide the security and safety that the distress of their diagnosis makes them crave. In the next section of this chapter, I explore the complex relationship between attachment theory and individualsÕ relationships with God.

God: The Ideal Attachment Figure

David A. Bosworth stated that, Òpsychologists of religion appear to agree that God is not *like* an attachment figure, God is an attachment figure,Ó and Òthe relationship with God is an attachment relationship.Ó[84] Beginning with the work of Lee A. Kirkpatrick and Phillip R. Shaver

[82] Bowlby, *Attachment and Loss*, 348.
[83] Bartholomew and Horowitz, ÒAttachment: Four Category Model,Ó 227.
[84] David A. Bosworth, ÒAncient Prayers and the Psychology of Religion: Deities as Parental Figures,Ó *Journal of Biblical Literature* 134, no. 4 (2015): 684.

in 1990,[85] various scholars have looked at the development of this relationship across the lifespan, the complex interaction between attachment style and attachment to God, and their

religion in adulthood. The literature also shows that adults reporting an insecure parental attachment in their childhood experience more dramatic religious conversions and spiritual changes, and more positive changes in their relationship with God, as compared to those with a secure attachment.[90]

One of the important functions of attachment relationships is that people will seek proximity to attachment figures in times of need. Although ÒOne cannot be physically proximal to God in the same way as to other persons,Ó Kirkpatrick argues that, in adulthood, psychological proximity or availability becomes more important than actual physical closeness.[91] [92] Additionally, Christianity often emphasizes the omnipresent character of God, which believers can turn to for comfort and strength.[93] Individuals often turn to God in times of distress, including when faced with illness or death. A look at scripture also reveals that believers often seek proximity to the deity in times of need.[94]

Scholars have found that a secure attachment to God can mitigate some of the effects of stressors in an individualÕs life, while an insecure attachment to God can exacerbate distress as a response to stressful life events.[95] Cassibba et al. found that a secure attachment to God is linked to increased use of religious coping mechanisms, such as prayer, as well as secular coping strategies, such as a fighting spirit. They noted that individuals often turn to a Òromantic partner and/or God to receive support when they feel threatened.Ó[96] A secure attachment to God has been linked to various psychological benefits such as lower depression and anxiety, as well as

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[90] Ibid., 129-131; Kirkpatrick, ÒGod as Substitute AttachmentÓ: 967.
[91] Ibid., 56-57.
[92] Ibid., 57.
[93] Ibid., 58.
[94] Bosworth, ÒDeities as Parental FiguresÓ: 686
[95] Christopher G. Ellison et al., ÒAttachment to God, Stressful Life Events, and Changes in Psychological Distress,Ó *Review of Religious Research* 53, no. 4 (2012): 503.
[96] Rosalinda Cassibba et al., ÒThe Role of Attachment to God in Secular and Religious/Spiritual Ways of Coping with a Serious Disease,Ó *Mental Health, Religion & Culture* 17, no. 3 (2014): 257

increased hope and positive coping.[97] An insecure attachment to God, conversely, is related to increased distress, including depression, anxiety, and negative coping. While all of these studies demonstrate the importance of attachment to God for physical and mental health, this insight has yet to be incorporated in the HIV and spirituality literature. As I show in the next section, attachment theory could complement and enrich research that looks at the implications of a relationship with God for individuals who have been diagnosed with HIV.

HIV, God, and Attachment Theory

A few scholars have explored the direct relationship between HIV and attachment style, which has shown that attachment may be related to various indicators of psychological and physiological health. As discussed in the previous chapter, the relationship between HIV and spirituality has been investigated more extensively, and there is ample evidence to show that spirituality is an important dimension of coping for PLWH. Recent evidence suggests that a relationship with God may be one of the most important aspects of many PLWHÕs spirituality. While the spirituality of PLWH can be characterized as a relationship to self, others, and the divine, scholars in the field have yet to apply an attachment theory framework to their analyses. Attachment theory could provide rich empirical insights into the connection between the experience of HIV and relationship with God for PLWH.

