FRAMEWORKS FOR ASCRIBING MEANING:
AN EXAMINATION OF ADOLESCENTS' LIVED EXPERIENCES OF ILLNESS

by

Eboni Chanel Winford

A dissertation submitted to the faculty of
The University of North Carolina at Charlotte
in partial fulfillment of the requirements
for the degree of Doctor of Philosophy in
Health Psychology

Charlotte

2013

Approved by

Dr. Amy H. Peterman

Dr. Jennifer B. Webb

Dr. Charlie L. Reeve

Dr. Jillian A. Tullis

Dr. Joanne Robinson

ABSTRACT

EBONI CHANEL WINFORD. Frameworks for ascribing meaning: an examination of adolescents' lived experiences of illness. (Under the direction of DR. AMY PETERMAN)

The importance of religion and spirituality (R & S) in adults' experiences of illness is well established. Findings range from lower reported levels of distress following diagnoses of illnesses to adults' use of these existential frameworks to understand life events. However, few such studies include adolescents, a group facing a series of normative, but potentially stressful changes. Most quantitative studies of R & S, adolescent health behaviors, and/or psychological well-being do not address R & S in the context of serious physical illnesses, and they do not allow adolescents to describe how meaning-making occurs during times of illness or whether R & S may be involved in this process. The current study addressed some of these limitations. Twenty-six undergraduate students provided stories of their illnesses and were asked to describe what R & S mean to them. Participants also reflected on issues related to meaning-making and the overall effect of illness on their lives. Lastly, participants were asked if R & S played any role in their meaning-making process. Results revealed that participants viewed R & S as multidimensional concepts characterized by beliefs, behaviors, and social connections. The use of social comparison and the Internet represent sample meaning-making categories, and responses such as "there's a reason for everything" suggest that R & S did play a role in participants' illness experiences. Consideration was given to issues of rigor as well as to researcher bias. Limitations, strengths, and implications of these findings are discussed in addition to potential future research directions.

ACKNOWLEDGMENTS

I would like to acknowledge and thank the following people and organizations for their assistance in my development as a person, a clinician, and as a researcher over the last six years. First, I'd like to say thank you, thank you, thank you to my chair and mentor Dr. Amy Peterman. You have always been there to offer guidance, support, an ear, a shoulder, and a gentle push when needed. I'm grateful to have experienced these past six years in such great care. Thank you Dr. Charlie Reeve for taking me under your research wing and for forcing me to think in ways that were challenging (and sometimes just plain hard!). In doing so, you helped me become the researcher I am today. Thank you to the additional members of my committee: Dr. Jennifer Webb, Dr. Jillian Tullis, and Dr. Joanne Robinson. With your direction and assistance, I have reached such an important milestone in my life. Thank you for being so open, encouraging, and approachable. Your doors (real and virtual) were always open for me, and I'm grateful for that.

In addition, I would like to acknowledge the Graduate School of UNCC and the Herschel and Cornelia Everett Foundation for their generous contributions to my graduate education. Receiving the Herschel and Cornelia Everett Foundation First-Year Graduate Fellowship was such an honor, and I just hope that I have met and exceeded your expectations for this fellowship. Thank you to the faculty of the Health Psychology Program for thinking enough of me to nominate me for this fellowship; for providing funding on numerous occasions for me to attend conferences and to conduct research, including this project; and for shaping me into the clinician, researcher, and teacher who writes this. Thanks to Dr. Lawrence Calhoun for his role in my pedagogical development.

All of your insight and feedback is valued greatly.

Thank you Tierra Caldwell and Heidi Haynes for your assistance with this project. I'd especially like to thank Amanda Hardy D'Angelo for your help with this endeavor and for keeping me sane over the last six years. Your thoughts, prayers, and sisterhood will forever be remembered. Of course, I would be remiss if I did not acknowledge the individuals whose experiences are contained within. To my participants, thank you for entrusting me with your stories and your voices. Without you, I would not have the document that I now call my dissertation.

Last but not least, I would like to thank my family. Not many people are blessed to say that they have a husband, two sets of parents, three grandmothers, a grandfather, five sisters, and a brother who have prayed for, encouraged, and poured into them over the course of their lives. I can say that with pride and gratitude. I thank God for you daily and am so glad that I get to walk through life with you supporting and uplifting me. Thank you!

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CHAPTER 1: BACKGROUND AND SIGNIFICANCE

Introduction

Illness has been described as a "biographical disruption" (Bury, 2001, p. 264) that causes an individual to reevaluate his or her life's purpose and identity. This disruption causes individuals to seek answers to questions such as "why me?" Existential questions such as this are often classified as religious or spiritual in nature because they cause a person to evaluate the very meaning of his or her life. Biographical disruptions that lead to such existential questions may affect a person's identity no matter his or her age; however, these disruptions may be particularly salient for adolescents who are just beginning to engage in the process of identity formation (Erikson, 1968). Adolescents who experience chronic illness, in particular, are said to experience a "dual crisis" because, in addition to accomplishing a series of normative developmental milestones such as changing bodies, attaining autonomy, evolving social relationships, developing cognitive abilities, and achieving academically, they must also negotiate the demands that are associated with the diagnosis and treatment of an illness that may or may not be life-threatening or visible (Woodgate, 1998, p. 210).

Religion and spirituality (R & S) have been proposed as frameworks in which individuals foster a sense of identity and ascribe meaning to their lived experiences (King & Benson, 2006; Mattis, 2002; Park, 2005). Issues of meaning, purpose, relationships, and identity are especially salient during the time period between childhood and adulthood as adolescents seek to establish their places in the world. King and Benson (2006) suggest that these individuals seek out opportunities to generate forms of meaning and order. With the onset of formal operational thought, which peaks around age 15, adolescents become capable of abstract and critical reasoning and thinking. According to these authors, R & S provide the very opportunities for adolescents to utilize their newfound intellectual capacities and to analyze and question beliefs, values, and previously ascribed meanings in order to consolidate their identities. R & S, they assert, provide answers to the existential questions such as “who am I?” and “why am I here?” with which young people often grapple. One of the ways in which religion, in particular, provides answers to such questions is via religious doctrines, which offer adolescents an understanding of their self-worth. For example, many doctrines provide explicit references to the ways in which one’s higher power views the individual (e.g., as beloved or chosen by the Creator, etc.), and these references may directly influence the process of identity development. Additionally, religion may provide answers to these existential questions through the worldviews, values, and beliefs of religious traditions. These religious traditions explicitly offer beliefs, moral codes, and values that may be useful for adolescents who are attempting to create a sense of meaning, order, and place in the world.

Moreover, King and Benson (2006) suggest that participation in religious and spiritual traditions build an adolescent’s sense of fidelity or commitment to others, to ideologies, or to roles, and these three commitments are essential components of a positive identity (Erikson as cited in King & Benson). The authors also assert that adolescents’ search for meaning, purpose, and connectedness occurs not just through affiliation with a specific religion but also through the process of spiritual development. This process involves the growing of "the intrinsic human capacity for self-transcendence, in which the self is embedded in something greater than the self" (p. 384). Like G. Stanley Hall (1904 as cited in King & Benson) who believed that religious and spiritual development during adolescence was a completely natural, normal, and universal part of adolescence, the authors also believe that the process of spiritual development was a logical way for adolescents to explore their purpose in life, their beliefs, and their places in the world. The authors conclude that, while adolescents do have several options available for finding a sense of meaning, belonging, and identity such as families, sports, and volunteer work,

> "In sum, religion offers an ideologically, sociologically, and spiritually rich context for identity formation. Religion is seen as affording a potent milieu for identity development through providing explicitly prosocial worldviews, values, and morals; fellow participants as models or sources of encouragement, teaching or inspiration; and spiritual experiences and environments that help youth internalize and integrate a sense of belonging and meaning." (King & Benson, 2006, p. 387)

Although several quantitative studies have established relationships between adolescents' R & S and a wide range of outcomes, specifically those related to health-related behaviors, there is currently a dearth of information that moves beyond simply establishing correlational relationships into the realm of understanding *why* these relationships are present. Qualitative studies in which adolescents are given the opportunity to reflect on what R & S mean to them may provide insight into potential explanations for these relationships. Furthermore, understanding the meaning-making process that may occur for adolescents within the context of R & S may also provide explanations about these mechanisms. Perhaps it is that R & S allow adolescents to more clearly understand their purposes in life, their beliefs, and their values, and this, in turn, influences the decisions they make and the way they respond to and understand events in life such as illness. Qualitative inquiries that ask adolescents to reflect on how R & S function as sources of meaning during times of illness may also provide insight into *why* the relationships between R & S and adolescent outcomes are found. Currently, few, if any, such studies exist. As such, researchers remain in the dark about how adolescents understand R & S and about how they utilize R & S as frameworks for ascribing meaning to their lived experiences.

One of the key reasons to examine R & S and illness among adolescents is that the process of identity formation occurs during the adolescent years (Erikson, 1968). This sense of identity, Erikson asserts, is fully developed when one overcomes crises in three areas: occupation, sexual identity, and ideology. The ideological crisis is most relevant for the present study because it includes, among other things, one's R & S beliefs. Furthermore, in the face of illness, one's identity becomes disrupted and is challenged, and this disruption may be particularly salient during the time period of adolescence when the normative process of identity formation is already at work. Examining R & S's influences on illness during the period of adolescence seems appropriate because it is during this time that theorists such as James Fowler (1981) argue that an individual's ability to cognitively understand and evaluate R & S ideals and beliefs emerge. Furthermore, "…it may be especially important to examine conceptions of spirituality among adolescents and young adults because at this life stage, self-identities coalesce, ways of thinking about the world become more reflective and nuanced, academic and career plans grow more realistic, and notions about how they want to conduct their family life take shape" (Rich & Cinamon, 2007, p. 10).

Given this information, health psychology may benefit greatly from the inclusion of qualitative methods such as illness narratives that are commonly utilized in other social science disciplines to garner further knowledge regarding the ways adolescents understand R & S and their potential effects on experiences of illness. Because health psychologists attempt to understand how biological, psychological, and social factors interact over time to influence both good health and poor health or illness, it would make sense for health psychologists to use methods such as the illness narrative. This method would allow health psychologists to not only understand how adolescents' illnesses impact various aspects of their lives such as family and school life (i.e., social factors), but it would also allow health psychologists to understand how R & S, which may be classified as either psychological or social factors, influence these illness experiences.

Rationale and Purpose

In a previous literature review of 24 empirical studies and eight literature reviews examining the relationship between R & S and health outcomes among adolescents (Winford, unpublished manuscript), two points arose that are relevant for the present study. Chief among these points was that none of the participants in the studies were asked to define R & S. Although two studies did include qualitative components (Cotton et al., 2009; Pendleton et al., 2002), the authors did not expressly ask participants to conjecture about their definitions of R & S. Given this dearth of information that explicitly explores the ways in which adolescents understand R & S, the present study is necessary in order to fill that gap.

A second issue that arose while completing the aforementioned literature review was that of the 24 empirical studies that were reviewed, only six (25%) examined physical health conditions among adolescents, while 18 studies (75%) examined either mental health conditions such as depression and anxiety or risk behaviors or both. This revealed an underrepresentation of physical health conditions in relation to R & S among adolescents.

A review of the current literature examining the meaning-making process of adolescents' lived experiences of illness reveals yet another gap. There are currently no studies that propose to explore the roles of R & S as potential frameworks for meaning-making among adolescents who live with illness. Albeit, R & S arose in adolescent participants' responses in one of the studies reviewed (Atkin & Ahmad, 2001), the authors gave no indication that they sought this information out.

In order to reconcile these gaps in the literature, the present study utilized qualitative research methods to elicit illness narratives from adolescents who have experienced a serious and/or chronic physical illness and who were enrolled at UNC Charlotte. In eliciting these narratives, the researcher explored the following research questions:

1. How do adolescents who have experienced a chronic physical illness define R & S?
2. What factors influence meaning-making among adolescents who have experienced a chronic physical illness?
3. Do R & S influence meaning-making among adolescents who have experienced a chronic physical illness? If so, in what ways?

Because of the interaction that occurs between participant and researcher during the research process, Lindlof and Taylor (2002) assert that it is imperative for qualitative researchers to be ever mindful of the roles they play in this process. Researchers must be aware that they are not only eliciting information from participants, but they are also influencing the type and the way this information will be received by virtue of the characteristics that researchers possess. Being aware of and interpreting one's experiences and recognizing one's effect on participants during the qualitative research process is referred to as reflexivity. To this end, it was necessary for me to be aware of and to address biases and concerns that arose throughout this process. Further detail regarding these biases and concerns are included in Chapter 6: Discussion.

The next chapter contains definitions of terms that are relevant for the present study. It includes an overview of definitions offered in the literature as well as this author's operational definitions for the present study.

CHAPTER 2: DEFINITIONS

Before proceeding to address the extant literature on the current subject, it is important to provide definitions of the key terms that have been used thus far.

Meaning-Making

Meaning-making has been described as a central and defining activity of human life (Krauss, 2005; Mattis, 2002). Krauss argues that “human beings have a natural inclination to understand and make meaning out of their lives and experiences” (p. 762). He further asserts that this inclination to understand is what makes humans unique. When life events and experiences happen, individuals draw meaning from them or give meanings to them. As the person begins to psychologically process the events and the experiences, they begin to assign meaning to and understanding of the events and experiences (Krauss, 2005).

“Faced with a chronic illness, from which cure is impossible or unlikely, people almost always ask, ‘What does this mean?’” (Garrett, 2004, p. 105). It is this process of seeking the answers to questions of this type accompanied by the attempt to make sense of and understand what happened that best characterizes the concept of meaning-making (Park, 2005). When major life events happen, including the diagnosis of illness for example, individuals attempt to understand both the causes and consequences of these events: “…We will naturally attempt to ask ourselves why it happened and how we can cope with it” (Pennebaker, 2000, p. 12).

Literature on the process of meaning-making distinguishes between two forms of meaning: implicit and found (Daaleman, Cobb, & Frey, 2001; Lee & Poole, 2005; Thompson & Janigian, 1988). Implicit meaning involves the appraisal process that individuals who are faced with stressful situations undergo, and it involves gathering and processing medical information (if the stressful situation is a medical diagnosis). Implicit meaning is also equivalent to the process of primary cognitive appraisal in Lazarus and Folkman's (1984 as cited in Lee & Poole, 2005) transactional stress and coping model. Found meaning involves an active search for the meaningfulness of an event and the steps taken to fit the events into a larger life context. Found meaning can be broken down into two further components: order and purpose (Lee & Poole). To obtain order, the individual must perceive that the event fits into his or her world and larger life scheme. Purpose is obtained if one can find a reason for the event. Meaning finding, then, becomes an integral part of an individual's adjustment process (Lee & Poole).

For the purposes of this study, meaning-making was operationally defined as the process individuals go through when answering questions that may arise when they are faced with illness. These questions may be related to why the illness has occurred or they may involve an evaluation of causes and effects of the illness. This process may also involve an explanation of the resources (e.g., R & S) an individual uses to grapple with the thoughts and emotions that accompany an experience of illness and how engaging these perhaps difficult thoughts and emotions may contribute to the enhanced understanding of the experience. Given these components, this operational definition is akin to found meaning and its two additional aspects, order and purpose.

Spirituality

There has yet to be a consensus reached about the definition of spirituality. The literature thrives with varying descriptions that include aspects such as purpose, meaning, peace, and a belief in God or a higher power (Hill & Pargament, 2008; Miller & Thoresen, 2003). Still other definitions suggest that spirituality may include religiosity and/or beliefs associated with a specific religion (Cotton, Larkin, Hoopes, Cromer, & Rosenthal, 2005; Good & Willoughby, 2006; “Spirituality,” 2010). For the purposes of the present study, spirituality was defined as an individual’s worldview that may include aspects of meaning, life purpose, and peace. Additionally, spirituality may or may not include a belief in a higher power such as God. Many individuals subscribe to beliefs in higher powers. These beliefs may influence their worldviews, contribute to their understandings of life purpose and meaning, provide peace, and influence the way individuals make sense of and talk about health and illness. It is important that this definition allows for such beliefs to be included. This definition incorporates a broad range of individuals without excluding those who do not ascribe to a belief in a higher power.

Religion

Likewise, there has yet to be a single definition of religion, and because of variations in the way that previous researchers have defined this term, it may very well be impossible to create a unifying definition. Indeed, religion has been defined in a plethora of ways among literature examining its relationship to adolescent health and illness. For example, various definitions have included components such as recognition of the sacred, attendance at services, formal institutions, an organized system of beliefs, and adherence to doctrines (see Cotton, Zebracki, Rosenthal, Tsevat, & Drotar, 2006; Good & Willoughby, 2006). Other definitions reference practices such as prayer (Cotton, et al., 2009) or make explicit reference to God ("Religion," 2010). Like definitions of spirituality that tend to include religion, definitions of religion also tend to include references to spirituality. For example, Pendleton and colleagues (2002) suggested that religion is:

> a multidimensional construct…defined in its broad sense, including both institutional religious expression, such as dogma and ritual, and personal religious expressions, such as feelings of spirituality, beliefs about the sacred, and religious practices (p. e8)

The authors subsequently defined spirituality as "a belief system focusing on intangible elements that impart vitality and meaning to life's events" (p. e8).

Among definitions of religion that lie outside of the realm of social science research are beliefs that religion represents truth or "the quest for the ultimate reality" ("Religion," n.d.). Other definitions suggest that "Religion announces to the world that meaning has been wrestled from the world" and that "the quintessence of religion" is the ability to befriend an enemy ("Religion"). From a religious perspective, religion involves "our search for the Ultimate Reality" and "the 'feeling of dependence' of man on a higher power" ("Religion"). Both within and without social science research, the ways in which people understand religion is varied.

For the purposes of the present study, the definition of religion proffered by Wong, Rew, and Slaikeu (2006) was utilized: "one's relationship with a particular faith tradition or doctrine about a divine other or supernatural power" (p. 163). In contrast to the definition of spirituality, which references an individual's worldview that may or may not be related to a belief in a higher power, this chosen definition of religion explicitly links one's beliefs to a "faith tradition" and a "divine other." It is this definite connection to a "divine other" and to a "faith tradition" that I believe separates spirituality from religion. Like other researchers such as Miller and Thoresen (2003), I, too, believe that religion is the more communal, social aspect of individuals' acknowledgement and devotion to the sacred, a common theme underlying both definitions of religion and spirituality (Winford, unpublished manuscript), and that spirituality is the more individualized and personal acknowledgment of the sacred. Unlike definitions of religion that explicitly reference "God" (e.g., "the service and worship of God or the supernatural," "Religion," 2010), this chosen definition allows one to input whatever deity or divine being or power that best fits. This definition also departs from many other definitions of religion that rely solely on one's attendance to services or engagement in activities such as prayer and doctrine reading. This departure is important because, as the variation in definitions suggest, there are several other aspects of religion besides attendance and participation.

It must be noted that while I have offered operational definitions of R & S, participants in the proposed study were blind to my understanding of R & S when telling their own stories. I wanted to understand the phenomenon of religious and spiritual meaning-making through the eyes of individuals who lived the experiences. These definitions have been provided as frameworks that assisted me in identifying R & S when they arose in the participants' narratives; however, participants' understandings prevailed.

The following chapter provides an overview of how illness impacts one's identity. It also includes an overview of the psychological, biological, and social effects of illness that are specific to the time period of adolescence. Furthermore, this chapter will include a summary of the extant literature that utilizes illness narratives among adults, children, and adolescents to understand the lived experience of individuals who have encountered or are encountering illness. It concludes with a presentation of studies that qualitatively assess the meaning of R & S among adolescents.

CHAPTER 3: LITERATURE REVIEW

Identity Disruptions

One of the biggest effects of chronic illness is on one's identity. While most people tolerate a fair balance in their healthy and sick identities, when illness becomes chronic and does not go away, nearly all aspects of one's identity becomes centered on one's illness (Geist-Martin, Ray, & Sharf, 2003). Whereas others may perceive the illness as merely a temporary disruption of self and identity, ill persons often view this disruption as a ongoing process in which one must renegotiate one's identity within self and with family, friends, and others in one's environment in an attempt to understand what it means to live a life defined by illness (Charmaz, 1983; Geist-Martin, Ray, & Sharf, 2003). This process has been termed identity work (Geist-Martin, Ray, & Sharf, 2003) and is characterized by a process of mourning the loss of one's former self and becoming increasingly aware of the aspects of self that were previously taken for granted (Charmaz, 1983). The positive resolution of identity work, which is accomplished by creating a modified life story with a modified identity, has the potential to bring about healing (Sharf & Vanderford, 2003). However, positive resolutions are not always the case. The experience of illness and suffering may bring about a diminished sense of self, and this damage to self may have lasting effects (Charmaz, 1999; Sunwolf & Frey, 2001).

When one's illness brings about immobility or other forms of disability, this poses further threats to one's identity and sense of self (Charmaz, 1983). Individuals who have illnesses that lead to immobility may feel as though they are burdens on their familymembers and friends, and this image of being a burden may be in stark contrast to one's self-image as someone who is not as ill as one's body suggests. Furthermore, this feeling of being a burden, which reflects what Charmaz (1994) termed an identity dilemma, may also contribute to feelings of uselessness and worthlessness (Charmaz, 1983). Identity dilemmas occur when one loses valued attributes, physical functions, social roles, and personal pursuits as a result of illness. Responses to identity dilemmas may vary depending on one's sex or age and may include explanations that attribute the illnesses to midlife crises that are temporary. Still others may respond negatively and report feelings of betrayal by their bodies, self-pity, and anger and/or envy of healthy individuals around them (Charmaz, 1994).

In line with the idea that chronic illness has a significant impact on one's identity, Bury (1982) calls chronic illness a biographical disruption in which taken-for-granted aspects of everyday life are called into question. This disruption, he asserts, brings with it a sense of uncertainty in almost all aspects of life. As a part of this disruptive experience, Bury states that ill individuals rethink their biographies as well as their self-concepts in an attempt to make sense of the disruption that illness has brought. Individuals may seek answers to questions such as "why me" and "why now," and in seeking these answers, they may explore aspects of causation.

Moreover, Asbring (2001) also suggests that chronic illness disrupts one's life and that those who have chronic illnesses often suffer from identity losses. She explicates the concept of biographical disruption, indicating that “the structures of daily life become disjointed…” and “activities which previously could be engaged in are more difficult or totally impossible because of the illness” (p. 314). This inability to participate in previously engaged in activities results in a “disruption between the individual’s definition of herself with regard to the past, the present and the anticipated future” (p. 314). Furthermore, Asbring proposes that illness brings to the forefront questions regarding biographical work related to identity such as discovering the aspects of life that have been lost, those that have been retained, and those that have been added. This biographical work “also includes a process of coming to terms with the situation that has arisen, which means that the illness has to become a sufficiently integrated part of the identity to make physical and biographical survival feasible” (pp. 313-314).

Identity issues are especially pertinent to adolescents who experience illness. During this time period, “the brain undergoes a dramatic growth spurt, cognitive capacities increase, hormones intensify emotional experience, and questions of identity are explored with angst” (King & Benson, 2006, p. 392). Adolescents may begin to question their places in the world and mourn their lives prior to the development of the illness (Stevens & Dunsmore, 1996). Because Erikson (1968) suggests that the process of identity formation is the most important developmental task of adolescence, a life-threatening illness that begins during this time period may alter an adolescent’s sense of identity: “…just as they are beginning to negotiate an independent existence, that ‘moving forward’ is dramatically disrupted or irreversibly halted” (Brown & Sourkes, 2006, p. 9). In the same way that adults may initially attribute their illness to changes brought about by normal life transitions such as midlife crises, adolescents may also initially perceive their illness as an “external intruder” that over time becomes ingrained in their identities (p. 6). Although this process of integrating one’s identity as an ill adolescent into one’s complete sense of self may be necessary, it is also important for adolescents to not begin defining themselves solely as patients instead of as adolescents who are experiencing illness.

Treatments for particular illnesses may result in transformed bodily appearances. Visible markers of illness brought about by treatments such as hair loss, weight gain or loss, amputation, and use of wheelchairs or walking canes may negatively impact body image and self-esteem and contribute to feelings of inferiority (Brown & Sourkes, 2006). These negative impacts are especially noteworthy given that adolescence is a time period during which the normal, rapid physical growth accompanying puberty brings with it heightened concerns about physical attractiveness and self-image (Stevens & Dunsmore, 1996). Adolescents may also fall victim to criticizing and teasing at the hands of peers who, while potentially responding to their own ignorance and discomfort, may further contribute to the adolescent’s diminished sense of self (Brown & Sourkes).

Older adolescents begin to consider their developing sexual identities, as well. They may express concerns over the inability to perform sexually as a result of the physical effects that may accompany illness (Brown & Sourkes, 2006). Furthermore, these older adolescents may also become worried about their ability to reproduce in the future as infertility may be a side effect of the treatment associated with their illness (Stevens & Dunsmore, 1996).

In sum, issues related to disrupted identities may characterize the experience of illness for some individuals. Issues of body-image, self-esteem, and developing sexual identities are particularly salient for adolescents. However, positive responses such as a newfound appreciation for previously taken-for-granted aspects of life may also result. Following is an overview of the effects of illness specifically for adolescents.

Adolescents

There are several effects of illness that may be considered unique to the time period of adolescence. This section will explore these effects on adolescents who have experienced chronic or life-threatening illnesses.

Well adolescents experience a multitude of developmental and social changes as they transition from childhood to adulthood. Adolescents who experience illness must endure these changes in addition to those associated with their illness, its treatment, and accompanying side effects of treatment (Stevens & Dunsmore, 1996). Common biological effects of chronic illnesses such as cancer on adolescent development include delayed puberty and growth, which may, in turn, contribute to reduced self-esteem when adolescents compare their bodies to those of their peers (Suris, Michaud, & Viner, 2004). This delayed growth also impacts social relationships with peers and parents. For example, adolescents who have not started puberty and who appear to be younger than their chronological ages may be treated by others as less mature. In addition, adolescents may experience difficulty separating from their parents and developing emotional and behavioral autonomy as a result of parents' responding to their apparent immaturity (Suris, Michaud, & Viner, 2004).

In addition, adolescents often report that they feel normal yet somehow different than their same-aged well peers. While ill adolescents enjoy many of the same things that their well peers enjoy and go through the same developmental changes, they cite differences such as being more mature, sensitive, and optimistic as well as being less interested in mundane things and material possessions than their well peers (Stevens & Dunsmore, 1996).

Adolescents experiencing illness may regress to previous developmental stages, particularly those related to cognitive functioning. For example, Piaget (1962 as cited in Arnett, 2010; Cobb, 2010; Feldman, 2008; Rice & Dolgin, 2008) asserted that by the time individuals reach adolescence, they become capable of formal operational thinking, which is characterized by the use of abstract and critical thinking processes. Adolescents experiencing illness may regress to previous cognitive stages such as the preoperational stage in which things are seen in very concrete and black and white terms. For example, instead of acknowledging that a diagnosis of illness is not a death sentence, adolescents who have regressed may come to believe that they will die soon instead of being able to live with their illness. Additional cognitive regressions may include the persistence of egocentricity, or the inability to take the perspective of another, even into late adolescence (Suris, Michaud, & Viner, 2004). One form of egocentricity, the personal fable, may dominate such that adolescents begin to see themselves as unique and special and as individuals who have experiences that cannot be shared with anyone else. While egocentricity is a common developmental stage during childhood and adolescence, its persistence into late adolescence when adolescents normally begin to be able to see multiple sides of a situation may be problematic.

Adolescents experiencing illness may exhibit reduced independence in a time when increased autonomy and separation from one’s parents is considered a normal part of development (Suris, Michaud, & Viner, 2004). Reliance on parents for things normally taken for granted such as hygiene, dressing, toileting, transportation, and illness management may serve to decrease this sense of independence (Brown & Sourkes, 2006; Stevens & Dunsmore, 1996). Alternatively, parents of ill adolescents may become overprotective and not allow adolescents to perform tasks on their own. Adolescents may lose the perception by parents and others that as a healthy person, they are autonomous, can exert a reasonable amount of control over their lives, and are somewhat invincible to physical and emotional harm. However, as an ill adolescent, this image of the independent and strong adolescent may come to be replaced with an image of the adolescent as “precious” (Stevens & Dunsmore, 1996, p. 110). This label, in turn, may strengthen parents’ and other adults’ resolve to protect the adolescent in order to prevent harm to this fragile individual. Being denied opportunities to experiment and to gain autonomy may result in adolescents experiencing anger and feelings of powerlessness. Older adolescents may be especially vulnerable to these negative feelings particularly if they have lived independently for a time and must return home after having been diagnosed (Stevens & Dunsmore, 1996).

Adolescents who have experienced illness may also experience distress associated with missing out on developmental milestones such as getting one’s driver’s license and those that occur at school such as taking tests, establishing and maintaining friendships, experimenting with intimacy (e.g., one’s first date, first kiss, first romantic relationship), and taking risks such as skipping class (Brown & Sourkes, 2006; Stevens & Dunsmore, 1996). Because adolescents may be uncertain about what their futures may hold, they may break off friendships and relationships in order to protect others from the possibility of death. This breaking off of relationships in addition to being perceived as different or as contagious by peers may contribute to social isolation and exclusion from peer groups (Stevens & Dunsmore; Suris, Michaud, & Viner, 2004). Frequent medical visits are associated with increased school absenteeism, and this, too, may contribute to social isolation. This increased absenteeism may, in turn, lead to an increased potential for educational failure (Suris, Michaud, & Viner, 2004).

The desire to fit in with one's peers may result in reduced medication compliance. Adolescents fearing ridicule or rejection from peers or seeking to increase the likelihood that they will be perceived as normal may respond by failing to properly adhere to medical directions (Brown & Sourkes, 2006). In addition to simply not following medical directions regarding medication, adolescents may also engage in risky behaviors such as smoking or refusing to wear a face mask in public in order to fit in with their peers. These adolescents may believe that nothing will happen to them if they do not follow their physician's advice, and they may fail to consider the consequences of their actions (Brown & Sourkes). This lack of consideration for future outcomes is yet another example of the egocentrism that may become especially pronounced for adolescents experiencing illness.

Control is yet another significant factor for adolescents who have experienced illness. "The very nature of illness, treatment, and the medical environment makes adolescents acutely vulnerable to a sense of loss of control" (Brown & Sourkes, 2006, p. 7). This lack of control has been described as Damocles Syndrome (Stevens & Dunsmore, 1996). Just as Damocles sat at the banquet table with the sword looming precariously close to his head, adolescents who have experienced chronic or life-threatening illnesses are forever aware of the possibility that their illness, like the sword, hangs by a thin thread over their heads. Even more tangible aspects of control have been cited as key to an adolescent's experience of illness. For example, when illnesses require frequent medical visitations, adolescents may feel that control is being removed from them if their medical providers speak only to their parents instead of addressing them when making treatment-related decisions (Brown & Sourkes; Stevens & Dunsmore). Furthermore, when hospitalized, having the ability to decide who will visit and when offers a sense of control to the adolescent who otherwise must endure frequent visits by medical staff and intrusive examinations by physicians and nurses alike often in non-private ways that may expose their bodies and cause embarrassment and shame (Stevens & Dunsmore). As noted, because adolescence is a time period during which self-esteem and attention to one's changing body is of high importance, these medical intrusions may represent a significant loss of control for adolescents experiencing illness. Efforts to establish and/or reassert control may be perceived as rebellion or a refusal to follow parental or medical advice; however, adolescents find small areas to exert control in order to make up for the loss.

In sum, adolescents experience biological changes such as delayed growth and/or puberty as well as a range of negative emotions including shame, embarrassment, and uncertainty. Furthermore, adolescents may take actions such as isolating themselves from those within their social networks in order to reduce these feelings. Developmental milestones related to legal privileges and school tasks may be missed, and peers may pose further difficulties for adolescents experiencing illness. Finally, issues of control are also prominent for adolescents experiencing illness.

The next section presents a detailed overview of the qualitative literature examining the lived experience of illness for adults and adolescents. This information has been organized such that literature that draws attention to the role of R & S in the lived experiences of illness for adults is considered first. This will be followed by literature that focuses specifically on adolescents. The section will conclude with a presentation of the limited number of studies that qualitatively explore adolescents' understandings of R & S.

Adult Illness Narratives

Some researchers have evaluated the influence of R & S on adults' experiences of illness, and these studies provide useful information for the proposed study even though they focus on adults instead of adolescents. For example, three hundred participants were interviewed within one week of their hospital admission for treatment of an acute illness (King, Speck, & Thomas, 1994). These individuals, whose diagnoses ranged from ischemic heart conditions to breast lump biopsies, endorsed high levels of distress as measured by the General Health Questionnaire (Goldberg & Williams as cited in King, Speck, & Thomas, 1994), which may have been due to their recent hospitalizations. In addition, the authors found that participants who expressed strong R & S beliefs had less favorable outcomes. This latter finding was explained in three ways: because R & S beliefs were assessed so soon after hospital admission, respondents overestimated their true beliefs; strong R & S beliefs may be accompanied by less fear of death and reduced struggle for survival; and those with poorer prognoses may have focused more on their R & S beliefs. The authors concluded that assessing R & S beliefs among individuals with acute illnesses is both feasible and relevant. Because participants in this study reported a mean age of 58 years, it further illuminates the need to include adolescents in studies such as this one to determine if similar findings emerge.

Another study involved twelve survivors of hematological cancers such as leukemia, lymphoma, and sarcomas were asked to share their stories of illness from before prediagnostic symptom presentation to the present (McGrath, 2004). Participants, eight men and four women between the ages of 25 and 60, each spoke of their experiences using language that reflected what the author referred to as a spiritual journey. It is unclear, however, whether this spiritual language was produced spontaneously by the participants or if they were prompted by the interviewer. Based upon participants' narratives, the author created a conceptual model of "Illness as Spiritual Journey" that outlined individuals' processes of meaning-making. Because many aspects of participants' spiritual journeys were positive, including beliefs that everything happens for a reason, pride in dealing with the situation, and feelings of being fortunate that one took the journey despite difficulties, McGrath labeled the positive aspect of meaning-making "spiritual comfort." The negative aspects of meaning-making, such as having to endure aggressive and invasive treatments, excessive pain, and uncomfortable physical symptoms, were labeled "spiritual pain." These negative aspects were viewed as factors that challenged the positive meaning-making of individuals. McGrath noted that while participants largely spoke in secular terms, their language at times reflected religious notions of a higher power or being that played a role in their experiences.

