

The Health Implications of Spirituality for Persons Living with HIV

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## Abstract

This essay explores the relationship between spirituality and health for persons living with HIV (PLWH). In the last twenty years, since the advent of antiretroviral therapy, scholars have turned their focus to healthy living and aging with HIV. A growing literature is showing that there are various links between spirituality and health for this population. In the first chapter, I look at some of this literature and discuss various spiritual changes PLWH can undergo after their diagnosis, and the variety of ways they cope spiritually with their illness. In the second chapter, I propose that attachment theory could be a useful analytical framework for scholars to study PLWH's relationships with God. In the last chapter, I look at physicians' incorporation of spirituality in health care, and suggest some avenues for future research, particularly in the Canadian context, where research is currently lacking. I argue that, given the various links between spirituality and psychological and physical health for PLWH, the spiritual dimension of coping with HIV should not be ignored.

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## Table of Contents

Abstract .....	i
Acknowledgements .....	ii
<b>Introduction .....</b>	<b>1</b>
<b>Chapter 1: Spirituality for Persons Living with HIV .....</b>	<b>4</b>
Defining Spirituality .....	5
Changes in Spirituality after HIV .....	10
Various Ways of Coping with HIV Spirituality .....	16
<b>Chapter 2: Attachment Theory, Relationship with God, and HIV .....</b>	<b>21</b>
Crash Course on Attachment Theory .....	22
God: The Ideal Attachment Figure .....	23
HIV, God, and Attachment Theory .....	26
<b>Chapter 3: Spirituality in HIV Healthcare .....</b>	<b>33</b>
Physicians and Spirituality .....	34
Expanding the HIV Health Care Team .....	40
Spirituality in Canada and the United States .....	43
Lack of Research in Canada .....	45
<b>Conclusion .....</b>	<b>48</b>
Bibliography .....	50

## **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 individual's appearance; and HIV even has the ability to insert itself into a person's 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 PLWH's life seem not to be impacted by this illness.

The experience and reality of HIV vary significantly across various demographic factors, such as age, sex, sexual orientation, and ethnicity. Certain communities, such as men who have sex with men (MSM), injection drug users, and people of colour are affected disproportionately by the epidemic, and each of these populations has different characteristics that impact the way they experience their illness. The reality of HIV also varies considerably by geographic location; HIV in North America is now considered a chronic illness, while the same diagnosis in Sub-Saharan Africa is often still considered a death sentence. For this reason, this essay focuses specifically on the reality of HIV for individuals living in North America. Most of the studies

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.<sup>1</sup> Since the introduction of ARTs in the 1990's, many PLWH are living longer and healthier lives, yet the prevailing stigma surrounding the virus can still have an impact on their mental and physical health. Fears 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 has been conducted with reference to the Christian tradition. Chapter 1 focuses broadly on how individuals with HIV

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<sup>1</sup> "HIV in the United States: *At a Glance*." Centers for Disease Control and Prevention. Accessed July 20, 2016, <http://www.cdc.gov/hiv/statistics/overview/ataglance.html>; Public Health Agency of Canada, *Summary: Estimates of HIV Incidence, Prevalence and Proportion Undiagnosed in Canada, 2014* (Ottawa: Public Health Agency of Canada, 2015).

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 their psychological and physiological health. In Chapter 2, I focus more specifically on one aspect of spiritual coping, namely PLWH's 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 relationships. Finally, in Chapter 3, I review the literature to date on the incorporation of spirituality in patient care. I argue that there is a paucity of research on physicians' inclusion of spirituality in their care of PLWH, particularly in Canada, and that the medical community needs to take this aspect of coping with HIV more seriously. This essay, therefore, will highlight some of the important work that has been done in the field of HIV and spirituality, as well as identify some of the gaps in this research and offer avenues for future inquiry.

## **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 individuals' lives are often interwoven intricately. In the last two decades, since the introduction of ART's in 1996, a growing number of PLWH are able to manage HIV as a chronic illness, and scholars have shifted their focus towards 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 PLWH's 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 individual's life, such as their mental and physical health, finances, relationships, and identity, it only makes sense that it could 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 must be more rigid in order for them to be truly quantifiable.<sup>2</sup> While he leaves his clinical definition of spirituality quite open, he uses what he terms a more traditional definition of spirituality for research purposes, defining those who are spiritual simply as those who are deeply religious.<sup>3</sup> The issue with this definition, however, is that although it does allow for ease of measure, it is not necessarily able to capture the wide breadth of beliefs, practices, and various other facets that individuals might include in their own definitions of spirituality.

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<sup>2</sup> Harold G. Koenig, *Spirituality and Health Research: Methods, Measurements, Statistics, and Resources* (West Conshohocken: Templeton Press, 2011), 194.

<sup>3</sup> Ibid., 196.

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.<sup>4</sup> 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.<sup>5</sup> 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.<sup>6</sup> This demonstrates that these categories are not as rigid as some make them out to be, and can both contribute to an individual's identity.

Another difficulty in the field of spirituality and health, and by extension spirituality and HIV, is not only the variety of definitions of religion and spirituality that exist, but also the array of measures that are used to quantify both of these constructs. In the literature on spirituality and HIV, around ten different scales of religion and spirituality are used routinely, and some of these may actually capture similar aspects of religion and spirituality.<sup>7</sup> Koenig warns that the issue with all of these scales is not only their possible overlap among each other, but also their potential overlap with other constructs that measure well-being and positive states of mind. He

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<sup>4</sup> Ibid.

<sup>5</sup> Kenneth I. Pargament, "Searching for the Sacred: Towards a Nonreductionist Theory of Spirituality," in *APA Handbook of Psychology, Religion, and Spirituality: Vol. 1, Context, Theory, and Research*, ed. Kenneth I. Pargament, Julie J. Exline and James Williams Jones (Washington: American Psychological Association, 2013), 266-267.

<sup>6</sup> Gail Ironson et al. "The Ironson-Woods Spirituality/Religiousness Index Is Associated With Long Survival, Health Behaviors, Less Distress, and Low Cortisol in People with HIV/AIDS." *Annals of Behavioral Medicine* 24, no. 1 (2002): 37.

<sup>7</sup> Koenig, *Spirituality and Health Research*, 198.

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.<sup>8</sup> The Spiritual Well-Being scale, for example, which has been used in a multitude of studies, has two subscales, Religious Well-Being and Existential Well-Being. The latter is considered to measure spirituality in the modern sense of the word, yet most of the items seem to measure general mental well-being rather than spiritual well-being specifically.<sup>9</sup> This contamination, as Koenig calls it, can be troublesome, particularly when the goal of the study is to determine how spirituality relates to mental health. If a spirituality scale itself measures general well-being rather than a clearly distinct spirituality construct, then the proposed relationships between these measures may be stronger than they would be in reality.<sup>10</sup>

These issues notwithstanding, it is necessary to offer a definition of spirituality and religion for the purposes of this essay. While religion will be touched upon, and as such a definition is provided, the focus will be much more centered around the concept of spirituality. The definitions that seem most pertinent to this discussion are those of Kenneth I. Pargament, one of the leading researchers in the psychology of religion. Pargament defines spirituality as the “search for the sacred,”<sup>11</sup> and religion as “a search for significance in ways related to the sacred.”<sup>12</sup> This definition of spirituality is fairly broad as there are so many ways that individuals define and experience the sacred. Pargament argues for a nonreductionist approach to defining and working with spirituality. While he acknowledges that definitions coming from purely sociological, psychological, or evolutionary perspectives have their place, and each of them may

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<sup>8</sup> Ibid., 198-201.

<sup>9</sup> Ibid., 201.

<sup>10</sup> Ibid., 202.

<sup>11</sup> Kenneth I. Pargament, “The Psychology of Religion and Spirituality? Yes and No.” *The International Journal for the Psychology of Religion* 9, no. 1 (1999): 12.

<sup>12</sup> Kenneth I. Pargament, *The Psychology of Religion and Coping: Theory, Research, and Practice*, (New York: The Guilford Press, 1997), 32.

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

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 than a static entity.<sup>14</sup> The three main processes he identifies are discovery, conservation, and transformation.<sup>15</sup> Individuals will look for and incorporate what holds sacred meaning for them in their own lives; they will work to conserve these pathways to the sacred once they have found something suitable for them; and these pathways may change as their circumstances change as well. He notes that traumatic events in particular will often incite those who are spiritual to find new ways to integrate the sacred in their lives, or to abandon that which is sacred altogether.<sup>16</sup> Pargament's definition of the sacred is kept purposely broad, so as to encompass not only God, but also other beliefs, practices, rituals, and whichever other concept or object a person chooses to sanctify.<sup>17</sup> As he states, "virtually any aspect of life can be perceived as sacred."<sup>18</sup> While this may seem like the easy way out, it is especially fitting for PLWH, as this community is so diverse that individuals find myriad ways to cope with their illness spirituality.

