

Article

Spiritual Needs of Patients with Chronic Diseases

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Abstract: For many patients confronted with chronic diseases, spirituality/religiosity is an important resource for coping. Patients often report unmet spiritual and existential needs, and spiritual support is also associated with better quality of life. Caring for spiritual, existential and psychosocial needs is not only relevant to patients at the end of their life but also to those suffering from long-term chronic illnesses. Spiritual needs may not always be associated with life satisfaction, but sometimes with anxiety, and can be interpreted as the patients' longing for spiritual well-being. The needs for peace, health and social support are universal human needs and are of special importance to patients with long lasting courses of disease. The factor, Actively Giving, may be of particular importance because it can be interpreted as patients' intention to leave the role of a 'passive sufferer' to become an active, self-actualizing, giving individual. One can identify four core dimensions of spiritual needs, i.e., Connection, Peace, Meaning/Purpose, and Transcendence, which can be attributed to underlying psychosocial, emotional, existential, and religious needs. The proposed model can provide a conceptual framework for further research and clinical practice. In fact, health care that addresses patients' physical, emotional, social, existential and spiritual needs (referring to a bio-psychosocial-spiritual model of health care) will contribute to patients' improvement and recovery. Nevertheless, there are several barriers in the health care system that makes it difficult to adequately address these needs.

Keywords: spiritual needs; chronic disease; coping

1. Background

Confronted with chronic or fatal diseases, many patients rely on spiritual and religious issues to cope. In fact, spirituality/religiosity can be regarded as an important resource to cope, particularly for patients with cancer [1-7]. In cancer patients, spirituality/religiosity may be beneficial for maintaining self-esteem, providing a sense of meaning and purpose, giving emotional comfort and providing a sense of hope [7]. There is increasing evidence that distinct spiritual/religious practices and convictions/attitudes may have a beneficial impact on health outcomes (overview in [8,9]). Yet addressing these issues is generally not seen as a task of conventional health care, although there is consensus that "genuinely holistic health care must address the totality of the patient's relational existence—physical, psychological, social, and spiritual" [10]. This bio-psychosocial-spiritual model of care provides a conceptual framework for supporting patients' overall health.

Patients with fatal diseases or in terminal phases of disease are especially likely to have unmet spiritual needs. In a recent study among patients with advanced cancer, a majority (72%) reported that their spiritual needs were supported minimally or not at all by the medical system, and 47% felt supported minimally or not at all by a religious community, too [11]. This is of importance because spiritual support was associated with better quality of life [11]. Although spiritual concerns are of relevance for many patients, it may be difficult too for patients to express their spiritual needs (even within close family relationships) and for health care professionals to address them [12]. What are these unmet spiritual needs that patients and family members may have difficulty expressing, and that health professionals have difficulty addressing in health care settings?

A review of the psychosocial needs of patients with cancer identified physical and treatment related needs (*i.e.*, physical impairment, fatigue, sleep disturbance, side-effects of treatment, *etc.*), psychological and social needs (*i.e.*, emotional distress, depression, loss of sense of control, affected body image, impaired social function and relationship, *etc.*), and informational and support needs (*i.e.*, management of illness, prognosis, treatment options and side-effects, support groups, complementary therapies, *etc.*) [13]. Inadequate emotional support can create new or at least aggravate preexisting psychological distress resulting in depression, anxiety, adjustment disorders, *etc.*; distress may also lead to diminished self-perceptions and limitations in personal self-efficacy [14]. Patients' struggle with chronic symptoms can bring about feelings of guilt, loss, sadness, anxiety, diminished self-esteem, loss of role-function, communication problems with family and friends, questions about meaning in life, and religious struggles ("Why me?"), *etc.*

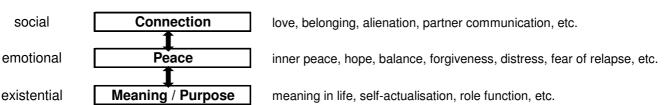
According to Maslow, the fundamental needs of humans can be categorized as primary (*i.e.*, food and drink, warmth and sleep, shelter, sexuality) and secondary needs (*i.e.*, security, friendship, belonging and acceptance, and finally self-realization) [15]. In contrast to conventional psychosocial needs which are often expressed as loss of social role function, lack of support by family or friends, needing help in managing disruptions in work or daily life, lack of material and logistical resources, depression and other negative emotions, disease associated distress, *etc.* (reviewed in [14]), spiritual needs are "the needs and expectations which humans have to find meaning, purpose and value in their life. Such needs can be specifically religious, but even people who have no religious faith or are not members of an organized religion have belief systems that give their lives meaning and purpose" [16]. Other would define the "need for peace of mind", the "need of overcoming despair and guilt", and to

