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The prevalence of prolonged grief disorder in adults aged 65 and over – a systematic literature review

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Background

The death of someone close confronts people with one of the most painful challenges of their lifetime. A bereavement can have an impact on health and psychological wellbeing. [1 2] Grief is the response to a bereavement; primarily an emotional reaction, but also involves cognitive, behavioural and physical reactions.[3] Grief varies between individuals and between cultures.[4] Most people "grieve normally" and cope by drawing on their own resources and their informal support networks.[5] "Grieving normally" includes acceptance of the death, processing related pain, adjustment to a life without the deceased and finding a way to stay connected while moving on in life. If these processes are not resolved, grief can become clinically relevant.[6] This has recently been acknowledged by including "Persistent Complex Bereavement Disorder" (PCBD) in the appendix of the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5)[7] and "Prolonged Grief Disorder" (PGD) in the International Classification of Diseases 11th Revision (ICD-11).[8] A debate about precise criteria and how to label clinically relevant grief is still ongoing (see method section). Given the similarity of both diagnostic constructs[9 10], this review uses the term "Prolonged Grief Disorder" for both.[11]

The main characteristic of PGD is separation distress, described as intense yeaning or longing for the deceased, emotional pain and preoccupation with the deceased person or the death. Other features include difficulties in accepting the death and continuing with life, emotional numbness, anger, and avoidance of reminders of the loss. [7 8 10] **Table 1** details a full list of symptoms. While PGD symptoms do not differ from normal grief per se, they last longer, are more intense, distressing and impairing, compared to what is normal within an individual's culture.[10] To avoid pathologising the initial often intense phase of grief, a

diagnosis of PGD cannot be made until 6 months after the death according to ICD-11 and 12 months according to DSM-5.

By impairing mental health, and potentially also physical health, PGD can have a profound impact on the life of the bereaved and their families.[1 12 13]

The prevalence of PGD in the adult population is unknown. Reported prevalence rates vary widely (**Supplementary Material 1**). Prevalence estimates for *general* population samples (bereaved and non-bereaved people) are 2.3% in Switzerland[14] and 3.7% in Germany.[15] The prevalence rate for the *bereaved* adult population is estimated to be 10%.[16 17]

Older adults (aged 65+ years)[18] are more likely than younger people to experience the loss of someone close. The "Changing Lives of Older Couples" study found 29% of widows in the study met criteria for PGD.[19] Studies of bereaved family carers, who are often older adults, frequently report PGD prevalence rates above 20% (**Supplementary Material 1**).

A common assumption is that grief in older adults is unproblematic and their support needs have in consequence been largely neglected.[20] This may reflect ageist perspectives[21], linked to assumptions that losing a loved one in the "autumn of life" is easier to accept and that older people are able to handle grief successfully because they are likely to have experienced other bereavements.[20 22] While research shows young age to be a risk factor for PGD[23], we cannot conclude that older age is a protective factor: the common belief that bereavement is "less" problematic in older age has been increasingly challenged.[23 24] There is increasing awareness of the negative impact of bereavement on older individuals, with emerging evidence that older age is associated with increased risk of PGD.[16 25]

It needs to be considered, that older adults are potentially more vulnerable to PGD than other age groups. Changes in physical health, loss of home and occupation and reduction in social networks can reduce the ability to adapt to loss.[24 26-29] Older adults experience a greater number and range of bereavements, including the especially difficult losses of spouse or child.[30-32] In addition, the Coronavirus pandemic has particularly caused deaths (and thus bereavements) among older adults.[33 34]

Although globally the fastest growing population group[35] precise estimates of the prevalence of PGD in older adults are not available, limiting attempts to develop age-specific screening and treatments.[36 37] We have reviewed the literature concerning this important and growing area of patient care.

Aims

To undertake a review to identify, appraise and summarise the literature concerning the prevalence of PGD in older adults.

Method

We followed recommendations of the Joanna Briggs Institute[38] and PRISMA guidelines.[39]

Study constructs and terms

"Older age" was defined in accordance with the UK Office of National Statistics as people aged 65 and older.[18] Studies were included if data were presented for a (sub)sample with a mean age of ≥65 or presented results in age categories including ≥65 or older old age" group (85+).[18]

Different labels and criteria have been suggested for clinically relevant grief. The American Psychiatric Association DSM-5 uses "Persistent Complex Bereavement Disorder" (PCBD)[7] and the World Health Organisation ICD-11 uses "Prolonged Grief Disorder" (PGD).[8] Previous criteria-sets developed by authorities in the field included "PGD-2009"[10] and "Complicated Grief" (CG)[17] and are compared in the literature.[40] The constructs of ICD-11 and DSM-5 are similar enough to be seen as one diagnostic entity (**Supplementary Material 2**) as is the PGD-2009. In contrast, CG identifies more people by including a broader set of grief reactions, including, but not restricted to, PGD.[9 40]

Table 1 Criteria sets of Prolonged Grief Disorder as per ICD-11 and Persistent Complex Bereavement Disorder DSM-5; retrieved from Treml, et al. [41]

Prolonged Grief Disorder defined by ICD-11 [8*]	Persistent Complex Bereavement Disorder defined by DSM-5 [7]
A. Disturbance following the death of a partner, parent, child, or other person close to the bereaved	A. Death of a close other
B. Persistent and pervasive grief response characterized by longing for the deceased or persistent preoccupation with the deceased	B. Since the death, at least one of the following on most days to a clinically significant degree, for at least 12 months after the death: 1. Persistent yearning for the deceased 2. Intense sorrow and emotional pain in response to the death 3. Preoccupation with the deceased 4. Preoccupation with the circumstances of the death
C. Accompanied by intense emotional pain e.g.: 1. Sadness 2. Guilt 3. Anger 4. Denial 5. Blame 6. Difficulty accepting the death	C. Since the death, at least six of the following on most days to a clinically significant degree, for at least 12 months after the death: 1. Marked difficulty accepting the death 2. Disbelief or emotional numbness over the loss 3. Difficulty with positive reminiscing about the deceased 4. Bitterness or anger related to the loss

Prolonged Grief Disorder defined by ICD-11 [8*]	Persistent Complex Bereavement Disorder defined by DSM-5 [7]
7. Feeling one has lost a part of one's self 8. An inability to experience positive mood 9. Emotional numbness 10. Difficulty in engaging with social or other activities	5. Maladaptive appraisals about oneself in relation to the deceased or the death (e. g., self-blame) 6. Excessive avoidance of reminders of the loss 7. A desire to die in order to be with the deceased 8. Difficulty trusting other people since the death 9. Feeling alone or detached from other people since the death 10. Feeling that life is meaningless or empty without the deceased, or the belief that one cannot function without the deceased 11. Confusion about one's role in life or diminished sense of one's identity 12. Difficulty or reluctance to pursue interests or to plan for the future (e.g., friendships, activities) since the loss
D. The grief response has persisted for an atypically long period of time following the loss (more than 6 months at a minimum) and clearly exceeds expected social, cultural or religious norms for the individual's culture and context. Grief reactions that have persisted for longer periods that are within a normative period of grieving given the person's cultural and religious context are viewed as normal bereavement responses and are not assigned a diagnosis.	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.	E. The bereavement reaction must be out of proportion or inconsistent with cultural or religious norms

[*] ICD-11 criteria were ordered by the authors analogous to the DSM-5 criteria for better comparability.

The most prominent research measure used is the 19-item Inventory of Complicated Grief (ICG)[13], which is linked to development of PGD criteria sets.[10 42 43] However, not all symptoms of PGD and PCBD are reflected by ICG and its successors: further assessment

tools have been developed recently in response to the introduction of PGD and PCBD as new diagnostic entities within DSM-5 and ICD-11.[41]

Prevalence is the proportion of a population who have a specific characteristic in a given time period[44]: point prevalence refers to characteristics being present at a specific time. PGD studies often report "conditional point prevalence" in the grieving population at a certain time after the death. We report prevalence as percentage and when provided, confidence intervals with frequencies data transformed into percentages.

