



February 2017 Article of the Month

This month's article selection is highlighted by John Ehman,
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Piderman, K. M., Egginton, J. S., Ingram, C., Dose, A. M., Yoder, T. J., Lovejoy, L. A., Swanson, S. W., Hogg, J. T., Lapid, M. I., Jatoi, A., Remtema, M. S., Tata, B. S. and Breitkopf, C. R. "**I'm still me: inspiration and instruction from individuals with brain cancer.**" *Journal of Health Care Chaplaincy* 23, no. 1 (January-March 2017): 15-33.

SUMMARY and COMMENT: This month's article is a further report of an initial investigation of a chaplain-led intervention that we previously highlighted in [June 2015](#): namely, a guided interview with brain cancer patients that allowed for the creation of a Spiritual Legacy Document --a bound book which a patient could then give to others. Those earlier articles focused on quantitative data and case examination. The current study looks at qualitative data from a subset of participants facing the "immediate challenges" of "threats to their cognition, personality, memory, expressive ability, and sensory and motor functioning, and the possibility of concomitant suffering" [p. 18], in order to explore their lived experience.

As explained in the [preceding articles](#) about this project, interviewers used a guide that highlighted nine themes: faith, importance, community, activity, call, contributions, changes, challenges, and communication [--see p. 18]. Transcripts from recordings of 19 patients were coded and analyzed by a step-wise process (i.e., Framework Analysis) useful for "reduc[ing] large amounts of data by paraphrasing and organizing it so as to be auditable and reproducible" [p. 18]. "To assure the qualitative rigor of the analysis and results reporting, this project adhered to the Consolidated Criteria for Reporting Qualitative Studies (COREQ)" [pp. 18-19, and see Items of Related Interest, §II, below]. The coding of transcripts is described on pp. 19-20.

Results from the spiritual life reviews are presented in terms of the influence of brain cancer on 1) God and/or the spiritual world, 2) other people, and 3) oneself. The text offers illustrative quotes that constitute the heart of the article. Major themes give a picture of the range of experiences:

Relationship with God and/or the Spiritual World --

"Almost all of the participants spoke about having an intimate and dynamic relationship with a higher power, and most spontaneously used the term 'God' to describe this relationship" [p. 20]. "*Consolation* in this relationship was defined as an experience of comfort, reassurance, peace, gratitude, hope or expectancy regarding a spiritual presence and/or the afterlife" [p. 20, italics added]. Trust in God's plan was a key element for many. Being active in a religious denomination was important for some but was "at least as often" not so for others [p. 21]. Distinct from the consolation theme, but often existing alongside of it [--see p. 23], was a theme of *desolation*. "Desolation in relationship with God or the spiritual was defined as spiritual struggle that may include pleading, bargaining and feelings of abandonment or fear... [and] was reported by many in their experience of God's plan as something that was hard to understand or

accept" [p. 22]. Some "struggled with their regret for not living a good or 'good enough' spiritual life, for which God's forgiveness was critical. However, "Despite struggling with brain cancer, some patients mentioned continuity in their spiritual perspectives, i.e., they continued with spiritual or religious beliefs or practices that they had held prior to diagnosis" [p. 23]; with social media, positive attitudes, and belief in providence playing a role. "Many reported that their spiritual life had changed for the better because of brain cancer," though "[o]thers had to limit participation in church or spiritual activities due to their illness..." [p. 24].

Relationship with Others --

"The experience of having brain cancer triggered changes in interpersonal relationships for all of the participants": "[m]ost claimed a positive deepening of relationships with others" [p. 24], as a function of such things as focusing on what matters most, greater spontaneity and expressiveness, and "appreciation for the goodness of others in their lives," which for some involved "memories and thoughts of loved ones who had died" [p. 25]. Still, "[t]he cancer experience...brought up relationship challenges, particularly an urgency about making amends and tying up loose ends with people, especially family" [p. 25], and "[m]ost participants were sad about 'leaving' family members and wished they could spare them or at least usher them through the pain of losing them in death" [p. 26]. Fatigue, worry, and anxiety with illness depleted energy to engage others for several participants, and yet "[p]atients spoke at great length about generativity in the midst of brain cancer... [with] [g]enerativity...defined as an intention, action or words aimed at making a difference in the lives of others" [p. 26].

