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January 2008 Article of the Month

This month's article selection is by Chaplain John Ehman,
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Pakenham, K. I. "Making sense of illness or disability: the nature of sense making in Multiple Sclerosis (MS)." *Journal of Health Psychology* 13, no. 1 (January 2008): 93-105.

COMMENT and SUMMARY: This month's article addresses two subjects of interest to chaplains: the importance of spirituality for people suffering from chronic illness--and especially Multiple Sclerosis--and the role of religious-spiritual belief in the process of *sense making* during illness. As with the vast majority of studies in spirituality & health at this point in the development of the field, the principal value of this research lies not so much in the results per se but in how those results suggest areas for further research. In this case, the finding that should stand out to chaplains is that "[p]articipants who reported having a religious-spiritual belief were more likely to report sense making than those who did not have such a belief" [p. 93, abstract]. The [Journal of Health Psychology](#) is an international, interdisciplinary journal that regularly publishes articles on spirituality, and while it has limited library holdings in the US, this month's article should be easily obtainable through interlibrary loan.

The study is well presented, beginning with an introduction to the psychological context of chronic illness which can "force a range of physical and symbolic losses such as the loss of function and loss of role identity that oscillate over time and require an ongoing process of adjustment"--losses that can "disrupt a person's self-definition, fundamental life goals and sense of meaningfulness" [p. 94]. Multiple Sclerosis may be "particularly threatening to an individual's sense of meaning" because of such factors as:

...the aetiology of MS remains largely unknown, it is usually degenerative, there is currently no cure, the disease course is variable, acute exacerbations can occur unpredictably, clinical symptoms vary widely and affect sensory-tactile, motor, visual, bladder, sexual and bowel functioning producing severe multiple disabilities (e.g., mobility, visual and speech impairments), the psychosocial consequences are profound (e.g., disruptions in employment, sexual functioning and activities of daily living), and onset is most often in young adulthood...[when it is]...likely to interfere with unrealized life plans.... [p. 94]

The author relates this circumstance of illness to the idea of *sense making* as central to the adjustment process:

Cognitive and trauma theories suggest that the most difficult negative life events are those that fail to make sense, throwing everything into doubt and turmoil that once held meaning. ...To reduce distress, redefine self and restore order, purpose and predictability, the individual strives to find reasons or an explanation for what has happened. [p. 94]

This process of "find[ing] reasons or an explanation for what has happened" is what Pakenham focuses on as *sense making* --one type of meaning making process. The goal of sense making is to *comprehend* what has happened in adversity (and this is distinguished by the author from the connected meaning-making process of *benefit finding*). Pakenham cites a number of theorists and researchers in discussing sense making, but he appears to rely most heavily here (and in some previous publications) on the work of [Ronnie Janoff-Bullman](#).

The study used a qualitative/quantitative mixed methodology by which 1570 members of the MS Society of Queensland, Australia, were mailed questionnaires. The final analysis comes from 388 completed questionnaires. Among the assessments, religious-spiritual belief was measured by asking whether "you consider yourself to be religious or have spiritual interests" [p. 96]. Sense making was measured in three ways:

The first was a closed question: *People make sense of their having an illness in different ways. For example, some have made sense of their having an illness by believing that it is fate or that their illness is a 'wake up call' to change their lifestyle. Do you feel that you have been able to make sense of or comprehend your having MS? Yes/No.* The second was an open-ended question, if the respondent answered *yes* to the previous question, he/she was asked to explain *what sense you have made of your having MS.* ... Third, as a measure of anticipated sense making, respondents were asked to rate on a four-point scale ...*the extent to which the following statement is characteristic of you: I believe that I will eventually be able to make sense of or comprehend my having MS, even if I am not able to make sense of it at this time.* [pp. 96-97]

Results indicated that "more (52%) participants reported sense making who had a religious-spiritual belief than participants who did not identify such a belief (36%)" [p. 100]. Evidence of this "beneficial link between sense making and religious-spiritual beliefs and adjustment" [p. 103] is cited by the author as one of five important findings, the others being:

...approximately half of the sample generated a variety of sense making explanations for their illness, ...over a third of those who could not make sense of their MS were able to anticipate comprehending their illness and the strength of this anticipation was related to greater life satisfaction, ...lower disability and disease severity and shorter illness duration were related to sense making, and ...sense making evidenced a beneficial direct effect on positive adjustment outcomes and depression after controlling for the effects of illness and religious-spiritual belief. [p. 101]

Chaplain researchers may be especially interested in 16 sense making categories derived from the qualitative data [Table 2 on p. 99]. Spiritual-religious explanations constitute one category and "included themes such as MS represent[ed] a test of spirituality or faith, God's will, destiny, being 'chosen,' and growth in faith or spirituality" [p. 98].

