ROSALYNN CARTER INSTITUTE FOR CAREGIVERS

June 28, 2024

The Honorable Robert Otto Valdez
Director
Agency for Healthcare Research and Quality
5600 Fishers Lane
Rockville, MD 20857

Dear Director Otto Valdez,

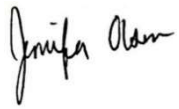
The Rosalynn Carter Institute for Caregivers (RCI) appreciates the opportunity to comment on the draft systematic review *Interventions to Improve Care of Bereaved Persons*.

Former First Lady Rosalynn Carter founded RCI in 1987 to promote the health, strength, and resilience of family caregivers. In our work, we are keenly aware that bereavement can be an incredibly difficult, albeit universal, human experience. The Agency for Healthcare Research and Quality (AHRQ) is to be commended for its recognition that interventions are needed to improve care of bereaved persons, and the report released in May 2024 is an important start.

While this comparative effectiveness research is an important step forward, we believe the science underlying the currently available tools for bereavement requires a stronger evidence base. Specifically, the evidence should include population-level data to estimate the prevalence for all bereaved adults and children. The evidence must also include a recognition of factors that shape the effectiveness of interventions, including cultural, ethnic, racial and gender considerations, and the relationship between the decedent and the bereaved. The evidence needs to explore the intensity (e.g. number of losses in a short period of time) and the context (e.g. caregiving role or experience). The attached Appendix provides a more in-depth response to the key questions explored in the systematic review.

RCI thanks AHRQ for their leadership in developing this report. Transformative change for our nation's bereaved will require the meaningful engagement of multiple sectors and effective partnerships. Fundamental structural and systems reforms are needed for effective delivery of bereavement care, as part of a family caregiving pathway, across health and care systems. We hope that our comments will enable AHRQ to drive the science and identify bereavement interventions, prioritizing high risk and under resourced groups within the US population. If you have questions about our comments, please contact me at 229-928-1234.

Sincerely,



Jennifer Olsen, DrPH
Chief Executive Officer

APPENDIX: Comments on AHRQ's draft systematic review *Interventions to Improve Care of Bereaved Persons*

Key Question 1: What is the effectiveness / harms of universal screening for bereavement and response to loss?

Background: Understanding the broad reach of bereavement requires an accounting of the number of bereaved persons linked to an individual death. In 2022, the United States reported 3.27 million deaths.[1] While number of deaths is monitored through our Vital Statistics system, the number of bereaved persons is not routinely measured and so we must use estimates. One such approach is to use a bereavement multiplier, which estimates that nine individuals experienced the death of a close relative (grandparent, parent, sibling, spouse, or child) during COVID-19.[2]

The need to understand the number of bereaved people should also be combined with an understanding of the increased healthcare costs and utilization after loss. In the first year post-death, quarterly Medicare costs for the surviving spouse were $1,092 higher than pre-death, and there were increases in hospitalization, emergency department visits, and post-acute care.[3] These increase in quarterly continued into year 2, while increases in some utilization extended into years two and three.[3] Cost increases in the first- and second-years post-death were larger if the deceased spouse was a caregiver or female[3] providing us with insights to consider when prioritizing high-risk groups.

Bereavement is not a medical condition; however, it is associated with other highly prevalent medical conditions. One common condition associated with bereavement is mental illness. In its 9th Annual report to Congress, the U.S. Preventive Services Task Force (USPSTF) identified mental illness as a High-Priority Evidence Gap requiring further research.[4] The report recognizes that mental illness co-occurs with substance use and violence-related injury and calls for more high-quality research to understand these complex health issues.[4]

Results: The CER determined that the strength of *evidence is insufficient* to make concrete statements regarding screening effectiveness or harms of universal screening. This finding means that more research is required to provide needed evidence.

Recommendation: Bereavement is an unmeasured factor influencing population-health and health care costs. By adding bereavement items to ongoing surveys of individual health, such as

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[1] Ahmad FB, Cisewski JA, Xu J, Anderson RN. Provisional Mortality Data — United States, 2022. MMWR Morb Mortal Wkly Rep 2023;72:488–492. DOI: http://dx.doi.org/10.15585/mmwr.mm7218a3

[2] Verdery AM, Smith-Greenaway E, Margolis R, Daw J. Tracking the reach of COVID-19 kin loss with a bereavement multiplier applied to the United States. Proc Natl Acad Sci USA. 2020 Jul 28;117(30):17695-17701. DOI: https://www.pnas.org/doi/10.1073/pnas.2007476117

