

From Death Anxiety to Meaning Making at the End of Life: Recommendations for Psychological Assessment

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Although careful assessment and intervention for depression can improve psychological research and practice with patients at the end of life, attention to this focal problem should be supplemented by a broader evaluation of factors relevant to both risk and resilience. In particular, substantial research on the assessment of suicidality, death attitudes, and grief has yielded an array of methods for evaluating additional domains of patient and family functioning of high relevance to end-of-life care. This article discusses some of the specific advantages of assessment tools targeting each domain and provides citations to comprehensive psychometric reviews in each area.

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At least since the pioneering work of Herman Feifel in the 1950s (Feifel, 1955, 1959, 1990; Neimeyer & Fortner, 1997), psychology has made a consistent and important contribution to understanding the human encounter with death. And yet it is only recently that the predominantly scientific and scholarly work of psychologists on such topics as suicide (Shneidman, 1999), death attitudes (Neimeyer, 1994), and grief and bereavement

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(Stroebe, Stroebe, Hansson, & Schut, 2001) has been augmented by the emergence of clearly defined clinical roles in such interdisciplinary contexts as end-of-life care. Viewed broadly, these roles include interventions (a) before illness strikes (e.g., in health promotion and advanced care planning), (b) after illness is diagnosed and treatment begins (e.g., in assisting patients and families with coping and communicating with treatment staff), (c) during advanced illness and dying (e.g., diagnosis of psychosocial complications and assistance with self-determined life closure), and (d) after the death of the patient, in working with the family (e.g., through supporting bereavement adaptation and where needed providing grief therapy; Haley, Larson, Kasl-Godley, & Neimeyer, 2003).

It is chiefly to the third of these areas—during advanced illness—that the work of King and her colleagues (this issue) makes a clear contribution. Surveying what is known about the prevalence, assessment, and treatment of depression at the end of life, these authors prompt readers toward controlled and carefully evaluated outcome studies of psychotherapy for those with life-threatening illness as well as clinical engagement in monitoring and ameliorating their suffering. My purpose here is to extend this effort by highlighting some further resources relevant to these goals that derive from the broader efforts of psychologists engaged in the field of death, dying, and bereavement.

THREE DOMAINS OF ASSESSMENT

As the psychological dimension of palliative and hospice care has grown more sophisticated, there is increasing recognition that fatalistic resignation at the end of life is not an inevitable outcome of confronting one's

mortality and that indeed this response can signal the presence of complications such as depression that unnecessarily vitiate the quality of life that such services do much to conserve and restore. The several methods of evaluating the presence of depression at the end of life that King and her colleagues review—ranging from single-item depression screens through self-report measures to elaborate clinical interviews—are therefore pertinent methods for assessing this dimension of distress in advanced illness and monitoring the patient's responsiveness to treatment efforts, whether psychological or pharmacological. However, it is likely that additional methods can add a useful degree of both specificity and breadth to such assessment, drawing on instruments and interviews developed by psychologists working in related areas.

The first of these concerns the assessment of one particularly troubling expression of end-of-life depression, namely suicidality. Although it would be comforting to believe that most psychologists are well trained in the evaluation of suicide risk, there is good empirical reason to conclude that this is not the case (Bongar & Harmatz, 1991). Moreover, far fewer are trained in the nuances of conducting risk assessments in the end-of-life context (Neimeyer, 2000), when requesting hastened death through the withdrawal of life-sustaining treatments is a serious option for many patients (Werth & Holdrick, 2000). For this reason, psychologists working with vulnerable populations could benefit from familiarity with the diverse methods for evaluating risk, the majority of which are brief (requiring 5 to 10 min to administer) and of demonstrated psychometric adequacy. Like assessments for depression—which typically give only cursory attention to suicide risk if they give any attention at all—such methods range from well-documented clinical interview protocols like the Scale for Suicide Ideation, with its useful distinctions between active versus passive desire for death and preparation for self-injury (Beck, Kovacs, & Weissman, 1979), to brief screening devices that can be completed by the patient as part of a larger clinical assessment. Other approaches evaluate the patient's endorsement of factors that buffer *against* suicide, such as moral objections or a concern about the impact of elective death on family and friends (Ivanoff, Jang, Smyth, & Linehan, 1994). Thus, the wide array of assessment options in this field provide measures

that could prove applicable for both identifying high-risk patients contending with a life-threatening illness and evaluating the impact of interventions designed to augment the patient's sense of meaning at the end of life. These scales also suggest themes and patterns of questioning that could be adapted by clinicians attempting to tailor their inquiries to the unique context of palliative care. Range and Knott (1997) offer a thorough discussion of the format, focus, time requirement, and psychometric properties of these instruments.

