

UNDERSTANDING AND ADDRESSING SPIRITUAL DISTRESS

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ABSTRACT

Spirituality is increasingly recognised as an important factor in health and coping with illness. This article discusses the relevance of spirituality to medical practice, the understanding of spirituality and the implications to clinical practice, in terms of recognising spiritual distress, ethical arguments of providing spiritual care, and the approaches to managing spiritual distress.

Keywords:

Spirituality, spiritual distress, spiritual care, family practice

SFP 2008; 34(1): 69-74

RELEVANCE OF SPIRITUALITY IN MEDICINE

There is growing recognition of the importance of the spiritual dimension in the maintenance of health and in coping with illness. While the specific causal mechanisms remain unclear, there is evidence to suggest that the patient's spirituality can be predictive of mortality and morbidity, clinical outcomes, and coping with life events. Reviews and studies by various authors have generally revealed positive influence of spirituality/religiosity on longevity¹⁻³; on mental health conditions such as depression, anxiety, substance abuse and suicide^{1,2,4}; physical health outcomes such as prevalence of hypertension, cardiovascular diseases, and health promoting behaviour such as exercise participation and proper nutrition^{1,2}; and on coping and recovery from illness and from significant stressors in life, such as bereavement^{1,2,5,6}.

As to the degree to which spirituality impacts on mortality, a 28-year prospective assessment of more than 5,000 respondents by Strawbridge and colleagues⁷ revealed a 36% reduction in mortality among frequent religious attenders compared with infrequent attenders. This reduction is somewhat attenuated to 23% after adjustment for social connections and health practices. However, the reduction in mortality among women, even after adjustment was 34%, which in perspective, is equivalent to the improvement in mortality observed when smokers quit cigarette smoking.

Moreover, the patient's spirituality or religiosity may have practical relevance in the provision and acceptance of medical care. Firstly, religious convictions can influence medical decision-making. The Jehovah's Witness patient who refuses blood transfusions is a well-known example. The expectation of cure from prayers or miracles may also result in delays in some patients accepting or seeking timely medical attention⁸. Secondly, a significant proportion of patients want their doctors to discuss about their spiritual beliefs^{9,10}, particularly in situations of life-threatening illness, serious medical

conditions and in death and dying situations. Many want such discussions in order that the doctor will understand their responses to sickness, understand them better and understand how they make decisions. The willingness of the doctors to participate in religious and spiritual discussions has also been construed by patients as a reflection of the patient-doctor relationship¹¹. Thirdly, it is a well-established doctrine, particularly in family medicine, that patients experience illness in a multi-dimensional way and not just the physiological disturbances that comes with the disease. In addition to the physical, emotional, and psychosocial dimensions to illness, the spiritual dimension to illness is a significant component of the total experience of their illness and suffering. Ignoring this component of care may leave patients feeling incomplete, and may even interfere with healing¹².

However, the relevance of spirituality in medicine is not without controversy¹³⁻¹⁵. Critics have pointed out that many of the studies, particularly the older ones, have methodological flaws. Much of the evidence is still based on epidemiological findings and was not obtained at the level of clinical intervention. And finally, any recommendation on measures to enhance spirituality and religiosity may connote a judgement value which may be prejudicial to the patient, or worse, may be construed in coercive terms in an inevitably unequal doctor-patient relationship. In addition, there will also be questions as to the appropriateness of the physician to engage in an area which may be beyond the boundaries of his or her expertise.

DEFINING SPIRITUALITY

Part of the controversy may be contributed by the lack of consensus regarding the definition of spirituality, making it a difficult subject for scientific inquiry. Instruments to measure spirituality are also relatively new and many of the studies measured indices of religiosity or religious commitment such as the level of participation in religious activities^{1,16}, which may be conceptually different from spirituality. So how is spirituality defined?

Numerous definitions of spirituality have been described. They range from those with clear religious references such as one's personal connection with the Divine, to those that focus on an existential orientation such as one's way of making sense of one's life experiences¹⁷⁻¹⁹. The plethora of definitions may be divided into the following major thematic categories: a relationship with God, a spiritual being, a higher power, or a reality greater than self; transcendence or connectedness unrelated to a belief in a higher being; existential, not of the material world; meaning and purpose of life; life force of the person; integrating aspect of the person; and summative definitions that combined multiple themes¹⁹.

The Royal College of Psychiatrist Spirituality and Psychiatry Special Interest Group gives a broad definition of spirituality

as “the essentially human, personal and interpersonal dimension, which integrates and transcends the cultural, religious, psychological, social and emotional aspects of the person”²⁰.

