*Original Article*

# Healing Connections: On Moving from Suffering to a Sense of Well-Being

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## Abstract

*Life-threatening illness is an assault on the whole person—physical, psychological, social, and spiritual. It frequently presents caregiver and sufferer with a paradox—suffering does not correlate with physical well-being alone. Drawing on a purposive sample of 21 participants, a phenomenological study was carried out to explore the relevance of the existential and spiritual domains to suffering, healing, and quality of life (QOL). The phenomenological method was used to achieve an in-depth description of both existential suffering, and conversely, the experience of integrity and wholeness, in persons with life-threatening illness; identify "inner life" and existential contributors to suffering and subjective well-being in advanced illness; and develop a narrative account of these QOL extremes. The importance of meaning-based adaptation to advanced illness was supported, as were Frankl's sources of meaning and Yalom's sources of existential anguish. Divergent themes characteristic of the two QOL extremes were identified. Four types of "healing connections" involving a sense of bonding to Self, others, the phenomenal world, and ultimate meaning, respectively, were identified. They situated the participant in a context that was greater and more enduring than the self, thus leading to enhanced meaning and QOL. The assumptions underlying the construct "health-related QOL" are questioned.* J Pain Symptom Manage 2007;33:372–388. *© 2007 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.*

**Key Words**
*Suffering, healing, quality of life, response shift, meaning, qualitative research*

## Introduction

Life-threatening illness is an assault on the whole person—physical, psychological, social, and spiritual. It frequently presents caregiver and sufferer with a paradox—suffering does not correlate with physical well-being. The patient may have significant pain or other symptoms but no anguish, no suffering. Conversely, the patient may be free of physical symptoms, yet suffer terribly. Suffering is experienced by whole persons, not bodies. It is subjective

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and personal, with possible origins in all domains of the individual's experience. It occurs with a perceived threat of destruction and ends when the threat has passed, or a sense of integrity is otherwise restored.[1]

The term quality of life (QOL) refers to an individual's personal assessment of subjective well-being. Like suffering, QOL is modified by all domains of human experience.[2,3] Fig. 1 presents the QOL continuum as a dialectic that extends from suffering and anguish at one extreme to an experience of integrity and wholeness at the other. Movement on this continuum toward an experience of integrity and wholeness may be thought of as healing, and toward suffering and anguish as wounding.

Assessment of QOL and specific aspects of being "healthy" has resulted in frequent counterintuitive findings. For example, one-third of a sample of 50 cancer patients with active disease considered themselves to be "fairly healthy" and two-thirds reported being "very healthy," including 12 who died during the study.[4] Similarly, in studies by Daltroy et al.[5] and Padilla et al.,[6] measures of health were found to fall below the patients' own subjective evaluation. Furthermore, several researchers have documented stable QOL scores for persons with life-threatening illness or severe disability, values that equaled those found in patients less physically ill and even in the general population.[7–12]

Adaptation to life-threatening or chronic illness may entail a "response shift," that is, a change in an individual's empiric QOL score resulting from 1) changes in internal standards of measurement (scale recalibration in psychometric terms), 2) changes in values (the perceived importance of domains determining QOL), or 3) a redefinition of QOL (reconceptualization).[13]

Whereas coping theory has traditionally focused on the management of psychological distress, Folkman[14] documented *positive* as well as negative psychological states among caregiving partners of men with AIDS. Using both quantitative and qualitative strategies, she noted four coping processes associated with the positive psychological states: positive reappraisal, goal-directed problem-focused coping, spiritual beliefs and practices, and the infusion of ordinary events with positive meaning. The feature common to these four modes of coping was the discovery of positive meaning.[14] The significance of this finding is further elucidated by the findings of Bower and colleagues,[15] who followed 40 HIV-seropositive bereaved men after the death of their partners and found that those who engaged in cognitive processing in dealing with their loss were more likely to find meaning. Furthermore, men who used cognitive processing and found meaning showed less rapid declines in CD4 T cell levels and had lower rates of AIDS-related mortality (all $P$ values $< 0.05$). The authors state that this study is the first to show an association between mortality and the experience of enhanced meaning, and the first to report an association between meaning and physical health outcomes that do not appear to be mediated by health behaviors or other confounds assessed in the study.[15] In a further study, Richards and Folkman[16] elaborate on the adaptive mechanisms involved in meaning-based coping, noting the particularly rich data obtained in the narrative accounts provided by their study participants.

The existential or spiritual domain is an important determinant of QOL in the palliative care setting and throughout the disease trajectory in cancer patients.[17–19] Moreover, overall QOL and measures of existential, psychological, and physical well-being can improve within

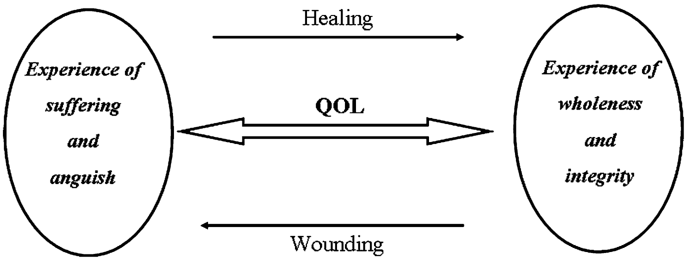

Fig. 1. The quality-of-life continuum.

one week after admission to a palliative care unit, suggesting the responsiveness of QOL and the spiritual/existential domains to skilled whole person care, even within days of death.[20] In their studies on spirituality and loss, Folkman and colleagues found that spiritual beliefs and practices contribute to both coping and the meaning reconstruction process involved in grief.[21–23]

How do we understand these findings? What are the factors that foster healing and enhanced QOL, or conversely, suffering and reduced QOL? Phenomenological research is the study of lived or existential experience for people in their everyday lives; its aim is to understand lived experience and transform it into narrative expression.[24] This study used the phenomenological method to achieve an in-depth description of the existential and spiritual experience of patients with life-threatening illness. Our study's objectives were to 1) provide a description of both existential suffering and conversely, the experience of integrity and wholeness, in persons with life-threatening illness; 2) identify "inner life" and existential contributors to suffering and subjective well-being in advanced illness; and 3) develop a narrative account of these QOL extremes.