There have been few investigations on the direct association between attachment theory and HIV. The literature suggests that a secure attachment style, as compared to an insecure one, relates to better psychosocial functioning for this population. PLWH reporting higher perceived stress are more likely to have an anxious attachment style, and to use behavioural and emotional

[97] Ibid.

disengagement to cope with their illness[98]

general studies, as will be shown below, have hinted at the importance of a relationship with God for this population.

In the last 20 years, since the advent of ART in 1996, numerous studies have looked at the spirituality of PLWH, yet few have explored relationship with God directly. A few studies, however, suggest that this might be one of the most important dimensions of spirituality for many people in this population. For example, in a study on end-of-life decisions for PLWH, nearly all participants believed in God and His forgiveness, and 84% indicated that they had a personal relationship with Him.[101] While almost half of participants believed that God sometimes punishes them, only one fifth expressed that their illness was a punishment from God. In another study on spirituality and well-being, more than half of the participants disagreed strongly that their HIV was a result of divine retribution or caused by their sinful behaviours, and three quarters believed that a higher power cared for them.[102] These findings suggest that many PLWH who are spiritual often see God as being involved directly in their health.

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and so attribute this negative life event to the work of the Devil. One possibility could be that those who felt that God may have abandoned them could have had an insecure attachment to the divine.

Many PLWH incorporate their spirituality in their decision to take their medication. While this can be positive for some, such as those who believe that not taking their medication is a sin, it can become harmful when people forego taking their medication and leave their illness in the hands of God.[105] A minority of PLWH feel that their illness has made them more alienated from their religious group.[106] For these people, fostering a personal connection with God may be particularly beneficial. As Lutz, Kremer and Ironson state, many PLWH may still attend services and participate in their Church community, but their individualized spirituality and personal connection with the divine are seen as more important than their institutional involvement.[107] Foster et al. found that some of the spiritual practices used by PLWH are praying nightly, Òconsistently acknowledging GodÕs presence in their lives,Ó[108] and Òturning to God for guidance and strength during challenging times.Ó[109] All of these, which reflect a more individualized spirituality,

the spirituality of PLWH.[110] Three main themes emerged from their interviews, one of which was pursuing a more intimate relationship with God or a higher power. Even though, as we have seen, a relationship with God is considered to be an attachment relationship, these scholars did not use attachment theory to enrich their analysis. This study shows that the spirituality of PLWH can be characterized as a relationship not only with the divine, but also with the self and others, and so could be complemented with insights from attachment theory.

Two other studies that were discussed in more detail in the first chapter provide support for the importance of a relationship with God for many PLWH. The first is Ironson et al.Õs study that showed how a PLWHÕs view of God as benevolent and forgiving or judgemental and punishing could impact their psychological and physiological health. This study is important because it was conducted longitudinally on a sample of 100 PLWH with diverse demographic factors. These scholarsÕ results also remained significant even after controlling for a variety of potentially confounding variables. The second is Lutz, Kremer and IronsonÕs qualitative study on thirteen PLWH who had undergone a positive spiritual transformation. Participants reported that an important feature of this transformation was the development of an individualized sense of spirituality, and for twelve of the participants, this was centered on an Òindividualized connectedness with a higher presence/entity.Ó[111] The findings from these two studies, which highlight the importance of a relationship with God for PLWH, may have been strengthened with insights from attachment theory.

Taken together, these results suggest that a secure attachment to God is related to many spiritual, psychological, and physiological benefits for PLWH, while an insecure attachment is associated with poorer health outcomes. A secure attachment style has also been associated with

[110] Nalini Tarakeshwar, Nadia Kahn

whether the latter results in the former, or whether other variables might mediate this relationship.