An encompassing definition that integrates the above mentioned themes and features might thus be:

“The sense of connectedness of oneself to humanity / universality / the Divine that transcends through time and space and that which gives meaning to the experiences of one’s existence or circumstances”.

Some explanation regarding the terms spirituality and religiosity is warranted. A religion may be defined as a system of beliefs and practices that is organised by the collective spiritual experiences of a group of people. Religiosity or religious involvement refers to the degree of participation in or adherence to the beliefs and practices of an organised religion². While many studies used religiosity and spirituality synonymously and often, used religiosity as an index of spirituality, this may have arisen for a lack of a better measurement of spirituality^{1,16,21,22}. Pargament et al showed that whilst religious attendance had previously been shown to reduce risk of mortality, certain forms of religiousness where the ill elderly expressed religious struggles (feeling punished by God, feeling abandoned by their religious community, questioning God’s love and power) was associated with increased mortality during a two year follow-up period²³. Daaleman also demonstrated that among 277 geriatric outpatients, those who reported greater spirituality but not greater religiosity were more likely to appraise their health as good¹⁶.

Nowadays, it is also not uncommon to encounter people who describe themselves as spiritual but not necessarily religious. In comparing this contemporary view and the conventional religion, Rumbold differentiates conventional religion as focussing more on the sacred, while contemporary spirituality attends more to the self. Religion points to the Spirit, of which the human spirit is a reflection, while contemporary spirituality attends to and expresses the human spirit²⁴. In essence, the need for people to seek spirituality or spiritual fulfilment remains unchanged and the difference between the conventional and contemporary stances reflects the evolution of the means by which this is done. Moreover, rather than two distinct patterns, many people may adopt a dualistic approach and may harbour beliefs, attitudes and practices of both orientations at the same time. It is conceivable that such a situation may pose a challenge to the medical professional, whose contemporary role has been largely secularised.

ELEMENTS OF SPIRITUALITY

Meaning

For many, the state of spiritual distress comes into consciousness after a major life event such as a life-threatening illness that forces one to reckon with the potential loss of life

or life-style, or at the end-of-life, when one is forced to reckon with the inevitability of death. However, the need for meaning, which is a key component in the spirituality construct, seemed to be inherent to human existence. Living without meaning and purpose tend to generate intense anxiety²⁵. The failure to find “meaning” connotes that one is at the mercy of random events that we cannot anticipate or control (for example, “why is this happening to me?”). This state exposes us to a “hostile”, unstable and unpredictable world and it generates an immense sense of vulnerability. Victor Frankl, from his observations of prisoners in a concentration camp in World War II, wrote that “Man is not destroyed by suffering; he is destroyed by suffering without meaning”. Pain and privation, according to Frankl, is insufficient to cause suffering as they can be endured if it is for a purpose²⁶.

This need to ascribe meaning to our existence and experience can perhaps be traced to the time when we first attempt to comprehend our environment in the early years of life. Parkes, though not explicit in describing spirituality, described similar concepts in his model of the “assumptive world”²⁷. Since birth, based on our perception and experience of the external reality, we internalised a set of assumptions about how the “world” works. The accuracy of these assumptions when compared with reality enables us to maintain our orientation in the world, as well as imparts a sense of control and security in our lives. Many of the assumptions that we have of the world have become established as habits of thought and behaviour and are generally automatic, that is, we are not normally conscious of them. For many people, these assumptions include ideas of justice, fairness, destiny, and hope, beliefs and expectations, such as good triumphs over evil, specialness of the self and invulnerability. These assumptions ascribe meanings and rules that help us make sense of what happens to us and around us and enable us achieve a sense of coherence and predictability and stability in an otherwise seemingly chaotic world with totally random events.

Minor contingencies in life may promote changes to the assumptions and can be adaptive as we update our assumptions. Such experiences may in fact be welcomed as rejuvenating or refreshing life experiences, such as one might feel from a holiday in a country which is culturally different from ours. Major challenges that occur when the reality is severely discrepant to our assumptions can however be incapacitating and will be resisted. The resultant state of distress will remain until new meaning can be found to redress the spiritual equilibrium²⁵. In the context of an experience of a major illness, spirituality may be conceptualised as how the patient integrates the illness experience within a larger life course and how well this meaning making empowers the patient to move on and continue to live life²⁸.

Transcendence

Another key component of spirituality is transcendence. The concept of transcendence allows one to look beyond the reality

and find meaning and purpose beyond the constraints of time and physical existence, so as to enable reconciliation and wholeness in the larger context of the after-life or next life, or in a larger or cosmic scheme of things. The idea that one can transcend current circumstances can be an empowering mental attitude²⁹ in coping with ill-health. Through transcendence, one can give meaning and purpose to their lives, to their joys and to their sufferings, thereby, maintaining hope despite irrecoverable illness, disablement, privation and the inevitability of death. For example, a traumatic paraplegic who finds a higher calling in helping other disabled people may cope with hope and fulfilment rather than despair at the irreparable loss.

