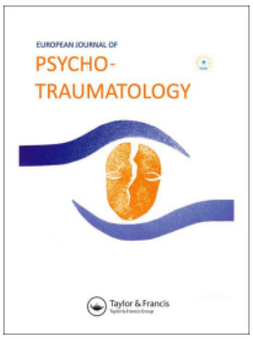

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BASIC RESEARCH ARTICLE

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Assessing DSM-5-TR and ICD-11 prolonged grief disorder in children and adolescents: development of the Traumatic Grief Inventory – Kids – Clinician-Administered

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ABSTRACT

Background: Around 10% of bereaved youths experience symptoms of prolonged grief disorder (PGD). Recently, PGD was included in the two main classification systems for mental disorders: the ICD-11 and DSM-5-TR. Assessing PGD symptoms in youth is currently hindered by the lack of instruments for ICD-11 and DSM-5-TR criteria. To fill this gap, we developed an instrument to assess PGD symptoms in children and adolescents, the Traumatic Grief Inventory – Kids – Clinician-Administered (TGI-K-CA), based on input of grief experts and bereaved children.
Methods: Five experts rated the items on alignment with DSM-TR and ICD-11 PGD symptoms and comprehensibility. The adjusted items were then presented to seventeen bereaved youths (Mdn_{age} = 13.0 years, range = 8–17 years). Using the Three-Step Test Interview (TSTI), children were asked to verbalize their thoughts while answering the items.
Results: Issues raised by experts were mostly related to alignment with the DSM-5-TR/ICD-11 symptom, ambiguous formulation of the items, or low comprehensibility for children and adolescents. Items raising fundamental issues according to experts were adjusted. The TSTI showed that children encountered relatively few problems with the items. Frequently reported problems with some of the items (e.g. regarding comprehensibility) led to final adjustments.
Conclusion: With input from grief experts and bereaved youths, an instrument to assess PGD symptoms as defined in DSM-5-TR and ICD-11 in bereaved youths was finalized. Further quantitative research is currently undertaken to evaluate the instrument's psychometric qualities.

Evaluación del Trastorno por duelo prolongado del DSM-5-TR y la CIE-11 en niños y adolescentes: Desarrollo del Inventario de duelo traumático – para Niños – Administrado por un profesional de la salud

Antecedentes: Alrededor del 10% de los jóvenes en duelo experimentan síntomas de Trastorno por Duelo Prolongado (PGD por sus siglas en ingles). Recientemente, el PGD se incluyó en los dos principales sistemas de clasificación de los trastornos mentales: la CIE-11 y el DSM-5-TR. Actualmente, la evaluación de los síntomas del PGD en los jóvenes se ve obstaculizada por la falta de instrumentos para los criterios CIE-11 y DSM-5-TR. Para llenar este vacío, desarrollamos un instrumento para evaluar los síntomas del PGD en niños y adolescentes, el Inventario de Duelo Traumático – para Niños – Administrado por un Clínico (TGI-K-CA por sus siglas en ingles), basado en aportes de expertos en duelo y niños en duelo.
Métodos: Cinco expertos calificaron los ítems sobre la alineación con los síntomas y la comprensión del DSM-TR y el CIE-11 PGD. Los elementos ajustados se presentaron luego a diecisiete jóvenes en duelo (Mediana Edad = 13,0 años, rango = 8–17 años). Usando la entrevista de prueba de tres pasos (TSTI por sus siglas en ingles), se les pidió a los niños que verbalizaran sus pensamientos mientras respondían los ítems.
Resultados: Los problemas planteados por los expertos se relacionaron en su mayoría con la alineación con el síntoma DSM-5-TR/CIE-11, la formulación ambigua de los ítems o la baja claridad para niños y adolescentes. Se ajustaron los ítems que plantean cuestiones fundamentales según los expertos. El TSTI mostró que los niños encontraron relativamente pocos problemas con los ítems. Los problemas informados con frecuencia con algunos de los ítems (p. ej., con respecto a la comprensibilidad) llevaron a ajustes finales.
Conclusión: Con aportes de expertos en duelo y jóvenes en duelo, se finalizó un instrumento para evaluar los síntomas de PGD tal como se definen en DSM-5-TR y la CIE-11 en jóvenes en

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Duelo prolongado; Niños; adolescentes; DSM-5-TR; CIE-11; Medición

关键词
延长哀伤; 儿童; 青少年; DSM-5-TR; ICD-11; 测量

HIGHLIGHTS

- Children with symptoms of Prolonged Grief Disorder (PGD) experience a debilitating longing for and/or preoccupation with a deceased loved one.
- Assessment of PGD in youth is hindered by the lack of an instrument.
- With the involvement of grief experts and bereaved youth, the current study developed an instrument that can be used in bereaved children and adolescents.

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duelo. Actualmente se están realizando más investigaciones cuantitativas para evaluar las cualidades psicométricas del instrumento.

评估儿童和青少年中的 DSM-5-TR 和 ICD-11 延长哀伤障碍：创伤性哀伤量表-儿童 – 临床医生管理版的开发

背景：大约 10% 丧亲的青少年经历过延长哀伤障碍 (PGD) 的症状。 最近，PGD 被纳入精神障碍的两个主要分类系统：ICD-11 和 DSM-5-TR。 由于缺乏符合 ICD-11 和 DSM-5-TR 标准的工具，目前无法评估青少年的 PGD 症状。 为了填补这一空白，我们开发了一种工具来评估儿童和青少年的 PGD 症状，即基于哀伤专家和丧亲儿童的意见的创伤性哀伤量表-儿童 – 临床医生管理版(TGI-K-CA)。
方法：五位专家根据 DSM-TR 和 ICD-11 PGD 症状和可理解性对条目进行评分。 然后将调整后的条目呈现给 17 名丧亲青少年（平均年龄 = 13.0 岁，范围 = 8 – 17 岁）。 使用三步测试访谈 (TSTI)，孩子们被要求在回答问题时用语言表达他们的想法。
结果：专家提出的问题主要与 DSM-5-TR/ICD-11 症状的一致性、条目表述不明确或儿童和青少年的理解力低有关。根据专家提出的根本性问题调整了条目。 TSTI 显示孩子们对条目的问题相对较少。一些条目经常被报告的问题（例如，关于可理解性）会被最终调整。
结论：根据哀伤专家和丧亲青少年的意见，最终确定了一种根据 DSM-5-TR 和 ICD-11定义的评估丧亲青少年 PGD 症状的量表。 目前正在进行进一步的定量研究，以评估该量表的心理测量学性质。

