Spirituality and Quality of Life in Chronic Illness

The focus of healthcare has shifted from acute, infectious diseases to chronic states (Lorig & Holman, 2003; Lorig, 1993; Schlenk et al., 1998). Chronicity is an irreversible state of disease for which there is no cure (Connelly, 1987). The prudent individual with chronic disease must employ strategies to reduce the impact of the illness. By reducing the impact of the illness and enhancing health, the individual strives for balanced bio-psycho-social-spiritual health and well-being.

The individual's subjective psychological outlook in the presence or absence of physiological and functional burden determines the individual's perceived quality of life (Buckhartz & Anderson, 2003; Murdaugh, 1997). Quality of life (QOL) then in the context of chronicity is a multidimensional, multifaceted, dynamic, subjective view of varying degrees of health-related satisfaction. This health-related satisfaction is connected to spiritual well-being. Spirituality is an important part of wellness and indispensable in holistic, multidisciplinary care (Young & Koopsen, 2005; Hill & Pargament, 2003; O'Connell & Skevington, 2005).

Some have confusingly represented spirituality as religiosity, but the two, although contiguous, are not synonymous. Spirituality is a broader, overarching domain that may include religiosity, but religiosity is not a necessary element of spirituality (Cooper-Effa, Blount, Kaslow, Rothenberg, & Eckman, 2001; Estanek, 2006). Spirituality is best described by the apt quote that is attributed to Pierre Teilhard de Chardin, "We are not human beings having a spiritual journey, but spiritual beings having a human experience" (Teilhard de Chardin, n.d.).

In recent years, numerous documents and research articles have been published on religiosity and health, but few have focused on spirituality and health (Peterman, Fitchett, Brady, Hernandez, & Cella, 2002). Even fewer have considered spirituality as a factor in maintaining quality of life. The purpose of this paper is to provide theoretical and research tools to support the inclusion of spirituality and quality of life assessments as inseparable, essential elements in the care of persons with chronic illness. Care that prevents the broken spirit and enhances spiritual balance has the potential for improving QOL. The implications of the constructs for practice, theory development, and research will be described.

Quality of Life

With today's healthcare delivery system and impact of managed care, it becomes imperative to justify interventions that promote quality of life, show cost effectiveness of treatment options (Thomas, 2000), and can holistically include spiritual needs (Krupski, 2006). The subjectivity and multidimensionality of individual's spiritual needs result in a phenomenon that is not clearly understood by others, as the individual adapts to disease and illness burden. The adaptation of the individual to a gap existing between expected and actual functional states may have health policy implications. Individuals with chronic illness, who unexpectedly tolerate more aggressive therapy, and demonstrate resilience, perplex healthcare providers, stakeholders, and expert planners (Bonomi, 1996; Cella et al., 1992). In chronic and palliative care QOL reports serve as a predictor providing prognostic input regarding survival and well-being (Dharmawarden, Au, Hanson, Dupere, Hewitt, Feney, 2004).

Definition of QOL

Quality of life is the "feeling of overall life satisfaction, as determined by the mentally alert individual whose life is being evaluated" (Meeberg, 1993, p. 37). This appraisal is subjective, and encompasses all domains of life, including elements of a biopsychosocialspiritual model (Hiatt, 1986). As individuals contend with chronic illnesses, their valuation of life will be based on the coalescing of all domains. Health related quality of life (HRQOL) must include and acknowledge health, illness, and QOL as part of the individual's experience.

Theoretical approaches to QOL

In chronic illness self-care management has been used as the theoretical underpinning for improved QOL. Health status also has been postulated as a direct influence on QOL (Jenerette, 2004). There is also the concept of response shift that explains the...
individual's vacillation and recalibration to adjust to illness-wellness shift and maintain QOL. With all the theoretical explanations that exist, the most fundamental is that of the individual's subjective, personal valuation.

