



EVERMORE

2101 L Street, NW | Suite 800  
Washington, DC 20037  
(P) 202.263.3656  
(E) info@live-evermore.org

May 20, 2020

American Psychiatric Association  
Internalizing Disorders Review Committee  
800 Maine Avenue, S.W.  
Suite 900  
Washington, D.C. 20024

Dear Dr. Lewis-Fernandez and distinguished colleagues:

The unexpected or untimely death of a loved one is the most common traumatic life event touching Americans; many of them ranking it the worst event of their lives.<sup>1</sup> Today, an estimated ten million children have experienced these uniquely devastating losses. 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. 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 requires the identification and diagnosis of real conditions. When it comes to bereavement, many of today's debates overlook one essential and often invisible demographic: minority and impoverished children.

Death and bereavement disproportionately impact communities of color, thereby widening and exacerbating the health and health care disparities that marginalize our nation's most vulnerable children. Given the limited resource allocations devoted to these communities, Evermore:

- 1) strongly endorses the prolonged grief disorder (PGD) amendments proposed by Drs. Christopher Layne, Benjamin Oosterhoff, Robert Pynoos and Julie Kaplow<sup>2</sup> for children and adolescents,
- 2) strongly encourages the American Psychiatric Association (APA) to adopt the proposed modification in the Diagnostic and Statistical Manual of Mental Disorders (DSM) 5-TR and
- 3) strongly encourages APA to prioritize bereavement education among our nation's mental health workforce, especially those working with children, youth, and families.

Access to timely, appropriate, and therapeutic mental health services may stem the health, economic, and academic decline experienced by many of these youth. To that end,

---

<sup>1</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4119479/>

<sup>2</sup> Developmental Analysis of Draft DSM 5-TR Criteria for Prolonged Grief Disorder: Report from the Child and Adolescent Bereavement Subgroup. Report submitted to the Panel on Developing Criteria for a Disorder of Pathological Grieving for DSM 5-TR (P. Applebaum, Chair). American Psychiatric Association.

bereavement itself is a risk factor for premature death. Eight million American youth are bereaved siblings<sup>3</sup> which is associated with a 71 percent increased all-cause mortality risk.<sup>4</sup> The two million bereaved children, who have lost a parent before age 18,<sup>5</sup> are more likely to experience a confluence of unique health and social hardships. Drs. Layne and Kaplow write, these youth experience “lower self-esteem,<sup>6</sup> reduced resilience,<sup>7</sup> lower grades and more school failures,<sup>8</sup> heightened risk of depression,<sup>9</sup> suicide attempts,<sup>10</sup> suicide,<sup>11</sup> and premature death due to any cause as a result of their loss,<sup>12</sup> drug abuse, violent crime involvement, youth delinquency, and a greater number of, and more severe, psychiatric difficulties.”

These risks are exacerbated—magnified, made more acute, and exert life-altering effects—for underserved, under-resourced minority communities. With 32 percent of black children, 31 percent of Native American, 26 percent of Latinx children, and 11 percent of white children living in poverty,<sup>13</sup> the lack of a reimbursable diagnosis to treat those at highest risk for bereavement and subsequent trauma perpetuates inequality. The cumulative disadvantage bereaved minority families and their communities face threatens every aspect of life.

Exposure to death earlier in life predisposes children to more negative social and health outcomes indefinitely. Black children are 300 percent more likely to lose a mother and 200 percent more likely to lose a father by age 10 when compared to whites.<sup>14</sup> Black children are 20 percent more likely than whites to lose a sibling by age 10 and three times more likely to lose two or more family members by the age of 30.<sup>15</sup> These are not just sad statistics, but life-altering life events for these youth. Nearly 90 percent of detained youth have lost a loved one. Of those, approximately 25 percent subsequently joined a gang.

Not including PGD for bereaved children and adolescents in the DSM 5-TR would continue to place these children in need at high risk of not receiving adequate health care services and support.

Proper diagnosis of PGD may lead to greater access to other social support programs and networks. If reimbursable, S-CHIP may determine services rendered are reimbursable. Access to Social Security benefits, federally qualified health center programs, or future inclusion criteria for Individuals with Disabilities Education Act (IDEA) may be considered as a byproduct of a diagnosis.