The death of a loved one is one of the most commonly experienced stressful life events among children and adolescents (Elklit, 2002; McLaughlin et al., 2013; Rheingold et al., 2004). The lifetime prevalence rate of parental bereavement in youths is around 2% (Statistics Netherlands, 2022). Evidently, the rates are higher when taking losses of other loved ones into account, such as siblings, grandparents or close friends (Kaplow et al., 2010). In a small but significant minority of children, bereavement is related to the development of psychiatric problems, such as post-traumatic stress disorder (PTSD), major depressive disorder (MDD), or alcohol and substance abuse (Brent et al., 2009; Melhem et al., 2008). The most commonly reported bereavement-related complaints are symptoms of maladaptive grief (Boelen et al., 2017). Although much evidence regarding the existence of maladaptive grief stems from research in adults, research shows that children and adolescents can also experience maladaptive grief. About 1 in 10 bereaved children develop symptoms of maladaptive grief, which encompass e.g. intense yearning for, or preoccupation with the deceased person, and persist over time (Melhem et al., 2011). Several studies among youths aged 8–21 years have found that symptoms of maladaptive grief are distinct from PTSD and depressive disorder (e.g. Boelen et al., 2017; Geronazzo-Alman et al., 2019). Maladaptive grief symptoms may cause significant functional impairments independent from symptoms of PTSD and MDD (Melhem et al., 2011; Spuij et al., 2012). Research shows that without intervention, maladaptive grief symptoms remain relatively stable and therefore may continue to impact children's psychosocial functioning (Melhem et al., 2011). This underpins the need for early detection of these symptoms, in order to prevent psychological problems related to childhood bereavement that may occur in adulthood (Lytje & Dyregrov, 2019; see also Boelen et al., 2023).

Maladaptive grief symptoms are defined as prolonged grief disorder (PGD) in the text revision of the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5-TR; APA, 2022) and the eleventh edition of the International Classification of Diseases (ICD) (ICD-11; World Health Organization [WHO], 2018). The prevalence of PGD according to the ICD-11 among children is estimated to be around 12% (Boelen et al., 2017). Given the recent recognition of PGD within the DSM and ICD, new tools are developed to assess these recent criteria. For instance, the Traumatic Grief Inventory – Self Report Plus (TGI-SR+; Lenferink et al., 2022) measures both the DSM-5-TR and ICD-11 criteria of PGD in adults. The TGI-SR + is a reliable and valid measure and is also available in a clinician-administered interview version (Traumatic Grief Inventory – Clinician Administered; Lenferink et al., 2023). Furthermore, in adults, the DSM-5-TR criteria can be assessed by the PG-13-Revised scale (Prigerson et al., 2021) and the ICD-11 criteria can be measured by the ICD-11 Prolonged Grief Disorder Scale (Killikelly et al., 2020).

However, to date, no instrument for the assessment of PGD according to the DSM-5-TR and ICD-11 criteria is available for children and adolescents. This limits research on these most recent conceptualizations of PGD in children. In the last decades, several instruments have been developed to assess PGD symptoms in children and adolescents, based on prior conceptualizations of maladaptive grief. Spuij et al. (2012) constructed the Inventory of Prolonged Grief for

Children and for Adolescents (IPG-C and IPG-A), based on Prigerson and Jacobs (2001) description of PGD. The Traumatic Grief Inventory for Children (TGIC) by Dyregrov et al. (2001) and the Inventory for Complicated Grief-Revised for Children (ICG-RC) by Melhem et al. (2013) were also based on Prigerson and Jacobs (2001) description. Kaplow et al. (2018) developed the Persistent Complex Bereavement Disorder (PCBD) Checklist, which measures PCBD symptoms according to DSM-5 (APA, 2013).

Considering the relevance of assessing the most recent conceptualization of PGD, there is an urgent need to develop an instrument to measure PGD symptoms according to DSM-5-TR and ICD-11 criteria in children and adolescents. We therefore constructed a clinician-administered interview for youths aged 8–17 years, the Traumatic Grief Inventory – Kids – Clinician Administered (TGI-K-CA). When developing such an instrument for youths, it is important to be aware of methodological challenges. For instance, responding to items might be challenging for children, due to, e.g. their limited attention span, which may increase the risk of response bias (Omrani et al., 2019). Administrating measures via interviews may prevent this bias, as interviewers can answer questions about the items and may probe further if an individual's response is inconsistent with other available information (Fresco et al., 2001). Moreover, developing items that align with the developmental level of children is crucial for reliable and valid assessment. Taking the perspective of children into account, in addition to the perspective of experts, seems therefore relevant. By using cognitive interviewing, the thought process regarding answering the questions in a measure can be made observable, as children and adolescents verbalize their thoughts the moment they read and answer the questions (Hak et al., 2008). Cognitive interviewing has been successfully applied in prior studies among children as young as five years old (e.g. Dalen et al., 2020; Davis et al., 2007; Rebok et al., 2001). It may lead to the identification of problems concerning the administration of the instrument, the formulation of items, and the items' response options that may be overlooked by experts (Jansen & Hak, 2005), and therefore improves measurement validity (Karabenick et al., 2007). By conducting both expert reviews and cognitive interviews in bereaved children and adolescents, we aim to construct developmentally appropriate items that measure PGD symptoms according to DSM-5-TR and ICD-11 criteria.

1. Method

Two studies were conducted to develop the TGI-K-CA (see Figure 1). Prior to the studies, a Dutch item pool was generated by IvD, LL, and PB. The first study consisted of the evaluation of this item pool by several experts in terms of comprehensibility and alignment with DSM-5-TR and ICD-11 symptoms. Subsequently adaptations to the items were made. In the second study, a sample of bereaved children evaluated this item pool, for which the Three-Step Test-Interview (Hak et al., 2008) was used, and final adaptations to the items were made. Study 1 took place in March and April 2021 and Study 2 in April 2021. Both were approved by the Faculty Ethical Review Board of Utrecht University (FETC 21-0030).

