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Predicting grief intensity after recent perinatal loss

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ABSTRACT

Objective: The *Perinatal Grief Intensity Scale* (*PGIS*) was developed for clinical use to identify and predict intense grief and need for follow-up after perinatal loss. This study evaluates the validity of the *PGIS* via its ability to predict future intense grief based on a *PGIS* score obtained early after a loss.

Methods: A prospective observational study was conducted with 103 international, English-speaking women recruited at hospital discharge or via the internet who experienced a miscarriage, stillbirth, or neonatal death within the previous 8 weeks. Survey data were collected at baseline using the *PGIS* and the *Perinatal Grief Scale* (*PGS*). Follow-up data on the *PGS* were obtained 3 months later. Data analysis included descriptive statistics, Cronbach's alpha, receiver operating characteristic curve analysis, and confirmatory factor analysis.

Results: Cronbach's alphas were ≥ 0.70 for both instruments. *PGIS* factor analysis yielded three factors as predicted, explaining 57.7% of the variance. The optimal cutoff identified for the *PGIS* was 3.535. No difference was found when the ability of the *PGIS* to identify intense grief was compared to the *PGS* ($p = 0.754$). The *PGIS* was not inferior to the *PGS* (AUC = 0.78, 95% CI 0.68–0.88, $p < 0.001$) in predicting intense grief at the follow-up. A *PGIS* score ≥ 3.53 at baseline was associated with increased grief intensity at Time 2 (*PGS*: OR = 1.97, 95% CI 1.59–2.34, $p < 0.001$).

Conclusions: The *PGIS* is comparable to the *PGS*, has a lower response burden, and can reliably and validly predict women who may experience future intense grief associated with perinatal loss.

1. Introduction

The goal of this study was to evaluate the reliability and validity of the *Perinatal Grief Intensity Scale* (*PGIS*) in women who experienced a miscarriage, stillbirth, or neonatal death within the previous eight weeks. The *PGIS* was developed as a clinical tool to help healthcare providers (HCPs) effectively identify women who experience intense grief after a perinatal loss and have the greatest need for professional follow-up in future months. Our previous research indicates the *PGIS* predicts intense grief in women 12–18 months after miscarriage and in the subsequent healthy pregnancy after a miscarriage, stillbirth, or neonatal death [1,2]. In addition, high *PGIS* scores are associated with clinical levels of depression, anxiety, and post-traumatic stress (PTSD), and couple relationship issues in the subsequent pregnancy after a miscarriage, stillbirth, or neonatal death [3]. This study extends our previous work by evaluating the concurrent, construct, and factorial validity of the *PGIS* in women with recent losses.

1.1. Background and significance

Perinatal loss occurs in about 25% of all pregnancies and includes miscarriage rates of approximately 15–25% [4–7]. In 2013, the United States fetal mortality rate for fetuses at 20 weeks gestation or more (stillbirths) was 6.05/1000. The perinatal mortality rate, which includes stillbirths and neonatal deaths, was 6.24/1000 [6]. Perinatal loss constitutes a major public health problem for American women and their families [4–7].

Women may experience a wide range of normal responses to perinatal loss, including feelings of profound grief and loss [2]. While most women experience normal grief reactions in response to perinatal loss, about 25%–30% may have significant, prolonged, highly intense, complicated grief reactions which may negatively affect their psychological well-being [8,9]. These highly intense grief reactions may be associated with the development of high levels of anxiety [8,10,11], depression [8,10,12], and post-traumatic stress [8,13]. Further, detrimental effects on the couple relationship are more common in couples

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experiencing intense grief, with these couple relationships having up to four times higher risk of dissolving after miscarriage and stillbirth compared couples who have live births [14–16].

There is wide variability in how women perceive perinatal loss. Not every woman who experiences a loss will feel intense grief [17]. Some women may feel little or no grief, particularly if the process of prenatal attachment has not yet begun [1,2,17]. Even if the loss is not experienced as a grief-inducing event, it may be traumatic, painful, and disruptive to women's lives [18]. For those who grieve intensely, professional follow-up is often necessary, appreciated, and desired [19]. The same degree of professional follow-up care is typically not needed for those who experience little or no grief. Providing the right type and amount of immediate and follow-up care is important because inadequate or inappropriate care can aggravate the loss experience, making a difficult experience even worse [20].

Appropriate and supportive care for families after perinatal loss is critical to prevent adverse short- and long-term outcomes for parents [15,19,20]. Engler and Lasker [21] found professional support to be the single most important predictor of whether a mother experienced psychological complications associated with grief after her baby's death. If bereaved mothers do not receive supportive care after their loss, they may be more likely to experience negative and prolonged psychological outcomes [15,20,22,23].

In a comprehensive review of the literature regarding complicated grief and perinatal loss, Kersting and Wagner [9] found only two factors that have been consistently documented in the perinatal loss literature as predicting highly intense or complicated grief after pregnancy loss. Their review found poor social support from significant others is associated with highly intense grief while high levels of social support from family members, friends, and others appears to be protective of and associated with reduced grief scores. In addition, a history of a pre-loss mental health disorder such as major depression or a high degree of neurotic personality characteristics has been consistently associated with more intense or complicated grief [9]. Common socio-demographic variables such as age, race, marital status, and occupation have not been found to predict grief outcome [9,12,14].

