



[[Back to the Articles of the Month Index Page](#)]

June 2004 Articles of the Month

This month's article selection is by Chaplain John Ehman,
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McGrath, P. [School of History, Philosophy, Religion and Classics, University of Queensland, St. Lucia, Australia]. "**Spiritual pain: a comparison of findings from survivors and hospice patients.**" *American Journal of Hospice and Palliative Care* 20, no. 1 (January/February 2003): 23-33.

Strang, P., Strang, S., Hultborn, R. and Arner, S. [Department of Oncology and Pathology, Karolinska Institutet, SSH, Mariebergsg 22, 112-35 Stockholm, Sweden]. "**Existential pain--an entity, a provocation, or a challenge?**" *Journal of Pain and Symptom Management* 27, no. 3 (March 2004): 241-250.

BACKGROUND: Language used in the literature of spirituality & health often contains imprecise, ambiguous, or at least poorly defined terms. This is a problem for research in the field, and one reason why there is a drive for greater clarity and standardization of concepts about spirituality in the health care context. It is also a problem to be addressed *through* research for the authors of this month's featured articles, focusing on the concepts of spiritual pain and existential pain. The concept of pain itself has developed in the clinical literature over the last 20 years and is now often seen to involve multiple dimensions, including a spiritual dimension. Such an idea has been championed by Cicely Saunders and the hospice movement as constituent to the idea of "total pain" in the dying, though understanding pain as having spiritual and other dimensions has also been encouraged by the growth of a holistic approach to health care in general, not only in end-of-life care.

At present, the language of "spiritual pain" in the literature is part of a developing conceptualization of *pain* itself paired with a developing conceptualization of *the spiritual* (--for more on the latter, see the September 2002 Article-of-the-Month page, addressing current health care definitions of *spirituality*). When such a combination of developing terms is used, it is worth asking, in any particular instance, which term a given author believes most basic and which term is secondary. Indeed the literature seems to cleave accordingly: the writers who ground their perspective in *pain* (as in this month's articles) seem--at least to this reader--to debate the concept of *spirituality*, using terms like *spiritual* and *existential*; and those who ground their perspective in *spirituality* seem to debate the concept of *pain*, using terms like *distress* (as in the NANDA nursing diagnosis of "spiritual distress"), *problem* (as in the DSM-IV classification of "spiritual problem"), and sometimes merely *suffering*.

It is worth noting that in pastoral care circles there is no common language in this area that could be offered to the health care literature to help standardize conceptualizations. Pastoral care writers sometimes use the broad terminology of spiritual *suffering* or *struggle* or *crisis*, but they seem often to tend toward poetic descriptions and analogies, comparing situations to St. John of the Cross' *Dark Night of the Soul* or perhaps Martin Luther's

sense of *Anfechtung*. In the Winter 2003 issue of the *Journal of Pastoral Care and Counseling* [see Other Items of Interest, below], an overview of spiritual pain begins with author Rod Burton's admission that he was unfamiliar with the term before being asked by a hospice group to give a presentation on it. Such is an illustration of how the world of pastoral care is often unaware of the conceptual development about spirituality that is occurring in health care.

THE McGRATH ARTICLE: Pam McGrath's article shows just how differently the health care research literature can treat the concept of spirituality than does most pastoral literature, for even though she has chosen to explore the language of "*spiritual* pain," she barely mentions religion--or, indeed, theism [but see esp. p. 31]. Her focus is on "non-theological notions" [p. 31], and her working understanding of spiritual pain may be found in her description of its "core etiological factors" that "include a sense of diffuse emotional/existential/intellectual pain directly related to the meaninglessness created as a result of a break with the expected/normal network of relationships that function to connect one to life" [p. 24]. So, for some pastoral care researchers, the results of the study may not seem at a glance to be very engaging, but this research from Australia is valuable, especially for its methodological implications.

The first reason this research is valuable lies in its overall approach to the task of *researching a concept*, in this case that of spiritual pain.

As an exploratory, qualitative research program, the *modus operandi* is to bracket preconceived assumptions about spirituality and explore the dimension through the phenomenological insights of those coping with the impact of serious illness. The conceptual starting point has been to build on, or challenge, the definitional assumptions about spirituality found in the literature. Although there is, as yet, no agreement, recent definitions posit "meaning making" and "experience as person" as the starting point for the exploratory research on spirituality. [p. 23]

With the current health care literature frequently working out of essentially non-theistic definitions of spirituality, the author may be justified in following the conceptual line that she does (though, of course, the literature is hardly devoid of definitions that revolve around the importance of religious traditions and "the sacred"). Her method could nevertheless be instructive to pastoral care researchers, even as they may view the notion of spirituality in the literature with greater theological/religious interest. The task of testing definitions of spiritual pain through research with a population believed to be experiencing it would seem a sound approach. In this case, fourteen hospice patients were interviewed, beginning with the prompt: "Could you tell me of your experience, in your own words and in your own way, from the time you became aware that you were ill and how that has changed how you see the world and what you believe is important?" [p. 24]. Interviews were transcribed and analyzed thematically by a process of coding responses and using the NUD*IST computer program.

