



## Commentary

# Responding to the new International Classification of Diseases-11 prolonged grief disorder during the COVID-19 pandemic: a new bereavement network and three-tiered model of care



C. Killikelly<sup>a, \*</sup>, G.E. Smid<sup>b, c</sup>, B. Wagner<sup>d</sup>, P.A. Boelen<sup>c, e</sup>

<sup>a</sup> Department of Psychology, University of Zurich, Switzerland

<sup>b</sup> University of Humanistic Studies, the Netherlands

<sup>c</sup> ARQ National Psychotrauma Centre, Diemen, the Netherlands

<sup>d</sup> MSB Medical School Berlin, Germany

<sup>e</sup> Department of Clinical Psychology, Utrecht University, Netherlands

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## ABSTRACT

The field of bereavement research and care is at a tipping point. The introduction of prolonged grief disorder (PGD) in the International Classification of Diseases (ICD-11) has ignited clinical interest in this new disorder, along with debate over challenges in validating and implementing these new criteria. At the same time, the global COVID-19 pandemic has launched several local and international efforts to provide urgent support and comfort for individuals and communities suffering from grief. Recently, grief experts have called for a collective response to these complicated bereavements and possible increase in PGD due to COVID-19. Here we outline a new European network that aims to unite a community of grief researchers and clinicians to provide accessible, evidence-based support particularly during times of unprecedented crisis.

The Bereavement Network Europe (BNE) has been developed with two main aims. Firstly, to develop expert agreed, internationally acceptable guidelines for bereavement care through a three-tiered approach. Secondly, to provide a platform for researchers and clinicians to share knowledge, collaborate, and develop consensus protocols to facilitate the introduction of PGD to diverse stakeholders.

This article outlines the current status and aims of the BNE along with the plans for upcoming network initiatives and the three-tiered bereavement care guidelines in response to the COVID-19 pandemic.

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The World Health Organization's eleventh revision of the International Classification of Disease (ICD-11) has catalysed action in the field of grief and bereavement.<sup>1</sup> For the first time, prolonged grief disorder (PGD) will be included as a diagnostic category on the international stage.<sup>2</sup> The importance of the new diagnosis has been underscored with the losses and complicated bereavements currently occurring during the COVID-19 pandemic. With widely varying global case fatality rates predicted to be in the range between 0.06 and 18.94% (as of June 9th 2020)<sup>3</sup> and the introduction of social distancing, individuals are faced with unprecedented challenges for grief and bereavement. Visitor restrictions in

healthcare settings, the postponement of funeral services, the rapid and distressing nature of death means that individuals are often confronted with complex and isolated bereavement situations.<sup>4,5</sup> The field is at a significant tipping point, whereby clinicians and researchers are being urgently asked to provide guidelines and support for the bereaved while also navigating the introduction of a new grief disorder, PGD.

Here, we outline key background information on ICD-11 PGD that may assist clinicians and researchers during this time, however, with an important caveat for continued research and discourse. In addition, we introduce the Bereavement Network Europe (BNE) and a three-tiered treatment approach that may be implemented by local communities and organizations urgently during the COVID-19 pandemic but also with a long-term outlook.

\* Corresponding author. Department of Psychology, University of Zurich, Binzmuehlestrasse 14/17, CH-8050 Zurich, Switzerland.

E-mail address: [c.killikelly@psychologie.uzh.ch](mailto:c.killikelly@psychologie.uzh.ch) (C. Killikelly).

## PGD for ICD-11

The WHO working group on stress-related disorders approved the inclusion of PGD as a disorder of grief after reviewing available research evidence and establishing expert consensus. The current definition of PGD for the ICD-11 is the latest iteration following nearly 30 years of research investigating different diagnostic definitions. Previously a disorder of grief has been described and researched under different names including pathological grief,<sup>6</sup> traumatic grief,<sup>7</sup> and complicated grief.<sup>8,9</sup> This has led to some confusion amongst clinicians and researchers, particularly during the COVID-19 pandemic. As clinicians seek information and guidance on symptoms and the course of grief the multiple definitions and disorder criteria can lead to different diagnostic thresholds and estimates of incidence.<sup>10</sup> The newest ICD-11 definition of PGD deviates from the previous definitions as it seeks to align with the WHO's remit for improved clinical utility and global applicability of mental disorders.<sup>11</sup> The result is a PGD definition with only two core symptoms, examples of emotional pain, duration since loss and an impairment criterion (see Table 1). Uniquely, the working group also included a cultural caveat, whereby symptoms of grief must exceed expected socio-cultural norms.

