



June 2007 Article of the Month

This month's article selection is by Chaplain John Ehman,
University of Pennsylvania Medical Center-Penn Presbyterian, Philadelphia PA.

Kaufman, Y., Anaki, D., Binns, M. and Freedman, M. [Behavioural Neurology Program, Division of Neurology, Baycrest, Canada; ykaufman@herzoghospital.org]. "**Cognitive decline in Alzheimer disease: impact of spirituality, religiosity, and QOL.**" *Neurology* 68, no. 18 (May 1, 2007): 1509-1514.

SUMMARY and COMMENT: Much of the research on spirituality in relation to Alzheimer's Disease has been focused on caregivers--and their use of spirituality in coping with the stress of caregiving--rather than on the influence of spirituality on patients themselves. However, the present research finds that "[h]igher levels of private religious activities and of spirituality predict slower cognitive decline in patients" with Alzheimer's Disease "after controlling for age, sex, education, and cognitive level at baseline" [p. 1511]

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.

The DUREL is a five-item measure designed to assess organizational and private religious and spiritual practices. The DUREL has three subscales: attendance (one item that asks about frequency of attending a religious meeting), private religious practices (one item that asks about frequency of spending time in private religious activities), and intrinsic religiosity (three items that ask about religious belief or experience). The attendance item assesses frequency of attendance at formal public religious institutions.... The Overall Self-Ranking subscale from the NIH/Fetzer Brief Multidimensional Measure of Religiousness/Spirituality is a two-item scale. ...One item refers to level of religiosity, and the other refers to spirituality. The interviewer asks participants to what extent they assess themselves as being spiritual or religious. [p. 1510].

For more on the DUREL, see: Koenig, H., Parkerson, G. R., Jr. and Meador, K. G., "Religion index for psychiatric research: a 5-item measure for use in health outcome studies," *American Journal of Psychiatry* 154, no. 6 (June 1997): 885-886 or Hill, P. C. and Hood, R. W., eds., *Measures of Religiosity* (Birmingham: Religious Education Press, 1999): 130-132. For the items from the NIH/Fetzer Brief Multidimensional Measure of Religiousness/Spirituality, see: items 37-38 on p. 88 of the [Multidimensional Measurement of Religiousness/Spirituality for Use in Health Research](#) (available as a PDF from the Fetzer Foundation). **[NOTE (added 11/2/09): This online text from Fetzer.org omits the printed booklet's covers, title page, preface, and**

table of contents --reproduced [here](#) and showing the booklet's statement that the publication "may be used and reprinted without special permission."]

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 [--see the discussion on p. 1511].

The authors consider potential weaknesses to their research, such as sample size, unattended variables, and limits to the measures used [--see p. 1512]. Still, the article presents a wealth of statistical data, is concisely written, contains an extensive bibliography, and suggests a number of options for follow-up study. For chaplains who have personally observed how religion/spirituality seem to be powerful aspects of the lives of patients with Alzheimer's, this work by Kaufman, et al. points to intriguing opportunities for further research that may guide pastoral intervention.

Suggestions for the Use of the Article for Discussion in CPE:

The article presents a great deal of information for its brevity, especially regarding statistical results. This may actually be problematic for some CPE students who are not versed in research methodology, but the presentation should be manageable for most students, especially if they are advised to focus on the introductory and discussion sections. Students should appreciate the opening paragraph, which gives a catalogue of research-based connections between spirituality/religion and health [p. 1509]. For CPE groups more interested in the topic of spirituality & Alzheimer's than in research methodology, the article could lead easily to a general discussion of the pastoral care of dementia patients, but methodology could yet play into such discussion by challenging students to think about the practical ramifications of Alzheimer's for patients' religious lives, as suggested by issues like difficulty attending religious services [--see pp. 1511-1512]. The relatively large bibliography [pp. 1512-1514] would provide a good start for any student wishing to develop a residency project on Alzheimer's.

