I. Research-Oriented Articles


From the abstract: ...The purpose of this literature review is to examine the existing body of knowledge about spirituality in coping with Alzheimer's disease and to apply a spiritual framework of coping in organizing the literature to identify themes and gaps in knowledge. ...A literature search was conducted to find research published between 1990-2006. ...Six research studies were reviewed. Findings suggest that persons with early-stage Alzheimer's disease draw from their spirituality and faith to find meaning and courage in facing the challenges of cognitive losses. Furthermore, they are able to provide rich information about their spirituality and the psychosocial aspects of living with Alzheimer's disease....


[From the abstract:] This qualitative study describes how individuals with early-stage AD use spirituality to cope with the losses of self-esteem, independence, and social interaction that they face. The purposive sample for this focused ethnographic study consisted of 15 participants living at home in central Arkansas. Holding onto faith, seeking reassembly and hope, and staying connected were the global themes. Personal faith, prayer, connection to church, and family support enhanced the ability of people with early-stage AD to keep a positive attitude as they face living with AD.

Carr, T. J., Hicks-Moore, S. and Montgomery, P. [University of New Brunswick and Laurentian University, Canada]. "What's so big about the 'little things': a phenomenological inquiry into the meaning of spiritual care in dementia." *Dementia* 10, no. 3 (August 2011): 399-414, August 2011.

[Abstract:] Although it is widely accepted that spirituality is an important aspect of health and healing in long term care, its meaning and day-to-day implications remain poorly understood. This study explored the meaning of spiritual care from the perspectives of patients living with moderate to severe dementia, their families and their care providers. Using a hermeneutic phenomenological approach, open-ended interviews were conducted in a dementia care unit with 29 participants, including patients, families, RNs, LPNs, and hospital chaplains. Interviewees were asked to share their stories and insights about spiritual care in dementia. Using hermeneutic analysis, the central theme of 'little things' was identified. Recognition and attendance to 'little things' promoted patients' sense of personhood and connectedness to self and others. Barriers to spiritual care in dementia were also identified. These findings inform our understanding about effective relational approaches in spiritual care with this unique population.


[Abstract:] BACKGROUND: Several studies have shown that religiosity has beneficial effects on health, mortality and pathological conditions; little is known about religiosity in Alzheimer's disease and the progression of its cognitive, behavioral and functional symptoms. Our aim was to identify any relationship between religiosity and the progression of cognitive impairment and behavioral disorders in mild-moderate Alzheimer's disease, and any relationship between the patient's religiosity and the stress in caregivers. MATERIALS AND METHODS: 64 patients with Alzheimer's disease were analyzed at baseline and 12 months later using the Mini-Mental State Examination (MMSE), the Behavioral Religiosity Scale (BRS) and the Francis Short Scale (FSS). Caregivers were also questioned on the patient's functional abilities (ADL, IADL), the behavioral disturbances (BPRS, NPI), and their stress (NPI-D, CBI). Patients were divided into 2 groups according to BRS: a score of <24 meant no or low religiosity (LR), while a score of > or =24 meant moderate or high religiosity (HR). FINDINGS: LR patients had worsened more markedly after 12 months in their total cognitive and behavioral test scores. Stress was also significantly higher in the caregivers of the LR group. Global BRS and FSS scores correlated significantly with variations after 1 year in the MMSE (r = 0.50), NPI (r = 0.51), NPI-D (r = 0.55) and CBI (r = 0.62). A low religiosity coincided with a higher risk of cognitive impairment, considered as a 3-point decrease in MMSE score (OR 6.7, CI: 1.8-24.7). INTERPRETATION: higher levels of religiosity in Alzheimer's dementia seem to correlate with a slower cognitive and behavioral decline, with a corresponding significant reduction of the caregiver's burden.


[From the abstract:] This exploratory study tested the efficacy of an innovative, spiritually based mantram caregiver intervention delivered using teleconference calls. A prospective, within-subjects, mixed-methods, and 3-time repeated-measures design with 36-week follow-up telephone interviews was conducted. Sixteen caregivers (94% women, 94% Whites with mean age 69.2 years, SD = 10.35 years) completed the intervention. Significant effects for time and linear terms were found for decreasing caregiver burden, perceived stress, depression, and ruminations and for increasing quality of life enjoyment and satisfaction, all with large effect sizes. Findings suggest that teleconference delivery of a spiritually based caregiver intervention is feasible. [This article is also published in the October-December 2009 special theme issue of *Alzheimer's Care Today* (vol. 10, no. 4, pp. 212-220) on spirituality.]

