

The Grief of Mothers After the Sudden Unexpected Death of Their Infants

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abstract

BACKGROUND: The loss of a child is associated with elevated grief severity, and sudden infant death syndrome (SIDS) is the leading cause of postneonatal mortality in the United States. The diagnosis of prolonged grief disorder (PGD) has gained broader acceptance and use. Little is known about PGD in mothers after SIDS.

METHODS: Between May 2013 and July 2016, we assessed 49 SIDS-bereaved mothers living in informal settlements near Cape Town, South Africa, and on the Pine Ridge Indian Reservation and 359 SIDS-bereaved mothers affiliated with SIDS parent-support organizations in the United States, United Kingdom, Australia, New Zealand, and the Netherlands. We examined PGD symptom severity and diagnostic prevalence rates between the samples and other significant grief indicators during the period 2 to 48 months after the deaths of their infants.

RESULTS: Extremely high, persistent, and similar rates of PGD were found in both samples at every time interval. The prevalence of PGD was 50.0% in either sample (mean months from loss: 20.5 vs 24.9). Daily, intrusive emotional pain or yearning was found in 68.1% of subjects; yearning was significantly associated with emotional pain ($P < .0001$). Role confusion and anger were the most prevalent symptoms, reported by the majority at every time interval. Rates of role confusion, anger, and diminished trust in others remained constant. Acceptance was less prevalent than other grief indicators at every interval.

CONCLUSIONS: Severe symptoms and heightened risk for PGD was seen in mothers after their infants died of SIDS, with discernible symptom profiles. Given their involvement with families after SIDS, pediatricians may have a unique role in identifying this problem and helping address its consequences.



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WHAT'S KNOWN ON THIS SUBJECT: The death of a child is associated with high levels of grief in the child's parents. Prolonged grief disorder affects health and well-being and may influence the lives of remaining and subsequent children in a family.

WHAT THIS STUDY ADDS: Half of the mothers suffered from prolonged grief disorder in the 4 years after their infants' deaths from SIDS, with daily, intrusive emotional pain or yearning in 68.1%. Their specific grief-related symptoms may be potential targets for screening and referral.

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Sudden infant death syndrome (SIDS) continues to be a prevalent cause of infant mortality. This category of infant death has a crude mortality rate of 0.9 in 1000 live births¹ and is the leading cause of postneonatal mortality in infants 28 to 364 days of life in the United States. Lacking preparation or warning, a seemingly healthy infant is discovered dead without apparent cause. Pediatricians make significant contributions to the prevention of SIDS.² They are also closely involved in the unfortunate cases when SIDS does occur, with a unique perspective on the burdens to parents and their young families in its aftermath. Consequently, pediatric researchers have historically conducted research on the psychological consequences of SIDS and its ongoing impact on the family after this loss.^{3–10}

Grief is the emotional response to the death of a loved one. It is a normal consequence of profound interpersonal loss yet involves extreme cognitive and emotional symptoms in most bereaved individuals.¹¹ A significant minority of bereaved individuals experience a more enduring grief response that exceeds social norms and causes impairment in daily functioning. Prolonged grief disorder (PGD), formerly called complicated grief and alternately called persistent complex bereavement disorder,¹² is diagnosed as a pathologic response at the extreme of grief and is distinct from posttraumatic stress disorder or depression.¹³ PGD involves the persistence of separation distress, characterized by significant emotional pain and yearning in addition to cognitive, emotional, and behavioral symptoms >6 months after a significant loss.¹⁴ A recent meta-analysis found PGD in 9.8% of bereaved persons 1 year after loss.¹⁵ PGD has been documented in populations worldwide.^{16–18} It is associated with diminished health and quality of life.¹⁴ PGD criteria

are included as an appendix in the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* under persistent complex bereavement disorder¹² and will be included in the *International Classification of Diseases, 11th Revision*.¹⁹

The experience of grief is unique to each loss, but certain factors predict more significant grief-related morbidity. Grief may be understood as an attachment response, and close kinship is a significant risk factor.²⁰ The bond between a parent and a young, dependent child is the prototypical attachment bond,²¹ and the death of a child has been shown to cause extreme and long-lasting grief in parents.^{22–24} Mothers in particular are at risk for especially severe grief.^{25–27} Other risk factors for more difficult grief include sudden death,²⁸ a lack of preparation,²⁹ and the death of a dependent, younger child³⁰ as well as poverty and previous losses.³¹ These risk factors for more severe grief are also specific aspects of a SIDS death and risk factors for SIDS. Researchers who study parents whose infants died of SIDS describe a difficult experience during bereavement³² with a lasting, often unrecognized, impact on the parents' daily lives.³³