Related Items of Interest:

I. The following articles may be of special interest to researchers. [For a larger bibliography, click [HERE](#).]

[ADDED 8/6/09]: Beuscher, L. and Grando, V. T. "**Using spirituality to cope with early-stage Alzheimer's Disease.**" *Western Journal of Nursing Research* 31, no. 5 (August 2009): 583-598. [(Abstract:) Alzheimer's disease (AD) robs persons living with the disease of their independence and self-esteem, which can lead to depression, anxiety, and loneliness. Understanding how people with early-stage AD cope is a critical step in enhancing their adaptive abilities and ultimately improving their quality of life. 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 reassurance 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.]

[ADDED 11/20/09]: Bormann, J., Warren, K. A., Regalbutto, L., Glaser, D., Kelly, A., Schnack, J. and Hinton, L. "**A spiritually based caregiver intervention with telephone delivery for family caregivers of veterans with dementia.**" *Family and Community Health* 32, no. 4

(October/December 2009): 345-353. [(Abstract:) Caring for veterans with dementia is burdensome for family caregivers. 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 rumination 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.] [Also published in the October-December 2009 special theme issue of *Alzheimer's Care Today* (vol. 10, no. 4, pp. 212-220) on spirituality.]

[ADDED 11/19/09]: Jolley, D., Benbow, S. M., Grizzell, M., Willmott, S., Bawn, S. and Kingston, P. "**Spirituality and faith in dementia.**" [2006]. 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; [published online by the Royal College of Psychiatrists \(Spirituality and Psychiatry Special Interest Group\)](#). [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.]

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.]

[ADDED 11/10/10]: Mackinlay, E. and Trevitt, C. "**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 (December 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 reframe 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 6weeks or 6months. 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'....]

Snyder, L. [Clinical Social Worker, University of California, San Diego's 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 frontal temporal 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.]

II. The articles below do not have a research emphasis but may be of general interest and may provide background and context for the development of studies. [For a larger bibliography, click [HERE](#).]

Bell, V. and Troxel, D. [Lexington/Bluegrass Alzheimer's Association, Lexington, KY]. "**Spirituality and the person with dementia -- a view from the field.**" *Alzheimer's Care Quarterly* 2, no. 2 (Spring 2001): 31-45. [(Abstract:) 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.]

Buckwalter GL. [Director of Pastoral Care, Episcopal Church Home, Louisville, KY; stlukchpl@aol.com]. "**Addressing the spiritual and religious needs of persons with profound memory loss.**" *Home Healthcare Nurse* 21, no. 1 (January 2003): 20-24. [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.]

Carlson, D. and Hellen, C. R. "**Undo the box--celebrate the gift: spirituality and activity.**" *Alzheimer's Care Quarterly* 1, no. 2 (Spring 2000): 56-66. [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.]

Clayton, J. [St. Joseph's Health Center, London, Ontario, Canada]. "**Let there be life: an approach to worship with Alzheimer's patients and their families.**" *Journal of Pastoral Care* 45, no. 2 (1991): 177-179. [(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 sermon or homily.]

Elliot, H. [University of Sydney, School of Studies in Religion, Australia]. "**Religion, spirituality and dementia: pastoring to sufferers of Alzheimer's disease and other associated forms of dementia.**" *Disability and Rehabilitation* 19, no. 10 (October 1997): 435-441. [(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.]

Everett D. [General Hospital of Edmonton, Alberta, Canada]. "**Forget me not: the spiritual care of people with Alzheimer's Disease.**" *Journal of Health Care Chaplaincy* 8, nos. 1-2 (1999): 77-88. [(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.]

[ADDED 11/19/09]: Higgins, P., Allen, R., Karamat, S., and Lawrence, R. "**Candlelight Group: a pilot project for people with dementia.**" [2004]. [Paper published online by the Royal College of Psychiatrists \(Spirituality and Psychiatry Special Interest Group\)](#). [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 that the prayer group 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.

