

UNIVERSITÉ TOULOUSE III – PAUL SABATIER
FACULTÉS DE MÉDECINE

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THÈSE

POUR LE DIPLÔME D'ÉTAT DE DOCTEUR EN MÉDECINE
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PREVALENCE DU TROUBLE DU DEUIL PROLONGE CHEZ LES
ENFANTS ET LES ADOLESCENTS : REVUE SYSTEMATIQUE DE LA
LITTERATURE

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Ce travail de thèse est présenté sous la forme d'un article original, en cours d'analyse dans le journal *Death Studies*. Nous présentons ci-après le manuscrit de l'article mis en forme selon les normes de soumission.

Le matériel supplémentaire associé à ce travail est quant à lui, présenté en Annexe 1.

TABLES DES MATIERES

ABSTRACT	13
1. INTRODUCTION	14
2. METHODS	16
2.1. Data sources and search strategy	16
2.2. Selection criteria	17
2.3. Risk of bias assessment	17
2.4. Data extraction	17
3. RESULTS	18
3.1. Study selection and screening	18
3.2. Study characteristics	18
3.3. Risk of bias assessment	19
3.4. Moderators of PGD prevalence	19
3.4.1. <i>Sociodemographic and death-related factors</i>	19
3.4.2. <i>Psychopathological factors</i>	20
4. DISCUSSION	20
4.1. Main results	20
4.2. Limitations	23
4.3. Future directions	24
5. CONCLUSION.....	25
6. REFERENCES.....	26
7. TABLES, FIGURES AND ADDITIONAL MATERIAL.....	31
7.1. Tables.....	31
7.1.1. Table 1. Risk of bias assessment scores.....	31
7.1.2. Table 2. Characteristics of the included studies.....	32
7.1.3. Table 3. Factors influencing prevalence in the included studies.....	35
7.2. Figures.....	37
7.2.1 Figure 1. PRISMA Flow diagram of the selection process.....	37
7.3. Supplementary material.	
7.3.1. Supplementary data 1. Search strategies to identify eligible studies.....	38

Prevalence of prolonged grief disorder in bereaved children and adolescents: A systematic review

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ABSTRACT

Purpose: Prolonged Grief Disorder (PGD) is a condition recently introduced in international classifications of mental disorders. Although PGD is associated with significant distress and impairment that may have developmental consequences, to date, little is known about its prevalence and associated factors in children and adolescents. The present systematic review registered in PROSPERO (CRD42021236026) aims to: (i) review existing data on the prevalence of PGD in bereaved children and adolescents; (ii) identify factors associated with PGD in this population.

Methods: Six electronic databases, grey literature and a journal hand-search identified 1,716 articles with no backward limit to September 2021. Epidemiological studies were included if they reported the prevalence of PGD in bereaved children and adolescents. Study characteristics, diagnostic and assessment tools, population, loss-related characteristics and prevalence of PGD were reviewed.

Results: Five studies met our inclusion criteria. The reported prevalences of PGD ranged from 10.4% to 32%. Female gender, cognitive avoidance, chronic stressors such as economic hardship, exposure to trauma or other losses appear to be associated with more severe symptoms or even a higher risk of PGD. Conversely, data suggest social support may be protective.

Conclusion: This first systematic review found a relatively high prevalence of PGD in bereaved children and adolescents. While further large epidemiological studies are needed, this review highlights the importance of evaluating PGD in current clinical practice and suggests further research into diagnostic and therapeutic approaches targeting this disorder is warranted.

Keywords: Prolonged grief disorder; prevalence; children; adolescent; systematic review.

1. Introduction

Bereavement, the loss of a loved one, is ubiquitous and triggers a grief response. Each individual will go through their grief a unique way. This singularity of grief trajectories is particularly true for children and adolescents, depending on their age, stage of development and personal resources [1]. The death of a parent or relative is one of the most traumatic events in a child's life [2] and is associated with a higher risk for developing psychiatric disorders [3,4], particularly anxiety [5], posttraumatic stress [2] and mood disorders [6,7]. Experiencing bereavement in childhood or adolescence have also been associated with increased all-cause mortality in early adulthood [8], including suicide [9]. Sometimes the grief process (i.e., attenuation of the grief response by coming to terms with the reality of the loss) proves to be longer and more intense, to be distressing and to have a significant impact on functioning. This clinical syndrome has been studied under various names including complicated grief, traumatic grief or prolonged grief. Recently, this condition has been introduced under the term of Prolonged Grief Disorder (PGD) [10], first in the International Classification of Diseases 11th Revision (ICD-11) in 2018 [11] and then in the main section of the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, Text Revision (DSM-5-TR) in 2022 [12,13], supporting further research as well as promoting clinical care both in adults and in children and adolescents. While the ICD-11 and DSM-5-TR diagnostic criteria sets have similarities, they also have certain differences. PGD_{DSM-5} can be diagnosed when a child suffers the death of a significant other and experiences symptoms of separation distress (e.g., yearning), combined with three of eight additional symptoms of “reactive distress to the death” (e.g., anger) and “social/identity disruption” (e.g., feeling alone or detached from others) to a functionally impairing degree, at least 6 months following the loss. PGD_{ICD-11} can be diagnosed when a child suffers from one of two symptoms of separation distress and at least one of ten accompanying symptoms (e.g., emotional numbness) to a distressing and disabling degree, at least 6 months after the death. In both diagnostic criteria sets, PGD identifies distress and impairment in response to the death of a loved one, while also clarifying certain age-specific clinical features in particular in children and adolescents. A recent study

suggested that these diagnostic criteria sets were valid and performed well in distinguishing PGD from Major Depressive Disorder (MDD) and Posttraumatic Stress Disorder (PTSD) [14].