Data sources and search strategy

Searches of five databases (Medline via OVID, PsycINFO via Ebsco, CINAHL via Ebsco, Cochrane Library and Web of Science) were undertaken by an information scientist (IK). We sought to identify papers which focused on prevalence of PGD and included those that assessed PGD and hence frequency data. We searched and screened existing review, overview and meta-analysis papers, other synthesis papers and perspective, opinion and guideline pieces on PGD (referred to as summary papers).

The search strategy combined a) key terms of PGD, b) prevalence or epidemiology and c) relevant study designs including reviews for the search strategy (**Supplementary Material 4 and 5** presents search terms and a search procedure example). The literature was searched from January 2009 (when the conceptualizations of PGD became more consistent[10], enabling a focus on the more recent literature) to November 2019. All age categories were included in order not to miss possible studies reporting results in those aged ≥65.

References identified were downloaded into EndNote X7 and duplicates removed.

Reference searching of the included papers was undertaken.

Applied inclusion criteria: studies published in English in peer reviewed journals that provided prevalence of PGD in adults who experienced the loss of a close person through mainly a nonviolent causes of death.[16] Studies were required to assess PGD with standardized, validated psychometric instruments at least 6 months post loss.[8] We excluded studies on grief prior death and studies focussing on bereavement by suicide, homicide, natural disasters, accident or war or terrorist attacks where higher prevalence rates may be found.[45-48]

Titles and abstracts were independently screened by two authors (SH, PT). Full text papers were screened for sample age details (AS, SH) and included if the mean age was 65 and over or if age categories included old age. Full texts were then reviewed individually by PT, SH and AS to asses whether papers enabled estimates of prevalence rates based on PGD assessment and recruitment method and study design. Study authors were contacted for further information when needed. Results were discussed disagreements reached by consensus and interrater reliability for abstract and title screening was assessed. Data extraction used a predefined piloted data extraction sheet (**Supplementary Material 6)**.

Quality assessment was undertaken independently by PT and AS using the Risk of Bias (RoB) approach of Hoy, et al. [49] for epidemiological studies and an adapted version of the standard quality assessment criteria of Kmet, et al. [50] for other studies (see **Supplementary Material 7)**.

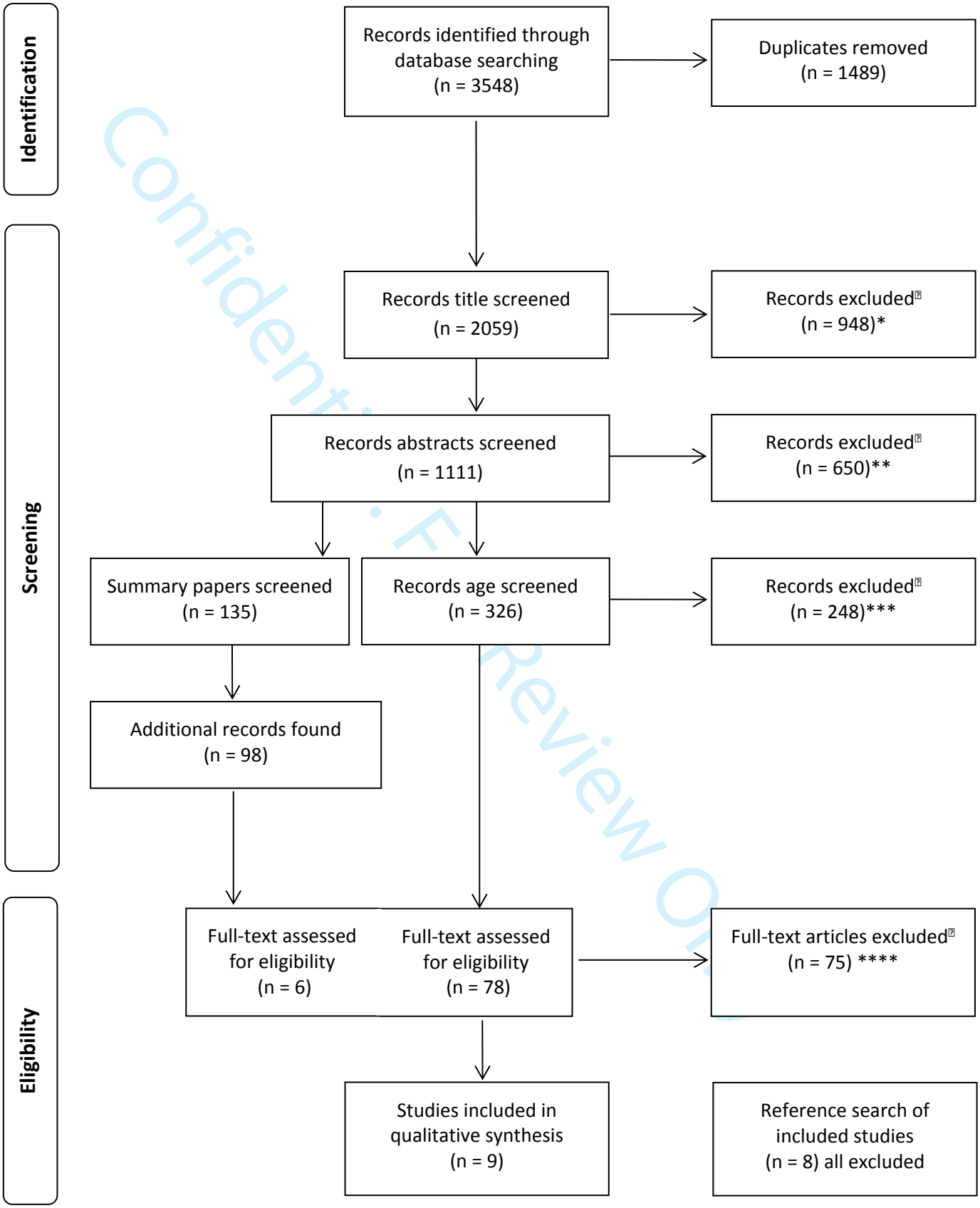
The study selection and screening process is summarised in **Figure 1**. Interrater agreement was evaluated using Cohen's Kappa statistic[51] following the interpretation of McHugh [52]. As few epidemiological studies were found, a descriptive analysis and thematic synthesis was

undertaken to optimise the inclusion of the diverse literature identified, focusing on factors with a possible impact on PGD.[15 53]

Results

The searches identified 2059 unduplicated titles, of which 1111 abstracts were reviewed, and 135 papers were included for reference screening. Of 326 papers screened for sample age, 78 met the age criterium. Review of study design, recruitment method and grief assessment identified 9 papers for inclusion. Screening of their references and of the references of the 135 papers yielded 8 and 98 additional records respectively, with no further papers being included in analysis. The interrater reliability for the title and abstract screening was excellent with a Kappa value of 0.87 (95% CI 0.81–0.92) and respectively 0.82 (95% CI 0.73–0.92).[52]

Figure 1. PRISMA Flow diagram of study selection.



*Title Screening Stage exclusion due to irrelevant subject or not meeting criteria	*** Sample Age Screening Stage exclusion due to not meeting criteria Age: Mean age < 65 (n=209) Missing age information (n=8) Other reasons e.g. language (n=31)
**Abstract Screening Stage exclusion due to not meeting criteria Assessment prior 6 months (n=5) Language (n=23) No PGD data (n=246) Publication type (n=160) Mean age (n=63) Source of evidence (n=63) Study type (n=40) Type of death (n=27) Type of loss (n=14) PGD assessment (n=4) Reworked data (n=2) Duplicate or amendment of included record (n=3)	**** Full-text Screening Stage exclusion due to not meeting criteria Design/recruitment does not allow prevalence estimation (n=10) PGD assessment: Use of non-validated or CG measures (n=21) No cut-off or diagnosis outcome (n=17) Assessment prior 6 months (n=7) Reworked data (n=17) Age: Mean age <65 (n=3) *from review screening*
For all stages most obvious exclusion reason recorded	

Study and study population characteristics are summarized in **Table 2.** The following text refers to included papers using the study numbers assigned in Table 2 in square brackets.

