

# Religio-Biography, Coping, and Meaning-Making Among Persons with HIV/AIDS

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*Recently, quality of life studies among patients with HIV/AIDS have shown high levels of life satisfaction. Spiritual and religious factors may contribute to these positive outcomes. We interviewed 19 patients with HIV/AIDS in order to understand better the role of religious-spiritual biographies and orientations in quality of life, and found four patterns to describe the ways in which past experiences with religion/spirituality and religious/spiritual meaning-making help to explain how patients are currently coping with HIV/AIDS. We illustrate each of these patterns with a prototypic patient: (1) the Deferring Believer (“God allows things to happen for a reason.”); (2) the Collaborating Believer (“This is where I’m supposed to be.”); (3) the Religious/Spiritual Seeker (“I’m trying to get my life together.”); and (4) the Self-Directing Believer (“What else is new?”). The findings support a previously described theoretical model of meaning-making in response to adversity, and they suggest the value of life course and narrative approaches to understanding religious coping.*

## INTRODUCTION

Whenever I talk to my clients [about spirituality], I look at, did they ever really have any spiritual background in the first place? And if they didn’t, um, probably they’re not going to grasp [it]. There are a few though, that, when this [HIV] comes upon them, that’s what they go into completely, and they leave nothing for chance with medicine, with life itself. They go to an extreme. So I think that if you’re working with people who have already experienced some kind of spirituality, whether it be organized or not, you can always, you know, kind of [ask], “How did you get this far, if you’re not holding on to something, whether it be the belief that God’s out there, or whether it be the belief that we live on? How could you get where you are without having something to hold onto?”

Responding to a question about how an understanding of his clients’ spirituality affects his own approach to social work, these remarks were made by “Thad,” a white 47-year-old, self-described homosexual, former Catholic man with HIV, who volunteers with a local AIDS service organization (ASO). Thad’s reflections on the role of his clients’ religious and spiritual backgrounds suggest the challenges of addressing the diverse spiritual-religious needs of persons with HIV/AIDS. His more general observation that to survive (“get this far”), a person must have “something to hold onto” (e.g., something to live for) also anticipates a key focus of our analysis of the religious life history accounts of Thad and others living with HIV: the importance of understanding lifelong, culturally shaped meaning-making frameworks (such as religious or spiritual worldviews) in human adaptations to major life changes, illness (e.g. HIV/AIDS), and trauma.

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In this article, we examine comments by Thad and 18 other HIV infected respondents who completed brief life history interviews that focused on family religious upbringing. In selecting religiously and spiritually oriented persons with HIV, we were interested in examining current versus lifelong religious/spiritual involvements and orientations and the impact of HIV on these trajectories. Couched within brief life history interviews with questions focused on religious socialization, and religious and spiritual involvements along the life course, the resulting semi-structured narratives took the form of short religious biographies punctuated by the acquisition of HIV. In the lives of individuals who considered themselves highly religious or spiritual, we considered these religio-biographies as a key window into their larger sense of purpose and order, including the ability to create meaning out of adversity. In this analysis, we qualitatively examine the reported impact of challenges (HIV/AIDS diagnosis) on religious meaning systems and, in this way, test key aspects of Park and Folkman's meaning-making coping framework (Park and Folkman 1997; Park et al. 2001).

### BACKGROUND

Since the introduction of highly active anti-retroviral therapy (HAART), quality of life studies among patients with HIV/AIDS have shown high levels of life satisfaction (Heckman et al. 1997; Demmer 2001), optimistic beliefs about prognosis (Holmes and Pace 2002), stress-related growth (Siegel and Schrimshaw 2000), and even perceptions that life is better than before being diagnosed with HIV (Tsevat et al. 1999). Although it is likely that improved survival and health outcomes provided by these new treatments contribute to the optimism reported by many patients, researchers have also begun to explore and document the role played by various forms of religious, spiritual, and meaning-focused coping (Tsevat et al. 1999; Woods et al. 1999; Barroso and Powell-Cope 2000; Heckman 2003).

Much of the research on religious coping with adversity is based on Pargament's theory and methods (Pargament 1997; Pargament et al. 2000) and the earlier work of Lazarus and Folkman (Lazarus and Folkman 1984; Park and Folkman 1997). According to these transactional stress models, the relationship between religious factors and coping with adversity can be considered a bidirectional process (e.g., adversity can affect faith, and faith can impact the effect of adversity). This relationship is also believed to be mediated by other complex factors such as identity development and social context (Ganzevoort 1998a; Moos and Holahan 2003). Nevertheless, much of the research into religious coping has tended to examine how religion as a complex set of experiences, attitudes, and behaviors shapes or frames the individual's response to crisis (rather than the other way around). Also, because "religiosity" and "spirituality"<sup>1</sup> are often assumed to be stable dispositions over time and are operationalized as concurrent measures (e.g., as "intrinsic" vs. "extrinsic"; see Kirkpatrick and Hood 1990) in cross-sectional study designs, most studies have not been able to explain how those beliefs and activities may change over time (say, in response to adversity), or how a particular individual's unique religio-biography and related assumptions may affect the meaning and efficacy of different strategies for coping with illness.