There are several screening and diagnostic tools for PGD, adapted from existing tools for adults, or developed specifically for children and adolescents. The Inventory for Complicated Grief – Revised for Children is a modified version of the adult scale which demonstrated convergent and discriminant validity [15]. The most recently-developed tools include the Inventory of Prolonged Grief for Children (8-12 years) and for Adolescents (13-18 years), which have shown good psychometric properties [16] and specificity in discriminating between PGD, MDD and PTSD [17]. It should be noted that no diagnostic tool for children under the age of seven is currently available.

Several epidemiological studies investigating the prevalence of PGD have been conducted in adults. In two recent meta-analysis including mostly adults who had lost a loved one, the prevalence of PGD was estimated to be 9.8% in non-violent circumstances [18] and 49% in non-natural circumstances [19] such as accidents, natural disasters, suicides or homicides, which is very high but may indicate that this type of loss is a risk factor for PGD. A study conducted in a representative sample of the German population estimated the prevalence of newly diagnosed PGD in bereaved people, all causes combined, at 3.3% for the PGD_{DSM-5-TR} and 4.2% for the PGD_{ICD-11} [20].

Bereavement does not only occur in adulthood, as it is also a common experience among children and adolescents. In a study of 1,746 adolescents aged between 11 and 16 years conducted in Northern England, 77.6% reported that at least one of their first or second-degree relatives or close friends had died and 4.1% had lost a parent [21]. In 2017, South Africa had 2.8 million orphans, representing 14% of children [22]. Despite this, there is little data on the prevalence of PGD in the paediatric population. In some cases, the primary objective is often not to estimate prevalence but to test diagnostic criteria [14,23] or when prevalence is sought, the diagnostic criteria for PGD are not fully met [24–27]. Others studies focused on specific situations such as adolescents exposed to a peer's suicide [24,28] or trauma [26,29]. Most research has concentrated on the evaluation of prevention or treatment techniques [30–33], but also on predictors and correlates [34] of PGD in the youth. In 2019, a prevalence of 12.4% was measured in a sample of n=291 bereaved children aged 8 to 18 years, using ICD-11 criteria [14]. Studies reported that PGD is related to a personal history of

depression and a family history of anxiety disorder [28], circumstances of death [35], significant functional impact [36] and psychiatric comorbidities [27,37] after the loss.

To our knowledge, no systematic review of the literature has investigating existing data on the prevalence of PGD in children and adolescents. Identifying factors associated with this condition is also critical to support its detection, and to develop targeted prevention and treatment strategies. Therefore, the present systematic review aims to: (i) review existing data on the prevalence of PGD in bereaved children and adolescents; and (ii) identify factors associated with PGD in this population.

2. Materials and Methods

A systematic review of the literature was performed according to the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines [38]. The review protocol was developed in advance and registered within PROSPERO, an international prospective register for review protocols, in March 2021 (CRD42021236026).

2.1. Data sources and search strategy

The following six electronic databases were systematically searched: MEDLINE, EMBASE, PsycINFO, PsycARTICLES, Web of Science, Cochrane Central Register of Controlled Trials (CENTRAL, Cochrane Library). In addition to this systematic screening, a grey literature search was performed using the OpenGrey database. A hand-search was also performed in *Death Studies* (1977-2021), *Bereavement Care* (1982-2021) and *Journal of Loss and Trauma* (1996-2021). Reference lists of relevant articles were also screened, as well as studies included in prior reviews and meta-analyses. All identified articles were included with no setback restriction until September 15, 2021. No language restrictions were applied.

The search equation was performed by combining MeSH terms and free text (keywords) related to the population (child OR adolescent), the condition (PGD) and the outcome (prevalence), adapted to each database. The search algorithms are presented in the supplementary data.

2.2. Selection criteria

We included epidemiological studies that estimated the prevalence of PGD among subjects under 18 years of age who have experienced the loss of a loved one. The prevalence of PGD had to have been assessed after a period of at least 6 months after the loss. The diagnosis of PGD had to be made using either a standardized and validated psychometric self-report instrument, or a clinical interview based on the criteria of a PGD conceptualization.

Interventional, qualitative and case studies were excluded, as were studies involving subjects over the age of 18. Where the sample contained both children and adults, only studies in which it was possible to isolate a prevalence in subjects under 18 were included. Other types of losses (e.g., divorce, separation, loss of a pet, loss of material goods) were excluded.

2.3. Risk of bias assessment

We used a tool developed for population-based prevalence studies [39] to assess risk of bias (RoB), which is composed of 10 items. External validity is assessed in the first four items and internal validity is assessed in the last six items. The items are binary questions, for example: “Was the likelihood of non-response bias minimal?”. Each item is scored as follows: 1 for yes or 0 for no. The sum of the items gives a RoB total score for each study (with lower RoB indicating higher methodological validity). In accordance with the guidelines, when a study provided insufficient information to enable a judgment, the item was rated high RoB (0 point). Studies scoring 6 points or less were considered to have high RoB, studies scoring 7 or 8 points were considered to have moderate RoB and studies scoring 9 or 10 points were considered to have low RoB. The RoB was evaluated independently by two reviewers (AF and AL).