## Methodology

### Data Gathering

*Sample.* Patients with life-threatening illness were recruited by referral from the nursing and medical staff of the McGill University Health Centre ambulatory and inpatient facilities. A purposive sample was developed so as to include a conceptually rich participant population representing both ends of the adaptive spectrum, that is, those with suffering and anguish at one extreme, and those experiencing a sense of integrity and well-being at the other. The inclusion criteria were English speaking adults with cancer or other life-threatening illness; active disease at recruitment; referral by primary caregivers based on extreme suffering, or conversely, an experience of integrity, wholeness, and well-being; sufficient mental capacity to give informed consent and to relate their personal experience of illness; and sufficient physical resources to participate in 90-minute interviews. Accrual of subjects continued until additional data accrual did not lead to further development of the suggested properties in the target categories.

*Interviews.* Three semistructured interviews were conducted with each participant according to I.E. Seidman's approach to phenomenological interviewing[25] in an effort to understand individual *inner life* experiences of spiritual and existential suffering and/or sense of well-being, throughout life and during their current illness. As suggested during preliminary trial interviews, the term *inner life* was frequently used to avoid the ambiguity and sensitivity associated with the words *psychological*, *existential*, and *spiritual* in discussing the overlapping domains indicated by these terms. The three interviews addressed the inner life experience before and during the illness (Table 1). Open-ended questions were used to explore the issues of concern, drawing on the content areas in Table 2. Pilot interviews conducted individually and together by two of the authors, B. M. M. and P. H. B., both experienced in qualitative research and palliative care, suggested synergistic value was achieved through joint interviewing. This became the norm throughout the study. Interviews were held at a location mutually agreeable to the participant and the interviewers; at least one interview was held in the participant's home. The time interval between interviews was determined by the patient, within the constraints of the interviewers' availability. Further interviews, beyond the three proposed by Seidman, were carried out with six of the participants based on agreement that additional time was required to fully explore the issues under consideration.

*Table 1*
**Interview Themes**

| | |
|---|---|
| First interview | Patient's experience of spirituality/existential well-being/inner life issues before illness. |
| Second interview | Patient's experience of spirituality/existential well-being/inner life suffering during present illness. |
| Third interview | Patient's reflection on the meanings and interpretations of spirituality/existential well-being/inner life issues reported in the first two interviews and any additional insights. |
| Optional further interviews | Similar to Interview 3. |

Adapted from I.E. Seidman.[25]

*Table 2*
**Interview Guideline Topics**

- Meaning of *spirituality* and *inner life* for the patient
- The influence of spirituality/existential well-being/ inner life issues in shaping the experience of illness
- Evolution of QOL over the course of the illness
- Perceptions of pain and suffering
- Caregiver response to pain and suffering
- Patient response to caregiver initiatives
- Communication issues
- The meaning and purpose of life
- Illness beliefs and cultural issues
- Ethical issues
- The quality and meaning of family and caregiver relationships
- Sense of personal health

*Field Notes.* Observational data describing the physical setting, and things seen, heard, or otherwise experienced during the interview, including the participant's affect, body language, dress, and other forms of nonverbal expression, were recorded by the researchers during and immediately after the interviews. The conjoint interviewing format facilitated unobtrusive recording of field notes by the noninterviewing research partner as the interviews proceeded. The field notes served as both an observational catalyst and an "aide memoire" concerning details of the setting, interactions, and feelings that might otherwise have gone unnoticed or forgotten. They also contain the researcher's reactions, insights, ideas, questions, and emerging understanding of the findings.

### *Ethical Review*

This study was approved by the McGill University Institutional Review Board.

### *Data Analysis*

Interviews were tape recorded, transcribed verbatim, and indexed into a computer by a research assistant experienced in the transcription of qualitative research data.

Data were collected and analyzed simultaneously in an ongoing process as the interviews progressed.[26] Of the first 21 persons entering the study, 13 completed 3 interviews (Table 3). These 13 participants accounted for the 81 hours of transcribed data (mean, 6+ hours per person) that were used in data analysis. Accrual of participants was then discontinued based on diminishing returns and the conclusion that additional data would not lead to further development of the suggested properties in the target categories. The eight other participants were able to complete only one interview before withdrawal from the study due to death, prohibitive weakness, or withdrawal of consent related to the increased priority of other issues, such as the need to use

*Table 3*
**Patient Demographics**

| Code | Age | Gender | Diagnosis | Completed Interviews |
|---|---|---|---|---|
| S001 | 41 | F | Cervical cancer | 3 |
| S002 | 51 | F | Malignant melanoma; breast cancer | 4 |
| S008 | 54 | F | Breast cancer | 3 |
| S009 | 63 | F | Ovarian cancer; breast cancer | 10+ |
| S010 | 46 | F | Lung cancer; colon cancer | 3 |
| S012 | 47 | F | Breast cancer; ulcerative colitis | 4 |
| S013 | 57 | M | Prostate cancer | 7 |
| S014 | 62 | F | Breast cancer; cardiac valve replacement | 3 |
| S015 | 59 | M | Prostate cancer | 4 |
| S017 | 39 | F | Breast cancer | 4 |
| S018 | 54 | F | Breast cancer | 3 |
| S020 | 50 | M | Idiopathic cerebellar degeneration | 3 |
| S022 | 39 | F | Necrotizing fasciitis; autoimmune disease; osteomyelitis; pneumonia | 3 |
| Discontinued | | | | |
| S003 | 94 | F | Cervical cancer | 1 |
| S004 | 47 | M | Glioblastoma | 1 |
| S007 | 58 | F | Cancer, primary unknown | 1 |
| S011 | 63 | F | Ovarian cancer | 1 |
| S016 | 75 | F | Malignant melanoma | 1 |
| S019 | 78 | F | Breast cancer | 1 |
| S021 | 79 | M | Prostate cancer | 1 |
| S024 | 67 | F | Arteriosclerotic vascular disease; congestive heart failure | 1 |

diminished energy levels to relate to family members.

