The role of spirituality in palliative care

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Introduction

Patients diagnosed with a terminal illness suffer beyond their physical symptoms; they also face a huge psychological burden as they try to find meaning and purpose amidst their suffering. The role of spirituality as a way for patients to find meaning in life, reduce suffering and improve wellbeing in the context of palliative care will be the focus of this article. The benefits and limitations of incorporating spirituality into palliative care and examples of spiritual interventions will also be discussed.

Palliative care aims to ease suffering and improve the quality of life of patients and their families who are facing a life-limiting illness, terminal illness or are at the end-stage of life.[1] Western medical systems typically adopt a biomedical model of care that focuses on cure and physical wellbeing. However, this model is inappropriate in the context of palliative care, as cure is no longer an option.[2] Therefore, it is important to consider dimensions of care that go beyond physical healing.

Spirituality is a broad term that has no universally accepted definition. Spirituality could be expressed in religious terms through a relationship with a god or other higher power. It could also be expressed non-religiously through beliefs and values, relationships, nature, art or music. Religion has a more specific definition that relates to a prescribed set of beliefs, values and moral codes that are observed by a community in the worship of a higher power. Spirituality can encompass religion, but it does not have to; people can be spiritual without being religious.[1,4]

The benefits of providing spiritual care

Patients with advanced illness suffer multi-dimensionally. This suffering extends beyond the physical symptoms of their relevant pathology, highlighting the downfalls of an approach that just focuses on alleviating physical distress.[5] Patients express feeling fearful, hopeless, angry, depressed and burdensome. A spiritual crisis around the end of life takes the form of someone losing the will to live, despair, demoralisation and a heightened desire for death.[3] Spiritual pain may also manifest itself physically and emotionally as seen in the diagram below (Fig1).[6]

Figure 1 The consequences of unmet spiritual need.

There is evidence that palliative care patients would like health professionals to attend to their spiritual needs. Grant and colleagues found that 87.4% of their 31 study subjects perceived themselves as being spiritual, while Post and colleagues found that across four American studies 40-94% of patients were interested in care catering to their spiritual needs.[6,7] Therefore, unmet spiritual needs can have an immense negative impact on a person's wellbeing during the end-stages of life.[6] In the context of medical care, hope usually rests in the potential for a cure and restoration of health. When the transition to palliative care occurs, a new definition of hope is needed. It takes on a new dimension that relates to finding meaning in life, maintaining quality of life in the time that is left, and dying with dignity.[8]

Including spirituality in palliative care is mandated by international policies and guidelines. For example, the 'Hospice New Zealand Standards for Palliative Care' requires spirituality to be incorporated into palliative care.[9] Spiritual care is defined as assisting people to connect or reconnect to practices, things and ideas that are at the core of their being and gives them meaning in life. It is about health professionals meeting a patient at a level of spirituality they are comfortable with and implementing care that suits the unique spiritual needs of the patient. It also relates to health professionals making a human connection with patients and their families through the expression of warmth, compassion and empathy.[10]

There are numerous benefits of providing spiritual care. Individuals who reported high levels of spiritual wellbeing were found to have some protection against spiritual distress.[3] Attending to spiritual needs allows people to find meaning in life and inner peace. It can also provide a form of physical relaxation, a sense of connection with others, and self-awareness. Spirituality can act as an outlet for patients to focus on things that give them meaning and peace rather than dwelling on their impending death. Spirituality provides familiarity to patients in an often unfamiliar environment. By focusing on this, patients can regain a sense of control of their life, which has been found to dramatically increase wellbeing.[3,10] A poignant quote by Viktor Frankl, "man is not destroyed by suffering: he is destroyed by suffering without meaning" shows the importance of spiritual care in providing meaning to those who are suffering.[2]

A study conducted by Greeley found that 81% of American physicians agreed that spirituality could directly affect clinical outcomes and 91% agreed on the importance of doctors understanding the spiritual beliefs of their patients.[11] Spirituality has also been shown to be an effective coping mechanism. In a study of 108 women with gynaecological cancer 93% reported using spiritual beliefs to cope with their diagnosis.[2] These aforementioned benefits justify the importance of incorporating spirituality into palliative care, as spirituality is a key component of wellbeing in many patients.

Assessing spiritual needs

As the benefits of spirituality have been ascertained it brings into question how do health professionals assess spiritual need? Spirituality is something that is unique and personal. Therefore spiritual care must be individualised – a one method suits all approach is inappropriate.[6] Patients often report difficulty when expressing spiritual needs. In Western countries there has been a loss of spiritual language and understanding the spiritual dimensions of life. This, coupled with the tension of traversing between medical and spiritual paradigms, has created uncertainty as to the best methods of assessing spiritual needs.[6] Patients often feel vulnerable when expressing their spiritual needs and may report feeling a sense of healing and positivity when their spiritual needs have been heard.[6] Conversely, patients report feeling hopeless, empty and rejected when their spiritual needs have not been addressed.[6] Therefore, an assessment method is needed to ascertain where a patient fits on the spirituality continuum and the level and type of spiritual care a patient desires, as the answer to this question will inevitably be different for every patient.[6,3]