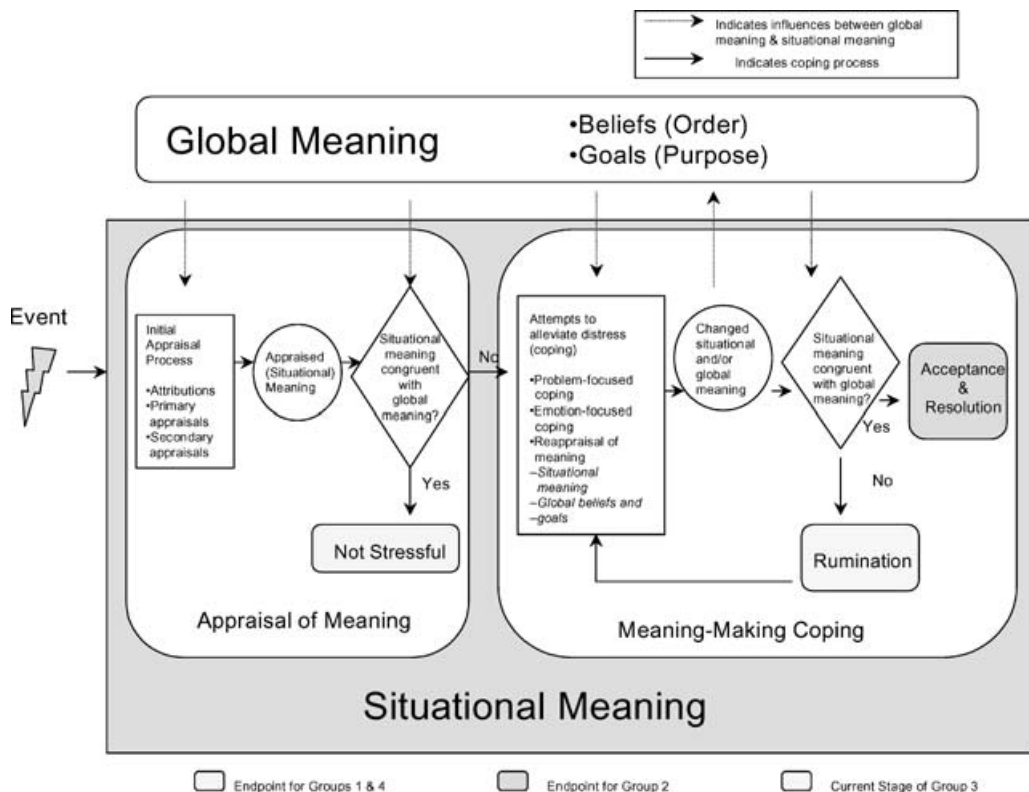
Although several qualitatively oriented papers have discussed themes gleaned from narratives of patients living with HIV/AIDS who describe their spirituality and quality of life since their diagnoses (Hall 1998; Fryback and Reinert 1999; Ezzy 2000; Trainor and Ezer 2000), those studies have made little or no reference to the temporal or developmental dimensions of meaning-making. By this we mean the accumulated patterns of shared meanings and experiences (personal and cultural webs of significance, schemas, and scripts) that contribute a sense of purpose, belonging, and religious-existential understanding to an individual's life and life experiences. While others have documented religious biographies (Roof 1994), we could find no studies that examined how individuals portray their spiritual-religious development or how they link accounts of their own spiritual and religious upbringings to their current sense of self (or identity) and adaptation in the face of an HIV diagnosis.

Following others (Pargament 1996; Park et al. 2001; Ganzevoort 1998a), we define coping as “the process through which individuals try to understand and deal with significant demands in their lives.” Much of the coping literature distinguishes between *emotion-focused* coping, in which strategies are used to regulate the distress associated with specific problems, and *problem-focused* coping, in which strategies are used to manage specific problems (Park and Folkman 1997).

In the context of stress and coping, “meaning” can be conceptualized in a number of ways. Park and Folkman (1997) have proposed a model to describe the relationship of different kinds of stress and coping to what they call *global meaning* and *situational meaning* (Figure 1; see Park and Folkman 1997). They define *global meaning* as “people’s basic goals and fundamental assumptions, beliefs, and expectations about the world”, (Park and Folkman 1997:116), which influence people’s understanding of the past and present, and influence their expectations regarding the future. For our purposes, an individual’s global meaning can be understood as a set of largely tacit psycho-cultural orientations and resources with which the individual responds to stress, adversity, or trauma. Religion is one example of a type of framework that can be integral to an individual’s sense of global meaning. (Park, in press)

Once a stressor occurs, a second type of meaning, *situational meaning*, comes into play. Park and Folkman define *situational meaning* as “the interaction of a person’s global beliefs and goals and the circumstances of a particular person–environment transaction” (Park and Folkman 1997: 121). This interaction involves three steps: meaning appraisal, search for meaning, and meaning as outcome, with a goal of reconciling the situational meaning of a stressor with the global meaning

**FIGURE 1**  
**MODEL OF GLOBAL AND SITUATIONAL MEANING (ADAPTED FROM PARK AND FOLKMAN 1997)**



of the person experiencing the stressor. Achieving this goal may ultimately require changing the person's global meaning from what it was before the stressor. For instance, in addition to religiosity/spirituality affecting health, illness can also affect a person's religiosity or spirituality, as a terminal or debilitating disease causes him or her to question his or her former concepts of the meaning of life (Hall 1998; Fryback and Reinert 1999). Disease can change a person's sense of identity, and the new identity might not fit into the former framework of meaning (Kleinman 1988; Mattingly 1988). On the other hand, an initial appraisal of situational meaning may be transformed to a point where it can be reconciled to the person's preexisting framework of global meaning without significantly changing that framework. This suggests that insofar as a stressor (e.g., illness) is perceived as fitting into a wider "global" meaning framework (say, a religious view that God has a purpose for everything), less adaptation will be needed. Park (in press) has found some evidence for this hypothesis among bereaved college students, and others have begun to examine meaning and quality of life among those with HIV/AIDS in terms of "sense of coherence" (Cederfjall et al. 2002; Reynolds and Alonzo 1998) and "assumptive worlds" (Tedeschi and Calhoun 2004), but again, no qualitative studies have explored the developmental dimensions of meaning-making, religious coping, and meaning-making coping among individuals with HIV/AIDS.

