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Mental Health Care during Pregnancy Loss

Considerations for Assessment and Treatment

Julia N. Riddle, MD[a,*], Tiffany Hopkins, PhD[b], Ashton M. Gores, MD, MPH[c], Margo D. Nathan, MD[a]

[a]Department of Psychiatry, University of North Carolina School of Medicine, 333 South Columbia Street, Chapel Hill, NC 27517, USA; [b]Department of Psychiatry, University of North Carolina School of Medicine, 77 Vilcom Center Drive, Suite 300, Chapel Hill, NC 27514, USA; [c]Department of Psychiatry and Behavioral Sciences, Johns Hopkins University School of Medicine, 600 North Wolfe Street, Baltimore, MD 21205, USA

KEYWORDS

• Perinatal loss • Miscarriage • Stillbirth • Grief • Prolonged grief • Reproductive psychiatry
• Women's mental health • Posttraumatic stress disorder

KEY POINTS

- Grief following perinatal loss has unique features from other bereavement experiences due to disenfranchisement and prospective grieving.
- Rates of mental illness are increased in the year following perinatal loss, particularly stillbirth.
- There is strong evidence that spouses, partners, and/or other family members experience clinically significant distress and may also need support.
- Several psychotherapies show promise following perinatal loss, including cognitive, interpersonal, trauma-specific, and mindfulness-based interventions.
- Additional research is needed in the treatment of patients and families following perinatal loss, particularly those at high risk of developing psychiatric comorbidities.

INTRODUCTION

Perinatal loss is estimated to occur in 20% of all known pregnancies [1,2]. Many miscarriages happen before the first prenatal appointment, and that combined with the fact that there is no formal reporting requirement for losses means that the true prevalence is likely higher. There have been few comprehensive studies on psychiatric outcomes following perinatal loss, and even fewer on effective treatment modalities. Nonetheless, there are myriad dedicated clinicians and community workers delivering care to these patients. This article uses both what is present in the literature as well as our clinical experience to provide recommendations for caring for these patients in the months and years following perinatal loss.

These recommendations are not directed at immediate obstetric care of loss, as there is some literature available with best recommendations; rather, this is for the providers who see these patients outside of the specific loss episode, which can occur at home, in an ambulatory setting, in an emergency room, or on an inpatient unit.

*Corresponding author. UNC-Chapel Hill, Department of Psychiatry, MacNider Hall, Campus Box 7160, 333 S Columbia Street, Chapel Hill, NC 27517. *E-mail address:* Julia_riddle@med.unc.edu

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TYPES OF PERINATAL LOSS

Perinatal loss includes multiple types of unexpected pregnancy outcomes. See Table 1 for common terms and definitions. In addition to these common types, there are other mechanisms by which pregnancies can fail, including molar, chemical, and ectopic pregnancies and blighted ova; these are not generally included in literature on losses but are clinically experienced as perinatal loss by many patients. Patients struggling with infertility may also experience a sense of loss as they deal with varied challenges and medical interventions. While this type of loss is vital to appreciate in a reproductive population, it is beyond the scope of this review.

STATE CONSIDERATIONS

Patient experience of loss in the settling of pregnancy complications differs from state to state, in part, because of differences in local and federal laws around maintenance and termination of pregnancy—and patient experiences will thus be affected not only by the loss itself but also by legal and political battles surrounding medical decision-making. In the case of TFMR, states vary in the standard by which a patient can access termination care. In some cases, patients will either have to travel outside of their state for access to termination services or have to remain hospitalized while monitoring the trajectory of a worsening maternal condition (eg, waiting for hemolysis, elevated liver enzymes, low platelet count [HELLP] syndrome to progress to becoming life threatening). It is vital for clinicians to understand these legal parameters of care, to relieve the patient from having to be the source of education.