Hypothesizing that a SIDS death would predict a severe grief response, here we investigate the prevalence and symptom presentation of PGD in mothers whose infants died of SIDS. We studied grief in 2 cross-sectional samples of mothers whose infants had died of SIDS in the previous 2 to 48 months, examining rates of PGD in settings with different degrees of socially determined risk based on poverty, education, and other factors. We investigated correlates of PGD and other grief indicators in the combined, heterogeneous sample of bereaved mothers to understand their grief-related symptoms.

METHODS

Subjects were recruited through 2 sampling methods. Subjects in the Prenatal Alcohol in SIDS and Stillbirth (PASS) Research Network sample were women enrolled in the PASS Research Network, which is a study of women at high risk for stillbirth and infant loss from Cape Town, South Africa, and the northern Great Plains of the United States that is funded by the National Institute on Alcohol Abuse and Alcoholism and the Eunice Kennedy Shriver National Institute of Child Health and Human Development.³⁴ The women were enrolled when their infants died of SIDS between May 2013 and July 2016. Surveys were administered by professional project staff. Bereaved mothers in the International Society for the Study and Prevention of Perinatal and Infant Death (ISPID) sample were recruited from mailing lists of parent organizations affiliated with ISPID. ISPID recruitment began in September 2014 and was completed in July 2016. ISPID enrollment was by response to notices on Web sites or in newsletters, and surveys were completed online. Potential participation in the ISPID sample was estimated to be 1600 based on mailing list estimates.

Measures

For a PGD scale, we used the Parental Bereavement Questionnaire (PBQ), which is a modification of the Prolonged Grief Disorder 13-Item Scale (PG-13)³⁵ that has been adapted for language specific to the loss of an infant. The PBQ, like the PG-13, is used to assess diagnostic criteria for PGD by using items scaled from 1 to 5 for the frequency or degree of a symptom, with 1 indicating the absence of a symptom and 5 indicating experiencing the symptom almost always or to an overwhelming extent. Constituent symptoms of separation distress (yearning and emotional pain), and

cognitive, emotional, and behavioral symptoms were surveyed, including confusion about one's role in life or diminished sense of self, difficulty accepting the loss, avoidance of reminders about the reality of the loss, inability to trust others since the loss, difficulty moving on with life (eg, making new friends and pursuing interests), emotional numbness since the loss, and feeling stunned, dazed, or shocked by the loss. The source PG-13 items were found to have a sensitivity of 1.00 and specificity of 0.99 for PGD.¹⁴ Adaptations incorporating parent-specific language into the PG-13 were pilot tested on a sample of parents in Massachusetts,³⁶ and input from local focus groups was used to increase reliability for local language preferences specific to Cape Town. Additional items used to assess indicators of disbelief, yearning, anger, isolation, depression, and acceptance as well as salient demographic and comorbidity data were also included. When multiple surveys were administered over time because of other components of the research protocol, the earliest response at >6 months from the loss was used. This research was approved by institutional review boards at Dana-Farber Cancer Institute (protocol 13-207); at the Eunice Kennedy Shriver National Institute of Child Health and Human Development in Bethesda, Maryland; at Stellenbosch University in Stellenbosch, South Africa; at Sanford Health in Sioux Falls, South Dakota; and of the Oglala Sioux Tribe.

Statistical Analysis

Material deprivation in South African participants was estimated by using the South African upper-bound poverty line,³⁷ an estimated income level below which the purchase of food and daily essentials puts a household in jeopardy of not meeting the daily minimum energy intake of 2100 kcal (R753 [South

African rands] or \$57 [US dollars] per month). Material deprivation in ISPID and northern Great Plains participants was determined by an inability to financially meet monthly obligations for necessities and US poverty income levels.