SPIRITUAL DISTRESS OR SUFFERING

It follows from the above that severe discrepancy leading to a state of distress can arise from unrealistic assumptions or major changes in life situations. Spiritual distress or suffering can be defined as the painful state when there is failure to reconcile the discordance between the assumptive world and reality. The circumstances leading to spiritual distress may occur in the setting of:

- a. **Illness.** While disease is a disruption to normal physiology, illness is the subjective lived experience of the disease. When illness occurs, it can challenge such beliefs and assumptions about our sense of health, lifestyle, and inviolability. Illness can disrupt one's existence by interfering with career, family life and the ability to enjoy life. It can lead one to ask questions about one's purpose and meaning in life.
- b. **Death and dying.** Many defend against the inevitability of death with two main mechanisms – the belief of “specialness”, as if one is not vulnerable to death; and the belief that they will ultimately be saved by a “Saviour”²⁵. Witnessing death and dying or going through the dying process forces one to question our beliefs and to acknowledge the inevitability of mortality as the indefensible.
- c. **Passing of life phases.** These may trigger review of one's life work and the meaning and purpose or the perceived lack of them in life.
- d. **“Traumatic” events.** These may be traumatic as a first person experience but may also occur vicariously from witnessing death and dying, or even reading about a serious human calamity like the tsunami or 9/11. Even an “uncomplicated” snatch theft that leaves one physically unscathed may well challenge one's sense of invulnerability and security. Physicians who perceive their primary purpose or calling as one that seeks to extend lives may find themselves traumatised and in spiritual anguish when their patients die.

Table 1. Verbal indicators of spiritual distress

“Why do people live?”
“Does life have meaning?”
“Life is meaningless”
“Is there a higher power such as God?”
“Why is God doing this to me?”
“Why do people suffer?”
“Why is this happening to me?”
“What's the point of living like this?”
“I just wish I were dead”
“Can't you do something?”
“Nobody can help me”
“What will happen after I die?”

RECOGNISING SPIRITUAL DISTRESS

When faced with a severe challenge to their spirituality, patients may begin to question some to their basic assumptions about life. They may struggle internally with such issues as the meaning and purpose of life and death; pain and suffering; or the presence of God or a higher power. Some of these struggles surface during the consultation process, usually in the form of verbal cues that should alert the physician to possible spiritual distress (Table 1).

Spiritual suffering may also be recognised in other manifestations: physically (e.g. intractable pain), psychologically (e.g. anxiety, depression, hopelessness), religious (e.g. crisis of faith), or socially (e.g. disintegration of human relationships)¹⁹. Some of these signs may be classified as in Table 2³⁰.

BARRIERS TO RECOGNISING SPIRITUAL DISTRESS

While many family physicians may recognise the importance of addressing the spiritual needs of patients, not many of them actually discuss these issues with their patients³¹⁻³². One reason may be the subtlety of the presentations mentioned earlier, which comes about because of the personal and intimate nature of spiritual issues. The finding that primary care physicians fail to respond to cues during the consultation most of the time may also be contributory to this phenomenon³³.

Ellis and colleagues investigated the perceived barriers that preclude the family physicians' discussion of spiritual concerns with their patients³¹. Lack of time was cited as the most commonly perceived barrier by the family physician (71%), followed by the lack of experience and training (59%), uncertainty about identifying the patient who needs discussion with (56%), and the concern that they will project their own beliefs onto the patients (53%). Forty two percent of the same cohort of family physicians indicated discomfort with the subject matter as a perceived barrier. Another known barrier to recognising spirituality and spiritual distress may be the conditioned bias against subjective experiences, like spirituality, because physicians tend to be trained as objective scientists in a medical education system, that is based largely on the biomedical model³⁴. From observations, other personal

Table 2. Signs that may indicate presence of spiritual distress (Modified from Knight³⁰)