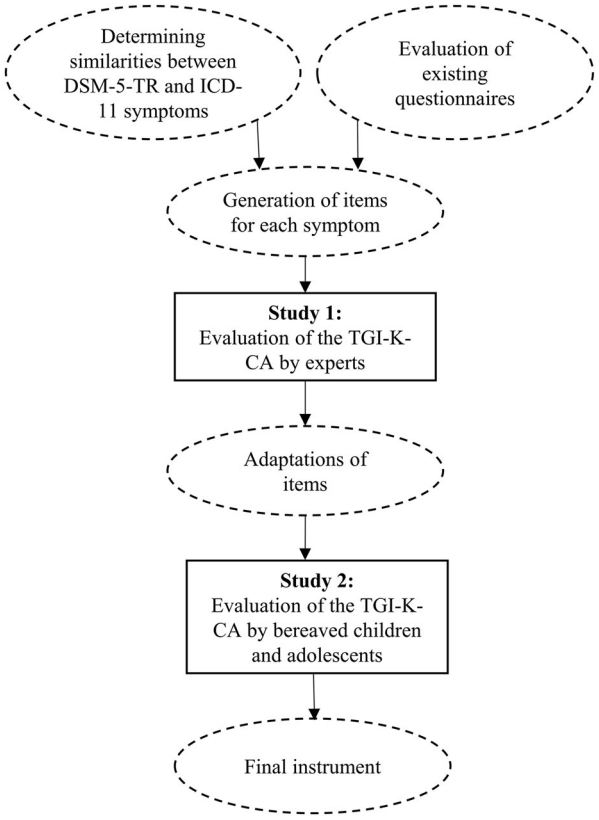

Figure 1. Overview of the development of the Traumatic Grief Inventory – Kids – Clinician-Administered.

1.1. Participants

1.1.1. Study 1: evaluation of the TGI-K-CA by experts

Experts on grief in children and adolescents were recruited through the social network of the research team. Eligible for participation were mental health professionals (e.g. psychologists, psychiatrists, family therapists, grief counsellors, etc.) and/or academics working with bereaved children. We aimed to recruit a heterogenic group of experts with a background either in research, clinical practice, and both. Nine experts were approached via e-mail with the request to participate in an expert review. Five experts agreed to participate by signing an informed consent form. All participating experts worked as a clinician with bereaved children and/or adolescents, and two out of five experts also worked as a researcher on grief in children and adolescents. See Table 1 for a detailed overview.

Table 1. Demographic characteristics and loss-related characteristics of the expert sample ($n = 5$).

	n (%)
Gender	
Woman	4 (80)
Man	1 (20)
Self-reported occupation[a]	
Master psychologist	1 (20)
Researcher	2 (40)
Clinical psychologist	1 (20)
Psychotherapist	1 (20)
Occupational therapist	1 (20)
Therapist focused on grief and trauma	1 (20)
Suicide prevention worker	1 (20)

[a]Multiple answers could be given.

1.1.2. Study 2: evaluation of the TGI-K-CA by bereaved children and adolescents

Children and adolescents aged 8 through 17 years who lost a loved one at least six months earlier were eligible for participation. They were recruited via advertisements on social media or through convenience sampling. We aimed to recruit bereaved children and adolescents of varying ages, genders, educational levels, and relationships to the deceased person. Seventeen Dutch children and adolescents participated ($Mdn = 13.0$ years, see Table 2 for additional characteristics of the sample). Participants were informed in an information letter about possible negative effects regarding participation in grief research. In this letter, it was stated that if participants need support because of participation, the researchers could aid them in finding adequate support. Before participating, children and adolescents and/or their parent(s)/caregiver(s) signed an informed consent form.

Table 2. Demographic characteristics and loss-related characteristics of the bereaved children and adolescent sample ($n = 17$).

Demographic variables	
Gender (*n* (%))	
Female	11 (64.7)
Male	6 (35.3)
Age (years) (*Mdn* (*SD*); range)	13.0 (3.1); 8–17
Age group (years) (*n* (%))	
8-12	8
13-17	9
Educational level (*n* (%))	
Primary school	7 (41.2)
Pre-vocational secondary education	1 (5.9)
Senior general secondary education	4 (23.5)
Pre-university education	2 (11.8)
Other	3 (17.6)
Loss-related characteristics	
Deceased is (*n* (%))	
Parent	11 (64.7)
Grandparent	4 (23.5)
Sibling	1 (5.9)
Aunt/uncle	1 (5.9)
Cause of the loss	
Physical illness	14 (82.4)
Accident	3 (17.6)
Time since loss[a]	$M = 3.31$ years, SD = 2.97 years
Perceived the loss as expected (*n* (%))	
Yes	7 (41.2)
No	10 (58.8)
Age of the deceased (years) (*M* (*SD*); range)	49.7 (17.1); 11–78

[a]Sample size is $n = 13$ due to missing values.

1.2. Procedure

1.2.1. Construction of an item pool

Our aim was to develop a measure that assesses both DSM-5-TR and ICD-11 PGD symptoms, with one DSM-5-TR and/or ICD-11 symptom represented by one item. An item pool was created by the authors IvD, LL, and PB, based on existing questionnaires for adults (i.e. the TGI-SR+; Lenferink et al., 2022), and children and adolescents (i.e. the translated German and adapted-to-youth version of the TGI-SR + [J. Unterhitzenberger, personal communication, 25 November 2020]), and the IPG-C (Spuij et al., 2012).

A 5-point Likert-scale was used for the response options, including 1 = never, 2 = rarely, 3 = sometimes, 4 = often, and 5 = always. This was deemed appropriate, given that other instruments designed for youth in the same age range also included a 5-point Likert scale, such as the Child PTSD Symptom Scale for DSM-5 (CPSS-5) by Foa et al. (2017) or the PCBD Checklist by Kaplow et al. (2018). Furthermore, a study showed that children between 6 and 18 years old preferred a 5-point Likert scale over other response options (such as a numeric VAS) (Van Laerhoven et al., 2004). Based on this, and that the PCBD Checklist showed measurement invariance with respect to age (Hill et al., 2020), no separate versions for younger and older age groups were constructed. The initial item pool consisted of 22 items. For five symptoms, two or three items were generated with the aim of presenting these to grief experts during Study 1, so they could evaluate which item represented the respective symptom best and was the most comprehensible for children. An example of a symptom that was represented by two items is the symptom regarding emotional numbness (see Table 3, column 3).

