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Complicated grief following the perinatal loss: a systematic review

Xi Zhang^{1,2}, Ye Chen¹, Meizhen Zhao¹, Mengmei Yuan¹, Tieying Zeng^{1*} and Meiliyang Wu^{1*}

Abstract

Background Perinatal loss is a severe stressor that usually triggers distressing symptoms of acute grief. Moreover, acute grief can worsen with time and become a chronic debilitating state known as complicated grief. However, there is a lack of comprehensive reviews on this topic. This systematic review aims to synthesize the existing literature on complicated grief following the perinatal loss.

Methods We systematically searched PubMed, Embase, Cochrane Library, CINAHL, ProQuest, and Web of Science to identify articles on complicated grief symptoms and influencing factors following perinatal loss. We performed a comprehensive, structured evaluation in full compliance with PRISMA guidelines.

Results A systematic search produced 1163 results. Of these, 38 articles met the full-text screening criteria, and 10 pieces of literature met the inclusion criteria. Individuals may experience complicated grief following perinatal loss, manifesting in symptoms such as emotional reactions, physical responses, and social impairments. Furthermore, based on existing evidence, influencing factors include demographic characteristics, reproductive characteristics, marital relationships, social support, and coping strategies.

Conclusions Complicated grief following perinatal loss is easily overlooked and has not been adequately studied. Further empirical research is needed to explore the symptoms and factors influencing this condition. A better understanding of complicated grief will help develop and optimize care strategies, informing future clinical practice and improving psychological support for individuals affected by perinatal loss.

Trial registration PROSPERO registration number: CRD42023473510.

Keywords Perinatal loss, Complicated grief, Symptoms, Influencing factors, Systematic review

Introduction

Perinatal loss (PL) refers to pregnancy loss or neonatal death occurring between conception and 28 days after birth [1], including embryo damage, fetal death, miscarriage, stillbirth, neonatal death, etc. [2, 3]. It is estimated that nearly 7,000 stillbirths and 6,700 neonatal deaths occur daily worldwide, and 14%–20% of all pregnancies end in miscarriage [4, 5]. With medical advances, the incidence of perinatal loss has decreased in recent years, but 30% of women still experience perinatal loss [6].

The occurrence of perinatal loss is a devastating and traumatic event for parents, seriously affecting their physical and mental health [7]. Perinatal loss often

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occurs suddenly and unexpectedly. Compared with other bereavement events, in addition to immense grief, there are also many ambiguous and misunderstood situations. The pregnant woman may not know the exact time and cause of death, may be unable to disclose the details to others, and may have no specific person to mourn [8]. Additionally, there is a public misconception about perinatal loss, which is generally perceived by society as a 'non-event' or 'just a miscarriage', and the fetus as a 'non-person' [9]. Under the influence of many factors, perinatal loss tends to have a tremendous psychological impact on women and their family members, who may experience extreme sadness, irritability, shock, and emptiness [10]. Between 15–25% of parents experience symptoms such as anxiety [11], depression [12], or post-traumatic stress [13] following perinatal loss. When parents experience symptoms such as excessive worry, excessive self-blame, low mood, or excessive stress, they are identified after and caused by the loss, they are part of "complicated grief [14]." Complicated grief also increases the incidence of cardiovascular disease, diabetes, substance use, and suicide [8, 15, 16].

