

# An Occupational Therapist's Contribution to Spiritual Care within a Palliative Care Setting: a student OT's perspective.

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## Abstract

*Occupational therapy (OT) is a health profession concerned with promoting health and quality of life through occupation. With the core attention to spirituality and quality of life, the holistic and client-centred practice makes the OT a "natural fit" with the philosophy and approach of palliative care (PC). This paper aims to explore: (1) The role of an OT in PC and how the paradigm shift has steered the focus of the OT's interventions towards provision of spiritual care, (2) The definition of spirituality and spiritual care from an OT's perspective, (3) How the 'core' of OT intervention can implicitly yet unequivocally address the spiritual needs of palliative patients and lastly (4) the OT's contribution to the multidisciplinary PC team. The discussion in this writing explicitly brought to light how spirituality and spiritual care is embedded in the everyday practice of an OT. Attempts have also been made to relate the use of 'spiritual occupation' as a grounding characteristic of OT's to contribute to and complement the working of a PC team (including social workers, nurses and chaplains), hence making OT a value-adding profession in a PC setting.*

**Key Words:** Occupational Therapy, Spirituality, Spiritual Care, Spiritual Occupation

## Introduction

According to the World Health Organisation (WHO, 2007) palliative care is defined as, '... the active total care, by a multi-professional team, of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families' (p1).

Most of the models of comprehensive palliation stressed that spirituality and the provision of spiritual care as being imperative when caring for patients (Purdy, 2002; Rumbold, 2003). According to Aranda (1998), the essential principles of palliative care (PC) include: (1) The emphasis on living and death as an inherent constituent of life; (2) Client and family centeredness in practice; (3) utilization of a multidisciplinary team in recognition of the needs of the patient and provision of holistic care; and (4) provision of comfort care through the relieving of symptoms.

Occupational therapy (OT) is a health profession concerned with promoting health and quality of life through occupation. The primary goal of OT is to enable people to choose, control and participate in the activities of everyday life. Occupational Therapists (OT's) work collaboratively with people who experience challenges or obstacles to participation and (with other healthcare professions) help people to return to their rhythm of life (WFOT, 2004). The Canadian Association of Occupational Therapists (CAOT, 2002) emphasises that all humans are occupational and spiritual beings hence claiming the significance of occupation and spirituality as constructs to meaningful living.

With a core focus on spirituality and quality of life, a holistic and client-centred practice of OT implied that the fundamental values of the profession is of a “natural fit” with the philosophy and approach of palliative care (Trump, 2001). Though the role of OT’s as rehabilitation professionals in PC setting had been cited in many articles, there are few mentioning the explicit role of OT in addressing spirituality (Kang, 2003). For a young therapist such as myself, the idea of spiritual care provision has always been daunting. Coupled with a general lack of literature and no detailed role-description that addressed a patient’s spirituality, working as an OT in a PC setting posed great challenges to me. Hence, this paper aims to examine:

- (1) The role of an OT in PC and how the paradigm shift has steered the focus of the OT’s interventions towards provision of spiritual care.
- (2) The definition of spirituality and spiritual care from an OT’s perspective.
- (3) How the ‘core’ of OT intervention can implicitly and unequivocally address the spiritual needs of palliative patients.
- (4) Explore the OT’s contribution to the multidisciplinary PC team.

## **Role of Occupational Therapist in Palliative Care: A paradigm shift**

The importance of including OT’s in PC has been promoted since the early 1980s (Picard & Magno, 1982; Pizzi, 1983; Pizzi, 1984; Lloyd, 1989). During this time, the OT’s intervention in PC revolved around the fundamentals of comfort care provision. Though the use of humanistic framework was emphasized (Pizzi, 1984), the interventions were mainly biomedical and biosocial in nature (Picard & Magno, 1982; Pizzi 1984). The role of OT’s in palliative care then, were largely focused on helping patients to participate in various occupations, promoting skills acquisition, maintaining independence and the provision of physical comfort (Picard & Magno, 1982; Tigges & Sherman, 1983; Pizzi, 1984; Lloyd, 1989). In summary, the focus of care for palliative patients during that period focused on the notion of ‘doing’ rather than being.