During the recent COVID-19 pandemic, researchers and clinicians are being asked to provide information to support individuals dealing with complicated bereavements and guidance on possible PGD cases.<sup>1,4,12</sup> However, as much as urgent information is needed it should be acknowledged that the introduction of PGD to the clinical community, during this current crisis, comes with several challenges. There are major scientific gaps in the field of PGD, particularly in terms of establishing a valid diagnosis, or assessment and treatment guidelines. There is a tremendous clinical need for guidelines and tools related to PGD; currently clinicians have limited assessment tools and receive almost no training on PGD.

As a response to these challenges, we offer two possible solutions. Here, we briefly outline a proposal for a three-tiered model of bereavement care based on the approach by Rumbold & Aoun.<sup>13</sup> Three-tiered models have been successfully implemented in

healthcare settings worldwide.<sup>14,15</sup> This model focuses on providing appropriate care, at the right time, for those who need it. Secondly, we introduce the BNE along with planned opportunities for clinicians, researchers, and European stakeholders during COVID-19.

## Scientific gaps

The clinical validity of the new ICD-11 PGD has yet to be established. Although research groups around the world are making significant strides towards establishing ICD-11 PGD validity,<sup>16–19</sup> there are significant difficulties in establishing a consensus on the exact diagnostic algorithm for PGD. One of the strengths of the ICD-11 definition is its narrative approach, i.e. there are no specific thresholds for determining a diagnosis, instead clinical expertise is prioritized. However, this has left clinicians and researchers at a loss for how to consistently operationalize a diagnosis of PGD. Until recently, different research groups have used different threshold for disorder yielding significantly different incidence rates within countries and worldwide.<sup>9,20–22</sup> Clinicians and researchers need to reach a consensus on how to validly operationalize the new ICD-11 PGD criteria. This can best happen with large international collaborations, such as those offered by the BNE (see in the following context).

Along with limited research on the validity of the ICD-11 PGD guidelines, there is very little research evidence in terms of disorder chronicity, predictors of severity and underlying etiological mechanisms. Using prior definitions of disordered grief, the field made significant strides towards establishing predictors of disorder,<sup>23,24</sup> (including violent circumstances of the loss and non-natural causes of death),<sup>25</sup> possible underlying mechanisms<sup>26,27</sup> and differentiation from other disorders.<sup>28</sup> Vulnerable groups have been identified, such as displaced people,<sup>29–31</sup> whose risk of a grief disorder may be increased due to non-natural circumstances of the death, socioeconomic disadvantage,<sup>32,33</sup> and cultural incongruity following migration (e.g., inability to perform appropriate rituals).<sup>34</sup> In addition, there is mounting anecdotal reports of a possible increase in PGD as a result of the COVID-19,<sup>4,35</sup> however currently it is too early for research to confirm.<sup>10,36</sup> Previous research on risk factors was carried out using heterogeneous diagnostic criteria, in different target populations using a variety of questionnaires.<sup>9</sup> The imprecision and diversity in research methods has been a major impediment for establishing consistent findings worldwide.<sup>20</sup>

Finally, there are almost no guidelines for the assessment and treatment of PGD. Although there are a number of existing interviews and questionnaires,<sup>37–40</sup> these have been validated in different populations leading to highly divergent findings and disagreements in the field.<sup>41–43</sup> Existing treatments for PGD (or complicated grief) have also been established with strong methodological design.<sup>44–47</sup> However, these treatments have not reached the larger medical community and remain difficult to access for many bereaved people.<sup>14,48,49</sup> Although there are new promising remotely available treatments.<sup>36</sup>

In summary, there are significant scientific gaps in the field in terms of diagnosis, assessment and accessible treatment options. At the moment researchers and clinicians work relatively independently in their own research silos with little opportunities for large collaborations. Currently, within a European Context, a Network (BNE) has been formed, inviting cooperation between a variety of universities, to address these issues conjointly, with a new rising urgency under the threat of COVID-19.