Grief occurs in all forms of loss, and 'normal grief' is a universal response to feelings of loss and is considered a physiological and instinctive response [17]. Although grief can be very painful, some people gradually regulate their emotions over time and adapt to the world in which the loss has occurred [18]. Yet, for many people, grief does not ease but remains intense and disabling, extending beyond the expected duration and course of the grieving process [19, 20]. In current research, we use complicated grief (CG) to refer to this ongoing grief response, which is also often known as prolonged grief (PG) or traumatic grief (TG), with CG being the most widely used term in the literature. It is more devastating and pervasive than 'normal grief,' and is characterized by persistent searching for and remembrance of the deceased, as well as intense and distressing emotions [21, 22]. CG describes a prolonged state of grief with a twelve-month duration criterion to ensure that 'normal grief' reactions in the acute post-bereavement state are not confused with complicated grief [23, 24], suggesting that the individual is unable to accept and release the death psychologically, and to integrate the death into life [25]. Currently, there is no consensus on the symptoms and influencing factors of CG, but it is a common and clinically significant disorder that represents a pathological grieving process [12, 26]. It is therefore not surprising that there is debate about CG in the medical and psychological literature, including its diagnostic classification and disease nomenclature. It is referred to as prolonged grief disorder (PGD) in the International Classification of Disorders (11th Edition) (ICD-11) [27], whereas

the Diagnostic and Statistical Manual of Mental Disorders (Fifth Edition) (DSM-5) called it persistent complex bereavement disorder (PCBD) [28].

Perinatal loss can be one of the most devastating events parents experience and may have serious long-term consequences for their mental health [29]. Kersting and Wagner [30] found that 25–30% of parents experience CG following perinatal loss. It is characterized by persistent, distressing, and debilitating symptoms, leading to physical, psychosocial, emotional, and cognitive changes. Lunderoff et al. [31] identified CG as a bereavement-specific syndrome that requires targeted treatment. Currently, the understanding of complicated grief following perinatal loss remains uncertain and insufficient. Some studies have focused only on the symptoms and factors contributing to 'normal grief' without exploring those associated with complicated grief. Overall, according to the findings, a significant proportion of parents with perinatal loss have experienced CG [16, 25]. However, the symptoms of CG following perinatal loss and its influencing factors remain unclear. Through searches in relevant systematic review databases, we have not found any published or ongoing systematic reviews on this topic. To fill this gap, we conducted a systematic review of the relevant evidence in this field, aiming to comprehensively synthesize the symptoms of CG following perinatal loss and explore the influencing factors contributing to its development. This study can provide a theoretical foundation for preventing CG following perinatal loss, reduce the incidence of CG among parents after perinatal loss, and ultimately enhance their psychosocial outcomes.

The purpose of this study was to conduct a systematic review of the existing literature on CG following perinatal loss. Specifically, there were two research questions: 1) What are the symptoms of CG following perinatal loss? 2) What are the factors influencing CG following perinatal loss?

Methods

Preregistration

This study was preregistered in PROSPERO's international registry of systematic reviews under registration number CRD42023473510. We complied with the Preferred Reporting Items for Systematic Reviews and Meta-Analysis PRISMA guidelines [32].

Search strategy

We conducted literature searches in PubMed, EMBASE, Cochrane Library, CINAHL, ProQuest, and Web of Science databases between 17 October and 12 November 2023. The search time frame in electronic databases was limited within the period from database inception through 12 November, 2023, for published articles. A

combination of keywords was used for searching, and relevant studies were traced and supplemented by consulting the reference list to ensure a complete search rate. The keywords searched were: perinatal loss OR fetal death OR perinatal death OR miscarriage OR stillbirth OR embryo damage OR neonatal death AND prolonged grief OR complicated grief OR traumatic grief OR delayed grief OR dysfunctional grief OR abnormal grief OR chronic grief OR distorted grief OR morbid grief OR maladaptive grief OR persistent complex bereavement-related disorder. Two researchers (X.Z and Y.C) performed the literature search independently. For detailed search strategies for each database, please see Supplementary File 1.

Inclusion and exclusion criteria

After the preliminary database search, two researchers (X.Z and Y.C) reviewed and screened the literature in two steps: 1) removing duplicate literature by reading the title and abstract and 2) reading the full text. Each potential literature was labeled as “included,” “excluded,” or “unclear,” and the presence of an “unclear” paper was judged and evaluated by a third researcher (T.Y.Z) and finally resolved through research group discussion. When full text was unavailable, we contacted the original authors to obtain it. Studies were selected according to the inclusion and exclusion criteria.

