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Agency for Healthcare Research and Quality
5600 Fishers Lane
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Re: Interventions to Improve Care of Bereaved Persons

Dear Secretary Valdez and AHRQ Staff:
Thank you for your service and leadership to our nation and for the opportunity to submit these comments as part of the Agency for Healthcare Research and Quality's (AHRQ) public comment solicitation for interventions to improve care of bereaved persons.

AHRQ's solicitation and evidence-based review are timely as millions of people in America are dually impacted by persistent concurrent morality epidemics and, more recently identified, increases in premature and unexpected mortality events among all of America's demographics, including children and adolescents.[i]

We submit this letter on behalf of Evermore, a national nonprofit dedicated to improving the lives of bereaved children and families, which was founded to help raise awareness of the consequences of bereavement on our society, advance sound research to drive policy and program investments, and advocate on behalf of families for who minimal legal protections are available.

Bereavement — a loss of a person through death — is increasingly a direct concern for millions in America, making the need for an organized, coordinated, and evidence-based approach both urgent and necessary. In AHRQ's development of bereavement care standards, there are five considerations that are important to consider:

(1) Bereavement is a vast but nascent field of care with multi-layered complexity that cannot be distilled into one quality measure or exercise.
(2) Effective bereavement screenings and interventions may diminish the bereft's susceptibility for public emergencies.
(3) Limitations of current professional practice standards hamper the delivery of consistent, quality bereavement care.

(4) Future reimbursement payment structures should support and promote qualified bereavement care and bereavement care systems outside the medical-industrial complex.
(5) A multi-disciplinary expert panel should be convened to develop and review AHRQ's proposed Key Questions and PICOTs.

Specifically, we suggest the following.

(1) Bereavement is a vast but nascent field of care with multi-layered complexity that cannot be distilled into one quality measure or exercise.
AHRQ's commissioned review detailing bereavement's impact is vastly oversimplified and narrow. Bereavement is a complex and multi-faceted *field* where quality or evidence-based standards cannot be distilled into a single quality measure or exercise. Notably, just as AHRQ has a multitude of care standards for the field of cancer survivorship or chronic pain management, bereavement's complexity is similar, but the field of advanced, evidence-based research to support intervention tools is severely limited.

From a population perspective, consider the scale of bereavement in the United States as concurrent mortality epidemics have impacted millions.

According to the Centers for Disease Control and Prevention (CDC), the United States experienced over 3.46 million deaths in 2021 — 80,500 more than in 2020.[ii] It is important to note that the CDC collects mortality data but not data on the implications for those who suffer losses as a result of these deaths. However, during the COVID-19 pandemic, experts projected that for every COVID-19 death, approximately nine people would be directly impacted.[iii] If we applied that same algorithm for all deaths (notably not its intended purpose), more than 31 million people in America were directly impacted by our nation's 3.46 million deaths in 2021 alone.

Bereavement shares a powerful intersectionality with multiple national public health emergencies in the United States. These include COVID-19, overdose, homicide, suicide, maternal mortality, traffic fatalities, and the most common causes of death, such as heart disease and cancer. Consider the following statistics:

- homicide rates rose more than 35 percent from 2019 to 2020;[iv]
- overdose deaths rose 30 percent from 2019 to 2020[v] but fell between 2020 and 2021 by only 15 percent, resulting in a net increase;[vi]
- traffic fatalities increased to more than 40,000 in 2020;[vii] and
- suicide remains one of the top ten leading causes of death among people between the ages of ten and 64 and the second-leading cause of death among people between the ages of ten and 14 and 25 and 34.[viii]

To further compound these trends, the emergence of increasing climate disasters will contribute to mortality rates of bereavement. Behind each of these epidemics and all

these deaths are real children and families who must identify and navigate care, often under tight budgets and timelines, frequently with little or no advanced warning or ability to prepare.

In Evermore's own analysis, and in collaboration with Penn State and the University of Southern California, it was found that in the United States in 2021, the rate at which children were being parentally bereaved was higher than at any time in the last twenty years, in every state in the nation but two, and in every racial and ethnic category.[ix]

- Since 2000, Indigenous children have experienced higher rates of parental bereavement than every other racial group, reaching a high of 2.2 times the national rate in 2020, up from 1.4 times the national rate in 2000. Any successful national strategy must address the disproportionate burden that bereaved and orphaned Indigenous children continue to experience.
- The rate of parental bereavement for Black children has increased by nearly 20 percent since 2000 and 51 percent since 2013. The 2020 rate of 579 newly bereaved children per 100,000 is second only to that of Indigenous children.
- From 2000 to 2021, the rate of parental bereavement among Asian children increased by more than 35 percent (rising from 183 to 249 per 100,000).
- The annual rate of parentally bereaved Hispanic children rose by 40 percent between 2000 and 2020, from 222 to 304 per 100,000.
- Between 2000 and 2020, the annual rate of parentally bereaved White children has steadily increased, from 341 to 499 per 100,000—a 50 percent rise.

Further, Black Americans are disproportionately impacted by the premature deaths of loved ones. Across their life course, Black Americans are more likely to experience the death of children, spouses, siblings, and parents when compared to White Americans. They are three times as likely as White Americans to have two or more family members die by the time they reach the age of 30.

Black and Brown Americans are exposed to death earlier and more frequently than White Americans. Individuals who are exposed to death at early ages are more vulnerable to negative social and health outcomes for the rest of their lives. These experiences cause greater cumulative disadvantages, induce greater levels of stress, and deplete financial resources.