In order to understand better the relation of religious-spiritual biographies to individuals' encounters with HIV/AIDS, we conducted an exploratory, qualitative study with a convenience sample of 19 patients enrolled in a larger study of health values and spirituality in patients with HIV (Mrus et al. 2003). Here, we describe and analyze what these 19 patients told us about their religious-spiritual backgrounds and current orientations, and the ways that these have given meaning to their experience of living with HIV/AIDS. We categorize our subjects based on both their current spirituality/religiosity (with group names borrowed from Pargament's religious problem-solving styles) and on the processes that led them to these current states. In accordance with Pargament, we differentiate roughly between "deferring" believers, whose framework can be interpreted as an externally oriented religious view in which individuals wait for solutions from a higher power; "collaborative" believers, whose framework allows for a more adaptable and partnership-like approach to a higher power; and "self-directing" believers whose framework emphasizes the freedom that a higher power gives individuals to direct their own lives. We also differentiate between these three types of "believers," who seem to have relatively stable spiritual/religious frameworks at present, and spiritual/religious "seekers," who do not currently have stable frameworks.

While initially analyzing and considering these data in more narrative and thematic terms during the course of our analysis, we found Park and Folkman's (1997) meaning-centered model to be consistent with and helpful for explaining different aspects of our own emergent (or grounded) typology. The discussion and analysis here attempt to combine the two frameworks (our own typology and Park and Folkman's model) and to examine critically their ability to make sense of the diverse ways in which, along the life span, religion, spirituality, and meaning-making shape, and are shaped by, an individual's response to a major illness stressor such as HIV/AIDS.

In the analysis we were interested in: (1) how adults with HIV who consider themselves spiritual or religious have developed a framework for global meaning over the course of their lifetimes; (2) how a diagnosis of HIV and other stressful situations have interacted with their global frameworks of meaning; and (3) how these interactions have affected meaning-making coping mechanisms.

## METHODS

### Subjects and Interviews

In this study we used in-depth interviews to explore, retrospectively, religious socialization and attitudes along the life course and in relation to current health-related quality of life of patients

with HIV/AIDS. The respondents were drawn from a larger study of patients with various stages of HIV/AIDS from four sites in three cities (Mrus et al. 2003). All participants recruited and interviewed for this study had completed a battery of related interview instruments (associated with the larger study) in the week prior to the interview. These instruments included the Functional Assessment of Chronic Illness Therapy-Spiritual Well-being Scale (FACIT-SpEx; Brady et al. 1999), the Duke Religion Index (DRI; Koenig et al. 1997), the Brief RCOPE (Pargament et al. 1998), and a pilot version of a religious and spiritual history questionnaire, all of which ask participants to reflect on their religious and spiritual involvements. We asked the Cincinnati-based research nurse for the larger study to refer participants who were interested in discussing further how spirituality/religion has affected their quality of life since being diagnosed with HIV, and interview appointments were arranged by telephone. In about half of the cases, the interview was completed immediately following the participant's completion of the interview from the larger study. All participants consented to the interview procedures and agreed to have the discussion audiotaped.

Each interview was guided by a checklist that consisted of three broad domains with probes: (1) family religious influences in childhood; (2) changes/continuities in faith and faith community; and (3) current spiritual/religious involvements, activities, and beliefs (including coping and quality of life with HIV). The same interviewer (CJJ) conducted all interviews, and all were transcribed verbatim. A brief summary of each transcript was prepared and line-numbered copies were printed for analysis. Although it is difficult to define or determine saturation of data in exploratory religious life histories, we conducted interviews among participants who described themselves as religious or spiritual until we heard no new information about how HIV/AIDS had affected their religious orientations and worldview. We slightly oversampled women (who represented 14 percent of the larger study population). The University of Cincinnati's Institutional Review Board approved the study.

## Data Analysis

Guided by the question of how religio-biography contributed to patients' current subjective quality of life with HIV, we set out initially to describe and characterize participants' religious trajectories and current styles of religious coping. This analysis was conducted in two stages. The first involved an open coding process by a team of experienced qualitative researchers who noted general themes, analytic categories, and issues. Working on the basis of this input and framework, two authors (CJJ and SEL) then continued to reread, analyze, and discuss each of the 19 transcripts. Various models for summarizing and understanding how religiosity was related to coping with HIV/AIDS were developed, tested, and rejected. We eventually settled on a typology of religio-biography/coping styles that allowed us to place all of the participants in one of four categories, named based roughly on the three religious problem-solving styles of Pargament (1988) and the distinction between "believers" and "seekers." In exploring how best to report these results, we found that Park and Folkman's meaning-centered coping framework best captured the processes of religious/spiritual coping of the participants considered here.

## RESULTS

### Subjects

Of the 19 participants with HIV/AIDS (Table 1), 14 were men, 5 were women (including 1 transgender female), and ages ranged from 34 to 62 years (median = 43, Table 1). Fifteen (79 percent) of the participants, including all of the women, were African American. Eleven of the men were homosexual or bisexual, and all of the women were heterosexual. Two subjects

**TABLE 1**  
**SUBJECT CHARACTERISTICS**

Sex ( <i>N</i> )	
Male	14
Female	4
Transgender	1
Age (Range)	34–62
Race/Ethnicity ( <i>N</i> )	
African American	15
White	4
Sexual Orientation ( <i>N</i> )	
Gay	10
Straight	7
Bisexual	2
Year of Diagnosis of HIV (Range)	1981–2000
Religious Affiliation ( <i>N</i> )	
Baptist (Southern or other)	7
Pentecostal	3
Methodist	2
Nondenominational	2
Roman Catholic	1
Other	2
Undesignated	1
Missing	1
Since Being Diagnosed with HIV, Life is. . . ( <i>N</i> )	
Better	7
Worse	2
About the same	4
Unsure	4
Missing	2

(11 percent) admitted to past injection drug use. Fifteen (79 percent) of the participants were Christians, three (16 percent) selected “other specific” or “undesignated” as their religious affiliation, and one (5 percent) had a missing response to the religious affiliation question.

### **Religio-Biographical Patterns**

We identified four religio-biographical patterns. The group names chosen for the patterns describe the current situation of members of each of our four groups, and correspond with outcomes or intermediate points (in the case of the Religious Seekers) illustrated by the model.

#### **Pattern 1: Deferring Believers**

The first pattern we identified to describe how the spiritual/religious global meaning framework of some patients affects how they cope with HIV/AIDS encompasses those individuals who developed a strong spiritual/religious identity (global meaning) based on deference to God early in life, and who seem to have continued to apply that foundation (including finding situational meaning) to cope since being diagnosed with HIV. This pattern is illustrated by the story of Larry.