2.4. Data extraction

Two reviewers (AF and AL) independently performed databases search and articles screening using Zotero software (<https://www.zotero.org/>) and Rayyan Software, a free web-tool designed to help researchers working on systematic reviews (<https://rayyan.qcri.org/>). Titles and abstracts were screened and all relevant articles were then reviewed in full-length. Any disagreement was resolved through discussion with the senior author (AR) to reach a consensus.

Information extracted from the studies included year of publication, country and study design. Diagnostic terminology and the diagnostic tools used and their cut-off points were reported. Population characteristics such as sample size, percentage of women, age range and mean age of participants, recruitment procedures were also detailed. Characteristics related to the loss were described: duration since the loss, relationship to the deceased and cause of death. Finally, the prevalence of PGD was retrieved.

3. Results

3.1. Study selection and screening

Our search yielded five articles, which was insufficient to perform a meta-analysis, but provided descriptive insight on the prevalence of PGD in children and adolescents. Most of the articles excluded either concerned PGD in adults or did not report data on the prevalence of PGD. The study selection process is reported in detail in Figure 1.

3.2. Study characteristics

The included studies were published between 2011 and 2020. Each study was conducted in a different country: the USA, Indonesia, South Korea, South Africa, and Greece. There were three cross-sectional studies and two longitudinal studies. All used self-administered questionnaires: the Inventory of Complicated Grief and its revised version for children (ICG-RC or ICG) for three of them [40–42], Prolonged Grief-13 (PG-13) and the Traumatic Grief Inventory for Children (TGIC) for the other two [43,44]. Sample sizes ranged from n=57 to n=339, with an average of 55.6% female and a total of 856 youth included. Mean age ranged from 7 to 18 years. Most of the youth were recruited through their school. For one study, recruitment was carried through coroners' reports and a newspaper advertisement [42]. The mean time since loss ranged from 18 months [43] to 61 months [41]. The deceased were mostly family members, close friends or classmates [40]. The causes of death were diverse, ranging from natural causes to illness [41], suicide [42] or ferry [40] and bus [43] accidents. The prevalence of PGD in the different studies ranged from 10.4% to 32%. More details are available in Table 2.

3.3. Risk of bias assessment

We found four studies with a total score ranging from 4 to 6 points, which means that the RoB was high [40–42,44]. The last study had a total score of 7, meaning that the RoB was moderate [43]. The majority of the studies show high internal validity (low Rob on items 5-10), except for one [42], and low external validity (high RoB on items 1-4). Regarding external validity, most of the samples in the included studies did not provide a close representation of the target population, especially during accidents or natural disasters [40,43,44], and did not use some form of random selection for their sample [40–42,44]. RoB scores are reported in Table 1.

3.4. Moderators of PGD prevalence

Most of the included studies investigated different common moderating factors of PGD such as: gender and socioeconomic level of the youth, relationship with the deceased, circumstances of death (traumatic or non-traumatic), time elapsed since the loss and influence of the environment before and after the death (e.g., life events, psychological health of parents, social support) as well as the psychological and functional impact on the youth (Table 3).

3.4.1. Sociodemographic and death-related factors

Girls seemed to report more PGD than boys and score higher on the PG-13 [44]. One study [41] found that the loss of a biological parent doubles the risk of PGD in adolescents. In addition, prolonged grief has been found to be predicted by the total number of losses a child has experienced [44]. Indeed, in the latter study, they found that having lost a parent in the tsunami, combined with the number of deaths experienced over the child's lifetime, significantly predicted the degree of severity of prolonged grief following the tsunami. On the other hand, direct exposure to the accident could be significantly associated with PGD in adolescents [43]. Finally, economic hardship (i.e. the level of adolescent economic disadvantage) since the loss appears to increase the risk of PGD among bereaved adolescents girls in South Africa. Post-loss economic hardships were experienced by 43% of the

adolescents girls in this study and those who experienced economic hardship were 88% more likely to experience PGD than their economically stable counterparts [41].

3.4.2. Psychopathological factors

A bidirectional relationship may exist between PGD and psychiatric vulnerability. Young people with a higher ICG-RC score and whose surviving parent suffered from PGD would have an increased risk of incident depression up to three years after the death [42]. Similarly, the likelihood of belonging to the "recovery" versus "persistent grief" group was positively related to not experiencing PTSD or depression 18 months after the loss in another study [41]. Conversely, a positive correlation was found between high CROPS (Child Report of Post-traumatic Symptoms) scores and PGD [40]. In the same way, each unit increase in the caregiver's ICG-RC score significantly increased the likelihood that the adolescent would experience PGD by 4% [41].

All these results also suggest that PGD is associated with difficulties in general functioning. Indeed, functional impairment scores (measured by the Strengths and Difficulties Questionnaire (SDQ)) are significantly higher in the "persistent grief" group [43] and the association between PGD and functional impairment may persist over time (up to 3 years after the loss) [42]. In addition, there is a significant correlation between high PGD scores and decreased scores in the "Autonomy and parents" section, in the KIDSCREEN-27 scale. This section examines the quality of child and parent interactions and how the child feels loved and supported by the family, but also the level of autonomy the child feels he or she has and the financial resources he or she values in the family [40]. On the contrary, perceived social support assessed in the first two months post loss is associated with a decrease in grief symptoms and the absence of PGD, at 18 months [43].