**Table 1**  
ICD-11 PGD narrative definition.

Criterion	Details
A. Event	Death of someone close at least six months ago
B. Core items	At least one of persistent and pervasive longing for the deceased, or persistent and pervasive preoccupation with the deceased
C. Accessory items	Accompanied by at least one example of intense emotional pain, e.g. Sadness Guilt Anger Denial Blame Difficulty accepting the death Feeling one has lost a part of one's self An inability to experience positive mood Emotional numbness
D. Impairment criteria	Substantial impairment in personal, family, social, educational, occupational, or other important areas of functioning as a result of the symptoms
E. Cultural features	The grief response has persisted for an atypically long period (≥6 months) and clearly exceeds norms for the individual's social, cultural, or religious context

PGD, prolonged grief disorder.

**Table 2**  
Three-tiered level of support for bereavement care based on the European Association for Palliative Care.<sup>58</sup>

Level of intervention	Type of support	Support provision	Target group
General	Leaflets, self-help basic guidance	friends, family, peer support GP, nurses, frontline workers	Low risk individuals, low need
Selective	Non-mental health specialist support	Community groups, trained volunteers, clergy, chaplains	At risk groups, medium need
Indicated	Professional support	Trained clinicians: psychologists, psychiatrists, grief and bereavement counsellors, Specialist clinicians: grief and trauma psychologists & psychiatrists	High risk groups, high level of need

## Clinical needs

There is an urgent clinical need for evidence-based care for grief and bereavement in Europe. The newly emerging populations losing their loved ones under the strain of COVID-19 has broadened the clinical needs. In Europe to date (as of September 25th 2020), 187,876 individuals have died directly due to the virus or complications resulting from contracting the virus.<sup>50</sup> Yet, loss during a pandemic is not limited to the virus. More than 5.2 million people died (naturally or unnaturally) in the EU in 2015.<sup>51</sup> If approximately four close people are affected this means that more than 20.8 million people in the EU experience some form of grief or bereavement. Most estimates find that, under normal circumstances, more than 60% of people experience normal bereavement and recover after one year. However, 40% of people may need some form of psychosocial support and, of these, 10% require professional mental health intervention.<sup>52</sup> Taken together, these figures suggest that more than 8 million Europeans may need mental health support after the death of a loved one. Cost estimates for healthcare structures are rare, as they are very difficult to obtain, yet, one complex study design, carried out for one country under an international team of researchers, found some alarming figures, prompting that government into immediate action.<sup>53</sup>

Although the inclusion of PGD in the ICD-11 underpins a clear clinical need, it may be considered premature, from the point of view of clinical infrastructure. Currently, there are no clinical guidelines for the assessment and treatment of PGD; there is little available training for clinicians and healthcare workers, and there are difficulties with the acceptability of grief as a disorder.<sup>54,55</sup>

Throughout Europe, most countries lack an official model of bereavement care. In many countries, bereavement care is primarily supported by voluntary sector organizations that usually specialize in supporting specific groups of bereaved individuals (e.g. the loss of a child, following homicide, suicide, trauma and bereavement) on a self-initiated basis. The UK and Ireland benefit from well-developed national organizations that are funded as registered charities, for example, 'Cruse' or the National Bereavement Alliance in the UK and the Irish Hospice Foundation. Unfortunately, in the majority of countries, there is no central funding for bereavement care and what remains are grass roots movements in times of crisis (e.g., Greece <https://merimna.org.gr/?lang=en>). Due to the informal nature of bereavement organizations, even within a country, certain groups may be non-intentionally prioritized to receive care over others.

With the introduction of ICD-11 PGD particularly following the COVID pandemic, there may be an increase in need for a diagnosis, however, without follow-up support this could easily lead to a bottle neck in care. It is clear that existing European bereavement organizations could benefit from up to date guidelines on bereavement assessment and treatment. In addition, organizations with less resources and infrastructure would benefit from

knowledge sharing and resource sharing from those more established organizations.

In sum, there is a strong need to develop European-wide best practice guidelines and standards of care for bereavement. A European bereavement network could easily provide a platform, where clinicians, healthcare workers, community organizations, researchers, and service users could establish better communication and coordination, easy to use information, and translated material.