The second reason that this research is important is that the author compares her results from hospice patients with those from a previous study of survivors of serious illness and discovers that hospice patients seem to indicate less spiritual pain than survivors report having experienced. This is not, according to the author, because of a lesser experience of personal loss or the trials of illness by hospice patients but because such trying experiences did not appear to engender so much meaninglessness. She addresses this rather counterintuitive finding by suggesting that "the opportunity that the hospice experience provides for patients to remain in their own homes, within the network of supportive family relationships, affirms meaning making and deflects the possibility of cumulative spiritual pain and the void of meaninglessness" [p. 25]. Actually, the research found among the hospice patients a strong sense of life satisfaction, in contrast to spiritual pain, as conceptualized here.

Pastoral care researchers may take these findings as a call to investigate not only how spiritual pain may be experienced at various points along the course from initial diagnoses to the final days of dying, but also how programs like in-home hospice may support patients spiritually, exploring further the connection between meaning-making, interpersonal relationships, and spirituality amid illness. Hospice chaplains, especially, may be in a prime position to capture through research the impact of their programs on the spiritual aspects of the

"total pain" of patients. In the process, chaplains may also contribute to definitional clarity about spiritual pain in the literature.

THE STRANG, ET AL. ARTICLE: If the article by McGrath contains overtones of existentialism, that by Peter Strang, et al. explicitly uses the very language of "existential pain." This recent Swedish study involving 173 hospital chaplains, 115 palliative care physicians, and 113 pain specialists, straightforwardly asked participants the question, "How do you define the concept of existential pain?" [p. 244]. The results show how "different groups define it differently" [p. 249], thus making the term problematically ambiguous for interdisciplinary communication. Chaplains tended to think in terms of "guilt, isolation, and religious questions, such as that of God's absence, prayer, and unexplained relationship to God or faltering faith" [p. 245]. In contrast, physicians focused more on death anxiety, with palliative physicians stressing "death anxiety related to annihilation, meaning of life questions and impending separation" [p. 246]. Pain specialists emphasized "painful living, that life hurts" [p. 246], much along the lines of the experience of chronic physical pain.

All three groups tended to think of existential pain as having more to do with *suffering* than with physical pain, and when they used the word *pain* they frequently used it as an abstraction, a metaphor. As to whether such suffering was even associated with physical pain in the minds of respondents, among the chaplains, "only 1%...emphasized that in certain cases strong existential suffering can be expressed as physical pain" [p. 246], but 32% of both palliative physicians and pain specialists made the connection. "The difference between chaplains and physicians was significant ($P < 0.00001$). These physicians explained that existential suffering could reinforce physical pain that already exists, or constitute the primary cause of the pain" [p. 246].

The authors provide two quite good graphs of analyses of responses. One breaks down the incidence of themes according to Irving Yalom's four existential domains of freedom, meaning & meaninglessness, existential isolation, and death [see p. 246]. The other compares the frequency of sixteen key words used in responses [see p. 248]. The article also begins with a relatively thorough introduction to the development of the concept of existential pain in relation to "total pain" and philosophical understandings of suffering in an existentialist context. The introduction comprises about a third of the text of the article and may be interesting to readers on its own.

The article by Strang and his colleagues would seem to be of particular interest to chaplain researchers, in that it lays out a research project that virtually begs to be replicated. Not only does this research highlight differences in the way that chaplains, physicians, and pain specialists think about concerns that may be grouped together under the heading of existential pain, but it makes a solid contribution in pointing up practical problems in interdisciplinary communication about matters of existential or spiritual pain or suffering. The more we are aware of ambiguities in our language the better we may intentionally seek clarity in our communication as professionals and address the concerns of patients.

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

Both articles are quite readable and do not require an extensive understanding of research methodology, though both exemplify a qualitative approach of analyzing narrative responses by thematic coding--a method potentially useful to CPE students doing research. The **McGrath** article may be most interesting to hospice chaplains or students concentrating on critical illness and loss (especially *loss of self*), though they may be dissatisfied with the relatively little attention afforded to religious beliefs [see p. 31]. The article may easily lead into a general discussion of the personal experience of critically and terminally ill patients and the factors that may connect people to a sense of the value of living. The many patient quotes used by the author to illustrate the research findings offer a wealth of insight and may help students to see how such research is in some ways an extension of verbatim analysis. However, the study by **Strang, et al.** may be more engaging to students as research per se and as a piece that considers the perspective of a population of chaplains. As an exercise prior to reading the article, students might be asked the study's central question, so that their own responses may be discussed in comparison. Group discussion could also follow the tangent of what other terms used in the clinical

context may be ambiguous or used differently by chaplains than by professionals from other disciplines. Furthermore, students might be pressed to think about the practical relationship of spiritual or existential pain or suffering to physical pain in patients.