Of the included studies three were epidemiological studies [1, 2, 3], two cross sectional and one prospective cohort study [2]. The six non-epidemiological studies comprised one RCT [6], three longitudinal [5, 8, 9] and two cross sectional studies [4,7]. Three were linked to or part of other research projects [2, 5, 9]. Seven recruited solely bereaved people and allowed calculation of conditional point prevalence. One [2] of the two studies [1,2] including bereaved and non-bereaved enabled calculation of PGD prevalence in the general population of older adults.

Sample sizes of older bereaved adults ranged between 82 - 901. Sampling frames included person register and census data [1, 2, 4, 9], households in randomly selected townships [7] and clients from nursing homes [6], hospice/palliative (home care) teams [5, 8] and elderly

services [3]. Two used random sampling procedures [1, 4], two included all members of a cohort [2, 9], four used convenience sampling [3, 5, 6, 8] and one was a mixture of quota and convenience sampling [7]. Only two studies were explicit about including nursing home residents [2, 5]. Response rates ranged between 39% and 85%. Dropout rates from baseline to PGD assessment point in longitudinal studies ranged between 28% and 72% and between 1% and 28% of participants were excluded for incomplete data. Four did not report response rates [3, 5, 6, 7] or we had to calculate response and/or dropout rates [2, 5, 8, 9]. Three provided non-responder analysis [4, 5, 9].

For seven studies data collection took place between 2002-2017 [1, 2, 4, 5, 7, 8, 9]. Grief reactions were assessed by self-reports via self-administered questionnaires [1, 3, 4, 5, 6, 8, 9] and structured interviews [2, 7]. Three instruments were used: ICG[13][2, 5, 6, 7], Inventory of Complicated Grief Revised short version* (ICG-R15)[54] [1, 4, 9] and Prolonged Grief Disorder (PG-13)[10] [3, 8]. These instruments represent approximately half of PGD criteria and a third of PCBD criteria.[41] **Supplementary Material 3 and 8** present detailed descriptions of instruments used.

Two approaches to diagnose PGD based on questionnaire items were applied: algorithm with 3-5 criteria [1, 3, 4, 9] concerning the presence of 4 -10 symptoms or sum-scores cut-off scores (ICG ≥25 [2, 6] or >25 [5, 7]; PG-13 ≥29 [8]). See **Table 2.** Three of the non-epidemiological studies provided prevalence rates in their results sections [4, 5, 9]; for the remaining three PGD frequencies were obtained by personal communication with authors.

Most studies were carried out in Western countries (Netherlands, Germany, US, Denmark, Portugal), two were in China [3, 7]. Five were located in large cities [2, 3, 4, 8, 9], one in a rural area [7], one rural and urban areas[1] and two did not provide location details [5, 6].

Two presented result in terms of age categories [1, 2] with older adults constituting 49% to 83% of samples. The sample mean age in the other studies ranged from 65.1 (SD 9.6) [5] to 80.1 (SD 7.3) [6] years. Four studies focused solely on adults >=60 years or older [4, 6, 7, 9]; one provided data on the older old [2]. Female / male ratio in the bereaved overall sample varied between 1:1[1] and 4.6:1 [3], men being the smaller group in every study.

* labelled in this review ICG-R15

Type of bereavement investigated varied widely, at times being undefined [1, 2, 3, 4] e.g. “Are you currently grieving?” [2],or referred to “the loss of a significant person” [1] or “the most significant loss in your lifetime” [4]. Some focused on specific losses such as spousal bereavement [6, 7, 8, 9] or the death of a person participants had cared for [5], most commonly a spouse. Spousal/partner bereavement was most common (46.5% of all participants, 31% of studies with undefined bereavement) followed by parental loss (32%). Time since the death varied in the overall samples (older adults + other age groups) from 0 - 71 years. In five studies the average time was less than 2 years [3, 4, 5, 8, 9], three scheduled assessment at 6, 7 or 12 months post bereavement [5, 8, 9]. Bereavement periods in the remaining four studies [1, 2, 6, 7] were longer, including the two larger epidemiological studies ranging between 5.8 (SD 9.0) [2] and 13.9 (SD not reported) [8] years.

Table 2 Study and sample characteristics

	First author (year)	Study location	Study aim Study design	Sample and recruitment characteristic N; n_b;$n_{\geq 65}$; n_{b65}	Response Rate (RR) Dropout Rate (DoR) Excluded participants (EP)	mean age (SD) age range (% older adults)	Measure (reference) Way of administration Way of diagnosing PGD (reference)
	Epidemiological studies						
1	Kersting (2011)[15]	Germany	To determine the prevalence rates of CG in all age groups, both genders, and among all bereaved groups Cross sectional study	Representative population-based sample (in terms of age, gender and education) from rural and urban regions, who had experienced the loss of a significant person, recruited with the assistance of an independent demographic consulting company using random multistage sampling procedures N = 2520; n_b = 1445; n_{b65} = 718	RR= 61.9% DoR= NA EP= 3%	61-95 years (78%)	15 items of the Inventory of Complicated Grief-Revised [55], German version[56] Questionnaire Algorithm of 5 criteria incl. presence of 7 out of 13 symptoms, trigger, duration, and impairment criteria): At least a score of 4 on two of the four separation items and a score of at least 4 on five of the 11 traumatic distress items in addition to the trigger, duration and clinical impairment criteria.
2	Newson (2011)[57]	Netherlands	To evaluate the prevalence of CG in a population-based cohort, examine the overlap between anxiety and depression and identify common bereavement-related and socio-demographic characteristics Prospective study	Grieving and non-grieving population-based cohort of adults over 55 years. All inhabitants aged over 55 years living in the Ommoord district of Rotterdam were invited to participate. N = 5741; n_b = 1089 $n_{\geq 65}$= 4686; $n_{b\geq 65}$ = 901 n_{85+} =402; n_{b85+} =79	RR=74.6% DoR=46% EP= 2% & 1.22%	≥65 years (83%)	Inventory of Complicated Grief[13] Dutch adapted 17 item version in which one item was removed and two further items where collapsed (no reference provided) Interview Cut-off score ≥ 22 (adapted to 17 item version) following cut-off in original sample[13]
3	Tang** (2016)[58]	China	To investigate rates and risk factors of PGD among bereaved Chinese Cross sectional study	A sample of bereaved adults in mainland China and older adults in Hong Kong. Recruitment using convince sampling through various sources including universities and elderly service centre. N = 623; n_b = 623; $n_{b\geq 65}$ = 178	RR=NR DoR=NA EP=NR	76.7 years (7.27)	Prolonged Grief-13[10] Chinese Version (no reference provided) Assisted questionnaire Algorithm of 5 criteria incl. presence of 6 out of 11 symptoms, trigger, duration, and impairment criteria): At least a score of 4 on one of the two separation items, a score of at least 4 on five of the 9 traumatic distress items. in addition to the trigger, duration and clinical impairment criteria[10]