The inclusion criteria in this review include 1) original studies, peer-reviewed and formally published; 2) parents over 18 years of age who experienced perinatal loss (miscarriage, fetal death, stillbirth, neonatal death, etc.); 3) studies focusing on complicated grief in parents with perinatal loss. Exclusion criteria included: 1) study subjects with severe psychiatric disorders or comorbidities; 2) literature with missing data and duplicate publications; 3) books, conference abstracts, reviews, news, or research protocols; 4) studies published in languages other than English.

Data extraction and quality assessment

Two researchers (X.Z and Y.C) reviewed the selected papers and extracted the key information of the research into Excel files after discussion in the research group. The selected papers were then reviewed to identify the findings related to the two research questions. The relevant information was extracted into the Excel file under the following research title.

- (1) the symptoms of CG following perinatal loss
- (2) the influencing factors of CG following perinatal loss

For quality review purposes, two researchers (X.Z and Y.C) were assessed separately using the Critical

Assessment Skills Programme (CASP) standards (<https://casp-uk.net/>). Each paper was reviewed and categorized as obvious or not obvious by the CASP criteria, and a third researcher (T.Y.Z) was asked if there was any disagreement. Papers were not excluded from this review, but the weighting of the body of literature was moderated.

Results

Literature search

According to the search strategy, 1163 articles were retrieved from six databases. After excluding studies that did not meet the inclusion criteria, 10 studies were finally included in the systematic review. The specific PRISMA flowchart is shown in Fig. 1.

Characteristics of included studies

The characteristics of the included studies are shown in Table 1. Studies were published between 2007 and 2023. A total of 10 articles from different countries were included in this systematic review: Australia ($n=2$), USA ($n=2$), Germany ($n=2$), Spain ($n=1$), France ($n=1$), Brazil and Canada ($n=1$), Denmark ($n=1$). The sample was recruited primarily through perinatal loss support associations, hospitals, social media, letters, or snowball sampling. The number of participants in each study ranged from 10 to 831, with 2374 participants included in this review. Six of the studies specifically focused on mothers after perinatal loss [33–38], one on fathers [39], and three included both mothers and fathers [40–42].

Symptoms of CG following perinatal loss

Given the different perspectives of scholars on CG, it is important to focus on the symptoms of CG following perinatal loss. In the literature included in this study, a range of symptoms of CG following perinatal loss have been identified. Firstly, the delayed onset and intensity of grief following perinatal loss are emphasized as a significant symptom [43, 44]. Parents may experience prolonged and profound grief that may persist for 5–10 years after perinatal loss [35, 45]. Another prominent symptom following perinatal loss is emotional reactivity, including intense feelings of sadness, guilt, anger, anxiety, and depression [33, 35–39, 42]. These emotional responses often intertwine to form a complex and profound psychological burden, making it difficult for parents to escape from distress and turmoil [46, 47]. Feelings of guilt may stem from a sense of responsibility for the perinatal loss [35], and anger may arise from perceived injustices [39]. At the same time, anxiety and depression may represent doubts about the future and one’s self [33].

CG following perinatal loss not only manifests itself as symptoms in terms of emotional reactivity but may also

