

## **Beyond Death Anxiety: Evolution of a Research Program<sup>1</sup>**

Robert A. Neimeyer, Ph.D.<sup>2</sup>

When Dr. Lilian Wong and Evelyn Tam invited my contribution to this very special volume saluting the multifaceted contributions of Paul Wong to our field across the last half century, I confess that I found the task a bit daunting. What might I have to add, I wondered, to the contributions of colleagues from many nations whose research, practice, and even lives and faith have been touched by Paul's presence, and, in some instances, even transformed? Though I readily accepted the call, as the months passed and the deadline loomed, I found myself hesitating to put finger to keyboard and join the chorus of what I imagined would be dozens of scholars echoing and extending his seminal contributions to a psychology of meaning, from the standpoint of a Victor Frankl-inspired existentialism (Wong, 2012; Wong & Fry, 1998), meaning-centered psychotherapy (Wong, 2015, 2016), studies of spirituality (Wong, Wong, MacDonald, & Klaassen, 2012), and even a bold new approach to contemporary positive psychology (Wong, 2011). Paul himself has been so prolific that his work hardly needs amplification or review, particularly if the charge of the editor was to demonstrate how the spirit of his lifelong inquiry also animates our own. I therefore flipped back the pages of the calendar to my own origins as a scholar whose career began just a few years after Paul's, and determined to review the development of one long-running current of research that animated my early work and that intersected repeatedly with his, namely, the study of our human attitudes toward death. In doing so, I will not so much recap Paul's intellectual sojourn through this territory as I will my own, though I will reflect on points of contact he and I had along the way, in print or in person. I hope that the reader will find this review valuable, and readily discern in these pages the imprint of Paul's research, whose impact on the field of death attitudes continues to be felt far beyond the walls of my lab.

In keeping with the reflective tone of the present volume, I will intersperse some informal comments throughout the formal review to convey something of my own developing thoughts about this diversified line of research, offering a "behind the scenes" view of the evolution of a body of scientific and professional literature. I therefore hope that this brief chapter will help summarize a widely dispersed literature for those readers sharing Paul's interest in thanatology—the study of death and dying—and acquaint those whose main interest is in meaning-centered approaches to therapy with one long-standing research program that takes inspiration from this perspective. After reviewing our research on death attitudes as well as its interface with suicide intervention, I will close by sketching very briefly the contours of the main research program that for me has followed this early work, namely, the study of meaning reconstruction in bereavement, which also converges in its own way with Paul's more recent contributions.

### **Death Threat and Anxiety**

The historical core of my interest in the role of meaning in configuring our attitudes toward life and death originated in research being conducted at the University of Florida in the early 1970s by Franz Epting, Seth Krieger, and Larry Leitner. Prompted in part by the upsurge of popular

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<sup>2</sup> *Department of Psychology, University of Memphis; Portland Institute for Loss and Transition; neimeyer@portlandinstitute.org*