*Case Narrative Construction.* B. M. M. and P. H. B. independently carried out a thematic analysis of interview transcriptions, as outlined by van Manen.[24] The results were then reviewed collectively and consensus was reached through an iterative process and detailed discussion. A systematic, chronological case narrative was then constructed for each participant, drawing on the self-reflective process of analysis described by Moustakas.[27] In this process, the researcher consciously reflects on his or her personal assumptions, viewpoints and judgments in processing and interpreting the participants' accounts of their experience. The phases of such an analysis are listed in Table 4. When completed, each patient narrative comprised a detailed description of that individual's existential/spiritual/inner life experience, before and during illness.

*Cross-Case Narrative Analysis.* The themes emerging in individual case narratives were reviewed by B. M. M. and P. H. B. and a comparison of major themes across cases was developed and verified by comparison with the original transcription and field note data. Through this process, an analytic framework was developed toward a further understanding of the experience of suffering and integrity in life-threatening illness.

## Findings

Seidman's interview schedule and the purposive sampling technique afforded a unique perspective on the dynamics of adaptation. While conjoint interviewing was labor intensive, it appeared to contribute significantly to the enrichment of interviews, field notes, and data analysis.

*Table 4*
**Moustakas' Reflective Process in Data Analysis**

1. Immersion: with the experience and data.
2. Incubation: drawing on researcher's insights, tacit inferences, new understandings, and awareness of the subject's experience and its meanings.
3. Illumination: recognition of expanding meanings and new clarity brought to the emerging research themes.
4. Explication: new connections within the emerging themes.
5. Interpretation: expression of new understanding.

Adapted from Ref. 27.

### *Meaning and Healing Connections*

A sense of meaning was evident in those able to find a sense of well-being and wholeness in facing serious illness, while a sense of meaninglessness was common to those experiencing suffering and anguish. Meaning-based coping was associated with a capacity to form bonds of connection, which we came to call *healing connections* in response to the evident revitalization, sense of security, and equanimity that accompanied them. These healing connections were of four types—connection with Self, others, the phenomenal world experienced through the five senses, or with God or Ultimate Meaning, however conceived by that person. The experience of healing connections, in large part, characterized the striking differences between those with "positive" and "negative" coping patterns.

Giselle provides an example of the latter group. Poverty, an imposed Roman Catholic conservatism, and hard work were the family norms during her childhood; life consisted of a never-ending pursuit of parental and church approval. As an adult, a 35-year teaching career provided her first experience of community. As her students became her surrogate family, her two daughters became estranged from her and her husband committed suicide (and did so on her birthday). On study entry, Giselle was 62 years old, retired, and had undergone surgery for breast cancer and cardiac valve replacement during the preceding 16 months. She lived alone in a small, fastidiously tidy flat overlooking a river. In spite of an unending quest for meaning through music, courses, nature, religion, reading, painting, and volunteering, her wistful, usually self-contradictory, expressions of appreciation of life rang hollow and sharply contrasted to her flat affect, monotonic voice, lack of spontaneity in movement and facial expression, sadness, and tears. She made repeated requests that we return for further visits.

> "I have a very nice life … my girls are gone and my husband died 20 years ago in June … I can do what I want … I walk along the water … and I pray along the water, too … Fall is so beautiful, but so short, and many trees are bare … Now I take time to do as I want … If only we could appreciate the present." (S014)

Her attempts to be positive failed to mask the desperation and loneliness she communicated to both interviewers, as suggested by a revealing field note, written after the second interview:

> "One notes deep feelings of countertransference. The bleakness is at times overpowering — a feeling of emptiness; a sense of silently going through the motions … a brittle, empty, lonely, world … (great) sadness. Attempts to find meaning but can never translate the idea into experience. I left feeling sad — with an urge to go back; to try to make it all better." (B. M. M.)

In contrast, Denise, a 54-year-old homemaker with widespread breast cancer, who had achieved a significant sense of well-being, identified multiple sources of meaning. Her mother had died due to a postpartum hemorrhage when she was 15 days old and, as a result, Denise was brought up by her father and an aunt who lived nearby. She recalled moving back and forth between "…two loving homes. I was so young. It was like having two families; we were so close. I found love." She explained,

> "It is important to remember that even if we are sick and have cancer, we are people, we are alive. We are not half dead people who cannot do anything. We are capable of being creative. We can still love. … It is important for me to live long enough to see the baby. … I was even drawing (and painting) — something I had never done … I had to do something that I could leave behind … That water color … it will be a souvenir for the grandchildren … One day I thought I would die soon and I wrote a letter to each one of these children." (S008)

Giselle's comments reflected her struggle and ambivalence. With evident despair, she noted,

> "I believe in God — I ask him to forgive me all the things I did wrong, and all the things I didn't do. … I still want to believe there is a God. … I don't think we live our lives just to die." (S014)

The transition from anguish to equanimity was described by Sophia, who came to see life as being richly filled with potential, but only after a long and painful existential ordeal. A 46-year-old housewife and mother of three with a history of both colon and lung cancer, Sophia experienced despair and meaninglessness as she struggled in her difficult journey through illness. On the way she encountered existential isolation. She commented,

> "[When I got cancer I felt] total isolation and no connection with anything. I really think that was probably the saddest feeling I could ever have, because that meant there was no god, no nature, no animals I care about. There are no people. There are only nothings. It's a black hole. No spirit, no soul, nothing left. [It was like being] a robot woman — just a body that breathes, functions, eats. The battery died. There was no spark. … Going through this whole experience is a solitary journey. It doesn't matter how lonely or not you feel, it is a solitary journey."

In the midst of this blackness, Sophia discovered a deepening experience of God.

> "Who is God? God for me is huge. He's not cold. He's got a twinkle. I can't see his face but there's a twinkle in his eye. I can sense it."

She found that conscious visualization led to experiences that were very "clear" and "real." When she visualized herself "sitting at the feet of God," he was stroking her hair. She recalled thinking,

> "I'm a nice Jewish girl. What's going on here? [Because] Jesus was stroking my feet and God was stroking my hair and saying to me, 'See? Darkness is just the other side of light. Death is just the other part of me.'"

She recalled asking Jesus, "Why are *you* here with me?," and Jesus replied, "I am compassion; I am compassion for your journey."