TABLE 1
Common Perinatal Loss Terms and Definitions

Type of Loss	Description
Spontaneous abortion/ miscarriage	Loss of pregnancy before 20 wk' gestation
Early	Before 12 wk' gestation
Late	Between 12 and 20 wk' gestation
Stillbirth/intrauterine fetal demise (IUFD)	Loss after 20 wk' gestation
Neonatal death	Death of newborn from birth to 28 d of life
Termination for medical reasons (TMFR)	Cessation of pregnancy due to fetal or maternal medical complications
Loss of fetus(es) in twin or multiple pregnancy	Fetal demise of one or more fetuses, while other fetuses survive, in a multiple pregnancy

PSYCHOLOGICAL SEQUELAE

Grief

Grief is the common and normal response to perinatal loss. An estimated 80% of women experience grief following perinatal loss, though the true prevalence remains unknown, particularly following miscarriage [3]. Grief following perinatal loss is often "disenfranchised grief"—a loss for which there is no physical manifestation to mourn and no standard rituals [4,5]. This can be particularly true in early loss, when the pregnancy has not been shared or celebrated with the patient's community. Thus, to gather support, patients will need to reveal to their family, colleagues, and communities their plans for pregnancy and family expansion as well as their loss at the same time. Another unique feature of perinatal loss grief is that it involves prospective grieving. Unlike retrospective grieving, which can include actual memories of the deceased that are shared by others, prospective grieving involves mourning future concepts of self, family, and the lost child [6,7].

One trajectory of grief following perinatal loss, based on Glen Davidson's model [8,9], is well articulated in Rich 2018 (abbreviated in later discussion).

1. Weeks 2 to 4: *Shock and numbness*—bereaved parents experience episodes of unreality alternating with emotional intensity. It is during this time that families share news and potentially plan for the handling of fetal/newborn remains.
2. Months 1 to 3: *Searching and yearning*—marked by profound longing for a relationship with the deceased child. Parents experience sleep disruption, decreased appetite, and difficulty with daily routines. There can be preoccupation with memorializing baby/pregnancy.
3. Months 4 to 6: *Disorientation*—a time of coming to terms with the new normal, including forced adaptation and grappling with the reality of a lost baby.
4. Months 9 to 12: *Reintegration*—parents become more actively involved in life, including normal activities and future planning. At this point, there is often also a subsequent pregnancy.

While the earlier mentioned timeline ends at month 12, patients often experience resurgences of grief

surrounding important dates (due date, loss date, holidays, and patient's own birthday) and/or at random. These are termed shadow grief or, more colloquially, "grief attacks." They are generally considered a normal process, though they must be differentiated from symptoms of posttraumatic stress disorder (PTSD).

Prolonged Grief

Prolonged grief disorder (PGD; previously complicated grief) remains a controversial diagnosis and one we discuss more at length in later discussion. Prolonged grief occurs in approximately 30% of women following perinatal loss [10,11]. Risk factors include history of mental illness, poor social support, ambivalence toward pregnancy, highly neurotic personality traits, and sudden and/or traumatic loss [12].

Mental Illness

Rates of psychiatric illness following perinatal loss are elevated, particularly in the first year. We describe in later discussion what is known about the link between psychiatric illness and perinatal loss, as well as existing gaps in this literature:

Depression or major depressive disorder (MDD) has been the most studied psychiatric condition in relation to perinatal loss, with studies showing that between 20% and 50% of women report subsyndromal symptoms and 10% to 20% women report symptoms that are moderate to severe within 6 months of the loss [13]. Some studies report an increased risk for suicidal ideation and self-harm in the first year after loss, even in the absence of prior psychiatric history [14,15]. Risk factors for developing MDD after a loss include prior perinatal loss, previous diagnosis of MDD, exposure to trauma, younger age, lack of social support, and IUFD [14].

In addition to depressive disorders, increased rates of anxiety disorders and symptoms of trauma-related disorders (eg, acute stress reaction and posttraumatic stress disorder [PTSD]) are also seen in relation to perinatal loss [16]. Within trauma disorders, PTSD rates are up to 7 times higher in women following a perinatal loss compared with a live birth [17], and some studies have shown that these symptoms can persist well beyond 1 year following the loss [17]. To date there has been limited investigation of perinatal loss in relation to primary psychotic disorders, such as schizophrenia; however, an increased risk for psychotic symptoms has been identified in this population [14]. Lastly, the association between substance use disorders and perinatal loss is under explored; however, one study following women within a year of loss showed increased rates of presentation to an emergency room or hospital setting for alcohol or substance use disorder [14], though additional research is needed to further explore this area.