Nonepidemiological studies							
4	O'Connor (2010)[54]	Denmark	To assess the factorial structure of complicated grief (CG) and investigate the relationship between CG and posttraumatic stress disorder (PTSD) Cross sectional study	A general sample of married elderly people living in Aarhus County who had experienced a significant interpersonal loss, recruitment through the Danish Central Person Register (CPR) and random sampling. N = 292; n_b = 292; $n_{b\geq65}$ = 292	RR=41% DoR=NA EP=27.7%	70.0 years (3.47)	15 items of the Inventory of Complicated Grief-Revised[55] Danish version[54] Questionnaire Algorithm of 3 criteria incl. presence of 10 out of 15 symptoms and the trigger criteria. Three of four daily symptoms of separation distress and six of eleven daily symptoms of traumatic distress in addition to the triggering event.[55]
5	Allen (2013)[59]	USA	To investigated risk factors that may predict psychological distress, which could aid hospice bereavement departments in targeting bereavement services Prospective study	A sample of family caregivers (66% spouses) of deceased cancer patients admitted to two hospice homecare programs in west central Florida in 2005-2008 N = 188; n_b = 188; $n_{b\geq65}$ = 188	RR=NR DoR= 72% EP=6.5%	66.4 years (11.66)	Inventory of Complicated Grief[13] Questionnaire Cut-off score >25, following cut-off score in original sample[13]
6	Barbosa (2014)[60]	Northern Portugal	To evaluate the effectiveness of a cognitive narrative intervention for complicated grief Randomized control trial	A sample of nursing home inhabitants of 3 nursing homes in northern Portugal, aged over 60 years who experienced spousal loss over six months ago N = 82; n_b = 82; $n_{b\geq65}$ = 82	RR=NR DoR=* EP=NR	80.1 years (7.34)	Inventory of Complicated Grief[13] Portuguese version[61] Questionnaire Cut-off score ≥ 25; referring to cut-off in original sample[13]
7	Pan** (2019)[62]	China	To investigate e effects of traditional Chinese culture on bereavement outcomes among older Chinese Cross sectional study	Sample of bereaved spouses aged 60 years and older with no cognitive impairment from rural Yongjia county (Zhejian Province). Recruited via quota sampling with 6 townships were randomly chosen from those 18 villages were selected in each potential participant were found by convenience and screened. N=352; n_b = 352; $n_{b\geq65}$ = 352	RR= NR DoR= NA EP= NR	77.63 years (8.74)	Inventory of Complicated Grief[13] Chinese Version[63] Interview Cut-off score >25, following cut-off score in original sample[13]

8	Lundorff ** (2019)[64]	Denmark	To investigate relations between levels of lose-oriented (LO) and restoration-oriented (RO) coping and adjustment outcomes and changes in LO/RO coping across time and their relations to adjustment. Prospective study	A sample of recently bereaved spouses whose partners were patients of Palliative Care Team at Funen, Odense University Hospital between Jan. 2014 to Aug. 2015. Recruited via routine follow up procedure of Palliative Care Team if judged eligible after clinical and ethical considerations N=239; n_b = 239; $n_{b\geq65}$ = 155	RR= 85.1% DoR= 35.2% EP= NR	65.1 years (9.6)	Prolonged Grief-13[10] Questionnaire Cut-off of >=29** abbreviated from PG13 algorithm: PG-13 question 1 or 2 must be experienced at least daily = minimum sum score for both items of 5; 5 of the PG-13 question #4-12 must at least be experienced "once a day" or "quite a bit" rated >=4 while the other four items could be rated 1= minimum sum score for the 9 items of 24; total sum score =29; functional impairment item was not accounted
9	O'Connor (2019)[40]	Denmark	To examine the specificity of four proposed diagnostic criteria-sets for pathological grief in a population-based sample Prospective study	Sample of persons aged 65 - 80 in the former county of Aarhus, who had lost a spouse in 2006; recruitment through the Danish CPR. N = 206; n_b = 206; $n_{b\geq65}$ = 206	RR=39% DoR=28% EP=13%	72.5 years (4.2)	15 items of the Inventory of Complicated Grief-Revised[55] Danish version[54] Questionnaires 3 algorithms matching PGD-2009, PCBD, PGD-ICD11 were applied all algorithm consist of 4 criteria incl. presence of 5,6,4, symptoms out of respectively 10, 13, 5 symptoms, the trigger and duration criteria: PGD-2009: At least one of the two separation items and at least four out of eight traumatic distress items, in addition to the trigger and duration criteria PCBD: At least one of the two separation items and at least five out of ten traumatic distress items, in addition to the trigger and duration criteria PGD-ICD11: At least one of the two separation items and at least three out of five traumatic distress items, in addition to the trigger and duration criteria[9]

NA= not applicable; NR= not reported; ND not derivable, F= female; M=male; RR=Response Rate total number of participants who participated divided by the total number who were eligible or contacted; DoR=Dropout Rate total number of participants who participated at follow up divided by the total number who participated at baseline; EP=Excluded participant rate number of participants who did not provided data or sufficient data (defined by study) divided by all participants
N = total sample; n_b= bereaved participants sample; n≥65 = participants sample mean age ≥ 65years; nb65 = bereaved sample mean age ≥ 65years;
** based on paper and personal communication with authors
*not relevant to prevalence data calculation
@ if not explicitly reported and not stayed otherwise most likely form of administration was put down Self-administered questionnaire

Risk of bias and quality assessment

Two studies had a RoB score of 8 [1, 2] indicating moderate risk of bias and one had a high RoB with a score of 5 [3] due to lack of external validity **(Supplementary Material 9).**

Three non-epidemiological studies had a summary score of above 0.9 which indicated high methodology and reporting quality, one study had a score of 0.86 and one 0.75. The one RCT scored 0.67 mainly due to blinding issues, which do not affect estimates of prevalence rates based on baseline data

RoB assessment and quality assessment were performed by two raters (AS, PT) independently with an interrater reliability at a moderate level, Kappa = 0.73 (95% CI 0.49–0.98) and a strong level, Kappa = 0.87 (95% CI 0.78–0.978) respectively.[52]

Prevalence rates of PGD

The conditional prevalence rates of PGD for older adults in the three epidemiological studies range between 3.4% and 26.2%. The rates for PGD derived from six non-epidemiological studies ranged between 6% and 48.7%. **Supplementary Material 10** provides a detailed description of each study including prevalence rate, study methodology and sample characteristics.

Discussion

Although older adults are a fast-growing population group and exposed to bereavement more than others, high-quality large-scale population-based studies of PGD prevalence in older adults are rare. We only found three epidemiological studies providing data on prevalence rates for PGD in older adults >= 65 years and only one included data for older old

adults >= 85 years. The six included non-epidemiological studies focused on older adults, with data that enabled us to calculate PGD frequency.

This lack of epidemiological studies of PGD might be explained by the relatively recent introduction of PGD into diagnostic classification systems, the preceding debate about pathologising normal grief reactions and ethical concerns about conducting bereavement research in general.[65 66] Disagreements about the criteria for a grief-specific mental disorder has led some to focus research on complicated grief rather than PGD.[67 68] This review can therefore only provide a first estimate of prevalence of PGD in older adults and highlights the necessity of future research.

The overall quality assessment of most included studies was satisfactory. However, while nearly all studies were characterised by good internal validity many studies had external validity issues, as found in a previous meta-analysis.[16] Selection biases were frequent: only one study was based on a nationally representative sample [1]. Potential non-response biases limited the generalizability of study findings with response rates as low as 39%, dropout rates high as 72% and up to 28% participants being excluded due to missing data.[69 70] Only three included papers provided partial non-response analyses [1, 4, 9].
The review reflects the know pattern that response rates decrease with increasing age[71 72], are often low when assessing the bereaved[73] and non responses are higher among those more impared.[74] The finding of Allen, et al. [59], that relatively more non-participants than participants had higher symptoms of depression at baseline raises concerns that PGD prevalence rates in studies with high nonresponses might be underestimated.

