



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

December 2009 Article of the Month

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

Pehler, S. R. and Craft-Rosenberg, M. M. "**Longing: the lived experience of spirituality in adolescents with Duchenne Muscular Dystrophy.**" *Journal of Pediatric Nursing* 24, no. 6 (December 2009): 481-494.

SUMMARY and COMMENT: Key to the development of the still-young field of spirituality & health research is the identification of organizing themes and concepts which may lead to "spiritual assessment and intervention strategies that can promote healing" [p. 481]. The authors of this month's article suggest how *longing* may be one such significant theme/concept, especially in terms of adolescents' "lived experience of spirituality in a chronic, debilitating, or life-threatening illness" [p. 481], though this chaplain reader can easily imagine how longing may figure into the lived experience of many populations.

Pehler and Craft-Rosenberg, both nurses, undertook this descriptive, phenomenological research with a purposive sample of 9 males, aged 12-17, with Duchenne Muscular Dystrophy (DMD); and they note it to be the first study of the "lived spiritual experience of teens with DMD" [p. 483]. Recorded interviews, conducted in the participants' homes, approached the subject of spirituality very broadly as "the propensity to make meaning through a sense of relatedness to dimensions that transcend the self in such a way that empowers and does not devalue the individual" [p. 482]. A follow-up phone call 1-2 weeks later was "designed to clarify any questions of the researcher and the participant" [p. 484]. An Interview Guide specified basic questions and subsequent probes (and is given in a table on p. 484).

The authors found *longing* to be "the essential and central theme of the lived experience of spirituality the participants shared" [p. 485]. They draw upon the work of Olle Holm, a Swedish researcher who in 1999 published an analysis of longing in light of research with adolescents [--see Related Items of Interest, §2 (below)]. Holm defined the concept as "a need for something--a thing, a state, a relationship--without which one's life does not feel complete" [p. 485]. Holm's own work does not associate longing with spirituality, but Pehler and Craft-Rosenberg see in their qualitative data a strong association when it comes to the *amelioration* of the experience of longing.

"The most prevalent component of the adolescents' longing was for missed activities" [p. 485], though the participants also emphasized longing for relationship with others and "to be seen as a person and not made a target for jest due to the disease" [p. 486]. When they talked about overcoming such longing, the themes that emerged in the interviews were: Connecting with Self, Connecting with Others, and Connecting Beyond Self through a Higher Power and/or Spirituality. The authors discuss each theme and give illustrative quotes from the participants. Connecting with Self involved being in touch with one's own strength and sense of purpose, yet also included the experience of physical activity and diversion. Connecting with Others entailed emotional

relationships and physical symbiotic relationships in daily life (e.g., with parents). Pets figured into this relationship category as well. Connecting Beyond Self through a Higher Power played out largely through the predominantly Christian perspectives of the sample, with a personal God watching over and intervening in the lives of the children. The role of prayer is considered. The theme of Connecting Beyond Self through Spirituality is the most abstract category here, and it is practically very similar to that of Connecting Beyond Self through a Higher Power, though less focused on formal religion or the person of God. "Most of the participants did not know what spirituality was when asked a general question from the Interview Guide" [p. 489].

Data additionally revealed that the participants did not see their DMD as a "crisis," but rather they saw their longing as part of being individuals who just happened to have the disease. The authors comment that in spite of the lack of a sense of crisis that could ostensibly precipitate "spiritual awareness" [p. 490], the teens did manifest strong spiritual awareness as expressed in the longing for *connectedness*. Here, Pehler and Craft-Rosenberg point to their very broad understanding of spirituality from the nursing literature:

[Spirituality] is how we experience and live, in the present moment, our connectedness with our body–mind–spirit Self, with others, with nature or the cosmos, and with the Sacred Source; however, we image or name this Source. Spirituality is the search for right relationships more than it is the search for right answers. [p. 490]