Conversely, while almost anything in an individual's life has the potential to be sanctified, not everything will be. Firstly, as Pargament highlights, it is important to note that the sacred is most often accompanied with strong feelings and emotions, such as awe, gratitude, and

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<sup>13</sup> Pargament, "Nonreductionist Theory of Spirituality", 258.

<sup>14</sup> Ibid., 260.

<sup>15</sup> Ibid., 260-266.

<sup>16</sup> Ibid., 277.

<sup>17</sup> Pargament, "Religion and Spirituality?": 12-13.

<sup>18</sup> Pargament, "Irreducible Human Motivation": 271.

reverence, or negative feelings such as fear, revulsion, and dread.<sup>19</sup> These strong emotions can ignite a passion for or incite individuals to prioritize the sacred in their lives. As Pargament explains, “people 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 pursuits.”<sup>20</sup> The sacred can act as a kind of organizing force, and serve to integrate seemingly disparate or contradictory pieces of an individual’s identity into a cohesive whole.<sup>21</sup> 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; “upon discovery, the sacred becomes a resource that can be accessed through life.”<sup>22</sup> Hence, while it is true that almost anything in an individual’s 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.<sup>23</sup> Spiritual coping can take many forms and serve many functions: sometimes “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.”<sup>24</sup> 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, “refer to

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<sup>19</sup> Kenneth I. Pargament, *Spiritually Integrated Psychotherapy*, (New York: The Guilford Press, 2007), 71-73.

<sup>20</sup> Ibid., 73.

<sup>21</sup> Ibid.

<sup>22</sup> Ibid., 75.

<sup>23</sup> Pargament, “Nonreductionist Theory of Spirituality,” 264.

<sup>24</sup> Ibid.

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

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 can incite a positive transformation not only in their spirituality, but

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<sup>25</sup> Ibid.

<sup>26</sup> Ibid., 264-266.

<sup>27</sup> Ibid., 265.

also in their lives more generally<sup>28</sup>. However, there are a substantial minority of PLWH who experience spiritual struggles and negative spiritual changes after being diagnosed. These transformations in PLWH's spiritual lives are associated with psychological and physiological changes as well. This section explores changes in individuals' 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 them reported that they had reflected on their spirituality after their diagnosis, and eighteen had undergone what they interpreted as a spiritual experience.<sup>29</sup> The percentages of PLWH reporting changes in their spirituality following their diagnosis seem fairly consistent. Cotton et al., for example, found that 41% of their sample had become more spiritual following their diagnosis, 10% less, and 40% were as spiritual as they were before;<sup>30</sup> these same numbers in Ironson, Stuetzle, and Fletcher's study were 45%, 13%, and 42%, respectively,<sup>31</sup> and in yet another study, these numbers were 37%, 10%, and 53%, respectively.<sup>32</sup> In a study on older adults living with HIV,<sup>33</sup> 74% indicated that their spirituality had changed after being diagnosed, and nearly half felt as though their illness was a blessing.<sup>34</sup> A diagnosis of HIV seems to incite many people to reflect on their spirituality, and this often results in actual changes to their spiritual lives.

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<sup>28</sup> Heidemarie Kremer, Gail Ironson, and Lauren Kaplan. "The Fork in the Road: HIV as a Potential Positive Turning Point and the Role of Spirituality." *AIDS Care* 21, no. 3 (2009): 371-373.

<sup>29</sup> Nalini Tarakeshwar, Nadia Khan, and Kathleen J. Sikkema, "A Relationship-Based Framework of Spirituality for Individuals with HIV," *AIDS and Behavior* 10, no. 1 (2006): 63.

<sup>30</sup> Sian Cotton, et al., "Changes in Religiousness and Spirituality Attributed to HIV/AIDS," *Journal of General Internal Medicine* 21 (2006): S17.

<sup>31</sup> Gail Ironson, Rick Stuetzle, and Mary Ann Fletcher, "An Increase in Religiousness/Spirituality Occurs After HIV Diagnosis and Predicts Slower Disease Progression over 4 Years in People with HIV." *Journal of General Internal Medicine* 21 (2006): S64.

<sup>32</sup> Kremer, Ironson, and Kaplan. "Fork in the Road": 371.

<sup>33</sup> In HIV research, older adults are considered to be 50 years and over.

<sup>34</sup> David E. Vance, "Spirituality of Living and Aging with HIV: A Pilot Study," *Journal of Religion, Spirituality & Aging* 19, no. 1 (2006): 69.

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.<sup>35</sup> 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), which measures meaning, peace, and faith in an individual's life, was associated with an increase in life satisfaction, social support, and self-esteem, as well as a decreased likelihood of presenting with significant symptoms of depression.<sup>36</sup> An increase in spirituality has also been linked to more optimism and less hopelessness.<sup>37</sup> Evidently, a positive change in spirituality after being diagnosed with HIV can be associated with various health benefits.

On the other hand, while a diagnosis of HIV can incite positive changes in spirituality, for some this can provoke a spiritual struggle, or make them become less spiritual than they were before they were diagnosed.<sup>38</sup> In Ironson et al.'s study, for example, those who reported becoming less spiritual after their diagnosis lost CD4 cells almost five times faster than those who reported an increase in their spirituality.<sup>39</sup> Those who became less spiritual also had an increase in their viral load, while the opposite happened for those who became more spiritual following their diagnosis. Even those who report a positive change in their spirituality overall

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<sup>35</sup> Gail Ironson and Heidemarie Kremer, "Spiritual Transformation, Psychological Well-Being, Health, and Survival in People with HIV," *International Journal of Psychiatry in Medicine* 39, no. 3 (2009): 269.

<sup>36</sup> Sian Cotton et al., "Spirituality and Religion in Patients with HIV/AIDS," *Journal of General Internal Medicine* 21 (2006): S10.

<sup>37</sup> Ironson, Stuetzle, and Fletcher, "Increase in Religiousness/Spirituality": S65.

<sup>38</sup> Cotton et al., "Changes in Religiousness": S17; Ironson, Stuetzle, and Fletcher, "Increase in Religiousness/Spirituality": S64.

<sup>39</sup> Ironson, Stuetzle, and Fletcher, "Increase in Religiousness/Spirituality": S65.

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

An HIV diagnosis can be more than a trigger for spiritual change, it can also bring larger changes in an individual's 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.<sup>41</sup> 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 the 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 HIV as 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 were isolation, hopelessness, loss of self-esteem and self-acceptance, or more simply, "hitting rock bottom" before their diagnosis.<sup>42</sup>

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.<sup>43</sup> They used a sub-

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<sup>40</sup> Tarakeshwar, Khan and Sikkema, "Relationship-Based Framework of Spirituality": 64; David E. Vance and Robert A. Woodley, "Spiritual Expressions of Coping in Adults with HIV: Implications for Successful Aging," *Journal of Religion, Disability & Health* 12, no. 1 (2008): 44-45.

<sup>41</sup> Kremer, Ironson, and Kaplan, "Fork in the Road": 370.

<sup>42</sup> *Ibid.*, 374.

<sup>43</sup> Franz Lutz, Heidemarie Kremer, and Gail Ironson, "Being Diagnosed with HIV as a Trigger for Spiritual Transformation," *Religions* 2, no. 4 (2011): 368-377.

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.<sup>44</sup> As in another study,<sup>45</sup> many participants described their spiritual transformation as a journey.<sup>46</sup> This fits well with Pargament's definition of spirituality as a search for the sacred, which implies an active component in the way individuals experience their spirituality.<sup>47</sup> Lutz, Kremer, and Ironson also described what they termed the "*triad of care taking*" (emphasis in original).<sup>48</sup> In the first stage, before the diagnosis, most participants were not taking care of themselves. In the second stage, after their diagnosis, most participants began to engage in self-care (e.g., taking medication, going to therapy, quitting substance abuse), though their care taking was mainly limited to themselves. In the final stage, this care taking orientation expanded not only to those close to them, but also transformed into a "general feeling of love and compassion for others."<sup>49</sup>

For most individuals in Lutz, Kremer, and Ironson's study, one of the important aspects of their spiritual transformation was the development of a more individualized form of spirituality.<sup>50</sup> For many, the stigma surrounding HIV found in traditional religious contexts contributed to the development of this more personalized spirituality.<sup>51</sup> PLWH often report a more personal connection with God following their diagnosis,<sup>52</sup> which may be due, in part, to mixed reactions towards HIV from church communities. Cotton et al., for example, found that

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<sup>44</sup> Ibid., 401.