Relationship with Oneself --

While illness had for many precipitated losses of careers, activities they once enjoyed, and independence, causing grief and frustration, the researchers found in these patients "an amazing determination to do what was possible" [p. 27]. And, "in the midst of the losses they experienced, patients reported certain gains, including opportunities to be humble, give thanks, be hopeful, and ask forgiveness, to make positive changes, and deepen spiritual and religious practices" [p. 28]. "Ultimately, participants spoke with a candid awareness of death" [p. 28].

Beneath and beyond identified themes, it is the "compelling quality to the voices of the participants" [p. 29] that makes this article most engaging. Expressions like, "I'm better because of this stinkin' tumor" [p. 28], "[You] realize that you are losing your mind," [p. 27], and "I am still me" [p. 24] are powerfully rich. Such quotes "invite those who hear them to understand that [these patients] have not been defeated by brain cancer, ...[that] [o]n the contrary, their words indicate that they are very much alive and are deeply engaged with God, others, and themselves. The participants here show that "[i]n essence, they remain themselves, with the human capacity for introspection, intentionality, and growth" [p. 29].

The authors detail how they believe this study "is instructive for chaplains and others on the health care team" [p. 29]. First, they note how much these patients "wanted to discuss their spirituality ...[and] wanted their spiritual beliefs and experiences to be remembered" [p. 29]. Second, the guided interview process "seemed to open the door for the participants to engage in deep introspection and sharing" and may be "an effective means of pastoral ministry" [p. 29]. This moreover affirms the "value of an active, focused approach to spiritual assessment" [p. 29] and suggests that the themes of the Spiritual Legacy interview may be useful toward that purpose. And third, it is a reminder of how important it may be to patients to share with caregivers the wisdom of their experience. "Their wisdom also invites chaplains and others on the health care team to remember that caring for cancer patients provides opportunities, not only to bless, but to be blessed" [p. 30].

This is a limited study, with the possibility of some selection bias [--see p. 30]. So, the authors address the need for further research (said to be underway with other groups [--see p. 29]) yet comment that the Spiritual Legacy interview -- and document -- piloted here might be implemented to even greater effect if not paired with the quantitative questionnaires that were important for this study but may be burdensome to patients most in need. In the end, the perspective of this project comes out of Narrative Medicine [--see pp. 16-17 and also Items of Related Interest, §V, below)], seeking to understand and convey patients' "voices."

The intention of this article is to let their voices be heard by chaplains and others who care for and about them. Their voices provide an opportunity for those who listen to know and respect their spiritual side more deeply. They invite us all to consider our personal and professional lives with honesty and humility, and to choose to live wisely and well today. [p. 31]

Suggestions for Use of the Article for Student Discussion:

For students newer to research, the qualitative focus of this article should make it quite engaging. Discussion could begin by noting the Narrative Medicine approach of the authors [--see pp. 16-17] and how that may relate to the work of chaplains. Next, they could look at the patterns of themes identified in this analysis: namely, the "codes" listed on p. 19. Can they connect these themes with their own experiences with patients? Which themes stand out especially? The group could then move into the illustrative quotes provided in the core of the text, reading aloud some of the patients' words and considering their richness. Any students working with patients contending with brain cancer or neurological impairment might take the lead here, but much of what the study participants say should have broad resonance for everyone. What of the authors' finding that "desolation" and "consolation" can exist side by side? One of the quotes in the article relates to a reaction to a pastor's exhortation that a patient "needed to pray that God's will be done" [p. 22]. What do students think of this, and have they ever felt caught between patients and their clergy? Can students relate to how important the Spiritual Legacy interview itself was for patients? (The article could easily be paired with the interview guide given in the very brief 2015 report, "The feasibility and educational value of *Hear My Voice*.") Note the quote: "Right here in this room and speaking about the change [which the patient has experienced] is, I think, the best thing I've done..." [p. 27]. The authors point out that 32% of their sample seemed to be "atheist, agnostic or not religiously affiliated" [p. 18], and a couple of quotes represent these participants explicitly [--see pp. 21 and 27], but they are not sharply distinguished as a group in the findings. Is this surprising or unsurprising to students, and why? Finally, as the authors hold that the wisdom of patients can be a blessing to chaplains [--see p. 30], what are some ways that the students feel "blessed" by the voices conveyed here?