Meaning making and/or sense making has to date been investigated primarily in relation to acute illness, trauma, or bereavement. The present study "provides the only published mixed method data from a large sample on sense making in the MS field specifically and the chronic illness area more generally" [p. 102]. Pakenham lists a number of questions for further research and discusses briefly the limits of this study [--see pp. 102-103], but one question that chaplain researchers may wish to explore is whether the data were influenced by the way that religious-spiritual belief was measured or by the reference to "fate" in the construction of the first part of the sense-making assessment. Chaplains may also want to investigate how sense-making may influence or be influenced by *benefit finding* from a religious/spiritual standpoint, and how the process of sense making may not only be encouraged by religious-spiritual beliefs but may lead to changes in those beliefs (as has been addressed elsewhere in relation to the circumstance of acute trauma, in the [May 2005](#) Article of the Month).

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

This month's article may be best suited for students in the latter half of their CPE programs or advanced students who have significant clinical experience with patients trying to make sense of their illness and overall situation. The subject of *sense making* (and of meaning making, more generally) is full of possibilities for discussion, but students might start off by thinking about Pakenham's references to a person's "assumptive world" [p. 94 and *passim*], and the comment that "the search for meaning can be triggered not only by a seismic shattering of the assumptive world,' but also through a more gradual breakdown of the assumptive world" [p. 103], as can happen with chronic illness. Students may even want to relate this to their own processes of sense making in the course of their lives, or to what some of them may be struggling with during the course of CPE. Another concept mentioned in the article that may intrigue students is the that of the "ruminative trap" [pp. 102 and 103]. The article obviously also provides an opportunity to discuss Multiple Sclerosis, and such a discussion might include an invited guest: health care specialist, a representative from an MS organization, or even a patient.

Related Items of Interest:

I. Students may wish to read more of Kenneth Pakenham's work, including that on the related meaning making dynamic of *benefit finding* in MS patients and other groups.

Dunn, J., Lynch, B., Rinaldis, M., Pakenham, K., McPherson, L., Owen, N., Leggett, B., Newman, B. and Aitken, J. "**Dimensions of quality of life and psychosocial variables most salient to colorectal cancer patients.**" *Psycho-Oncology* 15, no. 1 (January 2006): 20-30. [This qualitative study, consisting of analysis of 15 in-depth, open-ended interviews with colorectal cancer patients, identified themes related to quality of life and psychosocial variables, including making sense of the cancer experience. See the brief account of findings about sense making on p. 27 as well as the observation on p. 29 that "being able to find beneficial effects of the diagnosis...seemed to enable these individuals to make sense of their experience." Spirituality is also mentioned in passing.]

McCausland, J. and Pakenham, K. I. "**Investigation of the benefits of HIV/AIDS caregiving and relations among caregiving adjustment, benefit finding, and stress and coping variables.**" *AIDS Care* 15, no. 6 (December 2003): 853-869. [The present study explored the nature of benefit finding in HIV/AIDS caregiving, and examined relations among caregiver adjustment, benefit finding, and stress and coping variables. A total of 64 HIV/AIDS caregivers and 46 care recipients completed interviews and questionnaires. First, the study aimed to explore the types of benefits associated with HIV/AIDS caregiving. Content analyses of caregiver responses to an interview question inquiring about gains from caregiving revealed eight benefit themes. Second, the study aimed to examine relations between caregiver adjustment and both benefit finding and stress and coping variables. We hypothesized that number of caregiver reported benefits, social support, challenge and control appraisals, and problem focused coping would be inversely related to poorer adjustment, whereas care recipient reported global distress and illness, caregiver threat appraisal and passive-avoidant emotion-focused coping would be positively associated with poorer adjustment. Correlations indicated that poorer adjustment (measured by global distress, depression, caregiving impact, social adjustment and health status) was positively correlated with care-recipient distress, threat appraisals and passive avoidant coping and inversely correlated with social support, and number of reported benefits. Unexpectedly, problem-focused coping, controllability and challenge appraisals, and care recipient illness were unrelated to adjustment. Third, the study aimed to examine relations between benefit finding and stress and coping variables. Correlations indicated that benefit finding was related to social support use, seeking social support coping and problem-solving coping. Findings indicate that the benefit finding and stress/coping frameworks have utility in guiding research into adaptation to HIV/AIDS caregiving. Results also indicate targets for intervention in the provision of services for HIV/AIDS caregivers.]