4. Discussion

4.1. Main results

This systematic review of the literature included five studies and a population of 856 youth. To our knowledge, this is the first study to focus on the prevalence of PGD in children and adolescents in a systematic way. All studies are in developed countries. Three of the five studies involved populations

who had experienced bereavement under traumatic circumstances. The study [44] which found the highest prevalence (32%) was a cross-sectional study, on a sample of children who had lost a close friend or family member in a tsunami. Conversely, the study [42] with the lowest prevalence (10.4%) was a longitudinal study over several years, involving a sample of children and adolescents who had lost a parent in various circumstances, which was probably more representative of the general population. The prevalence rates of the included studies varied significantly, probably due to moderating factors and to the diversity of PGD diagnostic tools used. However, the use of self-administered questionnaires was fairly homogeneous, since four of the five included studies used the Inventory of Complicated Grief, whether revised for children (ICG-RC) or combined with the Trauma Symptom Inventory (TGIC).

Regarding the socio-demographic factors, girls appear to report more prolonged grief symptoms and more severe scores as well [44]. This may be due to the influence of Islamic cultural and religious factors in this population where women would be encouraged to keep their feelings silent. In this context, they would be less allowed to talk about grief and their grief reactions, which could influence the grieving process. This vulnerability was also found in a longitudinal study of adolescents experiencing parental bereavement [45] that showed chronic depression and increased anxiety in girls while both regressed in boys. According to the authors, this difference may be related in part to a higher initial level of stress and fear of abandonment in girls (related to interpersonal difficulties like separation from parents or conflict with peers). Their analyses also revealed that girls were at greater risk of developing symptoms of depression or anxiety (more than one year after death) because of their greater difficulty internalizing stressors.

We found in one of the included studies that PGD was almost twice as common when the deceased was a biological parent compared to other members of the entourage [41]. On the other hands, previous studies [46,47] have shown that the death of a friend can lead to more intense grief symptoms than the death of a family member. Finally, the factors for maintaining grief and those related to the intensity of grief could differ.

The severity of PGD may also depend on the number of deaths experienced by a child [44]. This phenomenon can be explained by considering that each bereavement experienced is traumatic

and can diminish the young person's internal resources to recover each time. In some cultures, like Islamic culture, where communal living and extended families are the norm, this impact could be increased [44]. In addition, direct exposure to the accident that caused the death could be significantly associated with PGD in adolescents [43]. This result was found in a singular context of collective trauma (bus accident), where children witnessed both the accident, the death but also the stress reactions of their peers. A recent study [35] found that children who have lost a caregiver due to a prolonged illness have higher levels of PGD and post-traumatic stress symptoms than children who have lost a caregiver due to a sudden natural death (e.g., a heart attack). It can be hypothesized that children's exposure to a parent's chronic illness and subsequent death may be more traumatic and expose them to the death and grieving process more often than a sudden death. The negative emotions of grief such as anxieties about the death, feelings of helplessness or guilt are more present. Indeed, peritraumatic distress has been shown to be a significant predictor of the severity of PGD symptoms [48].

We also found that economic stressors could have a significant impact on the risk of PGD [40,41]. In fact, a qualitative study in South Africa found that meeting a person's primary needs after the loss of a household member is most important and that attention to grief will be secondary [49]. In some circumstances, ensuring that the basic material needs of youth and their families are met may be an important step in care, allowing them to identify their potential need for help with their PGD in a second stage. However, this association was not found in one of the included studies [44] where material losses were high and poverty increased in this region of Indonesia where children's primary needs are often not met.

Three of the included studies found an influence of comorbidities such as depression, PTSD or trauma symptoms on the presence of PGD [40–42]. We might hypothesize that the youth's adaptive capacities are already strained in the case of additional trauma or depression, preventing them from using them in the grieving process. Indeed, it appears that the absence of associated comorbidity promotes the normal grieving process [41]. These results are related to other research [28,50]. Two of these three last studies also suggest that the psychological state of the surviving parent would strongly influence that of the child, whether in terms of depression [42] or the severity of PGD [40,41]. Several

studies have highlighted this association, particularly with regard to the parent's ability to take care of the child, to be available and attentive to the child's needs [4,34]. Furthermore, our results suggest that bereaved youth may have difficulties in functioning, including in terms of autonomy or relationship with their parent when suffering from PGD, in addition to other psychopathological conditions before and after the death [40,42,43]. However, if this functional impact is associated with other psychiatric comorbidities such as depression and PTSD, then they may increase the patient's difficulties in daily life [17].

Finally, social support seems to be a protective factor that facilitates the grieving process as well [51]. Bereavement support groups increase the sense of social support due to the sharing of experiences and emotions, in addition to the psychotherapeutic effect alone. Thurman et al. showed, in a case-control study that participation at the Abangane intervention (“friends” in isiZulu, the local language), which is a loss management support group that combines cognitive behavioral therapy with indigenous communal culture, decreased PGD scores [52].

Our results may not be generalizable to clinical practice for several reasons. Most of the participants in the included studies experienced bereavement under often traumatic circumstances (accident, natural disasters) [40,43,44]. It would be necessary to be able to analyze studies carried out on samples of the population recording the loss of a loved one, all causes combined, without any link with a particular event. In addition, there is a selection bias in most of the studies that selected a sample of young people in schools or during prevention programs. To conclude, to limit confounding bias, it would seem important to know whether participants received grief-focused care or not, which could not be done in one study [43].