Related Items of Interest:

I. In addition to the reports on the Spiritual Legacy project featured for our [June 2015](#) Articles-of-the-Month, see also the following article which is in line with the quantitative focus of earlier report:

Piderman, K. M., Radecki Breitkopf, C., Jenkins, S. M., Lapid, M. I., Kwete, G. M., Sytsma, T. T., Lovejoy, L. A., Yoder, T. J. and Jatoi, A. "**The impact of a spiritual legacy intervention in patients with brain cancers and other neurologic illnesses and their support persons.**" *Psycho-Oncology* (December 7, 2015): published online ahead of print. [(Abstract:) Objective: The objectives were to assess the feasibility of using a novel, comprehensive chaplain-led spiritual life review interview to develop a personal Spiritual Legacy Document (SLD) for persons with brain tumors and other neurodegenerative diseases and to describe spiritual well-being (SWB), spiritual coping, and quality of life (QOL) of patients and their support persons (SP) before and after receipt of the SLD. Methods: Patient-SP pairs were enrolled over a 2-year period. Assessments included the Functional Assessment of Chronic Illness Therapy-Spiritual Expanded Version, Brief Religious Coping Scale, Brief COPE Inventory, and QOL Linear Analog Scale. Baseline assessments were completed prior to an audio-recorded spiritual life review interview with a chaplain. Results: Thirty-two patient/SP pairs were enrolled; 27 completed baseline assessments and the interview. Twenty-four reviewed their SLD and were eligible for follow-up. A total of 15 patients and 12 SPs completed the 1-month follow-up; 10 patients and seven SPs completed the 3-month follow-up. Patients endorsed high levels of SWB and spiritual coping at baseline. Both patients and SPs

evidenced improvement on several aspects of SWB, spiritual coping, and QOL at 1 month, but patients' decreased financial well-being was also observed. Patients and SPs demonstrated favorable changes in peacefulness and positive religious coping at both time points. Conclusions: A chaplain-led spiritual life review is a feasible intervention for patients with neurodegenerative disease and results in beneficial effects on patients and SPs.]

II. Our authors state: "To assure the qualitative rigor of the analysis and results reporting, this project adhered to the Consolidated Criteria for Reporting Qualitative Studies..." [pp. 18-19]. The COREQ uses a 32-item checklist which some journals require for manuscript submission (for example, see the [checklist form](#) used by Elsevier). The basic article on the COREQ is:

Tong, A., Sainsbury, P. and Craig, J. "**Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups.**" *International Journal for Quality in Health Care* 19, no. 6 (December 2007): 349-357. [(Abstract:) BACKGROUND: Qualitative research explores complex phenomena encountered by clinicians, health care providers, policy makers and consumers. Although partial checklists are available, no consolidated reporting framework exists for any type of qualitative design. OBJECTIVE: To develop a checklist for explicit and comprehensive reporting of qualitative studies (in depth interviews and focus groups). METHODS: We performed a comprehensive search in Cochrane and Campbell Protocols, Medline, CINAHL, systematic reviews of qualitative studies, author or reviewer guidelines of major medical journals and reference lists of relevant publications for existing checklists used to assess qualitative studies. Seventy-six items from 22 checklists were compiled into a comprehensive list. All items were grouped into three domains: (i) research team and reflexivity, (ii) study design and (iii) data analysis and reporting. Duplicate items and those that were ambiguous, too broadly defined and impractical to assess were removed. RESULTS: Items most frequently included in the checklists related to sampling method, setting for data collection, method of data collection, respondent validation of findings, method of recording data, description of the derivation of themes and inclusion of supporting quotations. We grouped all items into three domains: (i) research team and reflexivity, (ii) study design and (iii) data analysis and reporting. CONCLUSIONS: The criteria included in COREQ, a 32-item checklist, can help researchers to report important aspects of the research team, study methods, context of the study, findings, analysis and interpretations.]