<sup>45</sup> Vance and Woodley, "Spiritual Expressions of Coping": 50.

<sup>46</sup> Lutz, Kremer, and Ironson, "Trigger for Spiritual Transformation": 402.

<sup>47</sup> Pargament, "Religion and Spirituality?": 12.

<sup>48</sup> Lutz, Kremer, and Ironson, "Trigger for Spiritual Transformation": 403.

<sup>49</sup> Ibid.

<sup>50</sup> Ibid., 405.

<sup>51</sup> Ibid., 404.

<sup>52</sup> Michael L. Foster et al. "'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* 13, no. 9 (2011): 1111; Lauris C. Kaldjian, James F. Jekel, and Gerald Friedland, "End-of-Life Decisions in HIV-Positive Patients: The Role of Spiritual Beliefs," *AIDS* 12 (1998): 105.

24% of their sample felt more alienated from their religious community following their diagnosis, yet 14% actually felt more welcomed after learning about their illness.<sup>53</sup> In a qualitative study on black MSM, many disconnected from the black church entirely because of the prevalence of homophobic attitudes and stigmatization they felt.<sup>54</sup> Some, however, revitalized their connection with the church because, despite the entrenched homophobia, they could still derive comfort and affirmation from it. It is important to recognize that churches vary greatly in their attitudes towards and support of the HIV community. Nevertheless, those churches that proffer stigmatizing messages from the pulpit may be contributing to some PLWH's spiritual struggles.

Undeniably, an HIV diagnosis is often a traumatic event, and it has the potential to incite a variety of positive or negative changes in an individual's life. In multiple studies, at least half of participants report some kind of change in their spirituality following their diagnosis. For most who experience a change, the outcomes are mainly positive; an increase in spirituality or positive spiritual transformation is associated with a variety of health benefits. However, a substantial minority experience negative spiritual changes, and even positive spiritual transformations can come with their own spiritual struggles. It is important to remember that each individual is unique and so their reactions to HIV and any resultant changes in their spirituality will be specific to that individual. In the next section, I explore the variety of ways that PLWH cope spiritually with their illness and their associations with psychological and physiological outcomes.

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<sup>53</sup> Cotton et al., "Changes in Religiousness": S17.

<sup>54</sup> Foster et al. "It's my Inner Strength": 1108-1109.

## Various Ways of Coping with HIV Spiritually

Just as there are numerous ways that a spiritual transformation can manifest itself following an HIV diagnosis, PLWH also use a variety of ways to cope with their illness spiritually. Fortunately, it seems that the majority of PLWH who are spiritual find ways to incorporate positive spiritual coping methods into the management of their illness. Positive spiritual coping methods are associated with a variety of psychological and physiological benefits. On the other hand, the minority of those who experience spiritual struggles or use negative spiritual coping strategies may experience poorer health outcomes. This section explores the variety of ways that PLWH cope spiritually with their illness, and how these coping strategies relate to psychological and physiological outcomes.

Just as the HIV community is a very diverse population, PLWH also hold a variety of spiritual beliefs and identities. In a study on long-term survivors and other PLWH, 66% of participants believed in God, but other studies have found rates as high as 98%.<sup>55</sup> The use of formal or institutional religious practices is fairly mixed, while individual spiritual practices such as prayer or meditation appear to be more common. In a large study by Cotton et al., nearly a quarter of their participants went to religious services at least once a week, while 32% of their sample practiced non-organized spiritual practices (e.g., prayer, meditation) at least daily, and 16% once a week or more.<sup>56</sup> Some of the practices endorsed most often by PLWH include prayer, meditation, and reading the Bible.<sup>57</sup> Many choose to communicate directly with God through prayer or meditation without the mediation of a priest.<sup>58</sup> A personal connection or

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<sup>55</sup> Kaldjian, Jekel, and Friedland, “End-of-Life Decisions”: 104; Tarakeshwar, Khan and Sikkema, “Relationship-Based Framework of Spirituality”: 63.

<sup>56</sup> Cotton et al., “Spirituality and Religion”: S8.

<sup>57</sup> Foster et al., “It’s my Inner Strength”: 1107; Lutz, Kremer, and Ironson, “Trigger for Spiritual Transformation”: 404; Tarakeshwar, Khan and Sikkema, “Relationship-Based Framework of Spirituality”: 65.

<sup>58</sup> Lutz, Kremer, and Ironson, “Trigger for Spiritual Transformation”: 405.

relationship with God seems to be an important aspect of spirituality for many PLWH. Individuals often mention feeling God's presence or influence in their lives, or having a more intimate connection with God, and this is particularly true for those who have undergone a spiritual transformation following their diagnosis.<sup>59</sup>

Most PLWH do not believe that their illness is a punishment from God or a Higher Power. In one sample, only 17% of participants held that belief,<sup>60</sup> and in another, 58% strongly disagreed with it.<sup>61</sup> Rather, some PLWH characterize HIV as a challenge from God, or feel as though they have been chosen by God to have this illness, and many even see their illness as a blessing.<sup>62</sup> Some are angry at God, or struggle to forgive themselves, but the majority of PLWH believe in God's unconditional love, forgiveness, and benevolence.<sup>63</sup> Most often, God is seen as a source of strength or guidance in times of need.<sup>64</sup> Many report that their spirituality or religiosity allows them to gather internal and external resources to help them cope with their illness and other stressful life events, as well as maintain a good quality of life.<sup>65</sup>

Additionally, the way one views God is associated with psychological and physiological outcomes. In a recent study by Ironson et al., more PLWH reported having a positive view of God as benevolent and forgiving rather than a negative view of God as punishing and

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<sup>59</sup> Cotton et al., "Spirituality and Religion": S8; Foster et al., "It's my Inner Strength": 1107; Vance and Woodley, "Spiritual Expressions of Coping": 51.

<sup>60</sup> Kaldjian, Jekel, and Friedland, "End-of-Life Decisions": 104.

<sup>61</sup> Anton M. Somlai and Timothy G. Heckman, "Correlates of Spirituality and Well-Being in a Community Sample of People Living with HIV Disease," *Mental Health, Religion & Culture* 3, no. 1 (2000): 58.

<sup>62</sup> Foster et al., "It's my Inner Strength": 1110; Lutz, Kremer, and Ironson, "Trigger for Spiritual Transformation": 402; Vance, "Aging with HIV": 64; Vance and Woodley, "Spiritual Expressions of Coping": 50.

<sup>63</sup> Kaldjian, Jekel, and Friedland, "End-of-Life Decisions": 104-105; Lutz, Kremer, and Ironson, "Trigger for Spiritual Transformation": 405; Tarakeshwar, Khan and Sikkema, "Relationship-Based Framework of Spirituality": 65.

<sup>64</sup> Cotton et al., "Spirituality and Religion": S8; Foster et al., "It's my Inner Strength": 1107.

<sup>65</sup> David E. Vance, Thomas C. Struzick, and James L. Raper, "Biopsychosocial Benefits of Spirituality in Adults Aging with HIV," *Journal of Holistic Nursing* 26, no. 2 (2008): 120-121.

judgemental.<sup>66</sup> Those who held a more positive view of God were able to preserve their CD4 cells better over four years and had better control over their viral load. Those who saw God as punishing and judgemental, however, lost CD4 cells almost five times faster and their viral load increased approximately eight time faster over those four years.<sup>67</sup> A view of God as merciful and benevolent was associated with less hopelessness, while a more negative view of God was linked to less optimism, more avoidance coping, as well as more depression.<sup>68</sup> While most PLWH find positive ways to cope spiritually, negative spiritual coping strategies can be detrimental to one's health.

Spirituality may also include relationships other than solely one with God. In a qualitative study seeking to understand how PLWH characterize their spirituality, Tarakeshwar et al. presented a relationship-based framework of spirituality based on their interviews.<sup>69</sup> The themes that emerged in their study were a renewed engagement with life, relationships with family, and relationships with God.<sup>70</sup> This renewed engagement with life manifested itself as PLWH started practicing self-care, re-evaluated their priorities, transformed their life goals, and accepted their mortality, which allowed them to focus more on living their lives in the present.<sup>71</sup> Many of Tarakeshwar et al.'s participants found a sense of purpose in staying alive and well for their family members, and found their families were an important source of support.<sup>72</sup> On the other hand, many of the women in the study reported family could also be a source of strain, as they reflected on how their illness could affect their family members.