CLINICAL ASSESSMENT

Initial assessment in any mental health intake following perinatal loss must accomplish the following:

1. Build rapport with the patient,
2. Screen for the presence of and/or risk factors for the development of mental illness and/or substance use disorders,
3. Perform a risk assessment,
4. Provide psychoeducation on grief and risk factors for developing mental illness, and
5. Develop an initial plan for the next steps.

Building Rapport

Setting the tone of a patient encounter should be the foundation of all clinical interactions. Many referrals for psychological/psychiatric care come from concerned obstetric or family medicine colleagues. For many patients, this is their first encounter with a mental health practitioner, and they are not clear on exactly what they are seeking. Pitfalls and pearls of clinical care for patients following perinatal loss are described in Table 2.

Screening for Mental Illness

Diagnosis is not always easy and immediate during the initial assessment following perinatal loss. The greatest risk factors for the development of mental illness following perinatal loss include prior diagnosis of mental illness, experiencing a stillbirth, younger age, history of trauma/abuse, being single, marital discord, history of infertility, and/or infertility treatments [12]. Gathering information on prior psychiatric care, symptoms, and treatments is imperative.

While there is urgency for a tool that can differentiate normal grief from illness, our highest recommendation is frequent appointments with patients, assessment of functioning, safety planning, and engagement/collateral report from their support system. Some helpful screening scales are listed in Box 1.

Additionally, assessing the use of alcohol and other substances is important. As mentioned earlier, rates of substance use and dependence have been shown to be increased following loss [14].

Differentiating Grief from Other Symptoms

Grief, PGD, depression, and PTSD occur commonly and often concurrently in the setting of perinatal loss [17].

TABLE 2
Building Rapport: Common Pearls and Pitfalls in Patient–Clinician Relationship and Rapport Following Perinatal Loss [6]

Pearl/Pitfall	Description
Consider language related to the loss	• Ask the patient how they would like to refer to the loss. Patients may prefer medical terms (eg, embryo and fetus), the term baby or child, or use of a specific name • Not using preferred terms can be invalidating to the patient
Validate grief regardless of gestational age at time of loss	• A common clinical error is minimizing the grief following miscarriage, particularly early miscarriages, due to a belief that the pregnancy did not progress far enough to allow for significant attachment [6]
Allow grief without the need for actionable items	• Part of psychoeducation is helping patients understand the grief process without pathologizing it • Often patients have not experienced loss/grief before and want help understanding what is "normal" • Allowing patients to grieve openly can be the primary goal
Take a reproductive history and consider prior losses	• A reproductive history of prior pregnancies and outcomes can help to clarify prior potential postpartum risks (eg, if they developed obsessions and compulsions following a prior pregnancy) • The current loss may reignite thoughts and feelings, including unresolved grief, from prior losses [6]
Consider culture and/or religion	• Understanding the role of familial, ethnic, and religious culture provides insight into feelings of isolation, pressures to ignore grief, and/or opportunities to find meaning [18]
Do not focus on future pregnancies	• Focusing on future fertility plans and/or assuming that grief will resolve with a subsequent pregnancy is a common pitfall [6] • Patients often receive messaging about the "next pregnancy" from their community (eg, family, friends, spouse, and work), so providing a space to focus on the present and prior loss is advised • Allow patients to dictate the discussion about future attempts at conception

BOX 1
Helpful Screening Scale: Some Screening Scales that May Help to Clinically Elicit Symptoms of Grief and/or Anxiety, Depression, and Posttraumatic Stress Disorder

Clinical screening scales

Validated in perinatal loss population:

- The Perinatal Grief Scale [19]

Not validated in perinatal loss population, but potentially helpful:

- Generalized Anxiety Disorder Scale [20]
- Posttraumatic Stress Disorder Checklist for The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) [21]
- Quick Inventory of Depressive Symptomatology [22]
- The Edinburgh Postnatal Depression Scale (EPDS) [23][a]

[a] If the EPDS is used, we advise careful consideration of the first sentence in the instructions, which is "Since you are either pregnant or have recently had a baby, we want to know how you feel." For patients dealing with loss, particularly if they are completing scales before meeting the clinician, the inclusion of this language may hinder trust and treatment. It may be beneficial to produce a version of the scale without this sentence for this population.