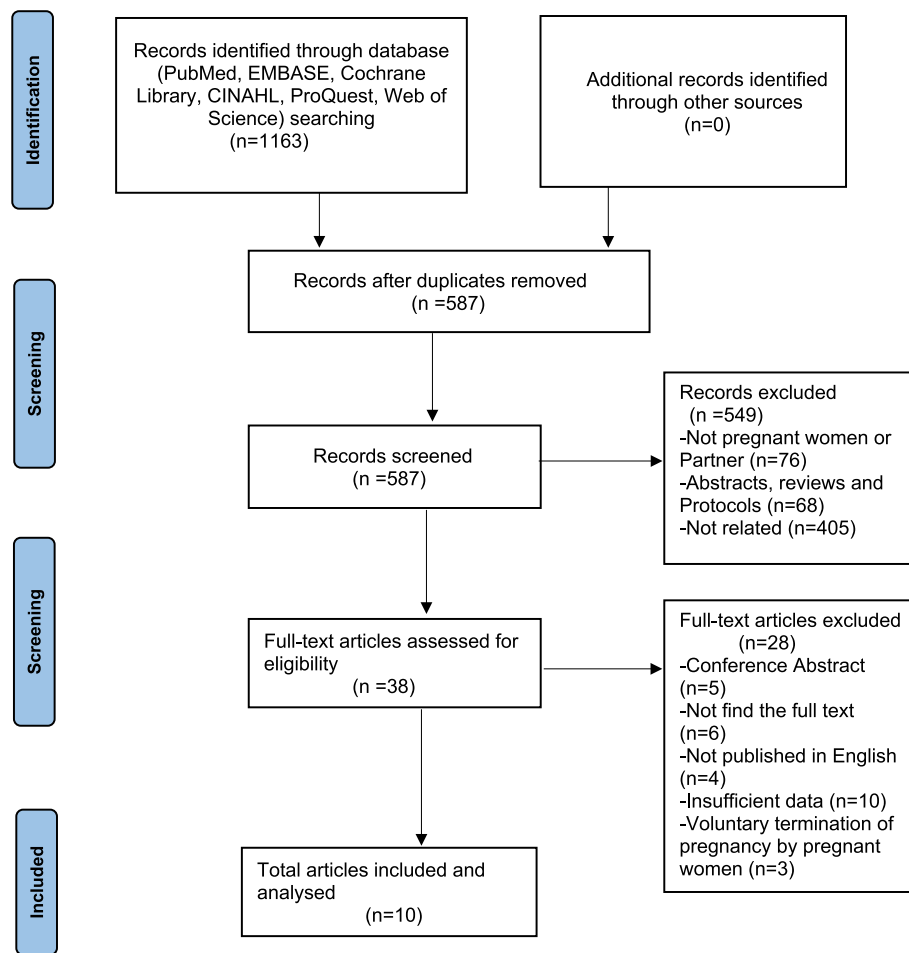


Fig. 1 PRISMA flow diagram of the studies screening process

trigger a range of physical responses. Many parents live in unending pain after loss, and this pain is not only psychological but may also translate into physical discomfort and symptoms, with physical discomforts such as sleep disturbances and stabbing pain [35, 39, 41]. Nightmares are also one of the common physical symptoms of CG following perinatal loss [19]. Parents may experience frequent nightmares that may be related to their lost child or scenes associated with the loss [42]. These nightmares may exacerbate their pain and grief.

In addition, social impairments are among the symptoms of CG of perinatal loss, including difficulties in communicating with others, interpersonal relationship disturbances, and the emergence of avoidance behaviors [38, 40, 41]. Parents may feel misunderstood and isolated as society often lacks understanding of the grief following perinatal loss [41]. This situation can lead to a range of avoidant behaviors and a reluctance to interact with others, resulting in difficulties integrating into everyday life. If this maladaptive state persists over a long period, it

can affect family and intimate relationships, leaving them alienated and disturbed in their interactions with others [34].

Influencing factors of CG following perinatal loss

In general, there was some overlap in the included literature in terms of the factors influencing the perinatal loss of CG. Some of the factors influencing CG were derived from qualitative studies ($n=3$) [34, 36, 39], and only one paper used questionnaire data from a large longitudinal cohort [42], limiting the applicability of this evidence. The specific factors included in the review are shown in Table 1.