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<sup>66</sup> Ironson et al., "View of God as Benevolent and Forgiving or Punishing and Judgmental Predicts HIV Disease Progression," *Journal of Behavioural Medicine* 34, no. 6 (2011): 416.

<sup>67</sup> Ibid., 418.

<sup>68</sup> Ibid., 420.

<sup>69</sup> Tarakeshwar, Khan and Sikkema, "Relationship-Based Framework of Spirituality": 63

<sup>70</sup> Ibid.

<sup>71</sup> Ibid., 65-67.

<sup>72</sup> Ibid., 67-68.

In terms of the third theme, almost all participants believed that God was benevolent and had nothing but a positive influence in their lives.<sup>73</sup> They connected with God mainly through prayer, meditation, and reading the Bible, though a few felt that going to church was a critical aspect of their spirituality. Many reported going through a spiritual struggle, particularly right after their diagnosis, but all felt that God had forgiven them, even if they still struggled to forgive themselves. As mentioned, a few other scholars have also noted that a relationship with God is often an important aspect of spirituality for PLWH,<sup>74</sup> but this will be explored further in the following chapter.

### Conclusion

What can be gleaned from these studies is that spirituality is an important aspect of many PLWH's lives. In particular, many PLWH highlight the importance of individual spiritual practices as well as a personal relationship with God. This makes sense considering homophobic attitudes and HIV stigma is often found in church communities, although many PLWH still find ways to reconnect with these communities and value the support they can gain from them. Looking at the literature, it seems that most PLWH who are spiritual have found ways to cope positively spiritually with their illness. This is important considering the connections that have been found between positive and negative spiritual coping methods and psychological and physiological health. Although a substantial minority of PLWH do find themselves struggling spiritually, the literature so far has tended to focus more on the positive aspects of spirituality. It would be important to explore further how those who are coping negatively are experiencing their spirituality, as this population may be the one most in need of spiritual care. In the next

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<sup>73</sup> Ibid., 63-65.

<sup>74</sup> Cotton et al., "Spirituality and Religion": S8; Foster et al., "It's my Inner Strength": 1107; Vance and Woodley, "Spiritual Expressions of Coping": 51.

chapter, I turn my attention more specifically to PLWH's 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

#### Introduction

A diagnosis of HIV can result in changes in a variety of relationships, including those with friends, family, romantic partners, and even the divine. Some of these relationships, such as those with romantic partners and God, are often characterized as attachment relationships.<sup>75</sup> As discussed in the previous chapter, there are many ways that PLWH cope spiritually with their illness. Most of the research in this field has looked at correlations among general measures of spirituality and various indicators of psychological and physiological health. One of the important dimensions of spiritual coping that has received far less attention, however, is the way that HIV can impact PLWH's relationship with the Christian God specifically. While few studies have explored this link, the literature leaves hints that this could be one of the most important aspects of PLWH's spirituality.

This chapter looks at how attachment theory can inform the discussion concerning PLWH's relationship with God, and how this relates to their health. The emphasis will be on studies conducted with HIV+ Christians in North America, as most of the research in this field has focused on this population. First, I provide a brief sketch of some of attachment theory's key themes. I then turn to the way that attachment theory has informed the conversation surrounding Christian individuals' relationships with God. Finally, I review some of the literature that mentions or explores relationship with God in the context of HIV. The studies reviewed in this chapter are those that could be found through the PubMed and ATLA databases using keywords

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<sup>75</sup> Marco Del Giudice, "Sex Differences in Romantic Attachment: A Meta-Analysis," *Personality and Social Psychology Bulletin* 37, no. 2 (2011): 193; Lee A. Kirkpatrick, *Attachment, Evolution, and the Psychology of Religion*, (New York: The Guilford Press, 2005), 52-74; Lee A. Kirkpatrick, and Phillip R. Shaver, "An Attachment-Theoretical Approach to Romantic Love and Religious Belief," *Personality and Social Psychology Bulletin* 18, no. 3 (1992): 267-268.

relevant to the topic. A more exhaustive and systematic review of the literature would be warranted, but is beyond the scope of this chapter. 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 1950's.<sup>76</sup> Using observations on infants and their caregivers, they looked at how the bond between them formed and how it could influence future relationships. The attachment between infant and caregiver is a dynamic relationship that serves to maintain varying degrees of proximity between the pair and elicit a feeling of safety and security during infancy. The caregiver can act as a safe haven for the infant in times of distress, as well as a secure base from which to explore its environment.<sup>77</sup> An attachment can be characterized as “secure” or “insecure”, with the latter category divided into “anxious/ambivalent” and “avoidant” styles.<sup>78</sup> This categorization was later expanded by Bartholomew and Horowitz to four different attachment styles: secure, preoccupied, dismissing, and fearful.<sup>79</sup>

This initial attachment can serve as a framework, or internal working model, for future relationships.<sup>80</sup> Some children, particularly those with insecure attachment styles, may turn to other figures such as counsellors, friends, and teachers to find substitute or additional attachment figures.<sup>81</sup> While initial attachment to the caregiver never disappears entirely, and not every close

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<sup>76</sup> Mary D. Salter Ainsworth and John Bowlby, “An Ethological Approach to Personality Development,” *American Psychologist* 46, no. 4 (1991): 333.

<sup>77</sup> John Bowlby, *Attachment and Loss: Attachment*, (New York: Basic Books, 1969), 1: 302.

<sup>78</sup> Mary D. Salter Ainsworth et al., *Patterns of Attachment: A Psychological Study of the Strange Situation*, (Oxford: Lawrence Erlbaum, 1978), 95-114.

<sup>79</sup> Kim Bartholomew and Leonard M. Horowitz, “Attachment Styles Among Young Adults: A Test of a Four Category Model,” *Journal of Personality and Social Psychology* 61, no. 2 (1991): 227.

<sup>80</sup> Bowlby, *Attachment and Loss*, 354.

<sup>81</sup> Ainsworth, *Patterns of Attachment*, 300-302.

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.<sup>82</sup>

It is important to highlight the dyadic and dynamic aspects 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.<sup>83</sup> 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 individuals' relationships with God.

### God: The Ideal Attachment Figure

David A. Bosworth stated that, “psychologists of religion appear to agree that God is not *like* an attachment figure, God *is* an attachment figure,” and “the relationship with God is an attachment relationship.”<sup>84</sup> Beginning with the work of Lee A. Kirkpatrick and Phillip R. Shaver

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<sup>82</sup> Bowlby, *Attachment and Loss*, 348.

<sup>83</sup> Bartholomew and Horowitz, “Attachment: Four Category Model,” 227.

<sup>84</sup> David A. Bosworth, “Ancient Prayers and the Psychology of Religion: Deities as Parental Figures,” *Journal of Biblical Literature* 134, no. 4 (2015): 684.

in 1990,<sup>85</sup> 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 links to spiritual and mental health. Research on adults reveals a complex relationship between attachment style and relationship with God. Attachment style and relationship with God have also been associated with a variety of mental and physical health outcomes. The literature shows that attachment theory can provide a useful model for investigating individuals' relationships with the divine.

In adulthood, two main models have been proposed in terms of people's attachment to God: compensation and correspondence.<sup>86</sup> While these models may seem contradictory at first, findings suggest that they may simply manifest themselves in groups of people with different attachment styles.<sup>87</sup> According to Kirkpatrick, the correspondence model seems to fit better with adults who had a secure attachment to their caregivers in childhood.<sup>88</sup> As he explains, those who report retrospectively a secure model of attachment in childhood will typically develop the same level of religiosity as their parents. For example, a child with a secure attachment to parents who are religious will usually become religious as well, while the same child with non-religious parents is more likely to become non-religious. The compensation model, conversely, seems to fit better with adults who report retrospectively an insecure attachment to their caregivers as children.<sup>89</sup> An adult who had an insecure attachment to their parents as a child, and whose parents are not religious, might turn to God as a substitute attachment figure, whereas an adult with an insecure attachment pattern as a child of religious parents will often turn away from

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<sup>85</sup> Lee A. Kirkpatrick and Phillip R. Shaver, "Attachment Theory and Religion: Childhood Attachments, Religious Beliefs, and Conversion," *Journal for the Scientific Study of Religion* 29, no. 3 (1990): 315-334.

<sup>86</sup> Lee A. Kirkpatrick, "God as a Substitute Attachment Figure: A Longitudinal Study of Adult Attachment Style and Religion Change in College Students," *PSPB* 24, no. 9 (1998): 961-973.