Fargeau, M. N., Jaafari, N., Ragot, S., Houeto, J. L., Pluchon, C. and Gil, R. [Department of Neurology, CHU of Poitiers, University of Poitiers, France]. "Alzheimer's disease and impairment of the Self." *Consciousness & Cognition* 19, no. 4 (Dec 2010): 969-976. Among the findings of this French study involving 47 patients was that while the Social Self was significantly impaired by Alzheimer's Disease, the Material Self and the Spiritual Self showed greater resilience.

1 This bibliography from the health care literature does not include research or other articles focusing on the spirituality of caregivers of people with dementia/Alzheimer's disease.

The paper reports preliminary findings from the quantitative component of a multi-layered exploratory study involving 29 patients. Among the findings: the patients indicated capability to complete the Royal Free Scale of spirituality, and in the early stages of dementia there is no obvious reduction of spiritual awareness. This study was originally published online (via www.rcpsych.ac.uk/college/specialinterestgroups/spirituality.aspx) as a paper presented at a meeting jointly organized by the Faculty of Old Age Psychiatry and Special Interest Group for Spirituality and Mental Health, Royal College of Psychiatrists, London, December 14, 2005.


[Abstract:] This longitudinal study examined 70 patients--aged 49 to 94--receiving treatment at the Behavioral Neurology Clinic at Bayside (Canada). They were assessed for QOL, spirituality and religiosity upon recruitment, with a mean longitudinal follow-up of 3.14 years. Spirituality and religiosity were assessed using the five-item Duke Religion Index (DUREL) plus two items from the NIH/Fetzer Brief Multidimensional Measure of Religiousness/Spirituality. While higher levels of spirituality and private religious practice were associated with slower cognitive decline in these patients, the study did not find such an association with attendance, self-rated religiosity, or quality-of-life domains; and the authors speculate about reasons including possible difficulties of Alzheimer's sufferers in participating in social religious activities.

Lenshyn, J. [Coordinator of Pastoral Care for the Fred Douglas Society in Winnipeg, Manitoba, Canada, and lecturer and supervisor of ministry students at the University of Winnipeg]. "Reaching the living echo: maintaining and promoting the spiritual in persons living with Alzheimer's disease." Alzheimer's Care Quarterly 6, no. 1 (January-March 2005): 20-28.

[Abstract:] This article shows, through references to research by the author, experts in the field, and the use of story, alternate methods of delivering spiritual comfort and promoting spiritual well being which move beyond traditional cognitive and rational based interventions. The methods brought to the reader's attention will be seen to be the kinds of interventions anyone can use. They are not confined to use by religious "experts." This offers hope to family members, friends, and caregivers of all disciplines who wish to be able to connect with and nurture the spirit/soul of the person living with Alzheimer's disease.

Mackinlay, E. and Trevitt, C. [Centre for Ageing and Pastoral Studies, School of Theology, Charles Sturt University, Barton, Australia, and Department of Cardiovascular Medicine, University of Oxford, Oxford, UK]. "Living in aged care: Using spiritual reminiscence to enhance meaning in life for those with dementia." International Journal of Mental Health Nursing 19, no. 6 (Dec 2010): 394-401.

[From the abstract:] 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 frame some of these events and come to 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. They were allocated to small groups for spiritual reminiscence, to meet weekly over 6 weeks or 6 months. Quantitative data were gathered using a behavioral 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'.

Snyder, L. [University of California, San Diego, Alzheimer's Disease Research Center]. "Satisfactions and challenges in spiritual faith and practice for persons with dementia." Dementia 2, no. 3 (October 2003): 299-313.

[From the abstract:] This qualitative study examines the role of religion and spirituality in the lives of persons with dementia. Quotes from 27 individuals with Alzheimer's and one person with frontotemporal dementia reveal the following themes: the role of religion or spirituality in finding meaning in dementia; the role of religion or spirituality in coping with the disease; the influence of dementia on religious or spiritual practices; and the influence of dementia on faith.


