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## The Care for the Dying: A critical historical analysis of occupational therapy in hospice.

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## The Care for the Dying: A critical historical analysis of occupational therapy in hospice.

### Abstract

This paper presents an historical analysis of occupational therapy's role in hospice care with relation to past and current hospice practices, as well as cultural forces that impact that role. Since the beginning of the movement, hospice has developed into a strong component of end-of-life care, and occupational therapy practice models and interventions are unique in addressing the occupational needs of clients during this stage of life. Despite compelling evidence of the positive impact of employing occupational therapists, there continue to be significant barriers to implementation of services. The author proposes that the concept of occupation, as experienced at the end-of-life stage, needs to be more clearly defined and occupational therapy's role broadened in order to strengthen the profession's presence in the hospice setting.

### Keywords

hospice, occupational therapy, palliative care, history

### Cover Page Footnote

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### Credentials Display and Country

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The present discourse examines the cultural forces behind the implementation of occupational therapy services in hospice care. In order to engage in this discourse effectively, it is essential to establish the vocabulary that underlies the concepts being discussed. The word hospice can be traced back to medieval times, and refers to “the wayside inns for pilgrims and other travelers, particularly at those places of greatest vulnerability and hardship” (Davidson, 1978, p. v). In today’s common usage, hospice signifies a care concept that is aimed at reducing discomfort associated with terminal illness, for the patient as well as the caregivers (Siebold, 1992). Focused not only on physical discomfort, hospice care encompasses the emotional and spiritual health of the patient (Siebold, 1992). The environments for hospice care are diverse, varying from inpatient hospital settings to clients’ homes and freestanding hospice agencies.

The term palliative care is frequently used when referring to the care provided in the hospice setting. As Cooper (2006) points out, “palliation refers to the alleviation of symptoms rather than the attempt to cure a disease, and it is associated with the advanced stages of all diseases” (p. 2). Palliative care can be distinguished from hospice care by the fact that “it can be initiated at any point in the course of the client’s illness” (American Occupational Therapy Association [AOTA], 2011, S67). Hospice care is reserved for the last stages of a person’s life. Another term that is predominant in the literature with regard to hospice care is end-of-life care. According to Hammill, Bye, and Cook (2014), this term can be understood as “a continuum of palliative care and is usually used to describe the

care that is offered during the period when death is imminent” (p. 582). This paper will use palliative care and end-of-life care as part of the scope of hospice services.

The philosophy of hospice care encompasses a positive approach to the role of death and dying as a part of the occupation of life. This perspective resonates with occupational therapy’s foundational values that seek to recognize the whole scope of human activity and experience. According to Koff (1980), “hospice exists neither to hasten nor to postpone death. Rather Hospice exists to affirm ‘life’—by providing support and care for those in the last phases of incurable disease so that they can live as fully and comfortably as possible” (p. 14-15). This historical inquiry paper will examine the development of occupational therapy’s role in hospice care and the cultural forces that continue to keep occupational therapy at the margins of this practice area.

### **Development of Occupational Therapy in Hospice Care**

Only a limited portion of the occupational therapy literature explores the historical development of the occupational therapist’s role in palliative or end-of-life care. Instead, the focus has been on establishing and justifying the role of occupational therapy in this particular setting. Frost (2001) referred to the fact that she was unable to find hospice providers who specifically mentioned occupational therapists as members of the care team. However, this research inquiry did not include occupational therapists who work indirectly in hospice settings, providing rehabilitative or consultative services to the terminally ill as part of a

home-health agency or in a hospital. One potential reason for the limited scope of occupational therapy in hospice care is that the parameters for such a role have never been clearly laid out. Holland and Tigges (1981) asserted that because “occupational therapy education and practice focuses on rehabilitation and re-entry into society. . . . ‘Our’ model of practice has traditionally been inconsistent, inadequate, and poorly defined” (p. 373) regarding hospice care. Dawson (1993) conducted the first study investigating the role of occupational therapy in the care of terminally ill patients.

It was not until 1986 that AOTA’s Representative Assembly endorsed a position paper on occupational therapy’s role in hospice (AOTA, 1986). This paper affirmed “people can lead productive and meaningful lives despite a terminal illness and that occupational therapy provides an essential service in this process” (AOTA, 1986, p. 839). This statement resonates with Meyer’s (1977) philosophy that mastery and control over our environment, which enhances our quality of life, is achieved through “the actual doing, actual practice” (p. 641) of an occupation. Michael Pizzi (1984), a proponent of occupational therapists’ role in hospice settings, argued that despite terminal illness or declining health, patients in hospice care are able to achieve control over their environment and, therefore, increase his or her quality of life, making hospice an appropriate and important setting for occupational therapists.