Albaugh (2003) also examined the experience of individuals who had been diagnosed with a life-threatening illness. Unlike McGrath who did not specify whether participants had to be spiritual in order to participate, Albaugh only recruited individuals who classified themselves as spiritual according to his definition (i.e., “a personal belief in a higher power or being that guides life” (p. 594)). In response to the request to “describe your experience as a spiritual person having been confronted with a life-threatening illness” (p. 594), seven individuals (mean age = 61 years), provided accounts from which five themes emerged. In contrast to the participants in McGrath’s study who described both positive and negative aspects of their spiritual journeys, Albaugh’s participants only described positive aspects of their illness experiences including feeling a sense of comfort and peace from their spiritual beliefs; trusting in God to provide a means for them to endure their illness; gaining strength from prayers, scripture reading, and songs; feeling blessed in spite of their illnesses; and discovering a deeper meaning to their lives after having faced the life-threatening illness. The author concluded that spirituality is a significant positive factor when individuals face illness because it enabled individuals to obtain a sense of meaning during the experience of illness.

Daaleman, Cobb, and Frey (2001) sought to understand and describe how individuals understand and define spirituality as it affects their health and well-being. These researchers conducted six focus groups comprised of 35 women between the ages of 35 and 75 years. Half of the participants had been diagnosed with diabetes mellitus, and the other half had no identified chronic medical condition. In response to the request to reflect on their own experiences with illness and health and to define both well-being and spirituality in their own words, eight categories emerged. These categories described changes in participants’ functional status, core beliefs including religious and philosophical orientations, the process of gathering and processing information related to health and illness, the process of understanding the illness events within their life schemes, processing life events and assigning meaning to these events, positive intentionality including believing that it was “mind over matter” (p. 1508), the importance of life schemes, the attainment of agency, which was achieved by turning things over to a higher power, for example, and subjective well-being, which included both a positive cognitive component and an affective state. Based upon these responses, the authors suggest that patient-reported spirituality is largely comprised of a cognitive component that incorporates the themes of life scheme and positive intentionality. These two components represent the process through which these individuals applied their spirituality to health events and within the health care setting.

Finally, Creel and Tillman (2008) took a unique approach to examining the meaning of spirituality among adults in that they studied individuals who self-described themselves as nonreligious. Despite the fact that religious affiliation may influence a person’s values, beliefs, and behaviors, many do not consider themselves to be religious individuals. In order to shed light on those who espouse spiritual but not religious beliefs, the authors interviewed 11 participants who were approximately 47 years old and who were diagnosed with illnesses such as cancer, AIDS, cardiovascular disease, diabetes, infertility, and skin disorders about what spirituality means to them. All participants revealed that they had been exposed to a formal religion in their pasts; however, they chose not to remain affiliated with it. Additionally, participants’ responses revealed that although they lacked religious affiliations, many still expressed a belief in God. This belief, however, was not associated with an expectation of God to protect them from their illnesses nor did it result in anger at God for allowing the illness to occur.

This was the first study to shed light on the role of spirituality apart from religious affiliation and beliefs, and the authors called for additional studies to expand this area of research.

Adolescent Illness Narratives

Across a host of academic disciplines, the illness narrative approach has been used with children and adolescents in order to understand their illness experiences (see Di Gallo, 2003; Forsner, Jansson, & Sorlie, 2005; Miller, 1999; Woodgate, 2006). For example, Woodgate (2005) asked 15 adolescents aged 12-18 who had been diagnosed with cancer questions such as, “Some kids with cancer have told me that since having cancer, things are different in their daily lives. What has it been like for you?” (p. 10). These adolescents indicated that their senses of self were impacted because their bodies were also impacted. They described six different ways of being in the world that they had to navigate since being diagnosed with cancer. These six different ways included: life as a klutz (e.g., “I don't know just like simple things that you don't even think about and most things that you take for granted, I just can't do anymore”); life as a prisoner (e.g., “Because I couldn't do anything by myself like if I had to go to the bathroom and I would have to get help off the couch but if everyone is sleeping, how am I supposed to go to the bathroom, you know?”); life as an invalid (e.g., “I mean I wanted my mom to, like carry me because I couldn't walk and I just kind of gave up"); life as an alien (e.g., “Like some people think I'm a boy [and I’m a girl] and people don't recognize me. Unless they know who I am"); life as a zombie (e.g., “when it takes too much energy to get up, get showered, or get dressed and by the time you are ready to go you just want to pass out and die and sleep for another 12 hours”); and life as a kid (e.g., “Yeah, I feel more energized and stuff like that like I, you know, like I got a new battery or whatever") (pp. 11-12). These adolescents also noted how important it was for their family and friends to treat them the same most of the time because they did feel that they were the same people; however, they also emphasized the need to be treated special sometimes. This study is important because it is one of the few that observed the changing bodies and the changing selves of adolescents with cancer. Attention to the changing body is noteworthy given the fact that during the period of adolescence, the body undergoes one of the biggest changes it will ever experience. When a body that is already undergoing a natural series of major changes (e.g., growing body parts, increased height, increased presence of hair, etc.) also undergoes a series of unnatural major changes such as those brought about by treatments for cancer, the adolescent's sense of self, which is often heavily influenced by his or her changing body, is dramatically impacted as well.

Another previous study by Woodgate (1998) included 23 adolescents ranging in age from 13 to 16 who reported illnesses such as diabetes, asthma, arthritis, Crohn's disease, and ulcerative colitis. These adolescents were interviewed about their experiences of chronic illness as well as the ways they deal with their illness. Interviews began with the prompt, "Can you tell me a little bit about your chronic illness?" (p. 212) and also included additional interview questions that were designed to assess participants' feelings, solicit disease-specific information, and enable the respondent to reflect on his or her experience with illness. These interviews revealed that adolescents all experienced similar experiences despite having different diagnoses. They described having to exert extra effort to stay healthy, experiencing pain, worrying, and negative feelings such as guilt, hopelessness, and frustration. In addition to these similarities that transcended all disease types, there were illness-specific findings including medication regimens and restrictions one must take in diet and activity to account for the illness. The author concluded that although quantitative methods could have shown some of the same findings that she ascertained through interviews with participants, the information would not have been as rich or insightful as the data that she gained from participants in this study. This argument lends further support for the qualitative approach taken in the present study.

Atkin and Ahmad (2001) examined coping strategies and resources that adolescents with either sickle cell disease or thalassemia major utilized. Twenty-six adolescents between the ages of 10 and 19 were interviewed twice over a period of six months about their illnesses and the larger social context. The authors asserted that adolescents experience illness within family relationships and other social networks, and they wanted to draw attention to the way these interactions affected adolescents' coping strategies and their overall experiences of illness. Most older participants reported that they began asking "why me?" when they were around age 12 and that this question resurfaced during particularly stressful events, life transitions, and changes in the status of their illnesses. They also expressed uncertainty about their futures and disrupted social relationships. In terms of coping strategies, respondents indicated that they engaged in positive reframing and that they sometimes attempted to forget about their illness. One of the biggest ways these participants attempted to forget about their illnesses was to resist anything that marked their difference, including treatments. Of particular interest for the proposed study is the information related to religion that emerged. For example, almost all participants who were diagnosed with thalassemia major saw Allah as a source of strength. In addition, these same participants also reported being angry with Allah for allowing them to have their illnesses. Those with sickle cell disease relied less on their religion as a coping resource. Many older participants with both sickle cell disease and thalassemia major reported praying for strength to cope with their illness; however, younger participants reported that they prayed for their illnesses to be taken away. Across diseases, religion seemed to have less relevance as adolescents got older except during painful crises. In fact, no participant over the age of 16 referred to religion as an important coping strategy. These adolescents had to make sense of their life transitions in the same way that their peers who are not ill have to make sense of their life transitions. Because of this, coping strategies employed by ill adolescents became increasingly important in bringing about positive adjustments to these transitions.

Concepts such as liminality and stigma emerged in the narratives of 17 former athletes whose careers were ended by a severe injury (Brock & Kleiber, 1994). Researchers interviewed nine participants who were still enrolled in college and eight former students who were injured 20 years prior to the study to learn how their lived experiences and identities were disrupted by the introduction of their injuries. Participants described experiences of moving from the sacred and highly revered positions of athletes to the secular state of non-athletes following their injuries. They also described an ambiguous status that made them feel socially invisible. This loss of status via the transition that followed the injury encompasses the concept of liminality. Participants also reported experiencing stigma associated with no longer being athletes. At times, they reported being treated differently by their teammates and also by non-teammate peers. These results further suggest that illness, and also injury, alters the individual's identity and challenges the meanings that one had previously ascribed to their worlds.

In addition to these more traditional ways of applying illness narrative techniques, innovative ways of eliciting adolescents' illness narratives have also been employed. Both Rich and colleagues (2000) and Buchbinder and colleagues (2005) utilized the medium of video in order to understand the experiences of adolescents who were diagnosed with asthma and insulin-dependent diabetes, respectively. Twenty-one children and adolescents (11 males, 10 females ages 8-25) visually recorded their lives for four to eight weeks (Rich, Lamola, Gordon, & Chalfen, 2000). These participants were challenged to "teach us about your asthma" (p. 157) in addition to recording standardized scenes (e.g., tours of their homes, self-care, medication management, visits to the doctor, etc.). Additionally, these participants were asked to interview people around them with whom they interacted frequently using a standardized interview that also allowed for the inclusion of their own questions. Participants were encouraged to use the video camera as a diary and to record their daily experiences including thoughts, feelings, and observations living with illness. Along with information obtained from the visual narratives, participants also completed the Pediatric Asthma Quality of Life Questionnaire and the Child Health Questionnaire-Child Form as well as the Condition-Specific Verbal Report, which is designed to assess the participants' medical history and psychosocial factors. Data from these three sources (video, health-related quality of life measures, and medical/psychosocial history) revealed important information about problems related to asthma of which the researchers were not aware. They also revealed that although participants may not have acknowledged particular aspects of their illness (e.g., triggers to asthma symptoms) on the standardized questionnaires, they did acknowledge these aspects on the video. This informed researchers that there might be a gap between the information that is elicited via questionnaires and that which is elicited via narrative. The video narratives also showed family challenges that were associated with the adolescent participant's chronic illness, and these challenges were also not endorsed on questionnaires. The researchers concluded that the visual narratives could be a tool that expands their understanding of chronic illnesses such as asthma outside of the medical setting.

Likewise, Buchbinder and colleagues (2005) recruited five adolescents who had been diagnosed with insulin-dependent diabetes (three males, two females, ages 13-18) who recorded eight hours of their lives over a one-month period. Unlike the study conducted by Rich et al. (2000), Buchbinder et al. utilized a less structured protocol. Although participants in this latter study were asked to interview friends, family, and others close to them, they were not given a structured interview to use, and they were not encouraged to record standardized scenes. Instead, participants were told to "show what they thought was most important about their illness experiences" (p. 71.e10). Results of this study revealed gender differences in the ways that the male and female participants managed their illness and in the types of social support they received. In addition, the visual narratives showed the negative impact of diabetes on family function as well as the positive relationship between parental involvement in their child's illness care and metabolic control. Like Rich et al. (2000), visual narratives in this study showed a disconnect between information that was disclosed within a formal, standardized setting (e.g., a doctor's office) and that disclosed in a more informal setting such as in one's home or around friends. The difference in information obtained in these two settings strengthens the argument for hearing adolescents' experiences directly from them instead of seeking information about them.

Qualitative Studies Assessing Meanings of R & S Among Adolescents

The present literature review revealed three studies that explicitly sought to understand how adolescents conceptualize R & S (Cotton et al., 2009; Rich & Cinamon, 2007; Singleton, Mason, & Webber, 2004). In an attempt to understand how adolescents from non-Western and non-Christian environments understand spirituality, Rich and Cinamon (2007) interviewed 36 high school and college students from diverse backgrounds. Eighteen participants (eight males and 10 females) were Jewish Israelis, and these individuals were either Modern Orthodox Jews (n = 9) or nonreligious Jews (n = 9). The remaining 18 participants (seven males and 11 females) were Arab Israelis; twelve of these participants were Muslim while the other six reported Christianity as their religious affiliation. The researchers asked participants to describe how they understand the concept of spirituality, whether religious and non-religious spirituality exist, how spirituality is expressed in their everyday lives, whether they had experienced any spiritual experiences, whether they viewed themselves as spiritual persons, and if they knew of any spiritual persons whose characteristics they could describe. Participants' responses revealed five domains and 17 categories reflecting their understanding of spirituality. The five domains were: the essence of spirituality (sample categories included a belief in the transcendental and a search for meaning); spiritual experiences (sample categories included changes in one's perspective as a result of specific experiences and supernatural experiences); expressions of spirituality (sample categories included supernatural abilities such as sports or artistic ability and religious beliefs and/or behavior); outcomes of spirituality (sample categories included serenity and peace with self); and spiritual images (sample categories included famous secular and famous religious figures who the respondents perceived to be spiritual). Eighty percent of the participants stated that a belief in the transcendental was a key aspect of spirituality. They indicated that the transcendental included a feeling of having a personal connection with something infinitely greater than themselves. More than half of the participants indicated that the transcendent was related to a Supreme Being while others noted that the transcendent had nothing to do with God. For many participants, spirituality meant something more than adhering to conventional practices or espousing traditional beliefs; it meant the process of understanding the world outside of the individual and the outcomes such as inner peace that resulted from that process. All participants stated that religious beliefs and behaviors are not spiritual in and of themselves and that it was indeed possible for nonreligious spirituality to exist. According to the authors, the study results revealed that many adolescents view spirituality as multidimensional and that late adolescents recognize multiple paths to spiritual fulfillment.

As previously noted, Cotton and colleagues (2009) also qualitatively assessed adolescents' understanding of R & S. After recruiting adolescents with sickle cell disease and their parents at a hospital-sponsored research fair, Cotton et al. utilized a mixed method approach to assess a total of 48 adolescents and 42 unmatched parents regarding their use of R & S coping methods in the management of sickle cell disease. Thirty-seven adolescents completed a 216-item survey, which included quantitative measures of R & S such as the FACIT-Sp and the Brief RCOPE, a measure of HRQOL, demographic questions, and other items that the authors did not describe. Eleven adolescents also completed 25-30 minute semi-structured interviews in which they were asked whether or not and how they use R & S to help them cope with sickle cell disease. Parents completed quantitative measures of their child's R & S coping methods and their perception of their child's HRQOL. All adolescents and the unmatched parents reported a belief in God or a higher power, and most considered themselves "very" or "moderately" religious and spiritual. Additionally, FACIT-Sp scores were high overall. The Brief RCOPE revealed that adolescents and the unmatched parents both endorsed more positive than negative R & S coping methods; however, adolescents reported using significantly more negative R & S coping methods than unmatched parents. In the qualitative interviews, participants were asked if being religious or spiritual were the same or different; five adolescents stated that they meant different things, and three stated that they did not know if they were different or the same. The authors suggest that more attention be paid to adolescents' R & S struggles and recommend that further qualitative studies focus on adolescents' perceptions of R & S conceptual distinctions.

A team of researchers sought to create an interview schedule that would allow them to assess spirituality in adolescence and early adulthood and presented an overview of the process in order to inform other researchers embarking on similar journeys (Singleton, Mason, & Webber, 2004). These authors noted the need to develop an age-appropriate methodology for examining youth and young adult spirituality. They posed questions about the feasibility and appropriateness of asking young participants directly about spirituality or less obtrusively, about ways to frame questions so that participants are encouraged to talk about their spirituality, and about how eclecticism, which may be a contemporary form of spirituality, should best be examined. After conducting a pilot test that assessed these concerns, the authors learned that asking younger adolescents (i.e., those between the ages of 12 and 13, by the authors report) what the word spirituality means to them in a direct manner is an ineffective way of understanding their perspective. Respondents in this pilot test often reported confusion and uncertainty about the term itself, and the authors determined that a direct question did not allow a useful method for asking follow-up questions. In direct response to this difficulty, the authors concluded that it would be better to avoid the use of the word spirituality when interviewing younger adolescents and instead to use more focused questions with individuals in this age group. The pilot test also revealed that eliciting personal narratives and stories about the participants' own experiences was preferential to asking questions that drew upon formal conceptual knowledge. Based upon the results of the pilot study, the authors devised an interview schedule that allowed them to understand how adolescents from a wide age range understood the concept of spirituality. Interview questions asked about feeling close to nature, experiencing a miracle, or experiencing a spiritual force. They also asked participants to tell a story about the activities and events in life when they felt most alive, about the most fun they have ever had, and about their favorite activities. The results of the pilot test and from subsequent studies revealed 10 dimensions of spirituality. These dimensions were the relationship of spirituality to religion; the expressions of spirituality, which included participants' beliefs, values, practices, and community; coherence, which represented the extent to which the participants' understandings of spirituality was comprised of an amalgamation of beliefs from several other systems (e.g., feminism or social justice) or one single theme;

eclecticism, which represented the extent to which the participants' ideas of spirituality contained elements (e.g., prayer, reading) from one source only such as a religion or from multiple sources; salience or the extent to which they were consciously aware of their spirituality; influence or the extent to which participants' spirituality shapes their lives and influences their worldviews and actions; anthropology, which represents beliefs and attitudes about self and society; authority, which looks at the authority from whom the participants' spirituality came including sacred texts, the media, personal experiences, family, friends, and/or churches; medium, which represents the primary method through which the respondents obtained the knowledge of their spirituality; and development, which examined the relationship between spirituality and the stages of one's personal development and how spirituality develops over time within a person. The authors concluded that these 10 dimensions merely reflect what their participants' revealed and that further lines of qualitative research, particularly those that further refine their interview schedule, should be employed to fully understanding the ways in which adolescents understand spirituality.

Significance of the Present Study

These studies offer contributions to the research examining the lived experience of illness among adolescents. In addition to sharing similarities with the present study, they do have their differences as well as limitations. For example, McGrath (2004) elicited narratives from individuals with a past history of illness in order to uncover the process of meaning-making for these individuals. In addition, the author also acknowledged the need to clarify people's understanding of the word "spiritual." Despite these similarities, the proposed study does vary from McGrath (2004). While McGrath only interviewed individuals between the ages of 25 and 60, the present study examined the meaning-making of individuals from lower age brackets—adolescents. Furthermore, McGrath limited his sample to individuals with similar illnesses, notably hematological cancers, because he was specifically interested in how being confronted with death via a life-threatening diagnosis affected meaning-making. In contrast, the present study did not limit the types of physical illnesses that participants experienced. In this way, I was able to elicit narratives from a wide range of illnesses, and this may have facilitated a more complete picture of the meaning-making process in which individuals with illness engage.

Albaugh's (2003) study is similar to the present study in that both draw attention to the role of spirituality in the lived experiences of individuals' illnesses; however, it does differ in significant ways. Most notably, participants ranged in age from 44 to 74 years, and this exceeds the time period of adolescence. Secondly, Albaugh provided participants with his definition of spirituality. While this can be conceived as an attempt to standardize participant characteristics, this also limits the type of individuals who participated to only those who shared the researcher's definition. As previously mentioned, definitions of spirituality vary greatly; as such, the researcher may have decreased the number of individuals he could have included had agreement with his definition not have been a condition for inclusion. In addition, this may have limited the types of responses that the participants would have provided had they not been required to adhere to the researcher's own definition. In contrast, participants in the present study were not provided the researcher's definition of spirituality. This was an important decision because one of the purposes of this study was to hear from adolescents how they perceive R & S and how it may or may not function as a source of meaning-making for those experiencing illness; it was not to see how well adolescents could take the researcher's definitions of R & S and apply them to their experiences of illness. Thirdly, in addition to recruiting at support groups and by word of mouth, Albaugh also recruited participants from easily accessible religious institutions. This latter location may have greatly influenced participant characteristics. For example, all seven participants described themselves as Christians who believed that God was their higher power. This begs the question of whether participants would have displayed greater variability in beliefs had this recruitment source been omitted. In order to avoid this possibility, participants in this study were recruited from non-religious sources only such as the psychology research sign-up system, the Student Health Center, the Office of Disability Services, classrooms from various departments (e.g., psychology, communications, and religious studies), and via emails to all registered undergraduate students. Lastly, Albaugh specifically examined the lived experience of individuals who experienced a life-threatening illness. While several participants in the present study were indeed diagnosed with life-threatening illnesses or experienced times during their course of their illness experiences where their symptoms were so bad that there was a threat of loss of life, it was not a requirement for participation. In this way, the researcher increased the likelihood that variations in illness narratives according to illness characteristics emerged.

Daaleman, Cobb, and Frey (2001) did specifically ask their participants to reflect on their experiences of illness and to provide their own definitions of spirituality; however, the average age of these participants was 53 years for those with diabetes and 48 for those with no known illnesses. In addition, the authors did not ask participants to define, in their own words, religion. The present study asked adolescents, not adults, to reflect on their experiences of illness and to also define both R & S.

Despite the creative way in which Rich et al. (2000) and Buchbinder (2005) gathered the illness narratives from adolescents in their studies and the insightful findings that were obtained, these two studies still did not examine how R & S played roles in the experiences of illness. Only one study (Atkin & Ahmad, 2001) reported results related to religion; however, it is unclear whether this information emerged spontaneously or in response to the researchers explicitly seeking it out. If R & S enable individuals to make sense of their lives and to seek meaning and purpose in their experiences, and narratives enable individuals to better understand, find meaning, and to find their places within their life experiences, it begs the question of why R & S have not been explored in the context of illness narratives.

As this overview suggests, there is a paucity of research, particularly qualitative research, illuminating the ways that adolescents may or may not utilize R & S as a method of facilitating the process of meaning-making during times of illness. Greater attention has been given to the roles R & S play in adults' experiences of illness than to adolescents' experiences. Furthermore, there is significantly less research examining the ways in which adolescents understand the concepts of R & S apart from those that quantitatively do so. Given the present state of the literature, the present study is appropriate and timely. The next chapter will describe the method used to address this study's research questions:

1. How do adolescents who have experienced a chronic physical illness define R & S?

2. What factors influence meaning-making among adolescents who have experienced a chronic physical illness?
3. Do R & S influence meaning-making among adolescents who have experienced a chronic physical illness? If so, in what ways?

CHAPTER 4: METHOD

Research Design

The present study utilized a qualitative research design. Advocates of qualitative data suggest that qualitative approaches allow individuals to create the spaces and contexts into which they are placed instead of forcing them to place their stories within predefined categories and boxes (Lindlof & Taylor, 2002). In addition, qualitative methods allow individuals to share the intimate and personal ways they make sense of and give meaning to their experiences, and the resulting data may paint a more complete picture of a phenomenon of interest. Furthermore, qualitative data, which emphasizes words instead of numbers, is necessary in the beginning stages of the research process in order to more fully understand the subject matter, which aids in its accurate measurement at later stages (Lindlof & Taylor). Although data that emerges from qualitative studies may be subject to varying interpretations and may not be generalizable to those who fall outside of the realm of characteristics of participants contained in the study, it is the versatility of qualitative data that lends support to the methods. Because qualitative methods seek to understand the experiences of individuals, one would expect there to be several individual stories that emerge instead of one, global story. Because of these characteristics, qualitative methods were selected to allow for a greater understanding of adolescents' experiences of illness and the potential role of R & S in the meaning-making process that occurs in the face of illness.

Illness narratives were elicited in the present study. Illness narratives are stories told by individuals who have experienced or who are currently experiencing illness. They represent the subjective experience of illness instead of the objective perspective of medicine; they are concerned not with disease but with the person's lived experience of illness (Brock & Kleiber, 1994; Hydén, 1997). When individuals tell narratives about their illnesses, they are able to give meaning to events that may have disrupted and/or changed the course of their lives (Hydén, 1997; Murray, 1997; Murray, 2000). They allow one to assess the ways the illness affects roles, relationships, and identities (Charmaz, 1999; Sharf & Vanderford, 2003). Moreover, illness narratives allow the narrator to come to terms with an altered identity and to manage the biographical disruption that the illness may cause (Charmaz, 1999; Geist-Martin, Ray, & Sharf, 2003). They reflect individual views of the world, provide explanations for why things happen in certain ways, help people to recall other individuals and events of significance, and help explain motives, causes, and reasons (Sharf & Vanderford, 2003; Vanderford, Jenks, & Sharf, 1997). Illness narratives answer the why and the why not questions by allowing people to make sense of their lived experiences of illness.

Because completely unstructured narratives do not allow for the comparison across participants, Groleau, Young, and Kirmayer (2006) designed the McGill Illness Narrative Interview (MINI), a theory-based semi-structured qualitative interview schedule that elicits retrospective accounts of illness or symptoms that were experienced in the past. The MINI is also designed to elicit three types of representations of symptoms or illness: explanatory models, prototypes, and chain complexes. Explanatory models are based on causal thinking and may include causal attributions. Prototypes are based on salient events in one’s own or in others’ experiences that allow individuals to establish the meaning of their illness via the use of analogies. Finally, chain complexes are past experiences that are linked to present symptoms through a sequence of events that surround the symptoms. These chain complexes do not make explicit causal attributions nor do they establish links between past and present events via analogies. The MINI is divided into five sections beginning with a solicitation of the individual’s narrative including when and how participants first learned of their illness or health problem. The remaining sections elicit narratives that reveal prototypes, explanatory models, narratives of the respondents’ experiences interacting with health services and hospitalization, and the impact of the health problem on the individuals’ life in general. In addition, the final section of the MINI asks the respondent to reflect on whether the health problem has caused changes in his or her identity since the onset of the illness. This interview guide does ask respondents about how their spiritual life, faith, or religious practice has helped them to go through the time period of their illness.

Despite this, I chose not to use the MINI to elicit the illness narratives of this study’s participants. While the MINI does assess explanatory models and cause/effect associations and does include a question about the role of R & S during the individuals’ experience of illness, the remaining questions were beyond the scope of the present study. For example, sample questions include: “Did a person in your family ever experience a health problem similar to yours?” and “What usually happens to people who have (the health problem)?” Indeed, participants offered this information spontaneously at times, and similar questions served as follow-up questions in the present study. However, in order to keep the focus of the illness narratives of the study on potential frameworks for ascribing meaning associated with adolescents' experiences of illness, specifically R & S, and not focused on broader social factors that may influence the experience of illness, I opted not to use the MINI. Additionally, I chose not to use the MINI because I wanted to influence the course of participants' narratives as little as possible. Whereas the MINI asked for specific pieces of information related to one's experience, such as participants' interactions with the health system, this writer chose to ask broader questions such as "Can you tell me a story about what life is like living with XXX" in order to allow participants' stories to emerge as naturally as possible. This also allowed participants the opportunity to decide which information they chose to reveal. For example, if they did not want to share their experiences with the health system, they did not have to; they were free to share whatever information they deemed significant. This was in keeping with the phenomenological framework, which guided this study and that will be explained further in the following section. In choosing not to use the MINI, I do acknowledge that larger social factors that are assessed within the MINI and prototypical responses did indeed influence participants' illness experiences, and they were welcomed when introduced into the interview.

Given all of this, it was appropriate that illness narratives were used for the present study. I believe that these narratives allowed participants to ascribe meaning to their illnesses, examine their identities, explore notions of cause and effect, and to reassert control. These are factors that may all be challenged during periods of illness.

Procedure

Theoretical Framework

This study was guided by phenomenological approach, which allows for the "unpacking of the essence of lived experience" and allows one to understand the essence of behavior by entering into the subjective experience of the individual (Lindlof & Taylor, 2002, p. 237). Although definitions of R & S have been provided and previous studies have examined R & S among adolescents, there is a gap in the literature that investigates the experiences of illness and R & S among adolescents in the proposed way. As such, phenomeonology directed my ability to both understand how adolescents who have experienced a chronic illness conceptualize R & S and to understand the ways that these adolescents ascribe meaning to their lived experiences of these illnesses. I did not presume to know the lived experiences of the individuals who participated nor did I want them to apply my understanding of R & S to their own stories. Instead, I wanted to understand, through their eyes, the phenomena of meaning-making and to explore the possibility that R & S served as a means by which to achieve this meaning.

While I considered a grounded theory design, the goal of this research was not to build a theory of adolescents' lived experiences of illness and the potential role of R & S in these experiences; it was to understand the essence and meaning of these experiences. In addition, symbolic interactionism was considered because religion, in particular, may have a social component to it, and there are also wide arrays of symbols that may convey the meaning attached to a particular religious tradition. This social component with its accompanying social interactions may influence the meaning participants ascribe to their lived experiences. However, this tradition was not adopted because the goal of this study was not to examine how meaning is derived as individuals interact with and interpret one another's actions but again to understand the meaning of adolescents' experiences of illness and the potential role of R &S and other meaning-making frameworks in these experiences. Because the present study sought to understand the lived experience of adolescents who had encountered illness as well as the way they conceptualized R & S, the phenomenological approach was deemed appropriate.

Sampling and Data Collection

This study focused on college students between the ages of 18 and 25, a group that has historically been neglected in research examining the role of R & S in the lived experience of individuals who have encountered illness. Adolescence was operationally defined as the period of time between ages 10 and 25 during which an individual experiences a broad range of biological, cognitive, social, and psychological changes (Arnett, 2000; 2010; Feldman, 2008; Rice & Dolgin, 2008). While this time frame may exclude some individuals who would otherwise meet most criteria for adolescence, it is a broadly inclusive age range that meets most definitions of adolescence and emerging adulthood (Arnett, 1994; 2000; 2007; 2010; Feldman; Rice & Dolgin). The United States culture makes it difficult to say definitively the age at which adolescence ends. However, it can be argued that college attendance delays the end of adolescence. Given this, the undergraduate population at this University was a sufficient group from which to sample.

An annual survey of college students' health and health behaviors (National College Health Association, 2012) revealed that 40.5% of surveyed students (n = 76,481; average age = 21.56 years) reported having been diagnosed with or treated for a mental or physical health condition in the 12 months prior to data collection. Among the physical health conditions respondents reported were asthma (8.8%), diabetes (1.0%), irritable bowel syndrome (2.6%), and migraine headaches (7.8%), for example. These specific physical health conditions were found among the present sample as well. Given this information, this writer believed that the undergraduate student population at this University would also provide a sufficient proportion of students who were diagnosed with chronic physical illnesses from which to sample.

Data was collected between March and May 2012. After obtaining institutional review board approval, flyers (Appendix A) were posted in the waiting rooms and restrooms of the Student Health Center and in the reception area of the Office of Disability Services. The flyers provided a brief description of the present study and encouraged potential participants to complete the prescreen questionnaire (Appendix B) on SurveyMonkey.com. Secondly, a description of the study was posted on the Psychology Department's online research sign-up system (henceforth, SONA), a website designed to recruit undergraduate psychology students for research that fulfills their introductory psychology research participation requirement. Students visiting SONA viewed the following information, which is identical to that found on the recruitment flyer:

> Were you diagnosed with a chronic physical illness or physical condition (such as asthma, diabetes, cancer, or lupus, for example) between the ages of 10 and 25? Are you currently between the ages of 18 and 25? Are you currently enrolled as an undergraduate student here at UNCC? Would you be willing to share your experience in an interview? If you answered yes to each of these questions, you're invited to participate in a study exploring the changes you may have experienced in your life since being diagnosed with a chronic physical illness/physical condition. All participants will receive EITHER 2 research credits OR a $10 Target gift card and will be entered into a drawing to win a $25 Target gift card

> when the study is over. If you are interested in participating in this study, please click the link below to complete a brief questionnaire.

Thirdly, this researcher visited four undergraduate courses in the following departments: communication studies, religious studies, and psychology. During these visits, the researcher explained the study by reading the recruitment flyer, and she then distributed copies of the flyers to each student in attendance. Students were allowed to ask questions. These flyers were identical to the ones posted in the Student Health Center and in the Office of Disability Services. Lastly, emails were sent to all undergraduate students between the ages of 18 and 25 who were enrolled during the Spring 2012 semester and who did not have privacy restrictions placed on their student records. The Office of Institutional Research provided these email addresses. Each of these students was emailed a copy of the recruitment flyer. All email addresses were placed in the BCC field of the email message; as such, the recipients were unable to identify who was on the list. In addition, all students were greeted in the following general way: "Dear Current UNC Charlotte Undergraduate Student."

All participants completed the prescreen questionnaire online on SONA or SurveyMonkey.com (including students recruited in the classrooms). Because of this, they were not able to provide signed informed consent. However, prior to beginning the questionnaire, participants viewed an informed consent document (Appendix C-D). Participants' consent was implied if they chose to complete and submit the questionnaire. Based upon responses to this questionnaire, eligible respondents were contacted via the email address provided in the prescreen questionnaire (see Appendix E for email script) to participate in the second portion of this study, the illness narrative interview. Participants and the researcher met at an agreed upon time to complete the interview.

All interviews occurred in a research suite within the Department of Psychology and were audio recorded for subsequent verbatim transcription. Participants were provided a brief description of the study both orally and in writing prior to obtaining informed consent (see Appendices F-G). After obtaining informed consent and using information obtained from the prescreen questionnaire (e.g., information about diagnosis), participants and I engaged in small talk about things such as any difficulty finding the research suite, their major in college, etc. This small talk allowed participants time to warm up to me and to the experience of sharing their stories.

The interview followed according to the interview schedule, which can be found in Appendix H. Participants were allowed to view this interview schedule and to ask questions about this document prior to initiating the interview. In addition to the questions contained in the interview schedule, one additional question, "Would you mind telling me the story of how you were diagnosed?" was added after three interviews were conducted. This question was added because all three of the first participants offered this information spontaneously. In order to receive consistent information from all participants, this question was inserted at the point during the interview when participants began mentioning their diagnoses (e.g., "when I was first diagnosed…"). If participants made no mention of their diagnosis story, this question was inserted following the question about changes observed since being diagnosed. The inclusion of an additional question after the data collection process has commenced is referred to as progressive focusing (Partlett & Hamilton as cited in Schutt, 2012). It reflects the process of modifying the data collection procedure in response to the researcher's perception that additional concepts need to be investigated.