and professional interest in issues of death and dying (Kübler-Ross, 1969), the Florida group brought to bear the conceptual and methodological resources of George Kelly's (1955) personal construct theory on the problem of assessing people's attitudes toward their own eventual mortality, a nascent area of research cluttered with what was, at the time, psychometrically shabby instrumentation and poorly designed studies. The result of this effort to upgrade the death attitude literature was the Threat Index (or TI) (Krieger, Epting, & Leitner, 1974), a repertory grid-based measure that operationalized Kelly's (1955) concept of *threat* as the "awareness of imminent, comprehensive change in one's core role structure," in other words, deeply perturbing change in the system of meaning anchoring one's sense of identity. Specifically, the TI required eliciting a significant sample of death-relevant constructs or polarities of meaning (e.g., painful vs. painless, familiar vs. unfamiliar, meaningful vs. meaningless) from the respondent through a triadic comparison of situations involving death (e.g., a tornado kills three children in an elementary school, your grandmother dies in her sleep). The respondent was then asked to rate the elements *self*, *preferred self*, and (personal) *death* on these constructs, with the number of splits in which both self-elements were aligned with one construct pole, and death with its contrast, serving as the index of the subjective threat that would be entailed in construing the death of self as a personal reality. If, for example, a respondent construed both himself and preferred self as *known* and death as *unknown*, this would represent one such split suggesting a potential threat to its inclusion in his system of personal meanings. As an undergraduate research assistant, I joined the research effort at the point that TI was being developed into a standardized measure to circumvent the rather cumbersome administration of full interview-based repertory grids to individuals, which limited the measure's use in research. Thus, my first task was to assist in the administration of dozens of grid-based interviews, in order to elicit thousands of death-relevant constructs, and then winnow these to the 30 or 40 most commonly occurring dimensions to comprise the items for the standardized self-administered form of the instrument. The work was initially fascinating, offering me a glimpse of people's views of life and death within the mutually reassuring structure of a grid-based interview. Primed by my own earlier and ongoing immersion in the existential philosophies of Sartre, Merleau-Ponty, and Heidegger, I fell in love with the work and the psychological theory behind it, and soon devised several studies of my own that helped establish the psychometric soundness of the resulting measure (Neimeyer, 1986; Neimeyer, Dingemans, & Epting, 1977; Rigdon, Epting, Neimeyer, & Krieger, 1979). As this research proceeded over the decade of the 80s, the TI consolidated its place as one of the most valid and reliable instruments in the broad death anxiety literature (Neimeyer, 1994a, 1994b), at approximately the same time that Wong and his team were validating their own multidimensional measure of death fear and acceptance, the Death Attitude Profile, which I later included in my handbook on death attitude research (Wong, Reker & Gesser, 1994).

But despite my initial enthusiasm for this research, the fairly compulsive methodological focus of the early work also generated a certain amount of restiveness on the part of the younger members of the research team. I recall strolling along a lake on the University of Florida campus in 1975 with Peter Dingemans, my principal co-investigator and graduate exchange student from the Netherlands, lamenting and laughing about the possible irony of spending our careers on picayune issues like the internal consistency of the TI, when our imaginations led us to far broader horizons. This intermittent dissatisfaction with a psychometric preoccupation yielded a handful of substantively interesting articles on such topics as the death threat experienced by suicide intervention workers (Neimeyer & Dingemans, 1981; Neimeyer & Neimeyer, 1984) and on the link between death anxiety and the completion of one's existential projects (Neimeyer,

1985; Neimeyer & Chapman, 1980), but, for the most part, research with the TI and its derivatives remained rigorously methodological until about 1990. This focus continued briefly into the 90s, producing a massive study of the TI with my student, Marlin Moore, which yielded a confirmatory factor analysis of the measure (Moore & Neimeyer, 1991), still to my knowledge the only one of its kind performed on a death attitudes instrument.

Eventually, however, the psychometric properties of the TI were established even to our satisfaction, allowing my students and me, now at the University of Memphis, to begin applying it—and a few other soundly developed death anxiety scales (Neimeyer & Gillies, 2003; Neimeyer & Moore, 1994)—to a host of substantive areas. Our first target was the frequently noted finding that women report greater fear of personal death than men, across dozens of studies in the vast death anxiety literature (Neimeyer & Fortner, 1997; Neimeyer & Van Brunt, 1995). Although this finding typically is explained in terms of the greater emotional expressiveness of women, our findings led us to call this interpretation into question, as this result held in a large sample of men and women even when we controlled for their level of self-disclosure (Dattel & Neimeyer, 1990). We also began to examine the personal anxieties about death experienced by vulnerable groups, such as a large number of gay and bisexual men living in the shadow of the AIDS epidemic (Bivens, Neimeyer, Kirchberg, & Moore, 1994). Here again, our findings were surprising and informative: HIV positive men (half of whom had developed AIDS symptomatology) and the caregivers who worked with them were actually far *less* threatened and anxious about the prospect of death than were gay/bisexual men who were HIV negative and uninvolved in caregiving. Further scrutiny of our data suggested a possible explanation for this pattern of results, as the former two groups reported significantly more intrinsic religious faith than their less directly affected peers. Our findings converge with broad themes in Wong's research program, which link faith to a more hopeful approach to personal mortality.