### ***Larry: God Allows Things to Happen for a Reason***

Larry is a 44-year-old heterosexual African-American male who became very involved in religion when he was invited to attend a Missionary Baptist Church with a friend and the friend's family in eighth grade. The thing he remembers most about the Missionary Baptist Church is the use of drums and other musical instruments.

Larry says that while attending this church, he was "saved":

I confessed Christ in my life, uh, and things started to change . . . my way of, lifestyle started to change.

The importance of Larry's early positive religious history is evident in his description of his initial response to being diagnosed with HIV. He even had his pastor with him when his doctor gave him the diagnosis, and he responded to the diagnosis as follows:

"Don't you worry about anything[.]" I said, "Everything is gonna be all right. I'm just fine, I'm gonna be fine," I said. Cause I know God to be a healer, you know, and if nothing else, I know God is real.

In the three years since his diagnosis, Larry has continued to use spirituality/religion to cope with his disease in many ways. Individually, he finds comfort in passages of the Bible that he calls "healin' scriptures," and he says that he is constantly in communication with God through prayer. Here, he describes how he experiences the presence of God through prayerful visualization.

I go unto the holy of holies, that mean[s] I forget all about myself, and, I begin to concentrate on God, and I take my mind there, and I, I can visualize Him, and you know, I see him as this light, and that's something I do, I get in his presence. And I can tell a difference, because I feel anointed, I can feel his presence.

Larry's religious framework also continues to provide him with social support, as it did at the time of his diagnosis. He continues to go to church "three times to four times a week." He has not shared his diagnosis with everyone, but the people in the church who know about it have been very supportive. They continue to reassure him that "God is a healer." Corroborating his deferring religious style, Larry says that, given a choice, he would not change anything in his life right now because "God allows things to happen for a reason." He believes that his illness has caused him to become closer to Christ and that other people now "see the Christ" in him. In this we can see not only how religion has helped him cope but, reciprocally, how his illness has also strengthened his religiosity.

### ***Other Subjects in Group 1 and Application of Model***

With regards to Park and Folkman's model of global and situational meaning, Larry and the other four subjects in this first group valued Christian religious involvement as a large part of their global meaning prior to being diagnosed with HIV. In their childhood recollections of church involvement, music was a common and positive theme, and they seem to have shared a strong emotional response to it. Another subject in this group, "Ron," fondly recalls traveling around to different churches with his mother, who was a gospel singer. He says he was also in the church choir and he "loved it." "Bobi's" father was a minister and her siblings were in the choir, and she says, "I like the church, I like the church." "Joan" describes being baptized in a creek and receiving candy after Sunday School as good childhood memories.

When confronted with the situation of being diagnosed with HIV, these subjects typically appraised the disease as a challenge, but nevertheless found this challenge congruent with a religious worldview (or theodicy) in which God would help them to solve problems, so they were able to fit the situation into their global meaning with relatively little distress. For instance,

Joan says that when her doctor told her that she had HIV, “I just started praying.” Ron used his religious beliefs to help him cope with his diagnosis of HIV by thinking about joining his (deceased) mother soon. Bobi was initially suicidal, but describes passing the burden to God after feeling His presence and understanding His message that He had plans for her. Paul says that when facing the diagnosis of HIV and other challenges, “I always remember about God.”

As shown in Larry’s story, subjects who fit this pattern tend to ascribe their ability to cope with HIV to a renewal of their (preexisting) faith and religious activity. Bobi also attributes her survival and positive attitude to God, saying, “I couldn’t have got through this without God and my family.” Joan attributes an improvement in her life since the diagnosis of HIV to increased prayer. Ron finds hope in his religious beliefs, saying that without religion, “I don’t think I would be even concerned about my health.” Paul visits different churches on occasion and has recently found comfort in the peaceful atmosphere of the Mormon Church, but continues to rely mostly on his individual prayer, faith, and Bible study for religious/spiritual coping and global meaning.

### **Pattern 2: Collaborative Believers**

The second pattern is one in which an initially positive childhood experience with (deferential) religion was challenged as a source of global meaning, but acceptance and resolution were achieved through finding new global meaning in a collaborative relationship with God and/or other transcendent ideals. This pattern is best illustrated by the story of Thad, whose reflections on religious and spiritual coping open the article. Thad generally had positive experiences with traditional religion in childhood, which provided him with a background for finding meaning through religion/spirituality, but Thad has had to adapt the spiritual/religious framework in which he grew up into a less traditional form in order for it to continue to work for him. Thad grew up in the Catholic Church, but now uses some similar values obtained from an ASO, instead of the church, to provide him with “spiritual” global meaning in his life congruent with his specific issues, including divorce, homosexuality, and HIV.

#### ***Thad: This is Where I’m Supposed to be***

Thad, a 47-year-old white homosexual man, was diagnosed with HIV in 1997. As a child, Thad attended a Catholic Church with his family and went to Catholic schools. When asked what God and the church meant to him growing up, Thad’s reply focused on the importance of Catholicism in his individual, family, and community identity:

I think it was the whole realm of being accepted. It was something that was structured, something that was needed to have a perfect family. Um, it was expected. It was part of being part of my family.

Thad felt that the Catholic Church taught that homosexuality was wrong, but he knew that he was “different” (attracted to boys) from an early age. His memorable experiences with religion during his childhood include meeting a lot of people who are still his friends. He says that these friends also believe that the church is too structured, and uses the example of marriage. He estimates that out of his large wedding party (despite his homosexual orientation, Thad did marry a woman), “19 are divorced, one never married, and one [is] still married.”

Around 1986, after eight years of marriage and traditional Catholic family life, several things happened that caused Thad to turn away from the Catholic Church as the source of structure and meaning in his life. He got divorced and divulged his homosexuality, which he describes as a “double whammy” in the eyes of the church. Also around that time, his mother went into a nursing home, and Thad felt that she was “dropped” by the church, both because of his divorce and homosexuality and because she could no longer contribute money to the church. Thad continued



to accept basic Christian standards for behavior toward other people, but felt ambivalent about what kind of framework his beliefs could fit into more comfortably than into Catholicism.