The researchers who developed the Functional Assessment of Chronic Illness Therapy (FACT) measurement system defined quality of life theoretically as the fundamental subjective appraisal and value system of the individual that is multidimensional and includes physical, functional, emotional, and social well-being (Cella, 1992). All of the multi-dimensions are intricately needed to maintain balance and determine quality of life.

**Measurement of Quality of Life**

The Functional Assessment of Cancer Therapy General (FACT-G) was developed by Cella, Tulsky, Gray, Sarafian, Linn, Bonomi et al. (1993). The FACT-G was revised as it underwent multilingual and multicultural testing (Bonomi et al., 1996). The most current version, FACT-G, version 4, is a subjective, self-assessment, 27 item core measurement of the Functional Assessment of Chronic Illness Therapy (FACT) measurement system. The FACT-G measures four areas of QOL: physical well-being, social/family well-being, emotional well-being and functional well-being. This self-assessment questionnaire although originally developed for individuals with cancer, can be used for any chronic illness, such as renal disease, fibromyalgia, AIDS, arthritis, and heart disease (Cella et al., 1993).

In terms of multidimensionality of QOL, four distinct, but correlated, areas are measured by the FACT-G: physical, functional, emotional, and social well-being. Physical well-being refers to perceived and actual body function or disturbances, such as pain or fatigue. Functional well-being, different from physical well-being, includes the individual's ability to perform activities pertaining to social role, personal needs, ambitions, activities of daily living, executing responsibilities inside and outside the home (Cella et al., 1993; p. 188). The physical and functional dimensions are related but can occur independently, as seen when an individual is able to continue working effectively despite pain. The physical and functional domains are separate but impinge on emotional well-being that is reflective of a position on a continuum, between positive well-being, and negative distress. Comprehensive evaluation will help to determine one's fulcrum point on this bipolar dimension. The social well-being includes "maintenance of gratifying relationships with friends, acquaintances and intimate relationships with family members and significant others" (Cella et al.; p. 188-189).

The FACT-G was validated in phases on a sample of 545 patients and has sound psychometric properties, including concurrent and construct validity, an internal consistency estimate of 0.89; and test-retest reliability coefficients ranging from 0.82 to 0.93. The FACT can be used with individuals with cancer and other chronic illness such as renal failure, HIV/AIDS, multiple sclerosis, and rheumatoid arthritis (Bonomi, 1996; Cella et al. 1993).

The developers of the FACIT recognized the importance of spirituality in chronic illness and assessed spirituality on a separate measurement of the Functional Assessment of Chronic Illness Therapy (FACIT) measurement system defined quality of life theoretically as the fundamental subjective appraisal and value system of the individual that is multidimensional and includes physical, functional, emotional, and social well-being (Cella, 1992). All of the multi-dimensions are intricately needed to maintain balance and determine quality of life.

**Spirituality**

Health is a process that Watson (1985) describes as involving unity and harmony within the mind, body, and soul. Health is related to the degree of congruence that exists between a person's sense of "I and me." This congruence or lack thereof is the essence of being. This essence is subjective, personal, influences every aspect of life, gives meaning, value, strength, empowerment, soul, and is called spirituality (Frey, Daaleman, & Peyton, 2005; Aldridge, 2005; Brady, Peterman, Fitchett, Mo, & Cella, 1999; Baker, 2003; Young & Koospen, 2005). Spirituality enables the individual to rise above adversity, cope, and make sense of the current situation. Spirituality invigorates the unique psychosocial strengths of the individual so that he or she can organize and value life (Bartlett, Piedmont, Bilderkock, Matsumoto, & Bathon, 2003).

Although spirituality has been regarded as an important element of life, there has been little emphasis on spirituality in medical care, with providers at times avoiding religious issues, categorizing it as personal and attributing little therapeutic value (Koenig & Larson, 1998; Koenig et al., 1988). Thus, spirituality has been considered elusive, non-scientific, soft, and personal. However, the positive impact (Cooper-Effa et al., 2001), and therapeutic value of spirituality have been documented.