Point prevalence for PGD by using established criteria¹⁴ was determined in 6-month groupings, and 95% confidence intervals (CIs) were calculated. To compare samples, logistic regressions were used to model interactions between the sample and time for specific symptoms and PGD, and then we investigated the effect of sample and controlled for time. In an analysis of the combined samples, we examined correlations between the intensity of emotional pain and the intensity of yearning, plotted them on a heat graph, and tested by logistic regression using yearning as the outcome and pain as the predictor. Point prevalences of the cognitive, emotional, and behavioral symptoms of PGD were calculated at 6-month time groupings. Point prevalences for grief indicators of disbelief, yearning, anger, depression, and acceptance (considered to be the stages of grief)³⁸ were calculated at 6-month time groupings.

RESULTS

Demographic data and risk factors for PGD in the samples are presented in Table 1. The PASS enrollment included 49 bereaved mothers. Five mothers were lost to follow-up. The sample was largely not white (94% were predominantly multiracial Cape Coloured; $n = 39$) and poor (73% were in jeopardy of malnourishment), and 10% of participants had an education beyond high school. Approximately 40% had experienced a previous stillbirth or another child loss. PGD symptom criteria were found in 49.0% of the sample, and its prevalence exceeded 43.8% at every time interval (Fig 1).

The ISPID sample included 372 participants, but 65 were excluded because the time since the loss was outside study criteria. The ISPID sample was largely white, better educated, and more materially secure. Approximately 35% had experienced a previous child or pregnancy loss. PGD symptom criteria were found in 42.3% of the ISPID sample, and its prevalence exceeded 41.3% at every time interval. In both samples, the rate of PGD was 50.0% when mothers with deaths that occurred more recently than 6 months, and thus by definition without PGD, were excluded (mean months from loss: PASS = 20.5, SD = 11.2, minimum = 6, maximum = 45; ISPID = 24.9, SD = 12.8, minimum = 6, maximum = 48). Internal consistency of the PBQ was $\alpha = .92$ ($n = 356$).

There was no statistical difference between the samples in PGD constituent symptom profiles. We found no significant interaction effects between time and sample by symptom except for the shocked symptom ($P = .01$), for which PASS mothers reported less shock. We found no significant differences in risk of PGD by sample when controlling for months since the loss ($P = .81$; odds ratio = 0.92; 95% CI = 0.49–1.73). On the basis of these similarities, we combined the samples for subsequent analysis.

In the combined sample, 42.7% of subjects reported daily, intrusive feelings of both yearning and emotional pain, and this increased to 68.1% if either symptom was present, thus meeting the PGD diagnostic criteria for separation distress (Fig 2). There was a 7.7-fold increase in the odds of increased yearning for each unit increase in emotional pain (95% CI = 5.8–10.1; $P < .0001$).

Reports of daily or disabling cognitive, emotional, and behavioral symptoms of PGD included highly prevalent role confusion and diminished sense of self

TABLE 1 Key Demographic Features of the Samples

	PASS Mothers	PASS Mothers With PGD	ISPID Mothers	ISPID Mothers With PGD	Total With PGD
No. (%)	49	24 (49.0)	307	130 (42.3)	154 (43.3)
Age at loss, y, mean	26.1	26.7	24.7	24.0	24.4
White race, %	6.0	0	93.0	88.2	76.4
Education beyond high school, %	10	20.7	77.5	69.8	62.9
Material deprivation, median income	73% material deprivation	75.8% material deprivation	20.8% material deprivation, \$31–\$75 000	21.0% material deprivation, \$31–\$75 000	22.5% material deprivation
Previous loss, %	39.6	20.8	34.5	34.0	32.0
Months since loss					
2–<6	1	—	47	—	—
6–<12	16	7	54	33	40
12–<18	7	4	35	19	23
18–<24	3	2	34	17	19
24–<30	9	5	35	18	23
≥30	13	6	102	43	49

—, not applicable.