---

<sup>3</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4302726/>

<sup>4</sup> <https://www.ncbi.nlm.nih.gov/pubmed/28437534>

<sup>5</sup> <https://muse.jhu.edu/article/732641>

<sup>6</sup> <https://journals.sagepub.com/doi/10.2190/P77L-F6F6-5W06-NHBX>

<sup>7</sup> <https://www.ncbi.nlm.nih.gov/pubmed/29724669>

<sup>8</sup> <https://www.ncbi.nlm.nih.gov/pubmed/24616354>

<sup>9</sup> [https://journals.lww.com/ionmd/Abstract/2009/01000/Re\\_Examining\\_the\\_Long\\_Term\\_Effects\\_of\\_Experiencing.5.aspx](https://journals.lww.com/ionmd/Abstract/2009/01000/Re_Examining_the_Long_Term_Effects_of_Experiencing.5.aspx)

<sup>10</sup> <https://www.ncbi.nlm.nih.gov/pubmed/21039482>

<sup>11</sup> <https://www.ncbi.nlm.nih.gov/pubmed/26558351>

<sup>12</sup> <https://jamanetwork.com/journals/jamapsychiatry/fullarticle/2469106>

<sup>13</sup> <https://datacenter.kidscount.org/data/line/44-children-in-poverty-by-race-and-ethnicity#1/any/false/37,871,870,573,869,36,868,867,133,38/asc/10,11,9,12,1,185,13/323>

<sup>14</sup> <https://www.ncbi.nlm.nih.gov/pubmed/28115712>

<sup>15</sup> <https://www.ncbi.nlm.nih.gov/pubmed/28115712>

Although the opportunity to forge change is great and the statistics are more than alarming, it is incumbent that APA prioritize bereavement by developing a trained professional workforce that can attend to the diagnosis, treatment, and recovery of bereaved individuals. Today's professional standards are too lax and allow unqualified professionals to "clinically practice" mental health bereavement care without proper training. *To be clear, this is dangerous.* We do not allow a podiatrist to treat cancer; thus, we cannot allow an art therapy enthusiast to "clinically practice" care with a traumatized, distressed, and unstable youth. This type of cavalier practice endangers lives and adds to people's trauma. It also runs contrary to basic tenets of responsible and professional care.

As such, in addition to adopting these measures, Evermore strongly encourages APA to concurrently increase educational opportunities for all mental health providers, regardless of discipline or background. Drawing clear and strong practice and professional boundaries is imperative for our children. Professionals must understand their sphere of practice, when or if to diagnose PGD or when a referral or secondary consult is necessary. Improper diagnosis, whether bereavement or cancer, can do great harm. We cannot accept minimal standards.

Evermore is dedicated to making the world a more livable place for bereaved families by raising awareness, advancing research, and advocating for a better tomorrow. We believe that bereavement care in America is broken. Our families and professionals deserve more support. Most recently, we successfully attached a bereavement care provision to the FY21 U.S. budget in the House of Representatives requiring key federal health agencies to report to Congress what bereavement care activities, if any, are being conducted within the agencies. This is the first time our nation's health agencies will be required to consider or report the implications of bereavement to our federal legislators. To that end, we believe that bereavement care is an essential element to a comprehensive public health strategy.

APA's adoption of these modifications continues to advance the issue, enable the development of tools, and facilitate needed conversations among our nation's thought leaders. We applaud APA for its leadership. Evermore is happy to serve as a resource to APA or answer any questions or concerns you have. Please feel free to reach me at [hello@live-evermore.org](mailto:hello@live-evermore.org) or 202-263-3656. Many thanks for your consideration of this important issue.

Sincerely,



Joyal Mulheron  
Founder & Executive Director

*About Evermore: Evermore is dedicated to making the world a more livable place for bereaved individuals and families. Bereavement care in America is broken and that's why we're here. We are committed to an equal America where all families and professionals have access to care, programs, tools and resources to cope and adapt to loss. We believe in a society where bereavement care is the rule, not the exception. Our nation needs it now more than ever. Help us make that change. To learn more, visit [www.live-evermore.org](http://www.live-evermore.org).*