Thad tested positive for HIV in 1993 and was given six months to live. At the time, he didn't recognize either a guiding higher being or a punishing higher being in his life, but now he acknowledges, in retrospect, "there had to be something there guiding me to know where to go." Thad still had not found a new framework of global meaning, but seems to believe now that there must have been some kind of physical force at play at the time to keep him from giving up.

After accepting his diagnosis, Thad strongly felt "a challenge for a new direction in life," which led him to become involved in an ASO. It seems that his involvement in the ASO finally gave him a new collaborative "spiritual" global framework in which he truly believed, and that was congruent with his true identity as a homosexual man who was not sure that there was a God, but who believed in the importance of helping and supporting other people. He says:

I think it made me aware that, um, I was probably not prior to finding out, probably not where I should have been. I was not fulfilling what I would consider my calling, I wasn't doing what I was expected to do. Um, whether it [was], like I said, morally right or not didn't matter. I wasn't doing enough of what I was supposed to be doing: giving back, learning, accepting, dealing with fatality. [Mortality] is part of life, and it's not necessarily the fault of what you get, just the progression of anybody's life.

Since starting to work at the ASO, Thad says that he has gotten to know a whole new population and has developed a new perspective. Part of that includes being more open about his sexuality and his HIV status, and part of the new perspective seems to be spiritual. He says his religious self was going downhill since the divorce, and the "organized structured thing" wasn't part of his life anymore, but now he thinks "[y]ou could have a spiritual aspect to you without the structured aspect." Although Thad's new framework of global meaning does not have the outwardly imposed structure of Catholic religiosity, it seems as if Thad needed to find some kind of community that would accept him for himself before he felt comfortable completely leaving the old framework behind.

When asked if he still feels that he is on "the right path," Thad admits that working full-time with HIV+ individuals can become "too much," but even when he leaves, he always comes back. Asked why, he gives a clear sense of the collaborative religious problem-solving style that characterizes Thad and his subtype.

Interviewer: What are you coming back to?

Thad: I guess to me that's the comfortable fit. This is where I'm supposed to be. I think it's a combination. I think that, 50% of it is probably past experiences, past roles. And then there's some guidance in there of this, this higher power telling me that this is your fit, this is where you belong, um, and then I think it also goes into the emotional part where, even if there isn't this higher thing, there's something inside me that says, this is where you belong. And that's what you're supposed to do.

### ***Other Subjects in Group 2 and Application of Model***

Thad and the other subjects in this second group started life with a framework of global meaning based on deferential religion, as taught by the churches of their childhoods. Somewhere along the line, usually long before being diagnosed with HIV, they were confronted with a situation from which they experienced a situational meaning that challenged their global meaning. For several of the subjects, including Thad, recognition of their homosexuality caused a clash in meaning with the teachings of the church.

Like Thad, Scott went to church for a sense of community, but believed that "their doctrine is not my doctrine." Like subjects in the first group, Stan has fond memories of the music at his childhood church, but says that he was not really into religion "as it is taught." He did not feel that the God he believed in would condemn homosexuality, as the church taught. Lewis remembers finding some comfort in his early exposure to religion, but "then there was some fear with it" when

he did not relate to the people who would “scream and holler and sweat” when overcome by the Holy Ghost. He also didn’t believe the church when they suggested that HIV was a punishment from God, because “I don’t believe that the God I serve is that mean.” Mary remembers the church experience on Sundays as “really nice,” but did not like the way religion divided her Methodist mother and her Baptist father.

As described in Park and Folkman’s model, subjects in this group attempted to reconcile their senses of global and situational meaning with coping mechanisms, including problem-focused coping, emotion-focused coping, and reappraisal of meaning. In order to make the situational meaning congruent with their global sense of meaning, either the situational or the individual’s global meaning had to be transformed. With a history of ambivalent feelings about religion, Lewis turned to alcohol and drugs after being diagnosed with HIV. An epiphany occurred, however, while he was watching a Donna Mills movie, in which her character’s family convinced her to get treatment for addiction, and Lewis realized that that was also what he needed. It was through the addiction recovery process that he discovered a spiritual/religious framework of global meaning that fit him:

It’s actually the recovery process that’s made me think a lot about God’s personality, my relationship with God. I always knew about the Father, Son, and Holy Ghost, but, to be actually introduced to the Spirit, this is like, a new process for me.

Scott found a new religious/spiritual framework when a friend gave him some literature to read about the Assembly of Yahweh. He says it sounded “a little truthful” to him so it replaced the Baptist framework in which he was uncomfortable, but he also studies other religions, such as Islam, Buddhism, and Hinduism. Stan has reached an accommodating global meaning through accepting himself and the things that have happened to him in the past (including abuse) to achieve inner peace.

Currently, the subjects in this group appear to have achieved a transformation in global meaning that has allowed them to reconcile the meaning of challenging events in their lives (including diagnosis with HIV) with their sense of a collaborative religious/spiritual global meaning. As can be seen from their descriptions of their current situations and plans for the future, this struggle has allowed them to reach an endpoint of acceptance and resolution (Figure 1). After finishing his rehabilitation program, Lewis returned to church with his new view of spirituality. With his new understanding, he finds strength in reading religious material and talking to his pastor and his (very spiritual) sister. Since accepting the doctrine of the Assembly of Yahweh, Scott says, “I feel that I have my life right.” Stan describes getting in touch with his “internal being” at a church healing service and finds strength both from support groups and people at his church. Mary says that she goes to church when she feels the need to go, but that since having a personal talk with “her” God, she is now the happiest she has ever been.