Many chaplains may find this conceptualization of spirituality too broad to establish a practical link with longing, but the association is reasonable. This is, after all, exploratory research with adolescents requiring more than a little interpretation of their expressions. The concept of longing seems promising for spirituality & health research, highlighting feelings of loss and the drive to overcome. Holm understood longing to be a secondary emotion made up largely of the primary emotions of love and sadness [--see p. 490]. Chaplains may find it worthwhile to think of longing in patients not merely as missing something or hoping for something but as a response to circumstances with deep implications for a patient's sense of relationship and spiritual coping. Shelley-Rae Pehler has said in a personal communication to this reader that she intends to offer further conceptual analysis and explication of longing in future publications, and she invites the input of chaplains (--you may e-mail her at PehlerShelleyRae@sau.edu). Greater clarity about longing should support the creation of measures for quantitative study. Other researchers have in recent years developed a questionnaire for Life Longing, based upon the German concept of *Sehnsucht* [--see Related Items of Interest, §3 (below)], but that measure does not seem entirely congruent with the phenomenon that Pehler and Craft-Rosenberg describe. The delineation of such concepts is integral to maturation of the field of spirituality & health, but it is also usually a fruitful exercise for individual clinical chaplains.

One final comment --really an aside: the authors of this month's article use the term *Judeo-Christian* seven times: twice as "the Judeo-Christian tradition" [pp. 483 and 488], twice as "the Judeo-Christian perspective" [p. 491], and three times in other phraseology [pp. 489 and 491]. Since this article focuses on key concepts, it seems worth noting that the concept of *Judeo-Christian* can be problematic in spirituality & health literature in general, in that it is often unclear exactly what it is meant to convey, in that it can implicitly gloss over stark differences between Jewish and Christian traditions/perspectives, and in that common parlance holds it almost always as a specifically Christian concept.

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

Some students may wish to discuss this month's article purely as a window on the lived experience of adolescents with Duchenne Muscular Dystrophy, and the authors' use of illustrative quotes gives some vivid material to consider above and beyond the formal analysis of the interview data. With that as a starting point, students could think about how the insights from this article might or might not be generalized to other populations with chronic, debilitation or life-threatening conditions. And, of course, the very idea of *longing* could be the crux of a discussion. For a research focus, however, the article shows well the complexity of

qualitative investigation. Would chaplaincy students see in the expression of these adolescents the same meanings as did Pehler and Craft-Rosenberg? How might the conceptual framework for spirituality, as found in the nursing literature, have shaped the interpretation of the interviews? By the same token, how might certain theological conceptualizations in the pastoral literature shape the way chaplains understand and talk about patients' lived experience of illness and treatment? Finally, the authors' methodology is guided by the phenomenological research theory of Max von Manen. Some students may want to explore this specifically [-- See Related Items of Interest, §4 (below)], but discussion could consider merely the idea of "staying as close to the experience as lived" [p. 483] when doing research with patients.

Related Items of Interest:

I. For more research pertaining in various ways to *longing* in patients (not cited in the Pehler and Craft-Rosenberg article), see:

[Added 8/27/14:] Pehler, S. R., Sjostrom, S. and Markwardt, M. "**Longing: a concept analysis.**" *International Journal of Nursing Knowledge* 25, no. 3 (October 2014): 133-138. [(Abstract:) PURPOSE: This paper uses Rodgers' evolutionary view of concept analysis to define the human response of longing. The purpose is to develop a definition of longing as the first step in diagnosis development. DATA SOURCE: A literature review was conducted by searching the Cumulative Index to Nursing and Allied Health Literature, American Theological Library Association Religion, JSTOR Philosophy, JSTOR Religion, PsycINFO, and PubMed databases to yield an across-discipline sample of articles. DATA SYNTHESIS: Three researchers identified the attributes, antecedents, consequences, situational context, and surrogate terms of longing. CONCLUSIONS: An operational definition was developed. IMPLICATIONS FOR NURSING PRACTICE: Longing is clearly a human response to loss, crossing illness and situations in which nurses encounter patients in multiple settings.]