In addition, it was also necessary to prompt participants at times during the interview, and this process of prompting was guided by my need to understand the participants' perspectives as thoroughly as possible. This was done carefully such that attempts were made to avoid substantially influencing the narrative that would have emerged had I not interrupted. Sample prompts and interruptions included "You've mentioned that you get flares. What's a flare?" and summary statements, which restated in different words what participants had described, respectively. Further examples of these prompts and follow-up questions are found in the next chapter where results are presented.

Although the results that will be presented are limited to responses that pertain to this study's three research questions, the remaining interview questions and their resultant responses served multiple purposes. Along with engaging in small talk, answering the questions preceding those corresponding to this study's research questions allowed participants to warm up to the interviewer and to the process of being interviewed. In addition, answering these additional questions permitted participants to tell their stories as they related to their illness experience. That the first question asked participants to "Tell me a story about…" allowed for participants to decide which aspects of their illness experience they wanted to reveal at that time, thereby increasing participants' control and reducing some of the power differential that inevitably resulted because of our differing statuses (i.e., researcher vs. participant). This story-telling method also facilitated participants' ability to ask and answer the "why me?" question, a process that Pennebaker (2000) asserts is key to ascribing meaning to one's experiences. Where necessary, however, to provide additional context and/or to add to the overall feel and richness of the data, additional responses from the remaining interview questions will be inserted as needed.

Because of the nature of the topics that were discussed (religion, spirituality, identity, and illness), some participants did appear to experience emotional discomfort when participating in the interview. In addition to reassuring participants that they were allowed to stop the interview at any time without penalty, all participants also received information about the Counseling Center and the Student Health Center both during the explanation of the study and review of the informed consent and also following the completion of their interviews.

Participants were compensated in one of two ways. Those who were recruited via flyers located in the Student Health Center, the Office of Disability Services, classrooms, or through email received a $10 Target gift card upon the completion of their interviews. Participants recruited through SONA received one-half research credit for completing the online prescreen questionnaire and were then given the choice of receiving either an additional two research credits or a $10 Target gift card upon the completion of their interviews. In order to ensure that all participants, regardless of method of recruitment, were compensated for the completion of the prescreen questionnaire, they were all entered into a drawing to receive a $25 Target gift card, which was held at the end of data collection. The random number generator function of Excel 2011 was utilized to randomly generate two numbers, which corresponded to identification numbers (see below) that were assigned to each of the individuals who completed the prescreen questionnaire, regardless of whether they completed the final interview or not.

Ethical Considerations

All participants, including those who completed the prescreen questionnaire but did not complete the interview portion of the interview, were assigned identification numbers when labeling the results of the prescreen questionnaire, the audio files containing the interviews, and the subsequent transcriptions. As much as possible, confidentiality was maintained by avoiding the use of participants' names during the recorded interview; however, several participants did use their own names and/or the names of other people and locations. The audio files were stored in an encrypted, password-protected file on the University's H:\ drive, which is a secure, password-protected network. Similarly, once transcribed, the data was stored in an encrypted, password-protected file on the H:\ drive. Data from the online prescreen questionnaire were downloaded into an Excel spreadsheet and stored in an encrypted, password-protected file on the H:\ drive. After contacting participants to schedule interviews, names were removed from the Excel spreadsheet leaving the signed informed consent documents from the interviews as the only remaining documents containing the participants' identities. Of note, these documents did not contain the participants' identification numbers. They were stored in a locked file cabinet.

Data Analysis

The data for the present study included the results of the online prescreen questionnaire, participants' stories and behaviors, and entries from this writer's journal. Two undergraduate research assistants, who received academic credit, assisted the researcher with transcribing each interview verbatim. Data analysis was influenced by the constant comparative method (Glaser as cited in Lindlof & Taylor, 2002). This approach involves a stage-based process in which the data, in this case interviews, are first read on an ongoing basis in order to gain a feel for what is being said. The researcher simultaneously identifies key themes that are unique to each interview, a process referred to as open coding, and continually compares these themes to prior interviews (Bernard & Ryan, 2009). When there is inconsistency between the themes across the interviews, revision or rejection of preexisting themes or creation of new ones may be necessary. Next, the themes from each interview can then be combined in order to identify larger, more universal themes that may apply to all participants and across all interviews. The comparison process continues until no new themes emerge. This process is largely inductive, relying on the data itself, rather than a priori theoretical understandings or assumptions, to guide the discovery of themes (Bernard & Ryan, 2009). This method lends itself to the phenomenological theoretical orientation in that both reject a priori assumptions and rely on the data, the illness narrative interviews, and its source, the participants, to guide the discovery process.

This constant comparative method was applied in a two-step procedure. This writer engaged in open coding across the all of the interviews in an attempt to reveal overall themes. However, in order to answer the research questions for the present study, this writer also engaged in a separate step of data analysis on the four questions that corresponded to this study's three research questions. For example, two questions (i.e., "What does spirituality mean to you?" and "What does religion mean to you?") were asked to assess Research Question 1 (i.e., "How do adolescents who have experienced a chronic physical illness define R & S?"). This researcher isolated the responses to these questions and engaged in the constant comparative method across all of the interviews until no new categories emerged for that particular question.

Logistically, this process entailed reading interview transcripts repeatedly in order to identify themes and categories. When reading these interviews, I wrote notes both within the margins of the interview transcripts themselves and in my journal, which I utilized throughout the entire research process. After doing this process by hand, I created tables on the computer, which contained each of the initial categories that emerged from this preliminary coding. I placed exemplars that I thought represented these categories alongside the proposed categories. Although several categories did indeed emerge from the data as I repeatedly read the interviews, others had been identified in my journal in the form of thoughts that I wrote immediately following each interview. The exemplars that were selected, in some ways confirmed or disconfirmed these initial categories. After organizing the initial categories and exemplars into these tables, the responses that were specific to the four interview questions addressing the three research questions were extracted, and new tables were created for each of the research questions. After much reading, journaling, and organizing, the categories, which are found in the following chapter emerged.

Ensuring Rigor

In the same way that issues of reliability and validity must be considered with quantitative research, they must also be considered with qualitative research. This researcher assessed these characteristics in several ways. For example, interrater reliability, also referred to as triangulation or the method of multiple researchers, is one method of ensuring reliability of qualitative data (Lindlof & Taylor, 2002). This is best demonstrated when two or more independent researchers agree on aspects of the data analysis such as what themes emerge and what text best exemplifies these themes. Although some level of discrepancy is expected when measuring interrater reliability in qualitative data by virtue of the fact that each researcher brings a unique perspective to the data, each researcher is expected to discover essentially the same meaningful pieces of data and to create themes and select exemplars in congruent ways.

Interrater reliability was assessed at two points during the present study. The first point occurred during the interview transcription phase. As indicated above, two undergraduate students assisted this writer in transcribing the interviews. In order to ensure that each researcher accurately transcribed the interviews, all three researchers transcribed the first interview that was conducted. Following that exercise, all three researchers met to review the resulting transcripts and to discuss potential discrepancies and/or difficulties encountered. During this exercise, discrepancies only occurred when the participant's voice was unclear or inaudible on the audio file. All three researchers re-listened to that portion of the audio file in an attempt to reach agreement about what the participant said. This same re-listening process occurred for each of the following interviews whenever a portion of the file was unclear or inaudible.

Interrater reliability was again assessed during the data analysis phase. After this writer performed the initial open coding procedure on all of the interviews in their entirety, ten percent of the interviews (i.e., three) were submitted to a second researcher who blindly coded the interviews using the same coding procedure. This second researcher was provided an explanation of the constant comparative method and asked to engage in this process for all three interviews. The results of the second researcher's coding were then compared to this writer's results. With the exception of variations in category names and the creation of main versus subcategories, there were no significant differences between this writer's coding and the second researcher's coding. For example, this writer labeled one category, which described practices in which participants engaged to manage their illness or condition, "illness management," and the second researcher labeled this category "health behaviors." Despite the difference in category title, both this writer and the second researcher selected the same exemplars to represent these categories. In addition, in another interview, the second researcher created a separate category entitled "stigma" to describe the participant's perception that her illness carried a negative connotation. This researcher, however, included "stigma" as a subcategory of the main category "identity." Again, despite the disagreement in labeling of categories, the same exemplars were selected to represent these themes. This consistency suggests that rigor was ensured throughout this process.

Validity refers to whether a research instrument accurately assesses the phenomenon or construct of interest. Because qualitative researchers seek to present credible data, they choose to present and interpret data that they perceive to be the most plausible and insightful; they choose data that "rings true" to the reader (Creel & Tillman, 2008; Lindlof & Taylor; Sunwolf & Frey, 2001, p. 122). The results that follow in the next chapter are in keeping with this spirit. Several exemplars have been included throughout to allow readers to also participate in this validating exercise. In reading the multiple exemplars, the reader will be able to decide whether the interpretations that will be presented are true to the text and if the categories under which the exemplars have been placed best represent the participants' stories and voices. This process has been called consensual validation (Büssing et al., 2009).

Care was taken to select theme exemplars that best demonstrated the relevant theme and that simultaneously ensured the confidentiality and anonymity of the participant whose words were used. What this means is that some exemplars, despite the strength with which they "rang true" to the researcher, were excluded because they were too unique to the participant and would increase the likelihood that confidentiality and anonymity would be compromised. Similarly, some identifying characteristics (e.g., the names of the hospitals in which participants were diagnosed or the names of their family members and physicians) were altered or excluded while still preserving the nature of the data.

Along with consensual validation, another method of ensuring validity is to perform member validation, which is also known as member checks (Lindlof & Taylor, 2002). Member checks involve taking the findings back to participants to see if they recognize the results as true and/or accurate representations of themselves. During member checks, participants may be given copies of the entire manuscript and/or the portion of the manuscript that contains their story, and they are asked if they can hear their voices within the story (Creel & Tillman, 2008; Lindlof & Taylor). Participants are given the opportunity to make corrections and provide further explanation, if necessary.

Member checks were employed in the present study. At the conclusion of the interview, participants were asked to provide an email address where they could be contacted up to two years later. All but one participant was contacted following data analysis and the completion of the results section that follows. One participant was excluded from this process because the email address provided was no longer valid. Participants were invited to review the results section and to provide comments, corrections, or additional explanations. In this way, I attempted to ensure that the results rang true not only to me, the researcher, or to members of the academic community who may read the final document but also to the participants themselves whose voices and stories provided the basis for the finished product. After contacting participants twice via email, 27% (n = 7) contributed to this member check process. Sample feedback from participants included correcting the gender of one participant who had been incorrectly identified. Others responded with gratitude for being allowed to be a part of this project and even provided life updates including getting engaged. One piece of feedback, in particular, caused the researcher to reconsider the way in which she presented the exemplars. This participant indicated: “I do wish I spoke more clearly and didn’t say UM as much!” Although I had initially presented the exemplars that follow in the next chapter as verbatim quotations, in order to respect this participant’s wishes to be perceived as someone who spoke more clearly, I began to make small edits within the exemplars, such as removing “likes” and “ums” and “you knows,” phrases also known as “hesitancies of speech” that may disrupt the flow of the narrative (Corden & Sainsbury, 2006, p. 18).

This type of editing comes with both pros and cons, however. For example, Corden and Sainsbury (2005; 2006) conducted a series of studies where they interviewed both qualitative research participants and social science scholars who conducted qualitative research in order to better understand the impact of including verbatim quotations within final reports compared to including edited quotations. From those participants who were in favor of verbatim quotations came the belief that there was no point in using participants' voices if they would be changed; such altering, these participants reported, would make the final report "untrue" (Corden & Sainsbury, 2005, p. 20). Other participants who were in favor of reporting verbatim quotations perceived that each individual spoke in unique ways, which contributed to the variety and interest in the final report, and editing the quotations would diminish this diversity. Consistent with participants' views, researchers who were in favor of using verbatim quotations argued that editing the quotations would reduce the likelihood that participants' voices would be heard (Corden & Sainsbury, 2006). These researchers feared that if they edited participants' voices, participants themselves would be unable to recognize themselves in the final report, should they read it. Another argument against editing quotations was the belief that doing so would reduce the "context and nuances" of the information presented (p. 18).

Not all participants and researchers were in favor of presenting verbatim quotations. Participants in favor of editing argued that the researcher's ultimate priority when preparing the final report should be readability. They indicated that "hesitancies of speech" should be replaced with "standard English" (Corden & Sainsbury, 2005; p. 20). Furthermore, these participants suggested that presenting unedited, verbatim quotations made the final report appear less professional and was a poor representation of both the participants and the researchers as well. These participants worried that reading quotations that were not necessarily clear and concise would reflect poorly on them and would reduce the likelihood that they would be taken seriously. Along those lines, they believed that readers would doubt the researcher's writing and literary ability if edits were not performed prior to presenting the final report. Similarly, researchers responded in ways that also indicated that, along with confidentiality and ethical considerations, readability was one of their top concerns. They believed that reading unedited words "would be tedious and put readers off, and thus make it less likely that the quotations would be read" (p. 18). Another set of researchers believed that including "ums" and "likes" was condescending and patronizing because they contained little additional information other than the fact that participants were considering their words prior to speaking. In addition to being condescending, researchers who were pro editing believed that not doing so would increase the likelihood that readers would form negative opinions of the participants.

Taking all of this into account, this researcher attempted to balance the pros and cons of editing participants' quotations. On one hand, I wanted the participants' voices to be heard and to dominate the narrative that follows. However, on the other hand, I wanted to both respect the participant's wishes to be presented more clearly and to increase readability and overall professionalism of this document. As such, I engaged in minimal editing, removing only words that were mentioned multiple times in a row and phrases such as "like," "um," and "you know" that were presented before the participant's intended response emerged or that interrupted the flow of the passage, for example. My aim was to ultimately improve the flow of the quotations so as to increase the likelihood that the reader would actually grant attention to them instead of them over. Of course, this process was entirely subjective, and care was taken to not alter the underlying meaning of participants' words even as I altered the actual words themselves.

The next chapter contains the results of the present study. They have been organized in the following way: a review of participant demographics including how study participants compared to those who completed the prescreen questionnaire and to all undergraduate students who were enrolled during the Spring 2012 semester; information about interview and transcript length; and, lastly, categories, which emerged from the illness narratives, grouped according to their corresponding research questions.

CHAPTER 5: RESULTS

Participants

The Institutional Review Board of the University of North Carolina at Charlotte granted approval for this study. A total of 82 participants (65% female) provided informed consent and completed the prescreen questionnaire. One individual was recruited via flyers displayed in the Student Health Center and in the Office of Disability Services, and this individual was also eligible to participate in the interview portion of this study. A total of 34 individuals completed the prescreen questionnaire through SONA. Of those 34 individuals, seven (20.59%) were eligible to participate in the interview portion of this study. Three individuals were recruited through classroom visits, and all three were eligible to participate in the interview portion of this study. Lastly, 44 individuals responded to the email sent to all qualifying undergraduate students. Of those 44 individuals, 31 (70.45%) were eligible to participate in the interview portion of this study. In sum, of the 82 participants who completed the prescreen survey, 42 (51.22%) were eligible to participate in the interview portion of this study.

All 42 eligible participants were contacted via the email address provided in the prescreen questionnaire. Two individuals responded that they were not interested and were not contacted further. Fourteen additional individuals were contacted on two occasions; however, no response was obtained. The remaining 26 individuals participated in both parts of the present study.

These 26 individuals were between the ages of 18 and 24 (mean age = 21.69 years) and reported being diagnosed with a chronic physical illness at an average age of 17 years. See Table 1 for additional demographic information. This sample size was in accordance with the recommendations of Conrad (1987) who suggests that at least 20 participants are necessary to obtain a sufficient range of responses in regard to illness narratives. He further argues that the most usual sample size for studies that elicit illness narratives is between 20 and 30 participants.

To ensure breadth of responses, few restrictions were placed on types of chronic physical illnesses that were included. However, individuals who reported psychological illnesses only such as major depression, obsessive-compulsive disorder, and dyslexia, for example, were excluded. In addition, participants who experienced an illness as a baby or as a young child (i.e., diagnosed prior to age 10) were excluded because it is unlikely that they had sufficient memory for these experiences. Finally, individuals who were under the age of 18 or over the age of 25 and who did not speak English were excluded.

Compared to students who completed the prescreen questionnaire only, study participants were more likely to be fourth or fifth year-plus seniors. In addition, those who completed both portions of the present study were diagnosed at an older age than those who completed the prescreen questionnaire only (mean age at diagnosis = 17 years and 11.62 years, respectively). Among those who completed the prescreen questionnaire only, there were fewer freshmen and sophomores and “other” majors. Compared to undergraduate students enrolled during the Spring 2012 semester, participants in this study were more likely to be female (69% vs. 50%) and European American/White (80.8% vs. 61.56%). In addition, participants were more likely to be psychology (34.6%

vs. 14.29%) and “other” majors (50% vs. 20.73%) than students enrolled during the Spring 2012 semester. In contrast, students enrolled during the Spring 2012 semester were more likely to identify as an “other” ethnicity (8.64% vs. 0%). Additional demographic information is presented in Table 1 at the end of this chapter.

Participants reported a host of chronic illnesses including diabetes, asthma, irritable bowel syndrome, and various forms of cancer, for example. See Table 2 at the end of this chapter for additional information on participant diagnoses. Among all respondents to the prescreen questionnaire, asthma was the most frequently reported chronic illness comprising approximately 30% of all illnesses. Participants reported being, on average, a little to somewhat spiritual and religious (mean = 2.65 and 2.58, respectively; range 1-5). Likewise, participants also reported, on average, that their spiritual and religious beliefs are a little to somewhat involved in their understanding or handling of stressful situations (mean = 2.46 and 2.35, respectively; range = 1-5). See Table 3 for additional information on R & S questionnaire responses.

Interviews

Interviews ranged in length from 14 minutes and 38 seconds to one hour and seven minutes (combined interview time = 15 hours and 12 minutes; average interview length = approximately 35 minutes). The resulting transcripts totaled 317 single-spaced pages. Although a total of 10 questions were asked during the illness narrative interview, only responses corresponding to the present study’s three research questions will be presented below.

Findings

A total of 71 categories emerged across all three research questions; however, both within and across these three research questions, no category was reported by all 26 participants. However, it was common for the same story and/or exemplar to contain multiple categories. As such, the reader may notice that some exemplars have been placed under multiple categories and presented more than once within the text that follows. Participants' words dominate the narrative that follows, which is consistent with the phenomenological approach of viewing someone's experience from his or her perspective. Where necessary, additional information regarding context has been added in brackets (i.e.,, [ ]). However, even information within brackets is based upon participants' stories; they are paraphrased summaries of what participants said at other points within their interviews. When selected exemplars included participants' names, names of others, or names of medical institutions where they received treatment, this identifying information was replaced with brackets containing either the letters XX for names or "name of hospital" for medical institutions to ensure confidentiality.

Research Question 1: How Do Adolescents Who Have Experienced a Chronic Physical Illness Define R & S?

A total of 28 categories (12 "religion" and 16 "spirituality") emerged in response to the following interview questions: "What does religion mean to you?" and "What does spirituality mean to you?" Following the interview schedule, these two questions were presented separately prior to the question inquiring about participants' meaning-making strategies. These categories are presented in Tables 4 and 5 at the end of this chapter. These tables also include the total number and percentage of participants who provided responses that fit within the categories. Exemplars from 10 of the 12 categories for religion were reported by at least two participants, while the remaining two were both reported by only one participant. Similarly, exemplars that fit within 11 of the 16 categories for spirituality were reported by at least two participants, while the remaining five were reported once by a total of three participants.

Religion

Specific examples from the 10 religion categories containing at least two separate individuals' responses are reported below followed by a sample of exemplars from the "other" category.

Belief in or Relation to God/Jesus or Higher Power (10 Participants, 38%):

One of the most common characteristics of religion that participants reported was that it was defined by the belief in or a relationship to God/Jesus or a higher power. Thirty eight percent of participants shared this belief. The following exemplars demonstrate this concept.

> Um, when I think religion, I think church, I guess God, Jesus, that kind of stuff going to church. Organized. That kinda stuff [clears throat] (22-year-old European American female—Type II diabetes; "A little" religious)
>
> Um, I think religion means to me just a way that people interpret God. Different ways…God comes to everyone in different forms but at the end, we're all worshiping the same person. So, religion to me is just a different form that you decide to worship than I do versus how I worship so. (21-year-old Hispanic female—Lupus; "A little" religious)
>
> …when Jesus is not the center, from my perspective, everything else is gonna fall apart and…whenever you set your sights on someone other than Jesus, they're always gonna let you down…It's just. So I mean, I don't wanna say it's hoopla cuz there's definitely beneficial stuff to it but it's more about a relationship with Jesus than it is a rules and like this is not the Old Testament. But yeah. (22-year-old European American male—Epilepsy; "Very much" religious)
>
> I think I'm more a religious person. I'm Christian, but I think those, in my mind they go together. Um, with spirituality [and religion because they go together], you have to have that belief that there is something other than just us I guess and

> that for me, it's God. (22-year-old European American female—Chronic urticaria/hives; "Very much" religious)

It is worth noting that all ten of the participants who provided this understanding of religion considered themselves "at least a little bit" religious as determined by their responses to the prescreen questionnaire, and the inclusion of God and Jesus in each of their responses was likely influenced by this identification. Is also noteworthy that only one participant included a deity other than the Judeo-Christian deity, God. This additional deity, Orula, was associated with the religion La Santeria.

> You know, all the spirits that follow me, God, Orula, they wanted me. The way I see religion is that they wanted me to somehow know about *this* to know that they exist… (21-year-old Hispanic female—Lupus; "A little" religious")

Negative Connotations (10 Participants, 38%):

Thirty-eight percent of participants reported that they associated religion with negative thoughts, emotions, and experiences. These negative connotations ranged from believing that religion is too rigid to being excluded from an entire church because of one's sexual identity.

> Religion to me is a little scarier. Yeah, to me, it's a little too rigid. (21-year-old European American female—Type I Diabetes; "Not at at all religious)

> [Religion is] Um [laughs]. The roots of my frustration, but I know that's not [laughs] So, I think religion is a big barrier that shouldn't be there. But, I don't know; religion is just weird. (20-year-old European American female—Irritable bowel syndrome and medullary sponge kidney; "Not at all" religious)

> Because you know, when I hear religion, I also think about the people who are kind of hard headed and [say things like], "This is the answer. I don't care what you come up with. This is the way it is so get used to it." Tend to think of it in that way too. But I tend to see religion as more rigid. You know, like religion has the answers before you even have the experiences. You don't even need to learn from the experience; you just learn from these words or whatnot so maybe that's... (23-year-old European American male—Irritable bowel syndrome; "A little" religious)

> Um, I said, I was raised in a Baptist church, and, I don't know. The people in in that church just seemed closed-minded, you know. And kind of kept to their own little group like exclusive. Um, and you know when I came out to my mother as you know being gay, I she was like, "Well, that's fine but don't tell your grandmother!" [laughs] And then one day, she told my grandmother. I don't know why. She texted her. Um, and I was like, "Really?!" And my grandmother goes to the church that I used to go to when I was growing up, and I remember being in that church and just hearing what they had to say about homosexuality, and it was just, it wasn't in line with you know any it wasn't supportive, and it was very demeaning and, it was just they said homosexuality is a sin and kind of like the stereotypically that you would expect. Um, and so I didn't really wanna go back to that church you know. Um, and that was a big part of losing the Christian faith for me. Um, and I haven't really replaced it with like Buddhism or what what-have-you. So I guess to me, religion has traditionally been about exclusion just because I feel like I've been excluded from the church. (22-year-old European American female—Chronic migraines and headaches; "Not at all" religious)

In describing these negative aspects of religion, some participants such as the preceding one did so by describing practices and actions performed by religious individuals, and this is related to next category, which follows.

Practices (10 Participants, 38%):

Bible-reading and church attendance were the two most frequently cited practices that illustrated participants' perceptions of the actions in which religious individuals engage; however, other aspects such as learning about God were also mentioned.

> When I think religion, I think church, God, the Bible, reading, reading the Bible, things like that. It's more…I think, um, that…to me religion is more about trying to learn about God and in a kind of read the Bible or, or whatever holy text it is…and then kind of work with each other and talk about it and try to figure out what God is from the words of a text. (23-year-old European American male—Irritable bowel syndrome; "A little" religious)

> Religion is two things. Religion is what you do. Religion is the acting on beliefs. But the word "religion" kind of bothers some people, and I understand why because religion is like what the Pharisees and Saducees did in the Bible. They do what they're supposed to do but their heart's not there; they're doing it for the wrong reasons. That to me is religion. But the word "religion" kind of has the connotation of you just do it because you think you should. Which I guess, sometimes you just have to do it because you think you should even if you don't feel like doing it. But religion would be just the actions. Whether it's for good

> reasons or not, religion would be what you do. (23-year-old European American male—Type I Diabetes; "Somewhat" religious)

> Religion is more the actual focus on Christianity I guess you'd say. The learning about what Jesus did, reading the Bible, actually more focusing on that and the different traditions in religion, of the religion. (22-year-old European American male—Asthma; "Somewhat" religious)

Religion and Spirituality are the Same Thing (5 Participants, 19%):

Approximately 19% of participants noted that they believed that religion and spirituality were related or that they believed they were the same things. In fact, at least one participant appeared to question her understanding of religion after being asked to define it apart from spirituality.

> I think I'm more, I'm a religious person. I'm Christian, but I think those, in my mind they go together. (22-year-old European American female—Chronic urticaria/hives; "Very much" religious)

> I think spirituality's a huge part of religion because spirituality in the Christian religion has a lot to do with faith. (21-year-old European American female—Charcot-Marie-Tooth; "Very much" religious)

> Spirituality, I don't really know the difference between spirituality and religion. I've always thought of those two as the same so, if it's not the same then… (20-year-old European American female—Asthma; "Very much" religious)

This latter exemplar again serves as a segue way into the next category, which describes participants' overall lack of clarity about how to define religion either because they had not attempted to do so or because they perceived that religion was not separate than spirituality.

Uncertainty (4 Participants, 15%):

> I really still don't understand it. I'm trying to understand cuz I thought it was the same thing [as spirituality], so I'm really trying to grab the concept of the difference. (20-year-old African American female—Celiac disease; "Very much" religious)

> And religion, to me, it feels like, it's used as a word for arguments and all these controversies and just all these groups that basically kind of separates us. And it just kinda makes I guess a blindfold over our eyes because we don't see the bigger picture. And, I'm starting to realize that, but I can't necessarily express exactly how I associate the word religion. So. But that's all I got! [laughs] (21-year-old Asian American female—Polycystic ovarian syndrome and metabolic syndrome; "Somewhat" religious)

Albeit this latter participant initially described religion in a negative way (e.g., "…it's used as a word for all these controversies…and…it kinda makes I guess a blindfold over our eyes…"), she later concludes that she really does not know how to conceptualize religion. For her, it seems that her experience of religion has contained so many contradictory aspects (e.g., her belief that "when I need help, I go to God" but also the fact that she perceives it as "a word for like all these controversies") that she is ambivalent about how to integrate all of these experiences into one coherent understanding.

Another participant expressed self-doubt over not knowing how to define religion. This may be associated with her self-identification as a Christian and as someone who utilized religion during the active treatment phase of her lymphoma:

> Um, I don't know. I should be able to answer…I don't know. Um, I'm Christian. Um, so I think I think that [it] was helpful just knowing or or having the idea that um that this was um that it was in hands bigger than mine. Um, and that maybe something would happen would come from it. Maybe it wasn't just some useless, futile experience. Um, yeah. (22-year-old European American female—Lymphoma; "Somewhat" religious)

Man-Made (4 Participants, 15%):

Along with the participants who perceived that religion evoked negative connotations, other participants suggested that religion was something that was "created by people." One individual believed that people created religion in order to understand

and explain things that they observed while another believed that religion was based on "the greatest fiction book in like the world."

> For me, religion is very much something that's created by people. I'm not a religious person at all so…I can see how, if for someone it's like the Bible was of a divine origin, then it would make a lot of sense, their mindset. But it's just different for me because I see it as being from a human origin where it's like people were living and wondering, "Well how can we explain things happening?" But I see it as something of a human origin as opposed to religion, which is very much of humans. Of humans. (23-year-old European American male—Type I Diabetes; "Not at all" religious)

> I just always thought religion was built upon the greatest fiction book in the world, and I always thought it was silly that people would disregard what is obviously right or what's obviously wrong because it's in this book. (22-year-old Multi-ethnic female—Lupus; "Not at all" religious)

Perceived Benefits (4 Participants, 15%):

For some participants, religious beliefs and/or practices evoked positive reactions and emotions including a sense of comfort and happiness. This concept is best exemplified by the following passages.

> And I understand that religion is comforting. I know it comforts a lot of people. (20-year-old European American female—Irritable bowel syndrome and medullary sponge kidney; "Not at all" religious)

> Um, I guess it gives someone a way…it's a way for people with set routes. It's something for them to latch on to, gives them stability, some comfort… (22-year-old European American male—Asthma; "A little" religious)

> But I always found…I don't have anything against religion, you know. I feel like if this is what's gonna make you a better person and makes you happy, then by all means, do it. I'm all for people making themselves happy so long as it's not at the sake of other people's happiness. (22-year-old Multi-ethnic female—Lupus; "Not at all" religious)

Interestingly, these three respondents each self-identified as atheists. Their descriptions of perceived benefits of religion were offered as a way to show that they did not ascribe to religious beliefs (e.g., they did not include themselves as individuals who could benefit from religion) but that they also respected how those who do identify as religious were able to benefit from doing so.

Faith in God (2 Participants, 8%):

In conjunction with believing in the existence of God or a higher power, participants who provided responses falling into the present category demonstrated that simply believing that God existed was not enough; having faith in him was also essential.

> You know, believing in God. Having faith the size of a mustard seed. Basically, I just think religion is, you have a faith, believing in God, born again, and you have a faith and the size of mustard seed like it says in the Bible, and it's basically it. Just having a one-on-one relationship with God. (24-year-old African American female—Lupus; "Somewhat" religious)

> living audaciously in faith if that's God's will, if you take the first step, He'll take He'll jump the oceans or something, I don't know. It's a terrible analogy or whatever it is. But yeah. (22-year-old European American male—Epilepsy; "Very much" religious)

This emphasis on faith, particularly by the first participant who made repeated references throughout her interview to finding a cure for lupus and waiting "for time to catch up with his word," may have been especially relevant given the current medical knowledge that deemed many of the chronic illnesses that participants reported incurable. For example, the first participant stated in another portion of her illness narrative:

> it's [lupus] a part of me now. It'll forever be a part of me 'til they find a cure so just because you know science hasn't caught up with God's word yet doesn't mean that I'm not healed. I'm already healed according to God; I just gotta wait for time to catch up with His word. (24-year-old African American female—Lupus; "Somewhat" religious)

This exemplar will also be discussed further under Research Question 3 given this participant's tendency to rely on scriptures from the Bible as a basis for her faith and for her view of herself as someone who is already healed.

Organized (2 Participants, 8%):

For the following two participants, the word religion conjured an image of organization. The first participant's response suggests that this organization may be divisive in that she separately labels the people who are associated with the different organizations (i.e., denominations), which represent religion to her. The latter participant does not offer such a response but rather states that she simply thinks of it as "organized…That kinda stuff."

> When I think of religion, I think of organized religion. You're a Presbyterian. You're a Buddhist. You're Hindu. You're Jewish. Whatever you are, you have a group of people that all do the same thing. It all means the same thing to them. (18-year-old European American female—Rheumatoid arthritis and fibromyalgia; "Somewhat" religious)

> When I think religion, I think church, God, Jesus, that kind of stuff. Going to church. Organized. That kinda stuff (22-year-old European American female—Type II Diabetes; "A little" religious)

Shared Beliefs (2 Participants, 8%):

Unlike individuals in the first category who suggested that the word religion implies a specific belief in God or a higher power, participants in this category do not label what it is that individuals whom they consider religious believe. Instead, they comment on their idea that religion represents the act of sharing a belief with others. This sharing evokes a communal understanding, which the first participant explains.

> Religion I think is just having a shared belief and then being able to, as a community, follow that and try to implement [clears throat] that with each other. (22-year-old Asian American female—Asthma; "A little" religious)

> Whatever you are, you have a group of people that all do the same thing. It all means the same thing to them. (18-year-old European American female—Rheumatoid arthritis and fibromyalgia; "Somewhat" religious)

Other (2 Categories, 1 Participant, 4%):

Responses in the "other" category further reflected the ways in which one of the participants understood religion. For example, although the following participant's comments also reflected her belief that faith in God was an aspect of religion, it was also included under a separate category given the uniqueness of her listing "the guiding principles" one must follow in order to be considered religious:

> So, I think the bottom line is as long as you born again, you saved, you believe in God, you have faith, you follow his word; those are like the guiding principles. (24-year-old African American female—Lupus; "Somewhat" religious)

She was the only participant to list the terms "born again" & "saved" when referencing religion. As such, her description of religion stood out.

Spirituality

As stated above, exemplars that fit within 11 of the 16 categories for spirituality were reported by at least two participants, while the remaining five were reported once by a total of three participants. Specific examples from the 11 categories containing at least two separate individuals' responses are reported below, and they are followed by a sample of exemplars from the "other" category. Of particular importance is the overlap between the definitions offered for both religion and spirituality. A total of five categories were similar for both concepts.

Belief in a Higher Power (Not Necessarily God or a Deity; 11 Participants, 42%):

In contrast to participants' definitions of religion, which specifically named God, exemplars from this category demonstrate that participants' understanding of spirituality included beliefs in non-specific higher powers. For example, one participant labeled this as "fate or karma or anything like that."

> Having someone to look up to like a higher power. Believing in something that well, I guess it could be fate or karma or anything like that. [clears throat] Believing that something or someone controls our life. Yeah. Guides the pathway to what's happening in life. (22-year-old European American female—Type II Diabetes; "Somewhat" spiritual)

Others provided no examples but explained that they believed that spirituality encompasses a belief in *a* higher power.

> I just know I believe that it's a higher power and everything happens from him, who, you know, if you, want to. (20-year-old European American female—Asthma; "Somewhat" spiritual)
>
> Ok. Spirituality what it means to me is I guess having faith in something other than mankind. Having faith that there's a higher being…. (21-year-old Hispanic female—Lupus; "Very much" spiritual)
>
> To me, spirituality is kind of belief. Belief in something. But I do believe that there is always something watching over us, and I believe that there is somewhere that we go once we pass on. I believe in heaven and hell. And for me, spirituality is the belief in those things. And I believe that there's, like I said, there's a higher power that's constantly watching over, constantly challenging, constantly just either watching out for you or challenging you in new ways to make you a better person. (21-year-old European American female—Type I Diabetes; "A little" spiritual)

This latter participant extends her description of spirituality as a belief in a higher power to include the role that the higher power plays in one's life. For example, she believed that the higher power served a dual purpose: "constantly you know just either watching out for you or challenging you in new ways to make you a better person."