In these experiences, she found a sense of grounding.

> "God … gave Man free will and free will gives Man the ability to make choices. No matter how bad things are, I seem to have developed a way of picking up my rose-colored glasses and finding something [positive] that [can] come out of it. Without question, there's something more than this. I can almost touch it. I know it's

> a whisper. I know it's like a fog, or a haze, but it's there!" (S010)

Finding, through suffering, a deeper meaning and experience of connectedness were recurrent themes. Anne Marie, a 39-year-old single parent of four school children, had a complex medical history that included amputation of her left arm and shoulder for necrotizing fasciitis; autoimmune disease with associated peripheral vascular insufficiency and progressive loss of toes and fingers; a cardiac arrest; pneumonia; seizures; deep vein thrombosis; and osteomyelitis. As a child, she had grown up surrounded by a close, supportive, loving family. In reflecting on her current horrific multiplicity of escalating medical problems she stated,

> "If you look from the outside, [my illness] is a bad experience. But it brought me to another point of view about life, about what's really important and what is not. About what is the meaning of life, *really*. Why are we here? We are here for a certain period of time. We have some things to do and in my case I think it's to take care of my children and bring them to adulthood in the safest way." (S022)

Other existential issues were commonly encountered, particularly anxiety related to loss of control and the threat of death. Thomas, a 59-year-old second generation Canadian, whose parents had emigrated from Eastern Europe, was in the retail business. A skilled planner, Thomas liked predictability—both in his personal life and in his clients. He had advanced prostate cancer.

> "You're just hanging there. You're on the wire and you're just suspended up there and you want to know where you are going … being a person who likes to try and plan things, suspension is a very difficult concept to accept … And to think about mortality — I don't know what's going to be in the hereafter. …Some people are very laid back about it — lackadaisical, and they are prepared to live like that. I find it very difficult." (S015)

Other participants were haunted by the unpredictability of illness. Giselle recalled with nostalgia the reassuring presence of an earlier sense of external structure that one could count on.

> "[I remember] the Sunday smell — always roast beef. … It was always the same. That's why it was good." (S014)

The world of the cancer patient, on the other hand, may be filled with uncertainty and a loss of predictability and order.

> "I'm falling through the cracks. Two weeks ago, I was supposed to be [presented] at the Tumor Board meeting, but they couldn't get me on the list. There were many before me. I could understand that. That happens. Dr. N. called up the following week to say there was *no* Tumor Board meeting! He went and *no one* showed up! … And I said to him, 'Well, what are we going to do now? I'm sitting here on a keg of dynamite, wanting to know what is happening to me!'" (S009)

*Healing Connections with Self.* As a child, Dorothy and her older sister had parents who, though apparently close to each other, were "very hard put" to demonstrate love to their children. In looking back, Dorothy recognized that in response to a deep innate feeling of detachment from herself and others, she had, as a child, constructed a fantasy world of imagined love and happiness to offset her "austere" childhood. After university, Dorothy lived for 20 years with a classics professor who subsequently left the relationship. She then moved to Montreal where she lived alone "very unhappily" while developing a successful business career. She describes herself during this period as having been "an injured person" who yearned for meaningful relationships, which she sought through a woman's group, travel, meditation, a brief relationship with another woman, and an increasing interest in Buddhism.

In the following years, her mother died with Alzheimer's disease, "too late" for reconciliation, and she met M, her current partner, a supportive kindred spirit who had also experienced a painful marital breakup. At age 49, Dorothy was found to have a malignant melanoma and, subsequently, both breast and brain metastases became evident. Her newfound happiness gave way to a sense of "loss of self" and helplessness, loss of control, anger, and grief. As the gravity of her condition became clear, Dorothy recognized the need to be proactive. “I had to get out of that spiral somehow. I really had to!” She practiced journaling, meditation, and other self-reflective practices. At the same time, she became more assertive in seeking medical treatment.

> “I was facing illness from a more forward position. … It was a matter of trying to work at this attitude and being active and yet [at the same time] ‘letting go’ of things.” (S002)

On entry into this study, she was able to comment on a new sense of deep connection with Self.[28]

> “I discovered that there was an energy inside of me that was not separate from me, but which was a different aspect of my life and maybe one that was able to be truer than the life I had lived on the surface. I had this feeling that I could forgive myself for whatever I had not done — to make my life what I wanted.” (S002)

As already noted, Sophia also experienced a new sense of potential and growth. She commented,

> “I wouldn’t be who I am today and [I wouldn’t] *like* who I am today, if I had not had cancer. Look at how much I have learned, and grown and changed … it was a chance to evolve spiritually.” (S010)

*Healing Connections with Others.* In facing her devastating multiplicity of problems, Anne Marie stated,

> “I was really lucky to have all those loving people around me. And [during my illness], instead of thanking God for what I had in the past, I was thanking God for what I had [now]. … If it wasn’t for the illness, maybe I wouldn’t be so concerned and touched by the love around me.” (S022)

*Healing Connections with the Phenomenal World.* The world revealed through the senses was a common source of profound healing connections. For some participants, this was most evident in relation to the world of nature. Jean was a guidance counselor and father of two. In his 40s, he developed idiopathic cerebellar degeneration and was hospitalized in a chronic care facility. Now, at the age of 50, he observed,

> “There is that feeling of ‘Presence’ — such as when I go into the sunroom. I go, not because I have to talk to people [but] … to look at the snow, or a tree outside.” (S020)

Similarly, although she was a single parent and had been hospitalized at a distance from her children for six months, Anne Marie commented,

> “Life becomes so precious when you almost lose it. I mean, after [being struck by illness], you cannot be depressed because you enjoy every little thing … every little thing you see. Beauty … I spent the whole summer here and I’ve looked …When I came here there were no leaves on the trees and I saw the leaves grow into the summer. They were green, green, green, and then they changed colors. Look at the colors!” (S022)

It is notable that this woman also expressed a deep connection to Self, others, and God.