Pakenham, K. I. "**Benefit finding in Multiple Sclerosis and associations with positive and negative outcomes.**" *Health Psychology* 24, no. 2 (March 2005): 123-132. [(Abstract:) This study examined the direct and stress-buffering effects of benefit finding on positive and negative outcomes. A total of 502 people with multiple sclerosis completed a questionnaire at Time 1 and, 3 months later, at Time 2 (n = 404). Measures of illness were collected at Time 1, and number of problems, stress appraisal, benefit finding, subjective health, and negative (global distress, negative affect) and positive (life satisfaction, positive affect, dyadic adjustment) outcomes were measured at Time 2. Factor analyses showed the Benefit Finding scale to have 2 dimensions: Personal Growth and Family Relations Growth. Hierarchical regressions showed that after controlling for the effects of demographics, illness, problems, and appraisal, benefit finding showed strong direct effects on the positive outcomes. Benefit finding did not have a direct effect on distress or subjective health but had a weak association with negative affect. Family Relations Growth had a stress-buffering effect on distress.]

Pakenham, K. I. "**The nature of benefit finding in Multiple Sclerosis (MS).**" *Psychology Health & Medicine* 12, no. 2 (March 2007): 190-196. [(Abstract:) This study examined the nature of benefit finding in MS and the adequacy of the Benefit Finding Scale (BFS; Mohr et al., 1999) as a comprehensive measure of perceived benefits in MS. A total of 502 people with MS completed questionnaires at Time 1 and 3 months later, Time 2 (n=404). Data on demographics and illness were collected at Time 1 and qualitative data on benefit finding was obtained at Time 2. Content analyses revealed seven benefit finding themes (personal growth, strengthening of relationships, appreciation of life, new opportunities, health gains, change in life priorities/goals and spiritual growth). Two of the themes were represented by several items on the BFS (personal, relationship growth), three were not reflected by items on the BFS (health, new opportunities, life priorities) and two were represented by one item each (spiritual, life appreciation).]

Pakenham, K. I. "**The positive impact of Multiple Sclerosis (MS) on carers: associations between carer benefit finding and positive and negative adjustment domains.**" *Disability and Rehabilitation* 27, no. 17 (September 2, 2005): 985-997. [(Abstract:) **PURPOSE:** This study examined benefit finding in MS carers including the dimensionality of benefit finding, relations between carer and care recipient benefit finding, and the effects of carer benefit finding on carer positive and negative adjustment domains. **METHOD:** A total of 267 carers and their care recipients completed questionnaires at Time 1 and 3 months later, Time 2 (n = 155). Illness data were collected at Time 1, and number of problems, stress appraisal, benefit finding, negative (global distress, negative affect) and positive (life satisfaction, positive affect, dyadic adjustment) adjustment domains were measured at Time 2. **RESULTS:** Qualitative data revealed seven benefit finding themes, two of which were adequately represented by the Benefit Finding Scale (BFS). Factor analyses indicated two factors (Personal Growth, Family Relations Growth) which were psychometrically sound and showed differential relations with illness and adjustment domains. Although care recipients reported higher levels of benefit finding than carers, their benefit finding reports regarding personal growth were correlated. The carer BFS factors were positively related to carer and care recipient dyadic adjustment. Care recipient benefit finding was unrelated to carer adjustment domains. After controlling for the effects of demographics, care recipient characteristics, problems and appraisal, carer benefit finding was related to carer positive adjustment domains and unrelated to carer negative adjustment domains. **CONCLUSION:** Findings support the role of benefit finding in sustaining positive psychological states and the communal search for meaning within carer -- care recipient dyads.]