There is a dearth of research to distinguish these conditions from one another in perinatal loss populations; as such, we borrow from the available literature in other bereaved populations to elucidate these diagnoses and their treatment implications. Several factor analyses among other bereaved populations suggest that PGD, depression, and PTSD are distinct conditions that can be independently determined [24,25]. Among these findings, symptoms of interpersonal isolation and hypervigilance tended to be separating characteristics of PTSD, while feelings of guilt or worthlessness and irritability distinguish depression, and role confusion and difficulties trusting others distinguish PGD [24,26,27]. Some studies suggest that early signs of PTSD may confer a higher risk of developing PGD later [11]. Understanding distinctions among these conditions may provide insight to guide more directed treatments. Distinguishing symptoms and criteria for grief, PGD, PTSD, and depression are presented in further detail in Table 3.

Risk Assessment

While different approaches can have value—more structured intakes versus open-ended patient-led intakes—it is critical that clinicians perform risk assessments. As with all patients, risk assessments have multiple components: static risks, dynamic risks, intent, access to means, and safety planning. In our experience, when assessing suicidal ideation, exchange thoughts/fantasies (ie, "I don't want to die, but I do wish it would be me instead of the baby") or thoughts of being with the child ("I wish I could be with them") are not uncommon. The true prevalence of these types of thoughts is not known, but clinical assessment of these types of statements and their changes over time are imperative.

The strongest risk factor for attempted or completed suicide is prior suicide attempts. Other risk factors include prior suicidal ideation, nonsuicidal self-harm, history of physical or sexual abuse, family history of psychiatric illness or suicide, and history of witnessing suicide or suicidal behavior [28]. Protective factors include other children, sense of support, and lack of prior suicide attempts [12].

Psychoeducation

Psychoeducation about grief and what to expect has been demonstrated to reduce symptoms of grief, anxiety, and depression [29]. Psychoeducation about grief can include information included earlier as well as discussion of the fact that grief often changes and morphs from day to day. Common analogies include grief spirals, riding waves of grief, or the ball-in-the-box. The ball-in-the-box metaphor is as follows: soon after loss, you can imagine yourself inside a small box with a ball and you are continually struck by the ball with intense grief. With time and support, the box gets bigger (or the ball gets smaller) and, while you are still hit with intense moments of grief, they will occur less often. This process happens naturally over time. Finally, while the data are still lacking on perinatal loss grief, there is some evidence that it peaks around 6 months [30].

TARGETED TREATMENT

Psychotherapeutic treatment can take many forms and should be determined on the basis of the primary presenting problem (ie, general or prolonged grief, depression, and PTSD), patient goals and preferences, and provider training. To date, there is scant research on applications of therapy to perinatal loss, so our recommendations are derived from studies of gold standard treatments for the common psychological sequelae described earlier and research on how these gold standard treatments perform in bereaved populations more specifically. There are several transdiagnostic psychotherapies that show evidence of benefit for general grief and an array of psychological disorders (eg, depression, anxiety, and acute stress disorders). Specifically, cognitive behavioral therapy (CBT), acceptance and commitment therapy (ACT) [31,32], and mindfulness-based interventions [33] all demonstrate some evidence of benefit for these presenting problems and have many commonalities. Interpersonal Psychotherapy (IPT) [34,35] also demonstrates some benefits for depression and prolonged grief related to perinatal loss. While most clinical structures and studies focus on the patient that carried the pregnancy and loss, there is strong evidence that spouses, partners, and/or other family members experience clinically significant distress [36]. Including them in assessment and treatment should be considered best practice.