However, as the profession entered the postmodern era, the concept of spirituality was increasingly recognised as a domain of an OT’s practice (CAOT 1991, c.i. Egan & DeLaat, 1994). Describing the notion of spirituality in the practice of an OT in a palliative care setting, Rahman (2000) found that OT’s had started to adopt a holistic approach in hospice settings, focusing not only on the physical, emotional and social needs of the patients but also the spiritual aspect of care. The role of an OT in a palliative care setting appeared to shift to include a more intangible dimension which included assisting the patient to find meaning in or of life, to help them to cope with losses, achieving closure in life, giving a sense of presence and providing them with a sense of control (Rahman, 2000). The focus of OT intervention has since shifted from the notion of ‘doing’ to concept of ‘being’ or a holistic approach to life.

## **Defining Spirituality**

Though spirituality was mentioned to be a discourse in both OT and PC, differences are noted in the way spirituality is defined. Spirituality in occupational therapy is secular in nature. In a thematic review of OT definitions of spirituality by Unruh, Versnel and Kerr

(2002), it was revealed that the common themes that surfaced from OT literature were: 'meaning and purpose in life, the life force or integrating aspect of the person, and transcendence or connectedness unrelated to a belief in higher being' (p10). On the other hand, the definition of spirituality in the context of PC includes both secular and sacred aspects and the notion of religiosity is evidently discussed in PC literature (Sinclair, Pereira & Raffin 2006).

Hence, coming from an OT's perspective, the working definition of spirituality for this writing will be secular, stating that: 'Spirituality is the "essence of self"' (CAOT 2002, p.42), it is something that people attempt to express in all their doing (Egan & DeLaat 1997). It provides a person with meaning in life and guides a person through his/her life's events, and choices (Zimmerman 1990). It can also be seen as the relationship and connectedness of a person with oneself, with others, with places and objects and transcendence (Lartey, 1997).

## **Occupational Therapist's perspective of spiritual care**

With reference to the above stated definition, to care for a person as a spiritual being, their intrinsic values have to be recognised, their beliefs need to be respected and their relationship needs to be esteemed. According to Cobb (1998), 'spiritual care is not an activity to be completed, nor is it simply an answer to be found' (p. 110). Rather, it is a process of communication and mutual exploration of the caregiver and the care recipient. Swinton (2001, c.i. Hoyland & Mayers, 2005), mentioned the entrance into the experience of a person and being connected and attuned with his/her being, thinking and doing is the very fabric of spiritual care. In spiritual care, the OT journeys with the care recipient and provides support as they work through re-establishing or strengthening their values and beliefs as well as their sense of connection in their relationships necessary to resolve their spiritual needs.

Despite it being unanimous across OT literature, that spirituality is an important domain of the profession (Egan & Delaat, 1994; Egan & Delaat, 1997; Kang, 2003), it was noted that there has been little attempt made by OT's in everyday practice to *overtly* address spirituality as part of their intervention (Johnston & Mayers, 2005). Though spirituality is implicitly present in the daily practice of OT's, it generally lacked acknowledgement as it was not framed into terms established in the discourse of spirituality (Egan & DeLaat 1997). This may be so, particularly in a palliative setting, as it could be argued that the needs of patients are largely spiritual in nature. Hence, the OT's' intervention in this setting already postulated to encompass elements of spirituality.

## **Implicit spiritual care in the Occupational Therapy practice**

According to CAOT (2002), the primary goal of an OT is that of enabling occupation. Occupational activities are defined as activities which are meaningful to the person. Occupation is often used as a *means* of treatment to facilitate the achievement of functionality and well-being. All meaningful and purposeful occupations have the potential to have an impact on the spiritual needs of patients (Johnston & Mayers, 2005). With this in mind, I examined the everyday OT interventions in PC setting and attempted to associate the inherent therapeutic values with spirituality and the provision of spiritual care.

### ***Maximising occupational role performance***

In the contemplation of death, terminally ill patients experience various losses. Not only will they lose their physical body and the opportunities to have experiences, but before that, the loss of social relationships and occupational roles (Lloyd, 1989). Maximising the patient's

occupational role performance can assist the patients to cope with the impending losses by restoring a sense of control in their lives and, subsequently, adaptation to their roles and identity. OT supports the patient in their changing life roles by taking into account the value and importance of one's previous roles. Relevant role-performance components are usually incorporated with the activity of daily living of patients, or in some cases through the use of creative activities. With all this re-establishment, it is hoped that patients will be able to reconnect themselves with the people, events and objects which they valued in their pre-morbid days. When this is achieved, it is also hoped that the spirituality of patients will be positively impacted (Rahman, 2000).