After reviewing the research findings, we have identified that sociodemographic factors, including age, religious beliefs, level of education, and work, can have a certain impact on the development of CG following perinatal loss [35–38]. Individuals aged between 20 and 34 years, who have no religious beliefs, have completed 12 years or less of formal education, and are unemployed, tend to be more

Table 1 Data extraction for included studies

First author, year, country	Title	Methodology	Demographic characteristics	Symptoms	Influencing factors
Azeez et al., 2022, Australian [39]	Overwhelming and unjust: A qualitative study of fathers' experiences of grief following neonatal death	Qualitative research design was used, and thematic analysis was adopted for data analysis	Participants for this study were ten Australian men and had experienced a neonatal death at least six months earlier. The aged range was 31–42 years (M = 35 years, SD = 3.46)	Highly emotional, grief on identity, physical symptoms (sleep disturbances, nightmares, stabbing pain, or general bodily pain), anger, sense of injustice	Gender role socialization, personality and culture, models of coping
Buskmitter et al., 2023, USA [33]	Validation of a Brief Measure for Complicated Grief Specific to Reproductive Loss	Cross-sectional study, The Brief Grief Questionnaire (BGQ) was used to describe grief after perinatal loss	140 women, the aged range was 31.2–39.0 years (M = 35 years)	Emotional response, trauma symptoms, anxiety, depression	Reminder symptoms, the use of psychiatric medications, Suboptimal timing of the next pregnancy
Cassidy et al., 2023, Spain [40]	The Disenfranchisement of Perinatal Grief: How Silencing and Self-Censorship Complicate Bereavement (a Mixed Methods Study)	Based on an ethnographic and mixed-methods research design	Three heterosexual couples and seven women in heterosexual relationships	Undermining support, meaning-making and continuing bonds	The passing of time, competing discourses of loss, the biometrics of pregnancy, gendered ideas of reproduction and feeling rules, asymmetries in social power, social spheres, social-materialities and performance/ritual, and structural aspects of social and familial organization
Grauerholz et al., 2021, United States [34]	Uncovering Prolonged Grief Reactions Subsequent to a Reproductive Loss: Implications for the Primary Care Provider	Qualitative research design was used, and summative content analysis was adopted for data analysis	164 recent website blogs from female participants who self-reported having experienced a miscarriage or abortion in their lifetime	Ambiguity of the loss, lack of acknowledgment, and support from loved ones, maladaptive occupational adjustment, impact of multiple pregnancy losses	Subsequent relationship problems, substance misuse, depression, suicidal ideation, and PTSD
Kokou-Kpoulou et al., 2018, France [35]	Persistent depressive and grief symptoms for up to 10 years following perinatal loss: Involvement of negative cognitions	Adopting a cross-sectional quantitative methodology	Sample included 98 bereaved mothers, all of French nationality. Their mean age was 33.89 years (range = 20–49 years, Mdn = 33)	Depressive symptoms, painful, prolonged and debilitating symptoms	Cause of the death, negative cognitions about the world, cognitions and type of death
Paris et al., 2016, Brazil and Canada [36]	Factors associated with the grief after stillbirth: a comparative study between Brazilian and Canadian women	This was a cross-sectional, descriptive, exploratory study	26 women that experienced a stillbirth registered in the Mortality Information System (SIM), living in the Mairingá, and 18 women that attended the Centre d'Études et de Recherche en Intervention Familiale (CERIF) in Canada	Intense, prolonged, distressing, disabling suffering; high anxiety and postpartum depression	Sociodemographic characteristics (age, religion, formal educational, paid job); reproductive characteristics (previous pregnancy with live-born baby; absence of occurrence of previous loss; and unintended pregnancy); marital satisfaction
McSpedden et al., 2017, Australia [37]	The presence and predictors of complicated grief symptoms in perinatally bereaved mothers from a bereavement support organization	The method of cross-sectional survey and questionnaire was adopted	A total of 121 mothers completed the questionnaire, ranging in age from 23 to 52	Intense distress; a range of cognitive, emotional, and behavioral symptoms; and functional impairment, all persisting for at least 6 months	The presence of living children, loss of time to occur

Table 1 (continued)