It is important to look at factors that stimulate a secure relationship with God. It seems as though an HIV diagnosis is usually followed by positive changes in spirituality. There is a paucity of literature, however, looking at the effects of spiritual struggle and an insecure attachment to God on PLWHÕs health. This could be due to scholars finding the positive relationship more interesting, or perhaps PLWH who are struggling spiritually are reluctant to participate in research studies. Whatever the case may be, future research should make sure not to overlook this important dimension, as it is associated with more rapid disease progression and other negative health outcomes. It is incredible that many PLWH manage to grow spiritually and find a more positive and fulfilling connection with God as a result of their diagnosis. Focusing too much on these positive aspects, however, can make us forget those who may be struggling the most to cope with their illness.

I would encourage researchers who work in the field of HIV and spirituality to start looking at PLWHÕs relationship with God as an attachment relationship. For those in the field of religious studies, PLWH can provide insight because of their struggle with existential questions concerning meaning, purpose and death. For those in the field of HIV and spirituality, attachment theory can provide a useful framework not only to look at a personÕs relationship with God, but also relationships with friends, family, and romantic partners. Attachment theory could provide rich empirical insights, and with its grounding in evolutionary biology and ethology, this theory might be taken more seriously by those in more biomedical fields. In the next chapter, I turn to physiciansÕ incorporation of spirituality in patient care in the context of

Chapter 3

Spirituality in HIV Health Care

Introduction

While there has been a proliferation of research on spirituality and health in recent

Considering the multifaceted nature of the virus, PLWH will most likely see a variety of health professionals; their health care team could include physicians, nurses, pharmacists, mental health professionals, physiotherapists, social workers, and others. Their primary health professional, however, will often be a physician they see every three to six months who ensures their treatment is working. In order to provide PLWH the best care, their spiritual needs would need to be assessed and addressed somewhere along this spectrum of care. The one best suited to take a spiritual assessment may be the physician who follows them regularly, who could make an assessment and refer them to a spiritual care provider knowledgeable about HIV.

In *Spirituality in Patient Care: Why, How, When, and What*, Koenig addresses why, how, and when health professionals should include spirituality in patient care, as well as what they can expect from including it.[118] Koenig states that it is most important to take a spiritual history when ÒÒa serious acute or chronic medical illness is threatening life or quality of life, [or] when a major psychosocial stressor is present that involves loss or change,ÓÓ[119] conditions that often occur after an HIV diagnosis. According to Koenig, there are relatively few negative consequences to spiritual history taking as long as it is done in a respectful, patient-centered, and gentle manner.[120] He suggests that physicians should do no more than assess the patientÕs needs, and then refer them to a spiritual care provider if the patientsÕ needs are complex.[121] In the case of HIV, it might be beneficial to patients to ask them if they would like to have their spiritual needs assessed at routine visits, unless the patient objects to it.

According to the articles that could be found through PubMed and ATLA databases, the majority of health professionals agree that assessing their patientsÕ spiritual needs is within their

[118] Harold G. Koenig, *Spirituality in Patient Care: Why, How, When, and What*, 3rd ed., (West Conshohocken: Templeton Press, 2013).
[119] Ibid., 95.
[120]

mandate as well as an important aspect of health care.[122] However, physicians in particular cite numerous barriers and challenges to taking spiritual histories and addressing spirituality with their patients. These can include the administration (e.g., working in a government setting),[123] a difference between their level of spirituality and their patientsÕ or a discordance in faiths, difficulty with boundaries (e.g., could make the patient uncomfortable, health professionals being uncomfortable with their own spirituality, fear of proselytizing), their own prejudices with regards to religion or spirituality, and competence. Undertaking spiritual assessments will require particular expertise.[124] The most important of these are

aware of their religious or spiritual beliefs, particularly if they were to experience a more severe illness.[128]

While many physicians would prefer referring patients to spiritual care providers rather than discussing spirituality with their patients themselves, these referrals may be infrequent; Best, Butow and Olver, in their recent systematic review of 61 studies focusing on physicians discussing religion and spirituality with their patients, found that physiciansÕ rates of referrals to spiritual care providers ranged from 5-42%.[129] This may be due, in part, to deficiencies in communication with spiritual care providers, a lack of availability, and a lack of effective structures and policies in place to access spiritual care services.[130] Some of the facilitating factors for incorporating spirituality in patient care cited by physicians are the primacy of spirituality in physicians or the patientsÕ lives, the setting (e.g., visiting at home versus office), respect, patience and openness.[131] What appears to be the most important factor is for the patient to be