Given the dearth of predictive variables for highly intense grief, there is a critical need for simple, accurate, standardized clinical screening tools to identify women with intense grief responses who need professional follow-up and support after perinatal loss [2,18,24]. A brief, reliable, and valid clinical screening instrument would allow intensely grieving mothers to be more effectively connected with post-loss services and supportive early intervention [15,24,25]. The purpose of this study was to examine the reliability and validity of the *PGIS* in women who experienced a recent perinatal loss. This is the final step in the psychometric evaluation of the instrument before it can be readily used in the clinical setting.

1.2. Perinatal grief intensity theoretical framework

The *PGIS* is based on the belief that the meaning women attribute to their loss experience is critical in determining their psychological response to perinatal loss [17,26,27]. Three factors have been found in our previous research to significantly influence grief intensity after a perinatal loss [1–3,17,26]. These factors include the perceived **Reality** of the pregnancy and baby within; the **Congruence** between the actual loss experience and the woman's perceived ideal regarding how the loss experience should unfold; and the woman's ability to make decisions or act in ways to increase this congruence, known as **Confront others**.

A mother's perception of the **Reality** of her pregnancy and unborn baby is her mental representation of the pregnancy and baby at the time of the loss. When women first learn of their pregnancies, they understand that they are pregnant but may not *feel* pregnant [17]. Later, as they develop pregnancy symptoms, the pregnancy begins to feel real, but the baby within still is more of an idea, an ideal baby without a perceived identity or personality. Later still, the baby begins to feel real, and women start to think of this baby as a son or daughter with specific characteristics and personality traits [17]. Côté-Arsenault and Dombeck use the term “fetal personhood” (p. 649) to describe this concept [28]. These inferred mental representations of the baby's identity become the basis for prenatal attachment [20], and the pregnant woman begins to perceive herself as a mother [20,29]. Once attachment has developed, if a perinatal loss occurs, grief is likely to follow [17,30].

Variations in grief cannot be completely explained by solely by length of gestation [27], as several studies have reported no difference in grief intensity based on gestational age [1,2,17,27,31–33]. Women with longer gestations have more time to develop the mental representations of the baby's identity that become the basis for prenatal attachment, and therefore are likely to experience significant grief with perinatal loss. However, women with early gestations may develop these mental representations and experience grief after miscarriage as well [1,3,9,17,18,28]. As a result, gestational age at the time of the loss cannot be considered a consistently reliable predictor of grief intensity.

Congruence evaluates the relationship between the actual loss experience and the mother's perceived ideal regarding how the loss should unfold [1,2,17]. Whether a woman feels supported after a loss by those who are significant to her is determined by the congruence between the way in which she perceives the loss and the interactions she has with her family members, friends, and healthcare providers [17]. If a woman perceives the loss as the death of her child, and she has interactions with her significant others that recognize and validate her ongoing bond with her deceased baby, then the woman will generally feel supported, regardless of gestational age [2,20]. Similarly, if the woman does not perceive the pregnancy and baby as real, she often will experience little or no grief [1–3,17]. Even if there is little grief, the pain, bleeding, and fear associated with a perinatal loss may still be traumatizing [17]. Our research has demonstrated that if her healthcare providers and significant others focus primarily on her needs for physical care and comfort, the woman will generally feel supported [17]. However, we have also determined if there is incongruence – such as a woman perceiving the loss as the death of her baby and her significant others treating the loss as if it was an insignificant event – then the woman will likely perceive this care as inappropriate and unhelpful, and feel unsupported and angry as a result [1,2,17]. Support that is well-meaning but incongruent with the woman's perception of the loss is usually not perceived as helpful, may lengthen and intensify the grief process, and may leave her feeling even more isolated, angry, and misunderstood [2,17,34]. These feelings may contribute to the development of more intense grief and associated psychological issues [20,23,35]. On the other hand, positive support may buffer the trauma associated with perinatal loss, and mediate the effects of stress on the mother [9,22,36]. In their Cochrane Review, Koopmans et al., reported the perception of positive, high levels of support was associated with fewer depressive and somatic symptoms after perinatal loss [15].

Confront others evaluates the mother's ability to make decisions or act in ways to increase the congruence of the loss experience. When the mother is unable to confront others, the people closest to her are not forced to recognize those times when their behaviors and actions – however well-meaning – are perceived as unsupportive. There is no motivation for these significant others to recognize and change their unsupportive behavior. Thus, the same unacceptable behavior continues, and the mother often feels increasingly isolated. If a grieving mother is unable to confront her significant others about behaviors she finds unsupportive and unacceptable, then she may experience additional feelings of anger and victimization. The lack of social support perceived by a bereaved woman may compound her ability to mourn, and increase her despair and overall grief intensity [1,2,17,20].

Our previous research has demonstrated that grief experiences with the greatest intensity are most likely to occur in women for whom the pregnancy and baby are perceived as real (↑**Reality**); when the actual loss experience is perceived as unfolding in a manner women find unacceptable (↓**Congruence**); and in women who perceive themselves as