



International Prolonged Grief Disorder Scale (IPGDS)

Killikelly, Stelzer, Zhou and Maercker (2019 in preparation)

Information for clinicians

The WHO ICD-II Working Group on *disorders specifically associated with stress* developed clinical guidelines for the prolonged grief disorder (PGD) (Maercker et al. 2013). These guidelines follow the new structure of ICD-11: a narrative definition of disorder, the inclusion of cultural features, a list of core symptoms and accessory symptoms in a brief and easy to use format (Reed 2010).

The IPGDS seeks to operationalize the ICD-11 definition of PGD in a self-report questionnaire format. The ICD-11 PGD definition is structured to have two core symptoms (item 1, item 2) and examples of emotional pain (accessory items 3-12). Item 13 indicates functional impairment and item 14 indicates the violation of cultural norms. The core and accessory symptoms are represented by questions from previous measures (i.e. the integration of items from the PG-13 (Prigerson et al. 2008) and the SCI-CG (Bui et al. 2015)). A new question on culture norms of bereavement is also included. *The threshold for clinical diagnosis of PGD is currently under investigation.*

As an exploratory step this draft of the scale pilots the introduction of the cultural supplement (page 3). These cultural supplement items provide further examples of emotional pain that may be more acceptable or representative of grief in different cultural groups. Following the best practice of scale development (Boateng et al. 2018) and guidelines for the development of culturally sensitive measures (Bolton 2008) these items are based on key informant interviews with experts specializing in grief and bereavement from Switzerland and China. Additional supplementary items are currently in development.

Guidelines on how to score the cultural supplement items and how to integrate the cultural items into the standard scale are pending.

Here are draft guidelines:

Scoring key (in development)

STANDARD SCALE

Below you will find instructions on how to score items in order to:

1. obtain a global score for **grief severity**: Create a summed score over items 1 - 13. The higher the value, the more severe the grief.
2. distinguish individuals with **Prolonged Grief Disorder (PGD)** from those without:



Core symptoms:

At least one of items 1 or 2 must be endorsed with often (4) or always (5).

Accessory symptoms:

Provisory Regulation: At least one of items 3-12 must be endorsed with often (4) or always (5).

Functional impairment criterion:

Item 13 must be endorsed with often (4) or always (5).

Culture criterion:

Item 14 must be endorsed with often (4) or always (5).

Criteria Description:

Items 1-2: Core symptoms

Items 3-12: Accessory symptoms

Item 13: Functional impairment criterion

Item 14: Culture criterion

Item 15: Time criterion



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Instruction: Using the scale below, please choose the answer that best describes how you have been feeling over the **past week**.

Standard Scale

	Not at all (1)	Rarely (2)	Sometimes (3)	Often (4)	Always (5)
1. I am longing or yearning for the deceased.	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>
2. I am preoccupied with thoughts about the deceased or circumstances of the death.	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>
3. I have intense feelings of sorrow, related to the deceased.	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>
4. I feel guilty about the death or circumstances surrounding the death.	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>
5. I am angry over the loss.	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>
6. I try to avoid reminders of the deceased or the death as much as possible (e.g., pictures, memories).	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>
7. I blame others or the circumstances for the death (e.g., a higher power).	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>
8. I have trouble or just don't want to accept the loss.	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>
9. I feel that I lost a part of myself.	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>
10. I have trouble or have no desire to experience joy or satisfaction.	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>
11. I feel emotionally numb.	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>
12. I have difficulties engaging in activities I enjoyed prior to the death.	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>
13. Grief significantly interferes with my ability to work, socialize or function in everyday life.	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>
14. My grief would be considered worse (e.g., more intense, severe and/or of longer duration) than for others from my community or culture	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>

15. When did the loss occur? (circle one)

a. less than 6 months ago

b. 6 to 12 months ago



- c. 1 to 5 years ago
- d. 5 to 10 years ago
- e. 10 to 20 years ago
- f. more than 20 years ago

Cultural Supplement: Accessory items

Instructions: please advise the participant to complete these culturally specific items if their grief experience was not adequately captured by the standard scale above

	Not at all (1)	Rarely (2)	Sometime s (3)	Often (4)	Alway s (5)
1. I experience strong physical problems since the loss (e.g., headache, problems with appetite).	1	2	3	4	5
2. I would do anything to feel close to the deceased (e.g., visit their grave everyday, sleep next to their picture).	1	2	3	4	5
3. Since the loss my behavior has changed drastically in an unhealthy direction (e.g., excessive alcohol consumption).	1	2	3	4	5
4. The loss shattered my trust in life or faith in God/a higher spiritual power.	1	2	3	4	5
5. It is impossible for me to focus.	1	2	3	4	5
6. My grief is so intense that I feel stuck in grief	1	2	3	4	5
7. I just can't seem to fall back into a rhythm.	1	2	3	4	5
8. I feel paralyzed and disconnected, (e.g., as if I am not in my own body)	1	2	3	4	5
9. I have no energy or desire to engage in activities.	1	2	3	4	5
10. This life holds no meaning since the death.	1	2	3	4	5
11. I want to die in order to be with the deceased.	1	2	3	4	5
12. I don't feel close to other people or feel no satisfaction when being around others.	1	2	3	4	5
13. I feel like I have completely lost control.	1	2	3	4	5



14. I am searching for the deceased with the hope to find him/her.	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>
15. I feel life is hopeless because of the loss.	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>
16. I constantly look back upon the past relationship.	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>
17. I feel so helpless since I lost him/her.	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>
18. I feel he/she is beside me.	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>
19. I cry loudly when I think of the loss.	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>
20. I can't trust others since the loss.	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>