



**Deutscher Hospiz- und
Palliativverband e.V.**

Geschäftsstelle
Deutscher Hospiz- und
Palliativverband e.V.
Aachener Str. 5
10713 Berlin

Statement

in support of a

culture of grieving

and

in support of applying the term
'post-loss stress disorder'
in ICD-11 6B42

to avert unbearable suffering
in the event of a loss

12.12.2018

Sie erreichen uns unter:
Telefon 030 / 8200758-0
Telefax 030 / 8200758-13
info@dhpv.de
www.dhpv.de

**Geschäftsführender
Vorstand:**
Prof. Dr. Winfried Hardinghaus
Vorstandsvorsitzender
Dr. Anja Schneider
Stellvertr. Vorsitzende
Erich Lange
Stellvertr. Vorsitzender

Amtsgericht Berlin:
VR 27851 B
Gemeinnützigkeit anerkannt
durch das Finanzamt Berlin

Bankverbindung:
Bank für Sozialwirtschaft
IBAN: DE 4337 0205
0000 0834 0000
BIC: BFSWDE33XXX

Background

The International Classification of Diseases, in short: ICD, of the World Health Organisation (WHO) is currently under revision. The new ICD-11 version introduces a new category: 6B42, 'Prolonged grief disorder'. ICD-11 is expected to be adopted by the WHO Assembly in May 2019 and come into force on 1.1.2022.

Standpoint adopted by the DHPV

The DHPV welcomes the introduction of a new diagnosis to enable people to receive psychotherapeutic treatment in their need after suffering an unbearable loss. The extensive experience which hospice services bring in accompanying and advising the bereaved shows that there are experiences of loss, which – combined with amplifying factors for the individual or through the life situation itself – necessitate transitioning to a therapeutic setting and/or working closely with therapists. Highly problematical for the DHPV, however, is the circumstance that the current version of ICD-11 labels it 'prolonged grief disorder'.¹, which runs counter to the notion of developing regional cultures of grieving and thus a positive notion of grief.

The DHPV suggests instead using a more appropriate term for the diagnosis cited in ICD-11 6B42. In grouping 6, 'Disorders specifically associated with stress', the DPHV advises selecting the term 'post-loss stress disorder'.² Loss triggers great stress, which can potentially lead to a disorder. In turn, grieving can relieve and reduce stress, though this does not occur every time. Where post-loss stress disorder is concerned, therapeutic treatment should therefore be offered in 6B42 – under the term 'post-loss stress disorder'.

¹ A survey conducted in 2017 revealed that the majority of professionals did not approve of the proposal to use 'prolonged grief disorder' (Leonie Dietl, Birgit Wagner, Thomas Frydich: User acceptability of the diagnosis of prolonged grief disorder: How do professionals think about inclusion in ICD-11? in: *Journal of Affective Disorders* 229 (2018), p. 306-313.

² For information on the labelling of the syndrome, cf. Leonie Dietl et al., in the place cited, p. 309

Reasoning

One of the concerns of the DHPV is that grieving not be pathologised but continue to be understood as a healing force, which takes time. ICD-11 6B42 expressly states that the individual's cultural and religious context should be taken on board.³ The situation in Germany is, in the opinion of the DHPV with respect to experiences of loss, characterised by a specific form of grieving which has developed over the past decades. This culture threatens to be significantly stunted by the term 'prolonged grief disorder', should such a term assert itself in general.

In post-war German culture after 1945, grieving was initially primarily perceived as a disorder, where there was virtually no time for grieving. Cultural grieving only slowly emerged in many areas (cf. on this point A. and M. Mitscherlich, *Die Unfähigkeit zu trauern* (The Inability to Grieve), 1967).

What characterises a culture of grieving is the lending of expression to one's own feelings, sharing them and finding understanding. This requires time; how long this takes varies, depending on the individual's situation, because every bereavement is different. Of great comfort is a process, following a loss, of experiencing grieving as a healing force⁴. Introducing the term 'prolonged grief disorder' poses the risk of reiterating the perception of grieving as a 'disorder' (in others and in oneself). Added to this, the current version of ICD-11 promotes the time-scaling of the grieving process.

At the same time, it is important to differentiate between the various situations encountered by the bereaved: the circumstances when losing a child are different from those when losing a partner; moreover, a loss suffered as a result of suicide is different from losing someone after illness or an accident. This raises a further point of criticism of the current version of ICD-11 in that the definition of the term 'prolonged' in the respective case of loss and, in contrast, of the term 'normal' remains unclarified.

³ Overall, ICD-11 emphasises that the respective cultural circumstances should be factored in when determining diseases and disorders. (See, in this context, the interview conducted with Andreas Maercker: "Burn-out ist eine deutsche Krankheit". *Diagnosen. Wer psychisch krank ist, bestimmt auch die Kultur.* (Burn-out is a German disease: Diagnoses. Who is mentally ill, is also determined by their culture) In: *Tages-Anzeiger Zurich* 31.7.2018, p. 38)

⁴ Cf. handout from the DHPV *Trauer und Trauerbegleitung (Bereavement and Grief Counselling)*, Berlin 2017, p. 10

International perspective

Corresponding experiences in dealing with bereavement based on the respective culture can also be found in other countries, as in the case of Uganda and Tanzania, for example. In both countries, a pronounced culture of grieving existed until their colonisation. It allowed for space and time for grieving, which was expressed with heart and soul in music and dance. In most cases, this was perceived as a 'disruption' by the colonialists; so this culture was confined to what was normal and respectable in Europe.

Kommentiert [BA1]: Oder sollen wir hier auch im Englischen wieder „disorder“ verwenden?

Through collaborative partnerships, the bereaved in some areas of Uganda and Tanzania have been encouraged over the past years to embrace their original culture, also in publicly expressing their grief with heart and soul in music and dance – and to follow their own personal rhythm. This is instilling in many a liberating and healing force and is resulting in the original culture of grieving gaining ground. As many grieving individuals have lost family members to AIDS, some of them are engaging in the AntiAIDS campaign based on their experiences. Within the culture of these countries, information is conveyed through music and dance, just as those concerned have come to know it in their grieving.⁵

In Uganda and Tanzania, too, there is a potential risk of the introduction of the term 'prolonged grief disorder' once again stunting the emerging culture of grieving. Similar negative reverberations to the envisaged adoption of the term 'prolonged grief disorder' are also to be expected in other cultural regions.

In light of these experiences concerning the culture of grieving in Germany – based on our own history and working with grieving individuals – as well as the development of cultures of grieving in other countries, the DHPV is calling for the ICD-11 6B42 coding system to amend the term 'post-loss stress disorder'.

⁵ Cf. the brochure titled *Coping with grief*, Bushenyi / Uganda 2014, 2nd edition. 2017