A second domain of assessment of high potential relevance to psychological care at the end-of-life concerns attitudes toward death and dying. In many respects it is ironic that this seemingly self-evident point requires emphasis, but research suggests that, without specialist training, counselors experience acute discomfort when faced with clinical situations involving the prospect of death and loss (Kirchberg, Neimeyer, & James, 1998; Terry, Bivens, & Neimeyer, 1995). Under such circumstances, it can be understandably tempting to translate a patient's poignant anxieties about dying into simple medical symptoms to be managed or mitigated. Arguably, however, a psychologist's preoccupation with symptoms rather than their significance constitutes a form of professional abandonment of vulnerable and potentially needy patients at the end of their lives.

As with the domain of suicide intervention, a broad array of tools exists to support clinical assessment and research documentation of a patient's attitudes toward his or her mortality. The best of these offer a refined view of different facets of death concerns, such as fears concentrating on the pain involved in dying, on spiritual issues, on existential questions regarding the confrontation with the unknown, on concerns for bodily integrity after death, on the inability to accomplish important life goals or purposes, and on the impact of one's death on others (Florian & Mikulincer, 1997; Hoelter, 1979; Lester, 1994; Neimeyer & Moore, 1994; Wittkowski, 2001). Thus, appropriate selection or modification of established measures for the end-of-life context could help target interviews and interventions to those domains of concern to a given patient, as well as document the efforts of treatment programs in ameliorating them. However, it is worth noting that not all feelings about death are negative, and some measures

specifically assess such attitudes as the acceptance of death as a natural conclusion of one's life, as a release from suffering, or as an entry to an afterlife of reward (Wong, Reker, & Gesser, 1994). As such, the extensive literature on death attitudes can provide guidance in identifying patient resources as well as vulnerabilities, and suggest etiological and illness-related factors that exacerbate death anxieties (Neimeyer, Stewart, & Anderson, 2005; Neimeyer, Wittkowski, & Moser, 2004). My colleagues and I have provided a thorough discussion of this area of psychological assessment elsewhere (Neimeyer, Moser, & Wittkowski, 2003).

A final domain of assessment of potential relevance to end-of-life care and research concerns grief and bereavement. Although the central drama of end-of-life care could indeed be the patient's own looming loss of life, it is worth remembering that on statistical grounds alone, older adults receiving palliative and hospice services are likely to have encountered a succession of losses of friends and family in recent years. Thus, as King and her colleagues note, conducting a differential diagnosis for complicated grief as distinct from depression could become important, not only because the core features of the former (such as separation distress) are distinct from those of the latter, but also because complicated grief does not appear to be particularly responsive to antidepressant therapies, whether psychological or pharmacological (Prigerson & Maciejewski, 2006). As with the assessment of suicidality and death attitudes, options for evaluating grief responses are varied, ranging from measures that focus on the evaluation of problematic bereavement reactions (Prigerson & Jacobs, 2001) to multidimensional assessment of more normative dimensions of grieving, including the personal growth that can result from the healthy integration of loss (Hogan, Greenfield, & Schmidt, 2001). Of course, such assessment can be relevant not only for the patient him- or herself, but also for surviving loved ones after the patient's death, bridging end-of-life care to grief therapy for those who need it (Jordan & Neimeyer, 2003). In addition, the growing body of qualitative research on bereavement can sensitize clinicians to the multiple meanings that patients and families construct to make sense of their shared losses (Nadeau, 1997; Neimeyer, 2001) and the ways these can vary for distinctive cultural and ethnic groups (Rosenblatt & Wallace, 2005). Readers interested in a

broad-ranging review of various methods for assessing grief can consult Neimeyer and Hogan (2001).

CONCLUSION

As psychologists explore the distinctive contributions they can make to end-of-life treatment and research, the issue of assessment emerges as one important focus of both areas. Building on the increasingly sophisticated attention to depression in the context of life-threatening illness that King and her associates review, I have argued here that psychologists can benefit equally from awareness, utilization, and perhaps adaptation of methods and measures developed for the study of suicidality, death attitudes, and grief, each of which is likely to have relevance at the end of life. On the one hand, the refined sense of patient vulnerabilities (level of risk or lethality as a function of depressive resignation; specific death-related anxieties; complications in grieving) that the integration of such assessment can afford could improve the focus of both research and care. On the other hand, such assessments can also allow psychologists to identify sources of resilience and resourcefulness in both patients and their families (e.g., reasons for living, death acceptance, personal growth). Ultimately, this broader target for assessment and intervention can help our profession broach important existential issues and processes of meaning making in both the context of end-of-life care (King et al., 2006) and our subsequent contact with bereaved survivors (Neimeyer, 2005, 2001). I hope that an expanded focus for psychological assessment contributes an element of specificity and sensitivity to this effort.

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