Assessing spiritual need must be done carefully to prevent offending patients and it is important to consider professional boundaries. Whilst health professionals should attend to the spiritual needs of patients, spirituality is only one dimension of care. Extensive spiritual counselling should be carried out by spiritual leaders or chaplains, as most health professionals have inadequate training in this area and also need to focus on other dimensions of care within time constraints. Moreover, health professionals imposing spirituality on patients or undermining their beliefs is unacceptable as this blurs the patient-professional boundary and patients may feel they have to adopt these values out of fear of disagreeing with health professionals.[2]

In order to assess spiritual need in the context of a functioning and practical patient-professional relationship the assessment tool "FICA" should be used (Box 1).[12] FICA provides a comprehensive framework for assessing spiritual needs in a format that patients and health professionals find comfortable, easily understandable and accessible. This tool should be administered both during the initial palliative care assessment and when appropriate, as spiritual needs may change. There are many benefits of obtaining a spiritual history through the use of a tool such as FICA. Obtaining a spiritual history opens the door for discussions around beliefs and values, provides an opportunity to discover patient coping mechanisms, allows patients to discuss what gives them meaning in life and how this can be incorporated into care plans.[2,3] The benefit of the FICA tool is that it is cross-culturally acceptable as the questions are open and the principles are general. This increases the usability of this questionnaire in a multi-cultural context such as New Zealand.[12]

Box 1 FICA Spiritual History Tool[12]

F (Faith and Beliefs): What provides you with meaning in life? Do you have spiritual beliefs that help you cope with stressors?

I (Importance and Influences): Do you feel spirituality is an important aspect of your life? Does spirituality influence your healthcare decisions?

C (Community): Are youpart of a spiritual or religious community?

A (Address and Action): How the healthcare professional can intervene to meet patients spiritual needs. For examples, referring to a chaplain or providing patients with spiritual resources.

Incorporating spirituality

After reviewing the literature on the benefits of spirituality and the use of the FICA tool, the question is raised about how best to incorporate spiritual care. There is no one answer to this question but an attempt will be made to provide a few examples. The literature highlights that before offering spiritual care it is important to consult with the patient if this care is in-line with what he or she desires. Spiritual care is not about resolving distress with medication; it is about allowing people to find healing within themselves.[13] Health professionals should always display empathy, warmth and compassion when interacting with a patient and their family. While these values are not inherently 'spiritual' they are a necessary prerequisite for the provision of spiritual care. The display of these values enhances rapport and communication between health professionals and the patient, thereby ensuring spiritual interventions are implemented in an appropriate manner in line with patient's desires.[13,3]

For patients that identify having a religious dimension to their spirituality it is important to cater to their religious beliefs. Patients should have access to religious leaders and members of their religious community, the ability to perform religious rituals, and access to religious texts.[4] As previously noted, not all patients that identify as spiritual identify themselves as religious, therefore non-religious spiritual care should also be offered.

Mindfulness interventions such as meditation, yoga and massage are some non-religious spiritual interventions that direct patients to focus on the present moment. These interventions improve wellbeing and reduce suffering by allowing patients to clear and rejuvenate their mind as they are not dwelling on stressful thoughts when engaging in these exercises.[14,15] Spiritual support groups where patients can network and build relationships also have the potential to improve wellbeing as people can share their experiences and avoid social isolation.[14]

Research literature also suggests that music, art and expressive writing may alleviate distress and improve patient wellbeing. These can be classed as spiritual interventions if they give patients a sense of enjoyment, comfort and meaning. Creative interventions have inherent soothing properties as they are familiar to the patient and allow a redirection of focus.[16,17] Music has been shown to calm neural pathways in the brain, which reduces anxiety. Investigating the benefits of music therapy in cancer patients found music increased patient wellbeing, increased a sense of control, promoted wellbeing, reduced pain, improved psychological and physical functioning, and improved immunity.[16] Art has similar benefits. Art

helps people express their feelings, while providing a tangible legacy and redirecting focus. Art therapy enhances quality of life by giving patients a challenge and a sense of achievement. Allowing the expression of feelings in a symbolic manner is important as some patients either may not be able to or are not comfortable expressing their suffering in words.[16] Expressive writing can improve control over pain and improve mood; it also provides an opportunity for self-reflection and the experience of writing is therapeutic for many patients.[16]

Garland and colleagues conducted a study that compared two groups of cancer patients. One group was assigned to mindfulness interventions (meditation, massage and yoga) while the other group was assigned to creative interventions (arts, music and expressive writing).[15] Participants in both groups showed improvements in wellbeing. However participants in the mindfulness group showed greater improvements in spiritual wellbeing and a greater reduction in anxiety, anger and overall stress symptoms when compared to participants involved in creative interventions.[15] The results of the study by Garland and colleagues provides evidence of the efficacy of both of these interventions, however it highlights the additional benefits of incorporating mindful interventions – indicating these interventions should be prioritised and supplemented with other types of spiritual intervention when appropriate.[15]

A novel form of spiritual intervention is dignity therapy. Patients are asked about their personal history, what they find meaningful in life and what they were most proud of. These sessions are recorded, transcribed and edited, which ultimately allows the patient to have a tangible legacy they can leave behind.[3] Chochinov and colleagues conducted a study of 100 terminally ill patients, reviewing dignity therapy. Ninety-one percent of respondents were satisfied with dignity therapy, 81% reported it had helped their family, 68% found a heightened sense of purpose and 47% of patients reported increasing their will to live.[3] This is an example of a simple intervention that can ease patient distress and improve quality of life.

