

Spirituality and Life-Threatening Illness: A Phenomenologic Study

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Purpose/Objectives: To examine the lived experience of individuals when confronted with a life-threatening disease.

Research Approach: Qualitative, phenomenologic using Giorgi's approach.

Setting: Patients' homes in the Midwest.

Participants: Five women and two men, aged 44–74 years, who had a variety of diagnoses, including breast cancer, colorectal cancer, prostate cancer, pulmonary fibrosis, and myocardial infarction.

Methodologic Approach: Subjects were recruited through flyers posted at support groups and religious establishments and by word of mouth.

Main Research Variables: Willingness to volunteer to share their stories.

Findings: Participants described how their spirituality provided comfort throughout their journey, strength in facing the life-threatening illness, many blessings despite the hardship of the illness, and trust in a higher power to see them through the journey. All participants described a sense of meaning in their lives throughout their experience.

Conclusions: Spirituality greatly affected patients' journeys through a life-threatening illness and provided a sense of meaning despite the illness.

Interpretation: Nurses need to acknowledge patients' spirituality and, in turn, assist patients in meeting their spiritual needs. By understanding the study participants' experiences, nurses can better support their patients, provide time and space for spiritual practices, and honor patients' spiritual journeys.

The diagnosis of a life-threatening illness can be devastating. A life-threatening situation, however, may be the very situation that provides ultimate meaning in patients' lives. Frankl (1992) based his theory of logotherapy on the premise that life's purpose is in discovering meaning and that meaning can be found even in the worst circumstances. Despite being confronted with a life-threatening illness and potential suffering, some individuals have found purpose and meaning.

The recorded experiences of individuals and a review of literature suggest that spirituality is an important component in finding meaning with suffering. Cardinal Joseph Bernardin (1997) found purpose in describing and acknowledging how his faith helped him to find peace in his illness. He even went as far as to describe his illness as a "special gift" (Bernardin, 2001). Pastor Gerald Harper, Jr., was able to find meaning and purpose through biblical teachings of Christianity after he was diagnosed with lymphoma. His book, *Living With Dying: Finding Meaning in Chronic Illness* (Harper, 1992), provides an honest view of his journey toward death. Morrie Schwartz, a Jewish man who described himself as a "religious mutt" stealing his spirituality characteristics from Buddhism, Chris-

Key Points . . .

- ▶ Spirituality plays an integral role in dealing with life-threatening illness.
- ▶ Nurses need to acknowledge and understand patients' spiritual beliefs to provide holistic care.
- ▶ Once nurses understand patients' spiritual beliefs, nurses can support patients in meeting spiritual needs, provide time and space for spiritual practices, and honor patients' spiritual journeys.

tianity, and Judaism, found meaning in teaching his final lessons as a professor to the world on the art of dying (Albom, 1997). Each of these individuals had strong spiritual beliefs. Spirituality has been identified in the literature as an important component for finding meaning and coping with illness (Duggleby, 2000; Hall, 1997; Highfield & Cason, 1983; Keefe et al., 2001; Livneh, 2000; O'Neill & Kenny, 1998; Schaefer, 1995; Strang & Strang, 2001; Thomas & Retsas, 1999). As some of these individuals have demonstrated, spirituality may help to illuminate meaning with life-threatening illness. If nurses are to understand the importance of spirituality in patients facing life-threatening illness, they must understand the essence of spiritual individuals' struggle to find meaning with life-threatening illness. The knowledge derived from this study will assist nurses in understanding the experience of spiritual patients in finding meaning with life-threatening illness.

Purpose

The purpose of this study was to examine the lived experience of individuals diagnosed with a life-threatening disease. Gaining insight into these experiences can help nurses to facilitate their patients' spiritual journeys in dealing with their diagnoses. Using Giorgi's modification of the phenomenologic method, the responses from seven patients were analyzed to answer the question "What is the lived experience of

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Digital Object Identifier: 10.1188/03.ONF.593-598

individuals, who consider themselves spiritual, when they are faced with a life-threatening illness?"