4.2. Limitations

Although our systematic review is not without limitations. First, we were able to include only five studies in our systematic review, which did not allow us to conduct a meta-analysis as we had envisaged when drafting our protocol. In addition, four of the five studies had small sample sizes. Second, we chose to include studies using standardized and validated but not PGD-specific tools as

newly included in international classifications. Similarly, one of the scales has not been validated in the country of the study concerned [41]. A final limitation concerns the study by Melhem et al [42] which looked at different trajectories of grief, one of which concerned the absence of symptom decline from the third quartile of the IGC-RC throughout the study follow-up period, without specifying that this corresponds to PGD (the prevalence of this category of young people being consistent with the 10.4% reported in our study). Despite this methodological difference, we chose to include this study, on the one hand because of the existing heterogeneity of definitions of PGD, and on the other hand because this prevalence seemed to correspond to the current conceptualization of PGD, namely a grief reaction that persists in time and intensity.

4.3. Future directions

Despite emerging data on the prevalence of PGD in children and adolescents, large epidemiological studies among children and adolescents of various ages, with different recruitment methods and including exposure to various bereavement situations, are needed, in order to examine moderating factors, including across different subgroups based on risk factors. As has been studied for MDD and PTSD [53], it would be important to know whether the onset of PGD is related to the developmental age at which the bereavement occurs. Furthermore, the interaction between the grief reactions of the surviving parent and the child seems to be an area of future research of particular interest. Studies could more accurately analyze the grief trajectory of the surviving parent versus that of the bereaved child, as has been studied for trauma and stress syndrome [54]. In addition, some symptoms are found in several diagnostic entities. It would therefore be necessary to always assess for the existence of PTSD or MDD in parallel, in order to screen for a differentiated comorbidity of PGD, in children.

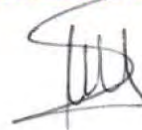
5. Conclusion

This systematic review allowed us to analyze existing data on the prevalence of PGD in bereaved children and adolescents and to identify factors associated with PGD in this population. However, it seems important to be able to conduct a new systematic search to identify more studies reporting a prevalence of PGD that would then allow for a meta-analysis and more meaningful results.

Vu, de Président du jury
9/9/22

Professeur Jean-Philippe RAYNAUD

Vu et permis d'imprimer
Le Président de l'Université Toulouse III – Paul Sabatier
Faculté de Santé
Par délégation,
La Doyenne-Directrice
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Professeure Odile RAUZY



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Tables

Table 1. Risk of bias assessment scores.

Studies/criteria	1	2	3	4	5	6	7	8	9	Risk of bias score
NM Melhem et al. (2011) (USA)	No	Yes	No	Yes	No	No	Yes	No	Yes	High
Dawson et al. (2014) (Indonesia)	No	No	No	Yes	Yes	Yes	Yes	Yes	Yes	High
SH Lee et al. (2018) (South Korea)	No	Yes	No	Yes	No	Yes	Yes	No	Yes	High
TR Thurman et al. (2018) (South Africa)	Yes	No	No	No	No	Yes	Yes	Yes	Yes	High
Giannopoulou et al. (2020) (Greece)	No	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Moderate

Criteria: 1. Was the study's target population a close representation of the national population in relation to relevant variables, e.g. age, sex, occupation?; 2. Was the sampling frame a true or close representation of the target population?; 3. Was some form of random selection used to select the sample, OR, was a census undertaken?; 4. Was the likelihood of non-response bias minimal?; 5. Were data collected directly from the subjects (as opposed to a proxy)?; 6. Was an acceptable case definition used in the study?; 7. Was the study instrument that measured the parameter of interest (e.g. prevalence of low back pain) shown to have reliability and validity (if necessary)?; 8. Was the same mode of data collection used for all subjects?; 9. Were the numerator(s) and denominator(s) for the parameter of interest appropriate?

Table 2. Characteristics of the included studies.

Author(s) (year)	Country	Study design	Diagnostic criteria (terminology, assessment instrument)	Cut off value	Interview	Study population (sample size, % female, age)	Sample recruitment and characteristics	Mean time post-loss	Relation to the deceased	Cause of death	Prevalence
NM Melhem et al. (2011)	USA	Longitudinal study	Prolonged grief reaction, ICG-RC	N/A	Self-report	n=182, 45.6% Age: 7-18 y-o M= 12.4 y-o SD= 2.8	Bereaved families were recruited via coroners' reports and responses to a newspaper advertisement.	33.2 months (SD=5.7)	Parents	Suicide (n=42), Unintentional injury (n=31) Sudden natural causes (n=51)	10.4%
Dawson et al. (2014)	Indonesia	Cross-sectional study	Prolonged grief, PG-13	Linguistic and cultural equivalency could not be established for item five so this item has been excluded from the scale. Experience yearning or emotional pain about the loss at least daily and score at least "4" on five of the remaining nine items	Self-report	n=110, 59% Age: 7-13 y-o M= 10.4 y-o SD= 1.38	Four schools in the Aceh region affected by the tsunami have been recruited. All children participating in the afterschool program, conducted by the Centre Mulia Hati, were invited to complete the survey. 60% reported experiencing the death of a loved one.	60 months	Close friend or family member	Tsunami	32%

Author(s) (year)	Country	Study design	Diagnostic criteria (terminology, assessment instrument)	Cut off value	Interview	Study population (sample size, % female, age)	Sample recruitment and characteristics	Mean time post-loss	Relation to the deceased	Cause of death	Prevalence
SH Lee et al. (2018)	South Korea	Cross-sectional study	Complicated Grief, ICG	Cut off ≥ 25	Self-report	n=57, 49.1% Age: 16-18 y-o M= 17.8 y-o N/A	This study was performed with Danwon high school students who survived the Sewol ferry disaster. 75% of the surviving students participated in the study.	20 months	Friend	Ferry disaster	24.5%
TR Thurman et al. (2018)	South Africa	Cross-sectional study	Complicated Grief, ICG-RC	Cut off ≥ 14	Self-report	n=339 female adolescents 100% M= 14.5 y-o SD= 1.2	Data were collected during the baseline phase of an evaluation of a bereavement support program. Participants were identified through a school-based intake process coordinated by the program implementer, Child Welfare Bloemfontein and Childline Free State, a nongovernmental organization based in South Africa's Free State province.	61 months (SD = 3.7)	Biological parent (49%) Grandparent (29.5%) Other (21.5%)	Illness (74.9%)	20%