Given the absence of specific adaptations for perinatal loss, we offer a few considerations for providers based on our clinical experience, alongside guidance from the literature when available. With regard to CBT, providers should be particularly thoughtful about orienting to the concept of cognitive distortions and cognitive restructuring, so as not to inadvertently invalidate normative thoughts, emotions, and behaviors central to loss. However, cognitive distortions are not uncommon, with frequent self-blame in the absence

TABLE 3
Overlapping and Distinguishing Characteristics of Grief/Prolonged Grief Disorder, Posttraumatic Stress Disorder, and Depression

Grief/PGD	PTSD	Depression
Overlapping characteristics: All		
• Feelings of bitterness or anger in relation to the loss	• Persistent negative emotional state • Irritability and angry outbursts with little/no provocation	• Low or irritable mood
Overlapping characteristics: PTSD and depression		
	• Sleep disturbance • Impaired concentration • Persistent, exaggerate negative beliefs about self, others, or the world • Persistent, distorted trauma-related cognitions leading to inappropriate blame of self/others • Loss of interest or participation in significant activities	• Sleep disturbance • Impaired concentration • Feelings of guilt or worthlessness/diminished self-attitude • Anhedonia
Overlapping symptoms: Grief/PGD and PTSD		
• Intrusive thoughts related to loss • Avoidance of reminders of the reality of loss	• Recurrent, involuntary, distressing trauma memories • Avoidance of internal (thoughts, memories, and feelings) and external (people, places, and activities) trauma reminders	
Distinguishing DSM-5 criteria		
• Intense separation distress • Distress related to yearnings over loss • Problems accepting loss • Confusion and/or a diminished sense of self such as feeling a part of them has died • Feelings of mistrust toward others since the loss • Experiencing life as unfulfilling, empty, and meaningless since the loss • Numbness or lack of emotion since the loss • Feeling shocked, stunned, or dazed by the loss	• Nightmares • Dissociative reactions or flashbacks related to trauma • Intense or prolonged psychological distress from trauma reminders • Marked physiologic reactions to trauma reminders • Reckless or self-destructive behavior • Exaggerated startle • Trauma-related amnesia • Detached/estranged feelings from others • Hypervigilance	• Changes in appetite • Psychomotor changes
Distinguishing characteristics based on factor analyses of population studies [24,26,27]		
• Confusion and/or a diminished sense of self such as feeling a part of them has died • Feelings of mistrust toward others since the loss • Experiencing life as unfulfilling, empty, and meaningless since the loss	• Avoidance of internal (thoughts, memories, and feelings) and external (people, places, and activities) trauma reminders • Detached/estranged feelings from others • Hypervigilance	• Low or irritable mood • Feelings of guilt or worthlessness/diminished self-attitude

TABLE 4
National Resources for Patients and Families Following Perinatal Loss

Resource	Overview	Web Address
Return to Zero Hope	Online resources, support groups, and provider networks for parents experiencing all forms of perinatal loss. Specific resources for BIPOC[a] and LQBTQ+[b] populations	rtzhope.org
The Compassionate Friends	Resources for families that have had a child die "at any age, from any cause," private social media groups, local in-person, and virtual support groups	compassionatefriends.org
Postpartum Support International	Access to online support meetings, provider directories, resources for providers, and a list of other online resources	postpartum.net/get-help/loss-grief-in-pregnancy-postpartum/
Sisters in Loss	Resources and community for black women experience perinatal loss, infant loss, and infertility	sistersinloss.com/
Star Legacy Foundation	Specific to pregnancy loss with online support groups for parents, partners, and grandparents	starlegacyfoundation.org/support-groups/

[a] Black, indigenous, and other people of color.
[b] Lesbian, gay, bisexual, transgender, queer/question, and other gender/sexuality minor populations (eg, nonbinary).

of any known causality of loss, as well as beliefs about failure, beliefs about weakness for not recovering the ways others in their environment expect, and general high intensity worry. In addition to psychoeducation and cognitive restructuring, the following elements can be particularly helpful: (1) use of values-based behavioral activation; (2) facilitation of exposure to grief-related emotions when avoidance or invalidation from the environment is present; and (3) use of present-centered grounding strategies for rumination, worry, or intrusive memories.

Mindfulness-based interventions, alongside ACT, which heavily incorporates mindfulness practices, also demonstrate utility after perinatal loss. Of note, there is some evidence that mindfulness practices can cause distress in trauma survivors when implemented without a trauma-informed lens [37], so providers should employ mindfulness interventions with attention to these practices (eg, psychoeducation about trauma, offering choice in implementation of practices, and in depth orientation to expectations for practices) in perinatal loss patients. Additional components of ACT are also particularly well suited for perinatal loss, given the therapy's explicit focus on the normative nature of painful life events, nonpathological focus, and importance of acting on values even when experiencing pain. ACT also incorporates skills related to defusing painful thoughts and associated emotions, without experiential avoidance or having to directly challenge or restructure thoughts, which can be helpful when thoughts fit the facts of the loss but are highly distressing [38].