Roscigno, C. "**Longing for everydayness: Implications of children's early experiences following moderate to severe traumatic brain injury in the United States.**" *Brain Injury* 22, no. s1 (Jan 2008): 10. [A longer report of this research is given in Roscigno, C. I., "Longing for everydayness: life after traumatic brain injury in children," *Communicating Nursing Research* 41 (Spring 2008): 77-83; cited below.] [(Abstract *only*:) Objectives: The purpose of this descriptive phenomenological investigation was to explore the common experiences of children in the US following a moderate-to-severe traumatic brain injury (TBI) within 3 years after injury. Method: IRB approval was obtained. Phase I of the investigation took place between 2005–2007. Children were recruited via a rehabilitation clinic, newspaper and a local and national website targeted to brain injury. Inclusion criteria included: (1) child between 6–18 years of age at time of injury, (2) with a moderate-to-severe TBI according to Glasgow Coma Scale criteria, (3) within 3 years of injury, (4) able to understand English, (5) children's assent and parent's consent to participate. Twenty children from across the US participated. In-person and open-ended interviews (90 minutes) were conducted. Analysis was guided by Colaizzi's steps for descriptive phenomenology. Common themes of children's narratives were melded into a conceptual model describing the essences of life following TBI. The model was validated through second interviews (90 minutes), which also allowed for follow-up on the child's experiences since their first interview. Results: The essence of surviving TBI as a child involves grieving a variety of losses and struggling to find their place in a social world that is often unprepared to handle their changes or their differences. Life after TBI was described as: (1) like waking up in a bad dream, (2) thought going home would get me back to my old life, but it didn't, (3) some people get it, but many people do not, (4) everything is such hard work, (5) you feel like you will never be like the person you were before and (6) it is not all bad. Conclusions: Most children needed immense emotional support in adjusting to any changes. Adjustment was strongly linked to any resulting impairments and the quality of social

interactions children received during this early period within their own social-ecology. Future healthcare interventions need to be targeted not only at supporting and sustaining children and their family following their TBI, but also at educating those who children will likely interact with following their injury.]

Roscigno, C. I. "**Longing for everydayness: life after traumatic brain injury in children.**" *Communicating Nursing Research* 41 (Spring 2008): 77-83. [This is a longer report of the abstract in the January 2008 supplementary issue of *Brain Injury* (vol. 22, no. s1, p. 10; cited above). The term *longing* does not seem to be explicit in the participants' interviews but is used as a summary concept by the author, based upon the work of Peter Marris (*Loss and Change*, 1975). The author mentions spirituality in passing: "[f]or those children with who had severe TBI [Traumatic Brain Injury], ...[they] found themselves deeply reflecting on their new disconnectedness from others and its meaning (spiritual reflections)" (p. 81).]

Schroeder-Sheker, T. "**Narrative medicine and unresolved, end-of-life longing.**" *Explore: The Journal of Science & Healing* 2, no. 2 (March 2006): 169-171. [This is a brief case account of a patient who has a powerful reaction of longing (regarding a past relationship) when he hears certain music (i.e., early preludes of Alexander Scriabin). The article presents the perspective of a music thanatologist --and chaplains may be interested in it for that reason alone.]

Spichiger, E. "**Being in the hospital: an interpretive phenomenological study of terminally ill cancer patients' experiences.**" *European Journal of Oncology Nursing* 13, no. 1 (February 2009): 16-21. [(From the abstract:) This article describes a study exploring terminally ill cancer patients' experiences of being in hospital and the meanings patients assigned to the hospital as their temporary residence. Ten patients and their closest family members participated in this interpretive phenomenological study during the patients' hospitalization. Data were collected in a public tertiary hospital in Switzerland. Patients' care was observed and participants were interviewed repeatedly. Data analysis included thematic analysis as well as searching for paradigm cases and exemplars. Patients described their existence in the hospital on a continuum from "prison" to "heaven." For most of their stay, patients occupied some place between these extremes and could be called "guests of necessity" who accepted the hospital as necessity but were longing for home. The quality of hospital life was not constant rather, patients' experiences were transitory and some faded away. The study revealed an aspect hitherto undescribed in the literature: patients' experiences of the hospital as a temporary residence....]

II. For more on Olle Holm's work on *longing*, see:

Holm, O. "**Analyses of longing: origins, levels, and dimensions.**" *Journal of Psychology* 133, no. 6 (November 1999): 621-630. [(Abstract:) Although everyone has experienced longing, it is an emotion that very seldom is discussed or even mentioned in the scientific literature. In this article, a tentative definition of longing is presented. Three models for analyses of longing are described. The first model presents longing as a secondary emotion, and it addresses the origins of longing in terms of primary emotions. The second model is a description of different levels, valences, and kinds of longing. The third model shows how different dimensions of longing can be depicted and provides data from interviews about longing with 6-year-old children.]