Other Items of Interest:

[ADDED 11/18/04]: Bartel, M. "**What is spiritual? What is spiritual suffering?.**" *The Journal of Pastoral Care and Counseling: JPCC* 58, no. 3 (Fall 2004): 187-201.

Burton, R. "**Spiritual pain: a brief overview and an initial response within the Christian tradition.**" *The Journal of Pastoral Care and Counseling: JPCC* 57, no. 4 (Winter 2003): 437-446.

[ADDED 10/17/06]: Mako, C., Galek, K. and Poppito, S. R. "**Spiritual Pain among Patients with Advanced Cancer in Palliative Care.**" *Journal of Palliative Medicine* 9, no. 5 (October 2006): 1106-1113.

McGrath, P. "**Creating a language for 'spiritual pain' through research: a beginning.**" *Supportive Care in Cancer* 10, no. 8 (November 2002): 637-646. [Comment by Musi, M., "Creating a language for 'spiritual pain': why not to speak and think in terms of 'spiritual suffering'?" in *Supportive Care in Cancer* 11, no. 6 (June 2003): 378-379; author reply: 380-381.]

Saunders, C. "**Spiritual pain.**" *Journal of Palliative Care* 4, no. 3 (September 1988): 29-32.

[ADDED 3/8/05]: For more on Pam McGrath's work, see the [March 2005 Article-of-the-Month](#) page.]

NOTE [ADDED 8/16/06]: The term *spiritual pain* also turns up in a number of titles in the Japanese health care literature. See, for instance these articles from *Palliative and Supportive Care* :

Murata, H. "**Spiritual pain and its care in patients with terminal cancer: construction of a conceptual framework by philosophical approach.**" *Palliative and Supportive Care* 1, no. 1 (March 2003): 15-21. [" ...In this article, spiritual pain is defined as "pain caused by extinction of the being and the meaning of the self," and its structure was evaluated according to the three dimensions of the human being, that is, a being founded on temporality, a being in relationship, and a being with autonomy. ...As a result, spiritual pain of patients with terminal cancer could be described as meaninglessness of life, loss of identity, and worthlessness of living derived from loss of the future, loss of others, and loss of autonomy of a dying individual. ...On the basis of these understandings, the author deduced principles of spiritual care of terminally ill cancer patients as recovery of the future beyond death, others beyond death, and autonomy toward death in each dimension of the human being...." (--from the abstract)]

Murata, H. and Morita, T. "**Conceptualization of psycho-existential suffering by the Japanese Task Force: the first step of a nationwide project.**" *Palliative and Supportive Care* 4, no. 3 (September 2006): 279-285. ["Although the relief of psycho-existential or spiritual suffering is one of the most important roles of palliative care clinicians, lack of an accepted conceptual framework leads to considerable confusion in research in this field. ...We used consensus-building methods with 26 panel members and 100 multidisciplinary peer reviewers. ...We defined 'psycho-existential suffering' as 'pain caused by extinction of the being and the meaning of the self.' We assumed that psycho-existential suffering is caused by the loss of essential components that compose the being and the meaning of human beings: loss of relationships (with others), loss of autonomy (independence, control over future, continuity of self), and loss of temporality (the future). Sense of meaning and peace of mind can be interpreted as an outcome of the psycho-existential state and thus the general end points of our interventions. This model extracted seven categories to be

intensively studied in the future: relationship, control, continuity of self, burden to others, generativity, death anxiety, and hope." (--from the abstract)]

Tamura, K., Ichihara, K., Maetaki, E., Takayama, K., Tanisawa, K. and Ikenaga, M. "**Development of a spiritual pain assessment sheet for terminal cancer patients: targeting terminal cancer patients admitted to palliative care units in Japan.**" *Palliative and Supportive Care* 4, no. 2 (June 2006): 179-188. [The Spiritual Pain Assessment Sheet, developed by Hisayuki Murata (see the article above) was piloted with palliative care patients in Japan and shown to hold promise for clinical use.]

Tamura, K., Kikui, K. and Watanabe, M. "**Caring for the spiritual pain of patients with advanced cancer: a phenomenological approach to the lived experience.**" *Palliative and Supportive Care* 4, no. 2 (June 2006): 189-196. [This qualitative study "elucidates the spiritual pain experienced by cancer patients." The authors also look at "the meaning nurses find in patients' experiences while caring for their patients" and discuss "opportunities for nurses to address the spiritual care of these patients." (--from the abstract)]

IV. For the topic of SPIRITUALITY & *PHYSICAL PAIN*, see the [January 2007](#) and [December 2005](#) Article of the Month pages.

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