For patients exhibiting PTSD after perinatal loss, trauma-focused interventions should be considered. Literature is particularly scarce on this topic, though a few case studies and series have examined the use of gold standard PTSD treatments following perinatal loss. Preliminarily, there is some evidence for the use of prolonged exposure [39], eye movement desensitization and reprocessing [40], and cognitive therapy for PTSD [41]. Common treatment elements include (1) exposure to trauma memories and emotions; (2) facilitation of approach behaviors or behavioral experiments to previously avoided but safe trauma stimuli; (3) trigger discrimination (ie, differentiating interoceptive or sensory cues that were present during the loss and cause ongoing struggle, such as menstrual blood or cramping); (4) challenging trauma-related belief structures (through direct restructuring or experiential learning); and (5) identifying personal meanings and ongoing impact of the trauma of loss on present functioning. While initial research is promising, treatments for the psychological sequelae of perinatal loss require significantly more investigation to determine best practices.

Psychopharmacotherapy

There are currently no published studies on medication for the treatment of psychological sequelae of perinatal loss. Nonetheless, many patients will receive medication.

One survey study found that, of 235 bereaved parents participating in an online support community, 88 were prescribed medications—most often an antidepressant and a benzodiazepine, and usually within the first month after loss [42]. Until further studies are done, some tenets of treatment remain true in the postloss period: (1) treat the underlying illness if present, for example, PTSD or MDD; (2) consider that the patient will most likely become pregnant again, so conversations about the risks of treatment in pregnancy versus the risk of illness in pregnancy are warranted; and (3) empower the patient to know that medications are a tool to assist in treatment to allow for grieving rather than to "numb away" grief. Additionally, short-term treatment of symptoms like early insomnia can be considered, though further studies are needed to assess efficacy. Newer medications, such as brexanolone and zuranolone, may be of interest, particularly following stillbirth, as the role of hormonal fluctuation and mood symptoms may prove to be similar to those following live birth.

RESOURCES AND USE OF VIRTUAL SUPPORT GROUPS

Patients experiencing perinatal loss often benefit from external resources for community, psychoeducation, and/or advocacy. Developing a list of resources, particularly local, for patients is highly recommended. At the time of publication, some helpful resources have been listed in Table 4. Further resources are needed for minoritized communities, including sexual and gender minorities.

In advising patients, we recommend understanding the role that online communities may be playing in their healing or worsening of symptoms. Many online communities are unmoderated, and patients may find themselves exposed to information or needs from the online community that are more harmful than helpful. Discussing this with patients can help empower them to set boundaries around their use of these communities or to leave unhelpful groups/communities.

SUMMARY

Perinatal loss remains a common and unexpected outcome of pregnancy. The psychological and psychiatric complications that follow perinatal loss require continued research on prevalence, risk factors, prevention of psychiatric illness, and treatment. Our hope is to make health care providers more comfortable and confident in caring for this population.

CLINICS CARE POINTS

- Grief following perinatal loss has unique features including disenfranchisement and prospective grieving. Understanding this process can help clinicians better separate mental illness symptoms from grief. Psychoeducation about grief may help patients in processing their feelings and experiences after loss.
- While grief is the most common response to perinatal loss, rates of mental illness, particularly depression, anxiety, and PTSD, are elevated. Clinicians must remain vigilent in assessing the progression of symptoms and safety risks throughout the post-loss period and not overlook concerning symptoms under the assumption that they are symptoms of grief.
- While more research is still needed, there are promising psychotherapeutic modalities for treatment of mental illness following perinatal loss. Psychotropic medication treatment should aim to treat the underlying illness. The use of medication for prevention of illness deveopment or for grief are currently not well studied.
- Clinicians should remain up-to-date on the local laws related to reproductive health and local perinatal loss resources in the locations where their patients live.

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