"find meaning and purpose in life" as existential needs [17]. Nevertheless, spirituality is a multidimensional construct which is connected to religion, existentialism, and also humanism. Underwood and Teresi described spirituality as an individual and open approach in the search for meaning and purpose in life, as a search for `transcendental truth', which may include a sense of connectedness with others, nature, and/or the divine [18]. Also in our definition of spirituality [19,20] we found the core motifs search and connection which may comprise aspects of formal religiosity and also unique and individual spiritual views which go beyond institutional religiosity. Religious patients may interpret their existential and spiritual needs in religious terms, while non-religious individuals would interpret the same needs as existential and humanistic. While it is adequate from a theoretical point of view to differentiate psychosocial, existential and spiritual needs, it is obvious that these `secondary needs' are interconnected.

2. Needs of Patients with Chronic Diseases

Cancer patients from the U.S. want help with overcoming fears (51%), finding hope (42%), finding meaning in life (40%), finding spiritual resources (39%), or identifying someone to talk to about finding peace of mind (43%), meaning of life (28%), and dying and death (25%) [21]. A qualitative study among French patients at the end of life identified the following needs: reinterpretation of life, search for meaning, densification of the connection to the world, to loved ones and to oneself, control, vital energy, ambivalence to the future, confrontation with death, relationship to transcendence [22]. In hospice cancer patients, family was the most frequently cited need (80%), while attending religious services was the most frequently cited unmet need [23]. In Korean patients with cancer, five sub-constructs of spiritual needs were differentiated, i.e., love and connection, hope and peace, meaning and purpose, relationship with God, and acceptance of dying [24]. In German patients with chronic pain diseases and cancer, factor analysis differentiated four main dimensions [25], i.e., religious needs (enrolling praying, participate at religious ceremony, reading religious/spiritual books, turning to a higher presence), need for inner peace (enrolling patients' wishes to dwell at places of quietness and peace, beauty of nature, finding inner peace, talking with other about fears and worries, devotion by others), existential needs (in terms of reflection and meaning in life and suffering, dissolve open aspects in life, talk about the possibility of a life after death), and actively giving (which addresses the active and autonomous intention to solace someone, to give away something from yourself, and turning to others). Galek's analysis of the literature revealed seven major constructs, i.e., love and belonging, meaning and purpose, hope and peace, the sacred, appreciation of beauty, morality and ethics, resolution and death [26]. A meta-summary of the qualitative literature on spiritual perspectives of adults extracted thematic pattern of spirituality at the end of life, which were spiritual despair (alienation, loss of self, dissonance), spiritual work (forgiveness, self-exploration, search for balance), and spiritual well-being (connection, self-actualization, consonance) [27].

If one analyses all these categories of spiritual need, one can identify four (interconnected) core dimensions, *i.e.*, *Connection*, *Peace*, *Meaning/Purpose*, and *Transcendence*, which can be attributed to the underlying categories of social, emotional, existential, and religious (Figure 1). The proposed model of spiritual needs can provide a conceptual framework for further research and clinical practice.



spiritual resources, relationship with God / Sacred, praying, etc.

Figure 1. Model of spiritual needs.

3. Quantification of Spiritual Needs in Patients with Chronic Diseases

Transcendence

3.1. Findings

religious

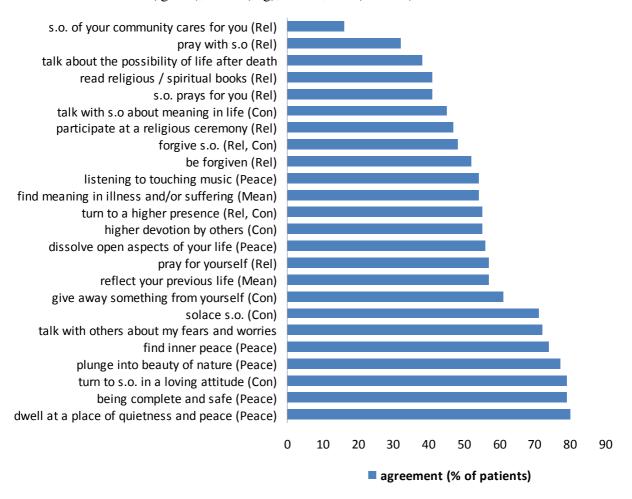
Using the Spiritual Needs Scale, Yong *et al.* [24] investigated the spiritual needs of Korean patients with cancer. They found that *Hope and Peace* were scored highest, followed by *Meaning and Purpose*, *Love and Connection* and *Acceptance of Dying*, while *Relationship with God* (divine, sacred) was less important. Patients' spiritual needs means did not differ with respect to age and education, but differed significantly with respect to religion (those without a religious denomination had the lowest sum scores).