In a landmark study Byrd (1988), concluded that intercessory prayer offered by Christians outside of the hospital for patients in a Coronary Care Unit (CCU) had beneficial therapeutic effect. Since the activity was unknown to the hospitalized patients, the outcome may not be related to religion, but rather to spirituality. The patients in the CCU were healed without their knowledge of the intercessors laboring on their behalf for their healing. Even though some have been critical of the findings of the Byrd study, other researchers have also documented the relationship between spirituality/religion and health (Koenig & Larson, 1998). Since health studies have indicated that spirituality/religiosity are powerful factors influencing adaptation to illness, it then makes sense to desist from the semantic struggle, entertain more research in the spiritual domain, and apply existing information to improve clinical practice (Weaver & Koenig, 2006).

**Theoretical approaches to spirituality**

Transpersonal caring, which was originally defined as human-to-human connectedness by Watson (1985, 1996), is a special type of therapeutic relationship in which there is caring, conscious connectedness between the nurse and the patient. Two people have come together in a conscious, caring, spiritual relationship. The "connection has a spiritual dimension that is influenced by the caring consciousness of the nurse" (1996, Watson, p. 152). The nurse offers self in a therapeutic relationship with the patient, helping the patient to move towards physiologic and spiritual health. This caring relationship is the maxim of the professional nurse.

Other conceptual frameworks have been suggested to explain the importance of focusing on the spiritual dimension. Hiatt (1986) posits a biopsychosocial/spiritual paradigm, which is an amalgamation of spirituality to Engel's biopsychosocial model. The interlocking of mind, body and spirit reflect the multidimensionality of individuals.

Peterman et al. (2002) discuss the importance of examining spirituality void of religiosity to capture the spiritual needs of individuals who may not express religious traditions or ideations. A theoretical approach to spirituality that is distinct from religion is especially needed due to the rapid global, demographic shift that has resulted in individuals of diverse spiritual backgrounds residing together in communities. Hence, spirituality is not a homogenous practice, but reflects individual expressions of being.

Harrison and colleagues (2005) in trying to explain the spiritual-health relationship refer to George's summarization of increased social support, positive health practices, connectedness, and psychological enrichment as explanatory factors of spirituality. These factors serve to enhance the positive wellbeing of the individual, and propagate increased ability to overcome adverse events (Harrison et al., 2005).
Measurement of spirituality in chronic illness

Spirituality, as a core domain, is not commonly measured in QOL chronic illness studies (O'Connell & Skevington, 2005), but spirituality serendipitously emerges when religion is assessed in studies as a side-bar issue, or an add on variable (Hill & Pargament, 2003). O'Connell & Skevington (2005) noted that when authors acknowledge the importance of including measures of spirituality, personal beliefs and religion in their study design; these measures have mostly been included in disease specific measurement tools. Many of the disease specific tools are not applicable for other population groups.

Researchers in developing measures, must first define the constructs of spirituality and religion, and then plan to include these constructs in measurement development. Targeting spirituality in measurement of QOL issues may help to preserve, or enhance well being even in the face of considerable symptom load or in the midst of other health decrements (Brady et al., 1999).

There has been difficulty in demonstrating, through measurement, the construct of spirituality as personal and singular (See Gray in this issue). Spirituality is difficult to measure because of confounding variables (Frey et al., 2005) and unclear definitions. Despite the challenge of isolating spirituality from other domains of QOL, researchers must consider the imperative to include the spiritual domain. This imperative exists because the spiritual domain encompasses important and unique information with clinical implications and explanatory power (Brady et al., 1999).

Without the inclusion of the spirituality domain in QOL measurement, the information on essence of 'meaning to life' is lost.

One measurement of spirituality, not religiosity that needs further discussion is the Functional Assessment of Chronic Illness Therapy Spiritual (FACIT-Sp). The FACIT-Sp is part of the larger FACIT measurement system of which FACT-G is the core instrument. FACIT-Sp is a 12 item spirituality version that can accompany the FACT-G scale that measures four areas of QOL, or can be administered as a single assessment.

