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April 2015 Article of the Month

This month's article selection is by Chaplain John Ehman,
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Fitchett, G., Emanuel, L., Handzo, G., Boyken, L. and Wilkie, D. J. "**Care of the human spirit and the role of dignity therapy: a systematic review of dignity therapy research.**" *BMC Palliative Care* 14 (2015): 8 [electronic journal article designation].

[Note: The article is [available freely online from Biomed Central](#). Because it is published as an individual 12-page unit within the electronic journal, page numbers cited below refer to its stand-alone numbering.]

SUMMARY and COMMENT: Dignity Therapy (DT) was introduced in 2004 by [Harvey Max Chochinov](#), et al., as "a brief individualized psychotherapy specifically intended for patients near the end of life...expressing psychosocial or existential distress, or...indicating the need or desire to bolster their waning sense of purpose for self-worth" [p. 139 of Chochinov, H. M., et al., "Dignity and psychotherapeutic considerations in end-of-life care," *Journal of Palliative Care* 20, no. 3 (2004): 134-142]. In the 11 years since, it has been the subject of over 29 articles in the academic healthcare literature. The current review assessed 25 of those articles representing 15 independent studies, including 12 quantitative studies, in terms of the acceptability, feasibility, and effectiveness of the intervention; and the authors look at the potential for spirituality research and use by chaplains.

"DT focuses on dignity conservation tasks such as settling relationships, sharing words of love, and preparing legacies of memory and shared values, all of which take on a heightened importance at the end of life" [p. 1]. Fitchett and colleagues offer a brief introduction to the model [pp. 1-2], but a full explanation may be found through the [Dignity in Care](#) website, including a listing of [core questions](#) used in interviews with patients in order to generate a "legacy document that the person shares with others important to him or her" [p. 2].

The authors' note that their "curiosity" was raised by the fact that while "[m]ultiple studies describe widespread acceptability and high satisfaction among those who experience DT"..., "rigorous evidence for any beneficial effects of DT on important palliative care outcomes has been limited" [p. 2]. They lay out the pertinent research in three tables, according to the studies' samples, methods, and results [--see pp. 4-6, 7, and 8], paired to an excellent bibliography. Among the findings of the analysis:

Evidence of DT's acceptability is clear and consistent; patients who receive DT provide exceptionally high ratings of satisfaction and benefits for themselves and their families. [p. 7]

Recruitment and retention were issues for almost all of the DT studies and a major problem for some. ...[However,] [p]roblems with recruitment and retention are not unexpected in research with

persons with advanced illness receiving palliative care. [p. 7]

In single group studies, DT often showed significant changes in study outcomes. When compared to usual care control groups, however, DT effects were often not statistically significant. Only one study was powered to detect small or moderate effects in study outcomes.... [pp. 7-8]

While the authors find that "from the scientific evidence, we cannot yet say if DT is efficacious" [p. 8], they see promise in future research, particularly in relation to spirituality.

We propose that DT should be studied as a spiritual as well as a psycho-social intervention that assists with the existential tasks faced by the majority of elderly patients, especially as they encounter a life threatening illness like cancer. Our conceptualization of DT as an intervention with a strong spiritual element leads us to note that, while they have not been used in prior studies, measures of the existential tasks associated with the end of life, as well as dignity impact, are appropriate outcome measures for studies of DT. [p. 9]

They go on to state that "...we perceive that its mechanisms may be related to role completion and spiritual aspects of a person's life," and they hold out the "possibility that [DT's] main impact is in a spiritual dimension" [p. 10].

Also considered in the article are questions of who should provide and who should receive DT in real-world settings/circumstances. The authors acknowledge how the intervention could resonate with nurses, but perhaps "chaplains might be more interested in DT than nurses due to significant and growing demand for evidence-informed interventions for chaplains" [p. 10]. "Studies are needed to evaluate DT efficacy by different health care professionals and in diverse settings" [p. 10]. And, as for who should receive DT, "studies present rich but preliminary evidence that DT has positive effects not only on the patients who receive it, but on their families and caregivers" [p. 10].