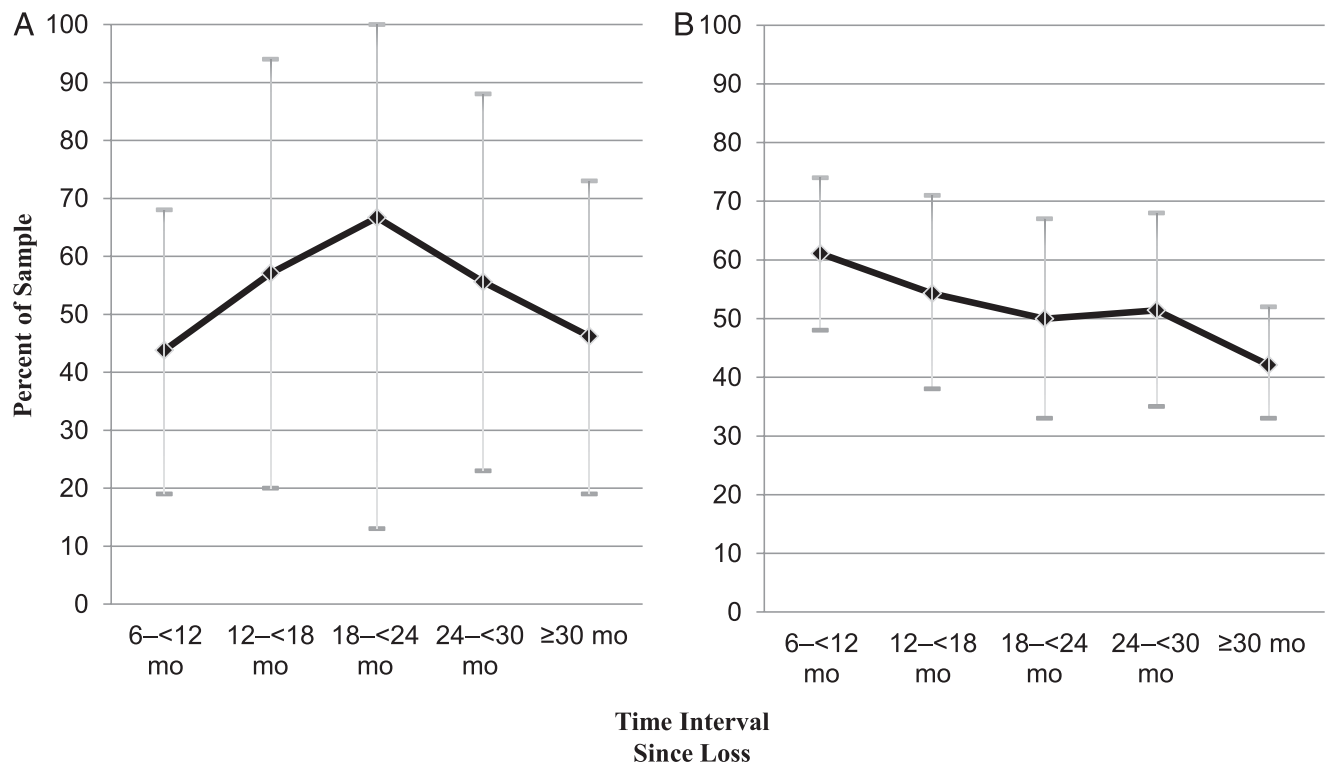


FIGURE 1

A, Point prevalence of PGD in the PASS sample. B, Point prevalence of PGD in the ISPID sample. Point prevalences of PGD in the PASS and ISPID samples and 95% CIs by time from loss (as a percent of the cross-sectional sample) are shown.

(80.9%–89.2%) and bitterness or anger (56.8%–62.9%). The data revealed that the point prevalence for role confusion and diminished sense of self, anger or bitterness, and the inability to trust others remained relatively constant at each time interval, and the

prevalence of avoidance, feelings of meaninglessness, shock, and numbness decreased over time. We did not formally assess these patterns because the cross-sectional design of the study limits any conclusions about individual subjects over time (Fig 3).

Maternal acknowledgment of grief indicators described in stage theories showed decreases in the mean reported severity of negative symptoms, but yearning, anger, and disbelief remained high (Fig 4). Yearning remained the most prevalent grief indicator. Levels of

Intensity of Yearning

	1	2	3	4	5
1	0	1 0.3%	0	0	0
2	4 1.3%	19 6.2%	3 1.0%	0	0
3	1 0.3%	30 9.8%	40 13.0%	0	0
4	2 0.7%	10 3.3%	48 15.6%	34 11.1%	5 1.6%
5	0	2 0.7%	16 5.2%	43 14.0%	49 16.0%

FIGURE 2

Cardinal signs of separation distress and their relative intensity. A heat graph showing the intensity of yearning and/or intensity of emotional pain in mothers 6 to 48 months after their infants' deaths is shown. Intensity is reported on a 1-to-5 scale, capturing absent to daily intrusive experiences. Yearning was significantly associated with emotional pain. Odds ratios increased and became highly significant with greater symptom intensity.

acceptance remained lower than other indicators.