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aromatherapy, colour therapy, and juicing.[132] This undermines the vast body of knowledge on spirituality and health that has been growing for the past 20 years, as well as the overarching framework that spirituality can provide for an individualÕs life. A website such as CATIE, which provides information concerning all facets of living with HIV, could be an excellent resource for physicians to learn about the spirituality of PLWH, as well as provide information on how to take a spiritual history, or a list of spiritual care providers who are trained to work with PLWH.

Additionally, the guidelines from the Public Health Agency of Canada on diagnosis counselling and follow-up visits for PLWH focus solely on biomedical and legal issues, reducing individuals to a set of symptoms and risk factors.[133] Public HealthÕs guide on complementary and alternative health also makes no mention of religion or spirituality, other than naming specific practices such as Aboriginal healing, Reiki, and yoga.[134] Those in charge of researching and designing interventions and treatment strategies need to start recognizing that health is more than biomedical factors, and that, for many, religion or spirituality serves as an orientation that guides individualsÕ choices and behaviours.[135] This is particularly important in the context of HIV, which can have an impact on various aspects of an individualÕs life, including their mental and physical health,[136] social support system,[137] and self-concept.[138] Treatment and prevention of

[132] Lori

HIV may be ameliorated if we were to start viewing PLWH as an integrated whole, rather than as a virus affecting an individual body.

Few investigations were found through the PubMed and ATLA databases on the incorporation of spirituality in patient care for PLWH. In one study of patients with HIV and their providers, Fredericksen et al. found that physicians ranked spirituality as the least important domain to be addressed in clinical care, while patients rated this domain significantly higher.[139] Additionally, there was an even greater discrepancy between patients who had been diagnosed more recently and their providers,[140] which coincides with the time many PLWH report changes in their spirituality.[141] According to this study, there seems to be a disconnect between the evidence supporting the importance of spirituality in health care, and providersÕ attitudes towards this dimension of health for this population. This could be harmful for PLWH whose spirituality is an integral part of their well-being, and particularly for those who are struggling spiritually but do not know who they can turn to for help.

Only one study was found that looked at whether or not physicians incorporate spirituality in their care of PLWH in practice. This study, which was conducted on adolescents, found that approximately 15% of HIV+ patients had been asked by their physician about their spiritual beliefs, and 30% had ever shared their spiritual beliefs with their providers.[142] The majority of participants endorsed that they wanted their physician to know about their spiritual

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[139] Rob J. Fredericksen et al., ÒPatient and Provider Priorities for Self-Reported Domains of HIV Clinical Care,Ó *AIDS Care* 27, no. 10 (2015): 1257-1258.

[140] Fredericksen, *“Patient and Provider Priorities”*: 1257.

[141] Gail Ironson, Rick Stuetzle, and Mary Ann Fletcher, ÒAn Increase in Religiousness/Spitiuality Occurs After HI 1 (t) 5

beliefs so they could understand them and how they make medical decisions in this study. This study, combined with FredericksenÕs findings, in which providers considered spirituality to be the least

AIDS Society (CAS) put forward another document outlining how faith communities and faith-based organizations can help in the fight against HIV/AIDS and in the spiritual care of PLWH in Canada. In it, they offered sample guidelines for the spiritual care of PLWH, which were based on the guidebook published by the Statewide HIV/AIDS Church Outreach Advisory Board in 2004.[146] Many of these guidelines, however, seem more focused on protecting the spiritual care provider rather than focusing on the unique challenges and spiritual needs of PLWH. Additionally, no evidence could be found as to whether these guidelines have been expanded since, or whether spiritual care providers have been implementing them in practice. It is a great step that organizations such as CAS are beginning to recognize the importance of working with faith-based organizations for HIV prevention and to care for PLWH, but we also need to ensure that these documents and words turn into action.