Belief in or Relation to God (10 Participants, 38%):

Despite some participants' tendency to make a distinction between spirituality as a belief in a higher power that was not necessarily God, 10 others did suggest that spirituality involved a belief in or a relation to God, and this is similar to definitions of religion presented earlier.

> Just, my personal beliefs, I believe in Jesus. He's the one person who can save us. He's the mediator between us and God, the father…It's really everything is God's and, he created it all but we don't necessarily vividly plain out see. It's there, and …my spirituality is a relationship. He's my God, and I'm not just gonna passively sit in the back seat while He does all these things. He's gonna teach me throughout my life. He's gonna show me things that I never even knew existed… (22-year-old European American male—Epilepsy; "Very much" spiritual)

This participant argued that his experiences have taught him that spirituality represents a belief in God or Jesus as "the one person who can save us." This participant further explained his belief that spirituality involves a belief in Jesus by stating that "…my spirituality is a relationship. He's my God." He took ownership over God as a way of demonstrating the strength of his personal relationship with God.

Relatedly, another participant also perceived that spirituality was characterized by a monotheistic belief in "one God." He stated:

> And quite honestly, I believe in a higher power and all that stuff. And just believing one God. (21-year-old European American male—Lymphoma and lupus; "Somewhat" spiritual)

Another participant who self-identified as both a spiritual and a religious individual on the prescreen questionnaire responded in a way that suggested that he had never considered what the word spirituality meant or what it meant to be spiritual. He initially expressed difficulty defining the word but later offered the following:

> That's tough. I mean, just knowing that there's somebody. Like I said that there's a God that is up there. He makes…he decides on everything and being faithful to him and thanking him, praying to him. That's ultimately what I'm trying to say. Ultimately you know it's his [God's] doing I guess. I don't really know a great definition but that's what I guess it means to me. (22-year-old European American male—Leukemia; "Very much" spiritual)

Spirituality and Religion are the Same Thing (9 Participants, 35%):

Similar to responses to the question regarding religion, 35% of participants also responded that they believed that spirituality and religion were closely related and/or the same things when asked to define spirituality.

> Kinda more, I guess, more along with religion, kinda religious experience… (22-year-old European American male—Asthma; "A little" spiritual)
>
> I [chuckle] W-when I think spirituality, I always think religion. (24-year-old European American female—Mitral valve prolapse; "A little" spiritual)

The following exemplars represent ways in which others around participants appeared to influence their understandings of spirituality.

> I know it's more of a religious connotation but I'm not religious. I don't associate it with that. (20-year-old European American female—Irritable bowel syndrome and medullary sponge kidney; "Not at all" spiritual)
>
> I *thought* that spirituality was kinda the same as religion. But I guess it's not from being in class [laughs] and so…To me, it was religion. I thought that it was just you know, as far as me going to church, and it had something to do with God and stuff. That's what I would think automatically of it. For me, it means the same thing… (20-year-old African American female—Celiac disease; "A little" spiritual)

This latter participant initially vacillated between what she believed spirituality to be and what she had learned in class about spirituality. She eventually settled on her own personal beliefs, which equated spirituality to religion given their inclusion of "…church, and…something to do with God and stuff."

What it is Not (6 Participants, 23%):

Instead of only describing what they believed spirituality was, 23% of participants also provided their ideas of what spirituality is *not*. For some, spirituality was something that was intangible and/or something that "helps you cope:"

> Spirituality is what is not physical. (23-year-old European American male—Type I Diabetes; “Very much” spiritual)

> It’s just the thing that helps you cope with things that’s within you but not actually a physical thing. Yeah. (21-year-old European American female—Charcot-Marie-Tooth; “Somewhat” spiritual)

> It’s knowing myself cuz I don’t believe in an external thing so, it’s really internal. (20-year-old European American female—Irritable bowel syndrome and medullary sponge kidney; “Not at all” spiritual)

Other participants described what spirituality is not by comparing it to religion.

Participants made distinctions regarding connections and practices.

> When I think of spirituality, I think of being connected to a higher being, not necessarily religion where it’s organized and laid out. Being connected to, like I said, a higher being and more your surroundings and being at peace and not necessarily reading from a book as much. (18-year-old European American female—Rheumatoid arthritis and fibromyalgia; “Somewhat” spiritual)

> but for me, going to church doesn’t necessarily mean you’re a spiritual person; it just means [laughs] you go to church every Sunday. I feel like, to be a spiritual person, you’re not just doing things in such a shallow basis like, “I’m a good person. I’m just going…I’m going to church and I’m going to attend it.” You’re not doing it so people can see you and make, and they’re like, “Oh, well she’s a good Christian.” It’s like, “Well…[laughs] she’s doing the right *things* but it’s not necessarily [laughs] doesn’t mean that she’s a spiritual person.” So, I don’t know if that’s making any sense but that’s how I see spirituality. It’s not something that you’re going to see and because I need help and it’s kind of…to me that’s kind of a selfish thing. Like I’m just going there when I need Him. Bbut just that, you know… (21-year-old Asian American female—Polycystic ovarian syndrome and metabolic syndrome; “Very much” spiritual)

Uncertainty (6 Participants, 23%):

In the same way that participants demonstrated uncertainty regarding their understandings of religion, they also provided definitions of spirituality that were admittedly ambiguous.

> Spirituality is just having a certain belief and living a certain lifestyle that follows that, I think. I’m not really too sure, but that’s what I think it is. (22-year-old Asian American female—Asthma; “A little” spiritual)

> I'm not sure. I think spirituality is a really interesting concept. I guess spirituality to me [pause] is I don't know. And I guess I don't really have a definition for it for myself but I'm kind of ok with not having a definition for it for myself. If that makes sense. Is that ok? (22-year-old European American female—Chronic migraines and headaches; "A little" spiritual)

> I guess I have an idea of spirituality. I'm not sure how to define it…that's what I kinda think of it, yeah. I can't really say much [laughs]. Being part of a bigger plan, maybe. (22-year-old European American male—Asthma; "A little" spiritual)

Despite indicating that they were unsure what spirituality means, each participant did proffer some definition even though none was confident in the definition he or she offered.

Characteristics and Practices of a Spiritual Person (5 Participants, 19%):

One way that participants were able to explain what spirituality meant to them was to describe their idea of a spiritual person or someone who engaged in spiritual activities. Each participant framed his or her response around the description of "a spiritual person" or "someone."

> Well it's different than… ok when I think about a spiritual person, I think about a person who thinks that there's something special about the world or the universe. They don't necessarily call it god but they think in some way, they're connected to a universe that ultimately works things out…But I tend to think of it as somebody who either doesn't believe in a god but still thinks there's a spirituality to the world or as somebody who does believe there is a god but doesn't necessarily think that they can be petitioned or by prayer or reached by prayer (23-year-old European American male—Irritable bowel syndrome; "A little" spiritual)

> I feel like to be a spiritual person, you're not you're just going…"I'm going to church, and I'm going to attend it." You're not doing it so people can see you and make, and they're like, "Oh, well she's a good Christian." It's like, "Well…[laughs] she's doing the right *things* but it's not necessarily [laughs] doesn't mean that she's gonna she's a spiritual person." For me, I feel like it's just being genuine about it, and it's knowing that you're going to make mistakes but for me, it's like God is there and I know what I'm struggling with now… (21-year-old Asian American female—Polycystic ovarian syndrome and metabolic syndrome; "Very much" spiritual)

> I would think it would be someone who it's, I'm looking for the best way I can say this. Someone who could just really take a third person view of where they are and tap into something else that they might not be too strong in excelling in or be too strong in like if they're not a very, if they're just in a very hard time, I feel like they have something to just give them just an extra push. It's just being able to take a third person view, an outer look of just how everything is and just become stronger. (22-year-old Multi-ethnic female—Lupus; "Not at all" spiritual)

Connection to the Universe, Earth, and/or to Others (4 Participants, 15%):

Unlike religion, which 38% of participants described as a connection to God or a higher power, 15% of participants argued that spirituality involved a connection to other people or to the earth.

> For me, spirituality involves a connection with other people, like the spirit of other people, their consciousness, and also maybe with the material earth as well. So really connection with other people, their minds, and the earth as a whole just matter is all I guess…whereas spirituality is more of like, "How do I fit in with the earth and other people? Other people but just the universe as a whole?" (23-year-old European American male—Type I Diabetes; "Not at all" spiritual)

Again, participants offered comparisons between religion and spirituality when providing their definitions as these next two exemplars demonstrate.

> But since then [since participant was excluded from the church after she came out as a lesbian], I honestly do see spirituality as a more positive thing than religion because I feel like spirituality is a feeling of unity with the world almost, which I can relate to in some ways. There are times when I do feel kind of, I guess, aligned with the world, you know. Like aligned with people. Especially since becoming a person who identifies with things that are atypical, I've become a lot more accepting of people, and I've just felt kind of this, "We're all in this world together," and the more I learn about people and about how everyone has these struggles, I kind of feel, what's the word? [pause] I'm thinking of a very specific word. [pause] When you…like I can commiserate. (22-year-old European American female—Chronic migraines and headaches; "A little" spiritual)

> When I think of spirituality, I think of being connected to a higher being, not necessarily religion where it's organized and laid out. Being connected to, like I said, a higher being and more your surroundings and being at peace and not necessarily reading from a book as much. (18-year-old European American female—Rheumatoid arthritis and fibromyalgia; "Somewhat" spiritual)

Faith (4 Participants, 15%):

One participant explained her perception that spirituality involved the act of having faith by paraphrasing the contents of one of her favorite biblical scriptures:

> For me, it means the same thing, so if someone asked me that [“What does spirituality mean to you?], I would still say I think of love, faith, and hope, which I think, even not really understanding what spirituality is, I really think those three words can relate back to that also in any situation. (20-year-old African American female—Celiac disease; “A little” spiritual)

The next participant linked her belief that spirituality involves faith to her religion, La Santeria, and the higher powers associated with this religion (e.g., God, Orula, and the saints). In doing so, she indirectly connected spirituality and religion together in a way that is similar to participants who directly indicated that spirituality and religion are related and/or the same. In addition, this participant described the nature of her relationship with God, Orula, and the saints and the reasons for which she has such faith in them (e.g., “Because I’ve already seen things so I already feel like I’m not following blindly”).

> Ok. Spirituality what it means to me is I guess having faith in something other than mankind. Having faith that there’s a higher being…For me, it means having faith in God, having faith in the saints that are gonna help me, having faith in Orula…So, I have a lot of faith in what he [Orula] says. If he tells me, “[Participant’s name], you cannot, as much as you wanna try to be number one or something, you cannot. Always refrain cuz you’ll always have people tryna bring you down.” I’m gonna listen. That’s having faith to me. Without having to question it. The faith that I have, I don’t question it. If they tell me I can’t do this because of this, I’m gonna listen. I’m not gonna question why; I’m not gonna try to ask them why. No. That’s the faith that I have. Because I’ve already seen things so I already feel like I’m not following blindly. You know. So I guess that’s what spirituality means. (21-year-old Hispanic female—Lupus; “Very much” spiritual)

A Feeling (3 Participants, 12%):

Related to participants' belief that spirituality involved something intangible, exemplars from this category reveal the idea held by 12% of participants that spirituality is a feeling.

> It's more of a kind of feel type thing. (23-year-old European American male—Irritable bowel syndrome; "A little" spiritual)

One participant likened this feeling to one's conscience, which provides guidance and helps one decide whether or not something "feels right [or] feels wrong."

> That's a good question. I never really thought about it. Um [long pause] hmmm. I don't know. It's more a feeling with me. It's like a feeling of righteousness or rightness in a sense. I think it would be more [of a] physical feeling for me. Like that's how I'd define it. Yeah, to me it would be more of a feeling. Kinda like how you have your conscience, like, "Ok, this feels right, and this feels wrong." Something like that. That's how I would define it. (24-year-old African American female—Lupus; "Somewhat" spiritual)

Peace (2 Participants, 8%):

As a result of channeling or being connected to "something" or "a higher being," 8% of participants believed that spirituality was associated with a sense of peace.

> That it's [spirituality] something that they can channel and you know, get a kind of inner peace or a way of understanding the difficulties of life. (23-year-old European American male—Irritable bowel syndrome; "A little" spiritual)
>
> Being connected to, like I said, a higher being and more your surroundings and being at peace and not necessarily reading from a book as much. (18-year-old European American female—Rheumatoid arthritis and fibromyalgia; "Somewhat" spiritual)

Something that Offers Guidance (2 Participants, 8%):

One of the two participants who provided responses that fall within this category defined spirituality in terms of one of its functions: providing guidance. The other, however, labeled the beliefs she associates with spirituality as the things that one follows in order to be guided (i.e., a guideline).

> Having someone to look up to like a higher power. Believing in something that well, I guess it could be fate or karma or anything like that. [clears throat] Believing that something or someone controls our life. Yeah. Guides the pathway to what's happening in life (22-year-old European American female—Type II Diabetes; "Somewhat" spiritual)

> To me, spirituality is kind of belief. Belief in something. But I do believe that there is always something watching over us, and I believe that there is somewhere that we go once we pass on. I believe in heaven and hell. And for me, spirituality is the belief in those things. And I believe that you know there's, like I said, there's a higher power that's constantly watching over, constantly challenging, constantly just either watching out for you or challenging you in new ways to make you a better person. So that you have some kind of guideline. (21-year-old European American female—Type I Diabetes; "A little" spiritual)

Other (5 Categories, 5 Participants, 19%):

Responses in the "other" category provided additional ways in which participants understood spirituality, and they reflected unique perspectives not shared by any other participants. For example, one participant associated spirituality with her overall sense of self:

> Letting myself, just knowing myself in and out, and it's really important to me, and that's what my spirituality is. (20-year-old European American female—Irritable bowel syndrome and medullary sponge kidney; "Not at all" spiritual)

In addition to describing spirituality in terms of her identity, this participant further personalized her understanding of spirituality by calling it "my spirituality."

Other participants identified additional aspects of spirituality, including being positive and representing a "personal inner thing," as they compared it to religion:

> But since then [since participant was excluded from the church after she came out as a lesbian], I honestly do see spirituality as a more positive thing than religion… (22-year-old European American female—Chronic migraines and headaches; "A little" spiritual)

> And spirituality is more of a personal inner thing. And religion to me is more of the showing off for everyone else. (18-year-old European American female—Rheumatoid arthritis and fibromyalgia; "Somewhat" spiritual)

The following categories were derived from participants' responses to the question, "How have you sought to understand what you are going through in terms of your illness or physical condition?" This question and the corresponding responses are associated with the second research question, which is found below.

Research Question 2: What Factors Influence Meaning-Making Among Adolescents Who Have Experienced a Chronic Physical Illness?

A total of 25 categories emerged in response to the following question: "How have you sought to understand what you are going through in terms of your illness or physical condition?" These categories are presented in Table 6 at the end of the chapter. Exemplars from 12 of these categories were reported by at least two participants each, while one participant each reported the remaining thirteen, making this question the one to yield the most diverse range of responses. Specific examples from the 12 categories containing at least two separate individuals' responses are reported below followed by a sample of exemplars from the "other" category. It is worth pointing out that six of the 12 categories containing exemplars from at least two participants involve some aspect of social interaction or engagement, which represents an overarching theme of meaning-making strategies.

In describing these categories, exemplars that represent aspects of the two forms of meaning defined by studies of meaning-making (e.g., Daaleman, Cobb, & Frey, 2001; Lee & Poole, 2005; Thompson & Janigian, 1988) will be labeled using these forms as guidelines. The reader may recall from Chapter 2 of this document that at least two forms of meaning, implicit and found, have been defined. Implicit meaning involves the gathering and processing of information in order to understand stressful experiences. Found meaning and its two accompanying subtypes, order and purpose, involve actively searching for the meaning of an event and steps an individual takes to fit such an event into his or her life. This may involve coming to view the event as a part of his or her world and larger life scheme and/or attempting to find a reason or a cause for the event.

Social Comparison (10 Participants, 38%):

Ten participants responded to this question in such a way that reflected their tendency to engage in social comparison, a process coined by social psychologist Leon Festinger in 1954. According to this theory, when one's sense of self is challenged or questioned, individuals compare themselves to others in order to develop a more accurate evaluation of themselves. This process also serves to potentially boost one's self esteem and/or to reduce anxiety about a perceived flaw. In general, social comparison has two forms: upward and downward. In upward social comparison, individuals compare themselves to those who are slightly better at something than they are. In doing so, the individual is able to create a goal that he or she can strive to obtain. Downward social comparison involves an individual's tendency to compare him or herself to someone who is obviously worse at something than they are, and this serves to boost self-esteem and to preserve the image of self (Festinger, 1954; Tennen, McKee, & Affleck, 2000).

Responses that fall within this category generally reflect downward social comparison, either to others who have the same diagnosis or to individuals who have diagnoses that are similar to their own. For these participants, it appears as though using downward social comparison helped them to see that they were better off than they thought they were even though they still had limitations and/or still lived with the illness every day. Social comparison did not take the illnesses away, but it provided a different way for participants to view themselves as individuals who lived with an illness. For example:

> There's a group on Facebook that I joined, and all these people are taking pictures of their legs and their arms and then in wheelchairs. And I'm like, "There's no way I have this." But then I got in contact with another college student who was in Australia or something, and she was telling me about how she was diagnosed the exact same year I was as a senior in high school, and hers was really mild but she was telling me how it affected her. And she told me something—I don't talk to her anymore—but it was something about when she was playing tennis, her ankle just gave out. And her dad had it, and she went to the neurologist after her ankle had healed and everything. And she was diagnosed. And it was just neat because I saw that you don't *have* to be extreme in a wheelchair or you don't have to have the visible disease for you to have it. And I think that's kinda how I came to terms with it. Like it's, I don't know, and it's still hard cuz people don't know why things are happening. But it's good to know that somebody else has the same thing as you. But just not to a degree that everyone else has it. Kinda hard to explain it. On that Facebook group. It's like a Charcot-Marie-Tooth Facebook group, so I went on there. And everybody shares their story. So I went on there, and I was like, "Here's what's going on with me." And there was some negativity because so long ago. There's was some negativity because people were like, "Why are you even on here? Like, "This is for people whose lives are altered each and every day." And I was like, "But you don't understand. I'm dying right now. You have no idea how much I can go through in 10, 15 years. You don't know how fast this is gonna progress." So, there was negativity but then this one girl was like, "I'm in the same boat as her." And so we just started Facebook chatting and realized that we had a lot in common. (21-year-old European American female—Charcot-Marie-Tooth)

This passage demonstrates how the participant read descriptions of others' symptoms of Charcot-Marie-Tooth and did not believe that she fit the profile because her illness was not as severe as everyone else's. She was initially unable to fit this illness into her life scheme as it currently existed. In the participant's attempt to learn more about the illness, she joined a Facebook group but was initially rejected by the members because they, too, did not believe that her presentation was consistent with their understanding of Charcot-Marie-Tooth. Despite this, in many ways, this Facebook group was also helpful to this participant because it challenged her notion that everyone who has Charcot-Marie-Tooth has debilitating limitations, which are visible, instead of invisible like her own. This passage also demonstrates how individuals may attempt to find more than one form of meaning when evaluating stressful life events. For example, this participant demonstrated her attempt to seek order in addition to how she engaged in information gathering in an effort to obtain implicit meaning.

Yet another participant perceived that attending support groups with other individuals who were diagnosed with lupus enabled her to have a newfound respect and appreciation for the abilities she still possessed.

> Yeah, exactly. And I meet people [at support groups], and I feel bad cuz it's bad for me but it's, you know there's a saying, "There's somebody out there doing worse than you." Now I see that effect that the illness can take on people. Some people really have it bad in their bones and their hands, and they don't have physical use of some things. And some people walk with a cane, and a walker, and I'm just like, "Ahh!" And I complain, well I don't say I necessarily complain. I don't complain but I'm just like, "Ahhh" you know when I feel bad. I'm like, "Ahhh, I feel bad" but these people could possibly lose their mobility, and I couldn't even imagine what my life would be like if I couldn't walk, do anything by myself. So, going to that has taught me to be grateful and more accepting of it and thank God it's not as worse as it could be. It was an eye-opener. It [going to support groups and seeing others who experienced more difficulties than the participant] put it in perspective a lot and, I don't wanna say I feel bad for them because I mean I know it's not their fault. It's not something they can control. You know, it's hereditary, genes. But I be wanting to cry sometimes when I leave because in a sense, I wanna cry cuz I feel bad but then again, I'm grateful because I'm in school. I can pretty much, 85% of the time, do stuff for myself and, I can still drive, and I can still kinda do almost the same things as normal people. But these people can't even do that. And I was talking, I met one woman, and, she can't work, she can't do anything. She basically feels like she is confined to the bed. She's like, "I can't even walk to my mailbox without falling or my bones cracking", and it's just like "Wow." I don't know. I feel, like I said, I don't wanna say bad but that's the first thing that comes to my mind. I'm just like, "Wow. I can still do those things." So. Absolutely. I am grateful that I am where I am, that my illness is not as bad as they are because these people I talk to are not old, you know, 50s 60s. They're late 20s or early 30s and I'm 24 so it's right around my age, and I'm just like, "Yeah" [sigh]. [chuckle] Like "Wow." (24-year-old African American female—Lupus)

One participant labeled individuals who have experienced significant comorbidities or consequences of their illness “those people,” a group into which she hoped she would never fall.

> I mean, just learn about it to make sure I didn’t fall into the group that loses their limb or has to go on insulin. I know of people who are on insulin pumps and basically, once you start it, you’re on it forever. And, it’s just awful. Yeah. I remember seeing a girl when I was really little always had to have a pump on her and I was like, “Oh, God, I can’t imagine.” And then once they put that out there that I might have to do that, it was just like a shock like, “Oh, I can’t be like that.” (22-year-old European American female—Type II Diabetes)

Another participant believed that his age allowed him to handle the treatment associated with his diagnosis of diabetes better than others who he knows who are significantly younger than he is.

> It’s kind of hard for a nine-year-old, and it wasn’t emotionally hard for me so, being able to talk to him another guy as well has been kind of making it one more good thing out of my own difficulties. (23-year-old European American male—Type I Diabetes)

The final exemplar reflects participants’ ability to experience feelings of gratitude and luck when compared to the diagnosis or treatment of other individuals.

> I know a kid that had brain tumors and I went to high school with, and he died within 6 months of being diagnosed. And I’ve been lucky to live this long. (22-year-old European American male—Leukemia)

“Google is My Best Friend” (10 Participants, 38%):

Ten participants reported that they utilized the Internet in order to understand their experiences of illness. This tendency to seek out medical information about their illnesses is akin to what Lee and Poole (2005) called implicit meaning, which involves gathering and processing medical information. In addition to researching their illness and potential long-term effects of their conditions on the Internet, participants also reported that they derived social support from portions of the Internet such as blogs and online forums. Again, this is a category that reflects the overall theme of social interaction as a means of understanding one's experience.

> but over the years, especially when they told me I needed to go on insulin if I hadn't changed, I, mean, Google is my best friend. I Google'd everything and looked at everything to do with diabetes just to see what I could do to change my lifestyle and my eating style everything. [clears throat] I mean, just learn about it to make sure I didn't fall into the group that loses their limb or has to go on insulin. I know of people who are on insulin pumps and basically, once you start it, you're on it forever. And, it's just awful. Yeah. I remember seeing a girl when I was really little always had to have a pump on her and I was like, "Oh, God, I can't imagine." And then once they put that out there that I might have to do that, it was just like a shock like, "Oh, I can't be like that." [clears throat] [I didn't initially believe what my doctors were saying because they only gave me statistics that I didn't understand] But [information about diabetes is easier to believe] when it's a blog with people telling you what they did and what changed and everything like that, like real people. I've gone through Google and done the information sites and then gone to the blogs. I've seen that kinda stuff. (22-year-old European American female—Type II Diabetes)

For this participant, the Internet, in particular Google, provided information about ways she could better manage the illness, including changing her lifestyle and eating style. Furthermore, blogs on the Internet provided a reality check that made the illness and its potential severity more real to the participant who had initially dismissed all of the statistics that her MDs had provided her about diabetes (e.g., "I guess I didn't really believe them. Like, they give you the statistics and you're just like, "Oh, ok.").

Another participant used the Internet to get information and support from others with chronic migraines through online forums:

> I've gone and seen some—I've looked online at some online forums and read about other people talking about their experiences with chronic migraines, and that helps…But there's endless people online who can relate, and that's always comforting to see that other people are going through the same thing… (22-year-old European American female—Chronic migraines and headaches)

For the next participant, reading information about celiac disease on the Internet along with talking to her physician and relying on faith and social support enabled her to answer the “why me?” question, which was her initial response to learning of her diagnosis.

> I guess through researches [on the Internet] on it it’s really gave me understanding of what it is and like I said, by researching, I find all I need to know. If I can’t find something, I just ask. And I think that helps me understand that it’s serious, but at the same time, it’s not that serious to where I need to sit around every day and think about it and be depressed or attend support groups even though I could probably help somebody else by doing that. But that helps me…When I first found out over the phone, I immediately started to cry because the first thing I thought about was more I guess, “Oh, this is the end of my life.” Cuz I didn’t know, “I don’t know what it is. I don’t know what she’s talking about.” So I was like, “You know, I’m really young, and I don’t wanna like die young.” And then I was like, “You know, this is not fair. Why me? Why do I have to have it?” A lot of “Why me? I don’t wanna have something.” I felt like it was gonna be hard. Like I said, I didn’t understand. When somebody says “disease,” you automatically, “Oh, my God! That’s the end of my life!” You know, “this is something that can’t be fixed!” But with understanding and research, I don’t feel that way anymore…I think more with the research and the all the support that I have, which is from others loving me, and having faith, I can continue to go on probably helps me with “why me.” That’s the only thing I can think of. (20-year-old African American female—Celiac disease)

This is another participant who demonstrated how she attempted to obtain multiple forms of meaning. She sought implicit meaning by researching her illness on the Internet and by asking others. She also sought both components of found meaning in her attempts to answer the “Why me?” question and to figure out for what purpose she was diagnosed with celiac disease. Unlike the African American female with lupus who attended support groups regularly, this participant indicated that she did not seek meaning through support groups because she did not perceive that she sat “around every day and think about it and be depressed.” Although she did not think that she could benefit from support groups, she did believe that had she attended, she could have helped someone else. In describing reasons why she did not attend support groups, this participant indirectly provided characteristics of those who do attend: those who “sit around every day and think about it and be depressed,” and this was not how she viewed herself.

In contrast to the responses of participants above, the following participant indicated that she did not perform any research on her illness, whether on the Internet or otherwise.

> I didn’t really research it that much. I didn’t really care to be honest. (22-year-old Asian American female—Asthma)

Social Support (9 Participants, 35%):

Very closely related to the social aspects of social comparison and utilizing Internet blogs and forums is social support, which a total of nine participants described as being meaningfully related to their ability to make sense of their experience of illness.

> and like I said, I talked to other people online that has either the same conditions or similar ones. Well a lot of people that have issues with the immune system causing problems and chronic pain and illness and stuff like that and so talking to them kind of helped, and reading what they have to say in their blogs and stuff helps, so it makes it a lil’ easier to understand I guess just cause you know you're not the only person out there that's having to deal with it. (22-year-old European American female—Arthritis)

Along with providing social support by being able to connect with others, the preceding participant also utilized conversations with others online to normalize her experience and to realize that she’s “not the only person out there that’s having to deal with it.”

In addition to perceiving that the students and teachers at her school were “more spiritual, more positive, more loving I guess,” the following participant also appeared to value the ways in which these individuals helped her to understand why and for what purpose she has irritable bowel syndrome. This participant’s method of understanding is akin to purpose, an aspect of found meaning, which reflects one’s ability to find a reason for a life event such as an illness. Specifically, these individuals helped her to understand that she was not being punished because she has irritable bowel syndrome.

> I went to a Christian private school and there was seven teachers for a total of 60 kids in the school so the teachers were really really involved in your personal lives, too. And they were very helpful with any problem that I had, and they were very understanding about my IBS. They really cared and then it was Christian, too, so. But just being around people who were more spiritual, more positive, more more loving I guess, more caring that was really really helpful. And then being able to talk to people and I guess they were also big thing about helping me understand that you know I'm not being punished and that's why that's not why I have what I have and that I can use it for my benefit. And so I think just being around a good amount of people has really helped me deal with what I have. (22-year-old European American female—Irritable bowel syndrome)

Another example of efforts to obtain implicit meaning are found in the exemplar below, which shows how the participant talked to her stepmother about potential conditions that could result from having lupus. In addition to providing this information, the participant's stepmother offered suggestions about how to handle particular symptoms that she may encounter, which the participant appeared to value.

> I have, actually cuz it's hereditary I have…It was just so weird how it ended up that my aunt has it. So I talked to her and she's...But then my dad, my stepmom, she has it, and hers is more severe than mine cuz she's had breast cancer and lost her kidney. I talk to her a lot about different stuff because I know those are possible conditions or things that could happen. So I talk to her a lot of times like, "What do you do for this?" Or "You know I'm experiencing this this day. I'm in really bad pain. I don't know what it is. What do you do?" And I talk to her every day. So I talk to her at least like once or twice a day, and she'll be like, "How're you feeling? And dah dah dah dah dah." So I get information from her… (24-year-old African American female—Lupus)

Unlike other participants who reported utilizing social support as a means by which to obtain information or to receive assistance in finding one's purpose for having the illness, the next participant appeared to interpret the question as "how do you cope with diabetes" because she described it as a way of having individuals around on whom she could count to help when she was experiencing difficult times.

> I guess, having that support system and having my family and my friends. They they've kind of gotten me through this, for sure. (21-year-old European American female—Type I Diabetes)

One participant, however, talked about how she did *not* have the social support that she perceives would have been valuable, not only for herself but also for her father who shared a similar diagnosis.

> Not really. I mean it makes me…it kinda in a way, it makes me resent my dad, which is bad. He, ever since I've been diagnosed, he's denied it. He's like, "You don't have this." He was like, "I've had it my entire life, and you don't have it." And I was like, "Dad, I do but mine's a lot more mild than yours." And so, it makes me resent him even more and the relationship that we have. We're really close. We eat lunch every Monday. We're really close but it makes me resent him every time we start talking about it because he doesn't believe that I have it for some odd reason. He thought, he was excited that insurance was paying for the surgery [to correct participant's toes, which had curled entirely under her feet as her disease progressed] because it wasn't just cosmetic. But he didn't get it. He was like, "You're just doing this. Your feet *don't* hurt." I'm like, "They *do*." And he doesn't get it. So it's really put one little blockade in our relationship because he can't see eye-to-eye. And I think that he's acting like that because he feels bad. He wants to deny that he passed the disease to me. So, he's just denying it, which is, in turn, making the whole thing worse. If we could just talk about it openly, it would be better. Mmm hmm. Cuz we could support each other. And I think that's a big thing being able to support each other when you have something even if it's not like a major life threatening disease, it's good to have a support system. And I don't have that, and I don't think he has that. Cuz the last relative that we had that he was close to that had it as extreme as dad, which he's not very extreme, but that it was visible was our uncle [uncle's name], and he passed, well my great uncle, and he passed away when I was five. So he doesn't really have anybody to share it with either. (21-year-old European American female—Charcot-Marie-Tooth)

In addition to pointing out the emotional response to being rejected by her father, this participant also expressed a longing for her father's support. Likewise, she described her perception that social support is pertinent for individuals who live with a chronic illness. By not supporting the participant or validating her perception of self as someone with Charcot-Marie-Tooth, it seems as though this participant's father denied her the opportunity to find order or a way in which this illness, which was genetic and which linked her to her father and other family members in a unique way, fit into her identity and into her life as a whole. In the participant's opinion, neither she nor her father had the support that she believed to be so important.

Moreover, one participant described how he did not just receive social support but that he found meaning and benefit in being able to give social support. He did, however, place limitations on how he offered this support.

> Yeah. One thing that's been helpful for me in terms of I guess understanding it, accepting it, being ok with it, has been being able to talk to some other people. Like I was saying, one little kid, he's 9, and it's kinda emotionally stressful on him. So I guess, just getting to go hang out with him and talk to him. Barely even talked about diabetes. We did a little bit. But just for him to be able to ask questions. I mean he's doing a really good job taking care of himself. But just for him to be able to talk to someone else about needle sizes and what he was reading about how all the terrible things that it can do to your body. It's kind of hard for a nine-year-old, and it wasn't emotionally hard for me so, being able to talk to him, being able…him and another guy as well, has been kind of like making it making one more good thing out of my own difficulties. If that makes sense. And that's been good. That's helped me accept it and be like, "Yeah, this is ok." Some good is coming out of it. Like me eating better, like me exercising better, this is one more good thing, and it helps me deal with, helps me understand it, and be ok with it. I don't purposefully look for them. I think it's something I'd like to do more of but I kind of feel like I have, I don't what it is…But I kind of feel like I shouldn't at least purposefully reach out and look for people to help until, I mean, cuz I can't even empathize yet cuz I haven't had 600 blood sugars for months on end or whatever. So I'm kind of gonna wait and see what happens with me. As opportunities come along, I really do enjoy talking to people. I really do enjoy helping but as far as looking for people to talk to, I'm gonna wait until I've kind of figured more stuff out myself, read more, learned more, maybe had more trouble with it. (23-year-old European American male—Type I Diabetes)

As stated, instead of receiving social support, this participant described how he extends social support to a younger kid who has also been diagnosed with and lives with diabetes. However, despite the benefits of doing this such as learning how to accept his illness and gaining healthier habits, he also perceived that he had not struggled with diabetes long enough to qualify him to volunteer to help others. Nevertheless, he did not turn down opportunities to help when they arose. In offering support, the participant was able to accept that diabetes was a part of his life, thus finding order, a subcategory of found meaning.