## **The Impact of Culture and Theory on the Development of Practice Area**

### **The Contribution of Occupation to “Dying a Good Death”**

During the 1960s and 1970s, after focusing on establishing a role in the medical and scientific community based on the curative paradigm (Kielhofner, 2009), the field of occupational therapy was returning to its original emphasis on occupation. Mary Reilly, in her 1961 Eleanor Clarke Slagle Lecture, highlighted this shift when she suggested that occupational therapists can maintain their role in the medical community while reconnecting their work with the occupational roots of the field because “man, through the use of his hands as they are energized by mind and will, can influence the state of his own health” (Reilly, 2011, p. 69). Out of this broad dialogue among occupational therapy professionals came an understanding of the interconnectedness of occupation and a person’s capacity to enhance his or her own health. The definition of occupation is multifaceted, neither exclusively medical interventionist nor limited to occupation as an end in and of itself.

The Occupational Therapy Practice Framework 3rd edition (2014) referred to occupation as “central to a client’s (person’s, group’s, or population’s) identity and sense of competence and have particular meaning and value to that client” (p. S5). But, what is the nature of occupation when placed in the context of the dying patient? Jacques and Hasselkus (2004) stated that occupation at the end of life “seemed to be viewed as soul nourishing and meaningful” (p. 51). These

are not necessarily groundbreaking or newly discovered occupations, but rather the simple ones that maintain a sense of identity and autonomy. Research has demonstrated that end-of-life occupations are centered around the maintaining of and engaging in relationships, a sense of purpose through impact on the environment and active engagement in reflection on life (Jacques & Hasselkus, 2004; Park Lala & Kinsella, 2011).

Wilcock (1998) defined occupation as the active “synthesis of doing, being and becoming” (p. 249). Lyons, Orozovic, Davis, and Newman (2002) referred to the act of doing as “the active part of occupation that is most readily observable” (p. 286), the term being “as in ‘being within self’ whereby the doer experiences an enhanced sense of self manifested, perhaps, in a sense of inner peace or in self-discovery” (p. 286), and becoming as “the transformative element whereby the doer strives to develop, change, grow, and be better” (p. 286). Occupation, then, is the vessel by which an individual may actively engage themselves in the world in a way that is meaningful. Terminally ill patients are not frequently considered active occupational beings, but rather are represented as frail and passive (Lyons, Orozovic, Davis, & Newman, 2002). The ability to engage in meaningful occupations in “the face of imminent death – is an option that all people should be allowed to choose if they so desire” (Marcil, 2006, p. 27).

Researchers have been endeavoring to make the case for the importance of occupational engagement until the end of life (Jacques & Hasselkus, 2004; Keesing & Rosenwax, 2011).

Lyons et al. (2002) described the impact of occupational experiences on the well-being of terminally ill patients in a day hospice setting. Although results revealed that participants experienced a loss of occupation through illness, the researchers were able to conclude that terminally ill patients did engage in all three components provided in Wilcock’s definition of occupation. Jacques and Hasselkus (2004) proposed that near the later stages of illness, “occupation is the good death experience” (p. 52-53). They further noted that, “enabling occupation in an end-of-life care environment ... can help bring about a good death experience for all involved in the dying process” (p. 53).

### **Occupational Therapy Practice Models Contributing to “Dying a Good Death”**

Occupational therapists are concerned with establishing independence for their patients, often following a rehabilitation model of practice. Hospice care does not have rehabilitation of patients at the forefront of its mission. However, it is concerned with maintaining autonomy and independence in patient’s lives, despite limitations, and this is in perfect alignment with occupational therapy goals. Holland and Tigges (1981) proposed that, “the occupational role performance paradigm ... appears to be the most appropriate occupational therapy approach in terminal care” (p. 375-376). This paradigm focuses on the person’s need to restore role performance, which may involve the “reduction of biological, social and/or psychological factors; it may be maintenance, or the learning of adaptive (manipulative) coping behaviours” (p. 375). Because of the special nature of the hospice

setting, occupational therapy models of practice focusing on prolonged engagement in occupation are deemed impractical (Holland & Tigges, 1981). Short-term models, perhaps ones with a primary focus on the ‘being’ and ‘becoming’ portions of Wilcock’s definition of occupation, need to be developed and implemented for the promotion of role performance in hospice settings.

Occupational therapy practice models can be used not only to design appropriate interventions but also to provide a lens through which the occupational therapist perceives client interactions. The Model of Human Occupation (MOHO; Kielhofner, 2008) is suitable for application in palliative care. Occupation, as it is integrated into the MOHO model, refers to the interaction between a person and his or her act of engaging in an occupation. This engagement happens in a specific temporal, sociocultural, or physical context (Costa & Othero, 2012). This model of practice takes into consideration the ways in which terminal illness can deny clients an occupational identity while they are still occupational beings. Occupational therapy interventions may engage clients in tasks that bring attention to the clients’ self-perceptions at this stage of their lives. As a client’s sense of agency in his or her own life changes, adapting to shifting levels of personal causation and volition may impact experience of self. Costa and Othero (2012) stressed the meaning of volitional narratives because they “give sense to past experience of the dying person associating the events of life with the themes of personal causation, value, and interest” (p. 320). This narrative provides room in which the

terminally ill client has the ability to redefine life roles in his or her current occupational context.