For others, the doorway to a sense of deep connection was music; for still others, it was the world of sports, an avenue characterized by connection both to the phenomenal world and to others. Since childhood, Yuri, a 57-year-old man born in Eastern Europe, had found in sports a life philosophy that was rich in meaning. His apartment was filled with memorabilia recalling the loves of his life—soccer and ping pong. The software programs on his computer and the prominent screen saver that dominated the living room had the same focus, as did our conversations. He expressed gratitude for his wife and daughter, even worried that his dependency produced an undue burden for them, but it was his connection to sports that brought him vibrantly alive! Although he acknowledged his impending death, it was an ongoing sense that he was still “playing the game” that brought him enthusiastically into the present moment and filled him with the glow of life fully lived. He was now in what he called *injury time.* He accepted the defeat, *but* he could still make a difference. He could still make his mark. He commented with feeling,

> "I feel sorry for people who just pray … I'm praying, too – every night before I go to bed, I say my few words, like I was a kid. But I'm lucky. I have something else with which to handle this. I don't feel pressure … I have been looking at everything in life through the soccer game … if you are a sportsman, you have the philosophy of accepting defeat. That is the thing that is strongest in me. I've developed this through my life. I won't stop trying … You have to be a sportsman and accept the outcome. You have to play the game. It is a tough thing because you know the end result. But now you are still playing the game. (When the game is over) there can be three or four minutes of "injury time." I saw injury time (count for something) many times in life – then the loser scored a goal! I'm not the type not to accept reality, but it's just that I'm not giving up." (S013)

*Healing Connections with Ultimate Meaning.* Ultimate meaning may be experienced as a powerful sense of unity with the cosmos, the More, or for many, a personal experience of God, as described by Sophia, above. Anne Marie commented,

> "[God] is giving me meaning in my life. If I don't see [the purpose of things], I will just let go and say, 'I leave it to Your will.' … I leave it to God's will to do whatever he thinks is best for me." (S022)

Similarly, Barbara, who had a past history of ulcerative colitis, was diagnosed to have breast cancer at age 44. She found healing connections through singing, dragon boat racing (the phenomenal world and community with others), and through her faith. She explained,

> "He is my God and my creator – and I talk to him about things I don't understand. About things that I find frustrating. … Sometimes I just want to get it off my chest and say, 'Okay, now *you* take care of it – and I promise not to take it back.'" (S012)

### *Features of the Healing Process*

Other features of the healing process that emerged from the data include the significance of the present moment; letting go, often involving a leap of faith; and a shift "from ego to deep center" (the Self of Jung),[29] from "head to heart."

*The Significance of the Present Moment.* Sophia came to see the present moment as being filled with creative potential.

> "It's important to recognize that we make the journey alone, and at the same time, enjoy and cherish the attachment to life in the present – to recognize the present and see its quality … Every minute is important. The shadfly lives just 24 hours. Can you imagine it worrying if another shadfly likes it? I mean, it spends 24 hours just being!" (S010)

Similarly, Anne Marie's description of the "green, green, green" of the leaves outside her hospital room suggests the intense presence to the moment that characterized her capacity to celebrate life in the midst of multifaceted stressful factors—uncontrolled pain, delays in laboratory tests and treatment, a multitude of complications, gangrenous fingers and toes, and distance from her beloved children.

*Letting Go.* Learning to let go of the need for control was a common feature of the healing process. As already noted, for those who were experiencing anguish, the need for control was often evident. Thomas stated,

> "You can't sit in suspension. I want the facts … you want to find out where you're going … I have to know … Being a person who likes to try and plan things, [death is] a very difficult concept to accept." (S015)

Similarly, Naomi had frequent anxiety attacks when she experienced a loss of control. This was not new. In reflecting about her previous marriage, she observed,

> "The man I married was very shy; I felt he was safe for me. Because he was a very quiet man; never raised his voice; loved me, I had total control! …He was safe." (S009)

In contrast, other participants expressed a capacity to move beyond control and into the unknown.

> "Learning to let go is [the same as] learning not to be in control of everything in your life. …[Before], I wanted to control everything. I wanted to control my husband. I wanted to control the way my kids were raised. I wanted everything to be perfect and you cannot do that. I mean that's not human … you have to let go of things. The lesson is … you have to accept [the illness]. It's like a death. It's kind of a grief. You have to say, 'Well, that's the way I was, and now [this is] the way I am, and that's the way I have to be, because I cannot change it.' Once you have taken that step – you can manage more." (S022)

Letting go may be enabled by a new sense of connection with Self. This process was clearly described by Dorothy, the business woman who felt she was "an austere, injured person" before having cancer, yet a person transformed through her illness.

> "I was a workaholic … very detached … an intellectual … [then, through the process of being 'medicalized' in illness], I thought, 'Where am I going to be in this great medicalization?' … I [decided] dignity would mean that I would be able to honor whatever 'that' is within me. When tubes are going all over the place and bits of me are sliced off … I feared [becoming] a bundle of pain and maybe not [being] able to connect with 'it' … [soul; my inner self]. Not fear of losing it, but of losing *contact* with it. If I can speak of 'it' being a separate being – I suppose you have to do this separation thing and say 'me and my being,' or 'me and my inner self, or higher self.' It is my inner strength. I do visualize this as kind of a very, very, very dense, energetic self in miniature. And I do visualize it as being inside me … the core – [but] that's when I *visualize* it. I'm not conscious of it being that way when I'm just walking around. I feel that this inner being, this higher self, functions on a completely non-intellectual plane. And I feel that practices like meditation and yoga are the things that strengthen that – *feed* that core being … One of the gifts of the [cancer] experience is this feeling of connectedness. And some of my strongest feelings have been when I am suffering physically – then I feel the connectedness." (S002)

The process of letting go of ego constraints and defenses may involve a conscious act of volition that is often experienced as a "leap of faith" or a "trusting step into the unknown." For Sophia, this metaphoric psychic leap was concretized by actually jumping!