The article ultimately emphasizes how "well-received" [p. 10] is Dignity Therapy --its "overwhelming acceptability, rare for any medical intervention, especially in psycho-social-spiritual care" [p. 10]. That aspect alone seems to make further research regarding its efficacy, and the exploration of its implementation, so attractive. The authors address a number of challenges along the way, including the hard issues of capturing measurable effects in palliative care populations and the logistics of incorporating DT as an intervention to be provided by those who are already stretched in their workflows [--see esp. pp. 9-10]; but a case is made here for chaplains to play a role in the continued study and development of DT, and the review offers a key resource toward that end.

Suggestions for the Use of the Article for Student Discussion:

While it may or may not be feasible for students to think of formally incorporating Dignity Therapy into their immediate practice, it should be fruitful for them to imagine how it *might* be an option and to consider how the ideas implicit in the intervention might affect their sense of palliative care, life review, and elements of pastoral visitation. Distributing copies of the [core questions](#) used in interviews with patients (which are not explicitly given in the article), may be useful. Further along those lines, students could be asked ahead of time to experience the core questions by asking them of themselves. How would it feel simply to be asked such questions? [Note: There are various numberings of the core questions in different publications, as items are sometimes grouped together or separated, but the content of the overall list is quite fixed.] Students could also look specifically at the article's discussion of DT's "action in the spiritual dimension of peoples' lives" [p. 9]. From a research perspective, one striking point raised in the article is the probable need to allow for more time with subjects in order to measure DT's effects, given the difficulty of recruiting and retaining participation from this population in the first place. This could help students understand some of the practical planning involved in research projects, and how the desire for ideal methodology is often up against realities and limits of study populations.

Related Items of Interest:

I. The [Dignity in Care](#) website is a good source for understanding Dignity Therapy in terms of being a researcher, a provider, or a patient. The [Dignity Interventions page](#) may be of special interest in suggesting the broad applicability of the therapy. Note too, on the site, the [Patient Dignity Inventory](#), and for more on that inventory, see:

Chochinov, H. M., McClement, S. E., Hack, T. F., McKeen, N. A., Rach, A. M., Gagnon, P., Sinclair, S. and Taylor-Brown, J. "**The Patient Dignity Inventory: applications in the oncology setting.**" *Journal of Palliative Medicine* 15, no. 9 (September 2012): 998-1005. [(Abstract:)]
BACKGROUND: The Patient Dignity Inventory (PDI) is a novel 25-item psychometric instrument, designed to identify multiple sources of distress (physical, functional, psychosocial, existential, and spiritual) commonly seen in patients who are terminally ill. It was also designed to help guide psychosocial clinicians in their work with patients. While its validity and reliability have been studied within the context of palliative care, its utility in clinical settings has not as yet been examined. PURPOSE: The purpose of this study was to determine how psychosocial oncology professionals would use the PDI within their practice and what utility it might have across the broad spectrum of cancer. METHODS: Between October 2008 and January 2009, psychosocial oncology clinicians from across Canada were invited to use the PDI to determine their impressions of this approach in identifying distress and informing their practice. RESULTS: Ninety participants used the PDI and submitted a total of 429 feedback questionnaires detailing their experience with individual patients. In 76% of instances, the PDI revealed one or more previously unreported concerns; in 81% of instances, clinicians reported that the PDI facilitated their work. While it was used in a wide range of circumstances, clinicians were more inclined to apply the PDI to patients engaged in active treatment or palliation, rather than those in remission, having recently relapsed, or newly diagnosed. Besides its utility in identifying distress, the PDI enabled clinicians to provide more targeted therapeutic responses to areas of patient concern. CONCLUSIONS: While this study suggests various clinical applications of the PDI, it also provides an ideal forerunner for research that will directly engage patients living with cancer.]