First author, year, country	Title	Methodology	Demographic characteristics	Symptoms	Influencing factors
Kersting et al., 2013, Germany [41]	Brief Internet-Based Intervention Reduces Posttraumatic Stress and Prolonged Grief in Parents after the Loss of a Child during Pregnancy: A Randomized Controlled Trial	Participants were recruited through a website, which presented general information about the intervention and its treatment modules, and outlined the study procedure	228 parents were identified as eligible, gave their informed consent, and were randomized using a true random number service	Traumatic stress, separation distress, intrusions thoughts, avoidance behavior, and hyperarousal	Self-confrontation, cognitive restructuring, social sharing
Kersting et al., 2007, Germany [38]	Complicated grief after traumatic loss: A 14-month follow up study	A longitudinal study design was used in the study	62 women who had undergone termination of pregnancy (TOP)	Grief related intrusions, behavior to avoid grief-related emotional stress, difficulties/ failures to adapt to the loss	Strength of religious faith, extent of belief in necessity of psychotherapeutically support, extent of fear that the child is not healthy, wish for a child, extent of social support, and life time mental health
Mork et al., 2023, Denmark [42]	Grief trajectories after loss in pregnancy and during the neonatal period	Used questionnaire data from the Danish longitudinal cohort	Parents bereaved in pregnancy from 14 weeks of gestation, during birth, or within the first months after birth, included 676 parents	Intense emotional pain, a profound longing for and preoccupation with the deceased to an impairing degree for a duration of at least six months	Type of loss, gender, previous losses in pregnancy, and any living children

vulnerable to experiencing complicated grief following perinatal loss [35, 36]. Additionally, reproductive-related characteristics, such as gestational age, manner of loss, unintended pregnancy, prior experiences of related loss, and timing of subsequent pregnancies, are closely associated with the occurrence of CG following perinatal loss. The presence of living children is an important risk factor [37]. If the presence of a living child may affect the formation of CG to some extent, parents can often put their emotions on the line and place their relational points on other children [36]. CG is also exacerbated by gestation periods greater than 28 weeks [36], which may be related to the attachment relationships formed by the fetus.

There may be risk factors for CG associated with the perinatal loss itself. For example, marital relationships, especially after loss, have been repeatedly proposed as risk factors for CG [36, 40]. The quality of the marital relationship after loss may significantly impact an individual's risk of CG [36]. Mutual support and understanding between spouses may ease the burden of grief and loss, whereas conflict, estrangement, or lack of mutual understanding may increase the risk of CG [41].

The formation of CG following perinatal loss is related to social support and coping strategies. Individuals who experience perinatal loss and receive adequate social support, including emotional support, informational support, and tangible assistance, are generally better able to cope with their sadness and loss [39–41]. Social support can alleviate feelings of loneliness and helplessness, assisting individuals in developing positive coping mechanisms [41]. Furthermore, the coping strategies adopted by individuals facing perinatal loss are crucial in the formation of CG [48]. Adopting proactive coping strategies, such as seeking social support and engaging in supportive activities, can help alleviate grief and anxiety, promote emotional regulation, and facilitate recovery [38].

Discussion

As far as can be ascertained, this is the first systematic review of the literature on CG following perinatal loss that systematically examines the symptoms and influencing factors. Different researchers have studied the symptoms and influencing factors of CG following perinatal loss. However, these studies have yet to form a comprehensive and systematic conclusion. Therefore, this study was designed to summarize the literature on the symptoms and factors influencing CG following perinatal loss using a systematic review approach, with the aim of providing an evidence-based foundation for the development of effective prevention and care interventions, as well as a scientific basis for improving psychological support and care for individuals following perinatal loss in future clinical practice.

A pertinent finding of this review is that parents experiencing perinatal loss have a higher frequency of CG than parents experiencing other types of grief [31, 34]. CG symptoms often persist for a long time, with some lasting up to 10 years or even a lifetime; it is characterized by a high degree of invisibility and diverse symptomatology [35]. CG symptoms following perinatal loss are not only emotional, including intense sadness, guilt, anger, anxiety, and depression [49], but also affect physical well-being. These symptoms can cause physical discomfort, such as sleep disturbances, tingling, and nightmares [50]. CG may also impact social interactions, leading to disconnection from family and friends [51, 52]. These physical and psychological effects can significantly reduce a person's quality of life, affecting work, family and social life [53].