DISCUSSION

In this study of maternal grief after the sudden and unexpected death of an infant, we document a population at high risk for significant grief-related pathology, specifically PGD. In comparison with the prevalence of 9.8% in bereaved adult life partners 1 year after a loss,¹⁵ 57.1% of these young mothers had PGD at 1 year and 41.3% had PGD in their third year postloss. By using a standardized metric on 2 well-characterized samples, similar levels of grief-related pathology were found despite striking differences in social circumstances. Specific patterns of

grief-related symptoms emerged that may prove informative in recognizing and addressing the difficult burdens on these bereaved young women.

Separation distress illustrates the intrusive, ongoing consequences of grief in these women. These are painful pangs of grief, and although not a mental disorder per se, they are a cardinal feature of pathologic grief.³⁹ Although persistent yearning and emotional pain has been found in other research on bereaved parents,⁴⁰ the high rates of PGD observed here reveals its prominence during adaptation to this loss. Theoretically, the strength and severity of separation distress reveals the importance of attachment bonds between mothers and their deceased infants. Clinically,

their emotional burden remains underrecognized in medical settings, where its implications are likely to be important,⁴¹ influencing a woman's bonding experience in a subsequent pregnancy or their parenting of other children. Current clinical practice in obstetrics and pediatrics may not attend to this morbidity in the settings where bereaved mothers present themselves, but given the fact that young adults are poor users of personal health care,⁴² few other opportunities exist to intervene on PGD. Even in settings where supportive medical and mental health relationships directed toward grief are established during the time leading up to a child's death, bereaved parents report difficulties discussing their experiences of loss and seeking assistance to support them in their grief.⁴⁰ Marginalized parents are especially likely to feel a lack of professional support,⁴⁰ an observation that has special relevance to the demographics of SIDS, which additionally carries a stigma of blame that other diseases do not share.

Few cognitive and emotional symptoms of PGD resolved decisively, as might be inferred from the general understanding provided by stage models of grief, although stage models are meant to explain normal grief. In our research, we identified categories of highly prevalent symptoms, symptoms that appeared to continue at consistent levels, and symptoms that diminished at successive time intervals. It may be helpful for pediatricians to inquire about role confusion, anger, and feeling stuck or unable to "get over" the loss (accepting loss or moving on) during clinical encounters involving their surviving and subsequent children. Role confusion, anger, and a lack of trust in others are aspects of coping that seem least likely to change over time and may represent therapeutic targets for referral once identified. Bereaved mothers may