[Abstract:] Increasing attention in the scientific literature is being given to the relationships among religion, spirituality, and overall well-being. Moreover, research has repeatedly identified religion and spirituality as significant coping resources throughout the life course. For this study, a group of 20 Catholic and Protestant older adults were interviewed; half were caregivers of a spouse with Alzheimer's disease and half were noncaregivers. The informants were asked about their views on religion, spirituality, and how they integrated their faith into their lives. Qualitative analysis identified several themes reinforcing previous work that has shown religion and spirituality are important dimensions to the human experience. All of the informants had integrated religious and spiritual beliefs and practices into their lives to help make sense out of stressful situations. The findings underscore the need for further scientific inquiry that examines how religion and spirituality promote healthy adaptation to significant life events.


This report of multi-phase research includes results from focus groups with 12 clergy, in which they offer their observations and recommendations for further scientific inquiry that examines how religion and spirituality promote healthy adaptation to significant life events.

II. General Articles:

Persons with dementia have spiritual needs that can be fulfilled by well-trained, sensitive family and professional caregivers. This article defines spirituality and differentiates that term from religion. Ways to meet the spiritual needs of persons with dementia are described, with the authors arguing that the cognitive losses of individuals with Alzheimer's disease and related disorders actually make spiritual needs more apparent. The authors argue that nurturing the spirit of the person with dementia is essential to quality of care and quality of life and that it also enhances the spiritual well-being of caregivers and staff.


This is a personal essay by a long-term care chaplain, drawing upon his own experience in order to offer practical suggestions for patient care.


This article suggests a number of ideas for working with patients and includes three appendices: "Religious, Spiritual, and Sacred Center Assessment of Compassionate Connectedness," "Activity-Focused Adapted Worship Guidelines," and "Opportunities for Sharing Ministry: Dementia Care Centers and Local Congregations." [Abstract:] All persons with dementia are unique and deserving of individualized respect, honoring, and care. The identification of disease stages or other categories may have value, but only when the person is offered unconditional positive regard and seen as having inherent worth and dignity. The essence of a person is within--one's personhood, one's am-ness. Celebrating this personal and spiritual-centered uniqueness includes spiritual well-being assessment; the offering of a praise, thanksgiving, and worship activity center; and participation in activity-focused adapted worship. The person's spiritual self is therefore invited to enter into the sacredness of each day, gifting one's self and others.


[Abstract:] Describes a novel approach to providing a meaningful worship service for Alzheimer's patients in which greater stress is placed upon familiar scripture, music, prayers, and other right-brain functions, rather than on a sermon or homily.


[Abstract:] This paper discusses the concept of spirituality from the perspective of the available literature in relation to dementia. Very little research exists focusing purely on dementia from the personal perspective or looking at dementia and spirituality in relationship to one another. Literature suggests that spirituality is an important element in dementia care yet little is done to address spiritual need, spiritual distress or spiritual care in nursing practice. Disciplines such as palliative care have explored the issues of spiritual care but spirituality in dementia care remains an under-researched area of care with most carers lacking a basic understanding of even their own spirituality. There is a need to explore the concept of spirituality in greater depth with regard to dementia care and how caring for the spiritual needs of people with dementia can be addressed.


[From the abstract:] This paper illustrates how religion and spirituality can be related to people suffering from various forms of dementia, particularly Alzheimer's disease, and how Churches as organizations can assist these people. The paper also covers ways of minimizing communication difficulties during one-to-one pastoral visits, the simplification of religious services for nursing-home residents, and some of the problems which may occur when a practicing Church minister develops symptoms of Alzheimer's disease.


[Abstract:] This article observes that many clergy do not seem to understand the importance of ministry to persons with dementia. New understandings about the relationship between dementia and spirituality are presented and theological foundations explored. The article ends with a discussion of pastoral strategies that are important in this ministry.

Gataric, G., Kinsel, B., Currie, B. G. and Lawhorne, L. W. [Department of Geriatrics, Wright State University, Boonshoft School of Medicine, Dayton, OH; gordana.gataric@wright.edu]. "Reflections on the under-researched topic of grief in persons with dementia: a report from a symposium on grief and dementia." American Journal of Hospice & Palliative Medicine 27, no. 8 (Dec 2010): 567-574.