Talking to MDs (9 Participants, 35%):

Another form of meaning-making involving a sense of social interaction involved participants' tendency to seek answers from their medical doctors. This category again represents the concept of implicit meaning whereby participants describing the process of gathering and processing information related to their diagnoses. The following participants expressed trust in their doctors' opinions and training. They perceived that the information they obtained from physicians was helpful.

> and my doctor, Dr. X, is lovely. He gave me different pamphlets and stuff that was like support groups. (24-year-old African American female—Lupus)

> And I ask my doctors all kinds of questions. And even when they speak to me in medical terms, I ask them, "What does that mean? Cuz I'm not gonna let you put something over my head. I wanna know!" And my doctors all know now they can't pull anything over my eyes cuz I will ask every question. I want to know what's going on. I wanna see the x-ray. I wanna be up in the x-ray. I want you to point *exactly* where, and if I don't see it cuz they would show me, "Like, oh, here's cysts and here's kidneys stones" and I would be like, "I don't see that. I need you to show me again like where exactly is it?" So that's definitely been a big strength is actually knowing what's going on because a lot of people just kinda let the doctor tell them something, and they go home and take the medicine the doctor told them to take but I wanna know what the medicine's doing, why it works, how it works, what are the side eff- I always ask the side effects even if they are 0.1% likely to happen, I wanna know cuz I wanna be aware of it cuz I wanna know if I'm having symptoms that could be side effects that are also symptoms of another illness, I wanna know, "Ok, this is a side effect of my medicine." (20-year-old European American female—Irritable bowel syndrome and medullary sponge kidney)

This participant explained her need to understand her diagnoses and medications so that she could be fully aware of what was going on in her body and with her treatment. In addition to providing information, the answers to these questions appeared to provide the participant with a sense of relief as well as a way to differentiate symptoms of her health conditions from side effects of the medications so that she would know how to properly respond.

The following participant made a conscious decision to not learn about his illnesses because he had complete trust in his medical doctor and in her ability.

> I really didn't wanna care. I didn't care. All I knew is that my hands were in the best oncologist in the world…But once I knew I was in her hands, I just said, "Let's do it. Let's get on with it." I really didn't care. "If you wanna put that in me and you know it's gonna do its job, go 'head. I'm not gonna fight it." Yeah, she knew what she was doing. Yeah, I didn't have any concerns. Once when I knew she knew what she was doing. I mean, she had many different degrees, and she's been in the field since the '70s, and she knew exactly what was going on, and I trusted her. And darn if she didn't save my butt, too. (21-year-old European American male—Lymphoma and lupus)

What was even more intriguing about this participant's trust in his oncologist was that this oncologist had previously treated his mother, who unfortunately passed away from bone and breast cancer. Despite the loss of his mother, the participant was able to reframe the experience such that he was grateful that, with the oncologist's help, his mother was able to live an additional four years following her diagnoses:

> And luckily, I probably had one of the best oncologists in the world because she's cured both my uncle, twice me, and she's allowed my mom to live for four years that she probably shouldn't have lived.

One of the two participants who described their encounters with physicians as unhelpful was one who expressed her frustration with "medical terms:"

> I mean, you try to talk to doctors but it's kinda hard. They tell you everything in technical terms, and you don't really understand what they're saying. I didn't really believe them. They give you the statistics, and you're just like, "Oh, ok." (22-year-old European American female—Type II Diabetes)

This method of understanding was ineffective for this participant because her physicians spoke in terms that were difficult for her to understand. This lack of understanding seems to have contributed to her initial denial of her diagnosis, which is suggested by her statement, "I guess I didn't really believe them." Because the participant was unable to integrate the "medical terms" into her identity at the time of her diagnosis, she was unable to find a sense of order, a component of found meaning (Lee & Poole, 2005) whereby individuals attempt to fit an event into their worlds and larger life schemes.

Religion and/or Spirituality (7 Participants, 27%):

Although a separate question was asked to assess participants' use of religious and/or spiritual frameworks for understanding, 27% of participants provided answers that included these concepts when asked to describe the ways in which they understand their illness experience. They were also given a chance to elaborate on this topic after this writer officially asked whether, and in what ways, participants used religion and/or spirituality to understand their experiences of illness. Responses to this latter question will be presented under the next section, Research Question 3. The extent to which participants utilized religion and/or spirituality to understand difficult life situations, two questions on the prescreen survey, are also included with exemplars in this section.

One participant's response removed any responsibility of his ascribing meaning to his own experience and attributed this process to God:

> Yeah, but I sought out, I don't necessarily think I sought it out myself; I think it was kind of God just being in control… (22-year-old European American male—Epilepsy; Spirituality "very much" and religion "very much" involved in understanding stressful life events; henceforth "involved")

Still another participant reported a strengthened relationship with God as a result of going through his experience of illness and perceived that he was diagnosed with leukemia because "there's somebody up there that's making me go through this…"

> I think I’ve become closer to my religion you know to God and being a Christian. I don’t think I’m as close as I *should* be but, I definitely have come closer and realized that there’s somebody up there that’s making me go through this but it’s probably it’s for a positive reason. It’s making me stronger, and I think that’s the only thing I really sought you know…Just knowing that there’s a reason behind me being diagnosed when I was 16. And there’s a reason why I’m still here. You know there’s a reason behind everything. (22-year-old European American male—Leukemia; Spirituality “somewhat” involved and religion “somewhat” involved)

The notion that there is a reason for one’s illness experience is a theme and an example of purpose, an aspect of found meaning, that will be explored further in the next section (i.e., Research Question 3).

One participant’s response to this question is worth describing in detail given the rich information that she offers. It is included here rather than in the following section (i.e., Research Question 3) because this is the question to which she provided this story. In the story that follows, the participant describes a hospitalization for the treatment of lupus that followed a cleansing ritual she performed as a part of her religion.

> I’m gonna say that ever since I started following that religion, it’s really changed my life because it’s not like, no offense to any of those religions out there, it’s not like blind faith. I see things. I’ve seen things that you could not explain not even with science. Things that I’ve seen that have changed my life. For one is this disease…it’s true; I did flare within that week but I didn’t flare for a whole week. I was there for three or four days, and I got to go home. My platelets went up; they said, “Ok, this isn’t as bad as what we thought. You’re free to go.” So, I was like, “Ok.”
>
> Interviewer: And that was different than previous flares.
>
> Every flare that I’ve had in history every one I’ve been in the hospital for more than a week.
>
> Interviewer: And that one you were only there for three, four days.
>
> So, doctors I guess, they expect the worse. They would expect the worse. They have to; they’re doctors. Had a bed ready for me and everything. I mean. She was like, I love her; she’s a great doctor. But she was just like, basically had was trying to set things up at [the hospital] so if anything happens, they have a bed

ready for me; they're gonna get me started so I can get better. Cuz my platelets were at 130. That was already above; I was already under normal, which is 150. What I didn't know when I got there is that 130 sometimes is the highest that I get. Cuz she told me that, too. She's like, "But you know, who knows? We'll see what happens. I look at you, and you look fine." She even told me that, she said, "You look fine. How do you feel? Dr. X was worried but you look fine." I was like, "I feel fine." When she checked my platelets, I just had to wait because I'm like, "I really wanna see this. I wanna put this to the test." You know. My platelets within the last four days after I did that cleansing raised from 130 to 165. So it put me above normal. Not even above normal but when she checked my records, she said, "You haven't been this good for over a year." 165! At that point, I'm not gonna cry in front of her, but when I leave the parking lot, I start crying, and I don't cry very often. I hate crying. I started crying because I'm like, "Oh, my God! This has never happened to me. There's no way in hell someone's gonna make me feel now that what I did isn't real. No way." Cuz in my whole time period of having lupus, that's never happened. I never from one day to another without getting steroids injected into me, IVIG [intravenous immunoglobulin], all these freaking medications, never have helped me as much as that did. Because even with IVIG, the reason why I stay there for a week is cuz IVIG will take one day, and my platelets might raise from 20 to 40,000, to 50,000. It's a slow process. But I did this cleansing, and look what happened. So, it's really amazing to me. So, I start crying and I call my mom, and she said, "What's wrong?" And she's expecting the worse I guess cuz I'm crying, and I'm like, "No, I'm fine." She's like, "You're fine?" I'm like, "Yeah." And I told her, and she sent a text to my boyfriend, she was like, "I know I don't know a lot about this religion but thank you." She was like, "Whatever you did worked." She was just—she's very hesitant about this. And ever since that day, you know I look at this religion, and I'm like, "Things are different." I mean, hell, who wants to go for the rest of their life thinking, "I may not be able to have kids. I may not have a long life. I may not be able to finish school" with being sick. But with this religion, I have that comfort of knowing, I can do it…But the whole point is that this religion does have an impact on my life and whether people think I'm worshiping the devil or I don't care what people think. And I met my boyfriend I feel for that may be the reason why I met him. Because I had no idea about this religion you know…So, to that effect, the whole point is that my platelets never went up so quickly, and they just they did. So, ever since then I'm more part of the religion I guess. So, this religion has gave me a lot of faith, you know? But I just look at everything in my life, and these spirits that help me, it's like they've always been there and the only difference is that now that I know they're there so I pay them their respects and I thank them for helping me…Um, I guess my religion, my spirituality, my faith has really made me look at life and made me feel more appreciative of it. I didn't have to find out about this religion but somehow they came to me. Somehow through my boyfriend, they came to me. All the spirits that follow me, God, Orula, they wanted me. The way I see religion is that they wanted me to somehow know about this to know that they exist so that that emptiness I've always felt my whole life of feeling different, of feeling even

> in my family, I feel like I'm the different one, you know. That emptiness, they fill it. That absence of not having a father. The absence of being different than all my brothers and sisters. You know, this religion really makes me feel as a person. I don't feel like I'm walking around half-full. Now I feel full if that makes any sense. This religion really makes me understand my life, and it just really showed me, "Hey, we're giving you a second chance if you're gonna be ok." They even told me a lot of things my health is always gonna be dependent on me and what I do, my mind. Cuz I have a very bad temper; I get angry very easily so they talked to me a lot about that and so I guess this religion really just helps me put everything into place that I always felt was empty. (21-year-old Hispanic female—Lupus; Spirituality "very much" involved and religion "very much" involved)

Although lengthy, this story has several points worth noting. One aspect of ascribing meaning involves looking for causes of one's illness, or in this case, the participant's healing. As a result of the temporal order of the cleansing ritual and the drastic increase in the participant's platelet level, which, by her report, "never" happens, she wholeheartedly believed that her medical recovery was caused by her participation in her religious ritual. Furthermore, for this participant, this event offered further proof that what she had come to learn about her religion was, in fact, true and not made up. She reported that this experience caused her faith in God, Orula, and in the saints of her religion to increase substantially. She believed that she had witnessed their power and their abilities firsthand, and this was momentous for the participant. In addition, she indicated that as a result of this experience and as a result of incorporating this religion into her life, she has developed a greater appreciation for life, and she now feels that her religion fills the hole that she felt prior to being found by God, Orula, and the saints and participating in the pivotal cleaning ritual. Ultimately, she concludes, "…this religion really makes me understand my life…" including how aspects of her personality contribute to her future health:

> They [the spirits and leaders within her religion called Babalawos] even told me a lot of things like my health is always gonna be dependent on me and what I do, my mind. Cuz I have a very bad temper; I get angry very easily so they talked to me a lot about that…"

"Disabled Role Models" (7 Participants, 27%):

Twenty-seven percent of participants described having individuals in their lives who provided examples of what it was like to live with illness. These "disabled role models" did not necessarily share the same diagnosis as the participants who looked to them for assistance in understanding what they were going through.

> I've always had a disabled role model. My grandfather was extremely ill. When he was probably 15, he started having heart attacks and that kind of thing. He had two transplants, heart transplants, in his life. He was going to get a kidney transplant until they realized that his body was just not well enough to accept it. He died in 2008, so until I was 15…But he was always very strong. He always made it through. I guess not always. He's dead now. He made it through when the doctors were saying, "You can't. You can't." And he always put on a happy face, and he kinda taught me that no matter how crappy you feel, you kinda gotta do what you gotta do. So, he was just always happy. He just never let it get him down. So, he'd be lying in bed not able to go wash his car or whatever old retired men do, and I'd be laying in bed not able to go to school and we'd just be happy together, you know. [laughs]. My mom has MS so, and she had a brain tumor last year before last. So, she's had health struggles. I've always had her around, so she's kinda the example of what not to do maybe cuz she's just kinda one of those "Woe is me" people. I'm not saying that she doesn't have real pain because I know just as well as the next person. I'm not gonna judge what she's going through but she is on disability. She doesn't go out much. She doesn't make friends unless she's in a mood to, you know. She kind of just, "Well, I'm disabled, so, you know, I'm not gonna be able to go out and do things as much as other people so I'll just not make friends to begin with because they'll be disappointed." So, she just kinda stays at home a lot, and sometimes it's a little hard to tell whether she's depressed because of her illness or if she's just that tired. I don't know which it is but either way, it's different than what I saw with my grandfather, and it's not what I want to be. Maybe there will a point where I get that depressed because of this [like my mother] but I don't ever foresee that happening because I like the way I am now. I liked the way my grandfather was. I know that it can be done. I just think your attitude has a lot to do with it. I was lucky enough to kind of know what that medical environment…I don't know what I'm trying to say here. I know a lot about the medical side of it because of them and I also know a lot about the emotional side of it because of them. So I kind of have a lot of background coming in. And I was like, "Oh, I'm sick; you're

> sick, too. Really big surprise." Obviously, my grandfather's ill; my mother's ill. It's really not a shock. (18-year-old European American female—Rheumatoid arthritis and fibromyalgia)

This participant learned indirect lessons about how to be sick from both her grandfather and her mother. Her grandfather provided the model of how to remain positive throughout illness while her mother provided an example of "what not to do" because, in the participant's perception, her mother was a "woe is me" kind of person who was not as positive as her grandfather was. The participant chose to align her identity as a "disabled" person with her grandfather's, whom she perceived as a better representation of how to "do what you gotta do" "no matter how crappy you feel."

Another participant looked to her brothers' examples for what to expect in her life with asthma. The way her brothers managed their illnesses normalized her experience. Because of this familial connection, she came to expect a diagnosis of asthma as something that was inevitable.

> Well, my brothers had it so, I guess seeing them have it didn't really make me feel too bad about it…No, I mean I just kinda did what he did, pretty much. And I mean he still tries doing sports, too, and he doesn't really do that good either but it was nice to see. If he didn't have it, I probably would've been a little bit more annoyed with it. But it's good my two brothers had it. It was a little bit easier to accept. It was actually, it seemed normal. Like it was expected for me to have it in a way. So, I'm not sure it ran in my family. I guess that was [laughs] kinda what happened but because my brother had it and you know, they just thought I would have it too. (22-year-old Asian American female—Asthma)

Having these role models and having the image of living with asthma be normal for the participant reflects one of the subcategories of found meaning, order, in that the participant was able to accept asthma as a part of her identity more readily than someone who did not have such examples.

Unlike this last participant who had multiple "disabled role models," the next participant lacked such an example. She felt that her experience was unique.

> I don't really know anyone else in real life who has them. At least not the way I do. (22-year-old European American female--Chronic migraines and headaches)

Books (5 Participants, 19%):

Nineteen percent of participants indicated that they relied on information obtained in books to understand their illness and their experiences living with those illnesses. Similar to the information gathering process that occurred with participants' use of the Internet and speaking to their medical doctors, responses in this category also reflect implicit meaning. Whether purely for an enhanced medical understanding of their illness or to learn about others' experiences with similar diagnoses, books served an important role for these participants.

> and I've seen some books about people writing about coping with chronic pain (22-year-old European American female—Chronic migraines and headaches)

> I read small things on it. I kinda read bits and bits and pieces like articles and things like that. (21-year-old European American male—Lymphoma and lupus)

One student incorporated her desire to learn more about her illness into her educational experience. Despite having two chronic illnesses, she appears to emphasize her desire to learn more about one illness versus the other.

> I've researched it a lot. And I've made it whenever I have…cuz in psych classes, they make you come up with your own disease, and you have to research all the literature on it in articles and books and stuff. Every single time it has something to do with chronic illness. It's either IBS or I'll look up other chronic illnesses. (20-year-old European American female—Irritable bowel syndrome and medullary sponge kidney)

One participant did not find the book that her cardiologist recommended helpful at all.

> That was really the only thing the cardiologist had recommend that book, and I had read it I wanna say over winter break and it was kinda really repetitive to me

> about what I had already heard from the doctor…it's more from my cardiologist than the book. One of the things that it mentioned in the book is exercise is really really hard for those people that have mitral valve prolapse and I'm like [excited voice] "THATS NOT ME!" [chuckle] [excited voice] "I exercise three times a day, I'm good!" Cause I remember it [the book the cardiologist recommended] saying that even just taking a walk on the treadmill was hard for those kind of people and how much cardiac rehab they had to go through. And ya know then doin a daily journal for what they eat and stuff like that. I'm just like, "Ya know, I'm glad I don't have to do that" (24-year-old European American female—Mitral valve prolapse)

Acceptance/Helplessness (4 Participants, 15%):

Participants' acceptance of their illnesses as unavoidable and as incurable revealed two somewhat discordant aspects of meaning-making. On the one hand, participants admitted to themselves that they were powerless to control their illnesses. However, on the other hand, they reported that admitting their helplessness was empowering and assisted in their ability to live their lives in the presence of their illnesses. This acceptance may represent participants' ability to find order or the way in which their illnesses fit into their lives in general.

> I guess, I think of it as just a thing I have and don't want. I have to deal with it. What can I do to get rid of it? (23-year-old European American male—Irritable bowel syndrome)
>
> Like I said before with medullary sponge kidney, knowing I can't change it…there's nothing I can do, is kind of a releasing thing. It's kinda like, there's nothing I can do. So, why stress myself out trying to do something if I can't do it. When it's just gonna block me and I'm just gonna hit my head against the wall. I need to go and deal with it. And knowing that it's not gonna change is fine. (20-year-old European American female—Irritable bowel syndrome and medullary sponge kidney)

One respondent described how he views diabetes as something that he cannot change and that will not go away unless "they would come up with something like an artificial pancreas." Because of the inevitability of his having to live with diabetes for the rest of his life, he believed that he might as well accept it. In order to best describe this mindset, the participant provided an example of one’s likelihood of winning the lottery.

> To more directly answer the question, I just feel like it’s something I’ve accepted and not questioned very much at all.
>
> Most things that I feel like I can’t change. If I feel like there’s something that I can change, then I’m not willing to just accept it but if I feel like I can’t. That’s something that’s been very very frustrating but yeah.
>
> Interviewer: You perceive diabetes as something that can’t be changed?
>
> Oh yeah. I mean, I guess it’s foreseeable in the future that they would come up with something like an artificial pancreas or something. I’m not gonna hold my breath though. If it happens, great, and so I mean, *can’t* be changed, I guess I maybe don’t, that’s not exactly how I phrase it if I’m really thinking about being technical. But it could be changed possibly but I’m just gonna accept that it won’t be and so I’m in the mindset that it won’t be. I’m not saying this about, “Oh, what if it could be?” For me, possible but very very unlikely so, I’m not even really considering. At one point in my life, I don’t plan on me winning the lottery. It’s like, “Well, I’m just gonna accept that I’m not gonna win it.” And if happens, I’ll shift my thinking paradigm and think in a whole different mindset but I’m just gonna consider my life as me living to plan it and live it as though I’m not gonna win the lottery. (23-year-old European American male—Type I Diabetes)

Avoidance (3 Participants, 12%):

Three participants described how they made conscious decisions to not learn about their illnesses following diagnosis. The following exemplar demonstrates how the participant felt that doing so would be contrary to his identity as someone who is not a person “that stud[ies] that every day.”

> I’m not one of those people…I guess I know some people that go and study the disease and have to know everything a little bit. I don’t. I’d rather not. I don’t wanna know everything about the disease. I don’t wanna know about the new medicines or anything like that. Leave that up to the people that study that [laughs] every day. (22-year-old European American male—Leukemia)

Have Not Considered It/Not Much (2 Participants, 8%):

While participants whose responses fell within the previous category reported making mindful decisions not to learn more about their illness, individuals who provided responses for the present category reported that they had not “really thought to…understand it in that sense.”

> I don't know…I haven't really thought to kinda under-um, this is gonna sound quite contradictory, but I haven't really thought a lot about what it means to have it or to understand it in that sense… to understand it as …“Well, ok, this is gonna change my life” and “Ok, you know, let's do something different.” I haven't really thought about it that way… (23-year-old European American male—Irritable bowel syndrome)
>
> I guess I haven’t really sought to understand it or anything. Not much. Yeah, I haven’t really thought about. Or anything. (20-year-old European American female—Asthma)

Therapy (2 Participants, 8%):

Two participants sought additional assistance in understanding their experiences of illness. This assistance came in the form of therapy and centered on evaluating ways to prevent symptoms of their illness including things they “might be doing to cause” their symptoms. For one participant, this process was effective; however, for another, it did not work as well and contributed to the participant’s ultimate discontinuation of therapy.

> I know that one of the therapists that I used to see, she kinda said it’s not clinical PTSD but I show some symptoms of someone with PTSD cuz I avoid situations that remind me of that [a distressing and embarrassing experience that occurred when participant first began experiencing symptoms of irritable bowel syndrome].
>
> Interviewer: When did you become aware of this cycle [of misinterpreting bodily sensations as symptoms of irritable bowel syndrome, then becoming anxious and fearful of having another distressful event, and subsequently exacerbating her symptoms of irritable bowel syndrome]?
>
> I think after a lot of therapy [laughs]! And so it was definitely after a lot of therapy [laughs]. But…

> I mean, *therapy*. A lot of therapy. The psychologist that I saw, the child psychologist she was really good. I liked her a lot. She really helped me look at the things that I might be doing that is causing my IBS that I'm not aware of and being more aware of that. The therapy has helped a lot. (22-year-old European American female—Irritable bowel syndrome)

Being able to apply a PTSD-like framework to her experience, in particular an extremely negative event that occurred when she was first diagnosed was helpful. One additional participant described the following experience:

> I did actually go see a counselor here on campus. [He asked me questions such as] "Do you tend to look at people as these things that I have to work with and take care of to make sure they don't react negatively to me? Or do you treat them [people with whom participant interacts] as another opportunity to make a good friend?" So, we talked about that and actually, I met with him for maybe six months or so and then I just suddenly stopped and it's just because he told me basically, the con…What I was getting from the sessions was that you just have to gradually become desensitized gradually to be more and more exposed and maybe, I looked at it the wrong way but I was kind of hoping somebody would help me along that process because it's difficult to do that on your own, you know? When you spend five years of your life trying to avoid it at all cost to suddenly get up and say, "Well now I'm gonna face this and do it today." I mean, you know…That's, that's pretty hard. So, I kind of expected him to go along and say, "Let me and you do this today"…And, that didn't happen, and I just started to feel like this just isn't gonna help. He's basically just telling me, "I'm waiting on you to, to start the process" you know? And I'm saying, "Well, I'm waiting on you." So, I just kinda stopped doing that …(23-year-old European American male—Irritable bowel syndrome)

This participant did not have a particularly positive experience in therapy. It seems as though his expectations of what should have happened during the experience went unmet. As such, he quit.

Classes (2 Participants, 8%):

Two participants obtained implicit meaning via classes about heath and asthma in particular. For one participant, an after-school class offered while he was in elementary school enabled him to learn more about asthma and how it affected his life. This class also enabled him to apply that knowledge to save the life of a friend on another occasion.

> And then when I was in elementary school, they had an after school class about- teaching about asthma and different ways to prevent it and help your symptoms and different things. It's a couple hours after class for just a couple weeks I guess. I don't really remember and that's where I learned a lot more. I learned more from that than I did the doctors and family and friends and stuff.
>
> Interviewer: And so were these the same classes you were talking about earlier when you said you learned about the asthma, which helped you to help the girl?
>
> Yeah, that was one of the places that I did learn a lot. I mean some basic stuff from doctors, the more in depth detail and information came from that class itself. It was just something that they offered and my mom thought it would be good since I did have asthma to sign up for it, to take. I mean we've learned about asthma in some other classes in high school like in P.E. and Anatomy and stuff. Here in college, we've learned some but not near in depth details, just your basic…(22-year-old European American male—Asthma)

Another participant attributed her attainment of knowledge regarding her diagnosis of mitral valve prolapse to classes she took for her exercise science major.

> And what I already knew from being a exercise science major so to me it [the book that the cardiologist recommended] didn't really help that much. (24-year-old European American female—Mitral valve prolapse)

Other (13 Participants, 50%):

As previously mentioned, responses to the interview question addressing Research Question 2 produced the greatest variety, yielding 13 additional categories reported by only one individual each. A few exemplars from these "other" categories will be presented below to demonstrate the breadth of responses participants provided.

One participant applied a common theoretical understanding to his experience of illness in order to understand what it meant for him.

> Initially, I guess it's kinda like the stages of grief. At first, you're just like, "This isn't this is...that was only one time. It's not gonna happen again. I can still do whatever I want." After the next couple times, once you realize it, you're just like, "This is just, this is terrible. I can't I'm not in control in any way, shape, or form of these things." The stress of it just, that only made it worse. Just after the first one, it was bam bam bam bam bam. Grief. Yeah. You can't, you don't believe it's

> happening, and it keeps happening, and you're like, "Wow, this is something I'm gonna have to live with." (22-year-old European American male—Epilepsy)

He described how he initially denied that he had epilepsy: "that was only one time. It's not gonna happen again." As the seizures became more frequent, however, the participant progressed through the additional stages of grief, a theory originally proposed in 1969 by Elizabeth Kübler-Ross (as cited in Kübler-Ross & Kessler, 2005) that explains how one understands his or her response to loss. In addition to denial, this participant also described at other portions of his illness narrative how he experienced the next stage of grief, anger, very intensely before finally reaching the final stage, acceptance. For example, he described:

> I had so much pent up anger and just I would lash out…anything anybody did, I would just lash out, and I was just taking all my anger out on other people…it's hard to describe the emotions. Depression, anger, rage…

Another framed his understanding of his experience in the following way:

> Well, I guess just genetic things. Must be, I don't know; it just happens…I don't know maybe. I don't know. Besides that, no, it's just a biological, genetic thing, yeah. (22-year-old European American male—Asthma)

For another participant, the duration of time during which he has lived with asthma vastly affected his ability to separate his self prior to being diagnosed with diabetes from his self following the diagnosis. This time period made it equally difficult for this participant to apply a framework through which to understand his experience of living with it.

> I feel like I was diagnosed with it at a young enough age that it almost, it really just became how I operate. I mean, people who just wait a hundred years ago where there were no weekends, and they woke up and worked every day. You know, they didn't have a weekend. So, if someone asked them, "Well how do you seek to understand not having a weekend?" the answer is, "Well, I've always had it so that's just how it is," and for me, that really is like. Yeah, I sort of cannot consider myself but just from what I can remember, I've always had it. (23-year-old European American male—Type I Diabetes)

Below, responses to the question corresponding to Research Question 3 are presented. As with previous sections, categories containing exemplars from at least two participants will be presented first followed by a sampling of passages that fall within the “other” category.

Research Question 3: Do R & S Influence Meaning-Making Among Adolescents Who Have Experienced a Chronic Physical Illness? If So, In What Ways?

A total of 18 categories emerged in response to the following question: “In what way, if any, has spirituality and/or religion helped you to understand what you are going through in terms of your illness or physical condition?” These categories are presented in Table 7 at the end of the chapter. Thirteen of these categories were reported by at least two participants each, while the remaining five were reported once by a total of four participants. As with religious and spiritual meaning-making strategies presented under Research Question 2, the extent to which participants utilized religion and/or spirituality to understand difficult life situations are also included with exemplars in this section.

Not Much/Not at All (11 Participants, 42%):

Passages in this section reveal that 42% of the sample reported that they were less likely to use R & S as frameworks to understand their illness experiences. Furthermore, this section demonstrates things that participants did not do in terms of applying a religious and/or spiritual framework to their illness experiences. In particular, this section demonstrates how participants reported a tendency to utilize one concept versus the other, most often spirituality over religion.

> I mean, not in a huge way. But… it was never like, “Why is this happening to me?” It was never that big of a deal, (20-year-old European American female—Asthma; Spirituality “somewhat” involved and religion “somewhat” involved)

> Around here, you don't get much of a positive reaction to it, but I would probably say that not much at all. In relation to my illness, I haven't really gone, gotten any verses or sought counsel from anybody like that. I've just never really related, when I think about spirituality, if I'm praying, I'm not praying for myself so I've never really, you know, "God help me get through this. God make the pain go away." That kind of thing. You know, it's "Help *him* get through this. God feed the starving children." Or "Help *us* make it through this fight." But I don't really sit around asking for someone to take away *my* problems. (18-year-old European American female—Rheumatoid arthritis and fibromyalgia; Spirituality "somewhat" involved and religion "somewhat" involved)

This participant utilized R & S very little to understand/get through her experience. She specifically indicated that she did not look for "any verses or [seek] counsel from anybody like that," and she also did not pray to God that her own suffering would be relieved. Instead, she found that she was more likely to pray for others. She also indirectly described the cultural milieu of the south as one where someone who does not incorporate R & S into his or her life or use it as a lens through to view specific life events is considered an anomaly.

The next participant described her tendency to rely on science over R & S when understanding most of her life experiences, including her diagnosis of lupus.

> You know I'm just a touch it, taste it, see it, hear it person. And I don't really see that changing [laughs] very soon and even with my illness, it hasn't hindered me in any way. I know a lot of people become very spiritual or they tap more into being spiritual when they become sick but I've always had such a very strong family behind me, I've never needed like an extra an extra boost and or anything else to really give me meaning. Just I think [laughs]. I kinda wanna go back and fix that but I'm just. It's once again, I can't say that I've ever had an outer body experience or ever felt, granted everyone thinks I've had a medical miracle [laughs]. I was passed out for that [when participant was initially diagnosed and was in and out of consciousness for several days]! I don't know. [laughs] But I could never say that I felt someone working something over me so I necessarily can't give you a very un-science-y definition. Unfortunately, hardly anything. I I've had to…I try to understand a little bit because my parents are Christian so they…everything I was going through, they were definitely like, "You know, you're blessed and \ this wasn't your time. Someone's looking out for you. You should've been dead." And I tried to understand from their point; I'm not gonna sit there and shoot them down like, "Oh, you're ridiculous! [laughs] What are you

> talking about? No!" I tried. I tried very hard to get a sense of it but it just didn't happen. It just, I don't know. And then I feel horrible trying to force it on me, I'm like, I feel like a big phony. It's like I'm trying to find it but deep down, I'm like, "Uh, this just isn't working but I'm trying to make it work, and it's just no!" (22-year-old Multi-ethnic female—Lupus; Spirituality "not at all" involved and religion "not at all" involved)

This participant perceived that science could explain everything (i.e., "I'm just a touch it, taste it, see it, hear it person") and because she did not believe that R & S belief systems fell into those categories, she was less inclined to use them to explain why she was experiencing what she was. On the other hand, she stated that she did attempt to apply her parents' religious framework and beliefs but she was not able to do so because it felt contrived. She expressed guilt associated with not being able to attach religious meaning to the experience, however. In addition, she felt that she received strength and meaning through the support that her family has provided throughout her experience rather than from something more existential.

The following passage is helpful in demonstrating participants' tendency to separate religion from spirituality in their efforts to understand the meaning of their illness experiences:

> Religion only minimally as in the people at my church have been very encouraging. But spirituality, significantly more so. (23-year-old European American male—Type I Diabetes; Spirituality "very much" involved and religion "a little" involved)

Again, this participant states that although he developed meaning from his experience by applying a spiritual framework, religion did not offer the same understanding. Further description of ways in which this participant utilized a spiritual framework to understand his illness experience is presented in the next category.

One final exemplar demonstrates how one participant perceived her R & S beliefs to be both a source of confusion and "a diversion" from ruminating over her illness.

> It hasn't. I think it's made it more complicated. I would say that it'd be easier to make up my mind about why is this happening or whatever on my own than all the religious stuff that is competing with each other and with me and all that stuff. So it's actually probably made it more complicated. It's been a good diversion though so that's helpful. But, I don't know of any concrete understanding that developed from it.
>
> Interviewer: How has it served as a diversion for you*?*
>
> Maybe cuz I guess the source of my frustration isn't the illness anymore. It's the trying to understand what's going on, you know. Ultimately what is going on here? And why is it happening? (22-year-old European American female—Lymphoma; Spirituality "very much" and religion "somewhat" involved)

This participant presented a dilemma that no other participant described. Although she considered herself to be "very much" a religious person per the prescreen questionnaire, she found that the beliefs that she had learned through her religion conflicted with her own opinions about her experiences. She expressed some ambivalence in this perception, however, because she begins her response by stating that religion and/or spirituality "hasn't" helped her develop "any concrete understanding." However, she later indicated that because she was attempting to resolve her existential conflict, she no longer expressed frustration regarding her illness. On one hand, this existential conflict was a source of stress (e.g., "I think it's made it more complicated."). On the other hand, however, the process of trying to integrate her personal beliefs and her religious beliefs allowed her to transfer the frustration surrounding her illness to something else. Based upon her responses both here and as her illness narrative continued, it seems as though this participant has yet to reconcile this dilemma.

Identity Work/Changes (7 Participants, 27%):

Exemplars from this section are consistent with King and Benson's (2006) assertion that "religion offers an ideologically, sociologically, and spiritually rich context for identity formation" (p. 387). This context may also play a role in adolescents' changing views of self when disruptions such as illness are introduced.

Two participants perceived that they would not be the persons they had become if it had not been for having their illness experiences. In explaining this, they applied R & S frameworks to understanding why they were diagnosed with their chronic illnesses.