Literature Review

Defining Spirituality

Spirituality is a significant part of culture and a phenomena in which interest is growing. According to a national poll of 1,012 adults, 90% said that they believed in God (Gallup Organization, 2001). Spirituality may be considered a belief in a higher power or God and may be defined as transcendence or a connection to a higher power. For example, Shelly (2000) viewed spirituality as "the whole person in a dynamic personal relationship with God" (p. 17). The word spirituality is derived from the Latin word *spiritus*, which refers to breath, wind, or air (O'Neill & Kenny, 1998).

The definitions of spirituality in literature today vary greatly. O'Brien (1999) defined spirituality as "an individual's attitudes and beliefs related to transcendence (God) or to the nonmaterial forces of life and of nature" (p. 4). Speck (1988) defined spirituality as broader than a belief in a higher power and as a search for meaning within relationships. Others defined spirituality as the transcendence beyond physical life (Barnum, 1996; Price, Stevens, & LaBarre, 1995). For the purpose of this study, spirituality is defined as a personal belief in a higher power or being that guides life. This definition is broad enough to cover a multitude of spiritual belief systems yet is specific enough for participants to understand and determine whether they define themselves as spiritual.

Spirituality in Illness

Currently, much attention is being given to the role of religion and spiritual beliefs in adapting to and coping with chronic illness. Livneh (2000) identified seeking comfort in or actively relying on religion and spirituality as increasing patients' psychological well-being and allowing for a smoother transition to the medical aspects of their disease. According to Thomas and Retsas (1999), spirituality transacted self-preservation by allowing participants to take in their diagnoses, get on with treatment, and assimilate their diagnoses into their lives. They concluded that spirituality played a crucial role in giving meaning to patients with terminal cancer and that more attention needs to be given to assisting patients in meeting spiritual needs. Ross (1995) determined that patients want spiritual support when dealing with their prognoses. Spirituality provided patients with AIDS with hope and the ability to live a positive life in the face of their illness (Holt, Houg, & Romano, 1999). Substance-abuse patients reported that spirituality and God were major factors in their recovery (McDowell & Galanter, 1996). Women suffering from chronic illness reported that meaning and discovery were possible by turning to a higher power and putting their faith in that power, thereby sustaining their hope (Schaefer, 1995).

Study Framework

Frankl based his theory of logotherapy on the premise that the goal of life is to find meaning. He believed that life holds potential meaning under any circumstance, even in suffering. His theory centered on the concept that meaning always exists in life (Frankl, 1958, 1966, 1986, 1992, 1995, 1997).

Logotherapy, stemming from the Greek word *logos*, denotes meaning and seeks to help individuals discover their own "why" to live so they can bear any circumstance. Frankl developed his theory from years of experience as a psychotherapist and several years spent in Nazi prison camps, including Auschwitz. According to Frankl, life has a unique meaning for each person that can be found despite any horrific situation. Frankl (1992) said, "People forgot that often it is just such an exceptionally difficult situation that gives man the opportunity to grow spiritually beyond himself" (p. 80). He believed that the worst tragedies could be turned into triumph if individuals chose to make it so by taking the opportunity to grow beyond themselves and find meaning. Several studies have used Frankl's theory as a framework for their work (Do Rozario, 1997; Halldorsdottir, 1999; Ross, 1995; Strang & Strang, 2001). For example, Strang and Strang used Frankl's theory to support the concept that finding meaning is central to quality of life in patients facing a severe illness. Frankl's theory provides a framework for finding meaning in every situation, including suffering and illness.

Methods

A qualitative phenomenologic approach explores the essence of the experience of individuals who consider themselves spiritual in finding meaning with a life-threatening illness. The phenomenologic method uses participants' descriptions of their experiences to reveal their essence. Analysis followed Giorgi's (1985) modification of the phenomenologic method. Giorgi's modification of phenomenology applies the concepts of rigor and precision to the study of the human phenomena and ensures the capture of the phenomena according to the participants' descriptions.