In German patients with chronic diseases, needs associated with the general categories Peace and Connecting were of highest relevance (*i.e.*, place of quietness and beauty, beauty of nature, being complete and safe, find inner peace, turn to someone in a loving attitude, talk about fears and worries, solace someone) [25] (Figure 2). The general category Meaning/Purpose was represented by three items (*i.e.*, reflect previous life, find meaning in illness and suffering, talk with others about the question of meaning in life) which were of intermediate importance for the patients. Grading of the importance of these needs using the Spiritual Needs Questionnaire (SpNQ) showed that needs for $Inner\ Peace$ had the highest scores, followed by $Actively\ Giving$ and $Existential\ Needs$, while $Religious\ Needs$ had the lowest relevance [25]. Spiritual Needs were only weakly associated with life satisfaction; however, $Actively\ Giving$ (which is a factor attributed to the $Connection\ category$) was associated with life satisfaction (r = 0.17; p = 0.012), and inversely with patients' symptom scores (r = -0.29; p < 0.0001), while need for $Inner\ Peace\ was\ associated\ with\ patients' satisfaction with the treatment efficacy (<math>r = 0.24$; p < 0.0001) [23]. To clarify these associations one has to recognize that life satisfaction correlates negatively with symptom scores (r = -0.43; p < 0.0001), and positively with health satisfaction (r = 0.61; p < 0.0001) and treatment satisfaction (r = 0.48; p < 0.0001).

With the same instrument, Höcker *et al.* found similar grading of spiritual needs in 285 patients with cancer [28]. Multivariate linear regression analyses revealed that anxiety had a significant impact on cancer patients' needs for *Inner Peace*, *Existential Needs*, and *Actively Giving* [28]. Thus, anxiety can serve as powerful motivation toward seeking the fulfillment of spiritual needs.

Moreover, recent findings indicate that the spiritual needs of patients with chronic pain diseases are moderately associated with both positive and negative interpretations of illness [29]. This means, the way patients view their disease has an impact on the needs they may express.

Figure 2. Spiritual needs of patients with chronic diseases as measured with the Spiritual Needs Questionnaire (SpNQ) (n = 210; 75% women, 25% men; mean age 53.7 \pm 12.2 years; 67% chronic pain conditions, 28% cancer, 5% other chronic diseases [25]). Abbreviations.: Rel(igious), Mean(ing), Peace, Con(nection).



In a study among chaplains from the United States of America and Canada, Flannelly *et al.* [30] used the Spiritual Needs Assessment scale (developed by Galek *et al.* [26] after analysis of the literature to assess patients' spiritual needs) to assess the number of times that chaplains encounter patients with various spiritual needs. They found that *Meaning and Purpose*, *Love and Belonging*, and *Hope*, *Peace and Gratitude* ranked the highest, and *Morality/Ethics* and *Appreciation of Art and Beauty* the lowest, while the dimensions *Religion and Divine Guidance* and *Death Concerns and Resolutions*, which could be regarded as the central tasks of chaplains, are ranked between [30]. Although this study did not addressed the spiritual needs of patients directly, it nevertheless supports the findings of others enrolling patients with chronic diseases. However, unfortunately the authors did not follow their own findings that the factorial structure of Galek's 28-item instrument is not fully valid [31].

3.2. Interpretation

The need for peace, unaffected health and social support are universal human needs which corresponds with Maslow's core needs `security/safety' and `love/belonging', and are of outstanding

relevance particularly for patients with long lasting or even fatal courses of disease. These needs can be interpreted as a desire to return to a peaceful state of save completeness (`lost paradise')—instead of suffering pain, distress, insecure future perspectives, daily life struggles, and finally death. In this context, it is important to emphasize that the `Peace' component of spiritual well-being (FACIT-Sp) was strongly related to cancer patients' mental health-related quality of life, while the `Meaning' component was just marginally related to physical and mental health; in contrast, `Faith' was just marginally (negatively) correlated with mental health [32]. This underscores the importance of `Peace' as a category highly important for emotional well-being of patients.

Most dimensions were clearly linked to the *Connection* category ('love/belonging'); these needs involve friends, family or caring others, while a transcendent connection (Religious needs) was less important. Nevertheless, the hierarchy of patients' needs clearly point to the fact that praying for the own concerns was of higher importance than praying with someone, someone praying for the patient, having someone from the community who cares, or participating in religious services. In terms of religious needs, connecting with others from the religious community was less important than the self-realizing aspects and patients' turning to a Divine source for help. Also in Korean patients, personal connection with God, the Divine or the Sacred was of particular importance [24]. However, one should not ignore that even non-religious individuals may have strong spiritual needs, particularly a need for *Inner Peace* and *Giving Attention*, which did not significantly differ from those with a religious denomination [25]. In fact, spiritual needs go far beyond formal religion, and thus are important also for conventional health care and social ministry rather than pastoral care alone.