> Well one thing that it's [spirituality overall and in particular, participant's relationship with God, which developed while she was hospitalized and found a copy of the Bible in the nightstand and began to read the Psalms] really helped me understand that what I'm going through in some ways has made me who I am. I don't think that I would be wanting to be a psychologist if I hadn't gone through what I've been going through. I don't think that I would have compassion for people the way that I do if I hadn't gone through the hard things that I have gone through. (22-year-old European American female—Irritable bowel syndrome; Spirituality "very much" involved and religion "a little" involved)

This participant believed that as a result of being hospitalized as a result of the difficulties she endured during her diagnosis process, she "found God" and was exposed to the Bible. In doing so, developed numerous positive traits including increased compassion for others as a result of being diagnosed and living with irritable bowel syndrome. In addition, she perceived that the experience influenced her future career plans. It seems as though there was a reciprocal relationship that occurred: the participant "found God" because of her illness, and because of her newfound R & S beliefs, she perceives that her identity has changed for the better. Another participant indicated:

> He [God] called me to play this role in this specific time frame to impact the people that I will come in contact with, and it's amazing how much now I see him. Back then when at the time you can't see a damn thing. I got in contact…this was like two or three summers go when I decided to be an actor. I took a summer

> at my parent's house in [a southern state] and, I was like what? So I been hearing all these, at [church], he's [the pastor] always like, "What is, who has God made you to be? "What is your calling?" And I was like, "I can make anything I like to be my calling at this point in my life," and I'm like, "So what do I, what are my strengths, what are my weaknesses, what am I good with, and what do I love?" Cuz I can half-ass something all day but it's never gonna be as good as I want it to be unless I love it. I mean, in every way shape or form. Just like I said earlier, I probably would not be the person that I am today if I didn't go through that. (22-year-old European American male—Epilepsy; Spirituality "very much" involved and religion "very much" involved)

In addition to believing that he was "called to play this role in this specific time frame," this participant also believed that living with epilepsy altered his perception of self. He considered his experience to be humbling, particularly as he described going from the star basketball player to someone who could no longer play because he could not overexert himself and thereby trigger seizures. He stated,

> We're all fallen beings. It's helped me relate to other people. It's humbled me greatly. And helped me learn that I'm not entitled to anything.

He firmly believed that he would not be the person he had become if he had not been chosen for this experience.

Another participant initially demonstrates ambivalence in the change in her perception of self as a result of her illness but later settles on a response that she perceives to be more representative of her true thoughts.

> I know when I was diagnosed, I felt like I was becoming closer to God because I'm like, "Ok, this is something that I need help with and I know I can't do it on my own." And so it helped me I guess become more spiritual. Well, nothing's perfect. Things happen for a reason, and sometimes I need that challenge or that struggle to see that it's not about me and that there's a bigger picture at hand or it's just helped me…But see, I feel like because I got diagnosed with it, and it wasn't like such an "Oh my gosh," heartbreaking impact that saying the word that I'm spirituality has helped me cope with my actual diagnosis is not the actual for me, it's not really truthful. I feel like because I've been diagnosed with it and now it sent me in the fact of trying to be a healthier person, and I'm struggling with this body image, that that's where my spirituality is kinda going with. I'm like, "Ok God. I'm really struggling and I know you're telling me what to do and I

> really need to open myself up [laughs] and but I'm having a hard time because I'm only human, and I get easily stressed! [laughs]" So, that's how what I believe in has helped me with my diagnosis. Not that it necessarily directly helped me with dealing with polycystic ovarian syndrome but just the effect it has had for me. (21-year-old Asian American female—Polycystic ovarian syndrome and metabolic syndrome; Spirituality "very much" involved and religion "somewhat" involved)

She initially describes her belief that everything happens for a reason and that her spiritual beliefs informed her ability to understand why she was diagnosed with her illnesses and helped her to cope with her illnesses. She postulated that she might have been diagnosed in order to endure a "struggle" or a "challenge," which would force her to rely on God more or to see "that there's a bigger picture." However, she clarifies this statement and instead settles on her conviction that her spiritual beliefs helped in her struggle with accepting her body image and her new identity as someone who lost a significant amount of weight since being diagnosed (approximately 50 pounds). Furthermore, she indicated that instead of her ability to ascribe meaning to her illness, her belief that she can rely on God during hard times was strengthened. In relying on God to help her come to terms with her self-image, she acknowledged that "I'm only human, and I get easily stressed!" She was able to accept aspects of her identity as a result of relying on God to overcome the body image and weight issues, which accompanied her illness experience. She became more spiritual as she grew to rely on God for help getting through the illness experience.

One participant described her belief that she was chosen to have lupus.

> I do. I really do cuz [chuckles] it just happened out the blue one day. For 20 years of my life, it coulda been dormant or whatever, and that may be the case but for 20 years of my life, I was, in a sense, normal. I was doing everything and I come out for college you know for 20 years of life and just like, "Bam!" [claps hands together once] like it happened. And it's hereditary and it does with genes, and my aunt has it so. You know, she's my aunt, so and she's the only one I know in

> my family that has it so I was expecting her daughter or somebody down the line even her cousins to have it. I didn't expect to be like, "Well my aunt and then me." You know, so I think I was chosen. I haven't fully grasped the purpose of it yet like the purpose that God has for me but I think I was chosen, and I don't know if it was to do the class presentations, impact or make people aware of disabilities or whatever. But whatever it is, it's something powerful so I just gotta wait [laughs] for my time to come. Cuz I find it real funny, like I was saying, cuz I have a twin. I don't know if I told you this but I have a twin brother. Yeah! So out of both of us, that's half a chance, 50/50. He's healthy, and I get it. Why? It's kinda like, "Why me?" But I'm not saying "Why me?" like "Oh, God why me?" But I'm just like, "Oh, you know, why me? He could have it, too." You know, not saying that I wish he did but, we both were in the same womb, both came from the same person, the same sperm made us and it's me; it's not him. You know because I have the sickle cell trait, too, so it's like, I just have it, and he doesn't have it, and he's healthy in a sense, and I have lupus and I have a sickle cell trait and it's like, "Huh?" [laughs] Like I said, I can't wait to see what for. But I think I was chosen, and all I can do is wait. And hopefully, you know I'll be good and well equipped to do whatever it is I need to do when I'm called. (24-year-old African American female—Lupus; Spirituality "somewhat" involved and religion "somewhat" involved)

She believed that she was chosen by God to have lupus. She made this attribution based upon her observation that although lupus is genetic, none of her immediate family members have been diagnosed with it. In addition, she considered the irony that her twin brother has neither lupus nor the sickle cell trait, which the participant also reported having. Based upon participant's tone and her smiles while answering this question, the interviewer believes that the participant considered it an honor that she was selected to live with lupus even above and beyond other family members, most notably her twin brother.

Two additional participants' stories warrant mentioning. The first participant's story described how she came to identify herself as someone with an "atypical" identity and that she felt more connected with others who also have "atypical identities."

> But since then [since being excluded from the church after coming out as a lesbian], I honestly do see spirituality as a more positive thing than religion because I feel like spirituality is a feeling of unity with the world almost, which I

> can relate to in some ways. There are times when I do feel kind of, I guess, aligned with the world, you know. Like aligned with people. Especially since becoming a person who identifies with things that are atypical, I've been able to identify with other people who have atypical identities.
>
> Interviewer: You just said you have an atypical identity. What did you mean by that?
>
> I meant like as a homosexual person, as someone who has chronic pain. As some-like in this region as someone who's not a Christian. Just little things that I see some maybe almost discrimination for. It makes me more aware of other people's discrimination. (22-year-old European American female—Chronic migraines and headaches; Spirituality "a little" involved and religion "not at all" involved)

One final passage demonstrates how a participant utilized symbols from a religion with which he does not identify to help him develop a new sense of self as an individual who lives with a chronic illness. This exemplar continues the story that began under the previous category "not much/not at all."

> Actually, it might help to tell the story a little bit. I have a necklace with a cross, my medical ID, and St. Jude. I'm not Catholic but for a lot of reasons, St. Jude is the patron saint of hopeless causes, and I kind of realized because my diabetes and a lot of other reasons, I am a hopeless cause. This has kind of helped me see that I am hopeless physically but also in a lot of other ways. By myself, I'm not much good. By myself, there's not a lot I can do. So, diabetes has kind of helped give me a way to see, "Yeah, I'm kinda messed up. I'm kinda hopeless" in a lot of other ways. But that also the cross is there at the same time at the same place that it doesn't have to be me, it doesn't have to be me by myself, which is really nice. So, that's really comforting but also just really helpful to let me let go of my own worries and my own concerns with diabetes and with a lot of other things. It just helps. Having diabetes has helped me be, just kind of accept that I am kind of helpless. That I'm not in control and that I have to trust God not myself. I'm very messed up. I'm human, and I believe because of the fall, every messed up thing is in my head and the way I stay away from those is because I know that. It's only by the grace of God that I stay away from those, that I don't do those, and when I do start heading in one of those bad directions, any number of sins, I'm like, there's forgiveness and that's what the cross is. So, does that answer your…(23-year-old European American male—Type I Diabetes; Spirituality "very much" involved and religion "a little" involved)

At times, it seems as though this participant attributes his changed identity as someone who is a "hopeless cause" to diabetes but as he continues to speak further, he explains that the cross and the image of St. Jude, the saint of hopeless causes, that he wears on his necklace and the meanings he attached to these symbols serve as a means by which to conceptualize his new identity.

“Everything Happens For a Reason…” (6 Participants, 23%):

Approximately 23% of participants explained their belief that everything happens for a reason. This belief guided the way they made sense of their illness experiences. Such a belief represents purpose, the aspect of found meaning that exists when one is able to find a reason for his or her experiences.

> But I kinda believe that everything happens for a reason and me getting diabetes has changed the way I eat, and I’ve changed the way my family has eaten because they can’t eat junk food around me [clears throat]. It’s made them healthier maybe in the long run and made them look at themselves. And there’s a history of diabetes in my family. I feel like that’s kind of helped or guided me along that way. And then also just everything, like I said, everything happens for a reason and so maybe my diabetes, I’ll work with kids with diabetes one day or who knows? Not really. I mean everyone ha..you have those days where you’re like, “Why me?” But, I mean, I always think about, there’s something out there and that’s why. Something else is happening and you just don’t know it yet. (22-year-old European American female—Type II Diabetes; Spirituality “somewhat” involved and religion “a little” involved)

This participant began to reflect about the reasons she believed she was diagnosed and lives with diabetes including serving as a means by which both she and her family members developed healthier lifestyles or as a way to inspire her future plans. In addition, she concludes that believing that everything happens for a reason may provide the answer to “why me?” (i.e., “Why was I diagnosed with diabetes?”). Another participant provided the following explanation:

> As far as as spirituality and religion go, I believe that things happen for a reason. There is a reason that I was challenged with this. So I just take that, and I run with it…[Interviewer: Do you think you know what the reason is? Or that there’s simply a reason?] No, there’s simply *a* reason. I’ll never know what the reason is. Maybe it was because I’m stubborn. I don’t know. Maybe…I mean, it could be

> anything. I don't know what the reason is. I don't think I'll ever know what the reason is but I think I have it for a reason. (21-year-old European American female—Type I Diabetes; Spirituality "not at all" involved and religion "not at all" involved)

While the participant initially says that she does not believe that she knows the reason for her diagnosis and life with diabetes, she does offer guesses at potential reasons including the idea that it was meant to address her stubbornness. In the end, however, she settles on the notion that she will never know the reason why she was diagnosed and lives with diabetes, and she seems satisfied with this conclusion.

Interestingly, one participant who indicated that she did not utilize R & S as frameworks for ascribing meaning was able to speculate about things she could have drawn from these frameworks if she did struggle with the question of why she was diagnosed and living with asthma.

> But I am sure if I was struggling with it or whatever, I could always think, "Everything happens for a reason. God wouldn't put me through something I couldn't handle." That kind of thing. (20-year-old European American female—Asthma; Spirituality "somewhat" involved and religion "somewhat" involved)

One participant did not believe that everything happens for a reason.

> Yeah just meaning you know, "You're going through the struggle now but there's gonna be reward in the end." Or "There's a reason, a good reason for why you're having to deal with this because of something that will come later" or "You'll help somebody else out or whatever." In response to somebody telling me that, "That's why you have it,", I say, "You know, well, okay maybe." (23-year-old European American male—Irritable bowel syndrome; Spirituality "not at all" involved and religion "not at all" involved)

In contrast to all of the preceding exemplars, this participant expressed doubt that everything happens for a reason because he questions why something so negative would happen to someone. He also questions what the reason could be for having someone suffer so much. He states:

> I don't believe that a loving all foreseeing god would…I don't think that there would be as much sickness and things like this in the world.

Additional exemplars of the tendency to question why bad things happen are presented under a later category.

Prayer (5 Participants, 19%):

Nineteen percent of participants indicated that they relied upon prayer as an aspect of religion and/or spirituality used to make sense of their experience. One participant put it simply:

> Prayer works. [chuckles] I can honestly say that…(24-year-old African American female—Lupus; Spirituality "somewhat" involved and religion "somewhat" involved)

An additional story warrants presentation in detail because it also presents rich and descriptive data that effectively illustrates responses from this category.

> First seizure I ever had, captain of the girls' soccer team, her name is [person's name]…but I can say that she's the female equivalent of me, the most beautiful girl I've ever seen to this day…but the night before my first seizure, I stayed up 'til, I don't even know what time it was, probably like 3 or 4, and I had class at 8 in the morning, and I was just staying up and I was like, "I will do anything to get this girl. I will go through any…the worst pain you can ever imagine and, I wanna spend the rest of my life with this girl." And this is gonna sound really crazy, but I feel like, I will marry her eventually. I will marry her.
>
> Interviewer: Because the very next day you had your first seizure.
>
> I had my first seizure…first seizure, I was walking to class and had a seizure right in front of the school. Second seizure, I was in my first period class with all my friends around. I went to, I graduated with like 65 people, so everybody knows everybody.
>
> Interviewer: And you had just said you'll go through whatever it takes to get her.
>
> And the thing is, it [the prayer] was God-centered. I was like, "I will stay abstinent. I will…" (22-year-old European American male—Epilepsy; Spirituality "very much" involved and religion "very much" involved)

This participant attributed his first seizure and subsequent diagnosis of epilepsy to the fulfillment of a prayer. He described his desire to marry one of his friends from school and declared that he "will do anything to get this girl. [He] will go through any…the worst pain you can ever imagine…" The following day, the participant described having his first seizure. Because of the proximity of this seizure to his prayer, he believed that his prayer was fulfilled and that he will eventually marry the girl about whom he prayed.

Something [Good] Can Come From This (4 Participants, 15%):

Related to the category "everything happens for a reason" comes a category that is presented separately because the participant explicitly stated that he or she believed that something, potentially good, could come from his or her experience. Participants did not necessarily make the statement that "everything happens for a reason" when describing the potential outcomes of their experiences. In general, exemplars from this category are future oriented.

> I tend to think of it as a more of a spiritual way of saying maybe there's something to this. I'm not sure, there are times when I feel like, "Ok, I can see why I have this" because you tend to treat people better you know…like when I was talking about being more sympathetic to them…and you can learn a lot about yourself when you have to deal with a problem too and you sometimes kinda see what you were doing wrong in the past. I'm trying to think of an example for that. Well I'm not I'm not sure but if you ever had a problem and you know this good thing came out of that [you say to yourself] "I'm kind of glad I have this." There are times when that happens and so spirit, yeah, I'm much more… if I'm anything, I'm much more a spiritual side; maybe there's something that's to this (23-year-old European American male—Irritable bowel syndrome; Spirituality "not at all" involved and religion "not at all" involved)

During times when the participant ponders why he was diagnosed and lives with irritable bowel syndrome, he sometimes concludes that it enables him to have more compassion for others and that it can also serve as a life-review of sorts. He challenged the interviewer to consider times when something difficult has happened to her that ended up having positive consequences as a result as a way to demonstrate his belief that "maybe there's something to" his experience.

A participant, who chose to focus her illness narrative on the time frame preceding, during, and immediately following her active cancer treatment phase, found solace in her belief that "something would happen would come from" her experience despite her perception of religion as "a source of anger:"

> At that time, it [religion] meant a lot to me. It was a source of anger. It was also a source of relief and just saying, "Ok. I'm not gonna be in control of this. You're gonna do something with this." I'm Christian, so I think that was helpful just knowing or having the idea that this was in hands bigger than mine. And that maybe something would come from it. Maybe it wasn't just some useless, futile experience. (22-year-old European American female—Lymphoma; Spirituality "very much" involved and religion "somewhat" involved)

This belief that "maybe something would come from it" provided the participant with relief during a very difficult time in her life. This relief came in being able to relinquish control to a higher power.

No More Than You Can Handle (3 Participants, 12%):

Among the three participants who held this view, one participant stated:

> He, my mom told me ever since I was diagnosed, he puts no more on you than you can bear, and she always encourage me like, "Oh you're gonna have a powerful testimony" (24-year-old African American female—Lupus; spirituality "somewhat" involved and religion "somewhat" involved)

This participant's mom encouraged her by sharing her belief that God never gives a person more than he or she is capable of handling. The participant appeared to value this advice given her statement that "she always encourage[s] me…" One final exemplar also represents participants' view that they were not given more than they could handle when being diagnosed with their illnesses.

> There is a reason that I was challenged with this. So I just take that, and I run with it. Obviously, I'm strong enough to handle it or else I wouldn't be here today. (21-year-old European American female—Type I Diabetes; Spirituality "not at all" involved and religion "not at all" involved)

Potential reasons why this participant was diagnosed with diabetes are revealed, including the idea that she is strong enough to handle the "challenge." Although not stated directly, one may imply that this participant was given *only as much as* she was "strong enough to handle."

Connection to Others (2 Participants, 8%):

Yet another lengthy passage best demonstrates the underlying message of this category.

> I've become a lot more accepting of people, and I've just felt kind of this, "We're all in this world together," and the more I learn about people and about how everyone has these struggles, I kind of feel um, what's the word? [pause] I'm thinking of a very specific word. [pause] When you… I can commiserate. [laughs] And I just feel a lot of compassion for people since the headaches started. Cuz I just feel because I have to be so aware of my own headaches, there's a lot of times when I just look at people, and I think, "What are you going through? What…" Cuz people look at me and, you can't tell that I had a headache. You can't tell that I'm in pain, and you can't tell that I have all this extra burden, and so it makes me look at other people and think, "Wow, what burdens do you have that I can't see?" And I think everyone has those burdens. And I guess, in a way, that's sort of spiritual that interconnectedness. Yeah. That's kind of one of the questions I would think I guess. I mean, I guess, if you could consider spirituality as a feeling of interconnectedness, it's made me feel a lot more compassion towards people, and a lot more consideration towards what people could be going through. And in doing research about chronic pain, I've found out about other chronic illnesses that you can't see like fibromyalgia and lupus, and I just feel a lot of compassion for people going through those things cuz I'm going through something so much like that. It just sometimes makes me angry at people if people who are smoking for example. When you walk on campus and someone's walking in front of you smoking, and I'm like, "You do not realize the pain that you are putting me in." But then it makes me, in turn, feel like, "Be a little more mindful of myself and what am I doing to other people. Am I putting them in pain? Am I…make do they have an illness? Do they, are they extra sensitive to light or sound today?" I've been a lot more able to forgive people. In having this, in having the migraines, I've been a lot more able to, for example, if someone is rude to me at a restaurant or something, I've been a lot more able to stop and say,

> "Well, what are you going through?" and think about the person as a person and not just as a waiter or whatever. It's made people a lot more human to me, and a lot less what their roles are. Like I really feel since I started getting the headaches, I feel like this person is my professor, but they're also a human like me, and we have *some sort* of connection because of that, which I can, like I said, I guess that's pretty spiritual. It's not very religious. But I guess that is the biggest way that spirituality has affected my understanding of people and the way that the migraines…I think the migraines have made me a little more spiritual as in interconnected with people, which is, in turn, made me more compassionate and understanding and able to humanize individuals. (22-year-old European American female—Chronic migraines and headaches; Spirituality "a little" involved and religion "not at all" involved)

This participant suggests "if you consider spirituality as a feeling of interconnectedness" then her experience with chronic headaches has made her acutely aware of the fact she and others around her engage in an exchange of behaviors that influence the other. In an effort to both minimize her own discomfort and to see through the eyes of those to whom she is connected, the participant now makes a conscious effort to consider the thoughts, feelings, and potential struggles of those around her.

Questioning Why Bad Things Happen (2 Participants, 8%):

Two participants appeared to struggle with the notion that a god or a higher power would allow individuals to be diagnosed with chronic illnesses that introduce suffering.

> I'm being kind of honest here. Honestly, I don't view it in religious context. I don't believe that a loving all foreseeing god would…I don't think that there would be as much sickness and things like this in the world. I know people say there's an ultimate plan… and there may be but I tend to not think in that direction because I just don't see why there, it's necessary to have so much sickness and terrible things… (23-year-old European American male—Irritable bowel syndrome; Spirituality "not at all" involved and religion "not at all" involved)

Because of his overwhelmingly negative experience with irritable bowel syndrome, this participant questioned why bad things could happen. He specifically questioned how "a loving all foreseeing god would" allow so much "sickness and things like this in this world." In contrast to others who may perceive that there is "an ultimate plan," this participant doubted the existence of such a plan, again drawing from his own negative illness experiences.

Likewise, the subsequent participant's experience with illness is also negatively colored. So much so that she questions why she even has the condition especially given the amount of suffering that she encounters as a result. Because she is unable to find answers to these questions, she reports that she has come to believe in the presence of a higher power even less. It is difficult for her to imagine that such a power would allow negative things to happen to people like her (i.e., those with arthritis).

> Honestly having arthritis makes me wanna believe it even less just cause I have this thing of wondering, "Okay well what did I do that was so bad that I have to deserve dealing with this?" Or even in like the grand scheme of things, "What have other people done that they have to deal with it [arthritis]?" So it kinda makes me wanna believe even less.
>
> Interviewer: mhm. Believe what?
>
> I guess just in the sense of a higher power or any sort of greater being out there. (22-year-old European American female—Arthritis; Spirituality "not at all" involved and religion "not at all" involved)

Guardian Angels (2 Participants, 8%):

Two stories demonstrate how two participants perceived that someone with whom they had been close and who subsequently died served as their guardian angels, watching over and protecting them even in death.

> It really didn't bother me as much because I always thought of my mom as my guardian angel, and needless to say, I kinda think my other grandma, my dad's mom, my grandmother is my other spirit. Because she, those two are both my guardian angels as far as I'm concerned cuz they did everything they could for me…Those two people in my life have basically, if I fail, I will be ashamed of myself because I would've let both of those two down. And I put a lot on that subject because I wanna do the best I can because they allowed me to do it. You know I have all the will in the world to survive, and I have all the will in the world to do everything I could. But without them, I couldn't have done it. I have to thank them every day for it. Count my blessings every day because of them.

> They're tthe heart and soul behind the reason why I'm still here. And it really was just my family. My family was everything. If I believed in angels, they were all angels to me. Yeah. Definitely. And like I said, that's the reason why I'm still here. (21-year-old European American male—Lymphoma and lupus; Spirituality "a little" involved and religion "not at all" involved)

This individual believed that his two guardian angels, his mother and his grandmother who have both died, are the main reason why he is still here and alive. In contrast to other participants who may have used their perceptions of R & S to help them understand why they were diagnosed and live with a chronic illness, this participant uses his definition of spirituality as something that includes guardian angels to provide a reason for why he is still alive. In this way, this exemplar falls within the category of purpose, the subcategory of found meaning. This participant demonstrates some ambivalence, however, in this idea because after labeling his mother and grandmother as his guardian angels, he then appears to question the existence of guardian angels: "If I believed in angels, they were angels to me."

The next passage tells the story of how the participant's deceased friend still influences her life even now. The participant's best friend died from undiagnosed diabetes approximately one year prior to her own diagnosis.

> [She] is my little guardian angel. She's everywhere. Specifically, over Christmas break, my insulin was locked in my boyfriend's apartment, and he was in [a northeastern state]. And I couldn't get to it. It was 3 o'clock in the morning when I realized that my insulin was locked up and I needed to change out my insulin pump. [My friend's] favorite color was orange. I called the 24 hour CVS in [the city], and the guy's like, "Oh, well you just had your insulin filled. It's not gonna go through again. Your insurance isn't gonna pay for it." And I was like, "Is there any way that you'd just be willing to try to push it through? If not, I'll do what I have to do. But if you would try, that would be great." And he was like, "It's not gonna do it. It's not gonna do it. Not gonna do it." So, he, I was just like, "Just try for me." So he does, and it goes through. I get to the CVS in [the city], and [laughs] the guy is not wearing a button up and a tie; he's wearing a bright orange tee shirt. The pharmacist is wearing a bright orange tee shirt. He doesn't ask me my name. He doesn't ask me my birthday. He grabs the insulin out of the fridge,

> puts it on the fridge, and tells me, “That’ll be $45.” Her favorite color was orange. The day of my diagnosis, there was a plane in the sky practicing skywriting. Doing As, just As. No other letter. So, it’s little things like that…Whether it’s [my friend] or not, I don’t know. It’s kind of comforting though. She’s everywhere…it gets weird. [laughs]
>
> Interviewer: Even your fingernails are orange!
>
> Oh, yeah, I didn’t even think about that. Yeah, my fingernails are orange. [laughs] Yep, there she is! Not even consciously. That’s pretty cool [laughs]. That kind of guardian angel aspect of spirituality is kind of my belief. And I believe that, like I said, there’s a higher power that’s constantly watching over, constantly challenging, constantly just either watching out for you or challenging you in new ways to make you a better person. (21-year-old European American female—Type I Diabetes; Spirituality “not at all” involved and religion “not at all” involved)

Since the friend’s passing, the participant has found reminders of her friend in multiple places. This story demonstrates a few ways in which her friend is “everywhere.” In addition, the participant offers her definition of spirituality as something that includes guardian angels and links this to her belief in a higher power that is “constantly watching over… just either watching out for you or challenging you.” Although she did not state so explicitly, the participant could be likening her guardian angel friend who is “everywhere” to the higher power that is “constantly watching over” her. This belief provides the participant comfort.

Yoga and Meditation (2 Participants, 8%):

Spirituality enabled one participant to learn more about herself and to become more in tune with herself. Spiritual practices such as meditation and yoga strengthen this awareness of self and also inform health behaviors including self-care and symptom management.

> I’m so in tune with myself now especially even during meditation when I’m so focused. Whenever I have time, I think about each part of my body and really focus on that part of my body and know what’s going on it all the time. So I’m

> very aware of what's going on. I know when something's wrong, and it's minor, and I can leave it, like a headache is a minor thing, and I'm aware of something that's abnormal that's maybe I should go to the doctor for this, and I make sure that I focus on that multiple times a day to see if it still feels abnormal. So knowing myself so much has been such a big help. Ever since I got out of the psych ward, I started doing yoga and learned meditation, and that really is where I started the upward movement from there. But [laughs]… that's [kidney stones] a really painful thing to meditate through but it helps me come to terms with a lot of things, and it helps me know myself well enough to know when to ask for help, or when to do something about what's going on. Cuz I can feel when kidney stones get to the point where they're about to move, and that comes from being really really aware of what my body is doing all the time. And just being aware of that helps me like, "Ok, so I need to get myself to a place where I can lay down. Let me make sure I have my medicine with me. Let me make sure this." And have everything ready, and as soon as it starts to move, I'm just like, "[exhales] ok. Just get through this next little bit of awful and be done and keep going." (20-year-old European American female—Irritable bowel syndrome and medullary sponge kidney; Spirituality "not at all" involved and religion "not at all" involved)

Similarly, practicing yoga and meditation, which the participant considered spiritual practices, helped the next participant to achieve a sense of calm and also facilitated gratitude for what he has. In his gratitude, he went through a process of social comparison whereby he compared his status on any given day to those of others to whom "other things [were] happening."

> Spirituality has helped some because I practice like, I started doing yoga some and I've also practiced some meditations and it's been helpful to keep me calm and keep me thankful for what I have and just take a step back and see that other things happening to other people today but today I'm fine, everything's going well. And see that, with diabetes and just other things that I'm in a place to make a lot of things happen in my life and I should do that now. So, I think it's something that keeps me from being inhibited. I talk about spirituality and that's helped some to be like, "Well, I really need to do the best I can today because I have a chance to really manage this well." (23-year-old European American male—Type I Diabetes; Spirituality "not at all" involved and religion "not at all" involved)

Faith (2 Participants, 8%):

> I read, and I have different scriptures. I have these little heart things. I put different quotes, different scriptures up around my wall. I mean, I believe that even though I'm taking medicine, I believe one day I'm not gonna have lupus no

> more, and it's not gonna be because I died or anything or I've gone to heaven. It's just gonna be because God says in His word that "by your stripes you are healed," and I totally believe that Jesus died on the cross for illnesses, everything. So I'm like, just because science hasn't caught up with God's word yet doesn't mean that I'm not healed. I'm already healed according to God; I just gotta wait for time to catch up with His word. And that's how I look at it. I have a positive outset and a positive look and let my faith guide me. So, yeah, I'm just waiting for God's word to catch up with time or time to catch up with God's word, and when it happens, all of us will be a living witness of what He can do. (24-year-old African American female—Lupus; Spirituality "somewhat" involved and religion "somewhat" involved)

> My spirituality was leading me, "Pray about it." And I put my faith in God that it *wouldn't* get worse and it *wouldn't* determine if my life's gonna be awful or amazing. (21-year-old European American female—Charcot-Marie-Tooth; Spirituality "somewhat" involved and religion "very much" involved)

Both participants drew strength and comfort from putting their faith in God that they would be healed of their illness entirely or that their illness would not progress. While the first participant reported deriving her beliefs from scriptures in the Bible, the second participant tended to rely mainly on "[her] spirituality." This tendency to draw from healing themes, which are prominent in many religious traditions including Christianity, appears to have allowed these two participants to maintain hope that their conditions would improve or be cured altogether.

Social Support (2 Participants, 8%):

The next participant explained the connection between her spiritual beliefs and how they led her to pray in church that her illness would not progress. As she prayed, she described feeling supported, to some extent, by those in church who were there to witness and participate in the prayer along with the participant and her mother.

> And then my religion background, the church came and surrounded me and prayed with me and it was just nice cuz you knew you had those people like they can't be empathetic because they don't know what you're going through. But they can be sympathetic and they can pray for you. (21-year-old European American

> female—Charcot-Marie-Tooth; Spirituality “somewhat” involved and religion “very much” involved)

Likewise, the following participant derived social support and an enhanced understanding of her experience of illness through members of a religious organization as well.

> Well, I was in youth group [chuckles]…but it [being in the youth group] showed me that there are still people willing to accept you and stuff and people you can have in common with, a shared belief…but they understood. They weren’t judging you ‘cause [clears throat] so it was just people who were more accepting, by nature, and I really like being around more positive people. I feel like some of them [in the youth group] were even jocks. But because they were in that community, they were just a little bit more different in their approach towards you. (22-year-old Asian American female—Asthma; Spirituality “a little” involved and religion “not at all” involved)

This participant had concerns about her identity as someone who was not athletic. Although she tried to play sports prior to and immediately following her diagnosis with asthma, she realized that she was not as adept in sports as she would have liked. For example, she stated, “I mean, I’m not as encouraged in sports. I guess I never really felt like I could do as well. I shy away from running…” As such, she sought out a new identity where she would not perceive limitations in her athletic abilities in comparison to others around her. She found this identity within her youth group where she reported feeling accepted for who she was not for what sport she played or what talent she possessed.

Optimism and/or Hope (2 Participants, 8%):

This last category for which at least two participants’ responses are available represents the notion that optimism and positivity are helpful in ascribing meaning to one’s experience of illness. In particular, optimism and positivity impact individuals’ futures (i.e., “pray it doesn’t lead to something else” and “let my faith guide me”).

> Yeah, I do believe [that the optimism that I have is created by my religious and spiritual beliefs]. I really think so. Being as a, like I say, praying that it doesn't lead to anything else. (20-year-old African American female—Celiac disease; Spirituality "a little" involved and religion "very much" involved)

> I have a positive outset and a positive look and let my faith guide me. (24-year-old African American female—Lupus; Spirituality "somewhat" involved and religion "somewhat" involved)

Other (5 Participants, 19%):

As stated, an additional five categories were derived from the illness narratives; however, these five categories were only reported by at most one participant. Exemplars from two of these categories will be presented now.

> I wanna say a test. As in God is testing me but I don't think it's a test as much as a chronic illness. Something I have to deal with for the rest of my life. I really don't know. I really think you know different things happen and it is what it is so I don't really. No, I don't think it's a test. I think a test is when you go through a hard time whether you're gonna give up or you're gonna succeed, and I don't really think this is a test. It's ongoing, and it's no way to stop it or reverse it back. So, I don't really think it's a test. So, the test, you *have* the option to give up or keep going and, if you give up, you fail the test. So, I guess you *can* relate it to a test, an ongoing test. But I mean, you can't give up. (20-year-old African American female—Celiac disease; Spirituality "a little" involved and religion "very much" involved)

This participant vacillated in her comfort in stating that her diagnosis of celiac disease was a test from God. She rationalized that because her experience did not fit her definition of test as "when you go through a hard time whether you're gonna give up or you're gonna succeed," her diagnosis would not be considered a test. In the end, however, she concluded that her experience might be an ongoing test because it offers her the option of giving up or continuing to push forward. The choice of whether to quit or pursue one's goals is the defining characteristic of a test for this participant.

The final passage to be presented represents one participant's conclusion that after having an experience where she was in a hospital for suicidal ideation, she was exposed to Christianity and "found God," and this discovery had positive effects.

> And I think that [finding God] was pretty important to figuring out why it was that I was going through what I am. (22-year-old European American female—Irritable bowel syndrome; Spirituality "very much" involved and religion "a little" involved)

In sum, numerous themes were derived from the 26 illness narratives that were obtained for the present study. While there was much overlap between participants' responses, there was also significant diversity among these responses, particularly among those addressing Research Question 2. Given that each participant's experience was unique, this diversity was expected. The next chapter includes a discussion of the implications of these findings. Attention will also be given to aspects of reflexivity including this writer's biases, her cognitive and emotional reactions to participants' stories of illness, and difficulties she encountered during this process. The next chapter will conclude with a discussion of study limitations, strengths, and future directions.