Bereavement has become a commonplace fact of life for many US residents, including children. Perhaps most concerning, as a result of mortality crises, America's national life expectancy — an index of overall population health — has dropped by more than one full year.[x] This last happened nearly 80 years ago following the United States' entry into World War II. The implications of these statistics are sobering: They not only indicate that many middle-aged people of childbearing and child-rearing years are dying but that many children and adolescents are losing their parents, grandparents, aunts, uncles, and mentors.

(2) Effective bereavement screenings and interventions may diminish the bereft's susceptibility for public emergencies.

Bereavement is a pernicious social concern threatening many aspects of family well-being and solvency for millions across the country. The unexpected death of a loved one poses a dual threat to our national well-being, as it is both among the most common major life stressors and the single worst lifetime experience reported by Americans in national surveys.[xi] Losing a loved one is not only a personal tragedy but casts a long shadow that can extend for decades as it places surviving parents, children, siblings, and spouses at significant risk for impaired health and premature death.[xii, xiii, xiv, xv] Some additional risks include serious mental health disorders, [xvi, xvii ,xviii] teen pregnancy,[xix] violent crime involvement,[xx] youth delinquency,[xxi,xxii] substance abuse,[xxiii, xxiv] diminished academic attainment,[xxv] diminished lifetime income,[xxvi] and less purpose in life, [xxvii] among many others.

For many public health concerns (like tobacco or obesity), defining the precise moment of initiation or the inflection point that diminishes an individual's short-term and long-term physiological, psychological, and sociological fitness remains elusive. However, bereavement is a defined event offering a distinct and rare opportunity to intervene on the bereft's behalf immediately and stemming their susceptibility for other public emergencies.

(3) Current limitations of current professional practice standards hamper the delivery of consistent, quality bereavement care.

Grief itself is an individual and iterative process. It is an exogenous shock that irrevocably alters lifelong health development pathways alongside other social and economic aspects of our lives.[xxviii] While the decision to pathologize grief is one of the most controversial and polarizing topics among leading bereavement professionals, we know that the planning, delivery, and reimbursement of appropriate treatment and care for any health condition requires well-trained professionals.

Today, therapists and social workers can self-identify as having the skills and training needed to serve bereaved families simply by checking a box on a for-profit website stating that they will accept patients experiencing grief. Notably, grief can result from many conditions, including job loss, divorce, relationship breakups, and limb amputation. Bereavement, by contrast, is the loss of a loved one through death, and given the vast variation in causes of death, therapeutic professionals should retain demonstrated competencies in subspecialties.

Current professional standards are thus too lax, allowing unqualified professionals to clinically practice mental-health bereavement care without proper training. This type of cavalier practice endangers well-being, risks lives — in the case of suicidal individuals — and can add to the profound pain bereaved children and families face. It also runs contrary to basic tenets of responsible professional care that are hallmarks of evidence-based medicine and evidence-based mental health practice.

Quality providers are a necessary component of any comprehensive public health strategy. In this sense, bereavement care merits national attention and a resource investment of the kind that trauma-informed care has enjoyed for the past twenty years, for example.

(4) Future reimbursement payment structures should support and promote qualified bereavement care and bereavement care systems outside the medical-industrial complex.

Reimbursable bereavement care is an important strategy for shifting the focus of the nation's healthcare payment and delivery systems toward the prevention of disease and poor outcomes. Bereavement providers may exist within healthcare systems, but more often, they exist within communities (as grief centers, religious centers or schools) where providers understand the multidimensional challenges families face.

Reimbursing providers outside medical settings may also help prevent the overmedicalization of bereavement and over pathologizing of grief. Indeed, the great majority of bereaved individuals grieve within the normative-adaptive range, which does not require specialized therapeutic intervention.[xxix,xxx] Rather, normative grief reactions may instead benefit from community-based support measures that promote adaptive coping and adjustment instead of, or in addition to, clinical diagnosis and therapeutic intervention, which requires specialized training and can be very costly.

(5) Convene a multi-disciplinary expert panel to develop and review AHRQ's proposed Key Questions and PICOTs.

While AHRQ's Draft Key Questions and PICOTs are a good first step toward enhancing bereavement care, Evermore recommends convening a multi-disciplinary expert panel to review, inform, and refine AHRQ's Key Questions and PICOTs. Bereavement is a complex, multi-layered field that brings together a diverse array of seemingly disconnected, separately raging crises that impact millions of individuals, families, and communities. Evidence-based quality practices have the opportunity to compassionately lighten the burden of bereavement that encumbers and shortens so many lives, and re-enable them to reach their full potential.

We applaud AHRQ for its leadership and initiative in addressing bereavement's impact on our nation. Unequivocally, AHRQ's leadership can shape bereavement's nascency into an evidence-base field for all in America to benefit from.

Thank you for the opportunity to submit these comments.

Joyal Mulheron
Executive Director

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[iii] https://www.pnas.org/doi/pdf/10.1073/pnas.2007476117
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[vii] Centers for Disease Control and Prevention, "Transportation Safety," https://www.cdc.gov/transportationsafety/index.html.
[viii] Centers for Disease Control and Prevention, "Department of Health and Human Services Fiscal Year 2023: Centers for Disease Control and Prevention Justification of Estimates for Appropriation Committees," 290, https://www.cdc.gov/budget/documents/fy2023/FY-2023-CDC-congressional-justification.pdf.
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[xxviii] https://evermore.org/wp-content/uploads/2020/11/Evermore-Bereavement-Facts-and-Figures-2020.pdf

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