Actively Giving seems to be of great importance, too, because it can be interpreted as patients' intention to leave the role model of a 'passive sufferer' to become an active, self-actualizing, giving individual. Support for this comes from qualitative results of Murray et al. that "spiritual needs were expressed in terms of the needs to maintain a sense of self and self-worth, to have a useful role in life, retaining an active role with family and friends" [12]. Spiritual needs may be regarded as patients' longing for spiritual well-being. Nevertheless, it was just weakly correlated with life satisfaction, indicating that both concepts are different. Actively Giving is associated with higher life satisfaction (and lower symptom scores). Moreover, this dimension of giving could be linked to Erikson's psychosocial development stage 'generativity' [33]. This stage of middle adulthood refers to the ability to care for others and guide the next generation. Erikson stated, "A person does best at this time to put aside thoughts of death and balance its certainty with the only happiness that is lasting: to increase, by whatever is yours to give, the goodwill and higher order in your sector of the world" [33]. Thus, Active Giving may either cause greater life satisfaction, or may be the result of already being satisfied with life.

4. Addressing Spiritual Needs as an Approach in Health Care

Needs assessment is a measure of the difference between the experiences of patients and their expectancies [34]. In several cases, patients' expectations might be higher than practicable by medical professionals. Particularly cancer patients experience high levels of unmet needs, also in relation to conventional psychosocial and medical communication/information [35-37]. Although there are attempts to address supportive care needs of patients with cancer, assessing areas such as psychology,

health system and information, physical and daily living, patient care and support, and sexuality [37], it is remarkable that spiritual and existential needs are in most cases either not recognized or even ignored. One may surmise that health care professionals assume other professions to be `responsible' for these `secondary needs'. Prioritization of `primary needs' in the medical system might be due to the reductionist nature of biomedicine [17], and thus, "repairing the defect or dysfunction" is supposed to restore health.

On the other hand, health policies focus on improving access to care and rapidly moving them through the system; therefore addressing spiritual needs may not be practical for health professionals. Health care professional may feel overextended that they should care not only for the physical needs of their patients, but also for the spiritual and existential concerns. In a study enrolling patients with chronic pain diseases, 23% would like to talk with a priest or chaplain about their spiritual needs, 20% had no partner to talk about these needs, while for 37% it is important to talk with their medical doctor about these needs [2]. Yet medical practitioners may lack the necessary time, skills or even interest to uncover and address these needs.

If it is true that many patients may have turned away from institutional religion and would instead like to talk with their medical doctor or nurses about their spiritual needs instead of trained and certified chaplains or pastoral counselors, then the key activities of health care professionals should be reconsidered. This means that there is a general need for adequate education and training for health care professionals to address and uncover patients' spiritual needs which are in most cases not exclusively religious. Regardless of their own belief system, health care professionals should not allow their own bias to blind them to the possibility that spiritual/religious beliefs play an important role for their patients. In fact, research indicates that health professionals can play an important role in enhancing psycho-spiritual well-being [38], *i.e.*, self-awareness, coping and adjusting effectively with stress, relationships, sense of faith, sense of empowerment and confidence, and living with meaning and hope.

Currently there are several barriers in the health care system that makes it difficult to address these needs. Molzahn and Sheilds found that nurses' reluctance to address spirituality involved "not having the right words, lack of education, a view that spiritual care is someone else's responsibility, influences of secularism and diversity in society, and the current health-care context" [39]. However, Koslander *et al.* [17] argued that "if a patient's existential and spiritual needs, like physical needs, are seen as resources that are to be taken into consideration in health care, then a holistic care approach can be developed". Puchalski clearly pointed to the fact that "by creating an atmosphere of caring compassion and a willingness to be open to whatever concerns the patient, the interaction becomes focused in a patient-centered model of care" [9].

5. Conclusions

Chronic illness has a significant impact on the life of patients and affects physical, functional, emotional, social and spiritual well-being. Health care that addresses patients' psychosocial and spiritual needs (referring to a bio-psychosocial-spiritual model of health care) will contribute to patients' improvement and recovery. Identifying and addressing these needs is essential, but there is a general need to develop better strategies for meeting these multidimensional needs of patients with

chronic disease. When these needs are identified, health care professionals and patients' relatives have the chance to react and support the patients in their struggle with chronic or fatal illness. Not meeting patients' needs means to ignore their dignity and fundamental rights, which "are now seen as core to health care ethics" [17]. A prerequisite for further research is having valid and reliable spiritual need assessment tools, which then must be implemented in well-designed health care studies. Such instruments are now becoming available.

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