Mayor imbalances in terms of ethnicity, study location in terms of urban vs rural areas and gender was observed. Most studies were conducted in western countries representing white Americans or European what leaves other ethnicities not or underrepresented. Seven of nine studies were based solely in urban regions [2, 3, 4, 5, 8, 9]. If PGD prevalence varies by setting as for depression, PGD prevalence might be overestimated if based on larger city studies.[75 76] All studies had more female than male participants: maybe due to women's longer life expectancy[77] or due to them experiencing more bereavement by having wider social networks,[78 79] or because they are more likely to participate in survey studies.[80]Because female gender is a risk factor for developing PGD [1] it is essential to look at prevalence rates separately for women and men.

Only one epidemiological study enabled calculation of the current prevalence rate of PGD in the *general* population of older western urban adults [2]. With a rate of 5%, this is close to the 7% prevalence of depression in the general older population, which is recognized as one of the most common mental disorder in old age by the World Health Organization.[81] Conditional prevalence rates of PGD for older adults ranged from 3.4% to 26.2% in epidemiological studies, increasing to 3.4% - 48.7% when including non-epidemiological studies.

The variability can not be attributed to the different criteria sets of ICD-11 and DSM-5. A recent study reported prevalence rates of 8.3% and 5.8% with overlapping confidence intervals for PBCD and PGD.[40] The wide range might be explained by the observed methodological heterogeneity including variations in measures and way of defining PGD cases and by variations in study sample characteristics.

Of the five studies with higher prevalence rates (17.6% to 48.75%) four [2, 5, 6, 7] used the ICG as study measure and all defined PGDcases by applying a cut-off score. Studies using the ICG-R15 and PG-13 following an algorithm approach for detecting PGD reported prevalence rates of 9.1% or lower [1, 3, 4, 9]. These findings are in line with a recent meta-analysis of 14 papers[16] three of which [1, 2, 4] are included in our review that shows that the ICG produces higher prevalence rates. The commonly used cut off of 25, from the original ICG validation study[13] might not be appropriate for samples with other characteristics.[82] In addition, a simple sum cut-off score compared to a algorithm scoring method is less akin to diagnostic criteria and can lead to a higher prevalence rate.[53] It is problematic that for the same measure different cut-offs and algorithm approaches exist, which rarely are based on validation studies: combined with different screening questions to identify the bereaved, this might account for much of the heterogeneity of results. Its also concerning that prevalence estimates in epidemiological studies were not based on clinical interviews the gold standard for assessing a mental health disorders.[83] Self-report measures might be at risk of underreporting mental health diagnosis especially in older age adults as shown for depression by Eaton, et al. [84]

Variation in sample characteristics (country, relationship to the deceased, place of residence) may also contribute to the wide range of prevalence rates. The lowest conditional PGD prevalence rate of 3.4% reported in this review originated from an Asian study[3] which was much lower than prevalence rates from other studies. Mental health disorder prevalences are known to be consistently lower for countries within North and South East Asia than other regions.[85]This might also be valid for PGD. Many of the included studies investigated spousal bereavement. It may be easier to recruit spouses. However,

spousal bereavement is known as a risk factor for complications in grief. [23 67] Four studies in this review which predominantly referred to spousal bereavement showed higher prevalence rates [5, 6, 7, 8] including the highest prevalence of 48.7% [6]. The latter was a study of nursing home residents, a population confronted by multiple losses and therefore more vulnerable for PGD.[86] Nursing home residents, were rarely represnted in the included studies, potentially leading to an underestimation of PGD in older adults.

Conclusion

While some of the variation in prevalence rates might be rooted in real differences such as cultural differences, a large proportion of variance can probably be explained by differences in methodology and sample characteristics. The heterogeneity of results makes it difficult to estimate the prevalence of PGD in older adults. Based on the low RoB of Kersting's study [1] and their representative population-based sample, which is likely to represent the whole spectrum of bereavement experience, we think their estimated conditional prevalence rate of PGD in older adults of 9.1% is the best estimate for western countries available at the moment.

Contrary to the assumption that bereavement is "less problematic" in older adults, research indicates that older adults are at least as vulnerable as other adults. Considering the possibility of current studies underestimating PGD in older adults, older adults might even have a greater risk of developing PGD. Bereavement in old age is associated with negative outcomes including weight loss, sleep disturbances and increased health services use.[24 87 88]

The main limitations of this review are linked to the PGD research area being an evolving field with yet different definitions for clinically relevant grief and shortcomings in its assessment including the use of self report measures only and measures not accounting for all criteria. Non epidemiological studies cannot provide strong evidence in terms of prevalence rates and exclusion of non-English publications introduced a western country bias. The use of different instruments for the quality assessment of epidemiological and non-epidemiological studies, did not allow a direct comparison of their quality. Although well undertaken most studies quality was rated “moderate” demonstrating difficulties of this area of research.

For more exact estimates of PGD among the general population of older adults more large-scale population-based studies with good external validity, from different parts of the world, are required. Ideally these studies should report results by age groups including older-old age and match the gender ratio of the respective age groups. To improve generalisability of study findings research needs to include all groups of older adults (e.g. rural and institutionalized residents) and must minimize inclusion and exclusion criteria (e.g. type of death).[74] In addition, efforts to reduce the number of non-responses from older adults are important. Studies should report efforts to minimize non-response and by default provide non-response analysis.[70] The above requires a mutual definition and tailored validated measures for clinically relevant grief. This is the joint task of clinicians and researchers. Until a consensus on the criteria set for PGD is found studies should use measures which represent all symptoms of the various PGD diagnosis and apply all their diagnostic algorithms. To help evaluate the current evidence performance of self-reports for PGD should be evaluated against clinical interviews.

It is important for policy makers to be aware that PGD is an important aspect of the mental health of older adults, particularly given the risk of ageism[21] and that bereavement support is under-represented in end-of-life care policy.[89] Only a subgroup of bereaved older adults develops PGD therefore effective identification is important to allocate resources to those most in need.[16]

Knowing the possible proportion of patients who may present with PGD will help raise healthcare professionals' awareness of the diagnosis, distinguish PGD from other possible bereavement outcomes such as depression and PTSD and foster appropriate treatment. Other frontline workers who engage with older adults such as clergy, care home staff and the bereaved themselves must also learn about PGD. This will improve the outlook of older adults suffering from PGD by enabling early detection and treatment.

Authors' contributions

SB and PT developed the project with PT leading on the project and writing the manuscript and SB providing support throughout. IK conducted the systematic literature search. SH, AS and PT screened the literature, SH and AS extracted the data and AS and PT conducted the quality assessment. SH, AS and TQ assisted PT in interpreting the results. All authors critically reviewed the manuscript and provided final approval for submission.

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Supplementary Material 1

Conditional prevalence rates reported for PGD based on ICG, ICG-R15 or PG-13 measure by sample characteristics – no comprehensive list

General Population

Kersting et al. (2011): 6.7%
Forstmeier et al. (2007): 4.6%
Maciejewski et al. (2016): 11.9-14.2%
Goldsmith et al. (2008): 12% and 21%
He et al. (2014): 1.8%
Li and Prigerson, (2016): 13.9%
Newsome et al. (2011): 25.4%
O'Connor et al. (2010): 9%
Vargar et al. (2015): 5.52%
Prigerson et al. (2009): 7%

Psychiatric patients

Kersting et al. (2009): 17.8%
Simon et al. (2005): 24.3%

Carers

Guldin et al. (2012): 40%
Tsai et al. (2016): 7.7%
Chiu et al. (2009): 24.5%
Wiese et al. (2010): 30%
Schulz et al. (2006): 20%
Anderson et al. (2008): 46%
Kim et al. (2015): 24.5
Nielsen et al (2017): 8%

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Supplementary Material 2

Symptoms PCBD and PGD matched based on the symptom list from Maciejewski et al., 2016 adapted after Treml et al., 2020