[Abstract:] This article describes a symposium about the clinical challenges of providing care to persons with dementia and their families. The plenary session addressed the bereavement process in the general older adult population, neurocognitive processes that alter the grief process in persons with dementia, and therapeutic approaches to support grieving persons in different stages of dementia. Participants from diverse health care disciplines met in small groups to identify (1) current responses to persons with dementia and their families who experience a loss; (2) barriers to providing effective responses; and (3) possible interventions to improve care. Two general types of interventions emerged: practical/agency support and spiritual/affective engagement.


Reports a pilot project designed to address spiritual needs of individuals with dementia attending Downs Day Hospital in Sutton, UK, for assessment and treatment. Data indicated that 50% of the patients expressed a desire to participate in the prayer group project, and responses of the people with dementia suggest was overall a positive experience, which may have helped to meet their religious needs. [See also: Karamat, S., Higgins, P., Head, J. and Lawrence, R., "Candlelight Group II: brief comments about congregational rituals in dementia care for a multi faith community" (2004), also published online by the Spirituality and Psychiatry Special Interest Group.]

Katsuno, T. [Tokyo Metropolitan University of Health Sciences]. "Personal spirituality of persons with early-stage dementia: Is it related to perceived quality of life?" Dementia 2, no. 3 (October 2003): 315-335.

[Abstract:] During times of stress and uncertainty, research has documented that individuals may turn to religion and spirituality as coping resources. But what about those with dementia who have a decreased cognitive capacity? Do they also turn to religion and spirituality and are these coping resources related to overall quality of life? The objective of this study was to describe the spiritual experiences of persons with early-stage dementia and to explore the relationship between personal spirituality and perceived quality of life. Twenty-three participants were interviewed using: a semi-structured interview guide; the System of Belief Inventory (SBI); and the Quality of Life Index (QLI). Qualitative data analysis illuminated an overall theme of 'faith in God' and six related categories: beliefs; support from God; sense of meaning/purpose in life; private practice; public practice; and changes due to dementing illness. There were significant relationships between the SBI scores and the QLI scores. Findings suggest that those with early-stage dementia often find personal spirituality and its internal meanings important in coping with their life situations, that is, spirituality is associated with their perceived quality of life.


[Abstract:] The primary focus of research related to spiritual and ministry needs of older people, historically and in the present, has been on those whose cognitive abilities are only minimally impaired. The older adult with a dementia like Alzheimer's disease, however, has not received as much attention. This may be related to a lack of any theoretical framework from which to understand what may be happening to a markedly confused person spiritually, and how a person with progressive cognitive impairment might still be able to maintain a relationship with God and be ministered to by a God who may only be remembered vaguely, if at all. Elderly persons with dementia with a faith background rooted in the Judeo-Christian worldview are often able to respond to various rituals of their faith, verbally, physically, and emotionally. Common practices like familiar prayers, Bible readings, hymns, and attendance at worship services where collective memory is shared can serve as memory joggers to reconnect the person, not only to the faith community, but to a faithful God. A spiritual care ministry to older people with dementia can be considered a ministry of memory.

Norberg, A. [Department of Nursing, Umea University, Sweden]. "Consoling care for people with Alzheimer's disease or another dementia in the advanced stage." Alzheimer's Care Quarterly 2, no. 2 (Spring 2001): 46-52.

[Abstract:] This article argues that people with Alzheimer's disease or another dementia in the advanced stage (AAD) need consoling care. Living with AAD means suffering, the core of which is not feeling at home. In addition to suffering as a consequence of the disease, people with AAD may also experience care that is degrading. People with AAD need consolation, the center of which is communion, that is, sharing with others. People with AAD can be offered bodily, psychological, and spiritual consolation.


This article is available on-line at http://www.parkridgecenter.org/Page482.html.


[Abstract:] The chaplain's ministry to persons with dementia, often of the Alzheimer's type, is vitally relevant to their clinical well-being. No chaplain should ever think that because someone is demented, they can no longer be reached spiritually. While few scientific studies exist, clinical experience and anecdotal accounts suggest that selected pastoral interventions can enhance the quality of life of the mildly, moderately, and even severely demented individual.