### ***Activity adaptation and environmental modification***

Often, the physical decline of palliative patients serves as the main barrier for active participation in a therapy session. Equipped with the skill of activity analysis and environmental modification, an OT is capable of grading the task and environmental demands of a particular activity to fit the functioning level of the patient. By doing so, an OT empowers the patient with limited abilities to be able to engage in their self-defined meaningful and valuable occupation. This is especially important for palliative patients as this empowerment brings about a sense of mastery and control as well as a sense of dignity in the midst of their physical frailty. According to Sinclair et al (2006), the sense of control and dignity are important constituents of the spirituality of the dying.

### ***Reminiscence and narrative therapy***

It is imperative to note as the patient's physical resources are limited, meaningful activities can be in the form of conversation (Kissane et al 2001, c.i. Boog, 2008). Sometimes, listening to their life stories and their conviction about things that are of value can be meaningful enough to patients (Boog, 2008). OT provides this in the form of reminiscence and narrative therapy. The therapeutic effect of this narration includes the ability to encourage the patients to actively reflect and make sense of their life situation, identify any potentials conflicts and subsequently to achieve reconciliation in these issues. According to Rahman (2000), doing a life review is a good way of helping the patient to find closure in life. The search for a closure is spiritual in nature and it is imperative for patients facing impending death. Through this process, the patients sought to reintegrate their life events, esteem their personal beliefs and values, and to actively disengage from one's life's role (Rahman, 2000).

### ***Caregiver (family/friends) training***

In a PC setting, the patient and family are sometimes seen as one entity (Aranda, 1998). This implies that caring for the caregiver is as important as caring for the patient (Lloyd, 1989). An OT often addresses the needs of the family through the provision of caregiver training. From which, Opts impart skills to the caregiver to cope with the general decline of the patient. Also, the OT can indicate ways in which the family can participate in meaningful activities *with* the patient (Lloyd, 1989). This empowerment is more often perceived as a relief for the caregiver as they are generally bewildered and lost about what to do with the patient. The caregiver will experience a sense of purpose in the process of care of the patient and will enrich and provide meaning for their visit to the patients. For palliative patients, their family remains a significant figure in their moments of impending death. By involving the family in their care regime, the patients will experience a sense of connectedness in their social relationship and a strengthened sense of belonging (Lloyd, 1989). Hence, this reciprocity of care, with its inherent value and meaning, will have an impact on the spiritual realm of both the patients and caregiver directly.

### ***Group therapy***

Group work is often employed in the OT practice. Though the benefits of group work have been well established among Opts, its relation to addressing spirituality had yet to be well documented. Finlay (1994) reasoned that group therapy is especially useful for patients experiencing losses and social isolation, rendering its use appropriate in a PC setting. Some of the cited benefits for group work are spiritual in nature, which include the ability to meet the patients' need for intimacy, esteem, sense of belonging, affirmation of values, and emotional catharsis (Cole, 1993).

### ***Passive activities***

In extreme cases, when the patient is unable to actively participate in any form of activities, they should be allowed times of passivity and inactivity, as passive participation can be successful in maintaining meaning in a person's life (Boog, 2008, p 13). In this case the focus of an OT intervention will be shifted from "doing" to "being" tasks. The meaningful occupation can simply be having the presence of someone (Rahman, 2000).

This is often provided by an OT through therapeutic, pain-relieving massage or through participating in meaningful activities *for* the patient (i.e., the patient is a passive observer in the process) (Boog, 2008). Human touch and presence may in some way restore the human-centred subjectivity and dignity as well as providing a sense of value and respect. (MacLeod, 2000; Watson, 1989). Touch and presence both provide a humanistic acknowledgement of the patient and is in line with the notion of non-abandonment which is the spiritual foundation of the hospice movement (Saunders, 1978).