Author(s) (year)	Country	Study design	Diagnostic criteria (terminology, assessment instrument)	Cut off value	Interview	Study population (sample size, % female, age)	Sample recruitment and characteristics	Mean time post-loss	Relation to the deceased	Cause of death	Prevalence
Giannopoulou et al. (2020)	Greece	Longitudinal study	Traumatic grief, TGIC (Greek version)	Traumatic grief symptoms scores were classified into 4 groups based on quartiles: resilient, recovery, towards recovery, persistent grief	Self-report	n=168 adolescents, 51.2% Age: 12-17 y-o M= 14.5 years SD= 1.3	Baseline data were collected from all students in grades 8 to 12, attending all three secondary schools in the rural community. The adolescents were classified into 3 groups based on their exposure to the bus accident: directly in the bus, in the area, indirectly affected.	18 months	Close friend or school peer	School bus accident (n=7)	21% scoring within the high and medium high range (above the 50 th percentile) at baseline and follow-up

Abbreviations: ICG, Inventory of Complicated Grief; ICG-RC, Inventory of Complicated Grief Revised for Children; N/A, Not applied; PCBD, Persistent Complex Bereavement Disorder; PG-13, Prolonged Grief Disorder 13 - Child Version; PGD, Prolonged Grief Disorder; PGQ-A, Prolonged Grief Questionnaire for Adolescents; TGIC, Traumatic Grief Inventory for Children; y-o, year old.

Table 3. Factors influencing prevalence in the included studies.

Study	Type of analysis	Sociodemographic factors	Factors related to loss	Psychopathological factors
NM Melhem et al. (2011) (USA)	Multinomial logistic regression for predictors Kaplan-Meier survival analysis to examine the time to onset of depression by bereavement class	N/A	N/A	Significant effect of the association of PGD in the surviving parent and child on the risk of depression up to 3 years after death (OR 1.2, 95% CI, 1.00-1.36, $p=0.049$) Significant effect of the presence of PGD in children on functional impairment over 3 years ($\beta=-14.1$, $p=0.006$)
Dawson et al. (2014) (Indonesia)	Hierarchical regression	PGD is more common in girls ($\chi^2 = 10.58$ $p<0.001$) Being a girl predicts more severe PG-13 scores in children ($B = 7.56$, $p<0.02$)	Having a parent die in the tsunami and the total number of deaths a child has experienced significantly predicts the severity of PGD ($B=18.60$, $p<0.000$) and explain >60% of the variance	Cognitive avoidance as a form of coping explains 6% of the variance in severity of PGD ($B=1.70$, $p<0.000$)
SH Lee et al. (2018) (South Korea)	Logistic regression with a Poisson distribution	N/A	N/A	Significant correlation between high CROPS score and PGD (coef. =0.030, $p=0.017$, 95% CI, 0.005–0.054) Significant correlation between high PGD scores and lower score in autonomy and relationship with parents, on the KIDSCREEN-27 (coef. =-0.051, $p=0.032$, 95% CI, -0.098 to -0.004)

Study	Type of analysis	Sociodemographic factors	Factors related to loss	Psychopathological factors
TR Thurman et al. (2018) (South Africa)	Logistic Regression	N/A	<p>The loss of a biological parent double adolescents' risk of PGD (OR 1.99, 95% CI = 1.09–3.65, $p < 0.01$)</p> <p>88% increase in the risk of PGD in adolescents due to economic stressors since loss (OR 1.88, 95% CI, 1.06–3.32, $p < 0.01$)</p>	4% increase in the risk of PGD in adolescents for each unit increase in the ICG-R score in the parent (OR 1.04, 95% CI, 1.00–1.07, $p < 0.05$)
Giannopoulou et al. (2020) (Greece)	Multinomial logistic regression model	N/A	PGD symptoms were significantly higher in adolescents directly exposed to the area ($p < 0.017$)	<p>Probability of belonging to the « recovery » versus « persistent grief » group is positively related to not suffering from PTSD or depression at 18 months after the loss ($p < 0.001$)</p> <p>Higher functional impairment scores among those in the « persistent grief » group than other groups ($p < 0.001$)</p> <p>Perceived social support after the first 2 months post loss is associated with a « recovery grief » pattern at 18 months ($p < 0.005$)</p>

Abbreviations: CROPS: Child Report of Post-traumatic Symptoms, CRIES: Children's Revised Impact of Events Scale, LCGA: Latent class growth analysis, N/A: Not available, PGD: Prolonged Grief Disorder, PG-13: Prolonged Grief Disorder 13, PTSD: Post Traumatic Stress Disorder.