A second vulnerable population to attract our attention in the early 90s was older adults, whose age and health status placed them at elevated risk of death. Together with my student, Barry Fortner, I first undertook a qualitative review of research on death anxiety in the elderly, trying to make sense of the often contradictory studies pointing to various markers of elevated fear of death (e.g., gender, health status) in an aging population (Neimeyer & Fortner, 1995). This effort convinced us of the need for a more systematic approach to integrating the literature, leading us to undertake a major quantitative review of all published and unpublished studies of death attitudes in older adults. The results were clarifying: across nearly 50 studies including over 4,500 participants, older adults' fears of personal death were found to be unrelated to gender and religiosity, departing from the modal finding in the death anxiety literature on younger populations. Instead, the most powerful predictors turned out to be their level of "ego integrity" or life satisfaction—the feeling that they had lived long and well—in combination with their level of institutionalization and physical health problems (Fortner & Neimeyer, 1999). Reflecting on these findings, we placed them into the context of life-span developmental theory, and considered those dehumanizing aspects of institutional care and medical difficulties that could exacerbate fears of death at the end of life (Fortner, Neimeyer, & Rybarczeck, 2000; Neimeyer & Fortner, 2001).

A second arm of this research effort in connection with older adults entailed examining not the elders themselves, but the healthcare professionals who work with them most frequently, at least in the United States. Thus, my student Steve DePaola and I began to study the psychosocial context of nursing homes, where dismissive, avoidant, or infantilizing attitudes on the part of staff toward residents is an all-too-common occurrence. Comparing a large group of

nursing home staff to demographically similar controls from the same community, we discovered that staff as a whole had comparable levels of death threat to controls, and the comparison group actually was more fearful of contact with dead bodies, perhaps as a function of their lesser exposure. However, we additionally discovered that increasing levels of death concern were associated with greater personal anxiety about aging, especially among nursing home workers, who also displayed significantly more negative attitudes toward the elderly (DePaola, Neimeyer, Lupfer, & Fiedler, 1992). Subsequent research extended these findings by providing evidence that nursing assistants, the least trained caregivers in elder care facilities, had higher levels of personal death anxiety than registered nurses and licensed practical nurses in these same facilities (DePaola, Neimeyer, & Ross, 1994). This enhanced my concern over the possible linkage between personal death attitudes and suboptimal caregiving practices, especially among less trained and less experienced helpers—a concern that found expression in the studies of counselors and suicide interventionists that I briefly discuss below.

A further line of work on death attitudes concerned the reactions of counselors to situations involving death and loss, testing the assumption—widely held in thanatology circles—that such situations trigger more discomfort and avoidance on the part of caregivers than other potentially serious problems. Providing masters level counselors a set of 15 written descriptions of both death-related counseling scenarios (e.g., grief, life-threatening illness, suicide risk) and non-death-related situations (e.g., sexual assault, intimate partner violence), Tom Kirchberg and I found that 5 of the 8 problems they rated as most uncomfortable were in the former category. In contrast, none of the 7 least distressing situations concerned death or loss. However, our attempts to link these reactions to levels of personal death threat or years of experience proved unsuccessful (Kirchberg & Neimeyer, 1991). Having discovered evidence of discomfort with death among these neophyte counselors, Marie Terry, Alex Bivens, and I then sought to test the generality of this effect by recruiting a large group of highly expert grief therapists (averaging 14 years of experience). Both in their ratings of brief presenting problems and in their written responses to detailed “transcriptions” of opening statements by clients, these expert counselors reversed the earlier finding, reporting death and grief issues more comfortable to respond to than other serious non-death-related problems (Terry, Bivens, & Neimeyer, 1995). Moreover, these counselors responded with greater coded empathy to clients presenting with grief and loss issues, a tendency that was enhanced with more years of training and practice in death education and counseling. However, neither comfort nor empathy was related to personal death fears in the counselors, who were characteristically quite death accepting and typically religious.