> "Every time I face a new challenge or a new obstacle, I'm scared, until I gather my strength and I jump off that bridge, or I leap into the unknown. I'm not a risk taker, but it's like I decide to BE a risk taker! That year that I had the lung out on July 12th, the next Christmas we went hiking … [in the Caribbean], and we went to this bridge – it was about 45 feet above the water – a suspension bridge … – and I saw people diving off the bridge – and I said I want to go. … And I said to the guide, 'Can you jump?' She said, 'Yeah,' and she jumped … It took me about ten minutes. I just stood there. And I knew people were talking but I zoned them all out. And I jumped – and for those few seconds in the air … I felt my spirits lift. I felt a sense of freedom I have never felt in my life. I *had* to jump! I had to do that." (S010)

### *Thematic Analysis Across Cases*

Our purposive sample involved subjects representing the extremes of the QOL spectrum. The data were analyzed for themes that were common to each of these groups: those experiencing suffering and anguish (Table 5) and those experiencing integrity and wholeness (Table 6).

*Common Themes Across Cases: Suffering/Anguish.* Themes common to participants experiencing suffering and anguish include a sense of

*Table 5*

**Themes Common Across Cases: Suffering/Anguish**

1. Sense of disconnection from self, others, phenomenal world, ultimate meaning
2. Crisis of meaning; an existential vacuum; inability to find solace or peace
3. Preoccupation with future or past
4. Sense of victimization
5. A need to be in control

*Table 6*

**Themes Common Across Cases: Integrity/Wholeness**

1. Sense of connection to Self, others, phenomenal world, ultimate meaning
2. Sense of meaning in context of suffering
3. Capacity to find peace in present moment
4. Experience of a sympathetic, nonadversarial connection to the disease process
5. Ability to choose attitude to adversity; open to potential in the moment greater than need for control

isolation and of being disconnected. In addition, these participants experienced an existential vacuum, a crisis of meaning, and an inability to find solace or inner peace. They often expressed feelings of victimization, and a need for control. Ruminations about unsettling issues of the past and anxieties about the uncertain future consistently removed them from the potential of the present moment. These coping patterns frequently had their roots in early childhood.

Naomi illustrates many of these features. The youngest of four children of working class parents, she recalls,

> "[Mother] didn't like me. She told me when I was three that I was unwanted and that she tried to abort me. She used to beat me, slap me and pinch me. She never hugged me or held me. ... I can't remember her ever smiling."

Naomi's brother Jonathan developed a chronic illness.

> "He was the apple of her eye. ... [My mother] used to vent all her anger on me, even before he got sick. We're talking about my young, formative years ... (crying) ... I felt that [she] was blaming me for his illness. ... I remember my mother beating me up ... It made me feel I'm not good enough, smart enough. It just reinforced my negative feelings that have always stayed with me."

In adolescence, Naomi was sexually abused by her father, a situation that continued until she developed the ability to stand up to him.

> "I developed skills around what was happening — how I could avoid him. ... He kept threatening to tell my mother ... whereas, it was pretty obvious that I should have told my mother at the start ... but I couldn't ... I didn't feel secure enough. I felt, 'maybe this is what I deserve' ... I guess I learned skills that I am still using today — to protect myself. ... I learned to be in control — or I would not survive."

In school, and later working as an administrative secretary, Naomi battled with low self-esteem.

> "Everybody had to love me. I worked hard at it. And when people *did* love me, I used to say to myself that I was a fraud. They don't know me."

As an adult, Naomi was found to have two primary malignancies. Her chronic feelings of victimization intensified.

> "Why does God do this to me? Why is it always me? Haven't I suffered enough?"

When chemotherapy resulted in a complete remission, she was unable to enjoy her restored health, instead was preoccupied by a multitude of past ghosts and by the thought of lab tests yet to come. Surely they would bring bad news! She lived glued to the Internet in search of new treatment options. Self-esteem remained low; relationships with others were filled with disappointments and problems; living was meaningless; an experience of God, something that had been with her from childhood, vanished amid ruminations of past and future hells.

> "I sometimes think it isn't worth it ... it isn't worth going on." (S009)

*Common Themes Across Cases: Integrity/Wholeness.* Analysis across cases when the participants experienced integrity and wholeness yielded strikingly different themes from those with suffering and anguish (Table 6). As already noted, these individuals tended to find a sense of meaning and connectedness in the context of their illness. They also tended to experience a greater acceptance of their illness. This might even be expressed as a degree of sympathetic connection to their disease. Dorothy observed,

> "People encouraged me to do these visualizations you know, where you see [your

> immune cells] going through the blood and eating those bad cells – and I… I couldn't really connect with cancer as the enemy, because it's a part of me." (S002)

Although healing connections may first be experienced at any one of the four levels noted (with Self, others, the phenomenal world, or ultimate meaning), it appears that openness to healing connections at one level fosters opening at others.

## Discussion

How can we reach a clearer understanding of the existential contributors to suffering, subjective well-being, and the determinants of healing for persons with advanced disease? Although quantitative research is the methodology of choice for the measurement and analysis of causal relationships between variables, qualitative methods are preferred when one wishes to better understand subjective experience relating to meaning, patterns, and relationships in dynamic social situations. As already noted, phenomenological strategies are ideal because they are specifically designed to elucidate the existential experience of people in their everyday lives. This approach has resulted in an abundance of rich data in the present study, and conjoint interviewing following the I.E. Seidman format has served us well. Our purposive sample involved Caucasian, Judeo-Christian persons who were aware that they had life-threatening illness; the majority was female. Although the findings may not be generalized to other populations, their congruence with current understanding concerning adaptation theory, the significance of perceived meaning, the dynamics precipitated by existential angst, attachment theory, and wisdom literature observations over the millennia lend a sense of validity to our conclusions.

In his landmark book, *Man's Search for Meaning*,[30] written in eight days after his liberation from the Auschwitz death camp (personal communication, 1980), Viktor Frankl suggested that the foundational human quest is not for fame, fortune, prestige, material goods, or sexual satisfaction, but for an experience of meaning. Frankl noted that meaning may be found in things created or accomplished, things left as a legacy, things loved, things believed in, and in suffering itself.[30] It is, he proposed, the basis for QOL. Furthermore, Frankl asserts, "Everything can be taken from a man but one thing: the last of human freedoms – to choose one's attitude in any given circumstances, to choose one's own way."[30] Frankl's "last of human freedoms" is echoed in Sophia's understanding of free will as the basis for her capacity to choose a transcendent response to having two malignancies. Frankl's insight was hard won, the hell that was Auschwitz adding weight to his words—freedom to choose, even in such circumstances? It supports the possibility that we may find the same freedom when facing our own personal challenges. As an extension of these observations, Frankl developed logotherapy as a means of fostering an increased sense of personal meaning and QOL.