1.2.2. Study 1: evaluation of the TGI-K-CA by experts

Experts were provided with the proposed instruction for clinicians (also containing an instruction that would be read aloud to the child by the clinician), the proposed response options that applied to all items, and the item pool, consisting of 22 items. Experts rated to what extent (1) the instruction was comprehensible for both the clinician and the child, (2) the response options were comprehensible for the child, (3) the items align with the DSM-5-TR and/or ICD-11 symptom (i.e. reflecting face validity), and (4) the items are comprehensible for youth. A 4-point scale was used for the ratings, with 1 = bad, 2 = poor, 3 = sufficient, and 4 = good. When they gave a bad or poor rating, they were requested to provide written feedback.

1.2.3. Study 2: evaluation of the TGI-K-CA by bereaved children and adolescents

The TSTI involves observation and cognitive interviewing in order to gain more knowledge about the

Table 3. Overview of the differences and similarities between DSM-5-TR and ICD-11 PGD criteria, and which items were evaluated by experts and bereaved children and adolescents.

DSM-5-TR PGD symptom	ICD-11 PGD symptom	Item(s) presented to experts	Item(s) presented to bereaved children and adolescents
B1. Intense yearning/longing for the deceased person	B1. A persistent and pervasive longing for the deceased	In the past month, did you miss _____ very much?	In the past month, did you miss _____ very much?
B2. Preoccupation with thoughts or memories of the deceased person (in children and adolescents, preoccupation may focus on the circumstances of the death)	B2. A persistent and pervasive preoccupation with the deceased	In the past month, was your head full of thoughts and memories of (the circumstances surrounding the death of) _____? In the past month, did you suddenly have thoughts or memories of (the circumstances surrounding the death of _____?)	In the past month, was your head full of thoughts and memories of (the circumstances surrounding the death of) _____?
C1. Identity disruption (e.g. feeling as though part of oneself has died) since the death	C7. Feeling one has lost a part of one's self	In the past month, did you not know who you were anymore and did you feel as if you lost a part of yourself? In the past month, did you feel as if a part of yourself has died? In the past month, did you feel as if you lost a part of yourself?	In the past month, did you feel as if you lost a part of yourself?
C2. Marked sense of disbelief about the death	C4. Denial	In the past month, did you have trouble believing that _____ has died?	In the past month, did you have trouble believing that _____ has died?
C3. Avoidance of reminders that the person is dead (in children and adolescents, may be characterized by efforts to avoid reminders)	-	In the past month, did you try to stay away from everything that reminds you of _____, such as places, things, or thoughts?	In the past month, did you try to stay away from everything that reminds you of _____, such as places, things, or thoughts?
C4. Intense emotional pain (e.g. anger, bitterness, sorrow) related to the death	C3. Anger C1. Sadness	In the past month, did you have strong feelings of emotional pain, sadness, or pangs of grief? In the past month, did you have intense feelings of emotional pain, sadness, or pangs of grief? In the past month, were you very angry because _____ has died?	In the past month, were you very sad because _____ has died? In the past month, were you very angry because _____ has died?
C5. Difficulty reintegrating into one's relationships and activities after the death (e.g. problems engaging with friends, pursuing interests, or planning for the future)	C10. Difficulty in engaging with social or other activities	In the past month, did you have trouble continuing with normal life (such as meeting your friends, or doing the things that you like)?	In the past month, did you have trouble continuing with normal life (such as meeting your friends, or doing the things that you like)?
C6. Emotional numbness (absence or marked reduction of emotional experience) as a result of the death	C9. Emotional numbness	In the past month, did you notice that it seemed as if you did not have any feeling, such as fear, anger, or sadness? In the past month, did you feel nothing anymore (no sadness, anger, or happiness)?	In the past month, did you feel nothing anymore (no sadness, anger, or happiness)?
C7. Feeling that life is meaningless as a result of the death	-	In the past month, did you feel as if life can only be pleasant if _____ is around? In the past month, did you have the feeling that your life is empty and meaningless without _____?	In the past month, did you feel as if life can only be pleasant if _____ is around? In the past month, did you have the feeling that your life is empty and meaningless without _____?
C8. Intense loneliness as a result of the death	-	In the past month, did you feel alone?	In the past month, did you feel very alone because of the death of _____?
-	C2. Guilt	In the past month, did you feel guilty about the death of _____?	In the past month, did you feel guilty about the death of _____?
-	C5. Blame	In the past month, did you blame other people that _____ is dead?	In the past month, did you blame other people that _____ is dead?
-	C6. Difficulty accepting the death	In the past month, did you have trouble accepting that _____ is dead?	In the past month, did you have trouble accepting that _____ is dead?
-	C8. An inability to experience positive mood	In the past month, did you find it difficult to feel cheerful, happy, or content?	In the past month, did you have trouble feeling cheerful or happy?
D. The disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning	E. The disturbance causes significant impairment in personal, family, social, educational, occupational or other important areas of functioning	In the past month, were you functioning worse, for example in school or with friends and family?	In the past month, did you notice that you did worse in different areas (for example in school, or with friends and family)?