Emotional
Restlessness/agitation/anxiety
Denial of illness or of reality of prognosis
Anger
Fear
Powerlessness and loss of control
Depressed/flat affect
Dreams or nightmares
Psychiatric
Depression
Anxiety
Panic attacks
Behavioural
Refusal to take pain medication (even when physical pain is present)
Refusal of assistance with ADLs
Power struggles with caregivers or family
Puts self in unsafe care position
Frantically seeks advice from everyone
Active forms of self-harm
Loss of independence
Lack of engagement with activities that bring comfort or joy (even when able to do so)
Withdrawal/Isolation
Questions about "why" or duration of dying process
Statements about "not wanting to be a burden"
Metaphorical or symbolic language suggesting distress or unresolved concerns
If history of religious practice/affiliation, refuses religious leader or stops practice
Physical
Unrelieved pain
Shortness of breath
Sleeplessness
Other signs
Conflict between the goals of palliation and religious beliefs

barriers include taking a clinical history instead of a narrative one, which frequently results in significant censorship of personal details that define the patients' lived experiences; the focus on patient-hood as opposed to personhood; the physician's fear and anxiety about spiritual issues; and excessive focus on clinical tasks rather than on the patient.

ETHICAL CONSIDERATIONS

The implementation of spiritual care into medical practice raises several ethical issues. These include questions as to the ethical basis for spiritual care; the appropriateness of the physician to discuss spiritual or religious issues with the patient; and the extent or boundaries of such an involvement. Most of the ethical arguments pertaining to the implementation of spiritual care into medical practice^{2,35-37} may be subsumed under the headings of three of the ethical principles: beneficence, non-maleficence and autonomy.

The available evidence on the impact of addressing spiritual needs on health related outcomes, coping and recovery from illness, may suggest that the physician has a duty of beneficence (to do "good") to enquire about the patient's spiritual concerns and support the patient's spirituality. In the report by McCord

and colleagues⁹, the proportion of patients who want to their physicians to ask them increases with the severity of their medical conditions. This is to be expected as it is known that patients use religion to help cope with illness. But what about those smaller but not insignificant proportion who does not want to be asked?³⁵ Does the principle of beneficence also allow the physician to initiate such conversations? Furthermore, while there is evidence to suggest that spirituality is associated with better health outcomes, there is little evidence to prove causality. Should the physician then prescribe spirituality-enhancing interventions to those whose spirituality has been deemed as weak? Some of these questions have to be deliberated in the context of the other ethical principles that follows.

The principle of non-maleficence dictates that the physician shall not do anything that may result in harm to the patient. In the context of implementing spirituality in medical practice, any of the actions must not result in a detrimental outcome for the patients. It is important here to emphasise that the physician-patient relationship is often lopsided in favour of the physician. Many of the patients are vulnerable in their illness and may feel compelled to accept recommendations, beliefs and values that they may not be comfortable with. There is little disagreement therefore that it is inappropriate for physicians to promote, prescribe, proselytise or evangelise religions. The interests of the patients can only be safe-guarded if no consideration other than their well-being takes priority. It becomes important that the physician be aware of his own spiritual needs and beliefs, since this may influence his/her ideas and expectations of what constitutes a state of spiritual well-being for the patient. The issue of expertise is equally important because discussing spiritual issues in sensitive situations may be a risky undertaking for the untrained that may result in emotional distress and trauma to the patient. The physician may, therefore, not be the best person to manage this aspect of care in certain situations. An example of this occurs when there is significant clash of opinions between the medical and religious approaches to care. In such situations, referral to the clergy of the corresponding faith may be useful.

Spirituality is a very personal aspect of being. Patient autonomy necessitates respect for the patient as a person with their own needs, choices, resources and preferences. The principle of autonomy generally requires the physician to follow the expressed wishes of the patient, which may include decisions based on religion and spirituality, the ideas and values of which may be radically different from those of the physician. But what if the religious coping is dysfunctional, as described by Pargament?²³ Going by the earlier arguments, there is no place for the physician to force any patient to relinquish his faith or practices. Likewise, the physician will have to be aware of his/her boundaries in expertise and ethics. A person whom the patient finds acceptable, such as a pastoral care worker or a religious leader of the same faith, may have to be called upon to explore the patient's belief systems and reduce the dysfunctional forms of coping.

IMPLICATIONS TO PRACTICE

There is general agreement that the role of spirituality in health and coping is positive and beneficial. So what can the physician do to implement spiritual practices?

Firstly, it would be good to acknowledge what should not be done. As discussed, physicians should not be prescribing religious beliefs or activities on the pretext of health reasons^{12,37,38}.

Secondly, spiritual discussions may not be appropriate as a matter of “routine” consultation, although such discussions may be required for dying patients or those with critical illnesses¹². If enquiry of spiritual needs were to be initiated by the physician, then this has to be done sensitively and centred on the patient’s needs. If the patient is not religious and does not want physician involvement in this area, then it is prudent to shift the questioning away from religion and towards what helps the patient to cope and gives life meaning¹⁴. Spiritual discussions need not endorse any religious values or practices.