Holm, O. "**Dimensions and aspects of longing: age and gender differences in Swedish 9-, 12-, and 15-year-old children.**" *Journal of Psychology* 135, no. 4 (July 2001): 381-397. [(Abstract:) Longing can be defined as a secondary emotion, as a blend of the primary emotions of love and sadness. There are several possible dimensions and aspects of longing (O. Holm, 1999). Both age and gender differences are well documented in earlier research on other emotions. In the present investigation, 122 girls and 120 boys, ages 9, 12, and 15 years, in compulsory school in Sweden, answered a questionnaire about dimensions and aspects of their own longing. The results showed both age and gender differences. Girls, especially in the 15-year-old group, experienced longing

significantly more than boys. The results were interpreted as generally in accordance with what is known from earlier research on other emotions.]

Holm, O., Claesson, V., Greaker, E., Karlsson, C. and Stromberg, A. "**Experiences of longing in six-year-old Swedish children.**" *Journal of Psychology* 134, no. 3 (May 2000): 346-348. [This brief article presents a reanalysis of earlier research with 41 Swedish 6-year-old children (25 girls and 16 boys) confirming a number of dimensions of longing. "Primary emotions, focus, specificity, coping, activity, occurrence, intensity, direction, and time could all be found" (p. 348).]

Holm, O., Greaker, E. and Stromberg, A. "**Experiences of longing in Norwegian and Swedish 4- and 5-year-old children.**" *Journal of Psychology* 136, no. 6 (November 2002): 608-612. [(Abstract:) Longing can be defined as a blend of the primary emotions of happiness and sadness. These primary emotions are experienced very early by children, and the meanings of the words happiness and sadness are also known by children early in their verbal development. To find out at what age children are able to understand and use the more developed concept of longing, the authors interviewed 74 preschoolers (4- and 5-year-olds) in Norway and Sweden about their experiences of longing. Chi-square analyses showed age and sex differences in knowledge of the concept, and some differences between categories of longing were also significant. Results showed that young children's ability to understand and use the concept of longing appears to be limited and that girls seem to mature earlier in this respect than boys do.]

III. For more on the Life Longing Questionnaire, based upon the German concept of *Sehnsucht*, mentioned in our Summary & Comment, see:

Scheibe, S., Freund, A. M. and Baltes, P. B. "**Toward a developmental psychology of *Sehnsucht* (life longings): the optimal (utopian) life.**" *Developmental Psychology* 43, no. 3 (May 2007): 778-795. [The Life Longing Questionnaire is given on pp. 794-795.] [(Abstract:) The topic of an optimal or utopian life has received much attention across the humanities and the arts but not in psychology. The German concept of *Sehnsucht* captures individual and collective thoughts and feelings about one's optimal or utopian life. *Sehnsucht* (life longings; LLs) is defined as an intense desire for alternative states and realizations of life. Presenting a first effort at capturing this phenomenon, the authors conceptualize LLs as composed of 6 interrelated core characteristics: (a) utopian conceptions of ideal development; (b) sense of incompleteness and imperfection of life; (c) conjoint time focus on the past, present, and future; (d) ambivalent (bittersweet) emotions; (e) reflection and evaluation of one's life; and (f) symbolic richness. Self-report data from 299 adults (19-81 years) support the postulated structure and support predictions regarding the functional role of *Sehnsucht*. Having LLs was evaluated as providing direction to development and helping to manage life's incompleteness. At the same time, the frequent and intense experience of LLs was associated with lower well-being. When LLs were perceived as controllable, however, this negative association disappeared.]

IV. Pehler and Craft-Rosenberg refer to the "phenomenology research method of van Manen" [p. 483] and cite his book, *Researching Lived Experience: Human Science for an Action Sensitive Pedagogy* (Albany, NY: State University of New York Press, 1990). Max van Manen is a professor at the [University of Alberta](http://www.phenomenologyonline.com/max), Canada. His personal website is www.phenomenologyonline.com/max. For a recent analysis of van Manen's work, in the context of the development of phenomenological theory and research, see: Dowling, M., "**From Husserl to van Manen: a review of different phenomenological approaches,**" *International Journal of Nursing Studies* 44, no. 1 (January 2007): 131-142.