Perspectives on Death and Dying: Implications for Health, Well-being, and Clinical Care Across the Lifespan

National Institute on Aging
Division of Behavioral and Social Research and
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With appreciation and gratitude, the organizers of this workshop acknowledge the many contributions of Dr. J. Randall “Randy” Curtis and honor his life and legacy.

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Meeting Summary

The Perspectives on Death and Dying Workshop was sponsored by the National Institute on Aging’s (NIA) Division of Behavioral and Social Research (BSR) and Division of Geriatrics and Clinical Gerontology (GCG) to provoke renewed attention and fresh approaches to the question of how death and dying impact the full human lifecourse. Perspectives on death and dying can substantially impact clinical care decisions and outcomes in individuals of all ages. Yet there is limited understanding of the ways in which these factors influence health-related decision-making in different individuals, populations, and clinical conditions across the lifespan. Identifying knowledge gaps and research opportunities in this area will help to address NIA’s strategic goal and objectives to better understand the effects of personal, interpersonal, and societal factors on aging; support research and develop strategies to improve decision making for long-term and end-of-life care; and develop effective interventions to reduce the burden of age-related diseases, disorders, and disabilities.

The two-day workshop featured five sessions: (1) Theoretical Perspectives and Applications to Death and Dying, (2) Population Differences, (3) Clinical Settings, (4) Measurement and Experimental Design Panel, and (5) Gaps and Opportunities. A discussion of the key themes followed the presentations for each session, and each day concluded with an overarching discussion of the research gaps and opportunities that emerged throughout the day. The contents of this workshop will eventually become the basis of a whitepaper that can promote more nuanced research in this critical area.

Session 1. Theoretical Perspectives and Applications to Death and Dying

Presentations in this session related to social and cultural experiences of death and dying. Dr. Allan Kellehear introduced Session 1 with a keynote presentation that called for researchers to recognize the socially diverse experiences of EOL. Those experiences depend in part on cultural factors (e.g., political internment, industrialization and access to care, religious practice, cultural views related to healthcare) that influence the type of death an individual experiences (e.g., dying alone, dying in war, suicide). The level and type of community support available, beyond the support of immediate family, shapes the experience a person has of their type of death.

Dr. Laura Carstensen began the session by noting that because chronological age is a proxy for closeness to death, studies of psychological aging may inform end of life concerns. Somewhat curiously, there is abundant evidence that older people are in better mental health than their younger counterparts and experience fewer negative emotions in daily life. Socioemotional selectivity theory accounts for this apparent paradox through changes in chronically activated goals. As people perceive constraints on future time, goal priorities change systematically: goals related to emotional meaning are prioritized, which directs attention to the preciousness of life; subsequently, negative emotions are reduced, including anxiety about death. Relative to younger people, older people experience less anxiety about death, although of course some
older people do experience death anxiety. Dr. Jamie Arndt described how individuals often seek to manage underlying anxiety about death. The Terror Management Health Model suggests that health-related contexts entail managing both conscious death thought activation and non-conscious death thought activation. Both approaches can lead to adaptive or maladaptive behaviors, though mechanisms may differ; differentially involve cultural belief systems; and ultimately impact physical health.

Dr. Laraine Winter proposed Prospect Theory to explain why EOL treatment preferences can change as an individual’s health declines, shifting toward greater acceptance of more aggressive life-prolonging treatment. Prospect Theory holds that an individual’s current health status influences decisions for or against life-prolonging treatments: individuals perceive a greater difference between two prospects (e.g., dying vs. being confined to a bed or chair in a nursing home) when those prospects are closer to their current health status. Thus, to healthy individuals, the difference between dying vs. living in poor-health state seems small, but as health deteriorates, this difference is perceived as larger. The Prospect Theory effect is also observed in proxies’ decisions. It thus accounts for shifts in individuals’ own treatment preferences and for discrepancies among proxy decisions by family members, which may lead to disagreements and family conflict.