<sup>87</sup> Kirkpatrick, *Attachment, Evolution, and Religion*, 158-159.

<sup>88</sup> Ibid., 111-114.

<sup>89</sup> Ibid., 144.

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.<sup>90</sup>

One of the important functions of attachment relationships is that people will seek proximity to attachment figures in times of need. Although “one cannot be physically proximal to God in the same way as to other persons,”<sup>91</sup> Kirkpatrick argues that, in adulthood, psychological proximity or availability becomes more important than actual physical closeness.<sup>92</sup> Additionally, Christianity often emphasizes the omnipresent character of God, which believers can turn to for comfort and strength.<sup>93</sup> 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.<sup>94</sup>

Scholars have found that a secure attachment to God can mitigate some of the effects of stressors in an individual’s life, while an insecure attachment to God can exacerbate distress as a response to stressful life events.<sup>95</sup> 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 “romantic partner and/or God to receive support when they feel threatened.”<sup>96</sup> 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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<sup>90</sup> Ibid., 129-131; Kirkpatrick, “God as Substitute Attachment”: 967.

<sup>91</sup> Ibid., 56-57.

<sup>92</sup> Ibid., 57.

<sup>93</sup> Ibid., 58.

<sup>94</sup> Bosworth, “Deities as Parental Figures” 686-688.

<sup>95</sup> Christopher G. Ellison et al., “Attachment to God, Stressful Life Events, and Changes in Psychological Distress,” *Review of Religious Research* 53, no. 4 (2012): 503.

<sup>96</sup> Rosalinda Cassibba et al., “The Role of Attachment to God in Secular and Religious/Spiritual Ways of Coping with a Serious Disease,” *Mental Health, Religion & Culture* 17, no. 3 (2014): 257-258.

increased hope and positive coping.<sup>97</sup> 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 PLWH's 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

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<sup>97</sup> Ibid.

disengagement to cope with their illness.<sup>98</sup> An insecure attachment style is also correlated with dissatisfaction with the quality of social support received, less positive adjustment to HIV, and more engagement in high-risk sexual behaviours.<sup>99</sup> Conversely, a secure attachment style is related to a variety of positive outcomes, including decreased depression, lower perceived stress and HIV-related stigma, as well as more positive adjustment and quality of life.<sup>100</sup> Evidently, attachment style is an important factor to consider when investigating the health of PLWH.

For the rest of this section, I review some of the literature that mentions or explores relationship with God in the context of HIV. As mentioned at the beginning of this chapter, these articles were found by searching through the PubMed and ATLA databases using keywords relevant to the topic (e.g., “HIV”, “spirituality”, “relationship with God”, “attachment to God”). It is important to keep in mind that other studies, chapters, and resources may have been found through other databases or search engines, and hence this review cannot be said to be exhaustive. The studies reviewed here are those that included men who have sex with men in their sample. While a more specific look at this population might be warranted, too few of the studies that were found have been conducted specifically on this population to perform an effective review. The majority of research in the field of spirituality and HIV has included a wide range of ages, as well as mixed genders, sexual orientations, and ethnicities. Although few of the studies that emerged looked specifically at PLWH’s relationship with God, findings from more

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<sup>98</sup> C. Koopman et al., “Relationships of Perceived Stress to Coping, Attachment and Social Support Among HIV-Positive Persons,” *AIDS Care*, 12, no. 5 (2000): 669.

<sup>99</sup> Julie M. Turner-Cobb et al., “Coping, Social Support, and Attachment Style as Psychosocial Correlates of Adjustment in Men and Women With HIV/AIDS,” *Journal of Behavioral Medicine* 25, no. 4 (2002): 374; Jeffrey A. Ciesla, John E. Roberts, and Ross G. Hewitt, “Adult Attachment and High-Risk Sexual Behavior Among HIV-Positive Patients,” *Journal of Applied Social Psychology*, 34, no. 1 (2004): 114-117.

<sup>100</sup> See Chris Hinnen et al. “The Contribution of Adult Attachment and Perceived Social Support to Depressive Patients with HIV,” *AIDS Care* 24, no. 12 (2012): 1535-1542; Luci A. Martin, Mark Vosvick, and Shelley A. Riggs, “Attachment, Forgiveness, and Physical Health Quality of Life in HIV+ Adults,” *AIDS Care* 24, no. 11 (2012): 1333-1340; Shelley A. Riggs, Mark Vosvick and Steve Stallings, “Attachment Style, Stigma and Psychological Distress Among HIV+ Adults,” *Journal of Health Psychology* 12, no. 6 (2007): 922-936.

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 ARTs 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.<sup>101</sup> 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.<sup>102</sup> These findings suggest that many PLWH who are spiritual often see God as being involved directly in their health.

Cotton et al. found that some of the positive spiritual coping strategies endorsed most often by PLWH were: “looked for a stronger connection with God,” “sought God’s love and care,” and “tried to see how God might be trying to strengthen me in this situation.”<sup>103</sup> All of these statements are indicative of a secure relationship with the divine. Some of the negative spiritual coping strategies endorsed most often by their participants included: “decided the Devil made this happen,” and “wondered whether God had abandoned me.”<sup>104</sup> The belief concerning the Devil suggests that even with their illness, many PLWH still believe in God’s benevolence,

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<sup>101</sup> Lauris C. Kaldjian, James F. Jekel, and Gerald Friedland, “End-of-Life Decisions in HIV-Positive Patients: The Role of Spiritual Beliefs,” *AIDS* 12 (1998): 103-107.

<sup>102</sup> Anton M. Somlai & Timothy G. Heckman, “Correlates of Spirituality and Well-Being in a Community Sample of People Living with HIV Disease,” *Mental Health, Religion & Culture* 3, no. 1 (2000): 64.

<sup>103</sup> Sian Cotton et al., “Spirituality and Religion in Patients with HIV,” *Journal of General Internal Medicine* 21 (2006): S8.

<sup>104</sup> Ibid.

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.<sup>105</sup> A minority of PLWH feel that their illness has made them more alienated from their religious group.<sup>106</sup> 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.<sup>107</sup> Foster et al. found that some of the spiritual practices used by PLWH are: praying nightly, “consistently acknowledging God’s presence in their lives,”<sup>108</sup> and “turning to God for guidance and strength during challenging times.”<sup>109</sup> All of these, which reflect a more individualized spirituality, are also indicative of seeking proximity to the deity, one of the main facets of attachment relationships.

As discussed in the previous chapter, Tarakeshwar, Khan and Sikkema, in their qualitative study of 20 subjects, were the first to put forward a relationship-based framework for

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<sup>105</sup> Heidemarie Kremer et al., “To Take or Not to Take: Decision-Making About Antiretroviral Treatment in People Living with HIV/AIDS,” *AIDS Patient Care and STDs* 20, no. 5 (2006): 343.

<sup>106</sup> Sian Cotton et al., “Changes in Religiousness and Spirituality Attributed to HIV/AIDS: Are There Sex and Race Differences?” *Journal of General Internal Medicine* 21 (2006): S17.

<sup>107</sup> Franz Lutz, Heidemarie Kremer, and Gail Ironson, “Being Diagnosed with HIV as a Trigger for Spiritual Transformation,” *Religions* 2, no. 4 (2011): 398-409.

<sup>108</sup> Michael L. Foster, Emily Arnold, Gregory Rebchook, and Susan M. Kegeles, “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* 13, no. 9 (2011): 1107.

<sup>109</sup> Ibid.

the spirituality of PLWH.<sup>110</sup> 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 analyses. 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.'s study that showed how a PLWH's 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 scholars' results also remained significant even after controlling for a variety of potentially confounding variables. The second is Lutz, Kremer and Ironson's 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 "individualized connectedness with a higher presence/entity."<sup>111</sup> 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

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<sup>110</sup> Nalini Tarakeshwar, Nadia Kahn, and Kathleen J. Sikkema, "A Relationship-Based Framework of Spirituality for Individuals with HIV," *AIDS and Behavior* 10, no. 1 (January 2006): 59-70.

<sup>111</sup> Ibid., 405.

positive health outcomes for PLWH outside of a spiritual context, while an insecure attachment style may have a negative impact on health. The language that scholars and participants use in these studies often sounds like attachment language: a connection to God, seeing God as benevolent or judgemental, and an individual or personal relationship with the divine. None of these scholars, however, have used an attachment theory framework in conducting their analyses. It would be important to look at PLWH from an attachment theory perspective not only as it relates to God, but also to other relationships. HIV intersects with relationships with friends, family, and romantic partners. As Riggs et al. note, “a diagnosis of HIV may be reminiscent of the coming out process,” especially as it relates to stigma and disclosure.<sup>112</sup> Attachment theory could provide a useful framework to investigate changes in a variety of relationships that may be affected after a diagnosis of HIV.