### ***Therapeutic use of self***

Therapeutic use of self is integral for all practising OT's (Kielhofner, 2008). Within OT literature, the most commonly cited characteristic of therapeutic use of self are: listening, openness, meeting patients at their level, validating their experiences and being *with* the patient (Kielhofner, 2008). Many similarities can be drawn from these characteristics to that of spiritual care. Echoing the definition of spiritual care by Cobb (1989), the therapeutic use of self is an ongoing process rather than an activity to be completed. It requires the OT to be attuned to the patient and the relationship to be highly dynamic and interactive and mutually benefiting (Rahman, 2000). When coupled with the use of meaningful occupation, it is evident that spiritual care is within the domain of OT.

## **Contributions of Occupational Therapists in palliative care setting**

In palliative care, the multidisciplinary concept has largely been adopted (Aranda, 1998). Due to the complexity of the spiritual needs which arise from palliative patients, no single discipline can completely address all aspects of these needs. Instead, professionals have to play complementary roles to ensure that spiritual care can be holistically and therapeutically presented.

As noted earlier, the everyday interventions of OT's which can be meaningful and purposeful to clients, contain elements of spirituality and spiritual care and thus render OT as a value-adding profession in helping to provide spiritual care in a PC team. According to Wilding et al (2005), occupations which are fundamentally meaningful, evoke deep feelings, cohere to values and are important socially, individually and maybe labelled as a spiritual activity or 'spiritual occupation'.

To me, 'spiritual occupation' is an overt manifestation of a person's spirituality emanating through their occupation/s and it serves as an avenue for others to understand or appreciate

a person's spiritual realm. Also, spiritual occupation can be a tool to facilitate one's reconstruction of identity and reconciliation with their spiritual self. Hence Opts, by recognising a person's valued elements of spirituality via their occupation – or what might be called recognising a person's 'spiritual occupational life elements' (S.O.L.E.)<sup>1</sup> – can enable an OT to undertake a form of spiritual assessment to explore and understand a person's spirituality. This also implies that other professions can collaborate with Opts to use the concept of 'spiritual occupation' as a medium to address spirituality or to ride on the relevance of the information obtained to plan and structure specific interventions.

Though the members in a PC team have their own roles and expertise, the need to provide high quality care is a common goal. Spiritual care is a personal journey that the caregiver can embark on with the patient. To provide spiritual care, however, one must be attuned to his/her own spiritual state and be aware of their own personal limitations on how far they can go physically, emotionally and spiritually in helping a patient. It is also worth noting that the ability to provide spiritual care to every patient is not an obligation of all members in the PC team (Walter 2002), rather OT's should draw on the strengths of the different team members to complete this journey with the patient.

## Conclusion

Due to the common emphasis placed on spirituality, quality of life, holistic care and client-centred practice, an OT's place in PC is viewed as a "natural fit". Though it was noted that OT's made few attempts to overtly address spirituality in their daily practice, the discussion in this paper explicitly attempted to bring to light how spirituality and spiritual care is embedded in the everyday practice of an OT. In a PC setting, OT's often uses occupations as form of therapeutic medium in their intervention i.e. utilising it as a means rather than an end. Attempts have also been made to relate the use of 'spiritual occupation' as a grounding characteristic of OT's to the ability to contribute to and complement the working of a PC team, hence attesting to its value in a PC setting.

I feel that knowing the connections between the inherent value of OT interventions and spiritual care can allow me to be aware and subsequently be more sensitive to a person's spiritual occupational life elements that can be used in maximising the therapeutic value of the different treatment approaches in addressing spirituality. However, as a newly practicing OT and a novice in PC, I feel that having a clear structure and a practice guideline is paramount in the provision of quality intervention, especially in a subjective area like spiritual care. Hence, I look forward to the development of a practice framework which provides guidance to OT's in addressing a person's spirituality or the provision of spiritual care. Also, explicit education and training in spirituality at university can serve to equip OT's with the skills to attend to this particular area of care.

Lastly, I believe that the ability to provide spiritual care is developed through experience, guided by a personal practice philosophy and enriched through personal reflection. This challenged me with the personal conviction that before embarking on my journey to becoming an OT providing PC, I need to be reflective and sensitive to my own spiritual self. Hopefully, as experience sets in, I will be more competent in integrating all these skills to

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<sup>1</sup> Spiritual Occupational Life Elements (SOLE): Those secular or penultimate elements in everyday occupational life that help to provide value, meaningfulness, feeling, motivation and sense of ultimate purpose for actively living.

provide a more holistic spiritual care which is grounded within the professional philosophy of occupational therapy.

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