Data Collection and Sampling

After obtaining institutional review board approval, the researcher distributed flyers to various support groups (e.g., Gilda's Club, Us Too!) and religious establishments that were easily accessible and recruited participants by word of mouth. The criteria for inclusion were patients who were 18 years of age or older; were alert and oriented to person, place, and time; were able to communicate in English; were willing to discuss experiences during an initial interview and a follow-up clarification session; were willing to have sessions audiotaped; defined themselves as spiritual according to the stated definition, "a personal belief in a higher power or being that guides life"; were diagnosed with what they considered to be a life-threatening illness a minimum of one month prior to the interview; and were undergoing treatment for the said life-threatening illness.

Ethical Considerations

All participants were informed of the nature of the study, their time commitment, and their involvement. Informed consent included agreement to participate in the study and be audiotaped. Confidentiality was maintained by omitting all participants' names. Only the participants' genders and ages were used in association with their narratives. The nature of their diagnoses will be discussed only in general terms in association with the group as a whole. Participants were informed that they could stop the interview or withdraw from the study at any time without penalty.

Researcher's Perspective

From the researcher's perspective of spirituality, a belief in a higher power or being who guides life is an integral part of a spiritual person's life and illuminates meaning in every circumstance. The researcher believes that finding meaning in every situation is a paramount human task. Meaning is unique for each person, clarifies purpose, and provides a reason for existence in every circumstance. As Frankl (1992) stated, "Man is willing to shoulder any suffering as soon as he can see meaning in it" (p. 65).

Data-Collection Process

All of the interviews were audiotaped and took place in the participants' homes, except for one that was conducted at the researcher's parent's home in a private place at the participant's request. Participants were asked to "describe your experience as a spiritual person having been confronted with a life-threatening illness." The investigator used encouragement and clarification throughout the interview to ascertain participants' descriptions of the phenomena. All recorded descriptions were transcribed. The study followed Giorgi's modification of the phenomenologic method to capture the human experience. The seven steps used in this method were described by Parse, Coyne, and Smith (1985) as dwelling with the description, returning to the subject for elaboration on ambiguous areas of description, identifying natural meaning units, identifying themes, identifying focal meanings, synthesizing situated structural description, and synthesizing a general structural description. Participants were asked for verification of the parts of their descriptions used for the study and the themes that emerged. Transcripts were checked randomly for verification of accuracy, and a doctorally prepared nurse who was experienced with qualitative research verified the emerging themes after reviewing the transcripts.

Data Analysis

The researcher used the audiotaped and transcribed descriptions to determine natural units of meaning. Participants were asked to clarify ambiguities during and after the interviews when necessary. Participants verified any description that was used. Themes arising from the participants' natural meaning units were identified. The themes were taken back to participants during the second meetings to determine validity. Next, five focal meaning units were identified using the language of the researcher. This allowed the researcher to synthesize situational structured descriptions. From this, a general structural description was derived, which incorporated all aspects of the phenomena that emerged from the research and its application to the nursing profession.

Results

Seven individuals who met the criteria for inclusion volunteered to participate. The participants responded after seeing a flyer or through word-of-mouth recruitment. The five women and two men ranged in age from 44–74 years and had a mean age of 61 years. The participants came from the Chicago, IL, and St. Louis, MO, vicinities. Two participants had breast cancer; one had colorectal cancer and throat cancer; three had heart disease with myocardial infarction, one of whom also had prostate cancer; and one participant had pulmonary fibro-

sis. All participants described themselves as spiritual according to the study definition, and each claimed Christianity as his or her religious affiliation. By the interview with the seventh participant, several commonalities were evident and no new themes were emerging; therefore, data collection was concluded.

Several themes emerged from the descriptions given by participants. Although participants experienced the phenomena in their own unique ways, commonalities did exist. In addition to the themes, participants universally began their descriptions by detailing the journey through the illness from start to current time. After describing the illness, participants delved into the impact and meaning of their journey through the life-threatening illness. The emergent themes are identified by a focal meaning description (i.e., a concise, short, descriptive title) in the language of the researcher, structured description (a paragraph describing the emergent theme in the words of the researcher) from the researcher, and participants' descriptions that support that theme. The final emergent theme surrounds how the participants described meaning.