Figure

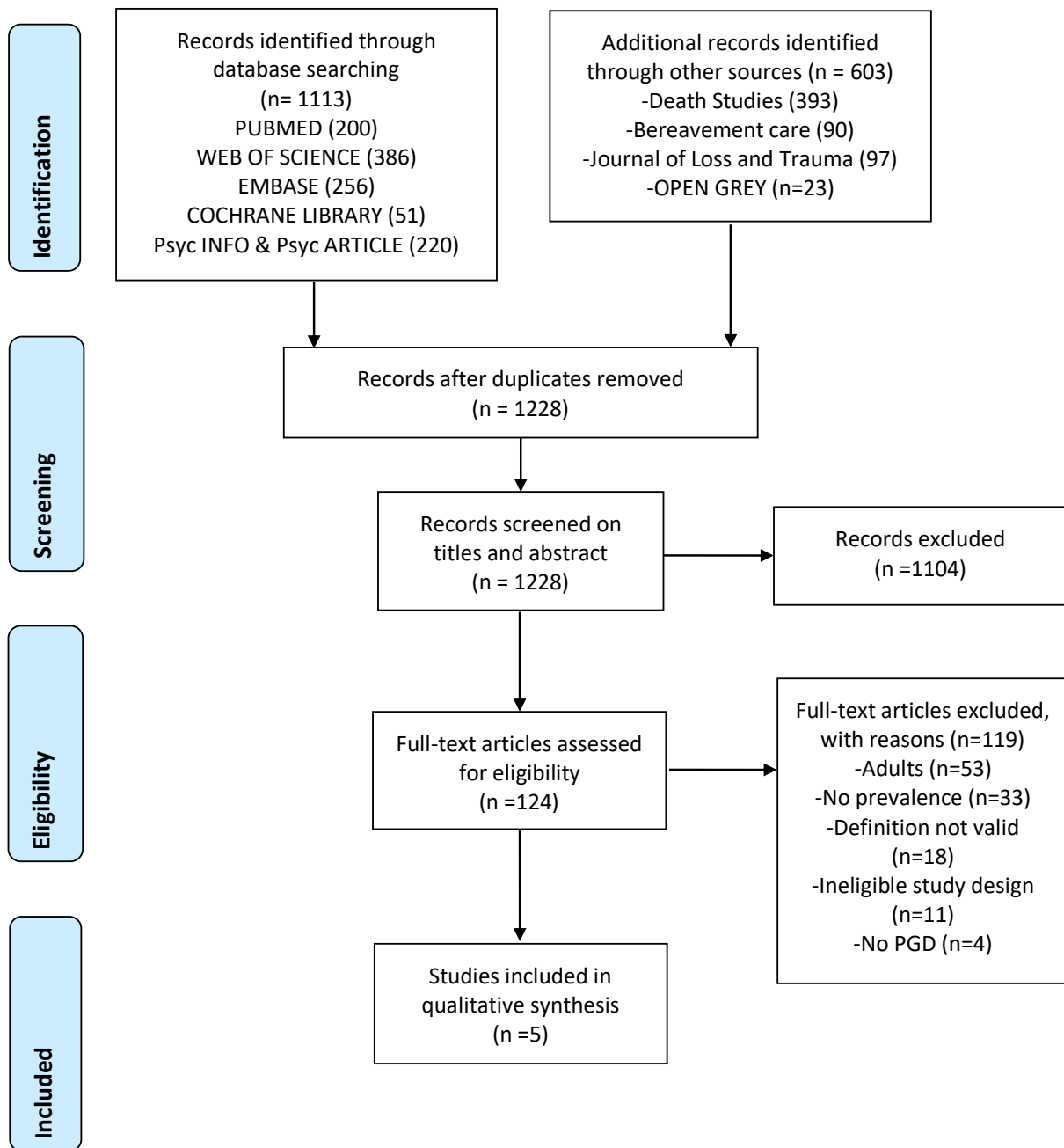


Figure 1. PRISMA Flow diagram of the selection process.

From: Moher D, Liberati A, Tetzlaff J, Altman DG, PRISMA Group. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *BMJ*. 2009;339:b2535.

Supplementary material

Supplementary data 1. Search equations according to the different databases

MEDLINE

("complicated grief" OR "prolonged grief" OR "prolonged grief disorder" OR "persistent complex bereavement disorder" OR "traumatic grief" OR "delayed grief" OR "dysfunctional grief" OR "abnormal grief" OR "chronic grief" OR "morbid grief" OR "maladaptive grief" OR "atypical grief" OR "unresolved grief" OR "complex grief" OR "complicated bereavement" OR "prolonged bereavement" OR "traumatic bereavement" OR "abnormal bereavement" OR "atypical bereavement" OR "unresolved bereavement" OR "complex bereavement" OR "complicated mourning" OR "prolonged mourning" OR "traumatic mourning" OR "unresolved mourning") AND (children OR adolescent OR youth OR infant OR teen) AND (prevalence or incidence or frequency or proportion or number or amount or percentage or distribution)

Web of Science and EMBASE

("complicated grief" OR "prolonged grief" OR "prolonged grief disorder" OR "persistent complex bereavement disorder" OR "traumatic grief" OR "delayed grief" OR "dysfunctional grief" OR "abnormal grief" OR "chronic grief" OR "morbid grief" OR "maladaptive grief" OR "atypical grief" OR "unresolved grief" OR "complex grief" OR "complicated bereavement" OR "prolonged bereavement" OR "traumatic bereavement" OR "abnormal bereavement" OR "atypical bereavement" OR "unresolved bereavement" OR "complex bereavement" OR "complicated mourning" OR "prolonged mourning" OR "traumatic mourning" OR "unresolved mourning") AND (child* OR adolescen* OR youth OR infant* OR teen*) AND (prevalen* OR epidemiology OR inciden* OR frequenc* OR proportion OR number* OR amount* OR percentage* OR distribut*)