The experiences of the participants in this study confirm Frankl's sources of meaning, and Yalom's sources of existential anguish (death; freedom—i.e., an absence of external structure; isolation; the fear of meaninglessness).[31] What seemed increasingly evident to the interviewers, however, was that meaning was not an end in itself, but a by-product of a related experience, a sense of connectedness. It was not meaning, per se, that brought the person alive but the underlying experience of being part of something greater and more enduring than the self. In each instance, movement toward a sense of integrity and wholeness was associated with an experience of healing connections. Conversely, suffering was associated with an experience of isolation and meaninglessness. Frankl has drawn our attention to the significance of meaning; our study participants have reminded us of his further observation that meaning unfolds in the context of relationship.[32] This understanding may enable the caregiver to more clearly discern the dynamics underlying healing or wounding and to be more effective in accompanying the patient with active listening and a focused presence.

As already noted, our participants experienced connectedness at one or more of four levels: 1) within the individual, perhaps reflecting a strengthening of the ego-Self axis and the "individuation" of Jung—an experience of realized personal potential;[28] 2) connectedness with others—an awareness of deep attachment that suggests the I-thou relating of Martin Buber;[33] 3) a profound experience of connection to the phenomenal world experienced through the senses, as with nature, music, or sports; and 4) an experience of connectedness to ultimate meaning, as perceived by that individual. An experience of connectedness at one of these levels frequently appeared to be associated with openness to connecting at the other levels. “Healing, begets healing, begets healing,” as it were. When our participants experienced “healing,” it appeared that the change in internal standards, values, or conceptualization of QOL responsible for the response shift was a consequence of the greater sense of connection to a deeper Self, and/or a reality greater than themselves. This may be understood as being due to reinforcement of their sense of “culture,” or worldview, and their place as meaningful participants in that culture, as posited by Becker[34] and the proponents of terror management theory.[35]

The significance of attachment has long been recognized. Cassell put it succinctly: “Our intactness as persons, our coherence and integrity, come not only from intactness of the body but from the wholeness of the web of relationships with self and others.”[1] Bell and Bell have summarized the evidence for the mammalian need to be cherished and nurtured and the complementary neurocircuitry involved, noting, “When the parent’s caregiving is matched with the child’s attachment, we observe a connection process that is based on warmth and the child’s active dependence on the parent. Children who receive caregiving from parents that is empathic and responsive to their needs develop internal working models that enable them to be open and secure in adolescent and adult relationships. With security and support comes optimism toward life. Higher levels of parental support (caring, closeness, affection) lead to higher self-esteem, more social competence, better psychological adjustment, and academic achievement.”[36]

Cassell’s felicitous “web of relationships” depends not only on connectedness, but also on individuation, that is, successful development of a differentiated self and personal autonomy. Bell and Bell view connection and individuation as separate and complementary processes. They find “…well-functioning young people reporting a close connection with parents while at the same time demonstrating high levels of autonomy and individuation;”[36] they concur with Napier and Whitaker’s suggestion that both processes must develop in synchrony: “The more forceful and independent they become, the easier it is to risk being intimate and close. The more closeness, the easier it is to risk independence.”[37]

Naomi’s narrative supports the suggestion that much depends on early life experience,[36] but the reports of our subjects also suggest that, for many, as Frankl implied, the freedom to choose one’s response to adversity is retained, and healing may be fostered by an environment that promotes a sense of security, a loosening of ego defenses, and openness to the healing potential that lies within.[38,39]

Fricchione suggests that the separation—attachment dialectic can serve to explain adaptation to change in both the biologic and nonbiologic world. It has been suggested that in human evolution, we left the metaphorical “garden of innocence” when development of the prefrontal cortex and its connections to the paralimbic cortex enabled “memory of the future,” that is to say, awareness of personal mortality. Fricchione posits that because every separation challenge has a tendency to reward an attachment solution, the acquisition of awareness of our own mortality also marked the birth of the spiritual imperative, that is, knowledge of the ultimate separation challenge (death) precipitating the quest for the ultimate attachment solution, (union with the sacred or divine), as understood by that person.[40]

Our findings suggest that our quest to better understand *response shift* should include examination of adjustment mechanisms that have traditionally been considered *spiritual*. Stanworth’s informative qualitative inquiry into how patient spirituality is expressed[41] provides a thoughtful entrée to the *spiritual domain* in this postmodern, secular age. She states, “I wanted to know where a dying person can ‘stand’ when it seems there is no ground underfoot and when all of life’s familiar landmarks have shifted.” She adds, “Beyond the limits broached by medicine, psychology or the humanities, is there a further and all-encompassing horizon that gives meaning to human life and its finitude?"[41] In listening for evidence of "spiritual needs" and "meaning-based adaptive strategies," Stanworth noted the frequent use of symbols and metaphors. Her examples bring to mind Giselle's poignant observation, "Fall is so beautiful, but so short, and many trees are bare," Yuri's touching source of hope in "injury time," and Denise's watercolors and letters left as "souvenirs for the grandchildren."

In our study, the themes found across cases at each extreme of the QOL continuum (Tables 5 and 6) draw a sharp distinction between these two states. They are consistent with the above findings regarding connection and individuation and with the teachings of wisdom traditions regarding the importance to healing of: acceptance of self and one's present reality; identifying, and opting for, what is still possible within the constraints of present circumstances; coming into the present moment; and letting go of the need for control and ruminations about past and future. Acceptance of this nature is the transcendent alternative to denial. Rather than representing defeat and passive "giving up," such acceptance suggests an active integration of reality that frees the individual to exercise all available options. ("So that is the way my cookie crumbled, now what am I going to do with it.")

Sprangers and Schwartz[13] have proposed a theoretical model for understanding response shift. More recently, Rapkin and Schwartz[42] have recommended the use of a modified comprehensive methodology to be used as an adjunct to existing QOL scales in assessing changes in reported QOL. The findings of the study we are reporting suggest that further qualitative research may complement such quantitative strategies.