### Conclusion

As Vance, Struzick and Raper state, “HIV can be a clandestine, isolating illness.”<sup>113</sup> For some, it seems that this isolation could be mitigated through fostering a more meaningful connection with the divine. Developing a more personal, positive relationship with God seems to offer a multitude of physiological and psychological health benefits for PLWH, and according to the literature on the psychology of religion, this could be characterized as an attachment relationship. One of the limitations of this literature is that most studies have been cross-sectional, and therefore it is difficult to infer causality. More longitudinal studies are needed to ascertain whether a secure relationship with God results in more positive health outcomes,

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<sup>112</sup> Riggs, Vosvick and Stallings, “Attachment Style, Stigma, Distress”: 930.

<sup>113</sup> David E. Vance, Thomas C. Struzick, and James L. Raper, “Biopsychosocial Benefits of Spirituality in Adults Aging with HIV,” *Journal of Holistic Nursing* 26, no. 2 (2008): 122.

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, and 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 PLWH's 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 PLWH's 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 person's 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 physicians' incorporation of spirituality in patient care in the context of primary health care for PLWH.

## Chapter 3

### Spirituality in HIV Health Care

#### Introduction

While there has been a proliferation of research on spirituality and health in recent decades, in practice, it seems that many physicians have yet to fully incorporate this dimension of health in their provision of care. Few studies have investigated the incorporation of spirituality into health care by physicians in Canada. Even fewer studies have looked at the incorporation of spirituality in health care specifically for PLWH. Most PLWH are followed closely by a health care provider, most often a physician they see every three to six months. Given the amount of research demonstrating a link between spirituality and mental and physical health for PLWH, the spiritual needs of this population should at the very least be assessed by their primary care provider, and they should be referred to spiritual care providers<sup>114</sup> should they have complex spiritual needs.

This chapter reviews some of the literature on physicians' incorporation of spirituality in health care outside and within the context of HIV. Both PubMed and ATLA databases were searched with keywords relating to the topic (e.g., "HIV", "spirituality", "physician", "provider"). Although this search is not exhaustive, and other resources may have emerged through other databases or search engines, this chapter focuses on some of the most salient points from the research articles that could be found. First, I explore the literature on physicians' attitudes towards and barriers to incorporating spirituality into their practice. I discuss the HIV health care team, and suggest that it be expanded to include faith communities as well as spiritual

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<sup>114</sup> Several terms are used in the literature (e.g., spiritual care providers, pastoral care specialists, chaplains), yet these terms often do not describe clearly demarcated roles. While in the United States "chaplain" remains the common term, in Canada there has been a shift to "spiritual care provider" to better reflect the diversity of care that is provided. "Spiritual care" and "spiritual care provider" will be used throughout this chapter as I will be focusing on the Canadian context.

care providers. I then look at the differences in religious and spiritual demographics between Canada and the United States, since most research in this field has been conducted in the United States. Finally, I examine the relative lack of research on the spiritual dimension of living with HIV in Canada, and suggest some avenues for future research. I argue that physicians who work with PLWH should assess their patients' spiritual needs, and then refer them for spiritual care should they have complex needs or be experiencing spiritual struggles.

### Physicians and Spirituality

In recent years, the medical community has begun moving towards a holistic, patient-centred model of care. For example, the Canadian Medical Association (CMA) released a policy document in 2008 emphasizing the importance of what they term "patient-centred collaborative care."<sup>115</sup> This requires "physicians and other providers using complementary skills, knowledge and competencies and working together to provide care to a common group of patients based on trust, respect and an understanding of each others' skills and knowledge."<sup>116</sup> According to the American Medical Association's (AMA) *Code of Medical Ethics*, one of the fundamental elements of the patient-physician relationship is a "mutually respectful alliance,"<sup>117</sup> entailing that the patient be actively engaged in his or her own health care. With few other populations could the holistic, patient-centred framework of care be as important as with PLWH. The multidimensional nature of the illness often requires a team of health professionals, and each PLWH might have unique needs that go beyond the biomedical aspects of the disease.

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<sup>115</sup> Canadian Medical Association, *Achieving Patient-Centred Collaborative Care*, (Ottawa: Canadian Medical Association, 2008), 1.

<sup>116</sup> Ibid.

<sup>117</sup> American Medical Association, "Opinion 10.01: Fundamental Elements of the Patient-Physician Relationship," American Medical Association, accessed June 15, 2016, <http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion1001.page?>

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.<sup>118</sup> Koenig states that it is most important to take a spiritual history when “a 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,”<sup>119</sup> two 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-centred, and gentle manner.<sup>120</sup> He suggests that physicians should do no more than assess the patient’s spiritual needs, and then refer them to spiritual care providers if the patients’ needs are complex.<sup>121</sup> 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 patients’ spiritual needs is within their

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<sup>118</sup> Harold G. Koenig, *Spirituality in Patient Care: Why, How, When, and What*, 3rd ed., (West Conshohocken: Templeton Press, 2013).

<sup>119</sup> Ibid., 95.

<sup>120</sup> Ibid., 108-110.

<sup>121</sup> Ibid., 77.

mandate as well as an important aspect of health care.<sup>122</sup> 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),<sup>123</sup> a difference between their level of spirituality and their patients' 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 – making spiritual assessments well requires particular expertise.<sup>124</sup> The most important of these are a lack of expertise, and a lack of time.<sup>125</sup>

Nevertheless, there are some physicians who routinely incorporate spirituality in patient care, but this seems to be infrequent. In a recent systematic literature review, Best, Butow, and Olver found that 9-63% of physicians often or always took a religious or spiritual history, while 17-57% of physicians took one at least rarely, and 4-66% never asked their patients about their religion or spirituality.<sup>126</sup> Discussions of spirituality increased with the severity of the illness, with 30-77% of physicians discussing spirituality during a health crisis or because of a terminal illness.<sup>127</sup> Other scholars have found that two thirds of patients wanted their physicians to be

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<sup>122</sup> Farr A. Curlin et al., "How Are Religion and Spirituality Related to Health? A Study of Physicians' Perspectives," *Southern Medical Journal* 98, no. 8 (2005): 763; Jeanne Maccauley et al., "Spiritual Beliefs and Barriers Among Managed Care Practitioners," *Journal of Religion of Health* 44, no. 2 (2005): 142; Joy M. Twersky, Linda K. George, and Martin J. Sullivan, "Spirituality in Medicine: Examining Physician Attitudes and Practices," *Southern Medical Journal* 91, Issue Supplement (1998): S44.

<sup>123</sup> Carol E. Fletcher, "Health Care Providers' Perceptions of Spirituality While Caring for Veterans," *Qualitative Health Research* 14, no. 4 (2004): 551.

<sup>124</sup> Mark R. Ellis, et al., "What Do Family Physicians Think About Spirituality In Clinical Practice?" *The Journal of Family Practice* 51, no. 3 (2002): 252; Fletcher, "Providers' Perceptions of Spirituality": 553.

<sup>125</sup> Mark R. Ellis, Daniel C. Vinson, and Bernard Ewigman, "Addressing Spiritual Concerns of Patients," *Journal of Family Practice* 48, no. 2 (1999): 105; Fletcher, "Providers' Perceptions of Spirituality": 551-553; Twersky, George, and Sullivan, "Spirituality in Medicine": S44.

<sup>126</sup> Megan Best, Phyllis Butow, and Ian Olver, "Doctors Discussing Religion and Spirituality: A Systematic Literature Review," *Palliative Medicine* 30, no. 4 (2016): 330.

<sup>127</sup> Ibid.

aware of their religious or spiritual beliefs, particularly if they were to experience a more severe illness.<sup>128</sup>

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 physicians' rates of referrals to spiritual care providers ranged from 5-42%.<sup>129</sup> 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.<sup>130</sup> Some of the facilitating factors for incorporating spirituality in patient care cited by physicians are the primacy of spirituality in physicians or the patients' lives, the setting (e.g., visiting at home versus in the office), respect, patience and openness.<sup>131</sup> What appears to be the most important factor is for the patient to be able to feel vulnerable, open and respected when the physician approaches them concerning their spiritual beliefs or if they open up concerning their faith.