Pakenham, K. I. "**Making sense of Multiple Sclerosis.**" *Rehabilitation Psychology* 52, no. 4 (November 2007): 380-389. [(Abstract:) **Objective:** In this study, the aim was to examine the dimensional structure of a multi-item measure of sense making in people with multiple sclerosis (MS) and to investigate relations between sense making and both positive and negative adjustment outcomes. **Method:** Participants were 408 persons with MS and 232 caregivers. Questionnaires were completed at the initial assessment (Time 1) and 12 months later (Time 2). **Results:** Factor

analysis of the Sense Making Scale (SMS) revealed 6 psychometrically sound factors: Redefined Life Purpose, Acceptance, Spiritual Perspective, Luck, Changed Values and Priorities, and Causal Attribution. Results of regression analyses indicated that the Time 2 SMS factors accounted for significant amounts of variance in each of the Time 2 adjustment outcomes (life satisfaction, positive states of mind, anxiety, depression, caregiver adjustment rating of the care receiver), after controlling for Time 1 adjustment and relevant demographic and illness variables. Conclusions: Findings delineate the dimensional structure of sense making in MS and the differential links between sense making dimensions and adjustment and have implications for the measurement of sense making.]

[ADDED 10/30/08]: Pakenham, K. I. and Cox, S. "**Development of the benefit finding in multiple sclerosis (MS) caregiving scale: a longitudinal study of relations between benefit finding and adjustment.**" *British Journal of Health Psychology* 13, pt. 4 (November 2008): 583-602. [Benefit finding (BF) is a meaning-making construct that has been shown to predict carer and care recipient adjustment. PURPOSE: This longitudinal study investigated the dimensions, stability, and validity of the benefit finding in multiple sclerosis caregiving (BFiMSCare) scale. METHODS: Participants were 232 carers of persons with MS and their care recipients. Questionnaires were completed at Time 1 and 12 months later (Time 2). RESULTS: Factor analysis of the BFiMSCare scale revealed six psychometrically sound factors: enriched relationship; spiritual growth; family relations growth; life-style gains; inspiration; and relationship opportunities. Results of regression analyses indicated that the Time 1 BFiMSCare factors and the total score accounted for significant amounts of variance in each of the Time 1 positive adjustment outcomes (life satisfaction, positive affect, dyadic adjustment) and in Time 2 positive affect and dyadic adjustment. The BFiMSCare total score predicted all Time 2 adjustment domains (positive affect, dyadic adjustment, care recipient adjustment ratings of carer) except life satisfaction and distress, whereas the six factors as a block predicted positive affect and life satisfaction. CONCLUSIONS: Findings delineate the dimensional structure of BF in caregiving and the differential links between BF dimensions and adjustment, and have implications for the measurement of BF.]

Pakenham, K. I., Sofronoff, K. and Samios, C. "**Finding meaning in parenting a child with Asperger syndrome: correlates of sense making and benefit finding.**" *Research in Developmental Disabilities* 25, no. 3 (May-June 2004): 245-264. [(from the abstract:) This study explored the nature of two construals of meaning, benefit finding and sense making, in parents of a child with Asperger syndrome, and examined relations between both meaning constructs and the Double ABCX family stress model variables (initial stressor and pile-up of demands, appraisal, social support, coping strategies and adjustment)... A total of 59 parents completed questionnaires. Content analyses of parents' responses to questions inquiring about gains and sense making explanations revealed 8 benefit and 12 sense making themes. Results of correlations indicated that one or more of the meaning variables were related to each of the Double ABCX model predictors of parental adjustment. The meaning variables were positively related to adaptive coping processes: social support, self-efficacy, and problem-focused and emotional approach coping strategies.]

II. The following articles note religion/spirituality in patients dealing with Multiple Sclerosis (in addition to Pakenham's, "Making sense of Multiple Sclerosis" and "The nature of benefit finding in Multiple Sclerosis (MS)," noted in Part I, above).

Benjamins, M. R. and Finlayson, M. "**Using religious services to improve health: findings from a sample of middle-aged and older adults with Multiple Sclerosis.**" *Journal of Aging and Health* 19, no. 3 (June 2007): 537-553. [(Abstract:) PURPOSE: The purpose of this study is to examine the use of religious services to improve health among middle-aged and older adults with multiple sclerosis (MS). METHOD: Data from the study "Aging With MS: Unmet Needs in the Great Lakes Region" were used to investigate religious service use among 1,275 adults with MS. RESULTS: The findings indicate that nearly two thirds of the sample currently use religious

services to improve their health or well-being. Individuals whose MS is stable and those who have had the disease longer are significantly more likely to use religious services to improve their health. CONCLUSIONS: Religious organizations should continue providing out-reach and increasing accessibility for individuals with disabling conditions. In addition, health care professionals should be aware of the importance of religious services to individuals with MS and do their part to facilitate participation for those who desire it.]