Table 1: Participant vs. excluded vs. university demographics

	Sample [a]	Excluded [b]	University [c]
Age *(*Current*)*			
Mean (years)	21.69	20.57	-
SD	2.58	2.72	-
Age *(*at diagnosis*)*			
Mean (years)	17	11.62	-
SD	3.27	6.16	-
Gender			
% Female	69	64.29	50
Race/Ethnicity [d]			
% Native American	3.8	0	.53
% Asian/Asian American	11.5	8.93	5.27
% Black/African American	7.7	16.07	17.17
% Hispanic/Latino	7.7	7.14	6.67
% White/European American	80.8	62.5	61.56
% Other	0	1.79	[e] 8.84
Religious Affiliation [d]			
% Baptist	19.2	21.43	-
% Non-denominational	23.1	19.64	-
% Roman Catholic	7.7	17.86	-
% Atheist	11.5	12.5	-
% Agnostic	19.2	3.57	-
% Other	23.1	25	-
Year in School			
% Freshman	3.8	26.79	-
% Sophomore	7.7	25	-
% Junior	11.5	28.57	-
% Senior	53.8	12.5	-
% 5+	23.1	3.57	-
College Major [d]			
% Psychology	34.6	14.29	4.90
% Mathematics	7.7	3.57	1.25
% Elementary Education	7.7	3.57	2.15
% Engineering	7.7	3.57	8.30
% Other [f]	50	78.57	20.73

Note. [a] n = 26. [b] n = 56. [c] n = 19.215. [d] The total percentage exceeds 100 for the following reasons: one participant self-identified as “All of the above except African American;” one participant self-identified as both atheist and agnostic; and two participants reported more than one college major. [e] Includes non-resident aliens, Pacific Islanders, and individuals who identified as more than one race/ethnicity. [f] Includes the following Other majors: anthropology, art, communications, criminal justice, economics, English, exercise science, international business, management information systems, meteorology, pre-business administration, pre-public health, and sociology. (*Source*: Office of Institutional Research, Spring 2012 Undergraduate Headcount Enrollment by Major, Option, Degree, Race and Sex for each College)

Table 2: Diagnoses

Diagnosis	%
Asthma	15.4
Diabetes (Type I & II)	15.4
Lupus	15.4
Irritable Bowel Syndrome	11.5
Cancer (Hodgkins Lymphoma & Leukemia)	11.5
Rheumatoid Arthritis	7.7
Other [a]	42.3

Note. n = 26. Five participants reported more than one diagnosis. As such, the total percentage exceeds 100. [a] Includes the following diagnoses: celiac disease, Charcot-Marie-Tooth, chronic headaches/migraines, chronic urticaria, epilepsy, fibromyaligia, hypothyrhodism, medullary sponge kidney, metabolic syndrome , mitral valve prolapse, and polycystic ovarian syndrome.

Table 3: Religious and spiritual identification and use

Variable	Mean (SD)	Total Not at All (%)	Total At Least a Little (%)
Spiritual Person?	2.65 (1.06)	3 (11.54)	23(88.46)
Spiritual Meaning-Making?	2.46 (1.14)	7 (26.92)	19 (73.08)
Religious Person?	2.58 (1.10)	5 (19.23)	21(80.77)
Religious Meaning-Making	2.35 (1.23)	10 (38.46)	16 (61.54)

Note: n = 26. Range: 1 (not at all) to 4 (very much)

Table 4: “Religion” categories derived from illness narratives and exemplars (n = 26)

Category	%	(n)
Religion is characterized by one of the following: a belief, being related to, or being in a relationship with God or a higher power “I guess God, Jesus, that kind of stuff.” (22-year-old European American female; Type II Diabetes)	38	(10)
Negative connotations “Religion to me is a little scarier. Yeah, to me, it’s a little too rigid.” (22-year-old European American female; Type I Diabetes)	38	(10)
Practices and actions performed by religious individuals “…religion is what you do. Religion is the acting on beliefs.” (22-year-old European American female; Type I Diabetes)	38	(10)
Religion and spirituality are the same thing “I’ve always thought of those two as the same so…” (20-year-old European American female; Asthma)	19	(5)
Uncertainty “I really still don’t understand it. I’m trying to understand cuz I thought it was the same thing, so I’m really trying to grab the concept of what the difference.” (20-year-old African American female; Celiac Disease)	15	(4)
Perceived benefits “It’s something for them to latch on to, gives them stability, some comfort…” (22-year-old European American male; Asthma)	15	(4)
Faith in God “Having faith the size of a mustard seed.” (24-year-old African American female; Lupus)	8	(2)
Religion is an organized entity “When I think of religion, I think of organized religion.” (18-year-old European American female; Rheumatoid Arthritis and Fibromyalgia)	8	(2)
Shared Beliefs “…religion I think is just having a shared belief…” (22-year-old Asian American female; Asthma)	8	(2)
Other	4	(1)

Table 5: "Spirituality" categories derived from illness narratives and exemplars (n = 26)

Category	%	(n)
Belief in a higher power (not necessarily God or a deity) "When I think of spirituality, I think of being connected to a higher being…" (18-year-old European American female; Rheumatoid Arthritis and Fibromyalgia)	42	(11)
Spirituality is characterized by either of the following: a belief, being related to, or being in a relationship with God "I guess it's just more of a relationship with God is what spirituality is to me." (22-year-old European American female; Irritable Bowel Syndrome)	38	(10)
Spirituality and religion are the same thing "W-when I think spirituality I always think religion." (24-year-old European American female; Mitral Valve Prolapse)	35	(9)
What it is not "It's just the thing that helps you cope with things that's not within you but not like actually a physical thing. Yeah." (21-year-old European American female; Charcot-Marie-Tooth)	23	(6)
Uncertainty "I'm not sure. I think spirituality is a really interesting concept. I guess spirituality to me [pause] is I don't know." (22-year-old European American female; Chronic Migraines and Headaches)	23	(6)
Characteristics/practices of a spiritual person "Someone who could just really take a third person view of where they are and tap into something else that they might that they might not be too strong in excelling in or be too strong in…" (22-year-old Multi-ethnic female; Lupus)	19	(5)
Connection to the universe, earth, and/or others "For me, spirituality involves a connection with other people, the spirit of other people, their consciousness, and also maybe with the material earth as well." (22-year-old European American female; Type I Diabetes)	15	(4)
Faith "Spirituality what it means to me is I guess having faith in something other than mankind. Having faith that there's a higher being…" (21-year-old Hispanic female; Lupus)	15	(4)

Table 5. *(*continued*)*

Category	%	(n)
A feeling “It’s more of a kind of feel type thing.” (23-year-old European American male, Irritable Bowel Syndrome)	12	(3)
Peace “Being connected to, like I said, a higher being and more your surroundings and being at peace…” (18-year-old European American female; Rheumatoid Arthritis and Fibromyalgia)	8	(2)
Something that offers guidance “[Something that] guides the pathway to what’s happening in life.” (22-year-old European American female; Type II Diabetes)	8	(2)
Other	19	(5)

Table 6: Meaning-making categories derived from illness narratives and exemplars (n = 26)

Category	%	(n)
Social comparison "But it's good to know that somebody else has the same thing as you. But just not to a degree that everyone else has it." (21-year-old European American female; Charcot-Marie-Tooth)	38	(10)
"Google is my best friend." "I mean, Google is my best friend. I Google'd everything…" (22-year-old European American female; Type II Diabetes)	38	(10)
Social support "And then being able to talk to people and I guess they were also a big thing about helping me understand I'm not being punished and that's not why I have what I have and that I can use it for my benefit." (22-year-old European American female; Irritable Bowel Syndrome)	35	(9)
Talking to MDs "And I ask my doctors all kinds of questions." (20-year-old European American female; Irritable Bowel Syndrome and Medullary Sponge Kidney)	35	(9)
Religion and spirituality "I guess my religion, my spirituality, my faith has really made me look at life and made me feel more appreciative of it." (21-year-old Hispanic female; Lupus)	27	(7)
"Disabled role models" "I've always had a disabled role model." (18-year-old European American female; Rheumatoid Arthritis and Fibromyalgia)	27	(7)
Books "…we [participant & her mother] looked up a lot of different stuff online;, we read books about it." (22-year-old European American female; Arthritis)	19	(5)
Acceptance/helplessness "I guess, I think of it as just a thing I have and don't want, I have to deal with, what can I do to get rid of it?" (23-year-old European American male; Irritable Bowel Syndrome)	15	(4)
Avoidance "You know, I'm not one of those people I guess I know some people that go and study the disease and have to know everything a little bit. I don't. I'd rather not." (22-year-old European American male; Leukemia)	12	(3)

Table 6. *(*continued*)*

Category	%	(n)
Have not considered/not much "I guess I haven't really sought to understand it or anything. Not much. I haven't really thought about. Or anything." (20-year-old European American female; Asthma)	8	(2)
Therapy "I mean, therapy. A lot of therapy." (22-year-old European American female; Irritable Bowel Syndrome)	8	(2)
Classes "…and then when I was in elementary school, they had uh, like after school class about-teaching about asthma and different ways to prevent it and help your symptoms and different things." (22-year-old European American male; Asthma)	8	(2)
Other	50	(13)

Table 7. R & S meaning-making categories derived from illness narratives and exemplars (n = 26)

Category	%	(n)
Not much/not at all "I mean, not in a huge way. But… it was never like, why is this happening to me?" (20-year-old European American female; Asthma)	42	(11)
Identity work/changes "I think I was chosen." (24-year-old African American female; Lupus)	27	(7)
"Everything happens for a reason" "I believe everything happens for a reason and I have these for a reason." (22-year-old European American female; Chronic Urticaria/Hives)	23	(6)
Prayer "I kinda prayed. I did pray… And just just hoping that I could wake up the next day…" (21-year-old European American male; Lymphoma and Lupus)	19	(5)
Something [good] can come from this "I think that was helpful just knowing or having the idea that that this was in hands bigger than mine. And that maybe something would come from it." (22-year-old European American female; Lymphoma)	15	(4)
No more than you can handle "He, my mom told me ever since I was diagnosed, he puts no more on you than you can bear, and she always encourage me…" (24-year-old African American female; Lupus)	12	(3)
Connection to others "If you could consider spirituality as a feeling of interconnectedness, it's made me feel a lot more compassion towards people, and a lot more consideration towards what people could be going through." (22-year-old European American female; Chronic Migraines and Headaches)	8	(2)
Questioning why bad things happen "I have this thing of wondering, "Okay well what did I do that was so bad that I have to deserve dealing with this?" Or even in the grand scheme of things, "What have other people done that they have to deal with it." (22-year-old European American female; Arthritis)	8	(2)
Guardian angels "…[my friend who died as a result of undiagnosed diabetes just before participant was diagnosed with diabetes] is my little guardian angel. She's everywhere." (21-year-old European American female; Type I Diabetes)	8	(2)
Yoga and meditation "I started doing yoga some and I've also practiced some meditations and it's been helpful to keep me calm and keep me thankful for what I have…" (23-year-old European American male; Type I Diabetes)	8	(2)

Table 7. *(*continued*)*

Category	%	(n)
Faith "And put my faith in God that it wouldn't get worse and it wouldn't determine if my life's gonna be awful or amazing." (21-year-old European American female; Charcot-Marie-Tooth)	8	(2)
Social support "And then my religion background, the church came and surrounded me and prayed with me and it was just nice cuz you knew you had those people, they can't be empathetic because they don't know what you're going through. But they can be sympathetic and they can pray for you." (21-year-old European American female; Charcot-Marie-Tooth)	8	(2)
Optimism and/or hope "Yeah, I do believe [that the optimism that I have is created by my religious and spiritual beliefs] I really think so. Being as, like I say, praying that it doesn't lead to anything else." (20-year-old African American female; Celiac Disease)	8	(2)
Other	19	(5)

CHAPTER 6: DISCUSSION

The present study investigated areas that have previously been missing in the literature assessing the role of R & S in adolescents who have been diagnosed with chronic physical illnesses. In particular, this is the first qualitative study to explore adolescents' illness experiences in a way that draws attention to meaning-making strategies and to ways that adolescents understand R & S as potential frameworks for assigning meaning. It is also one of the first to combine these features with other aspects that are pertinent to the period of adolescence such as identity formation and the effects of identity disruption. In order to accomplish these goals, illness narratives were elicited from 26 adolescents who live with a chronic physical illness. In general, the present study revealed 71 categories across all three research questions. The large number of categories that emerged suggests that there are indeed unique ways that adolescents understand their experiences of illness, and this variety provides support to this researcher's chosen research method and theoretical orientation. Additionally, findings suggest that participants viewed religion and spirituality as multidimensional constructs that have both areas of overlap and divergence. The results also reveal that participants engaged in a host of strategies to understand and derive meaning from their experiences of illnesses, including R & S. Below, findings will be discussed in more detail in order of their corresponding research questions.

Participants in the present study indicated that they conceptualize R & S in ways that range from uncertainty about what the two concepts mean to their belief that they represent the same things. In contrast to spirituality, which was described as “a more positive thing than religion,” participants’ descriptions of religion contained negative connotations such as “religion…is a little scarier.” Whereas participants indicated that religion involved a connection to God or a higher being, their descriptions of spirituality noted a connection to other things including “the spirit of other people, their consciousness, and also the material earth as well.”

Among definitions of R & S, five categories overlapped. In particular, over one-third of participants believed that R & S were the same thing. Furthermore, between 15% and 23% of participants reported a level of uncertainty regarding their understandings of R & S, respectively. The uncertainty expressed by participants is consistent with results attained by Cotton and colleagues (2009) who reported that three of the 11 participants interviewed in their study (27%) did not know if religion and spirituality were the same or different.

Seven participants spontaneously indicated that they utilized R & S as a framework through which to ascribe meaning to their experiences of illness. This finding lends support to the researcher’s belief that systems of meaning such as these provide ways for adolescents to draw meaning from and to fit their illnesses into their lives. They reported beliefs such as “everything happens for a reason” and “I’m not being punished” as ways to integrate their illnesses into their identities and overall life schemes. For many individuals, adults and adolescents alike, religion, in particular may offer a ready-made lens through which to view one’s experiences. This framework may help one more easily appraise situations as consistent with their global meanings including, for example, beliefs in a just world or beliefs that all things happen for a reason (Park, 2013). The ability to utilize R & S meaning-making may serve to alleviate distress by changing the meaning of the situation. However, if one is unable to position his or her experiences within the existing R & S framework, anxiety may arise. It may be that the participants of this study who spontaneously listed R & S as methods of understanding were able to obtain a sense of agency and control from believing that placing things in hands that are bigger than one's own provides confidence that the best will come from the experience. In addition, applying a R & S framework may limit the distress that would emerge in the process of grappling with the reasons why one is experiencing the physical illness and its consequences. It may be that for these adolescents, applying R & S meaning-making systems reduced their need to look for and apply other forms of meaning. Perhaps adolescents who spontaneously described using R & S as frameworks to view their experiences of illness were seeking to reduce the distress that inevitably arises when one's global meanings are challenged by applying the one thing that has consistently provided hope, support, and relief in the past: their R & S beliefs.

One finding worth mentioning is the large number of "other" categories that emerged from participants' responses to the question assessing their methods of ascribing meaning to their experiences of illness. These 13 categories represented the greatest variety in responses across all four questions used to address the three research questions. Responses referencing religious and/or spiritual beliefs and values may have limited participants in such a way that they may have felt compelled to only provide responses that were in line with their religious and/or spiritual beliefs. In contrast, responses in this category were not necessarily guided by a framework or doctrine. In addition, because this question was more open ended than the remaining questions in that it did not reference R & S in any way, participants may have perceived greater freedom in providing a range of responses instead of feeling as though they had to provide responses that were in keeping with the concepts contained in the questions. In this way, this question may have elicited responses, including those referencing R & S, that were “truer” than those provided in response to the remaining questions. Additionally, in the same way that the emergence of 71 categories across all 26 interviews and three research questions may lend support to the idea that individuals bring with them unique ways of understanding, perhaps this variety in general meaning-making systems was also reflective of the unique experiences that these adolescents brought with them to this study.

Elements of social interaction were found in five of the 25 categories that emerged in response to this question. This proportion of social elements compared to other strategies is noteworthy, and it raises the question of whether this social component represents a process that is unique to adolescents’ experiences of illness. One of the most common forms of social interaction that emerged involved social comparison, a term that describes individuals’ tendency to compare themselves to others when aspects of their identities are challenged or comprised (Festinger, 1954). The use of social comparison to boost one’s self-esteem or to seek additional information about what to expect over the course of one’s illness is not unique to adolescents (e.g., see Tennen, McKee, & Affleck, 2000 for a review of research where social comparison processes were utilized in health-related experiences). However, for adolescents, this propensity toward using one’s peers as a gauge by which to judge the self is not surprising given the importance of peer interaction and acceptance in the identity formation process. In addition, common biological effects of chronic illnesses on adolescent development have been shown to bring about changes in the physical, outward appearance of adolescents' bodies. (Suris, Michaud, & Viner, 2004). These changes may, in turn, contribute to reduced self-esteem when adolescents compare their bodies to those of their peers. Because participants of the present study tended to engage in downward social comparison more than upward social comparison, one may conclude that they used the process of comparing their bodies and abilities to their peers (whether age- or illness-matched) as a way to increase their self-esteem or at least as a way to make sure that it was not reduced further.

One of the most salient categories to emerge in response to the question addressing the potential use of R & S meaning-making strategies was that describing changes associated with one's R & S identities. Two participants whose stories provided exemplars for this category found that they were better people because of having gone through their illnesses. Two additional participants believed that they were chosen by God to have their illnesses. Although neither knew the exact reason for which they had been chosen, they both believed that the potential reason involved helping and sharing their stories with others. Other exemplars were consistent with King and Benson's (2006) assertion that religion offers adolescents the opportunity to "internalize and integrate a sense of belonging and meaning" (p. 387). One participant comes to mind when considering the way that religion may help adolescents "integrate a sense of belonging and meaning." This participant described how she joined a youth group at church and felt accepted by her peers in a way that she had never experienced before. In a sense, she found her place in the world through this group. This group also helped the participant to better understand the reasons why she was diagnosed with her chronic illness.

This evolution of one's identity in the face of illness seems particularly important for adolescents who experience the normative process of identity development. According to Erikson (1968), it is during this time that adolescents overcome identity crises in three areas including ideology. That participants used their religious and/or spiritual beliefs as a filter through which to view themselves as a person who now has an illness is noteworthy because it appears to represent a unique way to understand one's experience. Such a method of understanding has yet to be reflected in literature assessing the process of meaning-making among adults.

For those participants for whom R & S did not serve as frameworks for understanding their experiences of illness, they tended to rely on things such as science or support from their family, and these methods were sufficient for them. This may reflect the increasing number of non-religious affiliation and influence that is reported in national surveys of religious and spiritual affiliation (Newport, 2012).

Findings from this study are related to and extend the findings of existing literature. Participants' responses to questions regarding participants' understanding of R & S were reminiscent of the results offered by Singleton, Mason, and Webber (2004) in their study of an interview schedule designed to understand how adolescents from a wide age range understood the concept of spirituality. Participants in the present study provided definitions of spirituality that were consistent with three of the 10 dimensions of spirituality that emerged from Singleton and colleague's study: relationship to religion (e.g., spirituality and religion are the same thing); expressions of spirituality including beliefs, values, practices, and community (e.g., spirituality involves a belief in or relation to a higher power or a connection to others, the universe, or the earth); and authority or who or what decides what is spiritual (e.g., it does not involve "reading from a book as much"). At the conclusion of their study, the above authors called for additional qualitative research that will enable scholars to fully understand how adolescents understand spirituality. This study offers that additional research. It also expands upon Singleton and colleague's study by including definitions of religion in addition to spirituality in an effort to fully understand how adolescents understand both concepts.

As noted in Chapter 4, I decided against using the McGill Illness Narrative Interview (MINI; Groleau, Young, & Kirmayer, 2006) because many of the questions contained in that interview schedule were outside the scope of the present study's aims. Despite my not asking directly about the three representations of symptoms or illness (i.e., explanatory models, prototypes, and chain complexes), participants still provided descriptions of their meaning-making strategies that were consistent with each of these three domains. The reader may recall that explanatory models of symptoms or illness are based on causal thinking and may include causal attributions for illness. Without inquiring directly, participants responded in ways that revealed their causal models for their illnesses or for one participant, her cure. For example, this participant described how after participating in a cleansing ritual, her platelets, which were normally low because of lupus, rose to a level that was higher than their baseline. She attributed this improvement in her health to her obedience in participating in this ritual. According to Groleau, Young, and Kirmayer (2006), prototypes are based on key events in one's experiences that allow one to establish meaning of his or her illness via the use of analogies.

Analogies and/or metaphors were used on several occasions across responses to the interviews. One participant, in particular, provided two separate metaphors in answering the same question to both explain how his long-standing diagnosis of diabetes affected the way he was able to view himself before and after being diagnosed and also how he held little realistic hope that in the future, he could be cured completely of his illness.

Lastly, chain complexes represent how the individual's or someone else's past experiences are linked to their present symptoms through a sequence of events that surround the symptoms; however, in making these links, individuals do not make causal attributions or use analogies. Although not as relevant for the responses pertaining to these research questions, these chain complexes were evident in participants' diagnosis stories. They explained how they experienced symptoms for some time prior to being diagnosed and the frustrations that accompanied making repeated trips to physicians only to learn that no one knew what was wrong with them. One diagnosis story reflected how remembering an embarrassing event that occurred when the participant was first diagnosed with irritable bowel syndrome often triggers symptoms of anxiety and fear, which then, in turn, lead her to try to suppress the memory, which then exacerbates her symptoms, and also limits her social interaction with others. In addition to representing a chain complex, this last participant's story also represents an example of experiential avoidance, a term that describes how individuals engage in an "ongoing struggle to avoid, suppress, or get rid of unwanted thoughts, feelings, memories, and other 'private experiences'" (Harris, 2009, p. 18). As the participant's example indicates, experiential avoidance can also contribute to a person refraining from engaging in valued action because to do so would run the risk of triggering the experience that the person is attempting to avoid in the first place (Harris).

Although participants' responses fit nicely within Groleau and colleagues' (2006) framework for understanding participants' illness representations, it was interesting that they emerged without the writer having to ask for them. That these responses were offered spontaneously lends further support for this writer's decision to forgo using this measure. It does not appear that pertinent information was lost because a standardized interview was not used to obtain illness narratives.

Yet another framework for understanding participants' strategies of meaning-making was relevant, and that was the two types of meaning defined by Lee and Poole (2005). In making statements such as "I believe everything happens for a reason," participants were seeking a purpose for their illness experiences. This purpose is a subcategory of found meaning representing an individuals attempt to find a reason for their illness experience. In addition, participants engaged in implicit meaning-finding when they used strategies such as talking to their physicians, talking to others who shared their diagnoses, and using the Internet and books to find out information about their illnesses. Order was achieved when participants were able to fit their illnesses into their larger life scheme, when they came to accept that their illness is now simply "just a part of" their identities, for example.

In sum, in answering Research Question 1, participants defined R & S broadly, and some definitions overlapped between the two concepts. In regards to Research Question 2, participants offered even more unique methods of general meaning-making than both definitions of R & S and R & S methods of meaning-making. Regarding

Research Question 3, some of the adolescent participants did utilize R & S as frameworks for understanding their illness in a variety of ways. However, there was also a subset of participants who did not.

Before transitioning to a discussion of study limitations and strengths, it is important to acknowledge this researcher's biases and how they may have affected the research process and the findings presented above.

Reflexivity

As previously mentioned, it is important to attend to issues of researcher bias and to acknowledge this researcher's positionality across topics that are related to the present study. These include beliefs, values, and experiences that the researcher brings with her into the qualitative research experience. Positionality, or "the multiple, unique experiences that situate each of us," inevitability influences the way we understand, interpret, and experience things (Takacs, 2003). It is the way in which our experiences influence how we see and what we know about the world. Unlike quantitative data where one can statistically control for the effect of a specific variable on the outcome of interest, it is not possible to completely withhold one's self from the qualitative research process. Because I acknowledge that my own experiences, beliefs, and values influenced the way in which I viewed the participants and viewed the resulting data, it is necessary for me to address these issues along with concerns and emotional and cognitive reactions that emerged throughout this process. Failure to do so would be negligent and untrue to the spirit of qualitative inquiry.

My Religious and Spiritual Beliefs

One of the most prominent aspects of this writer's positionality concerns my own religious and spiritual beliefs. As stated in the definition of spirituality that I offered in Chapter 2, I view spirituality as something that allows individuals to make sense of their lives and as something that imparts meaning and helps individuals seek purpose. I also believe that spirituality can include reference to a deity and/or a higher power. I am able to make sense of my life and to evaluate the purpose of my life as a result of my belief in a higher power, which for me is God. In addition, I also have an established relationship with a specific faith tradition (i.e., Christianity) and adhere to principles outlined in my religious tradition's holy text, the Bible.

Because of my own religious and spiritual identification and because 65% of my participants also reported sharing faith traditions and beliefs similar to my own, I had to remind myself to remain curious and to approach each participant's story as someone who knew nothing about what the participants were describing. Even when participants made reference to something that I had heard, read, or seen myself, I had to make sure I did not assume I had heard, read, or seen this thing in the same way that participants did. For example, when one participant described how the words "faith, hope, and love" immediately came to her mind when asked about R & S, instead of responding in a way that suggested that I knew the origin of the words, I asked the participant to tell me why those words reminded her of R & S and where she had been exposed to these words. If I had responded, "Oh, I know what you mean," I may not have obtained a "true" description of the participant's views. In this way, I was able to hear what she thought about the three words without my ideas influencing her response.

Along these lines, 12% of this sample self-identified as atheist, and this identification is opposite my own. Although I initially thought I would experience discomfort if I heard negative descriptions of religion (e.g., “religion is based on the greatest fiction book ever written”) from those who identified as atheist, I found that I was intrigued by stories of participants who did not have religious and/or spiritual identities. Both out of personal curiosity and because studies investigating the effects of R & S among atheists or agnostics are less available than ones where respondents self-identify as religious or spiritual (Streih & Klein, 2013), I remember being really interested in how definitions of R & S were similar in many ways across groups. In one journal entry, I wrote, “I absolutely took the an outsider’s view this time. Remember this interview—do this with everyone!”

My Clinical Training

Although I thought being a trained therapist would be beneficial in conducting the interviews for this study, this skill ultimately ended up being a burden rather than an aid. For example, as a clinician, I have been trained to pay close attention to affect and to explore both the presence and the absence of this characteristic. Because the illness interviews were conducted for the sake of research and not therapy, it was difficult to withhold my clinical inclination to delve into participants’ affective presentations. Many participants indicated that they had been diagnosed with psychological disorders such as depression, anxiety, bipolar disorder, obsessive-compulsive disorder, insomnia, and substance abuse. There was variation in terms of whether these psychological diagnoses preceded and/or contributed to the presentation of participants’ physical symptoms or if they developed in response to the changes associated with living with a chronic physical illness. The following two examples demonstrate this variety:

> I used to get very high anxiety over stuff [before getting diagnosed] (22-year-old European American female—Chronic urticaria/hives)
>
> I think l mentally, as in my mental health, has gone down. I think the stress and the worrying and the anxiety are way worse than what they used to be. (23-year-old European American male—Irritable bowel syndrome)

The therapist in me wanted to explore participants' attributions for symptoms as well as strategies they utilized to address such symptoms. For example, when one participant described experiencing both insomnia and anxiety, the therapist in me wanted to conduct an assessment of sleep hygiene along with triggers of anxiety. I found myself fighting not to ask permission to demonstrate a relaxation strategy, which may have been beneficial for both the anxiety and sleeping difficulties.

That participants were aware of my role as a psychology graduate student may have also contributed to the tension I felt between my roles as researcher and clinician. It may have also influenced participants' perceptions of the interview such that they viewed it as a therapy session and not a research interview. After turning off the audio recorder, one participant even thanked me for allowing him to talk about his experience and told me how he had decided that, as a result of participating in this study, he now believed that "maybe therapy isn't so bad after all. Maybe I should keep talking about this stuff" (paraphrased from researcher's notes). Following interviews such as that one where particularly emotionally charged topics arose, I found myself replaying the interview in my head and viewing it through the lens of a clinician. I wondered what would have come from my asking additional questions about moments of sadness or anger or hurt and how the participants would be able to process their experiences on an even deeper level in doing so. I refrained from doing so for two reasons: I did not want to blend my role of researcher with my role as a therapist by providing psychotherapy to someone who was not in my clinical care, and I was honestly afraid of what would have happened had I opened the proverbial Pandora's box. On two occasions, I felt guilty that I was not a therapist in that moment because the stories that emerged were so filled with negative emotion that I felt badly for encouraging participants to share such sensitive information and then simply giving them a cold-hand off to the Counseling Center via a referral that all participants received.

In moments like those, however, I found solace in the fact that researchers such as Pennebaker (2000) have argued that simply telling one's story can be an intervention itself. Maybe it was not my role to facilitate deeper processing of emotional reactions to one's experience. Maybe the job was done already. Maybe, as Pennebaker argues, the act of sharing their stories offered a new opportunity for participants to integrate the experience into their identities or to create new meanings of the experience instead of just sharing with me the ways they had already done so. It is my hope that participants perceived some benefit from lending their voices to me for this project and did not interpret it as harmful or emotionally injurious.

My Illness Experience

A third potential source of bias concerns my own experience of illness approximately six years ago. During this time period, I questioned my identity as a woman, specifically if I could still be considered a woman even if I could not have children. During the time period involving my diagnosis, my subsequent surgery, and follow-up treatment, my identity was disrupted, and I had to come to terms with the fact that motherhood may not be an option for me. Fortunately, my treatment was successful; however, after learning of its success, I had to further negotiate my identity as someone for whom motherhood was again possible. During this difficult time, I utilized my R & S beliefs in addition to my religious holy text, the Bible, to help me understand the experience. This experience of utilizing R & S beliefs and resources to help me understand the events surrounding my illness may have also impacted the way in which I heard and understood participants' narratives. I acknowledge that there are differences in my experience of illness and in participants' experiences of illness. Most notably, my illness was cured through one surgical intervention whereas some participants take medication daily to manage or prevent symptoms or have to receive annual PET scans to ensure that their cancers have not returned.

When discussing potential reproductive consequences of one female participant's illness, I was reminded of my experience with this topic. In the same way that I attempted to remain curious and to ask questions regardless of my assumed understanding of R & S, I similarly asked this participant to describe her own experience without providing any information regarding my own experience. The participant was the focus of the interview, and I did not want her story to be altered because of something that I may have said regarding our seemingly shared experience.

I also acknowledge that participants' use of R & S as sources of meaning-making varied from my own use of the same to help me understand my experience. For example, participants described experiencing a greater connection to and compassion for others and believing that their illness experiences may have occurred in order to address particular personality features (e.g., "maybe it was because I'm stubborn." I did not rely upon either of these methods during my experience; however, this did not make participants' experiences invalid because they were not consistent with my own.

Being aware of these concerns (i.e., my spiritual and religious beliefs, my clinical training and experience, and my own encounter with illness) allowed me to remain as reflexive and transparent as possible throughout this research process. However, in addition to acknowledging and explaining these aspects of my positionality, it is also important to discuss how these beliefs and values impacted my reflexivity. Because it was impossible to remove these biases entirely, it was necessary to find ways to minimize the influence of these biases on both the interview process and on the data analysis procedure.

The process of engaging in journal writing was extremely beneficial. Immediately following each interview, I journaled about feelings; thoughts about how to categorize responses or about how I perceived the interview proceeded; and about potential interview questions to consider adding to subsequent interviews. Researchers suggest that engaging in journal writing has several benefits including how it may actually begin the process of data analysis and how it "permits researchers to discover things in their heads that they did not know were there" (Watt, 2007). This was the case for me because it helped me to identify preliminary categories that I was able to confirm or disconfirm as I proceeded through the data analysis process, and it also enabled me to be honest with my reactions to the interviews that preceded the journaling.

This journaling process was particularly important when it came to placing exemplars within the categories that emerged. For example, some participants described utilizing what this writer would have referred to as the coping strategy of social support in response to the question assessing the ways in which they understood their illness experiences. Despite my inclination to categorize such responses as coping strategies only, which was primarily driven by my experience as a clinician, I used my journal to remind myself to place such responses under the category that best reflected the participants' understanding. For example, if the participant perceived that talking to others was helpful in gaining knowledge about what to expect in the future regarding the disease progression, this was placed under the category of meaning-making, which contained a social component. My notes reflected this process of deciding under which category to place such responses. I wrote how I thought responses such as these reflected social support but that the participant provided these responses following the question about how they understood their experience. Staying true to the phenomenological approach, participants' understandings dominated. However, my notes reminded me to also consider that these responses could also reference a coping strategy. As such, responses such as those were at times placed into multiple categories to represent the multiple layers of meaning contained within each.

Limitations and Strengths

This study is not without its limitations. One of them involved the way the questions regarding R & S were presented. Because this writer asked participants about R & S separately, it raises the question of whether participants were primed to respond that R & S were two separate concepts. For example, it is unclear if this writer had instead asked a question similar to Cotton et al. (2009; e.g., "Do you think R & S are the same or different?") and then allowed participants to explain why or why not if their responses would reveal more overlap, variation, or uncertainty. Despite the potential effect of my presentation of these two questions on participants' responses, nearly one-fifth of participants appeared to feel comfortable enough to state their belief that they were, in fact, the same things. As such, two possible conclusions arise. First, it is possible that the way the questions were presented was not as influential as one may suspect. Secondly, there were simply individual differences in the way participants interacted with me, including their level of comfort with saying something that appeared contrary to what I asked. Nonetheless, this issue is worth noting because it may have influenced the responses participants provided for these two questions.

One of the more concerning limitations has to do with the possibility that demand characteristics were involved in participants' responses to the interview questions. The consequences of demand characteristics, or a participant's tendency to respond in ways that he or she believes the researcher expects, were evident in the responses of four participants. For example, in response to the question assessing whether she used R & S to understand her illness experience, one participant stated, "I don't think so. I don't know. I feel like I'm giving you the wrong answer*"* (18-year-old European American female—Rheumatoid arthritis and fibromyalgia; emphasis added). When providing her definition of spirituality, another participant stated,

> I'm not sure. I think spirituality is a really interesting concept. I guess spirituality to me [pause] is I don't know. And I guess I don't really have a definition for it myself but I'm kind of ok with not having a definition for it for myself. If that makes sense. Is that ok? (22-year-old European American female—Chronic migraines and headaches; emphasis added)

It is unclear whether the participant was asking if it was ok by the researcher that she had not yet developed a definition of spirituality for herself or if she was asking if the answer she provided was good enough.

