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The importance of translating evidence into practice in counseling individuals with life-threatening illness

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The Importance of Translating Evidence into Practice in
Counseling Individuals with Life-Threatening Illness

A review of *Counseling Individuals with Life-Threatening Illness* (2nd Edition) by Kenneth J Doka. New York: Springer Publishing Company, 2013. 324 pp. (ISBN: 978-0826195814). \$60.00. Reviewed by Elizabeth Lobb.

Kenneth J. Doka is the editor of *Omega* and the author of *Disenfranchised Grief: New Directions, Challenges, and Strategies for Practice* (Research Press, 2002) and co-author with Terry L. Martin of *Grieving Beyond Gender; Understanding the Ways Men and Women Mourn* (Routledge, 2010).

Elizabeth Lobb has established national and international research collaborations and pursued independent multi-disciplinary clinical collaborations in oncology, haematology, cancer genetics, and palliative care for 17 years. She has worked clinically as a bereavement counselor for 26 years. Her research interests include the communication of prognosis in metastatic cancer, doctor/patient communication, the needs of patients with high grade gliomas and their carers, bereaved carers of women with ovarian cancer, couple communication on end of life issues and complicated grief. Along with several co-authors, she wrote “Communicating with Realism and Hope: Incurable Cancer Patients’ Views on the Disclosure of Prognosis” (*Journal of Clinical Oncology*, **23**(6), 1278-1288),

The strength of this book is the author's extensive clinical experience spanning 40 years. It provides both the experienced counselor and those new to the field with grounding in theory and practice and importantly provides examples of clinical encounters with practical examples of how to accompany persons who cross that invisible threshold and enter the landscape of living with a life threatening illness, often unexpectedly. In Doka's words: "*The 2nd edition incorporates new material that reflects advances in the care of persons with life-threatening illness*" (p 3). To peruse the Table of Contents for this book is to introduce the reader to the trajectory of a life-threatening illness and its influence on individuals and their families. This journey may not be as logical or coherent as the Chapters suggest, but the humanity and compassion of the author creates a tapestry of whole person care which, when examined, leaves few threads untethered.

This review focuses on the importance of incorporating research evidence into clinical practice. The author's competence with the grief literature is evident; however, several sections in this book reflect a lack of familiarity of emerging and current research in oncology and palliative care.

The role of optimism and remaining positive in cancer survival

It is a popular belief that the psychological response to a diagnosis of cancer influences survival in patients; however, research has produced contradictory results. Whilst Doka acknowledges that "*....some question claims of longer survival* (p.119), this issue needs to be more equivocally addressed. A systematic review of the literature of the effects of coping with cancer identified 12 studies examining the prognostic value of fighting spirit for cancer progression and survival, with most of them having negative findings. (Petticrew, Bell, & Hunter, 2002) Overall, the authors found little evidence of the influence of psychological factors on cancer progression and survival. Since this systematic review, a 10-

year follow-up study found that fighting spirit conferred no advantage for survival (Watson, Homewood, Haviland, & Bliss, 2004). More recently, studies in non-small cell lung cancer found there was no evidence that a high level of optimism prior to treatment enhanced survival in patients. (Coyne & Tennen, 2010; Schofield, Ball, Smith, Borland, O'Brien, Davis, Olver, Ryan, & Joseph, 2004). This is not to deny the role of optimism which “may significantly influence mental and physical well-being by the promotion of a healthy lifestyle as well as by adaptive behaviours and cognitive responses, associated with greater flexibility, problem-solving capacity and a more efficient elaboration of negative information” (Conversano, Rotondo, Lensi, Della Vista, Arpone, & Reda, 2010, p. 25); however, to date there is little evidence of benefit to survival.

The wish to die at home

Research has shown that up to 90% of people with advanced cancer or other life limiting illnesses prefer to be cared for at home, and the majority wish to die at home too. (Higginson & Sen-Gupta, 2000) If congruent with patient wishes, dying at home can assist family members' perceptions of a “good death.” But when care needs are complex and/or unstable, maintaining patients at home becomes challenging, and availability of support services is among the most important variables enabling home death (Aoun, Kristjanson, Currow, & Hudson, 2005). Without the necessary support, patients who prefer to stay at home may seek care in acute, subacute, or residential facilities due to fear of excess suffering and a wish to reduce caregiver burden (Agar, Currow, Shelby-James, Plummer, Sanderson, & Abernethy, 2008). Agar et. Al. (2008) concluded that there are two conversations to be had: “preference for current place of care and preference for care at the time of death. Place of care is not a euphemism for place of death; and further research is needed to delineate these” (p. 787). Clinical implications suggest that patient and caregiver preferences may not

match, and issues such as carer fatigue and/or perceived competence in caring need to be explored.