Some of the major agencies and networks where physicians can garner the latest information concerning HIV research and guidelines have yet to pinpoint spirituality as an important dimension of care for PLWH. The Canadian AIDS Treatment Information Exchange's (CATIE) website, for example, one of the leading Canadian resources for information on HIV infection, categorizes spirituality as a complementary or alternative form of therapy, along with

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<sup>128</sup> Charles D. MacLean et al., "Patient Preference for Physician Discussion and Practice of Spirituality: Results from a Multicenter Patient Survey," *Journal of General Internal Medicine* 18 (2003): 39.

<sup>129</sup> Best, Butow, and Olver, "Doctors Discussing Religion": 331.

<sup>130</sup> Fletcher et al. 553-556.

<sup>131</sup> Mark R. Ellis and James D. Campbell, "Patients' Views About Discussing Spiritual Issues With Primary Care Physicians," *Southern Medical Journal* 97, no. 12 (2004): 1160; Mark R. Ellis and James D. Campbell, "Concordant Spiritual Orientations as a Factor in Physician-Patient Spiritual Discussions: A Qualitative Study," *Journal of Religion and Health* 44, no. 1 (2005): 44-45; Ellis et al., "Spirituality in Clinical Practice?": 252; Michael M. Olson et al., "Mind, Body, and Spirit: Family Physicians' Beliefs, Attitudes, and Practices Regarding the Integration of Patient Spirituality into Medical Care," *Journal of Religion and Health* 45, no. 2 (2006): 239.

aromatherapy, colour therapy, and juicing.<sup>132</sup> 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 individual's 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 post-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.<sup>133</sup> Public Health's 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.<sup>134</sup> 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 individuals' choices and behaviours.<sup>135</sup> This is particularly important in the context of HIV, which can have an impact on various aspects of an individual's life, including their mental and physical health,<sup>136</sup> social support system,<sup>137</sup> and self-concept.<sup>138</sup> Treatment and prevention of

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<sup>132</sup> Lori Lyons and Devan Nambiar, "A Practical Guide to Complementary Therapies," Canadian AIDS Treatment Information Exchange. Accessed April 28, 2016, <http://www.catie.ca/en/practical-guides/complementary-therapies>.

<sup>133</sup> Public Health Agency of Canada, "Canadian Guidelines on Sexually Transmitted Infections," Public Health Agency of Canada. Accessed April 28, 2016, <http://www.phac-aspc.gc.ca/std-mts/sti-its/cgsti-ldcits/section-5-8-eng.php>.

<sup>134</sup> Public Health Agency of Canada, "Complementary and Alternative Health," Public Health Agency of Canada. Accessed April 28, 2016, <http://www.phac-aspc.gc.ca/chn-rcc/cah-acps-eng.php>.

<sup>135</sup> Kenneth I. Pargament, *The Psychology of Religion and Coping: Theory, Research, and Practice*, (New York: The Guilford Press, 1997), 58.

<sup>136</sup> Claire E. Kendall et al., "A Cross-Sectional, Population-Based Study Measuring Comorbidity Among People Living with HIV in Ontario," *BMC Public Health* 14 (2014): 3-4.

<sup>137</sup> Seth C. Kalichman et al., "Stress, Social Support, and HIV-Status Disclosure to Family and Friends Among HIV-Positive Men and Women," *Journal of Behavioral Medicine* 26, no. 4 (2003): 324-327.

<sup>138</sup> Sarit A. Golub, H. Jonathon Rendina, and Kristi E. Gamarel, "Identity-Related Growth and Loss in a Sample of HIV-Positive Gay and Bisexual Men: Initial Scale Development and Psychometric Evaluation," *AIDS Behavior* 17 (2013): 753-755.

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.<sup>139</sup> Additionally, there was an even greater discrepancy between patients who had been diagnosed more recently and their providers,<sup>140</sup> which coincides with the time many PLWH report changes in their spirituality.<sup>141</sup> According to this study, there seems to be a disconnect between the evidence supporting the importance of spirituality in health care, and providers' 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.<sup>142</sup> The majority of participants endorsed that they wanted their physician to know about their spiritual

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<sup>139</sup> Rob J. Fredericksen et al., "Patient and Provider Priorities for Self-Reported Domains of HIV Clinical Care," *AIDS Care* 27, no. 10 (2015): 1257-1258.

<sup>140</sup> Fredericksen, "Patient and Provider Priorities": 1257.

<sup>141</sup> Gail Ironson, Rick Stuetzle, and Mary Ann Fletcher, "An Increase in Religiousness/Spirituality Occurs After HIV Diagnosis and Predicts Slower Disease Progression over 4 Years in People with HIV," *Journal of General Internal Medicine* 21 (2006): S64; Heidemarie Kremer, Gail Ironson, and Lauren Kaplan, "The Fork in the Road: HIV as a Potential Positive Turning Point and the Role of Spirituality," *AIDS Care* 21, no. 3 (March 2009): 371; Franz Lutz, Heidemarie Kremer, and Gail Ironson, "Being Diagnosed with HIV as a Trigger for Spiritual Transformation," *Religions* 2, no. 4 (2011): 403.

<sup>142</sup> Karen Bernstein, Lawrence J. D'Angelo, and Maureen E. Lyon, "An Exploratory Study of HIV+ Adolescents' Spirituality: Will You Pray with Me?" *Journal of Religion and Health* 52 (2012): 1258-1259.

beliefs so they could understand them and how they make medical decisions better. This study, combined with Fredericksen's findings, in which providers considered spirituality to be the least important dimension of clinical care for PLWH, suggests that the spiritual needs of this population may not be met by their primary care providers currently. It is important to keep in mind that while these were the only articles that could be found through PubMed and ATLA, other studies may have been found by using other databases and search engines. Nevertheless, more research is needed to determine whether these attitudes align with physicians' actual practices, and to look at whether PLWH want their physicians to assess their spiritual needs. Considering the evidence reviewed so far, it would be important for health professionals who work with this population to be trained on how to take a spiritual assessment, and to be aware of who patients can be referred to if they are in need of spiritual care.

### Expanding the HIV Health Care Team

As discussed, PLWH may encounter a variety of health professionals through the management of their illness. While a physician might follow them most closely, they might also see nurses, infectious disease specialists, mental health professionals, social workers, physiotherapists, spiritual care providers, and others. In order to provide PLWH holistic, person-centred care, those who work with HIV patients most regularly, mainly physicians, need to be trained in more than just the biological aspects of the virus. HIV impacts an individual entirely, and may impact how they see the world, which, as discussed in Chapter 1, often translates into various spiritual changes for many of those who are diagnosed with the virus. Physicians who work with PLWH should start integrating spiritual care providers into the HIV health care team, and draw on their support when their patients experience spiritual struggle or have complex

spiritual needs. Dialogue between medical and faith communities might help reduce HIV stigma, raise awareness about issues PLWH are currently facing, and provide patients with more holistic care.

Before referring patients to spiritual care, physicians should familiarize themselves with the roles of spiritual care providers, and what they can do to help. Spiritual care providers should be seen as an integral part of the health care team; they are trained to assess and address the spiritual, social and psychological needs of patients, but they are also trained to do much more. For example, they can help patients' families cope, or act as a liaison or advocate between them and health care providers.<sup>143</sup> In hospitals, they can also work with staff to help them through difficult situations, resolve interpersonal conflicts, as well as work at a more organizational level, ensuring that patients receive the highest quality of care that they can obtain.<sup>144</sup> Spiritual care providers can also work with health professionals to teach them how to take a spiritual assessment, as well as work through any assumptions or prejudice that they may hold.<sup>145</sup> Physicians might want to explore and be comfortable with their own spirituality before beginning to assess the spiritual needs of their patients.

Unfortunately, few resources could be found that address the spiritual care of PLWH outside of developing countries. Most literature engages with the spiritual care of HIV/AIDS outside of the North American context. In 2004, the Statewide HIV/AIDS Church Outreach Advisory Board published a guidebook for HIV/AIDS ministry in the Church. They had recognized that to truly address the spread of HIV in the Black community in the United States, the Black church and faith communities would have to be involved. More recently, the Canadian

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<sup>143</sup> Emily McClung, Daniel H. Grossoehme, and Ann F. Jacobson, "Collaborating with Chaplains to Meet Spiritual Needs," *Medsurg Nursing* 15, no. 3 (2006): 150.

<sup>144</sup> *Ibid.*, 151.