This is a basic and general introduction to caring for Alzheimer's patients and caregivers, but the author includes a brief description of "Care Team Network" model for faith communities, developed at the University of Alabama in Birmingham (see p. 269).


[Abstract:] As the number of older adults with Alzheimer's disease (AD) increases, healthcare providers may be aware that persons with AD have spiritual and religious needs but may be uncertain as to how to assess or respond to these needs. Studies show that spiritual and religious activities can help both persons with AD and caregivers cope with the disease. In addition, recent research suggests that spiritual and religious activities may slow the progression of the disease. A diagnosis of AD brings challenges as we determine how to assess and find meaningful spiritual and religious interventions for caregivers and persons with AD. [This is part of a special issue in Alzheimer's Care Today on spirituality.


[Abstract:] Declining communication skills in dementia threaten a person's sense of self. Building on enduring capabilities, pastoral visitors can significantly enhance spiritual well-being through the use of individualized, person-centered strategies. This article outlines the primary spiritual needs of older adults with dementia and some general strategies to improve communication based on enduring abilities. Detailed examples illustrate how these personhood-centered strategies can meet spiritual needs by connecting with individuals with dementia through life stories and through helping them to participate in religious life.

Snyder, L. [University of California, San Diego]. "Satisfactions and challenges in spiritual faith and practice for persons with dementia." Dementia 2, no. 3 (October 2003): 299-313.

[Abstract:] This article gives an account of a person who had memory impairment and received pastoral care, with an emphasis on pastoral needs and prayer. The author provides a first-hand account addressing both sides of the pastoral care interaction. She experienced years of memory impairment comparable to mild to moderate Alzheimer's disease. Now, however, she is a seminarian. She provides a detailed account of pastoral care received during the time of memory impairment and considers both the visiting pastor's intent and the author's recollection of the prayer and pastoral care received. Part of the uniqueness of this account is that persons with memory impairment do not usually regain their cognitive functioning and then also obtain pastoral education from which to provide the guidance gained as both patient and pastor.


[Abstract:] We discuss the various stages of Alzheimer's disease and related disorders (ADRD) and present a psychosocial model which spiritual caregivers can use in their ministry, the Progressively Lowered Stress Threshold (PLST) model. We argue that religious activities are very important to these patients and that spiritual caregivers can make an important contribution.


[Abstract:] Procedural and Emotional Religious Activity Therapy is a new approach for involving adults with Alzheimer's disease and related dementias with spiritually-laden activities. This therapy works by incorporating religious activities that are both emotionally-salient and have a procedural memory component. Thus, such activities are meaningful and intrinsically motivating for the adult with dementia. In addition, the procedural memory component is resistant to the neurological damage caused by Alzheimer's disease. Activities that use procedural memory can be employed well into later stages of dementia when activity therapy is more difficult to administer. This approach can be used to mitigate behavioral problems as well as increase quality of life. Due to the flexibility of this therapy, it can be used within a variety of religious paradigms. Guidelines and limitations in the use of this approach are provided.


[Abstract:] With an increasing number of older adults being diagnosed with Alzheimer disease, the need to find meaningful and enjoyable activities in which they can successfully engage is important for providing good quality of life while preventing behavioral difficulties that often accompany this diagnosis. Dementia-related neuropsychological impairments hinder engagement in a variety of enjoyable activities. For many older adults with Alzheimer disease who have been involved in a religious tradition, well-rehearsed rituals and emotionally salient behaviors can be employed well into the later stages of this disease. An approach called procedural and emotional religious activity therapy, or PERAT, can provide enjoyable and meaningful activities that may reduce agitation and increase quality of life for patients as well as for caregivers. Knowledge about the neuropsychology of procedural and emotional memory is needed to understand how PERAT works.


[Abstract:] The author uses case studies to illustrate the effectiveness of two techniques which pastoral caregivers may teach to family carers of dementia patients. In the last stages of dementia, it is important to seek meaning and keep in significant contact as long as possible, both for family members as well as for the dementia patients. After a brief literature review, implications for care theory, practice, and policy are reviewed, and a scientific bias is illustrated. These techniques build on the work of C. G. Jung and James Hillman, utilizing metaphor in non-rational uses of language. It is suggested that pastoral caregivers could teach these techniques to families of this population, in the hope of prolonging meaningful connection with their loved one.