Decision making processes at the EOL can also be influenced by a mental state of demoralization, the commonest expression of existential distress at EOL. Dr. David Kissane explained that demoralization is associated with lowered morale, a feeling of hopelessness, pointlessness about the value of any remaining life, and poor coping. Demoralization is a much stronger mediator of suicidal thinking than depression. Research on demoralization has defined diagnostic criteria, prevalence variations among different subpopulations of illness and socioeconomic settings, and the use of meaning-centered psychotherapy to ameliorate symptoms and sustain quality of life. Taken together, these conceptual approaches point to the need for health care professionals and families to appreciate that significant distress surrounding the end of life is not typical of older people and to intervene accordingly when indicated.

During the Session 1 discussion, participants discussed how death and dying can be normalized. For example, ideas surrounding death can be normalized through card games that stimulate conversations about death, death cafes where people discuss death over dinner, and online courses that document emotional responses to death. Normalization may lead to changing values about death, which may be measured through prospect theory. Maintaining a sense of meaning may also affect an individual’s approach to death: a loss of meaning can lead to demoralization, and the type of death may influence this state. Demoralization is clinically important in the early stages of a diagnosis, and it may be related to psychogenic death (losing the will to live).

**Session 2. Population Differences**

Presentations in this session addressed variability in experiences of death and dying among different sub-populations. Dr. Kimberly Johnson began the session by discussing racial
disparities in health care and EOL experiences. Individuals from groups that have historically marginalized face substantial barriers to accessing adequate palliative care and achieving a “good death.” Dr. Molly Maxfield noted that individuals may delay EOL planning out of a fear of the dying process rather than out of fear of death itself. Living with a degenerative disease, such as Alzheimer’s disease or another dementia, may be a source of existential anxiety based on the life-changing symptoms they cause and the burden they place on caregivers. Dr. Holly Prigerson suggested that psychosocial and spiritual factors largely determine both the experience and healthcare of death at EOL for both patients and caregivers. The grief that patients and caregivers feel when receiving a life-threatening diagnosis has an impact on health, healthcare choices, quality of life and relationships, and death; psychosocial and spiritual support for patients and caregivers has untapped potential to prevent detrimental physical and mental health outcomes.

During the Session 2 discussion, the panelists noted that meaning at the EOL is related to trust in the healthcare system. Lack of trust in the healthcare system may be more prevalent for marginalized groups, leading to racial differences in quality of care, health outcomes, acceptance of care, and use of different interventions. Race-specific healthcare chaplains may assist in restoring trust in the healthcare system. The ways that researchers and clinicians approach patients during clinical trials also affects their trust in the healthcare system; researchers should make clear to individuals that their contributions and input are valued and needed to improve future care.

Session 3. Clinical Settings
Presentations in this session discussed how to approach EOL care in clinical settings. Dr. Randall Curtis delivered the keynote presentation before the session began, discussing his experiences with EOL care as a physician, researcher, and person living with a terminal illness. The goal of palliative care is to improve the EOL experience and support the patient, which inherently requires compassion. However, the capacity for compassion can be hindered by physician burnout or discomfort with dying patients, and thus addressing both feelings can be a critical element of EOL care, in particular. Enhancing EOD interventions and care also requires improved outcome measures for the dying.

Dr. Bob Gramling shared that advances in computational methods can offer effective tools for scaling the study of discussions between seriously ill patients, their families, and clinicians. This scalability allows for sufficient sample sizes to better understand how conversation content and multilevel contexts interact to foster person centered care. Intuitive machine learning clustering methods, such as self-organizing maps, can help scientists identify complex patterns in conversation characteristics (e.g., lexical "arcs" of narratives and topics, expressions of emotions, turn-taking, silences). Such pattern recognition can provide the epidemiological grounding to discover a basic taxonomy of naturally occurring serious illness conversation.