Cochrane Central Register of Controlled Trials (CENTRAL, Cochrane Library)

("complicated grief" OR "prolonged grief" OR "prolonged grief disorder" OR "persistent complex bereavement disorder" OR "traumatic grief" OR "delayed grief" OR "dysfunctional grief" OR "abnormal grief" OR "chronic grief" OR "morbid grief" OR "maladaptive grief" OR "atypical grief" OR "unresolved grief" OR "complex grief" OR "complicated bereavement" OR "prolonged bereavement" OR "traumatic bereavement" OR "abnormal bereavement" OR "atypical bereavement" OR "unresolved bereavement" OR "complex bereavement" OR "complicated mourning" OR "prolonged mourning" OR "traumatic mourning" OR "unresolved mourning") AND (child OR adolescent)

PsycINFO and PsycARTICLES

("complicated grief" OR "prolonged grief" OR "prolonged grief disorder" OR "persistent complex bereavement disorder" OR "traumatic grief" OR "delayed grief" OR "dysfunctional grief" OR "abnormal grief" OR "chronic grief" OR "morbid grief" OR "maladaptive grief" OR "atypical grief" OR "unresolved grief" OR "complex grief" OR "complicated bereavement" OR "prolonged bereavement" OR "traumatic bereavement" OR "abnormal bereavement" OR "atypical bereavement" OR "unresolved bereavement" OR "complex bereavement" OR "complicated mourning" OR "prolonged mourning" OR "traumatic mourning" OR "unresolved mourning")

Filters have been added according to the databases to refine the search, notably for PsycInfo where the prevalence has been filtered in this way.

PREVALENCE OF PROLONGED GRIEF DISORDER IN BEREAVED CHILDREN AND ADOLESCENTS : A SYSTEMATIC REVIEW

ABSTRACT

Purpose: Prolonged Grief Disorder (PGD) is a condition recently introduced in international classifications of mental disorders. Although PGD is associated with significant distress and impairment that may have developmental consequences, to date, little is known about its prevalence and associated factors in children and adolescents. The present systematic review aims to: (i) review existing data on the prevalence of PGD in bereaved children and adolescents; (ii) identify factors associated with PGD in this population.

Methods: Six electronic databases, grey literature and a journal hand-search identified 1,716 articles with no backward limit to September 2021. Epidemiological studies were included if they reported the prevalence of PGD in bereaved children and adolescents. Study characteristics, diagnostic and assessment tools, population, loss-related characteristics and prevalence of PGD were reviewed.

Results: Five studies met our inclusion criteria. The reported prevalences of PGD ranged from 10.4% to 32%. Female gender, cognitive avoidance, chronic stressors such as economic hardship, exposure to trauma or other losses appear to be associated with more severe symptoms or even a higher risk of PGD. Conversely, data suggest social support may be protective.

Conclusion: This first systematic review found a relatively high prevalence of PGD in bereaved children and adolescents. While further large epidemiological studies are needed, this review highlights the importance of evaluating PGD in current clinical practice and suggests further research into diagnostic and therapeutic approaches targeting this disorder is warranted.

KEYWORDS: Prolonged grief disorder; prevalence; children; adolescent; systematic review.

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PREVALENCE DU TROUBLE DU DEUIL PROLONGE CHEZ LES ENFANTS ET LES ADOLESCENTS : REVUE SYSTEMATIQUE DE LA LITTERATURE

RESUME

Objectif : Le trouble du deuil prolongé (TDP) est une affection récemment introduite dans les classifications internationales des troubles mentaux. Bien que le TDP soit associé à une détresse et une déficience significative qui peuvent avoir des conséquences sur le développement, on sait peu de choses à ce jour sur sa prévalence et ses facteurs associés chez les enfants et les adolescents. La présente revue systématique enregistrée vise à : (i) examiner les données existantes sur la prévalence du TDP chez les enfants et les adolescents endeuillés ; (ii) identifier les facteurs associés au TDP dans cette population.

Méthodes : Six bases de données électroniques, de la littérature grise et une recherche manuelle de journaux ont permis d'identifier 1 716 articles sans limite de recul jusqu'en septembre 2021. Les études épidémiologiques ont été incluses si elles rapportaient la prévalence du TDP chez les enfants et adolescents endeuillés. Les caractéristiques des études, les outils de diagnostic et d'évaluation, la population, les caractéristiques liées à la perte et la prévalence du TDP ont été examinés.

Résultats : Cinq études répondaient à nos critères d'inclusion. Les prévalences rapportées du TDP variaient de 10,4 % à 32 %. Le sexe féminin, l'évitement cognitif, les facteurs de stress chroniques tels que les difficultés économiques, l'exposition à un traumatisme ou à d'autres pertes semblent être associés à des symptômes plus importants, voire à un risque plus élevé de TDP. À l'inverse, les données suggèrent que le soutien social peut être protecteur.

Conclusion : Cette première revue systématique a révélé une prévalence relativement élevée du TDP chez les enfants et les adolescents endeuillés. Bien que d'autres études épidémiologiques de grande envergure soient nécessaires, cette revue souligne l'importance d'évaluer le TDP dans la pratique clinique actuelle et suggère que des recherches supplémentaires sur les approches diagnostiques et thérapeutiques ciblant ce trouble sont justifiées.

DISCIPLINE ADMINISTRATIVE : Médecine spécialisée clinique

MOTS-CLÉS : Trouble du deuil prolongé; prévalence; enfants; adolescent; revue systématique.

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