Practical as well as theoretical concerns drew my attention once again to beginning counselors, as this was the group that was visibly death- and grief-avoidant, not only in our first study, but also in my supervision of doctoral trainees in psychotherapy in our departmental clinic. I therefore welcomed further collaboration with Tom Kirchberg, my co-investigator in the original study, in conducting a more tightly controlled and more realistic study of counselor responses to death and grief situations with clients. For this study, we enlisted the help of actors, carefully counterbalanced for gender and race, to enact the part of clients presenting with death-related (e.g., grief, AIDS) or non-death-related problems (e.g., marital discord, physical handicap), videotaping their performances. Counselors then watched one set of videos, rating their discomfort and recording their responses to the clients’ self-presentations. As we hypothesized, we found greater discomfort in responding to the death than non-death enactments, a response that proved to be mediated by the personal death fears of the counselor. Contrary to our predictions, counselors were actually slightly *more* empathic in relation to death and grief

situations, although the level of empathy was surprisingly small in absolute terms (Kirchberg, Neimeyer, & James, 1998). The least empathic responses were provided by counselors who construed death in fatalistic terms on the Threat Index, suggesting that working with death and loss can prove especially challenging for those neophyte counselors whose personal death concerns leave them vulnerable to such work.

Viewed in hindsight, our substantive research on death threat and anxiety over many years reached toward a kind of symmetry, beginning with a focus on the death concerns of vulnerable populations (e.g., persons with AIDS, the elderly), and then broadening the focus to include the potentially problematic role played by the personal death fears and concerns of those who work with them (e.g., caregivers, nurses, counselors). Although this complementary research strategy was at best only half-conscious at the time, a roughly parallel pattern was evident in my research in a second death-related area, namely, suicide intervention.

### **Suicide Intervention**

My early work with Dingemans had left more questions than answers about the death concerns of suicide intervention workers, as some findings had pointed to elevated death threat in this group (Neimeyer & Dingemans, 1981), while later work contradicted this conclusion (Neimeyer & Neimeyer, 1984). As an undergraduate, my research focus on crisis intervention services had been partly a matter of convenience, and partly a matter of personal curiosity, as I found myself working with life-threatening callers weekly in my role as a paraprofessional in one of the pioneering suicide and crisis intervention centers on the east coast of the United States. What role, I wondered, might staff anxieties about death and dying play in affecting their responses to clients who often were quite literally presenting with life-threatening situations? However, as I contemplated this question in light of our initial studies, I soon confronted a more basic problem: the dearth of credible assessments of suicide prevention skills that could make an empirical answer to this question feasible. Thus, I began as I had with the Threat Index research, constructing the first self-report instrument for the assessment of suicide prevention competencies—the Suicide Intervention Response Inventory or SIRI (Neimeyer & MacInnes, 1981)—and then marching it through a series of validation studies through the 1980s that collectively supported its psychometric soundness (see Neimeyer & Pfeiffer, 1994a for a review). The logic of the SIRI was straightforward, consisting of 25 responses on the part of a potentially self-destructive client (e.g., veiled suicide threats, perturbation, depressive helplessness), to which the respondent could choose one of two possible replies, one constructive and the other neutral to negative from the perspective of crisis intervention theory. The score on the SIRI was simply the number of preferred responses.

Ultimately, the SIRI was revised (Neimeyer & Bonnelle, 1997) and ready to be used in substantive research, which initially took the form of attempting to catalogue the ten most frequent errors of medical and non-medical suicide interventionists (Neimeyer & Pfeiffer, 1994b). Surveying over 200 professional and paraprofessional staff, we found a tendency toward superficial reassurance, avoidance of strong feelings, professional distancing, inadequate assessment of suicidal intent, failure to identify precipitating problems, and passivity to be relatively common responses. Medically trained interventionists in the sample tended to err in ways that were distinctive from the psychologically trained counselors: whereas the former tended toward defensive, distancing, advice-giving, and dismissive interactions, the latter displayed excessive passivity and failure to structure interactions with a potentially suicidal client. This rekindled old concerns about the personal factors that could contribute to such