Symptoms	**Persistent Complex Bereavement Disorder**	**Prolonged Grief Disorder**
Separation distress		
Yearning/Longing[T] Emotional Pain[T] Preoccupation	B1. Persistent yearning or longing for the deceased B2. Intense sorrow and emotional pain B3. Preoccupation with deceased person B4. Preoccupation with circumstances of the death	B1. Longing for the deceased or B2. Persistent preoccupation C1. Sadness
Other symptoms		
Part of yourself died	C11. Confusion about one's role and diminished identity (eg. feeling that part of self has died)	C7. Feeling one has lost a part of one's self
(~~Disbelief~~ [T]) Trouble accepting death	C1. Difficulty accepting the death	C6. Difficulty accepting the death
Avoidance of reminders	C6. Excessive avoidance of stimuli (places, people, objects) reminding of the loss	
Hard to trust others	C8. Difficulty trusting other people	
Anger; Bitterness	C4. Bitterness or anger	C3. Anger
Difficulty moving on	C12. Difficulties pursuing interests or making plans for the future (e.g. friendships, activities)	C10. Difficulty in engaging with social or other activities
Disbelief[T], Numbness	C2. Disbelief and numbness	C9. Emotional numbness,
Life empty, meaningless, unfulfilling	C10. Feeling that life is empty or meaningless or ….	
Loneliness, feeling detached	C9. Feeling alone or detached from others	

Symptoms	Persistent Complex Bereavement Disorder	Prolonged Grief Disorder
Survivor guilt	C5. Maladaptive appraisals about self, associated with the loss (e.g., self-blame)	C2. Guilt
Memories upset you	C3. Difficulty with positive reminiscing about the deceased	
Suicidal ideation	C7. A desire to die to be with the deceased	
Denial[T]		C4 Denial
Blame[T]		C5. Blame
Absent of positive mood[T]		C8. Inability to experience positive mood

[T] list of symptoms identified added or deleted following Treml et al., 2020

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Supplementary Material 3

Items of used grief assessment measures (ICG-19, ICG-R15, PG-13) matched to diagnostic B and C criteria of PCBD and PGD

	Yearning or longing	Emotional pian sadness/sorrow	Preoccupation	Part of yourself died	Trouble accepting death	Avoidance of reminders	Hard to trust others	Anger; Bitterness;	Difficulty moving on	Disbelief, Numbness	Life empty, meaningless, unfulfilling	Loneliness, feeling detached from others	Survivor guilt	Memories upset you	Suicidal ideation	Denial	Blame	Absent of positive mood	Number of B/C criteria represented by instruments	
																			PGD	PCBD
ICG-19[1]	4	-	1 (5)	-	3	12	9	6, 17	-	7	13	10, 19	16	2	-	-	-	-	6	11
ICG-R15[2]	3	-	1 (2)	12	9	5	6	15	-	7	10, 11	4,7	-	-	-	-	-	-	6	10
PG13[3]	1	2		6	7	4	8	9	10	11	12	-	-	-	-	-	-	-	7	10

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Supplementary Material 4

Box 1. Database search terms used

Key terms for complicated grief	Key terms for prevalence and study design
Complicated grief or grieving	Prevalence
Prolonged grief or grieving	Prevalence rate
Pathological grief or grieving	Proportion
Traumatic grief or grieving	Frequency
Chronic grief or grieving	Incidence
Persistent grief or grieving	Screening
	Assessment
Complicated bereavement	Epidemiology
Prolonged bereavement	
Pathological bereavement	Observational study
Traumatic bereavement	Descriptive study
Chronic bereavement	Analytic study
Persistent bereavement	Cohort study
	Cross sectional study
	Randomized control trials
	Review
	systematic review

Supplementary Material 5

Search procedure for Medline database

Medline

#	Query	Results
1	((grief or griev* or bereave*) adj2 (complicat* or prolong* or pathological or traumatic or chronic* or persistent*)).mp.	(1275)
2	Persistent complex bereavement disorder*.mp.	(37)
3	or/1-2	(1275)
4	exp Prevalence/ or exp Incidence/ or exp mass screening/ or (prevalen* or proportion or frequen* or INCIDENCE*or assess* or screen*).mp.	(5876848)
5	(epidemiolo* or cohort*).mp. or exp Epidemiology/ or exp Epidemiologic Studies/	(2834776)
6	exp Cohort Studies/	(1866550)
7	(trial* or placebo* or control* or random*).mp.	(5197723)
8	exp Randomized Controlled Trial/ or exp Clinical Trial/	(872090)
9	exp Placebo Effect/	(4498)
10	exp Random Allocation/	(101083)
11	(review* or systematic*).mp.	(3583000)
12	(observation* or descript* or analytic* or "cross section*" or "cross-section*").mp.	(1730602)
13	exp Observational Study/ or exp Cross-Sectional Studies/	(319127)
14	or/4-13	(12791332)
15	3 and 14	(896)

Supplementary Material 6

Information extracted from papers

Information extracted chosen based on the Joanna Briggs Institute Data Extraction Form for Prevalence and Incidence Studies (2014), the data extraction form from the European Commission (2002) and the Data Extraction form from Islam et al. (2017).

Details of publication

- First author
- First author's institution
- Year of publication
- Journal
- Title
- Full text reference

Study aims

- Aims / research questions / hypotheses
- Prevalence estimation as an objective?

Study characteristics

- Country
- Date of data collection
- Label and Definition of complicated grief
- Loss referred to (e.g. hospice death, spousal death)
- Response rate
- Ethical approval

Study participants

- Target population
- Description of population
- Inclusion criteria
- Exclusion criteria
- Sample size
- Sex female male ration
- Ethnicity
- Social class
- Geographical location/arear
- Relationship to the deceased

- sample size >= 65
- sample size >= 85
- older age inclusion criterion
- sample mean age (SD)
- age range
- Duration of bereavement
- Types of death included
- Additional information

Study method

- Data source
- Design
- Recruitment method
- Sampling frame
- Sample strategy

Study outcome

- Outcome variable (grief related measures only)
- Way of assessment (clinical judgement, questionnaire, other)
- Who measured/assessed?
- PGD measure
- Way of identifying PGD+ reference

Summary of data analysis methods

- Method of data analysis

Results

- Prevalence provided or extracted by us?
- Outcome measure in this analysis (absolute numbers, type of prevalence)
- Measure of the prevalence (crude or adjusted measure)
- If adjusted what factors were adjusted for in this study (list)
- Prevalence n/N (%)
- 95% Confidence Intervals
- Prevalence for subsamples (male female..)

Comments

- Relevant authors' comments
- Our comments

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Supplementary Material 7

Quality assessment

Risk of bias assessment

The risk of bias assessment by Hoy et al. (2012) consists of ten items and is specifically developed for population-based prevalence studies. It focuses on identifying whether studies had attempted to minimize bias rather than quality of reporting. Items 1 to 4 assess the external validity of the study (domains are selection and nonresponse bias), and items 5 to 10 assess the internal validity (domains are measurement bias and bias related to the analysis). The 10 items are scored with a value of 1 (yes) or 0 (no). If insufficient information in the article does not permit a judgment for an item, it is rated as high risk (0). The RoB total score is the sum score (range 0-10) with higher scores indicating lower RoB and higher methodological validity. Following the approach Lundorff et al. (2017) used in their meta-analysis a sum scores of 9 or 10 points considered to be low RoB, scores of 7 or 8 points were considered to be moderate RoB and scores of 6 or less points were considered to have high RoB.