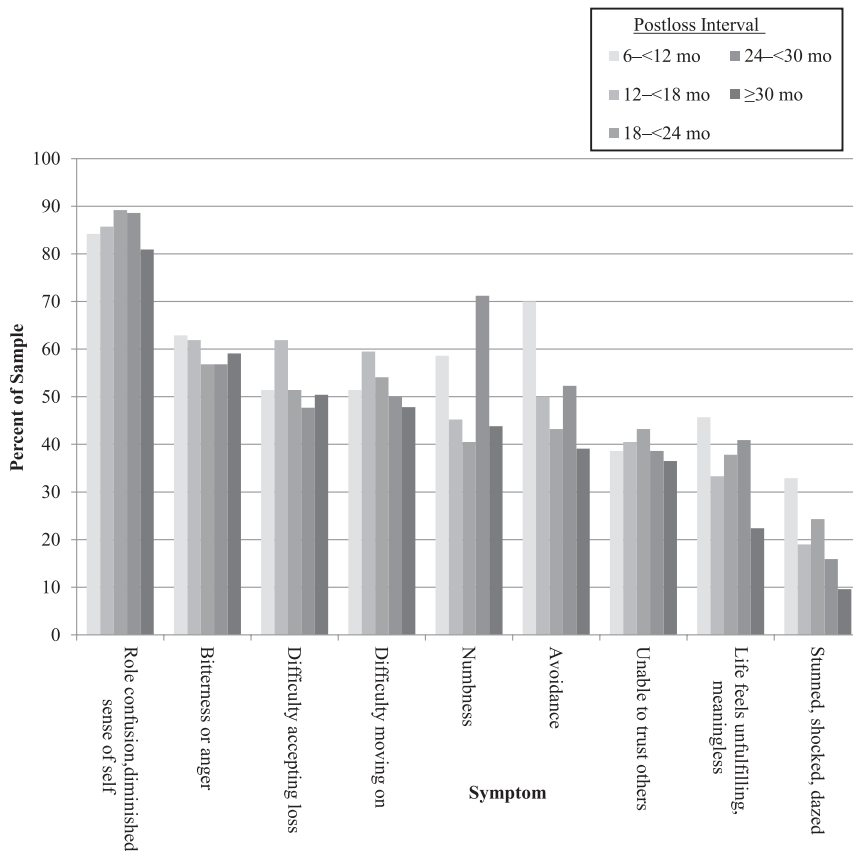


FIGURE 3

Cognitive, emotional, and behavioral symptoms of PGD. Symptoms included in diagnostic criteria for PGD are shown as a percent of the time interval sample. Symptoms are highly prevalent and are shown in decreasing prevalence. Different patterns of persistence or improvement in specific symptoms can be noted.

be relieved to know that feelings of shock, avoidance, or meaninglessness are likely to improve. As in other maternal conditions, an established pediatrician has unique access to this problem.^{43,44}

Researchers of stage models of grief,⁴⁵ which involve grief indicators such as disbelief, anger, yearning, depression, and acceptance, generally maintain that negative indicators peak in intensity within 6 months and then decline as acceptance increases while also finding that acceptance is the most frequently affirmed grief indicator at any time after a loss.³⁸ In this research, there was no time when acceptance exceeded negative grief indicators, whereas anger and yearning related to their infants' deaths and absence were found to be present at least

weekly throughout the study periods in most of the mothers. This would imply that the general emphasis in grief counseling on acceptance as an indicator of the resolution of grief may be problematic for mothers who experience a SIDS loss. Offering reassurances about developing acceptance may not prove helpful as a consolation. In conducting interviews with participants, we observed that mothers objected to questions about acceptance, pointing out that there is no replacement or moving on from their infants, which also preserves their deep identification as their children's protector and nurturer. Anecdotally, audiences of bereaved mothers in a number of settings explained that the emphasis on acceptance fails to recognize their challenges as mothers

who are responsible for maintaining memories and the value of their deceased children's lives. They shared the difficulties they face over time as their deceased infants are less remembered or considered, noting that it contributes to their anger and inability to embrace acceptance.

Risk factors for prolonged grief include those related to the nature of the loss and to the circumstances and resources of the bereaved.⁴⁶ Our methodology included 2 samples with starkly different social circumstances. The similar patterns of grief in these samples invite consideration of the relative contribution of social determinants as opposed to attachment bonds in PGD. It reveals that the challenges a mother, as a mother, faces after the death of her small, dependent infant are profound regardless of resources and disenfranchisement, and this reflects the fundamentality of the relationship that is altered.

This research has several limitations. The 2 samples were combined to enhance the sample size and generalizability, but each had different biases. The PASS sample was selected because it concentrates the risk factors PGD shares with SIDS, notably poverty, race, and alcohol use, recognizing the importance of the risk factors and also the generally limited recruitment of disenfranchised populations in this area of research. There was little ascertainment bias beyond the initial choice of the community to be studied. Despite this relevance for SIDS, however, we anticipated concerns about the representativeness of their experiences and also included a more typically studied end of the sociodemographic spectrum with greater resources and supports, the ISPID sample. Selection bias in the ISPID sample was due to recruitment from mothers who were affiliated with SIDS support organizations, who had the psychological capacity to seek bereavement support (not necessarily