suboptimal responses among interventionists. As a result, Barry Fortner, Diane Melby, and I studied a large and heterogeneous group of respondents likely to have contact with people in the midst of a suicidal crisis, who varied from untrained peers, through crisis paraprofessionals, to masters level psychologists and counselors (Neimeyer, Fortner, & Melby, 1999, 2001). This research was especially noteworthy in the present context, as we drew directly on the measure devised by Wong et al. (1994), the Death Attitude Profile-Revised (DAP-R), to assess not only death fear, but also death avoidance and three dimensions of death acceptance (Neutral, viewing death as a natural part of life; Approach, embracing it as a transition into a comforting afterlife; and Escape, regarding it as an alternative to a painful life). This level of precision in Wong's scale was a clear advance over most other measures of death attitudes, and made possible a more nuanced understanding of the relevance of personal meanings of death for one's effectiveness in working with suicidal clients whose death was a very perturbing possibility. In the context of our study, which included several measures of counselor experience, personal background, attitudes toward suicide, and feelings and beliefs about death, the dimensions of the DAP-R made a distinctive contribution, jointly comprising a factor in which all three subscales connoting a neutral or favorable attitude toward mortality loaded positively and death fear and avoidance loaded negatively. We therefore labeled this overarching construct "death acceptance."

The results of our study were illuminating: level of training, experience with suicidal clients, and death acceptance were positively associated with suicide intervention skills, whereas a personal history of suicidality and a casual, permissive stance toward suicide as a "personal right" were negatively associated with appropriate responding. Moreover, among the most highly trained professional interventionists, a personal history of suicidality was even more strongly associated with poorer suicide counseling skills. One "spin-off" of this research was our decision to use the SIRI as a screening device to ensure a minimum level of suicide management competency in our randomized controlled trial of mutual support groups and cognitive therapy for depression (Bright, Baker, & Neimeyer, 1999). These findings also informed my attempt to develop a more coherent training agenda for counseling psychologists in suicide and hastened death, one that gave attention to the experiential exploration of personal attitudes toward death and suicide, as well as systematic training in professional ethics and crisis management (Neimeyer, 2000b). Eventually, however, like the field of death attitudes research as a whole, my engagement in this research tapered (Neimeyer & Vallerga, 2016), and made room for a new development focused less on the anticipation of death and more on its aftermath.

## **Grief and Loss**

Approximately 20 years ago, our research program in thanatology took a new and integrative turn, shifting toward the study of grief and loss from our previous concentration on death attitudes and suicide intervention. In part, this represented a natural extension of the previous two foci, in combination with the impact of my clinical practice, which had long included significant numbers of clients dealing with losses of all kinds, through bereavement, assault, illness, job loss, relationship deterioration, and geographic displacement. But this move also embodied a more personal motivation to span my two largely separate identities as a thanatological researcher on the one hand, and psychotherapist on the other. The result was a new hybrid program of scholarship on meaning reconstruction in the wake of loss, a program that quickly moved to center stage as an orienting frame for my own thinking and that of my students.

The overarching proposition that has animated our work to date is that *grieving entails a process of reaffirming or reconstructing a world of meaning that has been challenged by loss*

(Neimeyer, 1998). Issues of meaning-making in the wake of loss had, of course, received some attention in earlier work on bereavement (Marris, 1974; Parkes, 2001), but, for the most part, this had been a side note to a much more central concern with emotional stages of adjustment in response to loss or a psychiatric preoccupation with acute symptomatology of grieving construed in largely pathological terms. In contrast, a new breed of grief researchers was beginning to attend to the ruptured assumptive world of the bereaved person (Janoff-Bulman, 1989), the cognitive processes by which the bereaved cope with loss (Bonanno & Kaltman, 1999), and the post-traumatic growth displayed by many of those who suffer adversity (Tedeschi, Park, & Calhoun, 1998). Likewise, it was apparent that the field of grief theory was in ferment, as scholars took a second look at timeworn assumptions about the need to “withdraw emotional energy” from the one who had died, in order to “reinvest” it elsewhere (Hagman, 1995). Instead, thinkers were beginning to focus on the potentially sustaining continuing bonds the bereaved construct to the deceased (Klass, Silverman, & Nickman, 1996), and the active processes by which they strive to “relearn the world” in the wake of loss (Attig, 1996). My own entry into these discussions in various professional settings was enthusiastic, as I saw the immediate applicability of meaning-oriented concepts and methods in advancing an alternative and more constructive understanding of the human response to loss.