One way to expand the HIV health care team would be to create a continuous dialogue between the medical and faith communities. The response from religious congregations concerning HIV/ADS, however, can be variable.[147] Some congregations will be much more accepting and involved with HIV/AIDS work while others may paint a more negative and stigmatizing picture of PLWH and the meaning of the illness. Those congregations that see HIV as a punishment from God or paint PLWH as sinners are typically the ones least involved in HIV/AIDS activism and charity work.[148] Some may even hold stigmatizing views concerning HIV and homosexuality, yet still participate in HIV/AIDS activism and ministry.[149]

with working with PLWH before referring patients to them. This is where dialogue between scientific and faith communities can also help, by transmitting knowledge to those faith communities that may be less accepting of PLWH.

PLWH will see a variety of health professionals throughout the course of their illness. Each of these providers will be trained and equipped to deal with a different facet of the multidimensional health needs of this population. So far, the spirituality of PLWH has been somewhat sidelined, and HIV has been treated mainly as a biopsychosocial issue. The HIV health care team needs to be expanded to include spiritual care providers as well as faith communities, to help reduce stigma, increase prevention, and provide PLWH with truly holistic, patient-centred care. For some, the consequences of ignoring the spiritual dimension of HIV can be devastating. The benefits of positive spiritual coping in PLWH are also too great to be ignored. Research and practice in the field of HIV need to start further recognizing and integrating this dimension of care.

Spirituality in Canada and the United States

The majority of research on physiciansÕ incorporation of spirituality in patient care has been conducted in the United States. In their recent systematic review of the literature, Best, Butow, and Olver found that 41 out of the 61 studies they reviewed were conducted in the United States, with the remainder coming from nine other countries, one of which was Canada.[150] There are some differences, however, in the religious and spiritual landscapes between Canada and the United States. In the last National Household Survey (NHS) where

[150] Best, Butow, and Olver, ÒDoctors Discussing ReligionÓ: 329.

religious affiliation was identified, 76% of Canadians declared a religious affiliation.[151] The

diagnosed for longer as well. Results from EricksenÕs study suggest that newly diagnosed PLWH felt it was more important for their providers to address their spiritual needs than those who had been diagnosed for longer.[155] The most dramatic changes and transformations in PLWHÕs spirituality also se

Conclusion

Health care communities have recently begun to move towards more holistic, patient-centred care. For few populations is collaboration among health care providers more necessary than for PLWH, who may have various health needs that extend beyond simply biomedical issues. According to the literature that could be found, many physicians still seem reluctant to incorporate spirituality into their patient care. HIV health care teams might benefit from extending to include spiritual care providers and faith communities. Further dialogue between medical and faith communities could benefit PLWH, many of whom undergo spiritual changes

who are experiencing spiritual struggles or who are using negative spiritual coping strategies. While it is wonderful that the majority of PLWH seem to find ways to frame their illness positively and to use positive spiritual coping methods, a substantial minority of this population is not as fortunate and this can have a negative impact on their psychological and physiological health. It would be important to elucidate why some people primarily use negative spiritual coping strategies, as well as how we can help them cope more positively.

As I said before, HIV is an existential illness; it has an impact on an individual in their entirety. Few facets of a PLWHÕs life are left unaffected by this illness. Given that many people use spirituality to orient their lives more generally, it only makes sense that this aspect of themselves would undergo changes following a diagnosis of HIV. While there is an abundance of research linking spirituality and health, and the connections between HIV and spirituality are becoming increasingly apparent as well, health care providers have yet to fully integrate this aspect of coping in their care of PLWH. The medical community, as well as agencies such as Public Health, need to start recognizing this dimension of coping and take it more seriously. For some PLWH, this might enable them to qualm their spiritual struggles and find more positive ways of coping with their illness. For others, this might simply reinforce their positive beliefs and spiritual coping strategies. What is certain, however, is that taking this aspect of health and coping more seriously could be beneficial to those in the HIV community.

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