

ESSAY REVIEW

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Introduction

Spiritual reminiscence is a form of communication that acknowledges the person as a spiritual being and seeks to engage the person in a more meaningful and personal way than, for example, can a purely biomedical approach to the problem of illness. Spiritual reminiscence is a way of telling a life story with emphasis on *meaning*. Spiritual reminiscence can identify meaning associated with joy, sadness, anger, guilt, or regret. Exploring these issues in older age can help people to reframe some of these events and come to a new understanding of the meaning and purpose of their lives. A total of 113 older adults with dementia, living in aged-care facilities, participated in this study described in this book. They were allocated to small groups for spiritual reminiscence, to meet weekly over 6 weeks or 6 months. Quantitative data were gathered using a behavioural scale before and after each spiritual reminiscence session. Qualitative data included taped and transcribed reminiscence sessions, individual interviews and observer journals. A facilitator led the small-group discussion based on spiritual reminiscence. New relationships were developed among group members that improved life for these people in aged care. This paper examines aspects of the qualitative data around the themes of 'meaning in life' and 'vulnerability and transcendence'. Spiritual reminiscence offers nursing staff a way of knowing those with dementia in a deeper and more meaningful way. The research completed by the authors of this book have demonstrated that interactions in people with dementia are significantly increased following group work in spiritual reminiscence for a period of 6 months. The small groups also help people to bond and develop friendships in a way that is often otherwise difficult to nurture in aged care facilities. The interaction, communication and bonding all increased, despite their cognitive skills further deteriorating over a 6 month period.

Stigma

There are, as the book describes, different views of ageing in our society. One view sees ageing as a period of physical decline that includes illness and disability, with an emphasis on the "burden" of an ageing population. Government policy has concentrated on the cost of this ageing population, exemplified by the Intergenerational Report. A second view is of "successful ageing". This promotes continued engagement with the wider community and pursuit of physical and psychosocial activities as a means of ageing successfully. However, this view begs the question of what happens to people who are not "successful" - older people who live with multiple chronic health problems, who are depressed or live with dementia. The reality is that the later years in life may frequently be accompanied by chronic illness requiring special care.

It is tragic that patents with significant dementia are often described as 'a physical shell of a person'. There is still a person in there. They still need somebody who can actually be present for them and with them, who can give them the time to recover those words that can be so difficult to find. Fear underlies much of the myths of dementia which is often described as a 'living death'. People who may well believe the myths of their disease are less likely to seek help. If people feel that life is no longer worthwhile or valuable then they are likely to experience depression and despair.

The stigma of dementia is explained by society placing high value on youth and cognitive attainment which leads to prejudice. This discrimination is seen in the provision of services, resource allocation, research funding, media coverage, professional status and training. The association of dementia with mental ill health also reinforces existing societal prejudices towards ageing. The inability to speak about dementia is a sign of the stigma of this condition. The authors found in their study that relatives were reluctant to include their loved ones in a 'dementia study'

– even though they were in residential care because of their dementia. They identify a number of publications which characterise Alzheimer’s disease and dementia as a living death – constrained by their disease with no sense of self-remaining. Focusing on the language used frequently around dementia to overcome stigma instead of concentrating on the ‘burden’ of caring, look for the joys, sharing compassion, forgiveness and reconciliation to be gained from caring. The authors present some of the actual words of people who have dementia to include laughter, joy, love and peace, as well as struggle, despair and burnout.

An alternative view of ageing

They propose an alternative view that sees ageing as a “spiritual journey”, with challenges that continue across the later years of life. This is a journey that searches to find meaning in one’s life and, therefore, reason for continued life and hope. This view accepts the possibility of death, while living life to the full. Taking this view allows people living with increasing disability to find hope and to flourish, even in the face of uncertainty. Elements of each of these views of ageing are true and it is important to take account of each in considering the wellbeing of older people and their holistic care. By examining concepts of spirituality and transcendence in later life, they explore ageing as a spiritual journey.

An understanding of spirituality

The concept of spirituality is about core meaning and connectedness and it is from this that people respond to all of life. Anger, hate, love, forgiveness and hope come from this core. For some people, spirituality may be expressed in a relationship with God or a higher being, while for others it may be expressed through family and friends, nature, and/or the environment. When we talk about spirituality, we are not specifically talking of religiousness, although for people who have a religious faith, religiousness is part of their spirituality. A better way to think about spirituality is to imagine it as an umbrella. Religion, being one way to express spirituality, comes under this umbrella. Describing the spiritual domain has always been difficult. It is deeply related to hope and is the spark that enlivens human beings. Essential elements of spirituality seem to revolve around a relationship with self, others and God, a sense of meaning and purpose, hope, connectedness and beliefs. Issues of spirituality appear more urgent when people face situational and developmental crises of life, such as coming to terms with a terminal illness and the rising awareness of one’s own mortality.