<sup>145</sup> *Ibid.*

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.<sup>146</sup> 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/AIDS, however, can be variable.<sup>147</sup> 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.<sup>148</sup> Some may even hold stigmatizing views concerning HIV and homosexuality, yet still participate in HIV/AIDS activism and ministry.<sup>149</sup> Physicians may need to ensure that spiritual care providers are knowledgeable about HIV and comfortable

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<sup>146</sup> Canadian AIDS Society, *Faith-Based Organizations Addressing HIV/AIDS in Canada: A National Framework*, (Ottawa: Canadian AIDS Society, 2014), 21.

<sup>147</sup> Ricky N. Bluthenthal, et al., “Attitudes and Beliefs Related to HIV/AIDS in Urban Religious Congregations: Barriers and Opportunities for HIV-Related Interventions,” *Social Science & Medicine* 74 (2012): 1522-1524.

<sup>148</sup> Ibid.

<sup>149</sup> Ibid., 1524.

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 for 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 physicians' 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.<sup>150</sup> 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

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<sup>150</sup> Best, Butow, and Olver, "Doctors Discussing Religion": 329.

religious affiliation was identified, 76% of Canadians declared a religious affiliation.<sup>151</sup> The main religious affiliations identified were Christian (67%) [with most Christians identifying as Catholic (39%)], followed by Muslims (3%), Hindus (2%) and then Sikhs (1%), and 24% declaring no religious affiliation. The NHS did not ask about other factors, such as spirituality, religious attendance, or importance of religiosity, so we cannot be sure what exactly those numbers tell us. In a more recent poll conducted by Forum Research, half of Canadians said that they were religious, while 65% considered themselves to be spiritual, and two thirds declared that they believed in God.<sup>152</sup> According to these surveys, the majority of Canadians currently affiliate with a religious tradition. Accordingly, it would be important to explore further whether or not Canadian physicians incorporate spirituality into their patient care. In the case of HIV, which can incite spiritual transformations and can affect the existential well-being of a person, it might be even more important to do so.

The United States, by comparison, is one of the developed countries with the most religious population. In the last Gallup poll on religion in the United States, approximately three quarters of Americans indicated that their religion was fairly or very important to them.<sup>153</sup> Seventy-nine percent identified they were affiliated to a certain religion, with 70% identifying as a denomination of Christianity, 2% as Jewish, 2% as Mormon, and 6% as other. Seventeen percent of respondents identified no religion. In 2014, 86% of those polled by Gallup identified that they believed in God, compared to 11% who said they did not. To a certain extent, religion seems to be somewhat more prevalent in the United States than in Canada, and so studies on

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<sup>151</sup> Statistics Canada, “National Household Survey (NHS) Profile: 2011 National Household Survey,” Statistics Canada, accessed June 13, 2016, <http://www12.statcan.gc.ca/nhs-enm/2011/dp-pd/prof/index.cfm?Lang=E>.

<sup>152</sup> Richard Johnson, “Polling Religion in Canada,” *National Post*, December 21, 2012, <http://news.nationalpost.com/news/graphics/polling-religion-in-canada>.

<sup>153</sup> Gallup, “In Depth: Topics A to Z: Religion,” Gallup, accessed June 13, 2016, <http://www.gallup.com/poll/1690/religion.aspx>.

spirituality and health may not translate entirely to the Canadian context. As will be explored in the following section, the majority of this research has been conducted in the United States, and should be replicated in Canada in order to evaluate Canadian physicians' application of holistic, person-centred framework of care, especially in the context of HIV.

### Lack of Research in Canada

According to a search through PubMed and ATLA databases, research on HIV and spirituality appears to be lacking in Canada currently; the majority of studies that could be found on this topic have been conducted in the United States. Almost no studies could be found exploring the link between HIV and spirituality, or physicians' incorporation of spirituality into patient care in Canada. Yet, one of the fundamental responsibilities of physicians, according to the *CMA Code of Ethics*, is to "provide for appropriate care for your patient, even when cure is no longer possible, including physical comfort and spiritual and psychosocial support."<sup>154</sup> Currently, we do not know whether the spiritual needs of patients with HIV in Canada are being met, as we have little evidence to show whether or not physicians are meeting this goal. Canadian researchers and physicians who work with PLWH need to start further incorporating this aspect of coping with HIV in their research as well as in their care of PLWH.

The first step for Canadian researchers could be to attempt to replicate some of the American studies in order to see if spirituality is as important and fluctuating in Canadian PLWH as they are in American samples. Longitudinal studies are particularly needed to determine if spiritual coping or spiritual changes post-diagnosis, whether positive or negative, have a causal effect on various dimensions of mental and physical well-being for PLWH in Canada. It would be interesting to look at differences between newly-diagnosed PLWH and those who have been

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<sup>154</sup> Canadian Medical Association, *CMA Code of Ethics*, (Ottawa: Canadian Medical Association, 2010), 8-10.

diagnosed for longer as well. Results from Fredericksen's 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.<sup>155</sup> The most dramatic changes and transformations in PLWH's spirituality also seem to occur mainly in the first few years after diagnosis.<sup>156</sup> This may be the best time for spiritual care providers to lead PLWH towards more positive spiritual coping strategies.

Only two studies were found in North America that looked at whether PLWH want their physician to be aware of their spiritual beliefs.<sup>157</sup> For those living with HIV who do receive spiritual care, no research was found that explored whether they are satisfied with the care they are receiving. Additionally, no studies emerged that addressed the efficacy of spiritual care in the context of HIV, and few resources or guides were found concerning the spiritual care of PLWH living in North America. More Canadian studies are needed on the efficacy of spiritual care within and outside of the context of HIV. While CAS has put forward some sample guidelines for the spiritual care of PLWH, no information was found on whether or not these guidelines have been implemented elsewhere, or whether spiritual care providers who work with PLWH have incorporated these guidelines into their practice. While the field of HIV and spirituality may be growing, there are still many avenues that have yet to be explored in this complex and multidimensional issue.

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<sup>155</sup> Fredericksen, "Patient and Provider Priorities": 1257.

<sup>156</sup> Ironson, Stuetzle, and Fletcher, "Increase in Religiousness/Spirituality": S64; Kremer, Ironson, and Kaplan, "The Fork in the Road," 371; Lutz, Kremer, and Ironson, "Trigger for Spiritual Transformation": 403.

<sup>157</sup> Bernstein, D'Angelo, and Lyon, "HIV+ Adolescents' Spirituality": 1258-1259.

## 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 following their diagnosis. Canadian physicians and researchers need to start recognizing spirituality as an important dimension in the lives of many PLWH, as well as incorporate this knowledge into their research and practice.

As it stands, few studies were found about the incorporation of spirituality into health care in North America in the context of HIV. Additionally, little could be found concerning physicians' incorporation of spirituality into health care in Canada. Considering the majority of Canadians identify with a religious tradition or identify as spiritual, rates of spirituality are most likely similar in PLWH. It would be important to start recognizing this dimension and incorporating it into the health care of PLWH in Canada. Given the gravity and the chronic nature of the illness, as well as research in the United States demonstrating the benefits of spiritual growth and detriments of spiritual struggles for PLWH, it is imperative that physicians in Canada assess the spirituality of this population and refer them to spiritual care should they be experiencing spiritual struggles or have complex spiritual needs.

## Conclusion

Spirituality is an important aspect of coping for many PLWH. The first chapter looked at the importance of spirituality for many PLWH, the various spiritual changes that individuals diagnosed with HIV can go through, and the myriad ways that PLWH cope spiritually. What stood out was the way that many PLWH develop a more individualized spirituality and connection with God, and that the way they cope spiritually can have an impact on their psychological and physiological health. The second chapter looked more specifically at PLWH's relationship with God, as this seems to be one of the most important aspects of spirituality for many in this community in the North American context. While scholars in the psychology of religion have been characterizing people's relationship with God as an attachment relationship for years, scholars in the field of HIV and spirituality have yet to utilize this framework in their analyses. Attachment theory could provide rich insights that could be validated empirically, and could potentially even be extended to look at PLWH's relationships with friends, partners and family. Finally, the third chapter reviewed the literature to date on physicians' incorporation of spirituality in patient care. What stands out from this literature are the various challenges physicians identify to addressing their patients' spiritual concerns, as well as the paucity of research in this field in Canada, and more specifically with PLWH.

Evidently, there are many avenues that have yet to be explored in the field of spirituality and HIV. One of the most pressing questions would be to look at how many physicians address the spiritual needs of PLWH in practice. Given that physicians are those who follow this population most closely, it would seem as though they would be positioned ideally to perform spiritual assessments and refer their patients to spiritual care providers if ever they were struggling spiritually. Another area that has received far too little attention as of yet is PLWH

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 PLWH's 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 quell 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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