Another participant appeared to respond in such a way as to ensure that his replies were beneficial to this writer's research. He stated, "So I don't know maybe that will be something to think about too as far as your research goes" (23-year-old European American male—Irritable bowel syndrome). This participant may have taken the "good-subject" role in that he wanted to make sure that he only provided information that would be useful for this study or future ones (Nichols & Maner, 2008). Yet another participant asked, "Does that answer your question?" (23-year-old European American male—Type I Diabetes) in a way that suggested that he was wondering if there was a "right" answer that I expected to hear. In an effort to decrease participants' expectations that they were to give me the "right" answers, in response to questions and statements such as these, I made comments such as, "There's no right or wrong answer. I'm really interested in understanding what you think about it."

The next set of limitations involves the composition of the study's sample. Participants in this study represented the higher age range of adolescence, 18-25. However, only one participant was 18; the remaining participants were between the ages of 20 and 23, with the mean age at approximately 21 years old. On the other end, there were only two participants older than 23-years-old. Likewise, this study was comprised of 69% of females. This number is in contrast to the proportion of students enrolled in the spring 2012 semester (50%). Of the total 26 participants, only eight identified as male. As such, the study participants did not fully represent the entire age range that this study was meant to target nor did it represent a gender-diverse sample. Although qualitative findings are not necessarily meant to represent entire populations at large or to generalize to others outside of the specific parameters in place for that study, this lack of age and gender variation may be perceived as a limitation of the study.

Another limitation of the study sample is the limited number of participants who identify as an ethnic minority. The European American/White ethnicity represented the greatest proportion of participants in the present study. The University reported that approximately 39% of its undergraduate student population during the spring 2012 semester classified themselves as a member of an ethnic minority group (Office of Institutional Research, 2012). This was consistent with the percentage of study participants who indicated that they were members of ethnic minority groups (approximately 30%). Proportionally, it appears as though ethnic diversity was achieved in the present study; however, the actual numbers indicate that only eight participants were members of ethnic minority groups, compared to 21 who considered themselves European American/White. The reader will note that this total exceeds 26 because one participant indicated that she identified with every ethnicity except African American. The ideal study sample would include an equal number of individuals from both the dominant and minority ethnic groups in order to ensure diversity of responses and experiences.

In addition, participants' religious and spiritual identities may have influenced their definitions of R &S and R & S strategies of meaning-making. On the prescreen questionnaire, 80% of participants considered themselves at least "a little" religious, and approximately 90% considered themselves at least "a little" spiritual. Given the high overall proportions of religious and spiritual identification, it is not unrealistic to believe that responses to this study's interview questions were more existentially flavored than would be in a study involving fewer individuals who labeled themselves in such ways. However, this high proportion of religious and spiritual identification is consistent with levels of religiousness, at least, within the Bible Belt, an area in the southern portion of the United States heavily influenced by Christian beliefs and activities. Results of an annual Gallup poll assessing each state's level of religiousness revealed that North Carolina was the eighth most religious state, with 50% of residents indicating that they were "very religious" (Newport, 2012).

When breaking down participants' responses by level of religious identification, 23% indicated that they "very much" consider themselves to be religious individuals. This 23% is more consistent with the respondents of the Gallup poll who described themselves as "very religious." Although the proportion of participants in this study who considered themselves to be "very much" religious individuals was only half that of those in the state of North Carolina, the influence of the southern Christian culture cannot be ignored. This high level of regional religious and spiritual affiliation may explain why 27% of respondents spontaneously identified R & S as methods of meaning-making. These spontaneous responses could also be attributed to the fact that 46% of the sample self-identified as Christian either in their definitions of religion or in their descriptions of personal R & S experiences. This particular religious background and identity may have also affected the percentage of participants who responded in the affirmative to the question regarding R & S meaning-making. The Christian influence on responses is also evident when one notes that, among those who self identified as at least "a little" religious, only two participants reported non-Christian affiliations (e.g., Jewish and La Santeria). These high levels of R & S affiliation, particularly Christianity, may have also skewed responses in a way that gives the appearance that R & S are used more frequently as meaning-making strategies than would be the case in a more religiously and spiritually diverse sample.

Approximately 12% of participants self-identified as atheist, and 19% self-identified as agnostic. These numbers (approximately 31% combined) exceed findings of a national telephone survey of 54, 461 respondents. Participants were asked, among other questions, "What is your religion, if any?" (Kosmin & Keysar, 2009). Combined, 12% of respondents identified as atheist or agnostic. Of course, sample size must be factored into this comparison. The inclusion of nonreligious participants is a strength of the present study. In addition to increasing the sample's diversity, that atheists, agnostics, and religious participants identified similar aspects of R &S suggest that adolescents' views of R & S may transcend religious or spiritual identity.

To try to reduce the potential for these sample limitations, this researcher made several attempts to recruit a sample that varied across age, ethnicity, and religious and/or spiritual identity. The study was listed on SONA, which primarily targets underclassmen who have to complete psychology research credits that are associated with introductory psychology courses. Indeed, respondents to the SONA survey who did not participate in the interview portion of this study were more likely to be either 18 or 19-years-old compared to participants who were included in both parts of the study. In addition, the researcher visited four classrooms, which were comprised of a mixture of both under- and upperclassmen. She also posted flyers in two public places that are potentially frequented by students of all ages, ethnicities, and R & S affiliations, the Student Health Center and the Office of Disability Studies. Lastly, she sent emails to all undergraduate students enrolled during the spring 2012 semester who did not have restrictions on their accounts.

In addition to elements of the sample that represent potential strengths and limitations, an evaluation of the presentation of the data is also necessary. One factor that can be considered both a potential limitation and a potential strength is the decision to edit participants' responses. In previous research, participants and researchers suggested that the choice to edit participants' words may have reduced the participants' voices (Corden & Sainsbury, 2005; 2006). It may suggest that this writer did not value the input of the participants who were interviewed. It may increase the likelihood that my style of writing versus the participants' styles of conversing dominated the narratives contained in the previous chapter. However, participants and researchers from these same studies (Corden & Sainsbury) also listed benefits of editing participants' quotations. Chief among these benefits is increased readability. When readers have to read between the "ums" and "likes" and "you knows," they may be less likely to complete the passages containing the quotations and more likely to skip to the researcher's summaries. Because the participants' words and stories should dominate the narrative presented, it is important to present the data in such a way that adequate attention is given to these elements. Again, this writer chose to edit the quotations both to improve readability and to honor the feedback provided by one of the participants whose story is contained within.

A strength of the present study is that it makes a contribution to the discipline of health psychology by expanding this field's tendency to conduct primarily quantitative studies to now incorporate a method used in other disciplines. In the spirit of health psychology with its focus on ways biological, psychological, social, and now spiritual aspects of a person's life interact and change over time, this study represents an interdisciplinary approach to studying a phenomenon (Sulmasy, 2002). It combines literature from psychology, communications studies, nursing, and epidemiology, for example, to shed light on the lived experiences of adolescents with chronic physical illnesses. This integration across disciplines increases this study's readership.

The greatest strength of this study is that it is the first of its kind. Although there are studies that explore the constructs contained in the present study separately, no study does so in such an integrated way. For example, although small in number, qualitative studies of adolescents' understandings of R & S (e.g., Cotton et al., 2009; Rich & Cinamon, 2007; Singleton, Mason, & Webber, 2004) and ones examining ways in which they make sense of their illness experiences (e.g., Di Callo, 2003; Forsner, Jansson, & Sorlie, 2005; Miller, 1999; Woodgate, 2006) do exist; however, studies that combine an attempt to understand and describe adolescents' views of R & S and meaning together are lacking. Furthermore, to this writer's knowledge, there are no studies that also examine other aspects unique to adolescents such as identity disruptions along with R & S and chronic illness together. This study does that. Additionally, although R & S have been proposed as frameworks through which individuals ascribe meaning to their lives in general, an unstructured exploration of the ways in which this plays out in the lives of adolescents living with chronic illness was missing (see Groleau, Young, & Kirmayer, 2006 for a description of a semi-structured interview of illness narratives). Again, this study fills that gap.

Future Directions

Taken together, these limitations provide information about considerations that future studies exploring R & S and meaning-making among adolescents living with chronic illnesses should include. Such studies may benefit from establishing stricter inclusion and exclusion criteria surrounding ethnic and R & S identification, age, and gender in order to increase diversity in these areas. The maximum variation purposive sampling technique may facilitate this given its focus on selecting a wide array of individuals who meet criteria for multiple dimensions. This method may help identify definitions of R & S and meaning-making methods that are applicable across the various dimensions of interest. In particular, studies that sample across the entire age range of adolescence (ages 10 to 25) may help reveal developmental differences in both definitions of R & S and in meaning-making strategies based upon adolescents' level of cognition and/or identity formation, for example. Similarly, future studies may want to evaluate gender as a potential influence on methods of meaning. Perhaps factors such as gender identification in one's youth may determine they types of explanations they are culturally allowed to or feel comfortable offering. Additionally, future studies should be conducted outside of the southern Bible Belt region with its preponderance of individuals who identify as religious and Christian, in particular. Extending the geographical location may decrease the likelihood that the majority of participants share the same religious and/or spiritual identification. This change may also offer more variation in the definitions of R & S and descriptions of adolescents' attempts to attain meaning, which may include R & S. Areas of the country such as New England may provide a location from which to sample given residents' overall low level of religious identification (Newport, 2012).

Because this study was cross-sectional and only heard from participants after they had lived with their chronic illnesses for an average of four years, future studies should also consider using a longitudinal method to follow adolescents over time. Participants in this study were asked to describe their diagnosis stories, and many included references to their emotional and cognitive reactions to their diagnoses including, "Why me?" They also described how they sought implicit meaning particularly following their diagnoses by searching the Internet or speaking with their physicians, for example. However, meaning-making strategies may differ for participants such as the 23-year-old male who indicated that he had lived with diabetes for so long that it was difficult for him to imagine his life without it. A longitudinal study would allow for an increased understanding of the meaning-making process across the trajectory of illness. Perhaps adolescents are more likely to seek implicit meaning or a purpose for their illness in the beginning stages when they are learning what the illness is and how to manage it and then transition to other forms after they have adjusted to their lives with illness.

Being diagnosed with an illness is a particularly stressful event, so much so that it is called a "biographical disruption" (Bury, 2001, pg. 264). However, for some individuals, these illnesses are considered acute because they last for just a short period of time. In addition, for many acute illnesses, there is an anticipated time frame during which an individual should expect the symptoms to dissipate. In contrast, participants in this study were diagnosed with chronic illnesses. Some had lived with these illnesses for more than 10-12 years prior to participating in this study. This raises the question of whether meaning-making strategies, religious, spiritual, or otherwise, differ based upon duration of the illness.

In addition to future directions that are directly related to this study's three research questions, other areas for further exploration are worth noting. One domain that may warrant additional attention is related to identity disruptions and issues of control. Three participants described having an invisible illness, or an illness that was not readily identifiable by others who observed them. One participant explained:

> I feel like sometimes we say we suffer in silence because you look at me, you wouldn't never know anything was wrong with me. I look normal according to society's standards…(24-year-old African American female—Lupus)

This invisible illness is in contrast to more visible illnesses. For example, another participant who described her experience of chemotherapy for her initial treatment of lymphoma explained how others would stare at her after her hair had fallen out because of chemotherapy's side effects. She explained: "[I would get] a lot of stares. A lot of second glances" (22-year-old European American female—Lymphoma). Unlike the previous participant whose illness characteristics were not readily perceivable, this participant's once bald head turned into a marker of her illness. The time period of adolescence contains normative identity crises and ongoing issues regarding achieving autonomy and control. This distinction between visible and invisible illness raises the question of whether there are variations in the way adolescents seek meaning when they know that they control how and to whom they disclose their illnesses and when their bodies clearly indicate that they are experiencing illness.

One final area for future study relates to the concept of being a healthy person. Participants at times made comparisons between healthy and unhealthy people or their belief that they were no longer healthy because they lived with a chronic illness. In many ways, this description of self as unhealthy demonstrated the cognitive regression that may occur when an adolescent's life is interrupted by the entrance of a chronic physical illness. Specifically, such thinking (i.e., that one is either healthy or unhealthy) represents concrete, black and white, all or nothing thinking that is common for younger children to exhibit. Although this writer inquired about participants' definitions of health when they mentioned it, further exploration is warranted to determine whether similar adolescents' identities can simultaneously contain healthy and ill parts. Such an integration of two seemingly opposite components of one's identity would represent the more complex formal operational stage of cognitive development and may also provide additional information regarding developmental differences based upon adolescents' level of cognition and/or identity formation.

Conclusion and Implications

Meanings that individuals ascribe to difficult life events such as illness influence how they adapt to and cope with these events. The introduction of illness may challenge one's core beliefs about self and the world and require individuals to examine these beliefs in ways that have previously not been required of them. When core beliefs are challenged following a diagnosis of an illness, individuals may struggle with what to do in and with their lives and also with who they are now that the illness has been introduced. To address this "biographical disruption," individuals try to make sense of what is happening. For some people, religion and spirituality may provide frameworks that foster this understanding.

This study revealed that among other mechanisms, adolescents did use religion and spirituality to seek meaning of their experiences of illness. In doing so, participants were able to integrate their experiences into their lives and devise ways of coping with the illness such as finding peace in knowing that one's illness is a part of God's plan and believing that "he gives you no more than you can handle."

In addition to examining adolescents' strategies for ascribing meaning to their lived experiences of illness, this study also attempted to understand what religion and spirituality meant to adolescents. This was important to address because it provided a framework through which to understand participants' stories and their own sense-making journeys. In fact, approximately one-third of adolescents did spontaneously report using R & S to understand and cope with their illness. Participants who reported that they were "very religious" or "very spiritual" were most likely to do so. Almost all (73%) identified some helpful aspects of R&S when queried directly about the role of these concepts in understanding their illness, even individuals who self-identified as atheist and/or agnostic.

Understanding these processes from the perspectives of a wide range of adolescents who have lived them may reveal universal strategies, methods, and frameworks that may, in turn, be helpful during the therapeutic process. Two participants of the present study described participating in therapy after being diagnosed with their illnesses, and this process of exploring underlying meanings and attributions of illness was helpful for one of them. Clinicians, such as myself, use the therapeutic process to help individuals make sense of and integrate their experiences into their existing life schemes. Potential universal themes that may emerge from future studies may allow for the use of more streamlined ways to help adolescents understand their experiences. Such a streamlined approach may increase the likelihood that therapy clients are able to receive the most benefit from the experience.

Likewise, being able to talk about concepts such as religion and spirituality using language similar to that used by adolescents is also important. In the same way that studies reviewed here demonstrated a degree of mismatch between definitions of R & S offered by researchers and those offered by participants, there might be similar misunderstandings within the therapeutic process. Seeking adolescents' own definitions and then facilitating discussion using their own words may also create a more beneficial therapeutic experience.

One of the advantages of being both a researcher and a clinician is the unique position that one holds in the process of translating research findings to practical application. As mental health professionals, we should be prepared to help clients to incorporate stressful life events such as illness into their identities and to process and better understand these events. Using the voices of the adolescents contained in this study as a guideline, this process may be designed such that it provides an experience that is most meaningful to the client.

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APPENDIX A: RECRUITMENT FLYER

Were you diagnosed with a chronic physical illness or physical condition (such as asthma, diabetes, cancer, or lupus, for example) between the ages of 10 and 25?

Are you currently between the ages of 18 and 25?

Are you currently enrolled as an undergraduate student here at UNCC?

Would you be willing to share your experience in an interview?

If you answered yes to each of these questions, you're invited to participate in a study exploring the changes you may have experienced in your life since being diagnosed with a chronic physical illness/physical condition.

All eligible participants will receive a $10 Target gift card and will be entered into a drawing to win a $25 Target gift card when the study is over. There is also an option to receive up to 2.5 credits in research participation for Psychology classes. If you are interested in participating in this study, please visit http://www.surveymonkey.com/s/XPS6RTM or the Psychology Research Sign-Up page* to complete a brief questionnaire.

Please contact me (Eboni Winford, Ph.D. Candidate in Health Psychology) at 704-XXX-XXXX or ehedgspe@uncc.edu if you have questions and/or want more details.

* Search for the study entitled "Exploring Changes that Happen Following the Diagnosis of a Chronic Illness-Part 1

APPENDIX B: PRESCREEN QUESTIONNAIRE

1. Age: ______ (years)
2. Gender
    a. Male
    b. Female
3. Year in College:
    a. 1st year
    b. 2nd year
    c. 3rd year
    d. 4th year
    e. 5 or more
4. Major: ____________________
5. With which of these racial/ethnic groups do you identify?
    a. Native American
    b. Asian/Asian American
    c. Black/African American
    d. Hispanic/Latino
    e. White/European American
    f. Other (*please specify)*:_____________
6. What illness/physical condition do you have? ______________________________
7. At what age were you diagnosed with your illness/physical condition? ______ (*years*)
8. To what extent do you consider yourself a spiritual person?
    a. Not at all
    b. A little
    c. Somewhat
    d. Very much
9. To what extent is your spirituality involved in understanding or dealing with stressful situations in any way?
    a. Not at all
    b. A little
    c. Somewhat
    d. Very much
10. To what extent do you consider yourself a religious person?
    a. Not at all
    b. A little
    c. Somewhat
    d. Very much

11. To what extent is your religion involved in understanding or dealing with stressful situations in any way?
    a. Not at all
    b. A little
    c. Somewhat
    d. Very much
12. Which of the following best represents your current religious affiliation?
    a. Agnostic
    b. Atheist
    c. Baptist
    d. Bible Church
    e. Disciples of Christ
    f. Episcopal/Anglican
    g. Jewish
    h. Lutheran
    i. Methodist
    j. Mormon
    k. Muslim
    l. Pentecostal
    m. Presbyterian
    n. Protestant
    o. Roman Catholic
    p. United Church of Christ
    q. Non-denominational
    r. Other (*please specify*): _____________
13. What is the best way for me to contact you to schedule an interview?
    a. Telephone (*please provide your telephone number*): _________________
    b. Is it ok to leave a voicemail? *Yes* or *no*
    c. Email (*please provide the email address that you check most frequently*): _____________

APPENDIX C: INFORMED CONSENT—PRESCREEN (SONA)

Informed Consent for
Exploring Changes that Happen Following the Diagnosis of a Chronic Illness

You are invited to participate in a research study entitled, "Exploring Changes that Happen Following the Diagnosis of a Chronic Illness." The purpose of this study is to explore the personal effects of being diagnosed with and living with a chronic illness. You are being asked to complete this brief questionnaire that will determine if you meet inclusion criteria for the full study. If you do meet the inclusion criteria, you will be asked to participate in an interview in which you will be asked a variety of questions about how being diagnosed with a chronic illness has impacted your life.

Your participation in this portion of the project will take approximately 10 minutes**.** If you decide to participate, you will be one of approximately 200 individuals who will be asked to complete this questionnaire. Of the anticipated 200 participants who complete this questionnaire, approximately 20 participants who meet inclusion criteria for the full study will be asked to participate in the interview portion of the study. You will receive ½ research credit for your participation in this portion of the study. If selected to participate in the interview portion of this study, depending on your preference, you will also receive a $10 Target gift card OR 2 additional research credits. Additionally, all participants, including those who complete the accompanying questionnaire but do not meet inclusion criteria, will be entered into a drawing to receive a $25 Target gift card, which will be held at the end of data collection.

This portion of the study has little potential for risks; however, it may or may not be possible that you may experience stigma associated with identifying yourself as a person with a chronic illness. As such, all students will view information about the Counseling Center and the Student Health Center located at the end of this survey, and you must acknowledge receipt of this information. The benefit of your participation in this study to the UNCC researchers and to society and the scientific literature is an improvement in the understanding of the impact of illness on the lives of adolescents including college students. The possible benefit of participation in this study for you is an increased understanding of the research process at UNCC and the general scientific community.

You are a volunteer. The decision to participate in this study is completely up to you. If you decide to complete the accompanying questionnaire, you may stop at any time. You will not be treated any differently if you decide not to participate or if you stop once you have started.

You will be assigned a unique identification number. The information that you will provide in the accompanying questionnaire will be stored in an Excel spreadsheet that will be stored in an encrypted, password-protected file, accessible only by the Principal Investigator and the faculty supervisor. Even if you are not selected to participate in the interview portion of this study, the information that you provide in the accompanying questionnaire will be used to provide an overall demographic description of all 200 anticipated participants (e.g., average age, year in school, etc.); however, no personally identifying information will be used when providing this demographic description. This informed consent will be stored in a locked file cabinet located in the Principal Investigator's office, and this file cabinet is accessible only to the researcher and the faculty supervisor.

UNC Charlotte wants to make sure that you are treated in a fair and respectful manner. Contact the University's Research Compliance Office (704-687-3309) if you have any questions about how you are treated as a study participant. If you have any questions about the project, please contact Eboni Winford, Health Psychology graduate student (704-XXX-XXXX) or Dr. Amy Peterman, Associate Professor of Psychology (704-XXX-XXXX).

Because this is an online survey, your consent is implied when you choose to continue. Before proceeding, please read the following statement; if you agree, please continue.

By continuing, I am indicating the following:

- I have read the information in this consent form.
- I am at least 18 years of age.
- I agree to participate in this research project.

APPENDIX D: INFORMED CONSENT—PRESCREEN (SURVEY MONKEY)

Informed Consent for
Exploring Changes that Happen Following the Diagnosis of a Chronic Illness

You are invited to participate in a research study entitled, "Exploring Changes that Happen Following the Diagnosis of a Chronic Illness." The purpose of this study is to explore the personal effects of being diagnosed with and living with a chronic illness. You are being asked to complete this brief questionnaire that will determine if you meet inclusion criteria for the full study. If you do meet the inclusion criteria, you will be asked to participate in an interview in which you will be asked a variety of questions about how being diagnosed with a chronic illness has impacted your life.

Your participation in this portion of the project will take approximately 10 minutes**.** If you decide to participate, you will be one of approximately 200 individuals who will be asked to complete this questionnaire. Of the anticipated 200 participants who complete this questionnaire, approximately 20 participants who meet inclusion criteria for the full study will be asked to participate in the interview portion of the study. If selected to participate in the interview portion of this study, you will receive a $10 Target gift card. Additionally, all participants, including those who complete the accompanying questionnaire but do not meet inclusion criteria, will be entered into a drawing to receive a $25 Target gift card, which will be held at the end of data collection.

This portion of the study has little potential for risks; however, it may or may not be possible that you may experience stigma associated with identifying yourself as a person with a chronic illness. As such, all students will view information about the Counseling Center and the Student Health Center located at the end of this survey, and you must acknowledge receipt of this information. The benefit of your participation in this study to the UNCC researchers and to society and the scientific literature is an improvement in the understanding of the impact of illness on the lives of adolescents including college students. The possible benefit of participation in this study for you is an increased understanding of the research process at UNCC and the general scientific community.

You are a volunteer. The decision to participate in this study is completely up to you. If you decide to complete the accompanying questionnaire, you may stop at any time. You will not be treated any differently if you decide not to participate or if you stop once you have started.

You will be assigned a unique identification number. The information that you will provide in the accompanying questionnaire will be stored in an Excel spreadsheet that will be stored in an encrypted, password-protected file, accessible only by the Principal

Investigator and the faculty supervisor. Even if you are not selected to participate in the interview portion of this study, the information that you provide in the accompanying questionnaire will be used to provide an overall demographic description of all 200 anticipated participants (e.g., average age, year in school, etc.); however, no personally identifying information will be used when providing this demographic description. This informed consent will be stored in a locked file cabinet located in the Principal Investigator's office, and this file cabinet is accessible only to the researcher and the faculty supervisor.

UNC Charlotte wants to make sure that you are treated in a fair and respectful manner. Contact the University's Research Compliance Office (704-687-3309) if you have any questions about how you are treated as a study participant. If you have any questions about the project, please contact Eboni Winford, Health Psychology graduate student (704-XXX-XXXX) or Dr. Amy Peterman, Associate Professor of Psychology (704-XXX-XXXX).

Because this is an online survey, your consent is implied when you choose to continue. Before proceeding, please read the following statement; if you agree, please continue.

By continuing, I am indicating the following:

- I have read the information in this consent form.
- I am at least 18 years of age.
- I agree to participate in this research project.

APPENDIX E: EMAIL SCRIPTS FOR STUDY ENROLLMENT

Email Initial Contact:
Good morning/afternoon, [participant first name]! My name is Eboni Winford. I'm writing because you provided your contact information when you completed a survey for the study "Exploring Changes that Happen Following the Diagnosis of a Chronic Illness" [on SONA/surveymonkey.com]. Thank you so much for your willingness to complete that survey.

I'm writing now because, based upon your responses to that survey, you meet criteria for inclusion in the second half of the study, the interview. I'm wondering if you are still interested in participating in the interview portion of the study. If so, I'd like to schedule a date and time to meet. The interview will take between one and a half and two hours. [SONA: You have already received .5 research credits for your participation in the survey, and if you decide to participate in the interview portion of the study, you will also receive EITHER a $10 Target gift card OR an additional 2 research credits.] [SurveyMonkey: If you decide to participate in the interview portion of this study, you will receive a $10 Target gift card for your participation.] You will also be entered into a drawing to receive a $25 Target gift card, which will be held at the completion of the study. Your participation in the interview portion of the study is entirely voluntary, and you will receive no penalty if you decide not to participate.

When replying to this email, would you provide the following information: whether or not you are willing to participate in the interview portion of this study and, if you are willing to participate, a ranked list of date/time preferences (1 = best choice, 4 = least favorite choice) from the selection below. If neither of these dates/times work for you, please provide three additional options for your availability.

Date/time #1:
Date/time #2:
Date/time #3
Date/time #4:

Again, thank you for your willingness to complete the first portion of the study, and I look forward to hearing from you soon.

Sincerely,
Eboni Winford
ehedgspe@uncc.edu
704-XXX-XXXX

Email Follow-Up Contact:
Hello again, [Participant first name]. I'm writing to follow-up on the email regarding your eligibility for participation in the interview portion of the study entitled "Exploring Changes that Happen Following the Diagnosis of a Chronic Illness". Thank you again

for your willingness to complete the survey portion of this study. Based upon your responses to this survey, you meet inclusion criteria for participation in the interview portion of the study. If you are interested in participating in the interview portion of this study, I'd really like to set up a date and time when we can meet. Whether you are interested or not, I'd greatly appreciate if you could reply to this email no later than [date] and supply the following information: whether or not you are willing to participate in the interview portion of this study and, if you are willing to participate, a ranked list of date/time preferences (1 = best choice, 4 = least favorite choice) from the selection below. If neither of these dates/times work for you, please provide three additional options for your availability.

Date/time #1:
Date/time #2:
Date/time #3
Date/time #4:

Whether I receive a response from you or not, this will be my last time contacting you. Thank you again for your help thus far; it is greatly appreciated!

Sincerely,
Eboni Winford
ehedgspe@uncc.edu
704-XXX-XXXX

APPENDIX F: INFORMED CONSENT—INTERVIEW (SONA)

Informed Consent for
Exploring Changes that Happen Following the Diagnosis of a Chronic Illness

You are invited to participate in a research study entitled, "Exploring Changes that Happen Following the Diagnosis of a Chronic Illness." The purpose of this study is to explore the personal effects of being diagnosed with and living with a chronic illness. You will be asked to participate in an interview in which you will be asked a variety of questions about how being diagnosed with a chronic illness has impacted your life.

Your participation in this project will take between 1.5 and 2 hours**.** If you decide to participate, you will be one of approximately 200 individuals in this study. While 200 participants are expected to complete the prescreen questionnaire, which you have already completed, approximately 20 participants who meet inclusion criteria for the full study will be asked to participate in this interview portion of the study. In addition to the one-half research credit that you received for completing the prescreen questionnaire, because you have been selected to participate in this portion of the study, you will also receive an additional two (2) research credits for your participation OR a $10 Target gift card. Additionally, all 200 participants who completed the prescreen questionnaire, will be entered into a drawing to receive one of two $25 Target gift cards, whether they participate in the interview or not. This drawing will be held at the end of data collection.

The proposed study has little potential for risks; however, because of the nature of the topics that will be discussed (the impact of illness on your life), it is possible that you may experience emotional discomfort when describing these effects or stigma associated with identifying yourself as a person with a chronic illness. Because of this potential, you will receive information about campus resources such as the Counseling Center and the Student Health Center should you require further discussion and processing of the topics mentioned while completing this study. The benefit of your participation in this study to the UNCC researchers and to society and the scientific literature is an improvement in the understanding of the impact of illness on the lives of adolescents including college students. The possible benefit of participation in this study for you is an increased understanding of the research process at UNCC and the general scientific community. By participating in this study, you may experience benefits associated with storytelling including being able to interpret the experience of illness and being able to better understand why the illness has occurred.

You are a volunteer. The decision to participate in this study is completely up to you. If you decide to be in the study, you may stop at any time. You will not be treated any differently if you decide not to participate or if you stop once you have started.

Your interview will be audio recorded and transcribed verbatim. You will be assigned a unique identification number, and the audio file and resulting transcript will not contain any identifying information. The audio files and subsequent transcriptions will be stored in an encrypted, password-protected file. Only the Principal Investigator, the faculty supervisor, and two trained research assistants will have access to these files. The information obtained from the online prescreen questionnaire will be stored in an Excel spreadsheet that will be stored in an encrypted, password-protected file, accessible only by the Principal Investigator and the faculty supervisor. This informed consent will be stored in a locked file cabinet located in the Principal Investigator's office, and this file cabinet is accessible only to the researcher and the faculty supervisor.

UNC Charlotte wants to make sure that you are treated in a fair and respectful manner. Contact the University's Research Compliance Office (704-687-3309) if you have any questions about how you are treated as a study participant. If you have any questions about the project, please contact Eboni Winford, Health Psychology graduate student (704-XXX-XXXX) or Dr. Amy Peterman, Associate Professor of Psychology (704-XXX-XXXX).

By signing below, I am indicating the following:

- I have read the information in this consent form.
- I have had the chance to ask questions about this study, and those questions have been answered to my satisfaction.
- I am at least 18 years of age.
- I agree to participate in this research project.
- I understand that I will receive a copy of this form after it has been signed by me and the Principal Investigator.

______________________________	__________________	_________
Participant Name (Please Print)	Participant Signature	Date
______________________________	_____________________	
Investigator Signature	Date	

APPENDIX G: INFORMED CONSENT—INTERVIEW (CLASSROOM, OFFICE OF DISABILITY SERVICES, STUDENT HEALTH CENTER, SURVEY MONKEY/EMAIL)

Informed Consent for
Exploring Changes that Happen Following the Diagnosis of a Chronic Illness

You are invited to participate in a research study entitled, “Exploring Changes that Happen Following the Diagnosis of a Chronic Illness.” The purpose of this study is to explore the personal effects of being diagnosed with and living with a chronic illness. You will be asked to participate in an interview in which you will be asked a variety of questions about how being diagnosed with a chronic illness has impacted your life.

Your participation in this project will take between 1.5 and 2 hours**.** If you decide to participate, you will be one of approximately 200 individuals in this study. While 200 participants are expected to complete the prescreen questionnaire, which you have already completed, approximately 20 participants who meet inclusion criteria for the full study will be asked to participate in this interview portion of the study. For your participation, you will receive a $10 Target gift card. Additionally, all 200 participants who completed the prescreen questionnaire, will be entered into a drawing to receive one of two $25 Target gift cards, whether they participate in the interview or not. This drawing will be held at the end of data collection.

The proposed study has little potential for risks; however, because of the nature of the topics that will be discussed (the impact of illness on your life), it is possible that you may experience emotional discomfort when describing these effects or stigma associated with identifying yourself as a person with a chronic illness. Because of this potential, you will receive information about campus resources such as the Counseling Center and the Student Health Center should you require further discussion and processing of the topics mentioned while completing this study. The benefit of your participation in this study to the UNCC researchers and to society and the scientific literature is an improvement in the understanding of the impact of illness on the lives of adolescents including college students. The possible benefit of participation in this study for you is an increased understanding of the research process at UNCC and the general scientific community. By participating in this study, you may experience benefits associated with storytelling including being able to interpret the experience of illness and being able to better understand why the illness has occurred.

You are a volunteer. The decision to participate in this study is completely up to you. If you decide to be in the study, you may stop at any time. You will not be treated any differently if you decide not to participate or if you stop once you have started.

Your interview will be audio recorded and transcribed verbatim. You will be assigned a unique identification number, and the audio file and resulting transcript will not contain any identifying information. The audio files and subsequent transcriptions will be stored in an encrypted, password-protected file. Only the Principal Investigator, the faculty supervisor, and two trained research assistants will have access to these files. The information obtained from the prescreen questionnaire will be stored in an Excel spreadsheet that will be stored in an encrypted, password-protected file, accessible only by the Principal Investigator and the faculty supervisor. This informed consent will be stored in a locked file cabinet located in the Principal Investigator's office, and this file cabinet is accessible only to the researcher and the faculty supervisor.

UNC Charlotte wants to make sure that you are treated in a fair and respectful manner. Contact the University's Research Compliance Office (704-687-3309) if you have any questions about how you are treated as a study participant. If you have any questions about the project, please contact Eboni Winford, Health Psychology graduate student (704-XXX-XXXX) or Dr. Amy Peterman, Associate Professor of Psychology (704-XXX-XXXX).

By signing below, I am indicating the following:

- I have read the information in this consent form.
- I have had the chance to ask questions about this study, and those questions have been answered to my satisfaction.
- I am at least 18 years of age.
- I agree to participate in this research project.
- I understand that I will receive a copy of this form after it has been signed by me and the Principal Investigator.

______________________________ ________________________ ___________
Participant Name (Please Print) Participant Signature Date

_________________________________ ________________
Investigator Signature Date

APPENDIX H: INTERVIEW SCHEDULE

1. Can you tell me a story about what life is like living with XXX?
2. What has changed since you found out you have XXX?
3. Can you tell me about a “normal day” before you were diagnosed with XXX?
4. What’s a “normal day” like for you now that you have been diagnosed with XXX?
5. In what ways has your illness/physical condition affected your identity or way you see your self?
6. How have you sought to understand what you are going through in terms of your illness or physical condition?
7. What does spirituality mean to you?
8. What does religion mean to you?
9. In what way, if any, has spirituality and/or religion helped you to understand what you are going through in terms of your illness or physical condition?
10. Is there anything that I haven’t asked or that you haven’t told me that you think I should know?