way children understand and interpret each item. Any problems that may occur during the administration of the instrument can also be identified, such as having too many items that may exhaust the child. We followed the procedure of the TSTI of Hak et al. (2008). In our study, however, the interviewer

administered the TGI-K-CA with the participant (instead of participants filling out a questionnaire by themselves), to match the proposed clinician-administration of the TGI-K-CA. During the first step of the TSTI, bereaved children and adolescents were asked to think aloud when completing the instrument. The interviewer's role consisted of reading the items of the TGI-K-CA to the participant, prompting the children to think aloud when they had difficulties doing that (e.g. 'Could you tell me what your thoughts are?'), and making notes of behaviour and verbalizations that might indicate a problem with the item. In the second step, bereaved children and adolescents answered questions of the interviewer, to clarifying observations that the interviewer made (e.g. 'Did I hear you say … ?'). The third step involves the child answering questions about his or her response behaviour and/or the content of the items in a semi-structured interview (e.g. 'Why did you say … ?' or 'Could you explain this question to me in your own words?'). Before the start of the TSTI, an exercise was conducted to practice thinking aloud (e.g. 'Think about what you had for dinner last night. When you are thinking about that, could you tell me aloud everything you are thinking?'). Moreover, questions about gender, age, educational level, and loss characteristics (i.e. kinship to the deceased, cause of death, time since loss, and age of the deceased) were administered verbally. The TSTI took place using videoconferencing and lasted about 50 min. Three undergraduate students in developmental psychology conducted the TSTIs after receiving a 2-hour-training. The training encompassed of elaborating the procedure of the TSTI with IvD and practicing with the TSTI. Supervision was provided by IvD throughout data-collection. During three interviews, the parent of the child was also present. The TSTI's were video-recorded. Parts of the interviews (in which children indicated an issue with an item) were transcribed verbatim by IvD.

1.3. Data analysis

1.3.1. Study 1: evaluation of the TGI-K-CA by experts

Inductive thematical analyses were conducted by I. Van Dijk for items that were rated with 1 ('bad') or 2 ('poor') by at least one expert on one or more aspects (i.e. alignment with the DSM-5-TR and/or ICD-11 symptom and comprehensibility). Following the framework of Braun and Clarke (2006), the analyses consisted of the labelling of comments and problems and the identification of overarching themes within the experts' comments and reported problems (e.g. problems in formulation or problems in alignment with the DSM-5-TR or ICD-11 symptom). Experts' feedback was subsequently implemented or dismissed after reaching consensus by IvD and LL. For the symptoms where two or three items were generated to measure one symptom (see Table 1, column 3), the item with the highest rating (based on the median) on comprehensibility and symptom alignment was retained. In case there was a discrepancy in the ratings of the items to assess one symptom (e.g. one item scored high on comprehensibility and low on symptom alignment or vice versa), the item with the highest rating (based on the median) for comprehensibility was retained.

1.3.2. Study 2: evaluation of the TGI-K-CA by bereaved children and adolescents

Using thematic analysis (Braun & Clarke, 2006), IvD analyzed children's comments regarding an item. This led to the identification of overarching problems with an item. Adjustments were made based on whether issues with the items commonly occurred. Regarding the symptom 'Feeling that life is meaningless or empty without the deceased', that is represented by two items (see Table 1, column 4), the item with the least comments from children was chosen as the final item. The adjustments resulted in a final set of items.

2. Results

2.1. Study 1: evaluation of the TGI-K-CA by experts

2.1.1. Instruction for clinicians and response options

Based on an expert's comment, the structure of the part that clinicians read to children was slightly changed, so that the question about which loved one was most in the child's thoughts would be asked prior to the explanation of the instrument. Furthermore, instead of the response option 'rarely' (Dutch: 'zelden'), a simpler alternative was used (i.e. 'almost never', Dutch: 'bijna nooit').

2.1.2. Item pool

Unchanged items. Twelve items were rated as at least sufficient (median of 3 or higher on comprehensibility and symptom alignment, see Table 4). These items were therefore not changed. One item (i.e. 'In the past month, did you miss ____ very much?') received a rating of ≤ 2 by three out of five experts on DSM-5-TR and ICD-11 symptom alignment. After careful consideration of the experts' feedback, we did not change this item because better alternatives were not provided. More specifically, one expert stated that the 'very much' may be suggestive. However, when removing 'very much', the aspect of intensity concerning the longing for the deceased within the DSM-5-TR and ICD-11 symptom would be missing. Even though an expert commented that the use of the word 'miss'

Table 4. Overview of encountered problems during the expert reviews ($n = 5$).

	Description of item	Median rating of DSM-5-TR alignment* (observed range)	Median rating of ICD-11 alignment* (observed range)	Average rating of comprehensibility* (observed range)	No. of experts indicating a problem**	Types of comments[a]	Change of item
1	In the past month, did you miss _____ very much?	2.0 (1–4)	2.0 (1–3)	4.0 (2–4)	3	1, 2	Unchanged
2	In the past month, was your head full of thoughts and memories of (the circumstances surrounding the death of) _____?	3.0 (2–4)	3.0 (2–4)	3.0 (3–4)	3	1, 2	Unchanged
3	In the past month, did you suddenly have thoughts or memories of (the circumstances surrounding the death of _____?)	2.0 (1–3)	2.0 (1–3)	3.0 (2–4)	5	1	Removed
4	In the past month, did you not know who you were anymore and did you feel as if you lost a part of yourself?	3.0 (2–3)	2.0 (2- 3)	2.0 (1–2)	5	2, 3	Removed
5	In the past month, did you feel as if a part of yourself has died?	3.0 (3–4)	3.0 (2–4)	3.0 (2–3)	1	1, 3	Removed
6	In the past month, did you feel as if you lost a part of yourself?	3.0 (2–4)	3.0 (2–4)	3.0 (2–4)	1	1	Unchanged
7	In the past month, did you have trouble believing that _____ has died?	4.0 (2–4)	3.0 (2–4)	4.0 (2–4)	1	3	Unchanged
8	In the past month, did you try to stay away from everything that reminds you of _____, such as places, things, or thoughts?	3.0 (2–4)	-	3.0 (2–3)	1	1	Unchanged
9	In the past month, did you have strong feelings of emotional pain, sadness, or pangs of grief?	4.0 (3–4)	4.0 (3–4)	2.0 (1–3)	4	2, 3	Removed (new item created)
10	In the past month, did you have intense feelings of emotional pain, sadness, or pangs of grief?	4.0 (2–4)	4.0 (2–4)	2.0 (1–2)	5	2, 3	Removed (new item created)
11	In the past month, were you very angry because has died?	4.0 (2–4)	4.0 (2–4)	4.0 (3–4)	0	-	Unchanged
12	In the past month, did you have trouble continuing with normal life (such as meeting your friends, or doing the things that you like)?	4.0 (3–4)	4.0 (3–4)	3.0 (2–4)	1	2	Unchanged
13	In the past month, did you notice that it seemed as if you did not have any feeling, such as fear, anger, or sadness?	3.0 (2–4)	3.0 (2–4)	2.0 (1–4)	3	2, 3	Removed
14	In the past month, did you feel nothing anymore (no sadness, anger, or happiness)?	3.0 (2–4)	3.0 (2–4)	3.0 (2–4)	3	2, 3	Adapted
15	In the past month, did you feel as if life can only be pleasant if _____ is around?	3.0 (1–4)	-	4.0 (2–4)	2	1	Unchanged
16	In the past month, did you have the feeling that your life is empty and meaningless without _____?	4.0 (3–4)	-	2.0 (2–3)	4	3	Unchanged
17	In the past month, did you feel alone?	3.0 (2–3)	-	3.0 (3–4)	1	1	Adapted
18	In the past month, did you feel guilty about the death of _____?	-	4.0 (3–4)	4.0 (3–4)	0	-	Unchanged
19	In the past month, did you blame other people that _____ is dead?	-	4.0 (3–4)	3.0 (2–4)	1	3	Unchanged