The FACIT-Sp primarily focuses on existential aspect of spirituality and faith, and assesses this on two sub scales: meaning/ peace and faith. The conceptual framework for the development of FACT-Sp is based on importance of studying relations between spirituality, interconnectedness of between mind, body and spirit, and the demographic change from organized worship and religion to a personal search for spiritual fulfillment (Peterman et al., 2002). The FACIT-Sp was "designed to provide an inclusive measure of spirituality that could be employed in research with people with chronic and/or life-threatening illnesses" (p.50).

Spirituality must be examined as a concept, rather than religiosity. Examining religiosity alone would exclude many who do not subscribe to denominational or specific religious beliefs yet have spiritual beliefs and practices (Peterman et al.).

The FACIT-Sp was developed with the input of cancer patients, psychotherapists and religious/spiritual experts who were asked to describe the aspects of spirituality and/or faith that contributed to QOL. FACT-Sp was validated in two phases with interviews with over 200 patients, and interviews with several hospital chaplains.

There are 12 items to this scale, which takes one minute to complete, when given as a single assessment. The statements pertaining to response to illness within the past 7 days are ranked by responses that range from not at all, a little bit, somewhat, quite a bit to very much. The FACT-Sp has sound psychometric properties, including concurrent and construct validity, and Cornbach's alpha from 0.81 to 0.88. The FACIT-sp assesses the role of nonreligious spirituality in quality of life and other health-related research, and its use has been documented in two other studies (Peterman et al., 2002).

Implications

Spirituality is intimately interlaced in healthcare issues and is fundamental to our human existence and survival (McSherry & Draper, 1998). Spiritual care is a valid part of healthcare delivery, and all team members must provide spiritual care, with special situations referred to pastoral care or chaplains. The spiritual experience invades all areas of life. Issues of healthcare and spirituality have a common meeting place in the parlour of suffering; both offer deliverance and healing in varying degrees. Healthcare providers (HCP) should be concerned about the individual's spirituality in the context of healthcare provision, healthcare decision-making, reduction of suffering and enhancement of quality of life (Young & Koopsen, 2005). Healthcare providers (HCP) need to open the dialogue halls and practice arenas to invite in the individual's cohabiter, spirituality. Spirituality is the convergence of issues from the mind, body, and soul connection. This convergence becomes a real, integral, holistic component of the whole person. Nursing, because of its philosophically caring and holistic underpinnings, is well positioned to implement spiritual interventions in practice, propel the development of theory, and build a body of evidence to promote quality of life for persons with chronic illnesses.

Practice Implications

Despite many differing camps on the specific impact of spirituality and religiosity and their combined inter-relatedness or separate impact on health and well-being, there is a constant thread. The constant thread is that spirituality is important to health, and individual expression of quality of life. This constant espouses the importance of spirituality and caring being the basis of nursing actions (Watson, 1985; van Leeuwen & Cusveller, 2004; McBrien, 2006; Kristeller, Zumbrun, & Schilling, 1999; Watson, 1988).

Spirituality is reciprocal in that the nurse with an attitude of caring, sensitivity, and competence, provides spiritual care to include the full illness trajectory (Bullard, 2004; Dyson, Cobb, & Forman, 1997), thus increasing individuals' involvement in care and decision making. The nurse emits spiritual transpersonal caring (Watson, 1985; Watson, 2002; Watson, 1988; Young & Koopsen, 2005), and in a reciprocal nature receives spiritual fulfillment and increased spiritual value from caring for the individual (van Leeuwen & Cusveller, 2004). The reciprocal continues as the nurse grows, matures spiritually, and with increasing ability and ease is able to identify components of spirituality that can be further utilized in new situations. This growth becomes obvious when the nurse is able to care spontaneously for the spiritual dimension of patients, regardless of culture, religiosity, and time constraints at the bedside, or any other characteristic that could possibly induce barriers. Then and only then is the transpersonal caring process fulfilled.

Spiritual care of patients is expected of nurses by the nursing code of ethics (ICN (International Council of Nurses), 2000).