## Proposal for a three-tiered approach to bereavement care

A tiered system of care is the current internationally recommended format for bereavement support as the amount of care required will vary for each individual, at different times. This approach is currently used by the European Association for Palliative Care. As research has shown, most individuals will recover with minimal or very little support, whereas others may need increased support over time.<sup>49,56</sup> This approach provides the right level of care at the right time. The tiered care approach outlined below has been utilized in several countries and organizations with success<sup>57</sup> and first suggested by Rumbold and Aoun.<sup>13</sup>

The BNE will provide evidence-based guidelines assisting with the challenges outlined previously, i.e. how to recognize PGD, appropriate assessment tools and how to differentiate PGD from other disorders. Research on predictors and chronicity of PGD will also be included. A key feature of these recommendations will be the framework for tiered care (see Table 2 and supplementary material). This care encompasses different forms of help for different levels of grief and can be conceptualized in the form of a tiered care approach.

### General intervention

Self-help and peer support (either in groups led by bereaved people or via books/the internet) could be sufficient for individuals with no PGD symptoms and low risk of health issues, additionally information and supportive care by volunteers, clergies/chaplains, or "watchful waiting" by general physicians may be sufficient for people with transient grief.<sup>2</sup>

### Selective intervention

Low-threshold interventions (offered by non-mental health specialists including social workers, or nurses, eHealth interventions, trained clergy/chaplaincy) could be appropriate for individuals with subsyndromal PGD or a range of risk factors.<sup>3</sup>

### Indicated intervention

Professional support (counselling, psychotherapy) should be offered to people with indicated symptoms of PGD. Specialist intervention including more intensive treatment would be appropriate for chronic comorbid PGD and PTSD or depression, following

multiple and/or traumatic bereavements. The development of assessment tools and a range of low and high intensity interventions required for the provision of such tiered care for grief is urgently needed. The BNE network aims to develop evidence-based guidelines and a stepped care framework for care and service provision that is relevant for different groups and contexts.

In order to provide a strong basis for the three-tiered approach, based on the most up to date recommendations, the BNE network will embark on a large international survey of current bereavement services. This has been similarly achieved for palliative care services.<sup>58</sup> This would be a vital resource for identifying existing successful service provision and areas with significant service gaps, as well as for best informing the content of interventions for the three service levels.

### Bereavement Network Europe

The BNE is an international network of organizations and professionals involved in bereavement care services and research across Europe. Although individual European states may have their own grief and bereavement networks, currently there is no platform for European-wide policy and guidance on challenges such as the introduction of PGD. The BNE was initially conceptualized as the Family BNE and launched in 2014 with an international steering group, website and initiatives to expand the network. Currently, the network has 30 different organizations represented by more than 16 different European states and 4 non-European countries. Since 2017, one of the new major remits of the BNE has been to organize an international response to the introduction of ICD-11 PGD. The primary concern of core members has been the lack of guidance for researchers and clinicians regarding assessment and treatment of PGD which, given the aforementioned, is increasingly in need of attention.

The BNE is taking the following steps to advance mental health support for bereavement across Europe particularly during the COVID-19 pandemic: (i) Access to a network for multiple stakeholders to unite under shared goals and a common framework for research and care (ii) a web-based platform to raise professional and public awareness on PGD (see <http://bereavement.eu>) (iii) The development of a toolkit to implement and regulate best practice standards and evidence-based guidelines for bereavement care (see three-tiered approach and supplementary material for examples of guidelines). The BNE will organize a conference in 2022 with the aim to unite bereavement researchers, clinicians and organizations in Europe. Until now, European grief researchers have not had a dedicated conference for grief and bereavement and have only met at large international conferences on other topics such as trauma or palliative care.

### Conclusion

Researchers, clinicians and bereavement organizations throughout Europe would benefit from a coherent, systematic and well-structured response to the inclusion of PGD in the ICD-11 and the COVID-19 pandemic. The BNE aims to provide a platform to engage in important dialogues and discourse, to start new collaborations and access up to date knowledge in a range of European countries. It is hoped that the BNE will be an open network with the participation of key research, clinical experts and other trained bereavement care professionals. Evidence-based clinical guidelines are an ambitious task, but the responsibility of the field of grief and bereavement is to provide accessible and high quality care to those who need it, particularly in a time of crisis.

### Author statements

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#### Competing interests

None declared.

### Appendix A. Supplementary data

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