A further implication of our findings is the need to reexamine the dominant concept of QOL in current health research, that of health-related QOL (HRQL). The term suggests that it is possible to isolate and measure the aspects of QOL that are *health-related* as if they are not influenced by other aspects of human experience. The prevalence of counterintuitive findings in recent HRQL research suggests the weakness of this assumption. HRQL instruments may measure *something* with validity and reliability but, we would suggest, that *something* does not predictably reflect the patient's QOL. We would hold that QOL refers to the individual's assessment of their present personal subjective well-being. It is the answer to the question, "How is it going for you just now?" or "How does it feel to be in your skin today?" We suggest that QOL is modified by *all* domains of experience, as suggested by Saunders' term "Total Pain"[43] and by Cassell's eloquent description of suffering. He observes, "Suffering can occur in relation to any aspect of the person," and goes on to provide a "simple topology of persons," listing the relevant domains: "A person has personality and character, a past, a family, a cultural background, roles, relationships, a political self, actions, an unconscious, a body, a secret life, a perceived future and a transcendent dimension."[1] Each domain may modify suffering, and thus QOL.

The relevance of these observations is clear in the story of Naomi. Since childhood, each of Cassell's domains played an ongoing role in her suffering. Through her decade-long struggle with two cancers, her QOL was never exclusively "health-related," it was *life*-related and Naomi-specific. To influence her QOL demanded consideration of the whole person. For example, severe discomfort due to her chemotherapy-induced peripheral neuropathy that was present before an interview was frequently lessened, and of a different, less troublesome, quality at the end of the session.

Those measuring HRQL hold that *perceived QOL* is a multidimensional construct incorporating at least three broad domains—physical, psychological, and social functioning.[44–46] They add that "Beyond this core set of QOL domains, additional issues may be more salient for some individuals (e.g., spirituality and intimacy) or more relevant for specific patient groups depending on the functional domains affected by the disease (e.g., sexuality and body image)."[13] We, on the other hand, posit that *all* aspects of the person are relevant determinants of QOL and suffering, in *all* situations. At a time when current research has shown that maternal behavior impacts on epigenetic programming;[47] chronic stress is associated with telomere shortening;[48] and cognitive processing leading to an experience of enhanced meaning during bereavement is associated with sustained CD4 counts and prolongation of life,[15] we must conclude that the domains of human experience are interdependent and richly interactive, if not inseparable. To continue to be selective regarding those issues we wish to attend to (and those we wish to ignore), by continuing to prop up the thesis that HRQL is a distinct entity, is to fly in the face of all that we increasingly know about the essential unity of our being.

This study directs our attention to what we have called "healing connections" as a prime determinant of QOL. We have noted that such connections place the individual in a larger context and this in turn supports meaning, self-esteem, and QOL. Once again our findings are consistent with Cassell's observation, "Suffering occurs when an impending destruction of the person is perceived; it continues until the threat of disintegration has passed or until integrity of the person can be restored in some other manner."[1] Several comments are relevant here. If Cassell is right that threat of destruction is an important determinant of QOL, death anxiety must be a potent variable in this regard. Terror management theory has demonstrated that this is the case.[35] The evidence is clear that death anxiety is always with us (whether conscious or unconscious) and has profound implications for our daily actions and reactions. If, as suggested by our participants, a sense of wholeness and integrity can be achieved in the face of death, the dynamic involved must be highly effective indeed. How is this achieved? Cassell suggests that the "transcendent dimension" is fundamental to this shift. He defines transcendent dimension as "…a life of the spirit, however expressed or known" and states, "It seems evident that the frequency with which people have intense feelings of binding with groups, with ideals, or with anything larger or more enduring than the person — of which patriotism is one example — is evidence of the universality of human transcendence. The quality of being greater and more enduring than an individual life gives this aspect of persons its timeless dimension."[1] He goes on to say, "Transcendence is probably the most powerful way in which one is restored to wholeness after an injury to personhood. When experienced, transcendence locates the person in a far larger landscape. The sufferer is not isolated by pain but is brought closer to a transpersonal source of meaning and to the human community that shares that meaning. Such an experience need not involve religion in any formal sense; however, in its transpersonal dimension it is deeply spiritual."[1] Our findings support this assertion and lead us to add that the source of meaning may be experienced as being intrapersonal, phenomenal or cosmic (relating to ultimate reality, however perceived), and transpersonal.

Our findings suggest a primary relationship between meaning and healing connections. An openness to healing connections seemed to be established in childhood in many, but not all cases. For some, as with Dorothy, for example, a proactive intentionality and the support of self-reflective practices with the assistance of an experienced coach seemed catalytic for "healing" in the face of established anguish. Our findings suggest that a number of strategies may lead to improved QOL (Table 7). Such strategies have characterized the personalized "whole person care" that has been part of hospice

*Table 7*
**Suggested Strategies for Improving Quality of Life**

| |
|---|
| Identify sources of meaning, both positive and negative, before and during illness; identify current meanings of the illness for the person and for the family; explore creation of a life narrative (Written? Tape recorded? Favorite music?). Explore possible legacies for loved ones. |
| Explore source of existential anguish before and during illness; attend to dreams as clues to sources of existential distress. |
| Identify sources of healing connections for this person before and during illness. |
| Minimize uncertainty: for example, introduce caregivers by name and occupation; discuss hospital routines, assessment, treatment options, related plans, possible side effects, and anticipated timing of interventions. |
| Identify and support expression of fears ("What is the worst part of all this?, "What has helped you most?"). |
| Identify ego defense mechanisms that increase distancing, denial, closure to others, blocks in opening to the hard reality at hand. |
| Promote a calming, pleasant atmosphere characterized by efficiency, accompaniment, and caring, thus promoting a sense of security. |
| Promote strategies that may bring the person into the present moment: meditation, music, discussion of their cherished interests ("What have you always been passionate about?"), domains of creativity; consider art and music therapy. |

and palliative care over the past three decades.[43,49,50] It seems possible that the resultant healing connections, enhanced meaning, and security may underlie the improvement in QOL that we demonstrated during the first week of admission to palliative care units, in spite of the looming presence of impending death.[20]

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