### **Pattern 3: Spiritual/Religious Seekers**

The third group of subjects differentiates themselves by their ambivalent current spiritual/religious situations, which fit more with the concept of spiritual/religious “seekers” than “believers.” By *seeker* we refer to those who consider themselves religiously or spiritually oriented but unfulfilled or adrift. Group 3 tends to describe positive experiences with the church during their childhoods, but like Group 2, Group 3 may have been skeptical about church doctrine. Members of Group 3 have not reconciled their beliefs to a point where they can effectively use their spirituality/religiosity to cope with HIV. Group 3, epitomized by Blake, seems to still be in a stage of rumination or struggle (Figure 1).

***Blake: I'm Trying to Get My Life Together***

Blake is a 34-year-old homosexual African-American male who moved to Cincinnati from Alabama about seven months prior to the interview and works as a traveling magazine and Bible sales agent. When asked about his childhood religious history, he says that he was raised by a “good ole Southern Baptist” family, although his father was “very abusive,” particularly toward his mother. They went to church every Sunday, and Blake says he:

Had a blast . . . I would sing in the choir . . . and I was just involved in everything and I loved it.

When asked if he considered himself a religious or spiritual person, he responded, “I did, until I started having them thoughts about men.” Uncomfortable with the conservative religious framework of his parents, he left home at age 16.

Blake learned of his HIV diagnosis after having a “very bad cough” and developing a fever four years ago. His ex-wife, a nurse with whom he was living at the time, had encouraged him to see a doctor. He says he was “in denial” of the idea that he might have AIDS despite the fact that he had been in a gay relationship for seven years with a man he knew to have HIV—because they had practiced safe sex except for a “couple of times . . . like twice.” He had broken up with this person by the time he had found out about the HIV. He reports feeling “devastated” when he found out. He called his sister and “was just crying big time.” He says:

The first thing I thought about was, “What is everybody going to say?” I was freaking about what other people were gonna say instead of my own feelings. The major problem I had with finding out was “what is everybody going to think?”

He says of his father (who did not learn of Blake’s HIV status until later), “we never got along,” and “I never lived up to his expectations.” Blake admits to feeling suicidal more than once in the past.

Eventually, Blake began taking HIV medications and was assigned a case manager. He says he did not get counseling at the time:

But I wish that I had counseling now because I get depressed a lot even though I got a new place and everything’s going great, [I] always find negative things to dwell on that keeps [sic] me down. I don’t know why I do that.

Blake says he is not currently churchgoing. He last attended services approximately six months ago, but he is thinking about going to the Baptist church across the street.

Interviewer: Why would you go?

Blake: So that God would know that I do honor him, praise him spiritually . . . and I would want him to give me pointers, feedback ‘bout being with guys. I want him to know that. This is not by choice. I can’t stop.

Blake criticizes today’s churches. “A lot of the churches that you attend now, you gotta have some money”—but he says of his current situation and the good things that have happened to him:

I know that they wouldn’t have happened if it wasn’t for God. It’s like He’s put me through a test, and I’m passing it, I’m trying to get my life together, to go to church to show Him my appreciation.

***Other Subjects in Group 3 and Application of Model***

Spiritually oriented and occasionally attending church services, this group of seekers—not unlike the baby boom “generation of seekers” (Roof 1994, 1999)—expresses doubt, ambivalence,

and criticism toward organized religion. When asked how he would describe his current religiosity, Eddie, another respondent from this group, said:

I would definitely say it could stand to be renewed. I was taught a long time ago, you're not supposed to question God. Well, I do. [I] wanna know why . . .

Theo tries to sound optimistic about his religious abstinence, but gives away his uncertainty and fear:

I've been a good person all my life so I don't think I'm goin' to hell, unless God sends me to hell for having HIV. I quite often have heard people say that.

Like other members of this group, Jean, who struggled with her religious family over her "bad girl" lifestyle at the time of her diagnosis of HIV, seems hopeful that things are getting better with time:

You have to keep yourself goin' . . . I'm not struggling with it [thoughts about death] . . . But I think, I can't help to think about it. When I first found out, it was really hard. And now, as time been pass, I'm so much better at it.

In Park and Folkman's model, Blake and the rest of this third group of subjects have not achieved acceptance and resolution, in contrast to the first two groups. Rather, their current stage could be interpreted as rumination. They have begun the process of using coping mechanisms, including meaning-making coping and religious/spiritual seeking, to reconcile their senses of global and situational meaning, but that global and situational meaning have not yet become congruent. Neither is it clear that their eventual global meaning-making framework will be religious.

#### **Pattern 4: Self-Directing Believers**

Not everyone who we interviewed was raised with a deferential religious framework of global meaning, so not everyone appraised the situational meaning they extracted from being diagnosed with HIV within such a framework. We found that the only subjects who did not seem to have anything positive to say about their experiences with religion during childhood also seemed to share a self-directing style of spirituality that has, for the most part, allowed them to incorporate stressful situations (including HIV) into their preexisting global framework of meaning because their frameworks do not depend on passive deference to a benevolent higher power. Group 4 subjects do describe several ways in which they use spirituality to cope with HIV, but their practices lie the furthest from traditional concepts and practices of Christianity, consistent with Pargament's (1988) description of a self-directing religious coping style. Most of these subjects endorse the idea of deism, or one higher being, but they tend to describe very individualized spiritual experiences that are not grounded in traditional Christianity. Lisa is our prototype for this group.

#### ***Lisa: What Else is New?***

Born in Pennsylvania, Lisa describes herself as a Quaker at heart (full of "peace and love"). Her parents separated when she was five, and her mother brought her to Cincinnati. She says they were never consistently churchgoing, and she had bad associations with religion in her youth because an abusive, "mean" grandmother was the adult who generally took her to church. Her mother was also physically abusive. Lisa left home at 18, "running from a situation" after her stepfather raped her. She had several children, was abused by her husband, got divorced, was gang-raped, and then gained weight (reportedly to make herself less attractive).

After all that, she says that when she first found out she was HIV positive:

Lisa: I just laughed.

Interviewer: You just laughed. Did you know what it was?

Lisa: Yeah, I didn't know nothin' else to do but laugh. Why? Because I've had a lot of things to really happen to me, hardship. Been beatin', attackin', gang rape, so, what else new? It was just like a joke! What else new?