A Sense of Comfort From Aspects of Spiritual Life

Participants described receiving a sense of comfort from their spiritual beliefs when facing a life-threatening illness. The descriptions included the feeling of not being alone in coping with the illness and a real belief that God would see them through the illness whatever the outcome. The participants also described the comfort they felt from the support of other spiritual individuals, including their prayers, well wishes, and get-well cards. In addition, participants sought out scripture, prayer, and devotions to provide a source of inspiration and comfort. Spirituality provided a feeling of peace that brought participants comfort in their most fearful moments during the journey through life-threatening illness. According to one participant,

The one thing that kept me going was the verse that said, "Whether you go to the left or go to the right, you'll hear a voice behind you saying, this is the way—walk in it." . . . In the middle of the night, I'll wake up a lot. I always wake up in the middle of the night. It's that quiet time where you can hear your heart beating and you can feel your pulse and you can feel every breath and every sound in the room. Sometimes it scares me, but I can feel a peace come over me and it's like, "It's okay, I'm right here."

Another participant said,

I believe very strongly in the power of prayer, and I feel that everybody that is praying for me . . . everybody who talked to me either when they're at church or friends around me, I thought that was wonderful. . . . A prayer is like a gigantic hug from a number of people, all the people that tell me that they prayed for me. It's just something that encompasses me, a good positive feeling that lifts me.

Trust in God

The participants' descriptions not only reflected a sense of comfort from their spirituality but also a trust in God (the participants all described God as their higher power). They

believed that God would provide the means for them to get through the illness to either restoration of health or death. They were willing to accept the outcome of their illness with the help of God. Participants reported putting their complete trust in God to see them through the illness just as they did with anything in life.

As I was going through that [the life-threatening illness], there were certain things that meant a great deal to me. We all know the serenity prayer. The first part says, "God grant me the serenity to accept the things I cannot change and the courage to change the things I can and the wisdom to know the difference." But that's not the end; I didn't know that. It goes on to say, "Living one day at a time, enjoying one moment at a time, accepting hardship as a pathway to peace. Taking, as Jesus did, [sobbing] this sinful world as it is, not as I would have it. Trusting that You will make all things right if I surrender to Your will. So that I may be reasonably happy with You forever in the next. Amen."

Another individual said,

I remember distinctly when I was in the hospital, and I was really sick thinking, "God, there's nothing I can do about this. It's in Your hands. Whatever way You think it should go, that's the way it should be. I'm fine with it either way. . . ." I just felt like, "Hey God, I'm laying here. I can't do a darn thing for myself. Take care of me because I can't do it. I'm in Your hands." And I was. . . . I trust in that and don't doubt it. It's my belief that in His hands I will be all right.

Strength From Their Spiritual Beliefs

Strength from spirituality coincided with comfort but emerged as another recurrent theme from the descriptions. Some participants described finding strength from verses, prayers, scripture readings, and songs. Participants felt they could not have coped with their life-threatening illness without the strength from God and their spiritual lives. They viewed the entire experience from the firm foundation of their faith in God, which sustained them throughout the illness. One participant reflected on the following.

I think the spiritualness was a part of the journey. I don't think I could have done the journey, because it is such a big part of me, I couldn't have done [the journey] without [the spirituality], which is obvious. When you have that spiritualness, whatever that is, to lean on, it really helps. . . . I don't think we can comprehend all the things that God does when you have to have surgery—all the things that have to work together . . . invisible hands [of God]. And that goes back to also, if you believe, then you know that that gracious God is going to take care of you.

According to another participant,

The prayers and songs made it possible for me to sleep. They let me sleep and cope with what was happening to me. It allowed me to carry on as best as I could, and apparently from what was going on around me, everybody was telling me I was doing really good. So, I think it worked. I don't think I could have done it by myself. . . . When I think of the help that I have gotten from believ-

ing in God, I mean, it's immeasurable. It is immeasurable! Then, you think to yourself, you are giving that legacy to your children and your grandchildren, and it's wonderful.