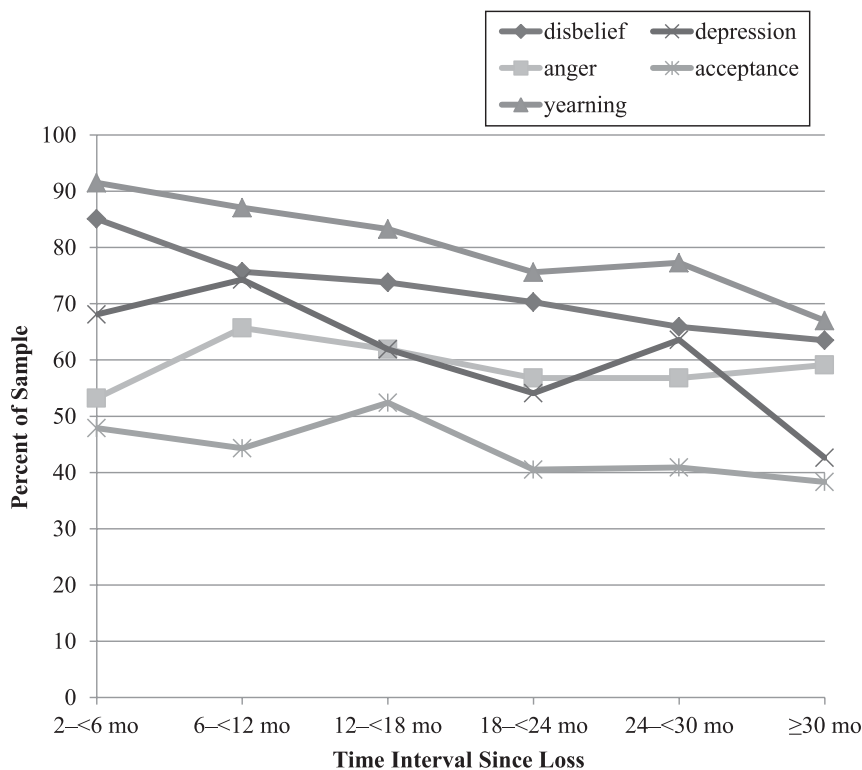


FIGURE 4 Symptoms associated with stage theories of grief. Historical grief indicators are related to the stage theories of grief. Acceptance was never more prevalent than negative grief indicators.

counseling), and possessed the resources to participate in an online survey. Despite these potential biases, responses were not significantly different between these 2 samples with highly dissimilar social determinants. Because of this, our findings are consistent with one conclusion of grief research: although culture and circumstances may influence the expression of grief, there is a core behavioral response to loss that is conserved regardless of setting.⁴⁷ This study is also limited by its cross-sectional design, which precludes conclusions about longitudinal trajectories. Associations, but not causality, can be established, notably with regard to social determinants, and confounders may be unequally distributed. The number

of observations limits the statistical power to assess trends.

In historic terms, contemporary times are the first in human history when the death of a child is a rare event,⁴⁸ adding isolation to the high, persistent levels of grief found among parents whose young children have died of a variety of causes.^{23,49–52} The role of this isolation in the development of their symptoms is unclear. The fact that PGD is present in such a significant proportion of these bereaved women also raises important questions about the PGD diagnostic framework in this population because it might not be accurate to describe the symptoms as abnormal (nonnormative) when so many experience them. The high prevalence of PGD may reflect

limitations in the diagnostic criteria but alternatively may reflect a largely unrecognized crisis in psychological health. This population, at an extreme boundary of newly embraced diagnostic criteria, warrants careful consideration.

CONCLUSIONS

PGD is common, distressing, and persistent in mothers whose infants have died of SIDS, with discernible symptom profiles. These findings have implications for the health and well-being of mothers of deceased infants. In considering young families, implications may extend to other dependent children living in their households, with consequences across varied levels of resources and social circumstances. Future researchers should confirm these observations in prospective longitudinal studies, investigate PGD after other child losses, examine the impact of subsequent births on PGD, and consider the grief of fathers. Pediatricians, in their role with families in the aftermath of SIDS, may be in a unique position to identify this problem and help diminish its consequences.

ABBREVIATIONS

- CI: confidence interval
- ISPID: International Society for the Study and Prevention of Perinatal and Infant Death
- PASS: Prenatal Alcohol in SIDS and Stillbirth
- PBQ: Parental Bereavement Questionnaire
- PGD: prolonged grief disorder
- PG-13: Prolonged Grief Disorder 13-Item Scale
- SIDS: sudden infant death syndrome

reviewed the manuscript; Drs Lichtenhal and Morris critically reviewed and revised the manuscript; and all authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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