Breaking Bad News

Much research has been undertaken to improve communication with patients for instance, breaking bad news. As an example, the following mnemonic in the oncology setting has been developed. – SPIKES (Baile, Buckman, Lenzi, Glober, Beale, & Kudelka, 2000)

S – SETUP. Set up the situation so it has a good chance of going smoothly

P = PERCEPTION. Find out the patient’s perception of the medical situation

I = INVITATION. Find out how much information the patient wants

K = KNOWLEDGE. Use language that matches the patient’s level of education

E = EMPATHISE. Use empathic statements to respond to patient emotions

S = SUMMARISE AND STRATEGISE. Summarise the clinical information and make a plan for the next step

Psychiatric disturbances

The statement that “*Psychiatric disturbances are far more common among persons with life threatening illness*” (p 89) needs to be put into context as recent research does not provide support for the common clinical assumption that the prevalence of depression and anxiety disorders increases as death nears. In a recent study of 298 patients, closeness to death was not associated with higher rates of mental disorders. (Lichtenthal, Nilsson, Zhang, Trice, Kissane, Breitbart, & Prigerson, 2009).

Model of disease trajectories

An examination of the trajectory of disease identified by Glaser and Strauss (1968) and reported on page 108 could be enhanced by a more recent model. The well-established Trajectories of Functional Decline developed by Lynn and Adamson (2003) plots the common trajectories of cancer and organ failure. The model acknowledges that with improved treatments individuals live longer – and more chronic diseases such as renal failure or congestive heart failure has a varied pattern, with frequent crises and lulls. This phenomenon has implications for carer fatigue and also for the planning of clinical services and interventions.

Desire for information and preference for involvement in decision making

The image of patient as protagonist “*who sets the pace and direction for the ensuing drama*” (p. 4) is useful, but the reader needs to consider the body of literature on preferences for patient involvement in decision making which indicates that patients vary in their desire for involvement in their care. Patients' decision-making preferences and need for information have been found to be highly dependent on their health. For example, patients whose disease had worsened before their consultation with a medical oncologist, appeared to maintain a preference for the doctor to make decisions, while those who were attending for routine follow-up were more likely to prefer more information and involvement over time.

The majority of studies that have measured patient preferences for involvement in decision making have found that the collaborative role, or shared decision making, is most preferred. However, some studies have found that over 30% - 40% of patients prefer to remain passive, deferring to their physicians on treatment-related matters. Particular patient profiles have been identified for those wanting active involvement in decision making. These profiles include younger patients, who are female and of higher education. Variables

predictive of a passive role preference include lower educational attainment, older age, male gender, and disease severity (see Hack, et al 2005 for a full review). The implications for clinical practice are that counselors need to be aware that preferences change and patients may welcome an opportunity to rehearse conversations that may be challenging or uncharacteristic for them.

Language

I have some concerns over some of the language used in the book, for example, use of the term “a growth” to define cancer (p.112). Counselors who are unable to use the correct language feed into the fear that has historically prevented cancer patients from asking questions leading to a misunderstanding of the goals of treatment and ultimately prognosis. (Dunn, Patterson, Butow, Herbert, Smart, & Tattersall, 1993). The use of the generic term “caregivers” is confusing at times and needs to be qualified that there are “professional” caregivers and even within this stream there are differing roles and responsibilities, and then there are the family caregivers which Doka addresses in Chapter 12.

I agree with Doka in the use of the word “terminal.” Patients do not like the term, interjecting that they are not waiting for a train or a bus and declaring that they are living with their disease, not dying from it. End of life care can take on a broader representation and refers to the period of time when a person is living with an advanced, progressive, life-limiting illness. Estimating when someone will die is very difficult. It is more useful to identify those for whom increasing disability and illness will lead to their death sometime in the next year. Palliative care (in Australia at least) describes designated specialist services provided by an interdisciplinary team of specialist palliative care professionals whose substantive work is with people approaching the end of life.

Chapters 7 – 10 represent for me, as a clinician, the best aspects of the book. Drawing on his 40 years of experience Doka takes the reader from Understanding the Illness Experience to the Pre-diagnostic Phase, the Crisis of Diagnosis, the Chronic Phase of Illness and the Terminal Phase with practical, empathic, and educative counseling skills and case histories structured well in a logical manner and drawn from “real life”. Doka provides a brave and realistic statement about touch (p. 215). “*Ill persons should never be touched or hugged without their permission, for touch may be physically painful, psychologically uncomfortable or culturally inappropriate*”. It is also refreshing to hear the word “sex” used in discussing life-threatening illness and a frank approach to identifying intimacy, body-image, and sexual difficulties. By acknowledging that “*Life-threatening illness is not only a medical crisis, it is a social, psychological and spiritual crisis as well,*” Doka addresses the relatively new concept of whole person care.

In conclusion, this is a practical reference book for clinicians. Researchers in oncology and palliative care may find some of the out-dated references frustrating, but one could never doubt the clinical skills and experience of the author. The book is a valuable addition to the repertoire of those who work and support those individuals and families living with a life-threatening illness.

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Lobb Review

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