[ADDED 11/20/09]: Karlin, N. J., Alejandra, E. and Torres, A. "**Hispanic family members and caring for those with Alzheimer's Disease.**" *Alzheimer's Care Today* 10, no. 4 (October-December 2009): 191-203. [(From the abstract:) Hispanic care providers report high levels of self-efficacy with regard to being a caregiver, an overall satisfaction with support provided, and burden levels that suggest a need for follow-up. Participants indicated a desire for more knowledge, improved caregiving skills, and more emotional support. The respondents stated that the spiritual side of life and religious involvement were important both prior to and as a caregiver....] [This is part of a special issue in *Alzheimer's Care Today* on spirituality.]

[ADDED 11/19/09]: Mooney, S. F. [Regis University, Denver, Colorado; sfmooney@adelphia.net]. "**A ministry of memory: spiritual care for the older adult with dementia.**" *Care Management Journals* 5, no. 3 (2004): 183-187. [(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.]

Post, S. G. [School of Medicine, Case Western Reserve University, Cleveland, OH]. "**God and Alzheimer's: a neurological reflection on religious experience, self, and soul.**" *Park Ridge Center Bulletin* 19 (January-February 2001): 9-10. [This article is available on-line at

<http://www.parkridgecenter.org/Page482.html> (--you must copy and paste this address into your browser).]

Post, S. G. and Whitehouse, P. J. [Center for Biomedical Ethics, Department of Religion, Case Western Reserve University, Cleveland, OH]. "**Spirituality, religion, and Alzheimer's disease.**" *Journal of Health Care Chaplaincy* 8, nos. 1-2 (1999): 45-57. [(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 even 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.]

Roff, L. L. and Parker, M. W. "**Spirituality and Alzheimer's disease care.**" *Alzheimer's Care Quarterly* 4, no. 4 (October-December 2003): 267-270. [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).]

[ADDED 11/20/09]: Ruder, S. "**Incorporating spirituality into the care of persons with Alzheimer's Disease.**" *Alzheimer's Care Today* 10, no. 4 (October-December 2009): 221-227. (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.]

Stolley, J. M., Koenig, H. and Buckwalter, K. C. [Trinity College of Nursing, Moline, IL]. "**Pastoral care for the person with dementia.**" *Journal of Health Care Chaplaincy* 8, nos. 1-2 (1999): 7-23. [(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.]

Vance, D. E. [NIH/NIA Postdoctoral Fellow, Edward R. Roybal Center for Research in Applied Gerontology, University of Alabama at Birmingham; devance@uab.edu]. "**Procedural and emotional religious activity therapy: connecting cognition and affective aspects of Alzheimer's disease.**" *Activities, Adaptation & Aging* 29, no. 1 (2004): 27-45. [(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.]

Wentroble, D. P. [Greenwich Chaplaincy Services, Greenwich, CT]. "**Pastoral care of problematic Alzheimer's disease and dementia affected residents in a long-term care setting.**" *Journal of Health Care Chaplaincy* 8, nos. 1-2 (1999): 59-76. [(Abstract:) Pastoral caregivers face

many challenges in providing ministry to institutional persons with dementia. This article describes the psychosocial perspective of Bowlby concerning the management of persons with dementia and a pastoral care ministry based on it. Specific pastoral programs and interventions are described. The article contains four case studies and concludes with reflections concerning the chaplain's ministry.]

[ADDED 11/19/09]: Woodman, C. E. [Stillwater United Church, 135 North Hudson Avenue, Stillwater, NY 12170]. "**Seeking meaning in late stage dementia.**" *Journal of Pastoral Care and Counseling* 59, no. 4 (2005): 335-343. [(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.]

III. It is worth noting that while relatively little research has been published on the spirituality of Alzheimer's patients, one of the major ongoing Alzheimer's research projects is the Religious Orders Study (sometimes called "The Nun Study"), which has closely followed over a thousand Catholic nuns, priests, and brothers. For more information on this project, including access to "The Palm Tree: The Religious Orders Study Newsletter," go to the [Rush University Medical Center's program description page](#).

If you have suggestions about the form and/or content of the site, e-mail Chaplain John Ehman (Network Convener) at john.ehman@uphs.upenn.edu .

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