There are many definitions of spirituality. It is that which lies at the core of each person’s being, an essential dimension which brings meaning to life. Constituted not only by religious practices, but understood more broadly, as relationship with God, however, God or ultimate meaning is perceived by the person and in relationship

with other people. In spite of the widespread view that some form of spirituality is important, many people who care for older people do not see spiritual care as a priority, because the person may not declare a religion or go to church.

A model of spirituality in ageing

As people grow older, especially from middle age onwards, they often become more introspective. The final stage in a series of psychosocial developmental stages of ageing is a moving towards integrity or despair, the outcome of which is wisdom. The development of a model of spirituality in ageing described in this book came about from many hours of interviewing, listening to and analysing the stories of older people. One study explored and mapped the spiritual journeys of independent older people: Where did they find meaning in life? Were they conscious of being on a journey? What was it like? What were the possibilities? Was there still hope in growing older and frailer? Other studies have concentrated on frail elderly people and those with dementia. Each of these studies has sought to explore the spiritual dimension of ageing.

The model of spiritual tasks and process of ageing

Models illustrated in the book are based on qualitative analysis, using grounded theory, of data obtained from in-depth interviews with older people. They have been refined and affirmed in subsequent studies. They illustrate that the central core of spirituality is what the person perceives as ultimate meaning in life. The person responds to life from what lies at the heart or deepest core of their being and this will vary with the individual. The models are dynamic, with interactions shown by arrows. They provide a framework for understanding spiritual processes in ageing. This centres on the human search for meaning and the associated responses to perceived meaning. Other tasks involve the development of transcendence (the ability to triumph over the psychosocial and physical challenges of ageing), moving from provisional to final life meanings, finding intimacy and finding hope. The models allow for continued spiritual growth and development until the end of life. They also suggest opportunities for spiritual assessment and intervention. Using spiritual reminiscence for people with dementia helps these people to find meaning, lowers stigma and affirms them as people of worth to themselves and to their families.

Ultimate meaning

What brings greatest meaning to each individual is the starting point for that person; it is from this point that he or she responds to life. For example, if the person thinks of

God as judgemental, then guilt may be a central feature of the person's life and he or she may not be able to feel hope. If core meaning comes through relationship with loved ones, it is important to know this, especially if there has been a loss of relationship through death or separation. Meaning is at the centre of what it is to be human and loss of meaning can be an important factor in grief and depression. The response to meaning is a reaching out from our depth to otherness and to others. If art, music or environment is a central source of meaning, then the person will respond to meaning through this. If God is central in meaning, then worship, prayer, reading of sacred scriptures or meditation may be the person's means of response. People who are depressed may feel that life is meaningless and may find it difficult or impossible to respond to life unless the depression is first treated.

The move from provisional to final meanings in life

At developmental stages of our lives or during critical life experiences, we assign meanings to our experiences. These "provisional meanings" are subject to change at a later point. Changes later in life, such as the diagnosis of a terminal illness or an increasing awareness of one's own mortality, may be triggers to examine provisional life meanings and move towards assigning "final meanings". Reminiscence therapy has been used in such circumstances to help people resolve past issues, including traumatic experiences. Reminiscence therapy has been used effectively with older people traumatised by their experiences of World War II.

Transcendence and ageing

A study of independent-living older people showed that all of them feared future vulnerability or losing control of their lives. In a similar study of frail elderly nursing home residents, 55% of participants said they had no fears. Yet, the latter group had many more disabling conditions than the independent-living group. The precarious balance between vulnerability and self-sufficiency was an important theme for these older people. As vulnerability increased, the move from "doing" (being active) to "being" (having little energy or ability to engage in activities) was more frequently observed. These changes, associated with self-transcendence (the move from self-centredness to other-centredness), are spiritual changes and were present regardless of religious and spiritual background. However, not all of the people studied had progressed along a continuum towards self-transcendence. While some very frail older people seemed at peace and expressed a deep sense of joy in their lives, others experienced despair. A sense of despair may lead to failure to thrive, a concept much studied recently in the broader context of frailty. It is contended that one aspect of failure to thrive may be a lack of nourishment of the soul, or lack of love and spiritual

care, similar to the failure to thrive concept in paediatrics. My work of mapping the spiritual dimension with frail elderly nursing home residents indicated a possible link between frailty, failure to thrive and lack of hope. In terms of the literature on frailty in older people, in which the multidimensional nature of frailty was acknowledged, only one study was found that included spirituality in a theoretical framework and none considered it in a research framework. While the 3 most common factors contributing to frailty were physical activity, ageing and disease, confusion exists about the relationship between frailty and the multiple identified factors.