II. Our featured article includes an excellent bibliography in relation to the studies analyzed. Special attention, however, is afforded the following study:

Chochinov, H. M., Kristjanson, L. J., Breitbart, W., McClement, S., Hack, T. F., Hassard, T. and Harlos, M. "**Effect of dignity therapy on distress and end-of-life experience in terminally ill patients: a randomised controlled trial.**" *Lancet Oncology* 12, no. 8 (August 2011): 753-762. [(Abstract:)]
BACKGROUND: Dignity therapy is a unique, individualised, short-term psychotherapy that was developed for patients (and their families) living with life-threatening or life-limiting illness. We investigated whether dignity therapy could mitigate distress or bolster the experience in patients nearing the end of their lives. METHODS: Patients (aged >18 years) with a terminal prognosis (life expectancy <6 months) who were receiving palliative care in a hospital or community setting (hospice or home) in Canada, USA, and Australia were randomly assigned to dignity therapy, client-centred care, or standard palliative care in a 1:1:1 ratio. Randomisation was by use of a computer-generated table of random numbers in blocks of 30. Allocation concealment was by use of opaque sealed envelopes. The primary outcomes--reductions in various dimensions of distress before and after completion of the study--were measured with the Functional Assessment of Chronic Illness Therapy Spiritual Well-Being Scale, Patient Dignity Inventory, Hospital Anxiety and Depression Scale, items from the Structured Interview for Symptoms and Concerns, Quality of Life Scale, and modified Edmonton Symptom Assessment Scale. Secondary outcomes of self-reported end-of-life experiences were assessed in a survey that was undertaken after the completion of the study. Outcomes were assessed by research staff with whom the

participant had no previous contact to avoid any possible response bias or contamination. Analyses were done on all patients with available data at baseline and at the end of the study intervention. This study is registered with ClinicalTrials.gov, number NCT00133965. FINDINGS: 165 of 441 patients were assigned to dignity therapy, 140 standard palliative care, and 136 client-centred care. 108, 111, and 107 patients, respectively, were analysed. No significant differences were noted in the distress levels before and after completion of the study in the three groups. For the secondary outcomes, patients reported that dignity therapy was significantly more likely than the other two interventions to have been helpful ($\chi^2=3550$, $df=2$; $p<00001$), improve quality of life ($\chi^2=1452$; $p=0001$), increase sense of dignity ($\chi^2=1266$; $p=0002$), change how their family saw and appreciated them ($\chi^2=3381$; $p<00001$), and be helpful to their family ($\chi^2=3386$; $p<00001$). Dignity therapy was significantly better than client-centred care in improving spiritual wellbeing ($\chi^2=1035$; $p=0006$), and was significantly better than standard palliative care in terms of lessening sadness or depression ($\chi^2=938$; $p=0009$); significantly more patients who had received dignity therapy reported that the study group had been satisfactory, compared with those who received standard palliative care ($\chi^2=2958$; $p<00001$). INTERPRETATION: Although the ability of dignity therapy to mitigate outright distress, such as depression, desire for death or suicidality, has yet to be proven, its benefits in terms of self-reported end-of-life experiences support its clinical application for patients nearing death. FUNDING: National Cancer Institute, National Institutes of Health.]

III. Harvey Max Chochinov is a prolific researcher and writer. The following two articles may be of special interest to chaplains inasmuch as they specifically consider spirituality and chaplaincy:

Chochinov, H. M. and Cann, B. J. "**Interventions to enhance the spiritual aspects of dying.**" *Journal of Palliative Medicine* 8, suppl. 1 (2005): S103-115. [(Abstract:) In recent years, medical and allied health publications have begun to address various topics on spirituality. Scholars have posited numerous definitions of spirituality and wrestled with the notion of spiritual pain and suffering. Researchers have examined the relationship between spirituality and health and explored, among other topics, patients' perceptions of their spiritual needs, particularly at the end of life. This paper summarizes salient evidence pertaining to spirituality, dying patients, their health care providers, and family or informal caregivers. We examine the challenging issue of how to define spirituality, and provide a brief overview of the state of evidence addressing interventions that may enhance or bolster spiritual aspects of dying. There are many pressing questions that need to be addressed within the context of spiritual issues and end-of-life care. Efforts to understand more fully the constructs of spiritual well-being, transcendence, hope, meaning, and dignity, and to correlate them with variables and outcomes such as quality of life, pain control, coping with loss, and acceptance are warranted. Researchers should also frame these issues from both faith-based and secular perspectives, differing professional viewpoints, and in diverse cultural settings. In addition, longitudinal studies will enable patients' changing experiences and needs to be assessed over time. Research addressing spiritual dimensions of personhood offers an opportunity to expand the horizons of contemporary palliative care, thereby decreasing suffering and enhancing the quality of time remaining to those who are nearing death.]

Sinclair, S. and Chochinov, H. M. "**The role of chaplains within oncology interdisciplinary teams.**" *Current Opinion in Supportive & Palliative Care* 6, no. 2 (June 2012): 259-268. [(Abstract:) PURPOSE OF REVIEW: The role of chaplains/spiritual care professionals and the importance of addressing spiritual needs within interdisciplinary oncology teams are in need of systematic review and critical appraisal. This review focuses on four key areas: basic concepts of spirituality within the healthcare domain; the relevance of spirituality within cancer care; the role of spiritual care within interdisciplinary cancer teams; and the current status of spiritual care professionals in interdisciplinary cancer teams. RECENT FINDINGS: Addressing cancer patient's spiritual issues is recognized as a component of comprehensive cancer care. Spirituality has a positive effect on subjective and emotional aspects of cancer patient's health, including quality of

life, wellbeing and distress. Failing to address cancer patients spiritual needs impacts patient wellbeing, satisfaction with care, perceived quality of care and is associated with higher healthcare costs. Although a variety of disciplines address spiritual issues, spiritual care professionals are recognized by patients, clinicians, researchers and within best practice guidelines of national health councils as specialists within this domain. SUMMARY: Spiritual care professionals are increasingly recognized as integral members of interdisciplinary oncology teams. However, the full integration of spiritual care professionals within the standard practice of oncology interdisciplinary teams is lacking, as spiritual care services continue to be treated as ancillary services within cancer care organizations.] [NOTE: This is a from a theme issue of the journal regarding spiritual care, with a brief introductory piece: Corn, B. W., Chochinov, H. M. and Vachon, M., "**Integrating spiritual care into the practice of oncology**," *Current Opinion in Supportive & Palliative Care* on pp. 226-227.]

IV. The following recent article out of Sweden uses the example of Dignity Therapy to reflect critically on biographical approaches in end-of-life care and challenges for research and practice.

Lindqvist, O., Threlkeld, G., Street, A. F. and Tishelman, C. "**Reflections on using biographical approaches in end-of-life care: dignity therapy as example.**" *Qualitative Health Research* 25, no. 1 (January 2015): 40-50. [AB The therapeutic potential of nonpharmacologic interventions using biographical approaches at the end of life (EoL) is being increasingly recognized, but less attention is paid to processes impeding realization of this potential. In this article, Swedish and Australian researchers reflect on and problematize experiences using one biographical approach, dignity therapy (DT), in EoL care in Sweden. We use this as an example, focusing on critical examination of the process of applying DT in practice, examining frictions experienced in recruiting participants, collecting the data, and creating a biography. We discuss issues regarding agency, which became evident in the recruitment process and choices made about participation, and the power differentials manifested in the interactive process of eliciting stories and crafting them into a final product. We also raise salient questions about how research and practice with biographical approaches in EoL care might better build on and further existing knowledge to better reflect the complexities of everyday life.]

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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