There are many such formal guidelines that help promote rigor and consistency in the research literature. A quick source for over 350 research guidelines is the **EQUATOR Network** (www.equator-network.org), from the UK EQUATOR [Enhancing the QUALity and Transparency of Health Research] Centre at the Centre for Statistics in Medicine, Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Sciences (NDORMS), University of Oxford. See, for example, their entry for the [COREQ](#), which gives a link directly to the Tong, et al. article (above). For a brief explanation of EQUATOR, see a 2015 [interview with Centre's Deputy Director](#).

III. While not a report of research, chaplains may be interested in the following article by a CPE Resident:

Sebastian, M. M. "**When God stops talking.**" *Journal of Pastoral Care and Counseling* 58, nos. 1-2 (Spring-Summer 2004): 111-112. [This is a brief, first-person reflection by a CPE Resident on the challenge of visiting with a brain tumor patient.]

IV. In addition to the articles referenced in this month's study, and those noted on our [June 2015 Article-of-the-Month](#) page, see also the following relating to spirituality and brain cancer:

Khalili, Y. "**Ongoing transitions: the impact of a malignant brain tumour on patient and family.**" *Axone [Journal of the Canadian Association of Neurological and Neurosurgical Nurses; Canadian Association of Neuroscience Nurses]* 28, no. 3 (Spring 2007): 5-13. [This article presents a patient case which, while mentioning religion only in passing, gives a good outline of a personal experience of brain cancer. The article is presented from the perspective of nursing, with attention to nursing involvement and intervention.]

Lucchiari, C., Botturi, A., Manzini, L., Masiero, M. and Pravettoni, G. "**Experiencing brain cancer: what physicians should know about patients.**" *Ecancermedicalscience* 9 (2015): 591 [electronic journal article designation]. [This Italian mixed-methods study involved 85 patients with high-grade gliomas, assessed three months after surgery and again three months later. The FACT-SW, a 12 items scale measuring spiritual well-being was included in the measures. Interviews (transcribed) were conducted by a psychologist. Among the qualitative findings: 80% of the patients indicated being religious (all Roman Catholic/Christian) and trusting in God, and 65% of those reported an increase in faith after diagnosis, including in increase in satisfaction with the practice of prayer. However, 5% reported having lost their faith. Regarding patients who did not indicate a religious faith to begin with, they reported belief in medicine and the development of technology; and the authors note a dominant theme of "needing to have faith in something." Quantitative findings include: Spiritual well-being was positively correlated with a good mood state and whole quality of life, and negatively correlated with depression. The authors state that spiritual well-being is "a main factor in the adjustment process." (*Spiritual well-being* is defined here as the "ability of a person to find a deeper meaning in their life beyond having some religious faith."). From these results, the authors recommend that spiritual and emotional domains "be addressed immediately in case of adjustment difficulties."]

Owensworth, T. and Nash, K. "**Existential well-being and meaning making in the context of primary brain tumor: conceptualization and implications for intervention.**" *Frontiers in Oncology* 5 (2015): 96 [electronic journal article designation]. [This Australian report addresses historical and theoretical perspectives on spirituality and existential well-being, notes major types of interventions for this population, and presents briefly findings of the efficacy of a Making Sense of Brain Tumor program developed by the lead author and colleagues. That program, including ten in-home psychotherapy sessions, focusing on supporting patients to understand the personal significance of the illness in their own life situation, appeared to lower depression and raise existential well-being, functional well-being, and global quality of life; with some lasting results detected 6-months afterward. The authors note: "These findings highlight that the social context in which people search for meaning and cope in their illness is essential to consider"; and they conclude: "Having the opportunity to express one's fears and values about life and death in a safe and supportive context can make a profound difference to a person's sense of inner peace and hope for the future."]