Spiritual reminiscence

Spiritual reminiscence is a form of communication that acknowledges the person as a spiritual being and seeks to engage the person in a more meaningful and personal way. The research described in the book has demonstrated that interactions in those with dementia are significantly increased following group work in spiritual reminiscence for a period of 6 months. Small groups helped the patients bond and develop friendships in a way that is often otherwise difficult to nurture in residential care settings. The interaction, communication and bonding, all increased, despite residents' cognitive skills further deteriorating over the 6 month period.

Spiritual reminiscence differs from reminiscence in that it focuses on the meaning of life through the life story, including connectedness and the faith context (where this is part of the person's story) and on what has given joy or brought sadness. The process of spiritual reminiscence may identify events that caused anger, guilt or regret. Expressing some of these issues in later life may help people to reframe events and come to a new understanding of how their life was lived. Spiritual reminiscence helps people find meaning in life in the present and to develop strategies to accept changes of later life, including losses of significant relationships and increasing disability. It offers people with dementia the chance to talk about their fears and hopes and where they find meaning. Outcomes of spiritual reminiscence work include facilitating transcendence and finding hope in the face of increasing vulnerability. Spiritual reminiscence is a way of telling a life story with emphasis on meaning. Spiritual reminiscence can identify meaning associated with joy, sadness, anger, guilt, or regret. Exploring these issues in older age can help people to reframe some of these events and come to new understanding of the meaning and purpose of their lives.

Although we live in the West, an increasingly secular society, spiritual care should not be seen as an "optional extra" for older people. The search for meaning in later life becomes more real for many older people and this search is essentially a spiritual search, with questions of meaning, transcendence and hope becoming important. One important view of ageing is of a spiritual journey. The spiritual quest does not cease with the onset of frailty or with the diagnosis of dementia. Older people often need

support and spiritual care that will include journeying with them in their search for meaning and grappling with the issues that arise when life itself seems threatened. Using spiritual reminiscence is one way of offering this care.

Providing spiritual care is about tapping into the concept of spirituality: core meaning, deepest life meaning, hope and connectedness. The search for meaning, connectedness and hope becomes more significant as older people are faced with the possibilities of frailty, disability and dementia. Spirituality, ageing and meaning in life can be discussed in the context of an alternative view of "successful ageing". A model of spiritual tasks in older age can help explain the spiritual dimension and provide a starting point for spiritual assessment. Healthcare is not just caring for people's physical needs. Spiritual care is a way of helping older people in their search for hope and meaning, especially as they face issues of grief, loss and uncertainty. Depression in older people, especially those in aged care facilities, is one aspect of loss of meaning and hope. This book presents an alternative view of ageing and a model of spiritual tasks in ageing. Spiritual reminiscence is proposed as one way to help provide spiritual care.

Malignant social psychology linked to people with dementia

Malignant social psychology refers to a social environment in which interactions and communications occur which diminish the "personhood" of those people experiencing that environment. In many cases these "malignant" interactions are not perpetrated from an intent of malice, but rather are brought about through lack of insight or knowledge of the negative effects. Stopping the spread of malignant social psychology (common among care providers who intimidate, outpace, give "the silent treatment", infantilize, label, disparage, blame manipulate, invalidate, overpower, disempower, disrupt, objectify, stigmatize, ignore, banish and mock) by valuing all human lives regardless of age or cognitive ability, recognizing uniqueness-personhood - and also understanding the perspective of the person is a way of enriching social environment in a way that supports body/mind/spirit.

Kitwood (1997) argues that people with dementia do not lose their personhood, but that this can be maintained through relationships with other people. Thus, Kitwood defines personhood as 'a standing or a status that is bestowed on one human being, by another in the context of relationship and social being'. Within person-centred care therefore, the personal and social identity of a person with dementia arises out of what is said and done with them. In addition, Kitwood adopts a moral and transpersonal position in which personhood is transcendent, sacred and unique and where people who have dementia warrant an ethical status that offers them absolute value. For Kitwood, therefore, communication is the point at which personhood arises and he outlines 17 different interactive processes that may occur in dementia care settings that impair personhood. He calls these processes 'malignant social psychology' and sees them as having a malign effect on

personhood and making a negative contribution towards people's experience of dementia. One type of malignant social psychology is 'treachery', which occurs when different forms of deception are used to manipulate or gain control over a person with dementia. Another type of malignant social psychology is 'objectification', which occurs when a person with dementia is treated as if they had no opinions or feelings, as if they were 'dead matter'.

Conclusion

This stimulating analysis of the meaning of the experience of dementia goes beyond cognitive damage of people and technical expertise of carers, through listening to the voices of individuals with dementia. The book is highly recommended for practitioners involved with people who have dementia. This valuable contribution to dementia care provided in this text should be an essential tool for chaplains, care home leaders and all the professionals who need the insights provided here to change attitudes and empower people with dementia. This paperback book for permanent study is great value for money in contrast to a very expensive training course.