Checklist for assessing the quality of quantitative studies

Standard quality assessment criteria for Evaluating Primary Research Papers developed by Alberta Heritage Foundation for Medical Research Initiative was designed to judge potential eligibility of papers for inclusion in a review (Kmet et al., 2004). It enables quality evaluation across a broad range of study designs. The used checklist for quantitative studies consists of 14 criteria relating to methodology (e.g. 'Method of subject selection') and reporting (e.g. 'Results reported in sufficient detail?'). To consider the external validity of study results an

extra item concerning nonresponses was added (see below). Items are scored with a value 2 (yes), 1 (partial) 0 (no) or n/a (not applicable). A summary score is calculated by dividing the total score summed across all applicable items by the highest possible score total [30 - (number of n / a · 2)]. It ranges between 0-1 with higher scores indicating higher overall quality. Different threshold scores for quality can be chosen a conservative score for unsatisfying quality is < 0.75.

Additional item for quality assessment of non-epidemiological studies

Was the likelihood of nonresponse bias minimal?

Scoring:

Yes: Study reports response/dropout rate, response rate is high and/or dropout rate is small and sample is being representative of the target sample (It is possible to have a very high response rate overall for a study, but the response rate for a certain subgroup is low), or response rate is moderate to high and or dropout rate is small and response bias analysis shows non-response appear to be unrelated to the outcome measured.

Partial: Study reports response/ dropout rate**,** Response rate is high - moderate and/or dropout rate is small and non-response bias analysis was conducted and possible differences between responders and non-responders were adjusted for and/or taken into account when discussing the results.

No: No response rate/ dropout rate is reported, or extremely low response rates or high dropout rate or non-response bias analysis revealed significant differences in responders and non-responders and no discussion

N/A: Should not be checked for this question

References

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Supplementary Material 8

Description of measures used by included studies

Inventory of Complicated Grief (ICG; Prigerson et al., 1995)

The ICG was devised by Prigerson et al. (1995) to assess indicators of pathological grief, such as anger, disbelief, and hallucinations and to distinguish pathological grief from other mental health disorders including depression. The instrument consists of 19 first-person statements concerning bereavement-related thoughts and behaviours: “I feel myself longing for the person who died”, “I feel stunned or dazed over what happened“. Items are answered on a 5-point frequency scale ranging from “Never=0” to “Always=4” with a total score ranging from 0 to 76. Higher scores indicating greater grief severity.

Various validation studies showed construct and criterion validity and found the internal consistency of the scale to be good to excellent, with Cronbach’s alpha ranging from 0.85 to 0.95. The test-retest reliability was reported to be good (r = 0.80) (Treml et al., 2020).

To identify PGD the authors originally suggested a threshold of the 20% most distressed (Prigerson et al., 1995). In the initial homogeneous sample of widows and widowers a score of > 25 corresponded to the upper quintile of scores. This cut off has often been used in subsequent research but other cut-off scores for example a total ICG-19 score of ≥25 (Barbosa et al., 2014), ≥30 (Shear et al., 2005) and >48 (Li and Prigerson 2016) have also been suggested.

Short version of the Inventory of Complicated Grief Revised **(ICG-R15)**

The ICG-15 is a short version of the 30-item long Inventory of Complicated Grief Revised (ICG-R, Boelen and Hoijtink (2009)[1]. In some publications (O'Connor et al. 2010 ,2019, Guldin et al.,2011) the 15-item version is not labelled as such and instead referred to as ICG-R, which can be misleading (Treml et al., 2020). To prevent confusion, we therefore labelled this version ICG-R15.

The ICG-R15 consist of the 15 consensus criteria of PGD of the ICG-R covering cognitive, behavioural and emotional symptoms of PGD for example, "I feel myself longing and yearning for [deceased name]", "I feel that life is empty or meaningless without [deceased name]". The presence of symptoms in the last month is rated on a 5-point scale ranging from "Never=1" to "Always=5". The total score is ranging from 15 to 75. Higher scores indicating greater grief severity.

Good to excellent internal consistency has been reported, ranging from 0.91 to 0.93 (Ekholt et al., 2018)

To identify PGD with the ICG-R15 different algorithms, which considered a symptom present if the matched ICG-R15 item was answered with a minimum rating of of4 (O'Connor et al. 2019, Kersting et al., 2011) and cut off scores 36 (Guldin et al., 2011) or a combination (ICG-R15 total score >= 36 when fulfilling the criteria of separation distress and traumatic distress; O'Connor et al., 2010) have been used.

Prolonged Grief Disorder (PG-13, Prigerson 2009; Prigerson et al.2008)

The PG-13 matched the PGD criteria proposed for ICD11 and DSM-V by Prigerson et al. (2009) and is used as self-report measure or structured interview, which refers to the last

[1] also known as Inventory of Traumatic Grief (ITG), Prigerson and Jacobs et al. (2001)

month. Of the 13 items two assess duration/frequency and impairment with “yes”/ “no” answer format. The remaining 11 items assess cognitive, behavioural and emotional symptoms of PGD, for example: “In the past month, how often have you tried to avoid reminders that the person you lost is gone?”, “Do you feel emotionally numb since your loss?” The items are rated on a 5-point scale either on a frequency scale ranging from: “not at all=1” to “several times a day=5” or an intensity scale ranging from “not at all=1” to “overwhelmingly=5” with a total score ranging from 11 to 55. Higher scores indicating greater grief severity.

Validation studies demonstrated construct and criterion validity and found the internal consistency of the scale to be good to excellent, ranging from 0.82 to 0.92 (Treml et al., 2020).

With the PG13 the criteria set of PGD 2009 (Prigerson et al., 2009) can be assessed by applying the following algorithm:

The bereaved person has to experience separation distress (Item #1 or 2 scored with 4 or 5) and cognitive, emotional, and behavioural symptoms (five items from item #4-11 scored with 4 or 5). Furthermore, the symptoms had to be elevated for at least six months (Item #3 must be answered “Yes”) and must have had led to significant functional impairment (Item #13 must be answered “Yes”).

Cut off scores have been used (≥29 Lundorff et al. (2020); ≥26 Tomarken et al. (2012) but have not yet been validated.

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Supplementary Material 9

Quality assessment

	Risk of Bias assessment (Hoy et al., 2011) Scoring: high risk =0, low risk =1										
Study	1 Representativeness	2 Sampling frame	3 Random selection	4 Non-responses	5 Source of data	6 Case definition	7 Instruments	8 Same mode of data collection	9 Prevalence period	10 Calculation /reporting errors	RoB sum score
Kersting (2011)	1	1	1	0	1	1	1	1	1	0	8
Newson (2011)	0	1	1	0	1	1	1	1	1	1	8
Tang** (2016)	0	0	0	0	1	1	1	1	1	0	5

	Standard Quality Assessment Criteria (Kmet et al., 2004) Scoring: yes = 2, partial = 1, no = 0 or N/A															
	1 Objective	2 Study design	3 Subject selection	4 Subject characteristics	5 Random allocation	6 Blinding investigators	7 Blinding subjects	8 Outcome	9 Sample size	10 Analysis	11 estimate of variance	12 Con-founding factors	13 Results	14 Conclusions	Additional item Non-responses	Sumscore
O'Connor2010)	2	2	1	2	n/a	n/a	n/a	2	2	2	2	2	2	2	1	0.92
Allen (2013)	2	1	1	2	n/a	n/a	n/a	2	2	2	2	n/a	2	2	1	0.86
Barbosa (2014)	2	2	1	2	1	0	0	2	1	2	2	0	2	2	n/a	0.68
Lundorff (2019)	2	2	1	2	n/a	n/a	n/a	2	2	2	2	2	2	2	2	0.96
O'Connor (2019)	2	2	2	2	n/a	n/a	n/a	2	2	2	2	n/a	2	2	1	0.95
Pan (2019)	2	2	1	2	n/a	n/a	n/a	1	2	2	1	2	2	1	0	0.75

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Supplementary Material 10

Prevalence rates together with information regarding study sample and methods are presented below for each included reference. At the end of each section we draw attention to study limitations and strengths in the light of prevalence rates research.