When asked if she was worried about dying, Lisa said:

You never worry about dyin' because you gonna always die. I never worry about dyin'. My problem was, I had already died, mentally, on a lot of things in life.

When asked if her spirituality has changed since learning of HIV, Lisa said:

I feel I have a better appreciation of myself, that someone cared about me, that the government cared about me, even though it should seem like I was dying all the way around. It makes me appreciate the flowers, the trees, the birds and the bees.

Involving a heightened appreciation of nature, Lisa's self-directing, though deistic, religious style can also be seen in her religious interpretations of dreams, her prayer practices, and her self-extraction from the social world. Lisa interprets a dream of seeing the sun from inside the grave to indicate that she is meant to live. Lisa also states that she prays often, mostly in the shower, to be "cleansed in her inner heart soul and mind," to ask God to forgive her if she has hurt others because "bitterness and hatred kills you more. Keep the faith, there's God up above." In describing her spirituality, Lisa notes that she has decided that excessive eating is bad for her and that letting people touch her is bad for her. Yet, with so much pain and suffering she feels (somewhat in a collaborative vein) that it has to be "the Spirit" that keeps her alive. She describes how she felt it rise in her at her grandson's football game and gave her the strength to walk up the bleachers in front of her ex-husband, when she had not previously been able to walk without assistance.

Lisa says she had been going to a church for about three years, but once word got out about the kind of medicines she was taking, she felt rejected, and so she stopped going. She explains:

It's not God I don't trust, it's people that I've had such a hard time, all my life, that I don't trust. I don't hate people, I don't like a lot of people's ways, I can't change that, but I love God dearly.

### *Other Subjects in Group 4 and Application of Model*

Another subject in this group, Jeff, describes his spirituality as "like Star Trek," saying, "I believe more in my spiritual being than in my physical life." Dirk describes an early recognition of his unique spirituality when his brother died:

I reached out with all my soul to save him. I was doing something spiritually. I can feel people's pain, or give pain.

Dirk continues to exhibit this kind of spirituality now in coping with HIV:

Seeing people dying, knowing when they're gonna die, or smelling death on 'em. I could tell her [his nurse] all you gotta [do] is think of me, and I know when you're coming. And my healing, I got both my legs back, got the blood clogs [sic] out . . .

Like the first group of subjects, this final group was able to fit having HIV into their framework of global meaning without adjusting their framework much. However, the preexisting framework

of global meaning for these subjects differed from the deferential religious framework of the first group in which a benevolent God only allows things to happen if they will lead to a good outcome. For this group of subjects, global meaning involves a more self-directed spirituality/religiosity. They never really used religion to make everything seem okay in the grand scheme of things but, rather, believe in focusing on life one day at a time and rejoicing in the little things in life. HIV is just one more problem to deal with, which they seem to face in the same way that they have faced prior problems, without a major shift in global meaning.

In summary, two of our groups (Deferring Believers and Self-Directing Believers) appear to have had early and relatively strong frameworks of religious/spiritual global meaning that were not significantly challenged before they were diagnosed with HIV, and that allowed them to accept their diagnoses with the “not stressful” outcome on the left side of the model. Group 2, the Collaborative Believers, has advanced through the steps of the model to the outcome of “acceptance and resolution.” Finally, Group 3, the Religious Seekers, seems to fit Park and Folkman’s intermediate stage of “rumination” (see Table 2).

**TABLE 2**  
**RELIGIO-BIOGRAPHICAL PATTERNS**

Group	Group 1: Deferring Believers	Group 2: Collaborative Believers	Group 3: Religious/ Spiritual Seekers	Group 4: Self-Directing Believers
<i>N</i>	5	7	4	3
Prototype	“Larry”	“Thad”	“Blake”	“Lisa”
Positive spiritual/ religious global meaning before diagnosis of HIV?	Yes	Yes	Yes	No
Challenge to spiritual/religious global meaning before diagnosis of HIV?	No	Yes	Yes	N/A
Result of initial appraisal processes upon learning of HIV diagnosis	Situational meaning congruent with global meaning	Situational meaning incongruent with global meaning	Situational meaning incongruent with global meaning	Situational meaning congruent with global meaning
Further processing		Attempts to alleviate distress (coping)	Attempts to alleviate distress (coping)	
Results of further processing		Changed situational and/or global meaning	Unable to resolve situational and global meaning	
Outcome	Not stressful	Acceptance, resolution	Rumination	Not stressful

## DISCUSSION

In this article, we sought to explore patterns of religious meaning-making coping with HIV through brief life history interviews with a small cohort of men and women living with HIV who consider themselves spiritual or religious. The brief religious biographies we obtained and qualitatively analyzed suggested a variety of religious developmental life trajectories, as well as the role religion played as a major meaning-making framework (Park, in press) in coping with the diagnosis of HIV and other stressful situations. While some of our participants (Group 2) apparently experienced challenges to and deviations in their religious orientations, many of them eventually made adjustments. Many of the others (Groups 1 and 4) were able to maintain their frameworks and orientations (some after brief crises) with little reported distress. A smaller group (Group 3) that we labeled “seekers” had drifted away from their religious upbringings and, though expressing the need for spiritual or religious renewal, neither currently use nor benefit greatly from religious or spiritual orientations.

We believe that the religio-biographical approach used here provides an important life-span perspective on the reciprocal relations between major stressors such as HIV diagnosis and the ability to maintain a sense of coherence or meaning (or to make meaning if assumptions are shattered). This approach not only allows one to see the considerable religio-biographic variation among those with HIV who consider themselves religious or spiritual, but it also clarifies what having HIV/AIDS means for an individual or why certain forms of religious problem solving or coping are used or are appropriate/inappropriate at given junctures in an individual’s life. Clearly, for counselors like Thad and others who may attempt to address their patients’ religious and spiritual needs, such biographical information is a key part of history taking and decision making.