Breitbart, W. "**Living with Multiple Sclerosis: a spiritual journey of loss.**" *Palliative and Supportive Care* 2, no. 3 (September 2004): 319-320. [This is a personal reflection by a physician who is well published in the field of spirituality & health and whose wife has MS.]

Finlayson, M., Van Denend, T. and Hudson, E. "**Aging with Multiple Sclerosis.**" *Journal of Neuroscience Nursing* 36, no. 5 (October 2004): 245-251 and 259. [In this study involving 27 people 55-years and older, one of the themes of "unmet needs" that emerged was that of religious service attendance.]

McNulty, K., Livneh, H. and Wilson, L. M. "**Perceived uncertainty, spiritual well-being, and psychosocial adaptation in individuals with Multiple Sclerosis.**" *Rehabilitation Psychology* 49, no. 2 (May 2004): 91-99. [(Abstract:) Objective: To examine the role of spiritual well-being as a mediator and moderator between perceived uncertainty and psychosocial adaptation to multiple sclerosis (MS). Participants and Design: Fifty individuals (40 women, 10 men) diagnosed with multiple sclerosis. Main Outcome Measures: Self-report measures on illness uncertainty, spiritual (religious and existential) well-being, and psychosocial adjustment to illness were analyzed by a series of hierarchical multiple regression analyses. Results: Both uncertainty and spiritual well-being independently predicted psychosocial adjustment to MS after the influence of demographic and disability-related variables were considered. Spiritual well-being demonstrated a mediator effect but, mostly, failed to show a moderator effect. Conclusion: Spiritual well-being exerts an appreciable influence on adaptation to MS and also acts to mitigate the impact of uncertainty on adaptation. Rehabilitation psychologists may wish to consider its beneficial role as part of their clinical work.]

Mohr, D. C., Dick, L. P., Russo, D., Pinn, J., Boudewyn, A. C., Likosky, W. and Goodkin, D.E. "**The psychosocial impact of Multiple Sclerosis: exploring the patient's perspective.**" *Health Psychology* 18, no. 4 (July 1999): 376-382. [(Abstract:) This study examined subjective patient experiences of the psychosocial consequences of multiple sclerosis (MS). Fifty patients were interviewed regarding the effects MS had on their lives and interpersonal relationships. These statements were collated and administered with a 5-point Likert scale to 94 MS patients. The responses were subjected to factor analysis. Three areas of subjective patient experience of the psychosocial consequences of MS emerged: demoralization, benefit-finding, and deteriorated relationships. Of particular interest was benefit-finding, which included a deepening of relationships, enhanced appreciation of life, and an increase in spiritual interests. Although benefit-finding was related to adaptive coping strategies such as positive reappraisal and seeking social support, it was unrelated to depression and was related to higher levels of anxiety and anger. These findings indicate that benefit-finding is a substantial and poorly understood part of the illness experience for MS patients.]

III. Other recent articles of special note regarding religion/spirituality and the search for meaning in illness:

Greenstreet, W. "**From spirituality to coping strategy: making sense of chronic illness.**" *British Journal of Nursing* 15, no. 17 (September 28-October 11, 2006): 938-942. [(Abstract:) This article explores how individuals might make sense of chronic illness. The spiritual aspect of self is described both as being central to finding meaning in suffering with a chronic illness and also the source of hope in meeting the challenges faced. Culture as the template for interpreting the significance of chronic ill health at a personal, familial and societal level is also considered. A conceptual model for understanding life transitions is modified to incorporate the spiritual and

cultural perspectives of making sense of chronic illness in relation to coping skills. In understanding how patients make sense of their circumstances nurses are more likely to be able to offer appropriate support to effect coping.]

Park, C. L. "**Religion as a meaning-making framework in coping with life stress.**" *Journal of Social Issues* 61, no. 4 (December 2005): 707-729. [This article is part of a special theme issue of the [Journal of Social Issues](#) on Religion as a Meaning System. See particularly Crystal Park's model in Figure 1 on p. 709. (Abstract:) This article explores how religion, as a meaning system, influences coping with adversity. First, a model emphasizing the role of meaning making in coping is presented. Next, religion as a meaning system is defined, and theory and research on the role of religion in the coping process are summarized. Results from the author's study of 169 bereaved college students are then presented to illustrate some of the pathways through which religious meaning can influence the coping process in making meaning following loss. Findings indicate that associations between religion and adjustment vary across time since loss, and that these associations are mediated by meaning-making coping. Finally, implications for individual and societal well-being and suggestions for future research are discussed.]

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