Ravishankar, N. and Bernstein, M. "**Religion benefiting brain tumour patients: a qualitative study.**" *Journal of Religion & Health* 53, no. 6 (December 2014): 1898-1906. [This qualitative study involving 36 adult patients who underwent surgery for benign or malignant brain tumors found that most patients indicated religion to be an effective coping mechanism, offering them strength, comfort, and hope through the surgery. The authors identify four themes from interviews: 1) religion significantly benefited neurosurgical patients; (2) neurosurgical patients did not require a dedicated religious room in the hospital; (3) neurosurgical patients required religious resources such as leaders and/or groups; and (4) patients were not in favor of their physician engaging in the religious ritual. One specific recommendation of the article is for a "religious time-out" before and after surgery.]

V. Our featured authors mention "narrative medicine" [see esp. pp. 16-17]. In addition to the article's references, the following may offer some additional basic context:

Charon, R. "**At the membranes of care: stories in narrative medicine.**" *Academic Medicine* 87, no. 3 (March 2012): 342-347. [(Abstract:) Recognizing clinical medicine as a narrative undertaking fortified by learnable skills in understanding stories has helped doctors and teachers to face otherwise vexing problems in medical practice and education in the areas of professionalism, medical interviewing, reflective practice, patient-centered care, and self-awareness. The emerging practices of narrative medicine give clinicians fresh methods with which to make contact with patients and to come to understand their points of view. This essay provides a brief review of narrative theory regarding the structure of stories, suggesting that clinical texts contain and can reveal information in excess of their plots. Through close reading of the form and content of two clinical texts—an excerpt from a medical chart and a portion of an audiotaped interview with a medical student—and a reflection on a short section of a modernist novel, the author suggests ways to expand conventional medical routines of recognizing the meanings of patients' situations. The contributions of close reading and reflective writing to clinical practice may occur by increasing the capacities to perceive and then to represent the perceived, thereby making available to a writer that which otherwise might remain out of awareness. A clinical case is given to exemplify the consequences in practice of adopting the methods of narrative medicine. A metaphor of the activated cellular membrane is proposed as a figure for the effective clinician/patient contact.]

Fioretti, C., Mazzocco, K., Riva, S., Oliveri, S., Masiero, M. and Pravettoni, G. "**Research studies on patients' illness experience using the Narrative Medicine approach: a systematic review.**" *BMJ Open* 6, no. 7 (July 14, 2016): e011220 [electronic journal article designation]. [(Abstract:) OBJECTIVE: Since its birth about 30 years ago, Narrative Medicine approach has increased in popularity in the medical context as well as in other disciplines. This paper aims to review Narrative Medicine research studies on patients' and their caregivers' illness experience. SETTING AND PARTICIPANTS: MEDLINE, Psycinfo, EBSCO Psychological and Behavioural Science, The Cochrane Library and CINAHL databases were searched to identify all the research studies which focused on the Narrative Medicine approach reported in the title, in the abstract and in the keywords the words 'Narrative Medicine' or 'Narrative-based Medicine'. PRIMARY AND SECONDARY OUTCOME MEASURES: number of participants, type of disease, race and age of participants, type of study, dependent variables, intervention methods, assessment. RESULTS: Of the 325 titles screened, we identified 10 research articles fitting the inclusion criteria. Our systematic review showed that research on Narrative Medicine has no common specific methodology: narrative in Medicine is used as an intervention protocol as well as an assessment tool. Patients' characteristics, types of disease and data analysis procedures differ among the screened studies. CONCLUSIONS: Narrative Medicine research in medical practice needs to find clear and specific protocols to deepen the impact of narrative on medical practice and on patients' lives.]

Also, the **Columbia University Medical Center's Program in Narrative Medicine**

(www.narrativemedicine.org) provides a list of resource links related to this subject, along with other information aimed at physicians but possibly of interest to chaplains. [*Editor's note: This resource was suggested by Chaplain and ACPE Supervisor Sean K. Doll O'Mahoney, who presented on Narrative Medicine at the 2015 Harborview Medical Center Palliative Care Conference (Seattle, WA).*]

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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