Blessed in Many Aspects of Life

The feeling of being blessed despite or through the illness was another theme that emerged from the participants' descriptions. All of the participants spoke positively about their lives, regardless of being diagnosed with a life-threatening illness. They described their lives as being blessed or as a gift. The life-threatening illness seemed to clearly delineate to participants the positive aspects of being alive. They attributed their blessings to God. One participant related the following.

You become actualized. It's like, I've had a conversation with God. How lucky I am! I'm dying, but I'm lucky because every day I'm one day closer to heaven. Not to death, but heaven. How many people can say at the first of the New Year, what a great opportunity for the New Year because I'm that much closer to my God?

Another participant said,

"I bless Him for the air and the earth and also for creating me and keeping me all these years." I didn't use that [phrase] before the operation . . . this idea of keeping me safe and watching over me.

Meaning in Life

The participants described a deeper meaning to life after facing a life-threatening illness. Although each individual's meaning was somewhat different, commonalities emerged. They described their experiences with life-threatening illness as a wake-up call to clarify what is really important in life. Some believed that the wake-up call was God asking something of them. This coincides with Frankl's (1958) theory that described how spiritual people who believe in God have a constant "invisible witness present" who expects something of them in any given circumstance. Other participants believed that the illness and its treatment were just a part of life and that bad things happen to believers just as they happen to nonbelievers. Participants felt that the illness provided a greater appreciation for time with loved ones and life itself. One participant described how the illness allowed the spirituality and goodness to come out in others in each of the acts they did for her. Not all participants felt they knew exactly why they had a life-threatening illness, but they found meaning in life despite the illness. They felt they did not need to understand the reason for the illness; instead, they believed that it was a part of their journey through life and that life still had meaning. One participant said,

What it's done is made me regroup, made me remember my roots, and go back to where I was and remember that I have a commitment in my heart. I think, for me, it's been more of a wake-up time. A wake-up time to which way are you really walking, which way do you really want to go. . . . So, my journey has been one of re-connecting and remembering where I've been. If you don't know where you've been, you don't know where you're going. To look at gaps in my life where I've stepped off the path.

Another participant stated,

I think because I have a long history of being knocked about by God saying, “You have got to get this because you’re not getting this.” Maybe I’m deaf. I pray for Him to speak up and then He does and it’s painful when He does, but I have found that’s where the answers are. . . . Why do bad things happen to good people? It means that it rains on the righteous as well as the wicked. We rejoice in the sun as well as we rejoice in the rain. That is the answer. So, the answer is—it just is!

A third participant noted,

I guess I would say that a life-threatening thing happening to you is not the worst thing that can happen to you, it can make you a better person. It can make you appreciate things more. I guess I’ve always been very family oriented, and my husband is, too. It just makes you know how important that is to you and, above all, how important your religion and your God is to you.

Discussion

Study Findings

The study findings correspond with the previous literature. Participants found strength, comfort, and meaning through their spirituality as described by Livneh (2000), Ross (1995), and Thomas and Retsas (1999). The participants’ descriptions affirm the findings of McDowell and Galanter (1996) and Schaefer (1995) that spirituality is a major factor when facing illness. As one participant stated, “I don’t know how you’d do a heart surgery if you didn’t have the faith that you need to get through.” Another participant said, “I couldn’t be this far without the Lord.” Clearly, participants felt that spirituality enabled them to go through their journey in a more positive way.

Frankl (1958) established the link between spirituality and finding meaning through his theory and lived experience. Frankl felt that people who believed in God had an even stronger sense of meaning in life, even in the face of adversity and death. Spiritual people who believe in God have a constant “invisible witness present” who expects something of them in any given circumstance. These spiritual people have transcended the question of “What do I have to expect of life?” Their new question is “What does life expect from me?” Under circumstances of suffering and impending death, the spiritual person has a “personal mission that is given to him by a personal being” (Frankl, 1958, p. 87), which is the source of meaning for the individual. As one participant stated, “To me, it was a calling back. You know, ‘I need you back.’ I have something I have to give to somebody else.” Frankl’s writing supports the premise that spirituality has a positive effect on finding meaning. In other words, “To be bestowed with meaning, life must transcend itself, but it must do so . . . in the sense of spirituality and growing beyond oneself” (Frankl, 1990, p. 8).