(*Continued*)

Table 4. Continued.

	Description of item	Median rating of DSM-5-TR alignment* (observed range)	Median rating of ICD-11 alignment* (observed range)	Average rating of comprehensibility* (observed range)	No. of experts indicating a problem**	Types of comments[a]	Change of item
20	In the past month, did you have trouble accepting that ____ is dead?	-	4.0 (3–4)	3.0 (2–4)	1	4	Unchanged
21	In the past month, did you find it difficult to feel cheerful, happy, or content?	-	4.0 (3–4)	4.0 (3–4)	0	-	Adapted[b]
22	In the past month, were you functioning worse, for example in school or with friends and family?	4.0 (3–4)	4.0 (3–4)	2.0 (1–4)	3	3	Removed (new item created)

* Answer possibilities were 1 = bad, 2 = poor, 3 = sufficient, 4 = good.
** Indicated by leaving feedback when they rated < 3 on one of the categories (i.e. DSM-5-TR and/or ICD-11 alignment, comprehensibility).
[a]Four categories of comments were identified: 1 = problems with suitability for DSM-5-TR or ICD-11 criterion, 2 = difficult formulation, 3 = problems in developmental appropriateness/comprehensibility, 4 = confronting concept for children.
[b]Even though all experts rated this item as at least sufficient, one example of positive feelings (namely 'content') was removed because an expert suggested that it did not add much meaning and would only make it a longer sentence.

would not capture the symptom well, we did not find an alternative for the word 'yearning' that would be understandable for children.

Adapted items. Four categories of issues were identified from experts' comments (see Table 4). Based on these issues, three out of 22 items were adjusted based on insufficient ratings on DSM-5-TR and/or ICD-11 symptom alignment and/or comprehensibility. The formulation of the item regarding loneliness (i.e. 'In the past month, did you feel alone?') was adapted so that it would be clear that it relates to the death of the loved one and the intensity aspect (i.e. *intense* loneliness) was included by adding 'very' alone (i.e. 'In the past month, did you feel very alone because of the death of ____'?).

Moreover, the item regarding problems in functioning (i.e. 'In the past month, did you function worse, for example in school or with friends and family?') was replaced (after adapting it to an interview-format) by an item from the IPG-C (i.e. 'I am doing worse (in school and with friends) since s/he died.'). This item measures the same symptom and has already been used in prior grief research with children (Spuij et al., 2012).

The third adaptation included a relatively small change to the item ('In the past month, did you find it difficult to feel cheerful, happy, or content?') by removing the word 'content'.

Multiple proposed items for one symptom. For some symptoms, two or three items were constructed (see Table 3, column 3). Considering parsimony and shorter administration times for the instrument, the goal was to develop one item for each symptom.[1]

Two items were generated for the symptom regarding preoccupation with the deceased and three items for the symptom regarding confusion about one's role in life. The items 'In the past month, was your head full of thoughts and memories about (the circumstances surrounding the death of) _____?' and 'In the past month, did you have the feeling that you lost a part of yourself?' were retained based on the higher ratings for both symptom alignment and comprehensibility compared to the alternatives.

The two generated items regarding the symptom about intense sorrow and emotional pain both raised issues in comprehensibility and/or difficulty in formulation by all experts. Therefore, a new item representing intense sadness was created, with a similar formulation as the item concerning intense anger (i.e. 'In the past month, were you very sad because ____ has died'), because this formulation was deemed more appropriate in terms of symptom alignment and comprehensibility.

The symptom regarding emotional numbness was also represented by two items. Ratings on symptom alignment were similar across the items, but the item with the highest rating on comprehensibility was retained. Based on a comment from an expert, a clarification for this item was added in the instruction for the clinician (not meant to be read aloud to the child), in case the child misinterprets this item in terms of physical pain, while it is about emotional pain. This clarification reads: 'This item is about emotional numbness. If the child interprets the item in terms of physical pain, clarify that the item is about having no emotional feelings anymore'.

Two items were constructed for the symptom 'feeling that life is meaningless'. According to experts, the first item aligned better with the symptom than the second item, but the second item was more comprehensible. While we initially argued to retain the item with the highest expert rating for comprehensibility, in this specific case we decided to not make the selection based on input from experts, instead we based our decision regarding item selection on evaluation by children and adolescents.

2.1.3. Study 2: evaluation of the TGI-K-CA by bereaved children and adolescents

Adjustments based on experts' comments led to an item pool of seventeen items that was presented to

bereaved children and adolescents during the TSTI (see Table 3, column 4). Ten categories of issues were identified from children's comments (see Table 5).

2.1.4. Unchanged items

Twelve items were not adapted based because only maximum 4 out of 17 children indicated a problem (see Table 5). Although the item 'In the past month, did you have the feeling that you lost a part of yourself?' had many reported problems (8 out of the 17 children indicated a problem), no adaptation of this item was made, as no alternative was offered by children, and no alternative could be found in existing instruments.

2.1.5. Adapted items

Children's evaluations of the items led to adjustments of six items. Regarding the item 'In the past month, could you not believe that _____ has died?', four children indicated that the sentence structure (i.e., the part 'not believe') of this item was confusing and difficult to respond to. Therefore, the item was changed to 'Did you have difficulties believing that _____ has died?'.

