A New Social Contract

Grief & Bereavement Engagement Principles to Advance Bereavement Research

An ethos and framework for engaging with bereaved people during research endeavors

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Bereavement's Impact Across the Life Course

Bereavement — the death of someone meaningful in our lives — is a nearly universal human experience that will touch almost every person in America. Yet despite its scale and profound consequences, few high-quality, evidence-based programs exist to care for and support bereaved individuals.

Large epidemiologic studies demonstrate that bereavement is a significant risk factor for poor health and premature death among:

It is associated with increased risk of adverse outcomes across the life course, such as: substance use, diminished academic attainment, psychiatric hospitalization, dementia, reduced lifetime income, violent crime involvement, youth delinquency, and diminished purpose in life.

In addition, bereavement quietly reshapes economic opportunity and redirects life trajectories downward. The loss of an anchor relationship — one that provides stability, identity, or meaning — can fundamentally alter individuals' life outcomes, shadowing our families, institutions, communities, and society.

Despite these far-reaching consequences, the United States lacks high-impact, high-quality, lived experience-informed interventions for bereaved people. This gap reflects bereavement's long-standing absence from national funding priorities and a broader lack of fluency among healthcare and policy leaders regarding its scale, scope, and impact.

Chronic underinvestment in bereavement care, combined with limited provider training, leaves bereaved individuals with few evidence-based options to cope and adapt. Too often, today's care systems focus on symptom management while overlooking the underlying driver: loss.

Recently, federal action has acknowledged bereavement's societal consequences. Congress enacted paid bereavement leave for members of the U.S. Armed Forces, who may now return home for the death of a child or spouse. The Substance Abuse & Mental Health Services Administration published informational fact sheets on grief and bereavement, and the Agency for Healthcare Research and Quality conducted the most comprehensive systematic review to date of psychosocial interventions for bereaved people.

These are meaningful steps, but they are not sufficient. Innovative approaches are required to enable bereaved people to functionally cope and adaptively process loss on their terms and within their own timeframes, cultural and relational contexts, and values. As the mantra goes, "Nothing about us, without us", these innovations must be developed by bereaved people and researchers together.

Evolution of Psychosocial Grief Research for Bereaved People

Grief and bereavement research has advanced significantly in recent decades. Notably, the field has moved beyond conflating grief — the physiological and psychological response to loss — with depression or anxiety and toward recognizing the vast neurological, physiological, and social changes that can unfold following loss Bereaved people and researchers alike have sought to characterize bereavement as a universal human experience, shaping how communities and care systems respond to those who are grieving.

Yet for much of its history, grief and bereavement research centered on what is "wrong" with us — questioning why individuals have not adapted within a prescribed timeframe and without incorporating the perspectives of those living with loss into their research frameworks. Additionally, research frequently co-mingles groups of people with different bereavement circumstances, minimizing the profound differences in experiences and outcomes depending on who dies, how they die, and when in the life course the death occurs. By extrapolating study results from a narrow population to all bereaved individuals without accounting for these distinctions, research overlooks important differences in our grief experiences.

Grief and bereavement science has not escaped the power imbalances often present between researchers and those they study. For years, bereaved individuals, community organizations, and thought leaders have raised alarms about the field's trajectory, particularly efforts to medicalize and pathologize grief. Without meaningful lived experience partnerships, researchers cannot reliably identify the most pressing questions or design interventions that meet real needs.

Reimagining Tomorrow's Bereavement Research

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Evermore, a nonprofit dedicated to making the world more livable for all bereaved people, convened individuals with lived experience in bereavement, along with leading grief and bereavement researchers and care providers, to explore ways to collectively reshape the future of bereavement research. Together, with the Lived Experience Bereavement Research Network (LEBRN) Advisory Council, we developed a social contract: the Grief & Bereavement Research Engagement Principles.

These principles establish a shared framework for meaningful partnership. They are designed to ensure that grief and bereavement research is responsive to our lived realities, protective against preventable harm, and accountable to the communities it seeks to serve.

Engagement Principles to Advance Grief & Bereavement Research

These Engagement Principles guide how researchers engage with people with lived experience from the very beginning of a research endeavor — before questions are finalized, before measures are selected, and throughout every phase of the work. Meaningful engagement is not advisory or symbolic; it is structural. This social contract affirms that research undertaken in collaboration with bereaved communities must be just and transparent.

Three Foundational Tenets for Engaging Bereaved People in Research

To accelerate innovation and responsibly translate research into community and clinical settings, collaboration must rest on three foundational tenets:

1

LISTEN WITH THE INTENT TO UNDERSTAND

Listening is not procedural, it is foundational.

Researchers must approach bereavement research with humility and openness. Reflective listening, curiosity, and a willingness to reconsider assumptions are essential. Lived experience may challenge established hypotheses or research norms.

2

ACKNOWLEDGE POTENTIAL HARM

Recognize that research can cause harm — and has.

Poorly designed or extractive research can traumatize participants, distort lived realities, and erode trust. Ethical engagement requires acknowledging this history and proactively safeguarding against future harm. Trust is not assumed; it must be earned.

3

COMMIT TO DOING BETTER

Commit to deeper understanding, shared power, and sustained collaboration.

Doing better requires more than methodological rigor. It requires partnership, shared decision-making, fair compensation, and transparency. Research quality improves when relationships are dignified, respectful, and compassionate.

Engagement Principles for Grief & Bereavement Research

PRINCIPLES	ACTIONS
Understand me Open lines of communication. Set aside preconceived notions. Seek to understand my experience, insights, and expertise. Grief is personal, contextual, and expansive.	**Researchers** prepare for dissonance. What people with lived experience say may challenge established research therories and norms. Approach differences with curiosity, not defensiveness.
Respect me Value lived experience and research expertise equally. Acknowledge the uniqueness of bereavement experiences and the legitimacy of lived knowledge.	**Researchers** create space for lived experience partners to hold equal weight in discussions, decisions, and the interpretation of findings.
Join me Prepare for collaboration. Do not assume you understand a community without engaging it. Ask what matters to me and my community, what I hope to gain from research, and how it may benefit my community. Stay engaged throughout the process.	**Researchers** and **Lived Experience Partners** invest in preparation for effective partnership. Support Lived Experience Partners in understanding research processes and strengthen researchers' understanding of bereavement realities. Build shared foundations for effective teamwork.
Be honest with me Establish trust. Acknowledge past breaches of trust. Be transparent about constraints and limitations. Demonstrate trustworthiness through action.	**Researchers** recognize where trust may have been damaged historically, ask about prior experiences with research, and demonstrate dignity and compassion for Lived Experience Partners. Practice transparency, consistency, and accountability.
Include me in decisions Establish shared power Partner with me to frame research questions, shape design, conduct research, and disseminate findings. Include me in leadership roles.	**Researchers** share decision-making authority. Engage with Lived Experience partners from the beginning — not as an afterthought. Ensure fair compensation and credit lived experience contributors equitably.

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1025 THOMAS JEFFERSON STREET, NW
SUITE 438 WEST
WASHINGTON, DC 20007

PHONE: 202-263-3656

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