Currently, CG symptoms related to post-perinatal loss are often overlooked or misdiagnosed. Therefore, healthcare workers should pay particular attention to possible CG symptoms and perform a comprehensive assessment when evaluating parents following perinatal loss.

This systematic review found that perinatal loss of CG results from multiple interacting factors, including demographic characteristics, reproductive characteristics, marital relationships, social support, and coping strategies [40, 41]. Although these influences can be difficult to resolve and alleviate, understanding them can help us recognize and respond to CG. Among the identified influencing factors, coping strategies and social support are very important [30, 39]; they can provide emotional support, information, and guidance while reducing feelings of isolation [38]. This review initially integrated the factors influencing CG in perinatal loss. However, it is important to highlight that most of the risk factors discussed in the literature are not empirically supported, but theoretical. Large-scale empirical studies are needed to further elucidate the factors influencing CG following perinatal loss. Despite the shortcomings, the factors identified in the studies are instructive for clinical practice.

Given the diversity of individuals and socio-cultural factors, some understanding exists, but the factors influencing CG following perinatal loss require further exploration. This will help identify high-risk individuals and provide a basis for personalized preventive and intervention measures.

A growing body of evidence supports the hypothesis that people with perinatal loss are at risk of experiencing CG [1, 31, 38]. Importantly, it is considered to be a clinically relevant disorder [54]. CG, which prevents a person from returning to pre-social functioning, has been linked to psychological disorders and an increased risk of death [55]. It is also listed in the DSM-5 as persistent complex bereavement disorder (PCBD) [56]. This systematic review is based on case reports and perspectives that

highlight the importance of focusing on CG in individuals with perinatal loss. However, in a systematic search of six databases, only ten papers met the inclusion criteria. This shows that this is an under-researched area. In particular, no studies with Chinese samples met the criteria. Following perinatal loss, parents are at a vulnerable time, experiencing physical, psychological and life-related stress [57]. If a person has experienced a perinatal loss, coping can become even more challenging and difficult [58]. Timely and accurate identification of symptoms and factors influencing CG following perinatal loss is clinically important in preventing its continuation. It can enable more effective support and interventions to assist parents through this difficult period and facilitate their recovery. Thus, we need larger, longitudinal, empirical studies to deepen our knowledge of this condition and provide evidence on the best ways to clinically support people experiencing perinatal loss with CG symptoms.

This systematic review also has some limitations. First, it only included peer-reviewed studies, excluding grey literature and unpublished studies, which may have led to the omission of some relevant information. Second, the study only searched for English articles and did not include studies published in other languages, which may have resulted in an incomplete literature search. Finally, to ensure comprehensiveness, this review included some studies with lower levels of evidence.

Conclusion

To summarize, this systematic review found that CG is indeed common in parents with perinatal loss. We note several key clinical findings, for the symptoms of CG following perinatal loss are diverse, not only in terms of emotional reactions, but also in terms of a certain degree of negative impact on physical health, and even in terms of impediments to normal social interactions; moreover, in addition to the general influencing factors, social support and coping strategies play an important role in influencing the situation. Currently, it is encouraging that an increasing number of studies have focused on CG following perinatal loss. Therefore, larger scale empirical studies are necessary to explore and study this population in depth, and to provide effective interventions in a timely manner.

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12884-024-06986-y>.

Supplementary Material 1.

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Authors' contributions

XZ, TYZ conceived this study. XZ, YC, MZZ, MMY, MLW, TYZ contributed to final study design and data analysis. XZ, YC, MLW, TYZ completed abstract and full text review and data extraction. XZ, MLW, TYZ produced the first manuscript draft. All authors have read and approved the manuscript.

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Data availability

No datasets were generated or analysed during the current study.

Declarations

Ethics approval and consent to participate

Not applicable.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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