External regulatory agencies such as the Joint Commission on the Accreditation of Healthcare Organizations mandate the inclusion of spiritual care in healthcare delivery. In keeping with professional and mandated requirements, spiritual care becomes a staple in healthcare delivery. Nurses must also encourage other healthcare team members to provide spiritual care. To provide best spiritual care, research activity and measurement must be ongoing.

In keeping with an integrated, holistic, bio-psycho-social-spiritual model, all patients should benefit from sensitive, non-imposing spiritual assessment, and incorporation of such information into rendered care by clinicians. The role of the clinician is to integrate spirituality, not to indoctrinate. Clinical practice, research, and education are areas for inclusion of spiritual care (King, 2000; Goldberg, 1998; Narayanasamy, 2006). Nursing curricula should include spiritual assessment in all programs (Watson, 2002). Emphasis should be placed on the impact of spiritual wellbeing on other aspects of life. Spirituality may act as social support, to buffer against stress and facilitate coping. Spirituality precipitates changes in individual's overall perspective of life and disease impact. Cooper-Effa et al (2001) offer concrete...
suggestions for clinicians who care for individuals with chronic illness.

It is imperative for clinicians to focus more on existential well-being rather than on religiosity. Spirituality is a broader concept, with possible inclusion of religiosity. The nurse must attempt to care for the spiritual needs of the patient by developing and using basic strategies such as listening, and being attentive to cues and body language. However, when the individual’s need for care is beyond the scope of nursing practice, it is appropriate to refer individuals for spiritual counseling.

Kristler et al. (1999) noted that all members of the care team must be involved in spiritual care, and consult with clergy or chaplains where appropriate. Caregivers should also advocate for provision of infrastructure to support the reality of spiritual care. The results from Kristlter et al.’s study suggest that time constraints and role uncertainty were factors that contributed to under-addressed spiritual distress experienced by cancer patients. Healthcare administrators can play a pivotal role in making resources and personnel available to address this paucity. Nurses can register their dissatisfaction with improper spiritual care and impress upon administrators the necessity of making changes to address the neglect.

Theoretical implications

Emerging models of spirituality must reflect the diversity of people and their spiritual needs, especially those persons who are chronically ill. Self-care approaches to spirituality within chronic illness would be helpful. More exploration of spiritual care for individuals of many faiths and cultures in a diverse society is also needed. Spirituality is evident in all facets of life, among all people, and needs explication beyond the usual ethnocentric perspective.

Research implications

Nurses can clarify research designs and utilize measurements that capture spirituality, using tools that capture the concept in a generic manner. Rigor has increased in looking at confounding factors influencing religion/spirituality and health related QOL among individuals with cancer and life threatening illnesses. Stefanek, McDonald, and Hess (2005) claim the trend will continue with the “inclusion of demographic, socio-economic, health status and psychological variables” (p.459). It is imperative to include such variables because they may affect disease outcomes, psychological adjustment and quality of life determinants (Stefanek, McDonald, & Hess, 2005).

Conclusion

The spiritual/religious link with health related issues and quality of life is known, but it remains unclear what exactly is this relationship. Further studies should help to elucidate the role of spirituality for individuals with specific chronic states, and demonstrate relationships of spirituality to QOL. Studies should be longitudinal, and interventional. Spirituality research activity must be increased and improved.

The discipline of nursing should champion activities to foster comprehensive inclusion of spiritual care. Nurses must influence policy makers and administrators to release funds for development of spirituality research centers, infrastructures and environmental conditions to support clinicians’ inclusion of spiritual care. Healthcare team members must incorporate spiritual care, and new findings into practice.

Since healthcare and specifically spiritual care promote deliverance and restoration, spirituality assessment and subsequent spiritual care offer deliverance, relief of suffering and mend the broken spirit. Healthcare providers and clinicians can actuate change by incorporating spirituality and QOL assessments in care delivery, and help individuals organize their lives and improve quality of life.

REFERENCES