Epidemiological studies

Tang et al. (2016)

In the subsample of a large-scale study of bereaved Chinese from Tang et al. (2016)[3], older adults from Hong Kong (average age 76.65 (7.27) years) who were recruited via elderly service centres had a conditional prevalence of PGD of 3.4%. PGD was assessed by using Prolonged Grief-13 (PG-13; Prigerson et al., 2009). PGD was diagnosed following an algorithm which includes duration and impairment criteria (see table 2). In the Hong Kong subsample the average period of bereavement was 1.9 years (1.5), most referred to loss of a spouse (80%) and for 40.1% the loss was sudden (Tang, personal communication). Limitations of the study are that the recruitment approach, screening question and response rates are not reported. A strength of the study is the provision of PGD data from Asia.

Kersting et al. (2011)

In the subsample of older German adults (61-95 years; 49% of the total sample) from the initial representative population-based sample of Kersting et al. (2011)[1] a conditional prevalence of PGD of 9.1% was found. Looking at female and males, the rates were 6.3% and 2.8% respectively. PGD was assessed using the German version of the Inventory of Complicated Grief Revised (Jacobs et al., 2000; Rosner, 2002) when participants indicated

that they had experienced the loss of a significant person. PGD was diagnosed using an algorithm which included duration and impairment criteria (see table 2). In the overall bereaved sample, the average period of bereavement was 9.8 years (10.3; 0–71 years) with most bereaved referring to the loss of their parent(s) (44%) or spouse (22%). For the majority (72.5%) death was unexpected (including sudden natural death, accident, suicide violent death). A limitation of this study is that it remained unclear to what extent the study sample was nationally representative taking the response rate of 61.9% into account. A strength of the study is the random nationwide selection of respondents and the inclusion of all bereavement groups (e.g., bereaved parents, death through suicide, sudden death, expected death; Kersting et al., 2011).

Newson et al. 2011

The Rotterdam Study, a population-based cohort study of adults 55+, revealed a general prevalence of PGD of 5% for the subsample of older adults (81.6% of the total sample).[2] Their conditional prevalence of PGD was 26.2%. In the age groups of 65-85 and 85+ the conditional prevalence rates were 26.5 % and 22.8% respectively. PGD was assessed using the 17-item Dutch version of the Inventory of Complicated Grief when participants indicated that they were currently grieving (Prigerson et al., 1995; Boelen et al., 2003).PGD was diagnosed applying a cut-off score and a duration criterion (see table 2). In the overall bereaved sample, the average period of bereavement was 5.8 years (9 years) most referred to loss of spouse (30.9%) and sibling (15.8). Whether bereavement was sudden or expected was not reported. Limitations of the study are that no non-response analyses are reported and the use of an adapted version of the ICG. Although the authors adapted the cut-off score it might influence the comparison with other studies. Strengths of the study are its

high response rate, the inclusion of all bereavement groups and reporting results for the older old separately.

Non epidemiological studies

O'Connor et al. (2019)

In a sample of 206 conjugally bereaved elderly Danes (average age 72.5 (4.2)) conditional prevalence rates of PGD six months after their loss ranged between 6 -9%.[5] Following the criteria sets for PGD 2009, PBCD and PGD ICD-11 produced prevalence rate of respectively 9.2% (CI: 5.2%−13.2%), 8.3% (CI: 4.5%−12.0%) and 5.8% (CI: 2.6%−9.1%) rate. O'Connor et al. (2019) assessed PGD 2009, PBCD, PGD ICD-11 by using a short version of the Danish version of the ICG-R (ICG-R15; Jacobs et al. 2000; O'Connor et al. 2010) and single items from the Danish versions of the Harvard Trauma Questionnaire (Mollica et al., 1992; Seignourel et al., 2008)) and Beck's Depression Inventory (BDI; Beck et al., 1996; Bach et al., 2003). Symptoms of the diagnostic entities, PGD-2009, PBCD and PGD ICD-11 were matched with items from the ICG-R15, HQT and BDI and formed three respective symptom-diagnostic tests. Limitations of the study are the low initial response rate, the focus on spousal bereavement only, that not all symptoms were represented by the included measures and the exclusion of the functional impairment criteria. A strength of the study is the population-based community sample recruited by the Danish Civil Registration System (CPR) and the non-response analyses which provided valuable information.

O'Connor et al. (2010)

In a sample of 292 elderly, married individuals (average age 66.4 (11.7)) from Denmark a conditional prevalence of PGD of 9% was found when asking participants to refer to the

most significant loss in their lifetime.[4] O'Connor et al. (2010) assessed PGD by using a short version of the Danish version of ICG-R (IDG-R15;not provided or referenced). PGD was diagnosed following an algorithm (see table 2). The average period of bereavement was 1.1 year (1.1); most referred to loss of a parent (63%) and spouse (13%). Limitations of the study are a relatively low response rate, that no reference for the applied cut-off score was provided and that the duration criterion of 6 months was not considered when diagnosing PGD as clarified in a personal communication with the author (personal communication O'Connor; O' Connor et al. (2010)). A strength of the study is the recruitment through the Danish Central Person Register which makes a representative sample more likely and provides information about the non-participants (O'Connor et al., 2010).

Pan (2019)

In a sample of 352 bereaved spouse (average age 77.63 years (8.74)) in rural China a conditional prevalence of PGD of 17.6% was found (personal communication Pan 2020). Pan (2019) diagnosed PGD using ICG applying a cut-off score of over 25. The average period of bereavement was 13.9 years (SD not reported). Limitation of the study is the not reported response rate and that the duration criterion of 6 months was not considered when diagnosing PGD as clarified in a personal communication with the author. A strength of the study is the recruitment of bereaved participants from rural area.

Allen et al. (2013)

In a sample of 188 cancer patient–caregivers (average age 66.4years (11.7)) from the US a conditional prevalence of PGD of 18.5% was found one year after the death of their relative (66% spouse).[6] Allen et al. (2013) assessed PGD by using the ICG. PGD was diagnosed by

applying a cut-off score of over 25. Limitations of the study are a high level of preselection of participants, a high rate of attrition and missing data regarding access to bereavement support services of participants. A strength of the study is the drop out analysis which provided valuable information.

Lundorff et al. (2019a)

In a sample of 155 bereaved spouse (average age 65.1 years (9.6)) from Denmark a conditional prevalence of 36% was found 7months after their loss (Lundorff et al., 2019b). Lundorff et al. (2019a) assessed PGD by using PG13 (Prigerson et al., 2009). PGD was diagnosed by applying a cut-off score of over 28 derived from the PG13 algorithm. Limitations of the study are the use of a non-validated cut off score and the exclusion of the functional impairment criteria. A strength of the study is the initial high response rate.

Barbosa et al. (2014)

In a sample of 82 Portuguese care home inhabitants (average age 80.1 years (7.3)) who had lost a spouse and were screened for a RCT, a conditional prevalence of PGD of at least 48.7% was found.[7] Barbosa et al. (2014) assessed PGD by using the Portuguese version of the ICG (Prigerson et al., 1995; Frade et al., 2009). PGD was diagnosed by applying a cut-off score of ≥25. The average period of bereavement was 10.2 years (10.0). Limitations of this study referred to the study definition of PGD. First the authors used a cut-off of ≥25 rather than the cut-off of >25 as suggested by the original publication of Prigerson et al. (1995) and second they did not define the term “borderline symptoms of CG” which they used. “53 participants had CG. Thirteen of the 53 cases displayed borderline symptoms of CG, and they were also excluded.” Taking the study’s liberal cut-off score into a count and our

conservative approach we extracted “40” as the confirmed number of PGD cases although the prevalence rate might have been even higher. Strength of the study is the assessment of PGD in care home inhabitants.

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