Our overarching metaphor in this work was the *self-narrative*, defined as the life story one both enacts and expresses that gives a sense of coherence to one’s identity over time. In our view, traumatic loss disrupts the continuity of the narrative construction of self, dislodging the individual from a sense of who he or she is (Neimeyer, 2000a). For example, the struggle to “emplot” traumatic events within one’s self-narrative can leave one with a fragmented sense of autobiographical continuity through time, as traumatic losses of many kinds would introduce sharp experiential discrepancies into the survivor’s self-narrative (Neimeyer & Stewart, 1996).

This new line of study quickly consolidated, and soon eclipsed my previous engagement in death attitudes, by the early 2000s becoming the predominant focus of our research network. Again, like Wong, who viewed issues of meaning as foundational to not only attitudes toward death but also to life challenges of all kinds, I found in a meaning reconstruction approach a broad and deep framework for studying adaptation to bereavement, which commonly entails an attempt to both process the *event story* of the loss itself and its implications for our lives, and to access the back story of our relation to the deceased to restore a modicum of attachment security or to process unfinished business with them (Neimeyer, 2016a). At this point, having developed and validated several measures of meaning making in loss and studied their impressive relation to bereavement adaptation to losses both violent and natural, and by adults of college age through later life, we have learned that a struggle to preserve or restore a world of meaning that has been challenged by the loss contemporaneously and prospectively predicts complicated and prolonged grief symptomatology in both end-of-life and bereavement contexts. Conversely, the ability to integrate the loss into the mourner’s system of meaning and social validation for this effort predict not grief but rather personal growth in the wake of loss. Because this 20-year corpus of research and some of its many rich clinical implications (Neimeyer, 2012, 2016b; Thompson & Neimeyer, 2014) have been reviewed extensively elsewhere (Neimeyer, in press), I will not summarize them here, but it is worth noting in this context that the import of this work for grief counseling once again converges with Wong’s (2015) advocacy for the relevance of a meaning-centered psychotherapy.

## Coda

In this brief chapter I have accepted the invitation of Dr. Lilian Wong and Evelyn Tam to reflect on my long involvement in the field of death attitudes, and to note its frequent intersection with Paul Wong's similarly extensive contributions to the same and cognate fields. This has afforded me a rare opportunity to reflect on a lengthy and multifaceted research program, glancing back occasionally in time to its undergraduate origins in an early fascination with the measurement of death threat, and sometimes noting the outline of findings that are still taking shape. No brief account can convey all the peregrinations of a lengthy and multifaceted program of study, but I have tried to suggest something of the braiding together of different strands of theory, research, and practice on death attitudes, suicide intervention, and grief that has animated, and perhaps constrained, my work in this area. I hope that the resulting account is a reasonably honest one—at least as written from my present position in late-career—and that the decision to focus reflexively on that work in which I have been most directly involved does not obscure the critical contribution made to this program by many others. No doubt each of my students and colleagues could, if given a similar invitation, provide his or her own unique account of some of these same developments, and see rather different significance in them!

Aside from any literal utility of this review in acquainting interested readers with the broad purview of a research program that they might explore, extend, or critique, I also hope that the frequent citation of the work and role of Paul Wong and his collaborators suggests something of the social nature of science, and the importance of collegiality and community in supporting our individual and joint initiatives. In his intellectual as well as organizational leadership of a meaning-oriented psychology, Paul Wong has made a significant contribution to the research reviewed here, and an even more robust contribution to cultivating an international and interdisciplinary group that has served as a home base for many of the authors in this volume. This might well prove to be as enduring an achievement as any that might be listed on his formal academic vita.

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