### **The Power of Occupational Interventions – Beyond Occupational History**

Occupational therapists provide a variety of services in hospice settings. One that has become important is the use of an occupational history. As pointed out by Marcil (2006), “the occupational history helps the therapist to view the patient as a person first and a diagnosis second” (p. 28). Identified activities in the occupational history must be attainable in a short time frame. Tasks can be activities of daily living, such as dressing or toileting. Alternatively, tasks may also be activities that represent the patient’s role in his or her family unit and community, such as preparing meals, managing finances, or engaging in religious activities.

Lloyd (1989) makes the case for occupational therapists’ capacity to capitalize on occupational role performance in terminally ill patients. Interventions are not limited to self-care tasks but also include energy conservation counseling so that existing energy can be used most productively to allow the clients to engage in their most meaningful activities. Occupational therapists can also help the family negotiate the transition between activities, and the occupational identities connected with them, to further support the patient’s agency and positive outcomes. Therapists can further offer education in terms of safe transfers and use of orthotic devices in order to extend hospice care in a home setting (Lloyd, 1989). These services can assist patients to “maintain a balanced level of activity while providing meaning and

satisfaction and a continuing sense of worth to the family and significant others” (p. 229). Through the use of an occupational history, occupational therapists collect information that will help them achieve this goal. In the hospice setting, an occupational therapist’s ability to listen actively to the patient is imperative to his or her success in meeting the needs of the patient. In the hectic health care world, this sometimes seems unattainable. However, occupational therapists are unique in their training in this area, and the occupational history offers a singular opportunity to make a comprehensive view of the patient the focus of attention. Davis, Asuncion, Rabello, Silangcruz, and van Dyk (2012) identified listening behaviors employed by occupational therapists in hospice settings as “consistent use of reframing, restating, and reflecting to allow patients the opportunity to hear back what they were attempting to communicate” (p. 17). Therapists further identified the value of silence when being present with a patient on the road to acceptance.

### **The Road to Success - Future of Occupational Therapy in Hospice**

The National Hospice and Palliative Care Organization (NHPCO) “estimated that 1.4 million patients received services from hospice in 2007, a 13-fold increase in 20 years” (Connor, 2009, p.107). Palliative care services in hospice settings demonstrated the largest growth and “increased from 26.2% in 2002 to 55.1% in 2006” (Connor, 2009, p.109). Occupational therapists need to better communicate their contributions to palliative and hospice care settings through publications of

evidence-based practices and increased training opportunities for qualifying occupational therapists.

Hospice care emphasizes five main areas of focus: “pain and symptom control, quality of life, diagnostic honesty, 24 hour care, and follow-up bereavement care for the survivors” (Marcil, 2006, p. 26; Tigges & Sherman, 1983). The future role of occupational therapy in hospice will likely depend on our success in providing appropriate services to meet each of these needs and advocating for our presence on hospice teams. As Marcil (2006) states, “activities and occupations can serve as a diversion from pain ... When one participates in an activity that brings one pleasure, the body produces endorphins, the body’s natural painkillers” (Marcil, 2006, p. 29). Aiding patients in identifying and engaging in occupations and occupational roles adds to their quality of life.

Stephanie Sahanow is an occupational therapist examining the role of occupational therapy in hospice care. During an interview, Ms. Sahanow stated that occupational therapists “use a holistic frame of reference, focusing on patient’s final goals, legacy work, safety in the home etc.” (S. Sahanow, personal communication, February 17, 2015). These kinds of interventions offer an opportunity to assist a patient in the process of occupational role development and negotiating the realities of their diagnosis. Trump (2010) stated:

Because of our training with group activities and our knowledge of coping mechanisms and stress reduction, we may be able to contract with hospice teams to lead groups to promote healthy ways to cope with stress and the emotional issues that hospice

professionals face daily. This is another way to market occupational therapy services to hospice administrators. (p. 2)

The same is true of occupational therapist's potential role in supporting family members and caregivers through the process of bereavement.

### Conclusion

Reilly (2011) asked in her 1961 Eleanor Clark Slagle Lecture whether occupational therapy is "a service vital and unique enough for medicine to support and society to reward?" (p. 77). The role of occupational therapy in hospice care has yet to fully realize this vision. However, occupational therapy holds a unique place among medical fields in its approach to client well-being and the role of occupation in facilitating a broad range of human experience at all stages of life. Flanigan (1982) asserted that occupational therapy's "awareness of the patient in a holistic perspective enables us to use our training to prescribe and adapt purposeful activity which gives the patient maximal opportunity for control and usefulness of physical, psychological and social functions of his life" (p. 276). This strikes at the very core of the occupational therapy goal of helping clients to live life to its fullest. While occupational therapists encounter all patients with this philosophy in mind, "the context of dying provides a unique temporal and sociocultural experience, remaking the 'ordinary' into 'extraordinary'" (Jacques & Hasselkus, 2004, p. 52). Occupation in a hospice setting has much to do with the expansion of the definition of activity to encompass an even broader psycho-social-spiritual perspective and the framing of these as meaningful, purposeful, and life-giving.

The history of occupational therapy in hospice suggests that the role continues to develop. If occupational therapists persevere in their engagement in this arena of patient care, their presence there will continue to have a powerful, reciprocal impact on both fields.

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