Dr. James Tulsky suggested that fostering empathic communication skills among the clinicians who must have these conversations can reduce patient anxiety, generate more positive patient responses, and build more patient trust. Empathic communication involves adapting
conversational style and patterns to a patient’s unique preferences and needs, and maintaining a capacity for curiosity, self-awareness, and equanimity to foster constructive communication. Dr. Stephen Ross described the need for clinical therapies to address the increase in anxiety, depression, and demoralization that patients experience at the EOL or when diagnosed with serious illness. Psychedelic-assisted therapy is one potential treatment for improving these dimensions of patients’ well-being at EOL. Dr. Sam Parnia closed the session by discussing recent scientific breakthroughs that raise questions about current clinical conceptions of death. These include studies showing restoration of circulation and cellular activity in the brains, hearts, livers, and kidneys of pigs hours after death, and the observation of transient high frequency brain electrical activity on electroencephalography in people during and immediately after death. People resuscitated from the brink of death, and perhaps beyond, describe having experienced lucid, purposeful, and meaningful re-evaluations of their lives, including all their intentions and actions towards others with a focus on morality and ethics. These recalled experiences of death differ from delusions, illusions, or hallucinations, and in particular from experiences during drug-induced states. Together, these findings suggest that death remains potentially reversible and amenable to medical treatments hours into the post-mortem period, and emphasize the need for a non-binary concept of life and death.

During the Session 3 discussion, the panelists noted that psychiatric training to increase empathy and communication may be beneficial for clinicians. However, social workers and psychologists found such training to be too mechanistic, even though this training is beneficial in a clinical context. Palliative care clinicians are not trained to stay within careful conversational boundaries, as psychiatrists and psychologists are. During such conversations, clinicians should determine what patients value at EOL is and develop a treatment plan with that in mind. Several research methods can be used to capture these conversations and to determine whether they lead to better outcomes.

Session 4. Panel Discussion: Measurement and Experimental Design
In this session, participants were asked to consider the most important aspect of EOL care to measure and to consider how experiments can be designed to capture this information. They noted the importance of focusing on positive rather than negative outcomes in EOL care, even though this focus is not always supported clinically. This discrepancy may arise because positive outcomes are less likely than negative outcomes to be scientifically validated, because positive outcomes do not offer a clear intervention target (e.g., depression and anxiety are ‘treatable’ whereas well-being is not). However, by researching positive outcomes rather than negative outcomes, the overall well-being of the individual can be better understood. The well-being of the patient can be further enhanced by integrating topics discussed during conversations with clinicians into interventions that will increase positive affect.

Barriers to measuring aspects of EOL care include: focusing only on the patient and not the community or caregiver, distrust in the clinician, and a lack of research on what occurs after death.
Session 5. Panel Discussion: Gaps and Opportunities

The session chairs remarked on the intense variability in patient response to dying and the several theoretical frameworks that can be integrated into EOL care plans. Positive rather than negative outcomes need to be prioritized when developing EOL care. This care should of course also focus on marginalized groups, or those less likely to trust the healthcare system. The meaning of death and dying will differ between subpopulations, influencing the individual’s response to EOL care, which can influence outcome measurement. New technologies are being developed that may enhance both EOL care and outcome measurement, such as the administration of psychedelic drugs, wearables, AI, and VR.

Participants discussed the effect that death has beyond the individual patient. Death is experienced not only by the dying individual, but also by families and caregivers. Caregiver burden is thus one area that requires active research, as is the role of community support of the dying individual. Health care proxies or surrogates should be involved in conversations related to death and EOL and advanced care directives. Addressing psychological barriers to acknowledgment of a patient’s impending death may not only promote mental health of caregivers but result in better EOL decision-making, care, and quality of death. Proxies should be informed as the patient’s health changes and those changes should be integrated into EOL care. EOL care and advanced care directives are even more paramount for marginalized groups who do not have proxies or community support. EOL care can be enhanced by investment in health promotion models (i.e., education and literacy focused on death and dying). These social models can work alongside clinical disciplines to understand continuity and quality of care. A more informed community can lead to increased support for the individual and better clinical care at EOL.