Is it realistic to provide spiritual care?

After reviewing the literature on this topic, spiritual care has the potential to improve patient wellbeing and reduce suffering. However, a number of questions are raised about the feasibility and appropriateness of providing spiritual care. Currently, many health professionals do not feel equipped to provide spiritual care. Therefore, many health professionals avoid approaching the topic of spirituality out of fear of misunderstanding and causing offense. Care must also be individualised due to the diversity of spiritual need.[6] Health professionals are already under increasing pressure and time constraints, therefore asking health professionals to provide spiritual care has the potential to become an additional burden.[18] If health professionals are expected to provide spiritual care they will need to be adequately trained in this field. Providing training puts pressure on already time-constrained health professionals as well as scarce financial resources.[1]

The appropriateness of offering spiritual care is also brought into question. Some patients may not want spirituality incorporated into their care plan. Spirituality is not an easy concept to define and some patients may find the concept of spirituality confusing.[6] Spirituality may cause an additional layer of distress for patients if they believe their illness is a punishment from a higher power. Spiritual beliefs may also be questioned during times of terminal illness, as patients question why they got their illness and what now gives them meaning. This highlights the importance of taking a detailed spiritual history and gaining an understanding of a patient's spiritual beliefs from their perspective, rather than making assumptions. [14,18]

Limitations of current research and recommendations for future research

Research in the area of spirituality and its role in palliative care is increasing as the move is made towards a more holistic paradigm of care. However, several limitations exist in the current research. As spirituality is such a broad concept it makes it difficult to untangle which domains of spirituality are having the greatest impact on patient wellbeing. It is also difficult to measure constructs such as spirituality, spiritual care, hope, meaning and wellbeing as the definition of these terms invariably differs. A lack of robust outcome measures has proved a barrier to scientific evaluation of interventions and programs.[3,18] Researching patients in palliative care has some additional challenges as patients and their families are already suffering with life-limiting illnesses, and asking patients to participate in research may be an unwelcome burden at an already stressful time.[3]

There are also several gaps in the literature that could be filled by future research. More research is needed around the practicalities of implementing these inventions. Much of the research that has been reviewed has been conducted on patients in a hospital or hospice setting, while many palliative patients remain at home.[3] Future research could focus on increasing the availability of these interventions to patients who remain at home through community-based interventions. There is also a lack of research on how spiritual needs differ among individuals of different, ages, cultures and genders. This is likely to have important implications for the provision of appropriate care. Future research should also have a multi-disciplinary focus that includes expertise across a range of fields and contexts, rather than the current paradigm where disciplines generally work in isolation. It would also be valuable to have more research in the New Zealand context as spiritual issues are culturally bound. It would be particularly helpful to have access to further literature that relates to the spiritual needs of Māori. Longitudinal studies are also needed to determine how spiritual needs change over time - however in a palliative context this may not always be feasible.[3]

Conclusion

In the context of palliative care cure is no longer an option. Therefore care must focus on more than physical wellbeing, as a terminal diagnosis has a profound impact on psychological wellbeing. This article has outlined the role of spirituality as a way to improve patients' wellbeing, reduce patients' suffering and provide patients with meaning. A lack of feasibility and the potential inappropriateness of incorporating spirituality have also been addressed, which raises the question about whether spirituality should be incorporated into palliative care.

Despite the limitations it is essential to incorporate spirituality into palliative care when appropriate. If spiritual care is not provided, health professionals may undermine patients' wellbeing, as spirituality is a large component of many patients' lives. Spirituality is especially pertinent for many individuals with terminal illnesses, as it provides patients with purpose and a source of hope. Of course, some patients may not want spiritual care, and health professionals must take this into consideration. The use of the FICA tool allows assessment of spiritual needs. This assessment is crucial as it gives patients the opportunity to express whether or not they want spiritual care and allows the development of personalised spiritual care plans. It is essential that patients guide their spiritual care journey in collaboration with health professionals. Health professionals should always show warmth, empathy and understanding when interacting with patients. The use of mindfulness, religious and creative interventions have also shown promise as feasible and beneficial spiritual interventions. Overall, research has shown the huge potential of spirituality to enhance patient wellbeing, reduce suffering and provide patients with meaning. Therefore, spirituality should be incorporated into palliative care when appropriate.

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