Thirdly, taking a spiritual history can be a first step to understanding the patient’s spiritual needs and to address them. Several strategies have been described. Puchalski recommends the acronym FICA to structure questions in spiritual history taking. F stands for Faith (e.g. “Do you consider yourself religious or spiritual?” or “What gives your life meaning?”); I stands for Importance (e.g. “What importance does your faith or belief have in your life?”); C stands for Community (e.g. “Are you part of a spiritual or religious community that can support you?”) and A stands for Address in care (e.g. “How would you like me, your physician, to address these issues in your care?”)³⁴.

Another model to explore the spiritual dimensions is the HOPE model by Anandarajah and Hight³⁹. In the HOPE questions, H explores questions of source of hope, comfort, strength, peace, love and connection (e.g. “What are your sources of hope, strength, comfort and peace?”, “What do you hold on to during difficult times?”). O refers to the inquiry on the patient’s participation in an organised religion (e.g. “Do you consider yourself part of an organised religion?”, “How important is this to you?”). P stands for personal spirituality and practices (e.g. “Do you have personal spiritual beliefs that are independent of organised religion? What are they?”, “What is your relationship with God?”), and finally E pertains to the effect on medical care and end-of-life issues (e.g. “Has being sick affected your ability to do things that usually help you spiritually?”, “Is there anything I can do to help you access the resources that usually helps you?”, “Are you worried about any conflicts between your beliefs and your medical situation/care/decisions?”)

Steinhauser and colleagues found that the concept of the end-of-life patient’s sense of being at peace may be a point with which to initiate a conversation about the emotional and spiritual concerns in a non-threatening and non-sectarian manner⁴⁰. They recommend that following the question of “Are you at peace?” the physician then explores the other dimensions of sufferings as directed by the patients’ responses.

MANAGING SPIRITUAL DISTRESS

A properly taken spiritual history that adequately respects the patient as a person can in itself be therapeutic¹². In the medical setting, specific interventions for patients should include the medical relief of distressing symptoms. A simple approach by Storey and Knight to alleviate spiritual distress for terminally ill patients may be remembered by the acronym LETGO – which represents Listening to the patient’s story; Encouraging the search for meaning; Telling of your concern and acknowledging the pain of the loss, Generating hope whenever possible, and Owning your limitations, gaining competence and referring when appropriate⁴¹.

Lo and colleagues pointed out some pitfalls that may occur when engaging patients in spiritual discussions⁴². The first is to try to solve the patient’s problems or resolve unanswerable questions. Spiritual suffering is unlikely to be amenable to the “fixing” approach that many physicians employ for acute reversible conditions. Moreover, many patients, as mentioned earlier, sought more for the understanding of the physician rather than expecting him/her to solve their problems. Patients are generally comforted when another person can share their distress and be with them

Secondly, the physician may overstep his expertise and role, by expounding or imposing their beliefs. The roles of spiritual counsellor and physician should be kept separate for ethical reasons mentioned earlier.

Finally, the physician’s urge to relieve suffering may result in the provision of premature reassurance. It is important to allow the patient to tell their story and to share their pain. Premature reassurance would have terminated this process, as well as the subsequent processes that help the patients to cope by finding new meaning to their experience.

In the clinic setting, the appropriateness of any spiritual discussion or intervention may be determined by a combination of ethical, practical, and interpersonal factors. Lawrence and Smith describes a set of principles that guide the physician to decide on the appropriateness of addressing spiritual issues in the clinical setting, based on the Evidence-Belief-Quality Care-Time (EBQT) paradigm⁴³. In this set of guidelines, the physician determines the usefulness of an action during the patient-physician encounter as follows:

1. E: Is there sufficient evidence of good quality to recommend this spiritual adjunct to therapy for this patient?
2. B: Does sufficient congruence exist between the patient’s belief, the physician belief and the relevance of therapy?
3. Q: Will this recommendation improve the quality of care for this patient?
4. T: Can this recommendation be made and implemented within the time constraints of the clinical encounter, respecting the time committed to other patients?

If the physician can answer affirmatively to all the questions, then the action is likely to be justified. However, when none or only one of the principles is upheld, then it is likely that the action may be inappropriate, unlikely to be useful or possibly unethical.

CONCLUSIONS

There is a growing body of evidence to suggest the importance of spirituality as an independent factor in the health of patients. But challenges remain in the understanding of spirituality, the available evidence on the topic, the ethical issues as well the clinical practice issues. Nevertheless, tested principles such as evidence-based approach, patient-centeredness, and awareness of personal and practice limitations continue to be useful in guiding physicians to help patients with spiritual issues.

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