Chapter 10

Spiritual Factors in the Experience of Alzheimer’s Disease and Other Dementias

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ABSTRACT

Alzheimer’s disease and other dementias raise important questions of personhood and connection for those affected. Finding meaning in the face of dementia is one of the most challenging aspects of dementia; spiritual reminiscence is a way of connecting with those with dementia when their cognitive decline seems to preclude them from participating in a meaningful life. In this chapter a context for spirituality in later life is given through description of the spiritual tasks and process of ageing. This leads to presentation of work based on a mixed methods study of 113 people in residential aged care with a diagnosis of dementia who participated in either six or 24 weeks of weekly sessions of guided spiritual reminiscence (MacKinlay & Trevitt, 2012). Relationship was found to be almost synonymous with meaning for these people. Other important themes identified were vulnerability and transcendence, wisdom, hope, despair, and response to meaning.

INTRODUCTION

Alzheimer’s disease and other dementias raise important questions about the notion of personhood and connection for the affected person; do they remain a person as they lose their cognitive capacities, are they still “the same person?” Is the cognitive domain the only way into the spiritual dimension of being human? These issues raise deeply spiritual/theological issues about the nature and value of humanity. With the increasing numbers of people diagnosed with dementia in current ageing societies, these issues are of considerable significance. One of the greatest issues facing people with dementia and their
loved ones is how to connect with each other; is it possible still to communicate with the person as they travel this journey into dementia? A second closely associated issue is how to find meaning in the face of dementia.

Reminiscence was first acknowledged as an important process in later life by Robert Butler and published in his 1963 paper (Butler, 1968). Spiritual reminiscence is a development of the process of reminiscence by especially focusing on spiritual meaning and connections. Spiritual reminiscence is a way of connecting with those with dementia when their cognitive decline is often seen to preclude them from participating in a meaningful life or even spiritual activities. It is a particular way of communication that acknowledges the person as a spiritual being and seeks to engage the person in a more meaningful and personal way. For over a decade the authors have explored the use of spiritual reminiscence with people who have dementia. Results from these studies have provided evidence of that “something more” that has been so elusive to care providers and researchers alike.

This chapter is essentially about the process of spiritual reminiscence and finding meaning in the face of dementia. The scene for spiritual reminiscence is set first by providing a context for spirituality in later life through a description of the spiritual tasks and process of ageing (MacKinlay, 2001). This leads into the process of spiritual reminiscence as a way to assist people with dementia in finding meaning in their lives. The study included people with Alzheimer’s and other dementias, but the umbrella term “dementia” will be used throughout. This exploration is based on the mixed methods study, “Finding Meaning in the Experience of Dementia” (MacKinlay & Trevitt, 2012) and uses the themes arising from the study to describe the process of spiritual reminiscence as a means of connecting with people with dementia. The qualitative component was of greatest value in understanding the experiences of the participants, and it is that component that will be the focus of this chapter.

BACKGROUND

Spiritual Tasks of Ageing

The model of spiritual tasks used to provide a framework for discussion topics in spiritual reminiscence is based on the six themes that emerged from in-depth interviews of independent living older people using grounded theory (MacKinlay, 2001). These were ultimate meaning, response to ultimate meaning, and four continuums of self-sufficiency/ vulnerability, provisional life meanings/final meaning, relationship/isolation, and hope/despair. These spiritual themes are regarded as developmental themes, and in that way are similar to the psychosocial tasks identified by Erikson (1986). Further, the themes are closely related to the process of finding meaning described by Frankl (1984). Each of these themes has a corresponding developmental task: to develop self-transcendence, to find personal final meanings, to find relationship (in spiritual terms, intimacy), and to find hope. These four tasks then interact with and influence the way the other two spiritual tasks of ultimate meaning and response to ultimate meaning are worked out in the individual’s life. These tasks have been drawn from the themes raised by older people themselves in telling their life stories, and the model developed of these tasks (Model of Spiritual Tasks and Process of Ageing, MacKinlay, 2001) was trialled in a subsequent study of frail older people (MacKinlay, 2006). Subsequently, the model was used in working with people who have dementia (MacKinlay & Trevitt, 2012).