The item regarding emotional numbness ('In the past month, did you feel nothing anymore (no sorrow, anger, or happiness?)') was also adapted. Seven children indicated problems with this item: either regarding the formulation or unclarity of whether the item related to the death of their loved one arose. We changed this item into 'In the past month, did you have trouble having any feelings at all (like sadness, anger, or happiness)?'. This adapted item now corresponds closely to an item of the Child PTSD Symptom Scale for DSM-5 (CPSS-5; Foa et al., 2017), which reads: 'Trouble having good feelings (like happiness or love) or trouble having any feelings at all'. This CPSS-5 item assesses the DSM-5 PTSD symptom 'Persistent inability to experience positive emotions', which shows strong similarities with the PGD symptom 'Emotional numbness (absence or marked reduction of emotional experience) as a result of the death'.

Furthermore, for two items (regarding the difficulty to pursue interests or to plan for the future, and difficulty experiencing positive mood), a few issues were raised regarding unclarity about to what the item relates to. The instruction for the clinician was therefore supplemented with the notion that these items relate to the death of the significant other, which can be read aloud in case the interviewer notices that the child interprets this more generally. This supplementation read: 'If needed, repeat that the item is about the reactions in response to the death of _____.'

A minor change was made for two items. As three children indicated an issue with the formulation or the use of words of the item regarding avoidance of reminders of the loss ('In the past month, did you stay away from everything that reminds you of _____, such as places, objects, or thoughts?'), the item was

Table 5. Overview of encountered issues during the Three Step Test Interviews.

	Description of item	No. of participants indicating an issue*	Types of comments (no. of participants indicating this issue)[a]	Change of items
1	In the past month, did you miss _____ very much?	1	10 (1)	Unchanged
2	In the past month, was your head full of thoughts and memories of (the circumstances surrounding the death of) _____?	2	1, 5 (1)	Adapted
3	In the past month, did you feel as if you lost a part of yourself?	8	5 (1), 3 (5), 7, 4, 9, 8 (1)	Unchanged
4	In the past month, did you have trouble believing that _____ has died?	6	1, 5, 7 (2)	Adapted
5	In the past month, did you try to stay away from everything that reminds you of _____, such as places, things, or thoughts?	3	1 (2), 3 (1)	Adapted
6	In the past month, were you very sad because _____ has died?	1	6 (1)	Unchanged
7	In the past month, were you very angry because _____ has died?	1	6 (1)	Unchanged
8	In the past month, did you have trouble continuing with normal life (such as meeting your friends, or doing the things that you like)?	3	1 (1), 2 (2)	Unchanged
9	In the past month, did you feel nothing anymore (no sadness, anger, or happiness)?	8	8 (1), 1 (2), 2 (5)	Adapted
10	In the past month, did you feel as if life can only be pleasant if _____ is around?	1	1 (1)	Removed
11	In the past month, did you have the feeling that your life is empty and meaningless without _____?	0	N/A	Unchanged
12	In the past month, did you feel very alone because of the death of _____?	0	N/A	Unchanged
13	In the past month, did you feel guilty about the death of _____?	1	4 (1)	Unchanged
14	In the past month, did you blame other people that _____ is dead?	4	3 (2), 4, 6 (1)	Unchanged
15	In the past month, did you have trouble accepting that _____ is dead?	1	3 (1)	Unchanged
16	In the past month, did you have trouble feeling cheerful or happy?	3	1, 4, 2 (1)	Unchanged
17	In the past month, did you notice that you did worse in different areas (for example in school, or with friends and family)?	3	1 (1), 2 (2)	Unchanged

* For items 1–4, $n = 17$; for items 5–17, $n = 16$ (one missing because of a technical error).
** For the corresponding DSM-5-TR and ICD-11 symptoms, two items were generated.
[a]Ten categories were identified: 1 = difficult formulation; 2 = it is unclear to what item relates to; 3 = item contains difficult words; 4 = confusion about the meaning of the item; 5 = confronting item; 6 = problems in differentiation; 7 = problems with the response options; 8 = participant suggests improvement; 9 = item is similar to other item; and 10 = response is dependent on period/time after loss.

shortened, by placing the examples between brackets, meaning that it would be read aloud by the interviewer only when the child indicates he or she does not understand the item. Moreover, based on difficulties of the interviewers with reading the item 'In the past month, was your head full of thoughts and memories about (the circumstances surrounding the death of) ____?' aloud, the brackets within the item were removed and this part was moved to the end of the sentence (Table 5).

2.2. Two items for one symptom

Two items were proposed for the symptom regarding the feeling that life is meaningless or empty without the deceased. The item 'In the past month, did you had the feeling that your life is empty and meaningless without ____?' was chosen instead of the other item ('In the past month, did you feel as if life can only be nice if ____ would be still alive?') because of its better alignment with the symptom according to experts and its sufficient comprehensibility for children (given that no children indicated a problem with this item).

2.3. Final version of the TGI-K-CA

The adjustments based on children's evaluations led to the final instrument, consisting of sixteen items. The Dutch and English TGI-K-CA are both freely available at https://osf.io/2cmdp/ (see also the Supplementary Materials for the English version).

3. Discussion

The TGI-K-CA was constructed considering the need for adequate assessment of symptoms of PGD in children and adolescents. As it is important to prevent the persistent disruptions in children's daily life as a consequence of maladaptive grief, timely identification of these symptoms is required. Prior instruments, such as the IPG-C/A, TGIC, ICG-RC, and the PCBD Checklist already provided means to assess symptoms of maladaptive grief. However, these instruments are based on several earlier conceptualizations of maladaptive grief. The TGI-K-CA differs from these instruments, as it measures symptoms of PGD as currently defined in the DSM-5-TR and ICD-11. The recent recognition of PGD in the DSM-5-TR and ICD-11 and the accompanying TGI-K-CA may be valuable in adequate assessment and treatment of PGD following loss, considering the widespread use of these classification systems among researchers and clinicians. The TGI-K-CA may consequently facilitate research and early identification of PGD symptoms in clinical practice. Moreover, its brief (16-item) and child-friendly format, facilitates the assessment of PGD symptoms. This is one of, if not the first study focused on developing an instrument that measures PGD symptoms as defined by the DSM-5-TR and ICD-11 in youth, using the input of grief experts as well as a thorough analysis of children's understanding of the items.