Lending general support to the cognitive and transactional stress model of Park and Folkman (1997), our findings allow for a fuller conceptual representation of the ways in which crises and major orienting systems interact in an individual’s life experiences. However, based on retrospective self-reports these religio-biographies can also be understood in terms of narrative theories and models. In this article we have been largely interested in the religious biography as an accurate account of formative experiences, religious meaning frameworks, and challenges to those orientations. We have not used a narrative perspective, i.e., one concerned with the particular kind of story, audience, and interaction involved in the biographical interview. Nevertheless, in further considering the significance of the results it is helpful to first briefly consider “meaning” from a narrative perspective.

Although the growing body of qualitative research on HIV/AIDS includes a number of studies of quality of life (Bloom 2001, others), spirituality, (Hall 1998; Fryback and Reinert 1999; Ezzy 2000), resilience (King et al. 2003), and other key meaning-centered themes (Mosack et al. 2005; Davies 1997), few have examined these constructs in life historical, narrative terms. Life history narrative approaches consider meaning-making and coherence development as characteristics of key life narratives, such as self-accounts of career development (Linde 1993; Mishler 1999) or accounts of trauma and its effects on faith (Ganzevoort 1998b). Linde (1993) has suggested, for example, that meaning or coherence in people’s life stories lies in the choice and sequential or temporal ordering of life events as told. Such accounts can be considered both structured and fluid. Through the ordering of events (partly guided and shaped by the interviewer), the individual expresses her understanding of what her life means and how she arrived at this particular situation. The more fluid nature of the narrative becomes apparent when a significant new event or “story” is added to the life history (say, a new job, or a diagnosis of HIV). Under such circumstances, the larger life history must undergo revision to express a current or updated understanding of what one’s life means (Linde 1993:25).

Ganzevoort (1998a,1998b) similarly uses a narrative approach to examine the influences of crisis and coping on faith. His approach emphasizes not only the bidirectional nature of the relationship between coping and religion, but also the way in which key religious or identity

narratives frame and influence actors' interpretations and representations of adverse events. The creation of meaning and "meaning-making" are manifest in the narrative itself and in its capacity as a performance and communicative act to attain certain socially defined goals (respect, socially acceptable identity, etc.) (Ganzevoort 1998a, 1998b). In the more cognitive-behavioral approaches represented by the model explored here (Park and Folkman 1997), meaning and meaning-making refer to practices, orientations, and events that reportedly occurred before and were meaningful prior to their narrative (re)telling. Both approaches recognize the importance of the ability of the individual to "make sense" of crises and both recognize the dynamic, bidirectional relationship between religious coping and adversity.

From the narrative perspective, however, the life stories produced by individuals who considered themselves spiritual or religious, and who have maintained or retained positive religious or spiritual orientations and problem-solving frameworks in relation to HIV and other life stressors (Groups 1, 2, 4), could be thought of as more formulaic or culturally prescribed. As in other domains, there are conventional genres of story telling and accounting giving. In this study, because of their self-definition as religious or spiritual, and their self-selection as persons willing to discuss the role of spiritual and religious factors in their lives, we could expect participants' religio-biographies to use the accepted cultural forms or prototypes of such narratives. Although little studied in life-history narrative terms, religious stories of religious people, for example, Christian evangelical salvation stories, often express and elicit hope (in response to suffering) as one of their defining characteristics (Ganzevoort 1998b; Luther 1992). Keeping this and the fluid nature of narratives in mind, it is possible to interpret the apparent forms of religious meaning-making *coping* exhibited by many of our participants (Groups 1, 2, 4) rather as *narrative competence*, or the ability to tell a coherent story about how (in this case) individuals relate the presence of God to their sense of purpose and meaning in life. Future research should not only explore other kinds of meaning-making frameworks (e.g., nonreligious or non-Christian) but should also consider the role of local cultural norms in the formation of key life narratives.

Distinguishing between "coping" and "good religious story-telling" based on our data is difficult without more objective measures of stress and well-being, and without a better ethnographic sense of what constitutes normative coping or a "good" story in our participants' communities. Because of these limitations and because everyone we interviewed considered himself or herself spiritual or religious, we are unable to resolve this issue and to answer questions about forms of coping (or story-telling) among persons with HIV/AIDS who do not consider themselves religious or spiritual. By interviewing only those religious/spiritual persons who were willing to talk about their religious upbringing and HIV/AIDS we may also have missed other important religio-biographical coping styles. For example, some who consider themselves to be religious may not want to discuss such issues because of feelings of persecution or religious-moral shame.

We also note that the religious life histories, which we elicited and have called religio-biographies, were relatively brief, and in their focus on spirituality and religion along the lifespan, they have likely given short shrift to other significant meaning-making frameworks and coping-related themes (the development and social acceptance of their sexual identity is one example). Although we tried to ask similar questions of all of the interviewees, the richness of their answers varied widely from short sentences and phrases to well-developed stories and examples, especially with regard to their childhood spiritual/religious experiences. We did not employ member-checking, a recursive process often used in qualitative research. As in previous qualitative studies in the literature, interpretations of the data have been integrated with information from the literature, which can be both a strength and a limitation (King et al. 2003).

In conclusion, we studied 19 patients with HIV/AIDS and discovered four patterns to interpret the ways in which religio-biographies influenced the use of meaning-making to cope with HIV/AIDS. Our results have implications for both coping and narrative theory as well as health



care practice. They give some empirical support to Park and Folkman's model for meaning-making coping, while adding to the understanding of religious developmental narratives in responses to chronic illness. Because there is some evidence that meaning-making coping leads to improved mental health (Park et al. 2001) and, potentially, improved quality of life, it is important to consider different patterns of meaning-making when caring for individual patients facing chronic and/or terminal diseases such as HIV.

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#### NOTE

1. We are following Pargament (1997; Hill and Pargament 2003) in defining spirituality as the "search for the sacred," or the "process through which people seek to discover, hold on to, and when necessary, transform whatever they hold sacred in their lives." As such, *spirituality* may or may not unfold within a religious context (Hill and Pargament 2003).

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