[3] Lei L, Norton EC, Strominger J, et al. Impact of Spousal Death on Healthcare Costs and Use Among Medicare Beneficiaries: NHATS 2011–2017. J GEN INTERN MED 37, 2514–2520 (2022). DOI: https://doi.org/10.1007/s11606-021-07339-7

[4] *Ninth Annual Report to Congress on High-Priority Evidence Gaps for Clinical Preventive Services*. US Preventive Services Task Force. November 2019.

the Behavioral Risk Factor Surveillance System (BRFSS), all-payer claims data, the Healthcare Cost and Utilization Project (HCUP), and Medical Expenditures Panel Survey (MEPS), we will be closer to having the evidence needed to assess universal screening for bereavement. This is a systems level strategy that goes beyond the current literature on limited small and/or biased samples.

This would be building off an approach taken by the state of Georgia where a 3-item module was added to its 2019 survey to assess bereavement occurring in 2018 and 2019.[5] The module started with the question, '*Have you experienced the death of a family member or close friend in the years 2018 or 2019*?', and more than 70% of survey participants responded translating into a 45% prevalence rate of bereavement among adults 18 years and older in Georgia.[5]

Key Question 1.b: Does effectiveness of screening vary by patient characteristic or setting?

Background: The research suggests that bereavement can be viewed as either an anticipated event or an unanticipated event. Anticipated deaths – for example, in the case of prolonged chronic conditions – provide time for patients and their networks to put into place strategies that buffer the worst effects of loss. Unanticipated deaths do not provide time, and these deaths have the potential to increase the intensity of related injury.

Health care systems see both types of events because of their placement in the life cycle of death. Hospitals are a common place for death, with 29.8% of deaths occurring there in 2023; other places of death include freestanding inpatient hospice facilities and skilled nursing facilities (SNFs).[6]

To address what is being accomplished by screening, we recognize that current clinical tools for intervention are focused on mental illness and complicated bereavement. Bereavement is not a medical condition, but it does destabilize chronic diseases such as diabetes, asthma, and ongoing self-care. Mortality is a well-studied health disparity, and bereavement has recently begun to be appreciated as a factor underlying health disparities.[7]

Results: The CER determined that the strength of *evidence is insufficient* for numerous key outcomes due to lack of identified studies and where inconsistency could not be determined at all due to the absence of studies reporting on the outcome.

Recommendations: Based on the research linking bereavement with increased healthcare utilization, it is reasonable to propose that screening be conducted in all sites of care.

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[5] Li C, Miles TP, Shen Y, *et al.* Measuring bereavement prevalence in a complex sampling survey: the 2019 Georgia Behavioral Risk Factor Surveillance System (BRFSS). *BMC Med Res Methodol* **23**, 138 (2023). DOI: https://doi.org/10.1186/s12874-023-01917-5

[6] QuickStats: Percentage of Deaths, by Place of Death — National Vital Statistics System, United States, 2000–2018. MMWR Morb Mortal Wkly Rep 2020;69:611. DOI: http://dx.doi.org/10.15585/mmwr.mm6919a4

[7] Umberson D, Olson JS, Crosnoe R, Liu H, Pudrovska T, Donnelly R. Death of family members as an overlooked source of racial disadvantage in the United States. Proc Natl Acad Sci USA. 2017 Jan 31;114(5):915-920. DOI: https://www.pnas.org/doi/10.1073/pnas.1605599114

A further proposal would be to explore the effectiveness of an intervention based on the characteristics of an individual before and after the loss occurs. There are 53 million family caregivers, supporting many of the most medically complex people in our society over the course of years or decades. These individuals will often experience challenges and complexity at each stage of the caregiving journey. The emotional and mental health toll for family caregivers does not end when the person they are caring for dies, and this population would provide meaningful insights about intervention impact across many characteristic and setting experiences.

By acknowledging that health behaviors associated with poor outcomes (e.g. binge drinking, smoking, physical inactivity) are significantly more common among bereaved adults,[1,8] it is reasonable to consider how screening tools for such behaviors could be paired with a question such as '*Have you experienced the death of a family member or close friend in the past 24 months*? to increase the effectiveness of any proposed interventions.

[8] Miles TP, Li C, Khan MM, Bayakly R, Carr D. Estimating Prevalence of Bereavement, Its Contribution to Risk for Binge Drinking, and Other High-Risk Health States in a State Population Survey, 2019 Georgia Behavioral Risk Factor Surveillance Survey. *Int. J. Environ. Res. Public Health* **2023**, *20*, 5837. https://doi.org/10.3390/ijerph20105837