The current study identified important issues with some proposed items of the TGI-K-CA. For instance, children showed difficulties with negatively phrased items (e.g. 'Could you not … ' or 'Did you feel nothing … ') using a positive ascending scale (i.e. 'never', 'sometimes', etc.). Research on children's response behaviour on instruments that measure several psychological constructs has also shown that children have difficulties responding to negatively phrased items (e.g. Marsh, 1986; Borgers & Hox, 2000). These difficulties may arise from the increase of cognitive burden which can affect children's decision making skills (Omrani et al., 2019). Therefore, using positively phrased items may lead to higher response reliability.

There are several limitations to the present study. First, convenience sampling was used. Most bereaved minors identified as girls and most lost a parent to physical illness, which limits generalizability to all bereaved minors. Furthermore, conducting (bereavement) research in minors comes with important but challenging ethical issues, such as obtaining consent from both parent and child (Park et al., 2022). This may have resulted in self-selected biases, such as an underrepresentation of children whose parents are more protective towards their child.

Second, even though the sample consisted of children with varying educational levels, specific cognitive abilities were not measured, while this may be of influence on children's ability to understand the items (De Leeuw, 2011). It might also be possible that items could be interpreted differently by children with varying cultural backgrounds. That is, it may be needed to develop a cultural-sensitive PGD tool to account for cultural differences (e.g. Killikelly et al., 2020). Moreover, children who lost a loved one due to a homicide may understand the concept of blame differently than children who experienced a non-homicidal loss. While a validation study in bereaved adults using the TGI-CA did not find evidence for this, as it showed no difference in the factor structure of PGD items between people with and without traumatic loss (Lenferink et al., 2023), it is still important to further examine the TGI-K-CA's psychometric properties in a more heterogenous sample of bereaved children.

Furthermore, we only focused on the Dutch version of the TGI-K-CA. Therefore, our results may not generalize to other languages. Future research should evaluate the psychometric properties of the translated TGI-K-CA, including the comprehensibility of the items, before implementing in research or practice.

Third, the format of the TGI-K-CA may bring limitations. Responses on the TGI-K-CA mainly depend on children's judgment of their own thoughts,

feelings and behaviours. Children may not always be capable of reporting their own symptoms, as not all children have the required cognitive and emotional skills to do so (Omrani et al., 2019). For instance, in the current study, half of the youths reported problems with the item regarding the loss of a part of oneself. It may be possible that the item is unclear for children, because children have difficulties thinking abstractly about the self (Shaffer, 2008), which may be required for understanding what is meant by losing a part of oneself. More research may be needed to investigate the validity of the PGD symptom regarding identity disruption in youth, especially in younger children. Nevertheless, the interview-format of the TGI-K-CA may bring the benefit of more reliability regarding children's responses, since clinicians can provide explanations, can probe further if the child's response does not match prior information, and may encourage the child to thoroughly think through their response (Fresco et al., 2001). Parent reports may also add valuable information about children's PGD symptoms that may otherwise not be known through children's self-report (De Los Reyes et al., 2015). Considering these reasons, a parent-report version of the TGI-K-CA was developed by our research group and its psychometric qualities are currently studied. Nevertheless, as parental psychopathology may lead to overreporting of children's symptoms (De Los Reyes et al., 2015), future research should focus on examining the additional value of using parent report next to child self-report.

Finally, it could be argued that using a top-down method (i.e. basing the TGI-K-CA on the DSM-5-TR and ICD-11 symptoms and existing questionnaires for children and adults), instead of a bottom-up method (developing an item pool based on literature specifically on maladaptive grief in children), we might have missed developmental manifestations that are not included in the description of DSM-5-TR and ICD-11 symptoms. That is, some researchers have suggested to make developmental modifications to symptoms of maladaptive grief, considering that developmental processes may lead to differences between adults and children in the manifestation of grief reactions (Kaplow et al., 2012). For example, intense sorrow related to the loss may manifest in children through play and separation-reunion behaviour with caregivers (e.g. separation anxiety, followed by anger, withdrawal, and/or protest behaviour at reunion with a caregiver) rather than observed through their mood, as in adults (Kaplow et al., 2012). Even though some developmental modifications have been adopted into the DSM-5-TR criteria (for example, a $\geq$ 6 months timing criterion instead of the $\geq$12 months timing criterion used for adults), most PGD symptoms within the DSM-5-TR (or ICD-11) do not have a developmental modification. As the goal for the TGI-K-CA was to measure maladaptive grief according to the DSM-5-TR and ICD-11 symptoms, only those developmental modifications that were specified in these classification systems were taken into account. Deviating from the DSM-5-TR and ICD-11 to include more developmental manifestations would possibly lead to yet another conceptualization of maladaptive grief. In 2022, the ICD-11 added a text in which it is stated that intense grief reactions could be regarded as normal at various points during the child's development and that PGD should therefore be diagnosed with caution. As there is a scarcity of knowledge around this, while beyond the scope of our study, future research should focus whether more developmental modifications should be made to these criteria.

Despite these limitations, the development of the TGI-K-CA allows for identification of the newest PGD criteria, the most commonly reported bereavement-related complaint in children and adolescents who experienced the loss of a loved one. Regarding research that shows that treatment is most effective when tailored specifically to PGD symptoms (Shear et al., 2005), this underpins once more the importance of identifying PGD symptoms in children, as currently defined in the DSM-5-TR and ICD-11. Future research should evaluate the psychometric properties of the translated TGI-K-CA, including the comprehensibility of the items, before implementation in research or practice.

Note

1. There is one notable exception regarding the DSM-5-TR symptom 'Intense emotional pain (e.g., anger, bitterness, sorrow) related to the death'. This symptom is described in ICD-11 as two separate symptoms (i.e., 'sadness' and 'anger'). Resembling the TGI-SR+, we therefore decided to capture this with two items (one referring to sadness and one referring to anger).

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Data availability statement

Due to the nature of this research, participants of this study did not agree for their data to be shared publicly, so supporting data is not available.

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