Through the lived experience of spirituality’s impact on finding meaning with illness, the present study provides insight into the experience of patients facing a life-threatening illness. All of the participants demonstrated an incredible aptitude for turning a potentially tragic illness into a triumph of the human spirit. Their spirituality provided a focal lens

through which they could view the experience as a victory. As Frankl (1986) wrote, “Man is ready to shoulder any suffering as soon and as long as he can see meaning in it” (p. 65). If nurses can better understand this experience, they can better facilitate their patients’ healing process. In helping patients to cope with a life-threatening diagnosis, nurses must understand their patients’ spirituality and search for meaning. This study provides knowledge to nurses through personal descriptions of individuals’ experience with spirituality and coping with a life-threatening illness.

Limitations of the Study

Descriptions of seven individuals from a Christian background were analyzed; therefore, the results captured the phenomena experienced by those particular patients. Individuals from other backgrounds or belief systems may experience things differently. Another limitation of the study is that the participants were recovering from illness. They all were well into the treatment process. Further research is needed to understand the phenomena more completely during various stages of life-threatening illness and with various individuals from other belief systems.

Implications for Nursing

Participants stated that spirituality was such an integral part of their lives that they could not imagine coping with life-threatening illness without it. They could not separate their spirituality from themselves because their spirituality greatly affected their journeys through life-threatening illness. Many participants were comforted and strengthened by spirituality during difficult times. Participants entrusted their lives to their belief systems, which consequently gave them a sense of meaning throughout the illness. Nurses can facilitate and enhance patients’ spiritual journeys by supporting and accommodating them in meeting their spiritual needs. By understanding patients’ spirituality, nurses can provide support and allow for spiritual needs. Opening the channels of communication with patients about spirituality gives patients permission to discuss vital spiritual issues with their nurses.

Nurses must address spiritual issues in treating the whole patient. With this knowledge, nurses can support patients’ spiritual needs, provide time and space for spiritual practices, and honor patients’ spiritual journeys. Nurses must identify patients’ spiritual needs and ensure those needs are being addressed to treat the whole patient (Hermann, 2001; O’Brien, 1999). In providing holistic care, nurses must address patients’ minds, bodies, and spirits.

Nurses have the privilege and honor of accompanying patients on their unique life journeys. If nurses open themselves to understanding the profundity of patients’ experiences with life-threatening illness, nurses will learn life lessons of triumph despite tragedy, bravery in the face of fear, and laughter through tears. This requires nurses to commit to the nurse-patient relationship so that patients and nurses might be changed forever by the experience. Through the current study, the researcher experienced the triumphant spiritual journey of seven individuals. The beliefs and spiritual framework that encompassed the lives of each participant illuminated meaning through and despite life-threatening illness.

Recommendations for Future Research

Spirituality can be a vital part of patients' journeys through life-threatening illness. Further research is needed to understand this phenomena. Research must be conducted at different stages of diagnosis with life-threatening illness, such as with newly diagnosed patients and patients during and after treatment. Research also could focus on the impact of spirituality on a multitude of different illnesses that are not necessarily life threatening. Individuals of different spiritual belief systems should be studied, as well as those from various age groups and ethnicities. Additional research could build on this study and further the knowledge base. Studies should be conducted to determine how nurses should approach spiritual is-

suess with patients, how nurses can assist patients in meeting their spiritual needs, and how nurses' own belief systems may affect the nurse-patient relationship.

The author gratefully acknowledges the North Park University faculty in Chicago, IL, who helped to complete this project, including Research Advisor Louise Hedstrom, DNSc, RN, Visiting Associate Professor Julie Donalek, PhD, RN, and Director of Graduate Programs Wendy Burgess, PhD, RN, CS, for their continued advice. This research study is dedicated to the memory of Xavier P. Smith, MS, RN.

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For more information . . .

- ▶ Medscape: Role of Spirituality
www.medscape.com/viewarticle/407758
- ▶ Supportive Care of the Dying
www.careofdying.org

Links can be found using ONS Online at www.ons.org.